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Impact of COVID-19 pandemic on families living with autism: An online survey

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ABSTRACT

Background: The current SARS-CoV-2 global pandemic presents a great challenge for governments, health care professionals and the general population. Individuals with autism spectrum disorder (ASD) might be especially vulnerable to restrictions imposed by the crisis.

Aim: The objective of the study was to examine the impact of the SARSCoV-2 pandemic on children with ASD and their families.

Methods and procedures: We conducted an online survey two months after the beginning of lock-down (18th of May to 5th of July 2020) in Germany and Austria. We investigated behavioral and emotional changes of children related to the lock-down alongside parental stress and intrafamilial burden

Outcome and results: Of the 216 participating families with an autistic child (mean age: 12.23 years), nearly 50% reported aggravation of autistic symptoms and heightened parental stress. Families reported discontinuation of therapy, more intrafamilial conflicts and increase of psychopharmacological medication of the child.

Conclusions and implications: Our report on short-term detrimental effects of the pandemic calls for thorough investigation of long-term sequelae for children and families

What this paper adds

This paper analyses the impact of the pandemic's outbreak on an especially vulnerable population (i.e. children with autism and their families in Germany and Austria). We did not only investigate the effects of the crisis on the children's psychopathology but also on the intrafamilial situation and the parental stress level. In addition to challenges occurring with the pandemic we also considered

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potential chances and opportunities associated with COVID-19 and its restrictions.

1. Introduction

Since the beginning of 2020, the SARS-CoV-2 pandemic has been a continuing challenge for our daily life, sociopolitical and health-care systems all over the world. Measures to limit the risk of infection include school closures, quarantine, social distancing and restrictions of public life. While these strategies have proven effective in reducing the risk of infection and preventing corona virus disease, they create a high degree of stress in everyday life and increase the risk for mental health problems like depression and in the population, including children and adolescents (Loades et al., 2020; Racine et al., 2020).

Shortly after the detection of the first COVID case on January 28 2020 in Germany, all 16 German states closed schools and daycare centers on March 16. Cultural and sport institutions as well as shops (excluding supermarkets and grocery stores) were locked down. Children and adolescents suddenly were no longer able to pursue their usual leisure and sports activities or their peer contacts for about 2 months. Thus, the responsibility for child care and teaching had been shifted entirely to parents. At the end of May, the German federal states - with different timetables - began the reopening process. At first, this applied mainly to those students preparing for exams. The majority of students was allowed to return to classes between May and June under special conditions, in such a way that many children had classes only every other week or only one or two days per week. Daycare centers and kindergartens were closed longer than most schools, with the exception of emergency care provided for a limited group of parents, namely those working in so-called system-relevant professions, like physicians, nurses, bus drivers etc. Thus, COVID-19 directly affected formal care arrangements, education and leisure services. Recognizing that the impact of these measures will hit some groups of children harder than others is crucial. These groups of vulnerable children include for example those with mental health problems and children with disabilities. Furthermore, the pandemic has the potential to create new vulnerable children and countries must prepare to respond to growing needs for support.

In Germany, Ravens-Sieberer et al. (2020, 2021) conducted the first population-based online survey immediately after the first lock-down, investigating mental health and quality of life of children and adolescents aged between 11 and 17 years ($n = 1040$ children and $n = 1568$ parents). Results indicated a heightened risk for psychological problems (30% vs. 18% pre-pandemic) and increased levels of psychosomatic complaints in this age group, with high concordance between parents' and children's information.

The impact of COVID-19 related restrictions on mental health are highly heterogeneous and not at all uniformly detrimental (Prati & Mancini, 2021). Still, children with preexisting mental health issues might be at elevated risk of experiencing increased levels of psychopathology (Jefsen, Rohde, Nørremark, & Østergaard, 2021; Nissen, Højgaard, & Thomsen, 2020; Zhang et al., 2020). Findings from a recent longitudinal survey to estimate the impact of COVID-19 on child and adolescent psychiatry (CAP) services in Europe revealed the perceived impact on the mental health and psychopathology of children and adolescents to dramatically increase from "medium" (> 50%) in 2020 to "strong" or "extreme" (80%) in 2021 (Revet et al., 2021).

Children with intellectual and developmental disabilities and their families may be particularly affected by changes and restrictions associated with the current pandemic. Previous studies underlined the heightened stress level of parents caring for a child with disabilities, even before the outbreak of COVID-19 (Feizi, Najmi, Salesi, Chorami, & Hoveidafar, 2014; McStay, Trembath, & Dissanayake, 2014; Woolfson & Grant, 2006). For children with higher needs, disruption of schooling and respite care placements have the potential to push some families into crisis. School closures and lack of access to therapeutic support can introduce significant stress and disruption to the lives of children who under normal circumstances thrive on structure and routine.

In the UK, Asbury, Fox, Deniz, Code, and Toseeb (2021) conducted a survey on 214 parents of children with special educational needs and disabilities asking parents to describe the impact of COVID-19 on their own mental health and that of their child. Results showed an increase in anxiety and stress in parents and children, more worries and a loss of routines and support network. Similar results were reported from India by Dhiman et al. (2020) who assessed mental health and parental strain of 264 caregivers of children special needs. Findings showed a significant increase of parental strain ($p < 0.001$, effect size = 0.93) compared to pre-pandemic levels, as well as a high prevalence of depression (62.5%) and anxiety (20.5%). Jeste et al. (2020) investigated on changes in health care services for children with a genetic and neurodevelopmental disorder in the US. Seventy-four percent of participating parents reported that their child lost access to at least one therapy or education service, and 36% of respondents lost access to a healthcare provider.

Until now, little is known about how children and adolescents with ASD and their families are affected by the pandemic. As a neurodevelopmental disorder, ASD is characterized by deficits in social communication, reciprocal interaction as well as restricted, repetitive behavior and interests (American Psychiatric Association, 2013). Individuals with ASD usually prefer predictable, familiar contexts and may respond to abrupt changes and disruption of routines with heightened levels of anxiety or stress (Courtenay & Perera, 2020; Eshraghi et al., 2020). On the background of high symptom severity, chronicity and frequent comorbid disorders, children and adolescents with ASD are in need of complex and continuous therapeutic and psychosocial support (Gjevik, Eldevik, Fjaeran-Granum, & Sponheim, 2011; Hodgetts, Zwaigenbaum, & Nicholas, 2015; Joshi et al., 2013; Simonoff et al., 2008).

It is suggested that the limited access to services and support potentially increases symptom severity, the family's burden and parental stress levels (Tarbox et al., 2020). Colizzi et al. (2020) conducted a parent online survey to examine the psychosocial and behavioral impact of the pandemic on 527 children and adolescents with ASD in Italy. They found that pre-pandemic behavioral problems predicted symptom severity during the crisis. The vast majority of respondents described the ongoing pandemic as a challenging time, especially with regard to the management of leisure time and structured activities. An online survey of children with ASD and their families in Michigan, USA, revealed that increased stress levels of parents caring for individuals with ASD were associated with a younger age and a higher symptom severity of the child (Manning, Billian, Matson, Allen, & Soares, 2020), while a study conducted in the UK (Nonweiler, Rattray, Baulcomb, Happé, & Absoud, 2020) found heightened levels of emotional and behavioral

problems in children and adolescents with neurodevelopmental disorders (including ASD and attention deficit/hyperactivity disorder) as compared to controls.

Whereas the majority of studies focus on negative effects of the pandemic on mental health and intrafamilial stress levels, [Singh and Sim \(2021\)](#) discuss possible opportunities the crisis may hold for families and their well-being. They suggest that the COVID-19 related conditions may create intrafamilial closeness, joint problem-solving and deeper relationships. [Pavlopoulou, Wood, and Papadopoulos \(2020\)](#) conducted a survey study including 449 participants caring for a child with ASD. Besides not feeling sufficiently supported by the government's health care strategies during the pandemic, caregivers also described new opportunities and benefits, e.g. spending more time with the family and establishing new routines that positively affect the child's well-being. Given a plethora of studies on the effect of the COVID-19 viral pandemic, to the best of our knowledge, this is the first online survey in Germany aiming to investigate the effects of the COVID-19 pandemic on families with children diagnosed with ASD.

Based on the difficulties of autistic individuals to cope with abrupt changes in routines and unexpected situations ([Colizzi et al., 2020](#)), we hypothesized that 1) the pandemic and its restrictions would result in an increase of autistic symptoms and behavioral difficulties of children with ASD. Moreover, based on existing literature on aggravated family strain and psychological problems of parents caring for a child with ASD ([Manning et al., 2020](#)) we expected that 2) heightened levels of intrafamilial burden and parental stress would be associated with an increase in the child's symptom severity. Single studies already give an outlook on possible opportunities and chances the crisis may hold for families and their well-being ([Pavlopoulou et al., 2020](#); [Singh & Sim, 2021](#)). Therefore, an additional aim 3) was to explore positive opportunities and benefits perceived by parents or caregivers as a result of the crisis and to identify potential associated predictors.

2. Material and methods

2.1. Participants

Participants were recruited by contacting therapists in institutions working with children and adolescents with ASD in Germany and Austria (e.g., autism therapy centers, child and adolescent psychiatry departments, early intervention centers and other health care services working with children with special needs). Therapists passed on a description of the study and a link to our online questionnaire to their clients. Additionally, the description and link to the survey were accessible through websites of relevant institutions associated with ASD. The online survey was hosted on the limesurvey-platform ([Limesurvey GmbH, 2003](#)) from 18th of May to 5th of July 2020. Ethical approval for the study was obtained by the research ethics committee of the University Medical Center Göttingen. Prior to completing the survey, all respondents completed an electronic informed consent containing information about the purpose of the study, contact information of the researchers, anonymous collection, storage and publication of their data and voluntariness of their participation.

2.2. Design and Procedure

The online survey consisted of 74 questions, of which 34 were multiple choice questions, 20 were open-ended questions and 20 were yes/no questions. The average time to complete the questionnaire was 15–25 min. The original questionnaire in German language can be requested from the corresponding author. Open-ended questions referred to, for example, the size of living space, diagnosis of siblings, as well as possible benefits experienced through COVID-19. The questionnaire was organized into six subsections: 1) informed consent; 2) socio-demographic variables; 3) clinical characteristics of the child (e.g., diagnosis, therapies, medication); 4) questions relating to the familial changes during the pandemic (e.g., intrafamilial burden due to home schooling, care-taking situation, financial worries), pandemic-induced changes in core symptoms of ASD (e.g. less use of gestures and facial expressions, more monologuing, more pursuing of special interests), and changes in general psychopathology (aligned with key items from the Child Behavior Checklist e.g. "cries a lot", "argues a lot", "worries" (CBCL, [Achenbach, 1991](#)) assessing emotional, behavioral and social problems). "Changes" in autistic symptoms and general psychopathology refer to parents' perception of change due to lock-down. We thus applied an indirect, retrospective measure of change. We additionally assessed media consumption of the child as well as parent's individual stress level (adapted from the Autism Parenting Stress Index, [Silva & Schalock, 2012](#)); 5) parents' mental health (e.g. self-efficacy; ASKU, [Beierlein, Kemper, Kovaleva, & Rammstedt, 2013](#)), adjustment (adapted from the Adjustment Disorder – New Module 20; [Lorenz, Bachem, & Maercker, 2016](#)), and resilience; and 6) perception of positive changes and opportunities due to the crisis (open ended).

2.3. Statistical analysis

Statistical analyses were conducted using SPSS Statistics 26 (IBM Corp, 2019). Participant answers regarding pandemic-related changes in autistic symptoms and general psychopathology of the child, parental stress level, intrafamilial burden and climate were each aggregated and the resulting sum scores were used for further analysis. For example, for the sum score of changes in autistic symptoms, 14 items (ranged from “0” = “not applicable” to “3” = “often applicable”) were aggregated to a total score. Similarly, 38 items assessing changes in general psychopathology of the child (ranged from “0” = “not applicable” to “3” = “very true or often true”) were combined to a sum score. When computing the sum score, missing values on single items were treated as “not applicable” (“0”). All Cronbach’s alpha for the aggregated scores ranged between $\alpha = 0.82$ and $\alpha = 0.95$, indicating a good or very good reliability. As answers to open-ended questions were diverse (e.g. for possible benefits experienced through the crisis), we conducted a cross-validated procedure within the research team. Based on the pool of answers, superordinate categories were created and individual answers were assigned to the respective categories. Inter-rater agreements for the category assignments were between Cohen’s $\kappa = 0.79$ and Cohen’s $\kappa = 0.87$. Descriptive analysis of the study population and changes since beginning of the COVID-19 pandemic and the closing of schools was implemented using mean (standard deviation) for numeric variables and frequency (percent) for categorical variables (see Table 1 and Table 2). Correlations were analyzed using Pearson product-moment correlation for numeric data and Spearman’s rank correlation for categorical data (see Table 3). Values of $r = 0.1$ represent a small effect, $r = 0.3$ a medium effect and $r = 0.5$ is a large effect (Cohen, 1988, 1992). Results of correlation analyses are Bonferroni adjusted to control for alpha error accumulation.

Generalized linear models (i.e. multi-step regression models) were used to analyze effects of several predictors on the aggregated sum scores of changes in autistic symptoms and general psychopathology (see Table 4 and Table 5). The perception of positive consequences in relation to child and family associated variables was analyzed with multiple t-tests. Cohen’s d was used as an effect size, with $d = 0.2$ representing a small effect, $d = 0.5$ a medium effect and $d = 0.8$ a large effect (Cohen, 1988, 1992). Statistical significance was set at $p < 0.05$. Bonferroni adjustment was adopted for multiple comparisons to control for alpha error accumulation.

3. Results

3.1. Description of the study population

In total, 457 parents/caretakers participated in the survey. 239 participants had to be excluded due to a high amount of questions left unanswered (>50% missing values). Two participants reported about themselves and were therefore excluded from the main analyses. Our final study sample thus consisted of 216 families (11 from Austria). Mean age of the family member to fill in the survey was 43.91 years, $SD = 7.97$, 87.5% of respondents stated to be the biological mother, 77.5% had a partner. The majority (68.8%) of the parents lived together as a family with their child in one household, 58.6% in a house with garden, 33.9% in an apartment with garden or balcony. The mean age of the children was 12.23 years ($SD = 5.24$), with 76.4% males. 75.8% of the children were reported to speak fluently, 72.6% of them attended school, 45.8% of whom with a classroom assistant. 22.9% visited a school for children with learning difficulties. Boys and girls did not differ in their changes in autistic symptoms and general psychopathology, neither was the parental stress level or intrafamilial burden significantly influenced by the child’s gender ($p > 0.05$). The child’s age was significantly associated with changes in general psychopathology ($r = -0.24$, $p < 0.001$), the parental stress level ($r = -0.16$, $p = 0.023$) and adjustment problems ($r = -0.14$, $p < 0.05$). Almost a quarter (22.5%) of children with ASD had a sibling with a psychiatric diagnosis, out of these 13.4% were also diagnosed with ASD. Table 1 shows further information on the study population.

At the time the survey was conducted, 65.3% of the participants felt to be well-informed about COVID-19. The majority (69.8%) retrieved information about the pandemic mainly from the internet. A few (7.4%) of the parents knew a person in their closer environment infected by COVID-19. Two respondents stated that they had experienced the loss of a person in their closer environment due to COVID-19. Another two stated that they were infected themselves.

3.2. Impact of the pandemic on clinical characteristics and the families’ stress level

Almost half of the study population (44.4%) stated an exacerbation of autistic symptoms in $\geq 50\%$ of the autism related questions. Similarly, 43.3% of respondents described an aggravation of overall psychopathology in $\geq 50\%$ of questions concerning the behavior/psychological state of the child, and 15.7% of the parents reported an increase of their children’s pharmacological medication dosage (Table 2). Children with comorbidity showed significantly stronger exacerbation of autistic symptoms and general psychopathology than children without ($p < 0.05$). Changes in the autistic symptoms and psychopathology related to lock-down were neither associated with the child’s level of speech, the level of care, the ASD-subtype nor the continuation or discontinuation of therapy (all $p > 0.5$). School closure was related to enhanced media consumption, intrafamilial conflicts, aggression and physical violence (Table 2).

Parents experienced the continuous caretaking of their child as a significant burden ($M = 2.62$, $SD = 1.40$; range: 0–4, see Table 2). Similarly, home schooling was described as a challenge ($M = 2.54$, $SD = 1.46$), followed by the restriction of social contacts ($M = 2.53$, $SD = 1.37$; Table 2). The majority (75.4%) reported a discontinuation of all or single therapies. 30.3% of the respondents made use of alternative supporting services (e.g. telephone and video-based consultations) offered by clinics and other institutions. 89.1% claimed to benefit from this support.

Results of correlation analyses showed significant associations between the two child-related outcome variables (i.e. changes in autistic symptoms and general psychopathology) and the caregivers’ psychosocial variables (Table 3). In general, we found a large

effect for the association between changes in autistic symptoms with parental stress as well as with changes in general psychopathology. An aggravation of autistic symptoms was strongly associated with the level of parental stress ($r = 0.62, p < 0.001$) and the child's general psychopathology ($r = 0.68, p < 0.001$). Similarly, a higher level of intrafamilial burden (i.e. stress related to COVID-19, such as care-taking situation, home schooling) was related to the increase of the child's level of autistic symptoms ($r = 0.51, p < 0.001$) and general psychopathology ($r = 0.46, p < 0.001$). As a contrast, an improvement in the intrafamilial atmosphere and the reciprocal support was related to the decrease of autistic symptoms ($r = -0.31, p < 0.001$) and psychopathology ($r = -0.41, p < 0.001$), representing a medium effect. Parental adjustment problems were significantly related to the child-related outcome variables (changes in autistic symptoms: $r = 0.39, p < 0.001$; changes in general psychopathology: $r = 0.42, p < 0.001$). The size of the living space did not significantly affect the child-related outcome variables. The same holds for the parental educational level ($r = -0.17, p > 0.05$) and the family net income ($r = -0.18, p > 0.05$). Also the parental educational level was not significantly related to the general psychopathology ($p > 0.05$) of the child.

Tables 4 and 5 show results of multiple regression analyses. We carried out two 3-step regression models with every step representing a different domain ((1) child-related variables, (2) family variables, (3) socioeconomic variables). The first regression model (Table 4) proved to be significant, with changes in the child's general psychopathology ($\beta = 0.48, p < 0.001$) explaining the largest amount (49%) of variance in the pandemic-related changes in autistic symptoms of the child. The parental stress level ($\beta = 0.25, p < 0.001$) significantly improved the model fit.

The second regression model (Table 5) revealed similar results, with changes in autistic symptoms ($\beta = 0.41, p < 0.001$) and parental stress level ($\beta = 0.24, p < 0.001$) explaining 61% of the variance in exacerbation of the child's general psychopathology. Out of the family-related variables, only the intrafamilial climate ($\beta = -0.15, p < 0.05$) was significantly associated with the outcome variable, with positive changes within the family being related to a lower level of emotional and behavioral problems of the child.

3.3. Positive consequences of COVID-19

Forty-Nine percent % of participating families experienced also benefits and positive effects through restrictions due to COVID-19, e.g. pursuing professional growth and career perspectives (32.2%), being able to cherish family time (17.8%) and time for oneself (8.9%), focusing on what's important (14.4%), the need to slow down (11.1%) and being able to reorganize oneself (8.9%). Parents perceiving benefits through the pandemic significantly differed from those perceiving no opportunities (Table 6) in their reported well-beings. Respondents perceiving benefits through the crisis reported significantly lower levels of mental health problems in their child (autistic symptoms: $M = 19.98, SD = 5.55$ vs. $M = 22.68, SD = 6.68$; small effect of $d = 0.44$; general psychopathology: $M = 55.63, SD = 13.35$ vs. $M = 62.69, SD = 18.83$; $d = 0.40$). Moreover, they described a higher level of self-efficacy ($M = 12.48, SD = 2.05$ vs. $M = 11.52, SD = 2.05$; medium effect of $d = 0.53$), lower levels of adjustment problems ($M = 35.58, SD = 11.23$ vs. $M = 42.63, SD = 14.20$; $d = 0.62$) and overall intrafamilial burden ($M = 18.26, SD = 8.19$ vs. $M = 21.79, SD = 7.90, d = 0.46$), as well as a more positive intrafamilial climate ($M = 16.75, SD = 4.55$ vs. $M = 13.86, SD = 5.04$; $d = 0.50$). They also had a higher educational level ($\chi^2(1) = 17.92, p < 0.001$) with a small effect of $r = 0.28$.

4. Discussion

To the best of our knowledge, this is the first study systematically assessing effects of the COVID-19 pandemic on a population of individuals with ASD and their parents throughout Germany and Austria. Although covering a short time period of three months, results of the survey not unexpectedly revealed a significant impact of the pandemic on the lives of autistic individuals and their families. School closures and limited therapeutic support increased the burden for caregivers and had a negative impact on the mental health of children and adolescents with ASD.

4.1. Child-related variables

Many participating parents described an aggravation of autistic symptoms and overall psychopathology since the beginning of the pandemic. This finding is consistent with Panda et al. (2021) who presented the effects of COVID-19 on mental health of children and adolescents in a systematic review indicating that almost 80% of children were negatively affected by the crisis and its restrictions. Especially children with pre-existing behavioral problems including ASD and ADHD were found to have an increased risk of worsening of their symptoms during the pandemic (Panda et al., 2021).

Discontinuation of therapies was associated with increased levels of media consumption. This finding is consistent with the study of García, Lawrence, Brazendale, Leahy, and Fukuda (2021) showing heightened levels of time spent on screen and less physical activity during COVID-19 in a sample of nine adolescents with ASD. In our study sample, 41.7% of caregivers reported that their child did not have any social contacts before the outbreak of the pandemic. Current restrictions and the associated social isolation may further limit the children's opportunities to develop their socio-communicative skills in real-life social contexts (Ameis, Lai, Mulsant, & Szatmari, 2020) and exert a negative influence on comorbid symptoms of ASD (e.g., sleep problems and aggressive behavior; Fitzpatrick, Sri-voorakiat, Wink, Pedapati, & Erickson, 2016; Richdale & Schreck, 2019).

4.2. Intrafamilial situation

Our findings highlight the increase of intrafamilial burden since the beginning of the pandemic. Parents reported an aggravation of

intrafamilial arguing, aggression and physical arguments. The worsening of children's autistic symptoms and overall psychopathology was associated with increasing parental stress levels. Various studies underlined the increased care demands of children with ASD and the heightened stress level that is experienced by parents (Bonis, 2016; Manning et al., 2020; Niemczyk et al., 2019; Valicenti-McDermott et al., 2015). Disruption of routines and unpredictability (e.g., home schooling, interruption of therapies and the challenging care-taking situation) due to the pandemic may have additionally increased parental worries and resulted in even higher care needs. This presumption is consistent with answers to open-ended questions in our survey. When being asked about the need for additional support services during the crisis, 54.8% of parents expressed a desire for the resumption of school activities and even before day nursery because of the difficult caring and home-schooling situation. Similar to the findings of Manning et al. (2020), we found that higher parental stress levels were associated with a younger age of the child, an increased level of the child's overall psychopathology, and more pronounced intrafamilial burden.

Results of our regression analyses point to positive intrafamilial changes as a potential protective factor for the child's mental health. Parents rating the level of interfamilial atmosphere, reciprocal support and emotional exchange as improved during COVID-19, also reported less increase of autistic symptoms and general psychopathology in their children. Studies conducted before the onset of the pandemic confirmed the positive effects of a warm, supportive family climate on the child's psychopathology, including autism-related symptoms (Hickey et al., 2019; Klasen et al., 2015; Schulte & Petermann, 2011). Reports from both parental stress level and intrafamilial climate in our survey suggest the necessity of parental support during the pandemic in order to moderate the child's symptom severity. However, while our study design does not allow a causal explanation of this association, we assume a reciprocal process.

4.3. Socioeconomic variables

Correlation analyses indicated a negative relationship between socioeconomic variables and the exacerbation of the child's psychopathology. Including these variables in the regression analyses did not markedly improve the fit of the model. In our study sample, 58.8% reported a net income around or above the average income in Germany (3.661 € in 2018; *Einkommen privater Haushalte*, 2020). Almost half of the study population (46.8%) completed tertiary educational level; 88.9% stated to live in either a house or an apartment with garden or balcony. This means that in terms of socioeconomic conditions, we studied a small, more privileged sample of the ASD-population and the variance of SES might be small in this sample. This might partly explain why socioeconomic variables exerted only a minor influence on the child's psychopathology and the intrafamilial situation.

A rather large proportion of respondents (49.1%) described positive changes arising with the pandemic. Perceived benefits through COVID-19 were associated with 1) less increase of the child's symptom severity reported by parents and 2) higher parental capability of adjusting to the challenges and burden related to the pandemic. This result again underlines the importance of identifying and promoting parental protective factors (e.g., functional stress coping strategies and a higher self-efficacy) to enhance the family's overall well-being (Zaidman-Zait et al., 2018).

Some limitations of the study have to be considered. The study sample was not representative regarding the socioeconomic status (SES), which may limit the generalizability of our results. Furthermore, our survey aimed to capture the immediate impact of the pandemic-related lock-down on children and their families. Thus, the survey was conducted in a limited time period and based on the clinical experience of experts in the field of ASD. We did not have the chance to conduct a cross-validation of the survey. Although a significant part of our psychopathological investigations was adapted from established standardized measures (e.g., Child Behavior Checklist, CBCL), we were not able to do this for all the related survey items. In asking parents/caregivers about their perceptions of changes of autistic symptoms and general psychopathology since the beginning of the lockdown, we performed indirect measures of change in children's symptomatology. Direct measures would have required a baseline assessment in order to conduct specific pre-post comparisons, which was not available at the time when the study was conducted.

4.4. Possible implications for services

Our findings reflect a significant impact on the daily life of children with ASD and on their families shortly after the outbreak of the COVID-19 pandemic. Although the current study focused on a short time period of the beginning of the pandemic, some potential unfavorable long-term consequences of the crisis need to be considered. Even before the outbreak of the pandemic, long waiting lists of special services prevented children from receiving prompt diagnosis and treatment (Höfer et al., 2019). In the future, healthcare providers might have to intensify their use of alternative strategies to deliver interventions and diagnostic assessments. One might speculate that, for example telehealth (both tele-education and telemedicine) could be among the most practicable solutions for services, when direct contact is not possible. Although we did not assess our participants' attitudes towards or experiences with telehealth, recent studies provide first evidence on the effectiveness in the treatment of individuals with ASD (Bearss et al., 2018; Johnsson, Kerslake, & Crook, 2019). In a randomized controlled trial, a parent training of the Early Start Denver Model (Dawson et al., 2010) delivered by telemedicine was compared to Treatment as Usual (Vismara et al., 2018). Findings indicated a higher parent fidelity and satisfaction in the remote telemedicine group as compared to the community group. Moreover, one might assume that the ongoing pandemic will result in additional delay of not only intervention (see e.g. Ameis et al., 2020), but also diagnostic assessment of children in need, although this was not assessed in our study as participating parents had children already diagnosed with ASD. Nevertheless, the delivery of alternative, technology-aided diagnostic services also needs to be considered. Conti et al. (2020) suggested a remote diagnostic procedure for toddlers being at risk for ASD. This telehealth model includes a video recording of the parent-child play and three online interviews with the parents. This approach allows to identify atypical development and to initiate

individualized interventions for at-risk toddlers, when face-to face assessment is not possible.

Although alternative diagnostic and therapeutic services may be available, the current pandemic perpetuates the risk of augmenting existing inequalities by limiting the access to relevant information and support services for families with fewer resources (lower SES, single parent households or families with cognitive impairments or high workloads, as suggested by [Ameis et al., 2020](#)). In consequence, these families are at increased risk of heightened intrafamilial burden, stress levels and emergency visits in psychiatric clinics during the crisis. Alternative access to diagnostic and therapeutic services should be made available to these families at a low threshold (e.g. informing them by mail, letter). Moreover, therapeutic institutions and other services involved in the care of children with ASD should have the necessary technical equipment (e.g. web-enabled tablet with integrated camera) which they can distribute to families so that therapies can be continued online without direct contact. In addition, consideration should be given to whether periodic SARS-CoV-2 screening testing could be a useful strategy for resuming at-home services for families.

5. Conclusion

Our findings underscore the importance of two major issues: First, in times of crisis, we need to focus our attention more on those children who are especially vulnerable to sudden changes and discontinuation of support. Second, as we observe a considerable impact of parents' stress level on their children's well-being, support needs to extent to the whole family. Information gained from this study may help in preparing for future crisis situations and potential following waves of the COVID-19. In particular, low-threshold access to alternative supporting services which are tailored to the individual needs are necessary to promote mental health in challenging times.

Our study focused on a short time period with a large proportion of high functioning individuals with ASD (i.e. 76% speaking fluently, only 22.9% visiting a school for children with learning difficulties). Additional studies including more heterogeneous populations, focusing on the long-term consequences of the pandemic are needed to further clarify its impact on the life situations of individuals with ASD and their families.

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CRedit authorship contribution statement

Corinna Isensee, Benjamin Schmid, Luise Poustka, Peter Marschik, Dajie Zhang: Conceptualization, Corinna Isensee, Benjamin Schmid, Luise Poustka: Methodology, Corinna Isensee, Benjamin Schmid: Formal analysis, Corinna Isensee, Benjamin Schmid, Luise Poustka: Writing – original draft, Peter Marschik, Dajie Zhang & Luise Poustka: Writing – review & editing.

Declarations of interest

none.

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Appendix A

See [Tables A1–A6](#).

Table A1
Sample characteristics.

Variable	n	%
Caregiver Variables		
SES		
Family net income	211	100%
< 1250 €	5	2.4%
1250–1750 €	20	9.4%
1750–2250 €	23	10.9%
2250–3000 €	39	18.5%
3000–4000 €	65	30.8%
4000–5000 €	31	14.7%
> 5000 €	28	13.3%
Education ^a		
Tertiary level	102	47.2%
Higher Secondary level	74	34.2%
Lower Secondary level	39	18.1%
No education	1	0.5%
Child variables		
Autism Spectrum Disorder (ASD) Diagnosis		
Childhood autism	45	30.6%
Asperger Syndrome	77	40.9%
Atypical autism	18	9.7%
Not otherwise specified	44	16.7%
Suspected ASD diagnosis	4	2.1%
Comorbidity		
≥ 1 therapy	186	86.1%
Speech and language therapy	44	20.4%
Occupational Therapy	58	26.9%
Physiotherapy	40	18.5%
Autism therapy (including behavioural, developmental and relationship-based therapy)	129	59.7%
Other therapies ^b	53	24.5%
Level of care ^c	157	72.7%
Pharmacological medication	71	33.0%
Sibling with a psychiatric diagnosis other than ASD	48	22.5%
Sibling with ASD	29	13.4%

^a Categorization adapted from ISCED 2011 (UNESCO Institute for Statistics, 2012): lower secondary level includes graduation from Hauptschule or Realschule; higher secondary level includes Abitur, Lehre, Fachhochschule; tertiary level includes Meister, Bachelor, Master and Diplom.

^b e.g. behavioral therapy or animal-assisted therapy

^c In Germany, the level of care (Pflegergrad) is determined through evaluation by the Medical Service of the Health Insurance (MDK), if benefits of the care insurance are claimed. The higher the level of care, the more severe the disabilities.

Table A2
Perceived changes since beginning of the COVID-19 pandemic and school closure.

Variable	n	Answer	Percentage
Increase of child's pharmacological drug dosage	70	yes/no	15.7%
Treatment break (fully or partly)	203	yes/no	75.4%
More hours engaged in media	212	yes/no	59.8%
More intrafamilial arguing	206	yes/no	39.8%
More intrafamilial aggression	204	yes/no	32.7%
More intrafamilial physical arguments	202	yes/no	15.3%
Variable	n	Min/Max	M (SD)
Increase of intrafamilial burden due to			
Care-taking situation	210	0–4	2.62 (1.40)
Home-schooling	199	0–4	2.54 (1.46)
Lack of social contacts	213	0–4	2.53 (1.37)
Meaningful occupation of child throughout the day	214	0–4	2.44 (1.36)*
Lack of physical activity	211	0–4	2.34 (1.45)*
Pausing of the child's therapies	207	0–4	2.08 (1.56)*
Fear regarding development of pandemic	214	0–4	2.04 (1.25)*
Fear of getting sick with COVID-19	215	0–4	1.33 (1.20)*
Financial worries	213	0–4	1.29 (1.35)*
Pausing of own therapies	167	0–4	1.17 (1.49)*
Sum of intrafamilial burden	216	0–40	19.88 (8.11)
Sum of autistic symptoms	178	10–38	21.26 (6.20)
Sum of general psychopathology	214	8–101	60. (16.46)

* $p < 0.05$ in repeated measures analyses; "care taking situation" as reference category for multiple contrasts

Table A3
Correlation Analyses of participant characteristics and psychosocial variables.

Variables	n	M (SD)	Min/ Max	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
Child variables												
(1) Changes in autistic symptoms	178	21.26 (6.20)	10–38	1	0.68**	0.62**	0.51**	0.39**	-0.31**	-0.18	-0.17	-0.14
(2) Changes in general psychopathology	214	57.60 (16.46)	8–101	–	1	0.61**	0.46**	0.42**	-0.41**	-0.08	-0.17	-0.05
Caregiver variables												
(3) Stress level	214	27.93 (9.49)	8–60	–	–	1	0.53**	0.49**	-0.38**	-0.07	-0.08	-0.06
(4) Intrafamilial burden	216	19.88 (8.11)	0–40	–	–	–	1	0.55**	-0.31**	-0.17	-0.25**	-0.12
(5) Adjustment problems	214	38.92 (13.63)	6–74	–	–	–	–	1	-0.23**	-0.11	-0.22**	-0.13
(6) intrafamilial climate	213	14.94 (4.95)	3–30	–	–	–	–	–	1	0.01	0.06	-0.02
Psychosocial variables												
(7) Family net income	211	–	–	–	–	–	–	–	–	1	0.31**	0.37**
(8) Educational level (caregiver)	216	–	–	–	–	–	–	–	–	–	1	0.01
(9) Size of living space	212	122.23 (45.38)	18–380	–	–	–	–	–	–	–	–	1

Besides family net income and educational level (Spearman-Rho) all correlation coefficients are based on Pearson Correlation Analyses. Results of correlation analyses are Bonferroni adjusted with $p < 0.001$.
** $p < 0.001$

Table A4
Results of multiple regression analyses with changes in autistic symptoms as outcome variable, $n = 154$.

Predictors	Korr R^2	RegB	SE	β
Step 1	0.49**			
Child’s comorbidity		-0.65	0.76	-0.05
Child’s general psychopathology		0.19**	0.03	0.48
Step 2	0.53**			
Parental stress level		0.17**	0.06	0.25
Intrafamilial burden		0.04	0.06	0.06
Parental adjustment problems		0.00	0.03	0.00
Intrafamilial climate		-0.01	0.08	-0.01
Step 3	0.54			
Family net income		-0.72	0.68	-0.07
Educational level (caregiver)		-0.79	0.52	-0.01
Size of living space		-0.01	0.01	-0.04

Results shown are based on model 3 including all predictor variables.
** $p < 0.01$.

Table A5
Results of multiple regression analyses with changes in general psychopathology as outcome, $n = 154$.

Predictors	Korr R^2	RegB	SE	β
Step 1	0.50**			
Child’s comorbidity		3.22	1.75	0.10
Child’s autistic symptoms		1.03	0.17	0.41
Step 2	0.61**			
Parental stress level		0.41	0.13	0.24
Intrafamilial burden		0.20	0.14	0.10
Parental adjustment problems		0.09	0.08	0.07
Intrafamilial climate		-0.48*	0.18	-0.15
Step 3	0.61			
Family net income		1.82	1.58	0.07
Educational level (caregiver)		-0.02	1.22	0.00
Size of living space		-0.01	0.02	0.02

Results shown are based on model 3 including all predictor variables.
* $p < 0.05$.
** $p < 0.01$,

Table A6

Parents' perception of positive consequences through COVID-19, in relation to socioeconomic status and health care variables.

variables	Perceiving chances through COVID-19		test statistic	P*	effect size
	yes M (SD) / n	no M (SD) / n			
child variables					
age of child	12.35 (5.50)	12.18 (5.01)	$t(207) = -0.23$	0.821	$d = 0.03$
speech level (no) words sentences to fluent speech	17 88	15 88	$\chi^2(1) = 0.11$	0.745	$r = 0.02$
Comorbidity no yes	66 24	53 42	$\chi^2(1) = 6.20$	0.013	$r = 0.13$
autistic symptoms	19.98 (5.55)	22.68 (6.68)	$t(169) = 2.88$	0.004	$d = 0.44$
general psychopathology	55.63 (13.35)	62.69 (18.83)	$t(205) = 2.76$	0.006	$d = 0.40$
Parental/ family variables					
self-efficacy	12.48 (2.05)	11.52 (2.05)	$t(205) = -3.79$	< 0.001	$d = 0.53$
adjustment problems	35.58 (11.23)	42.63 (14.20)	$t(207) = 4.44$	< 0.001	$d = 0.62$
stress level	26.31 (9.08)	29.58 (9.82)	$t(206) = 2.52$	0.013	$d = 0.35$
intrafamilial burden	18.26 (8.19)	21.79 (7.90)	$t(207) = 3.37$	0.001	$d = 0.46$
intrafamilial climate	16.75 (4.55)	13.86 (5.04)	$t(204) = -3.58$	0.001	$d = 0.50$
socioeconomic variables					
net income					
1st percentile	16	32	$\chi^2(1) = 7.91$	0.019	$r = 0.19$
2nd percentile	70	61			
3rd percentile	16	9			
Educational level					
No education	0	1	$\chi^2(1) = 17.92$	< 0.001	$r = 0.28$
Primary level	13	26			
Lower secondary level	29	43			
Higher secondary level	64	33			
Size of living space	126.16 (41.46)	116.37 (47.37)	$t(203) = -1.57$	0.117	$d = 0.22$

* Results of t-Tests are Bonferroni adjusted with $p < 0.00625$.

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