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The impact of COVID-19 on children and adolescents with Autism Spectrum Disorder and their families: A mixed methods study protocol

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The impact of COVID-19 on children and adolescents with Autism Spectrum Disorder and their families: A mixed methods study protocol

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Abstract

Background: The COVID-19 pandemic is a challenge for everyone, particularly for children and adolescents with autism spectrum disorder (ASD). ASD is a developmental disorder that is characterized by limitations in social communication, repetitive behavioral patterns, and limited interests, and activities. Current circumstances rely heavily on the capacities which many children and adolescents with ASD and their families struggle with. It is expected that many families with children with ASD, will experience more problems due to the COVID-19 pandemic. At the same time, some may experience improved functioning, due to fewer expectations, social demands and less pressure from society. Primary aim is to identify the impact of COVID-19 on families with children with ASD. Additionally, we aim to identify risk and protective factors as well as the impact on parents and family functioning.

Methods/design: In a mixed-method study, parents of children with ASD (ages 4-21) and adolescents with ASD (ages 12-21) who were in care pre-COVID-19 at one of three large mental health care institutions in the region of Rotterdam will participate (aim 200 parents and 125 adolescents). Pre-COVID-19 baseline clinical data will be retrieved from clinical records. Participants will fill out two surveys (one during a COVID-19 peak and one thereafter) and parents are invited to participate in interviews (aim 90 participants). Surveys include measures which were included pre-COVID-19 (i.e., overall functioning and autism symptoms) as well as specific measures to identify family functioning and COVID-19 impact (e.g., parenting load, loneliness, anxiety, stress, and behavioral consequences of COVID-19). The semi-structured interviews focus on family functioning, and care- and informational needs of parents.

Ethics & Dissemination: The Medical Ethics Committee (METC) of the Erasmus MC has approved the study. Findings will be available to families of children with ASD, their care providers, the funders, autism societies, the government and other researchers.

Article summary

Strengths and limitations of this study:

1. As pre-COVID-19 clinical data is available, a natural experiment occurs in which direct comparisons in functioning can be made from pre-COVID-19 to during COVID-19 functioning of children/adolescents with ASD.

2. The mixed-method design allows a comparison between quantitative and qualitative data for clarification, nuancing, and validation (mixed methods research), as well as an exploration of unknown or unanticipated experiences and needs (qualitative research).

3. By including a large number of participants, we may identify trajectories of subgroups regarding the impact of COVID-19, identifying both risk and protective factors with regard to resilience.

4. The primary limitation is the dependence on pre-COVID-19 data from three different clinical institutions, which may mean that not all participants have the same baseline measurement(s).

5. A potential limitation is the risk that less participants may be willing to partake than expected (both at T1 and T2).

1. Introduction

The COVID-19 pandemic holds the world in its grip since it first emerged in Wuhan, China in December 2019 [1]. With millions of lives lost, a highly taxed health care system, significant social and economic disruptions and most of public life that has come to a (partial) standstill, the pandemic presents a unique challenge to all. To combat the virus and avoid future outbreaks, many countries worldwide have enforced local to national lockdown up to months at a time, and even without strict lockdowns, have developed rules of living with most including social distancing and quarantine [2]. Previous research on the effects of citywide quarantines, for example during the 2003 Severe Acute Respiratory Syndrome (SARS) outbreak, suggests lockdowns are associated with negative psychological effects including anger, confusion, and post-traumatic stress symptoms [for a review see 3]. First studies conducted during the COVID-19 lockdowns suggest a similar effect, with an increase in mental health problems like depression, anxiety, insomnia and stress [4–6].

While challenging to each and every one of us, the COVID-19 pandemic may be particularly challenging for children and adolescents with Autism Spectrum Disorder (ASD) and their families [7–11]. ASD is an early-onset neurodevelopmental condition characterized by a co-occurrence of impairments in social reciprocity and social communication, and rigid, repetitive patterns of behavior, interest, or activities (DSM-5; American Psychiatric Association 2013). Worldwide prevalence is estimated at 1% of the population [12], and many present with co-occurring conditions such as anxiety and depression [e.g., 13,14]. While ASD is best-known for its profound impact on the social-emotional domain, its impact on the non-social domain, which includes externalizing behavior, atypical responses to sensory input, difficulty processing non-verbal information and anticipating the behavior of others, should not be overlooked [15,16]. As such, navigating a COVID-19 pandemic may pose particularly challenging for those affected by ASD.

Research into how individuals with ASD deal with circumstances like the COVID-19 pandemic is practically non-existent. Even though authors indicate that individuals with ASD may pose a particularly vulnerable population [e.g., 17–20], few studies have actually investigated this. Research into the effects of life-changing events and trauma also indicates such experiences are related to mood and anxiety symptoms, in adolescents/young adults with ASD [21]. Importantly, changes over time in general psychopathology (emotional and behavioral problems) have been found to be related to quality-of-life outcome in children and adolescents with ASD [22], indicating long-term consequences as well. In addition, resilience

may be an issue as two reviews found that individuals with ASD are more likely to experience long-term negative consequences of (childhood) traumatic events [23] and that stressful life events may result in an increase in symptoms which could be perceived as ASD, although may also be post-traumatic stress symptoms [24]. A recent study by Nonweiler and colleagues [10] showed that during a lockdown in the UK as a result of the COVID-19 pandemic, children and young people with neurodevelopmental disorders (*n* = 106 with ASD) compared to neurotypicals (*n* = 82) experience more emotional and behavioral problems, and present with less prosocial behavior. However, as there is no baseline measurement, it is difficult to indicate if this difference is due to the pandemic. Considering typical ASD symptomatology, however, one could expect certain difficulties to arise in the COVID-19 pandemic.

First, the social-emotional difficulties that often present with ASD [25] may provide a challenge, as the COVID-19 pandemic has drastically changed the social landscape, with social distancing, less face-to-face social contact, more online interaction, and difficulties interpreting social cues due to face masks. Due to their social-emotional difficulties, this could lead to increased tensions, which in turn may result in difficulties in behavioral regulations as well as emotional stress in children and adolescents with ASD. Informal social interactions are less common in adolescents with ASD [26], thus online education may lead to a decrease in social contacts as well as less social cues which may aid learning. In addition, the COVID-19 measures, such as social distancing and minimizing exposure to people [27] may also result in less tangible support experienced by individuals with ASD, which has been related to emotional issues such as depression [28]. Online interactions may be beneficial, however concerns have been raised in terms of exposure to inappropriate content and cyberbullying [29,30]. Furthermore, online social interaction may not be a suitable alternative for face-to-face for all individuals with ASD. In addition, previous research has shown that feelings of loneliness and limited social support lead to more anxiety, low mood and suicidal ideation specifically in individuals with ASD [31]. As the COVID-19 pandemic may trigger feelings of loneliness as well as limit the available social support, depression, anxiety, and suicidal ideation may now be more likely in children and adolescents with ASD.

A second characteristic of ASD that may prove particularly challenging when facing a pandemic (and consequent lockdowns) is that individuals with ASD are known to present with rigid, repetitive patterns of behavior, interest, and activities [25]. Many individuals with ASD, children in particular, rely on clear structures and routines in order to function well on a day-to-day basis and minimize externalizing behavior [e.g., 32,33]. These structures and routines

are rarely subject to change under normal conditions. However, the COVID-19 pandemic measures often included lockdowns, with school and day-care closings, limited social gatherings and most of cultural, sporting or religious events cancelled. When schools and health care facilities re-open after lockdown, this often involves significant changes as well (e.g., different entrance and exit routes, online consultations, mandatory facemasks) rather than going back to business as usual, with a second wave of structure and routine disruptions as a result. In addition, there is variation in terms of how strict individuals adhere to the governmentally imposed rules and regulations [34], which can also lead to frustration and stress particularly for individuals with ASD. Such changes, the limited adherence to the rules by others, as well as the uncertainty related to the COVID-19 pandemic may all contribute to increases in behavioral and emotional problems, such as more restricted, repetitive behaviors, sleep problems, anxiety, depression and aggression [35–37].

A third important element relates to information processing abilities as seen in individuals with ASD. While individuals with ASD are often particularly skilled at processing low-level, detailed information, integrating large-scale information into a meaningful whole or incorporating various sets of information into context often proves more difficult [38]. Broadcasted or published news updates about COVID-19 hardly ever use the so-called "autism-friendly" guidelines [39,40], while using frequent updates, contrasting information and many nuances to take into account. For example, Asbury and colleagues [41] found that some children may think some of the measures are in fact punishments for something they did. A recent study by Mutluer and colleagues [36] found that the majority of children, adolescents, and young adults with ASD had difficulty understanding the COVID-19 measures. Unfortunately, feeling like the information one receives during a pandemic is inadequate or finding it difficult to stick to the guidelines (in part because of unclear information) has been associated to post-traumatic stress symptoms within the general population (Brooks et al., 2020). Post-traumatic stress symptoms have also been found in those with ASD in the COVID-19 pandemic [36], speculatively this may be an indication of the struggles this specific group has with the provided information and/or lack of autism-friendliness of the information.

Lastly, as many individuals with ASD present with comorbid problems, particularly anxiety, depression, and externalizing behaviors, in varying rates [13,14], extra concerns may rise with the COVID-19 pandemic and related measures. The social isolation is likely to increase anxiousness and depressive symptoms, particularly in those with pre-existing psychiatric problems [19,20]. Therefore, individuals with ASD, who are already more

vulnerable to comorbid symptoms, may be at an even higher risk during the pandemic of developing symptoms of behavioral problems, anxiety and depression. As discussed above, such problems may have more longer-term consequences as well [31,42]. This may mean that particularly individuals with ASD with pre-existing comorbid issues, may be extra vulnerable to the COVID-19 pandemic measures and consequences.

Friends and relatives of individuals with ASD, or parents and siblings of children with ASD, may also find themselves particularly challenged during the pandemic. Most informal support and professional mental healthcare guidance were significantly reduced due to the pandemic measures, known to be important protective factors under normal circumstances (Drogomyretska, Fox & Colbert, 2020). Informal support, particularly the satisfaction with such support, predicts family resilience (Fong, Gardiner & Iarocci, 2020), i.e., the lack of such support can decrease resilience in families. During a school-closure period in the UK it was found that a large portion of families with children with special educational needs (>80% ASD) experienced negative effects on their mental health, with more anxiety, stress and lower mood [41]. A recent study in Turkey found that mothers of children with ASD had more health anxiety, less dispositional hope, and less psychological well-being than mothers with neurotypical children during the COVID-19 pandemic [43]. Similarly, parents of children with ASD in Saudi Arabia were also negatively impacted (more stress and less emotional well-being) by the COVID-19 pandemic [44]. Relatives of individuals with ASD have to both assist their affected family members, next to potentially facing other challenges such as working or financial worries. Role confusion, meaning they have to navigate the role of parent, advocate, educator, spouse and possibly others, is most likely increased as well [45]. Overall, the COVID-19 pandemic and corresponding measures seem to result in an increase in stress and decrease in well-being, and the limited informal support may possibly impact the resilience of families with children with ASD [7,46,47].

Interestingly, while difficulties with regard to social-emotional functioning, changes to structure and routines, and difficulties with information processing or comorbidities may result in extra challenges under pandemic circumstances, it is not unlikely some of these characteristics may serve as a protective factor at the same time. As the COVID-19 pandemic results in mandatory distancing, less or no exposure to group activities and less social interaction, some individuals with ASD might feel less pressure from society to participate in everyday (social) life and typical sensory overstimulation might be reduced, or they may be able to engage more in the repetitive behaviors which sooth them and decrease anxiety [35].

Moreover, individuals with ASD may differ less from neurotypicals at the moment, as most people spent their time alone at home with little to no social activities. As such, individuals with ASD may experience less rejection or bullying, feel less stigmatized or outside the norm, possibly leading to less suffering of minority stress [41,48] and may therefore function better rather than worse [49]. Lastly, they may benefit from more online social interaction with friends as it may allow a way to improve quality of friendships with less anxiety [30]. During the COVID-19 crisis, parents also gain positive experiences in dealing with their child (e.g., maintaining a schedule for their children and setting boundaries), which may also have positive effects in the longer term (degli Espinosa, Metko, Raimondi, Impenna & Scognamiglio, 2020).

Taken together, research suggest that, while a pandemic may prove challenging to each and every individual, individuals with ASD may prove particularly vulnerable [9,e.g., 19,20]. Individuals with ASD and their families present with a number of characteristics that limit coping and resilience in light of the COVID-19 pandemic as well as the continuously changing counter-measures, making them potentially extra vulnerable for negative outcomes, such as stress, anxiety, depression, loneliness and a decline in general functioning, increase autistic symptoms, and confusion regarding the COVID-19 measures [19,20,31,35–37,39]. Moreover, previous research has shown that major-life events, trauma and stress have long-lasting impact on mental health in individuals with ASD [23], which leads to the expectation that the COVID-19 pandemic will have long term consequences for children and adolescents with ASD and their families. In addition, family members of individuals with ASD may be subject to significant stress as well, due to extra stress as well as the varying roles they have to take within their families [43,44,46]. Research investigating the effect of major-life events, like a large-scale pandemic, are limited in both scope and number, with research into children with ASD and their relatives particularly lacking. No research yet has been conducted into the impact of such a large-scale event in this target group, and knowledge from the current study can inform and improve care in both the short and long term, so that the negative impact in this vulnerable group is minimized. Similarly, no research has been conducted on such a large scale where the same life event impacts families with children with ASD at the same time, and information is available about their functioning before the event. By analyzing the impact of the COVID-19 pandemic on families with children with ASD, it is possible to examine which subgroups are specifically vulnerable to the impact of this life event and which subgroups show more resilience. This information allows for a better specification of guidelines for the mental

healthcare during and after COVID-19, as well as other impactful events, to better support families with children with ASD, and to minimize the negative impact in the long term.

The aim of the current study is threefold; (1) to investigate the impact of COVID-19 on overall functioning and autistic symptoms of the child/adolescent with ASD, as well as on family functioning and care and informational needs, in both the short- and longer-term, and (2) to investigate risk and protective factors (in light of resilience), and (3) to investigate the impact on parents, in both the short- and longer-term. The study will take place in collaboration with three mental health care institutions providing specialized care to families of children with ASD in South-Holland.

2. Methods

2.1. Study design

The study is a mixed-methods multi-center cohort study involving children and adolescents with ASD and one of their parents/guardians/caregivers (referred to as "parents"). The study will be conducted in the larger Rotterdam region of the Netherlands. Figure 1 shows the study design. Clinical data pre-COVID-19 (March 1, 2019 until March 1, 2020) of the participants will serve as baseline data (T0). Participants will be invited to join the study in January 2021 (T1) during the second lockdown in the Netherlands, and a second survey during spring of 2021 (T2) in a period with less COVID-19 infections and restrictive measures. In addition, the parents participating in the survey will be asked to partake in an interview regarding family functioning, quality of life, and care and informational needs, after filling out the T1 survey. We aim to include 30 parents per collaborating institution (i.e., total of 90). Participants are compensated for their participation, with gift vouchers for the different elements they participate in.

There are two main limitations to our design. First, baseline measurements may vary within limits between the different institutions and participants. As an inclusion criterion is pre-COVID-19 (March 2019 – March 2020) availability of the Child Behavior Checklist (CBCL) and/or the Social Responsivenes Scale (SRS-2; see measures for details) some participants may only have 1 of the measures. However, as this is an inclusion criterion there will be sufficient data to compare pre-COVID-19 functioning to during COVID-19 functioning. Second, possible loss of follow-up data at T2. Given that T0 has already taken place, there will be at least the possibility of investigating T0 to T1 functioning. In addition, our team has extensive experience

with long-term follow-up studies and will exert all efforts to minimize loss of follow-up data, such as the graded compensation.

< insert Figure 1. Study design here >

2.2. Participants

All parents with children diagnosed with ASD (4-21 years old) of whom clinical data, i.e., the Child Behavior Checklist (CBCL) and/or Social Responsiveness Scale (SRS-2), is available between March 2019 and March 2020(pre-COVID-19) at one of the three collaborating mental healthcare institutions, will be approached for participation. In addition, the adolescents/young adults (12 to 21) who are capable of providing consent (based on developmental age > 12 and IQ > 75) and filling out the self-report survey are invited to participate, with parental consent if necessary. Our expectation is that approximately 200 parents and 125 adolescents with ASD will participate.

Exclusion criteria for the study are (1) the participant (and/or parent) do not provide active consent, and (2) for self-report: children older than 12 years with a FSIQ < 75.

2.3. Sample size calculation

The three participating mental health care institutions provide care for 600+ families with children with ASD. The participation rates in previous research of this target group vary between 35% and 75%, therefore the expected number of participants will be between 210 and 400 of the 600 approached potential participants. The aim is to include a minimum of 200 participants in the parent report surveys and 125 self-report surveys, and 90 participants in the interviews.

We want to be able to detect differences with a small to medium effect size (d = 0.4 – 0.5) with 95% power. If we translate such effect sizes into clinical impact, it indicates that 25% of the surveyed group experiences a significant change [50].

Research to determine sample size for Structural Equation Model (SEM) applications has so far been inconclusive and difficult to model [e.g., 51,52]. Instead, various sample size guidelines have been proposed -- 50 observations per variable, no less than 100 observations total, 5 to 10 observations per parameter, and so on. Moreover, adequate sample size depends on the size, complexity and type of model, distribution and reliability of the variables, and strength of the relations among those variables [53,54], all of which are difficult if not impossible to predict beforehand. Recent simulation data [55,56] for complicated models,

including multiple parameters and two or more outcome variables, suggests that small to medium effect sizes ($d = 0.4 – 0.5$) reach sufficient power given a sample size of $N = 250 - 300$. For correlation analysis G*Power was used to conduct a power analysis. In order to analyze small to medium effect sizes ($d = 0.4 – 0.5$, $α = .05$), a sample size of $N = 34-59$ should reach sufficient power. For the qualitative analyses we aim to include a relatively large sample of 90 participants (30 per institution), to allow for comparison between the three mental health care institutions as well as for a sufficiently varied sample for mixed-method analyses (e.g., ASD severity; comorbidity; and IQ). Lastly this sample size will allow for inductive analyses based on specific qualitatively-oriented research questions, such as experience of agency and family dynamics, role-confusion/change and parental burden due to COVID-19. For these questions, sub-samples will be used in which sample size will be determined based on the qualitative saturation principle [57] and the sample will be selected using the at random, purposive of critical sampling [58].

Based on these calculations, to allow for both simple correlational and qualitative analyses as well as SEM/Latent Growth curve Model (LGM), we should aim for a sample size of 250-300 participants for the quantitative data. Note that, in case we cannot include 250-300 participants, SEM/LGM models can be simplified to include less variables and parameters, to still allow for sufficient power to detect differences with a small to medium effect size.

2.4. Measures

2.4.1. Demographics

Age, gender, nationality, educational level, language skills, intelligence quotient (FSIQ, and if available other indices), medication use, and family composition are obtained from the questionnaires. Gender will be scored as female, male, or other. Nationality will be extracted from the electronic patient files, based on parent nationalities the child's nationality will be determined. This will be divided into seven subgroups: Dutch, Surinamese, Turkish, Moroccan, Antillean, Cape Verdean, and other. Parents will be asked what type of education their child receives. Language skills of the child during the baseline measurement will be scored as fluent, telegraphic, no spoken language, or not specified. If an IQ test was conducted as part of the diagnostic or guidance procedure, this will be noted as well including the relevant outcome(s) of the IQ test. Lastly, the family composition will be obtained (e.g., siblings, relation to the child).

2.4.2. Overall functioning

To determine overall functioning of the children with ASD, several Achenbach System of Empirically Based Assessment (ASEBA; Achenbach & Rescorla, 2013) questionnaires will be used. At baseline, overall functioning could be reported by a parent/guardian by filling out the Child Behavior Checklist (CBCL; Achenbach, 1999), as part of standard care. Each item is scored on a 3-point Likert scale ranging from 1, Not at all to 3, Clearly to describe the behavior of the child during the last 6 months. The CBCL consists of an Internalizing (subscales: Anxious/Depressed, Somatic Complaints, and Withdrawn/Depressed) and an Externalizing domain (subscales: Rule Breaking Behavior and Aggressive Behavior). A Total Problems score can also be determined, this score gives a general view of the extent of both behavioral and emotional problems based on the scores of the two domains and the three remaining syndrome scales: Thought Problems, Social Problems, and Attention Problems. The CBCL 6-18 parent-report has high test-retest reliability, internal consistency, and criterion validity [61].

Overall functioning during the pandemic (T1 & T2) will also be assessed, for which the Brief Problem Monitor – Parent form (BMP-P; Achenbach et al., 2011), a shortened version of the CBCL. The BPM-P will be scored similar to the original CBCL on a 3-point Likert scale ranging from 1, Not at all to 3, Clearly. The internal consistency of the BPM was high, and the total score of the CBCL and the BPM-P highly correlate [63].

If the participant was ≥ 12 years at baseline, self-reported overall functioning will also be included if available, by means of the Youth Self Report (YSR; Achenbach, 1991). The CBCL and the YSR can be transformed into similar domains and syndrome scales. During the pandemic self-reported overall functioning will be assessed using the Brief Problem Monitor – Youth form (BMP-Y; Achenbach et al., 2011). Good reliability and validity have been confirmed for the Dutch version of the YSR in the Dutch population by Verhulst and colleagues [65]. The test-retest reliability of the BPM-Y varies between medium to high, and the internal consistency is acceptable to good (Achenbach et al., 2011).

2.4.3. ASD characteristics

To assess ASD characteristics within the children, the Dutch version of the parent-report Social Responsiveness Scale [SRS-2; 66], and if applicable the self-report Social Responsiveness Scale [SRS-A; 67] will be used, which can be part of baseline measurements as well. The SRS-2 will be filled out by the parent, the SRS-A is a self-report measure and will therefore be filled out by the adolescent (if ≥ 16 years old). The SRS-2 is comprised of six subscales: 1) Social

Awareness, 2) Social Cognition, 3) Social Communication, 4) Social Motivation, 5) Restricted Interests, and 6) Repetitive Behavior. The SRS-2 parent report demonstrated good sensitivity, reliability and validity [e.g., 68]. The SRS-A has satisfactory psychometric qualities [67], and consists of 64 items, which group into four dimensions: 1) Social awareness, 2) Social communication, 3) Social motivation, and 4) Restricted interests and repetitive behavior. Both on the SRS-2 and SRS-A each item is scored on a 4-point Likert scale (Not true, Sometimes true, Often true, Always true).

If other relevant diagnostic materials, for example the Autism Diagnostic Observations Scale (ADOS), are administered in addition to the SRS-2, the results of both instruments will be documented.

2.4.4. Quality of Life

To assess the quality of life of the child with ASD the Dutch version of the Pediatric Quality of Life Inventory (PedsQL; Bastiaansen et al., 2004) will be used. The PedsQL will be completed as part of the survey at T1 and T2. It will be filled out by the parent/guardian, and if the child is ≥ 12 years old, by the child as well. The items are scored on a 5-point Likert scale, ranging from "Never a problem" to "Almost always a problem". The PedsQL is comprised of four subscales: 1) Physical, 2) Emotional, 3) Social, and 4) School functioning, as well as a psychosocial health summary and a total score. Satisfactory reliability and validity are reported for the Dutch translation of the PedsQL (Bastiaansen, Koot, Bongers, Varni & Verhulst, 2004).

2.4.5. Parenting burden

To assess the parenting burden during the pandemic the Parenting Stress Questionnaire (PSQ; in Dutch: *Opvoedingsbelastingvragenlijst*; OBVL) will be used [70]. The PSQ will be completed by the parent/guardian as part of the survey at T1 and T2. The items are scored on a 4-point Likert scale, ranging from "not true' to "very true". The PSQ is comprised of five domains: 1) parent-child relationship problems, 2) parenting problems, 3) depressive mood, 4) parental role restriction, and 5) physical health problems. The instrument has a good reliability and validity [71,72].

2.4.6. Parental functioning

The subscales anxiety and depression of the Brief Symptom Inventory [BSI; 73,74] will be administered to gain insight into the functioning of parents at T1 and T2. The subscales

consist of 6 items each which are scored on a 5-point Likert scale, ranging from "not at all" to "very much".

2.4.7. Generalized anxiety in the child

To measure generalized anxiety of the child the subscale *generalized anxiety* of the Dutch Screen for Child Anxiety Related Emotional Disorders [SCARED; 75] will be used at T1 and T2. The subscale consists of 9 items and is scored on 3-point Likert scale, ranging from "not at all" to "clearly or often".

2.4.8. Impact of COVID-19

The impact of COVID-19 is explored using newly developed questions. The questions concerning the impact of COVID-19 are based, for example, on the CoRonavIruS Health Impact Survey [CRISIS; 76] and national collaborations (e.g., Grow-it Study, Generation R), commonly used overall functioning instruments such as the CBCL (Achenbach, 1999) or are developed by colleagues prof. dr. Wieser and dr. Andreatta, which will be published as part of separate research later. The COVID-19 questions provide important insights about elements which are expected to be impacted by COVID-19; e.g., general anxious/depressed feelings, atmosphere at home, effect on the child's sleeping (e.g., nightmares and problems with sleeping), social problems (e.g., loneliness), non-suicidal self-injury, suicidal thoughts, rumination, and specific COVID-19 behavior, stress, and anxiety.

2.4.9. Informational and care needs

The informational and care needs will be assed using a newly developed semi-structured interview for parents, specifically designed for the current study. The themes that will be discussed during this interview are: 1) experience of the changes, 2) emotional impact on the child, 3) emotional impact on the parent(s) or other caregiver(s), 4) informational and care needs, and 5) role confusion. Interviewers will be trained by FT to ensure uniformity in the interviews.

2.5. Statistical analysis

Data analysis include LGM, SEM, correlations and qualitative analyzes. LGM enable us to chart potential functional developments of children with ASD (from T0 until T2) and the impact of COVID-19. In LGM, subgroups can be identified. SEM enables us to analyze risk and

protective factors of COVID-19 in one or more complex models. Interviews are thematically analyzed with narrative analysis. Correlation and mixed-method analysis enable us to map the (current) care and informational needs, as well as impact on parents. Whereby the T1 and T2 survey information and the results of the semi-structured interviews are compared.

2.6. Patient and Public Involvement

Patients nor public parties were involved in the design of the study. As soon as data collection has taken place and results have been processed, participants to the study will be informed of the study results via a study newsletter suitable for a non-specialist audience.

2.7. Ethics and dissemination

Medical ethical approval for the study was provided by the Medical Ethics Committee (METC) of the Erasmus MC (MEC-2020-0720). Informed (e-)consent will be obtained prior to participation.

The study was registered on The Open Science Framework platform prior to its start [osf.io/b6ghz]. Additionally, a data management plan was created.

The EUR data vault of the university will be used for data storage and backup of the data, supported by the Erasmus Data Service Centre. All personal data will be stored with care and the researchers will act within the limits of the General Data Protection Regulation (GDPR). Study data will be de-identified as much as possible and a master linking log with identifiers will be kept and stored separately from the data, either at the clinical institutions (for quantitative data) or at the Erasmus University Rotterdam vault (for qualitative data). The data will be kept for at least 15 years (in accordance with article 454, paragraph 3 of the Medical Treatment Contracts Act, WGBO).

Due to privacy reasons, there will be restricted access to the data for further research. A request needs to be submitted to the principal investigator (L. P. Dekker) after which the Rotterdam Autism Consortium (R.A.C.; founding members are the authors on the current paper) decides if and how the data can be shared, based on ethical and privacy standards which will be defined in a Creative Commons license adapted to the requirements within the current study.

Outcomes of the study will be made available as soon as possible to participants and interested parties; to clinicians and other professionals working with families with children with ASD; the government; and Autism Associations and networks in the Netherlands and abroad,

by means of for example newsletters, social media, white papers, scientific publications (including pre-prints), meetings, and in the education of students.

3. Funding statement

4. Competing interests' statement

All authors declare that they do not have conflict of interest.

5. Authors contributions

LD & RVDH were responsible for conceptualizing the study. LD, LH and RVDH drafted the manuscript. All authors participated and contributed to the design of the study and manuscript development.

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7. Figure Captions

Figure 1. Study Design

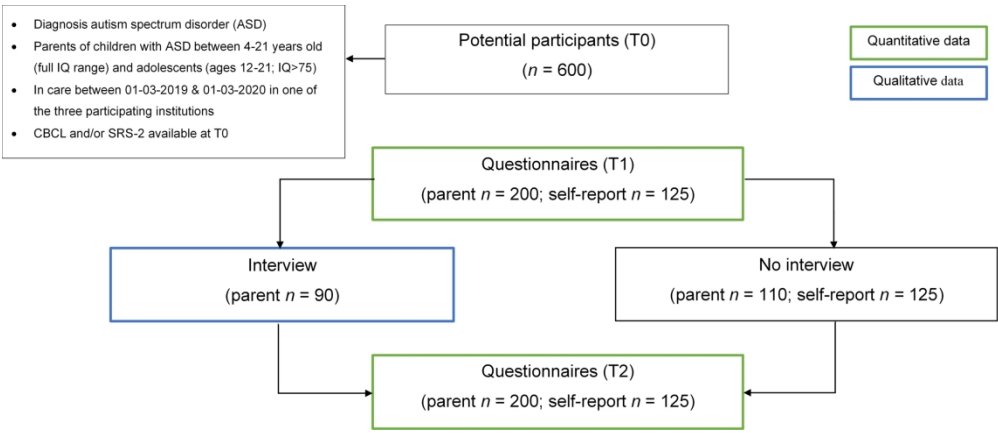- Diagnosis autism spectrum disorder (ASD)
- Parents of children with ASD between 4-21 years old (full IQ range) and adolescents (ages 12-21; IQ>75)
- In care between 01-03-2019 & 01-03-2020 in one of the three participating institutions
- CBCL and/or SRS-2 available at T0

Potential participants (T0)
(n = 600)

Quantitative data

Qualitative data

Questionnaires (T1)
(parent n = 200; self-report n = 125)

Interview
(parent n = 90)

No interview
(parent n = 110; self-report n = 125)

Questionnaires (T2)
(parent n = 200; self-report n = 125)

Figure 1. Study Design

247x104mm (300 x 300 DPI)

The impact of the COVID-19 pandemic on children and adolescents with Autism Spectrum Disorder and their families: A mixed-methods study protocol

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Manuscripts

The impact of the COVID-19 pandemic on children and adolescents with Autism Spectrum Disorder and their families: A mixed-methods study protocol

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Abstract

Background: The COVID-19 pandemic is a challenge for everyone, particularly for children and adolescents with autism spectrum disorder (ASD). ASD is a developmental disorder characterized by limitations in social communication, repetitive behavioral patterns, and limited interests, and activities. It is expected that many families with children with ASD will experience more problems due to the COVID-19 pandemic and the related public health restrictions. At the same time, some may experience improved functioning, due to fewer expectations and social demands.

Methods/design: In a mixed-method study to identify the impact of the COVID-19 pandemic, parents of children with ASD (ages 4-21) who were in care pre-COVID-19 at one of three large mental health care institutions in the region of Rotterdam participated (68 for T0, 57 for T1). The aims are (1) to investigate the impact of the COVID-19 pandemic on overall functioning and autistic symptoms of the child/adolescent with ASD, as well as parental and family functioning (QUANT-QUAL), in both the short- and longer-term, and (2) to investigate risk and protective factors (in light of resilience) (QUANT-qual), and (3) to investigate care and informational needs (QUAL-quant). Pre-COVID-19 baseline data will be retrieved from clinical records. Participants will fill out two surveys (one during a COVID-19 peak - January-May 2021 - and one thereafter). Survey participants were invited to participate in interviews ($n = 27$). Surveys include measures thar were included pre-COVID-19 (i.e., overall functioning and autism symptoms) as well as specific measures to identify family functioning and COVID-19 impact. The semi-structured interviews focus on child, parent and family functioning and care- and informational needs.

Ethics & Dissemination: The Medical Ethics Committee (METC) of the Erasmus MC has approved the study. Findings will be available to families of children with ASD, their care providers, the funders, autism societies, the government and other researchers.

Article summary

Strengths and limitations of this study:

1. As pre-COVID-19 clinical data is available, a natural experiment occurs in which direct comparisons in functioning can be made from pre-COVID-19 to during COVID-19 functioning of children/adolescents with ASD.

2. The mixed-method design allows a comparison between quantitative and qualitative data for clarification, nuancing, and validation (mixed methods research), as well as an exploration of unknown or unanticipated experiences and needs (qualitative research).

3. The primary limitation is the dependence on pre-COVID-19 data from three different clinical institutions, which may mean that not all participants have the same baseline measurement(s).

4. A potential limitation is the risk that less participants may be willing to partake than expected (both at T1 and T2).

1. Introduction

While challenging to each and every one of us, the COVID-19 pandemic may be particularly challenging for children and adolescents with Autism Spectrum Disorder (ASD) and their families [1–6]. ASD is an early-onset neurodevelopmental condition characterized by a co-occurrence of impairments in social reciprocity and social communication, and rigid, repetitive patterns of behavior, interest, or activities [7]. Worldwide prevalence is estimated at 1% of the population [8], and many present with co-occurring conditions such as anxiety and depression [e.g., 9,10]. While ASD is best-known for its profound impact on the social-emotional domain, its impact on the non-social domain, which includes externalizing behavior, atypical responses to sensory input, difficulty processing non-verbal information, and anticipating the behavior of others, should not be overlooked [11,12]. The key diagnostic criteria, related to social-emotional challenges and rigid, repetitive patterns of behavior, interest, and activities, in addition to information processing difficulties and comorbid disorders (e.g. anxiety), could lead to both an increase as well as a decrease of problems given pandemic related measures that are taken such as nation-wide lockdowns, social distancing, less face-to-face and more online social contact, and the use of face masks.

Indeed, recent studies considering the impact of the COVID-19 pandemic and its associated public health measures on individuals with ASD and their close ones show mixed results. Several authors suggest that individuals with ASD may pose a particularly vulnerable population [e.g., 13–16], yet only a handful of empirical studies have investigated the impact of the COVID-19 pandemic on individuals with ASD. For instance, a recent study by Nonweiler and colleagues [4] showed that, during a COVID-19 related lockdown in the UK, children and young people with neurodevelopmental disorders ($n = 106$ with ASD) compared to neurotypicals ($n = 82$) experienced more emotional and behavioral problems and presented with less prosocial behavior. Moreover, two Italian studies [17,18] found increased problematic behavior and intensity of autistic symptoms in children with ASD as measured during a COVID-19 related lockdown in Italy spring 2020. In addition, a large cohort study in the U.S. [19] found that the pandemic led to significant disruptions in therapies, worsened ASD symptoms and family distress. In a broader sense, the Co-Space study [20] has found that children with special educational needs and/or neurodevelopmental difficulties (among whom children with ASD) have elevated levels of behavioral, emotional, and attentional difficulties, which have not subsided post-lockdown in this group contrary to neurotypicals. Along that line, a study by Mutluer et al. [21] revealed that special needs education was either partially or

completely suspended as during the COVID-19 pandemic, and noted more behavioral problems. Other authors have also suggested that school disruption may potentially result in frustration [22]. The increased complexity of social interaction with different social cues in online communication, a decrease in exposure to social situations, routines that have been broken, disrupted mental health care services, and information and public health restrictions which are constantly changing may all contribute to increases in behavioral and emotional problems, such as more restricted, repetitive behaviors, sleep problems, anxiety, depression and aggression [21,23,24].

Along with individuals with ASD, relatives of individuals with ASD, like their parents or siblings, may also find themselves particularly challenged during the pandemic. Most informal support and professional mental healthcare guidance were significantly reduced due to the pandemic measures, known to be important protective factors for parents and families under normal circumstances [25]. Informal support, particularly one's satisfaction with informal support, is known to predict family resilience [26], i.e., a lack thereof is likely to decrease such family resilience. Actually, during a school-closure period in the UK, it was found that a large portion of families with children with special educational needs (>80% ASD) experienced negative effects on their mental health, with more anxiety, stress, and lower mood [27]. Moreover, a recent COVID-19 study in Turkey found that mothers of children with ASD had more health anxiety, less dispositional hope, and less psychological well-being compared to mothers with neurotypical children [28]. Similarly, parents of children with ASD in Saudi Arabia were negatively impacted (i.e., more stress and less emotional well-being) by the COVID-19 pandemic [29]. It seems that particularly parents of school-aged children had an increase in overall distress, which may increase their risk of crises [19]. Relatives of individuals with ASD have to both assist their affected family members, and face other potential challenges such as work demands or financial worries [30]. Role confusion, i.e., having to navigate the role of parent, advocate, educator, spouse, and so on, is most likely increased as well [31]. Overall, the COVID-19 pandemic and corresponding measures seem to affect relatives of individuals with ASD by an increase in stress and decrease in overall well-being family resilience [1,17,19,26].

Interestingly, while the beforementioned ASD characteristics may thus leave individuals with ASD as well as their relatives at increased risk, some of these characteristics may also serve as a protective factor at the same time [32]. As the COVID-19 pandemic includes mandatory distancing, less-to-no exposure to group activities, and less social

interaction, some individuals with ASD may benefit from the measures related to the pandemic [33]. For example, they might feel less pressured by society to participate in everyday (social) life, typical sensory overstimulation might be reduced, or they may be able to engage more in the repetitive behaviors which soothe them and decrease anxiety [23]. Moreover, individuals with ASD may, all of a sudden, feel less different from neurotypicals, as during the pandemic most people spent their time alone at home with little-to-no social activities. As such, individuals with ASD may experience less rejection or bullying, feel less stigmatized or outside the norm, reducing so-called minority stress [27,34] and potentially improving overall functioning [35]. Lastly, individuals with ASD may benefit from more online compared to offline social interaction with friends as an online environment may elicit less anxiety, allowing friendships to blossom [36]. During the COVID-19 pandemic, parents to individuals with ASD may also have gained new, positive experiences in dealing with their child (e.g., maintaining a schedule for their children, learning new skills to their child and setting boundaries), resulting in potential positive long-term effects [33,37].

Taken together, previous research suggests that, while a pandemic may prove challenging to each and every individual, individuals with ASD and their relatives may prove particularly vulnerable [e.g., 3,15,16,18]. Individuals with ASD and their relatives present with characteristics that may limit coping and resilience in light of the COVID-19 pandemic as well as the continuously changing public health measures, putting them at risk for negative outcomes, such as stress, anxiety, depression, loneliness, a decline in general functioning, increase autistic symptoms, and confusion regarding the COVID-19 measures [e.g., 15,16,18,19,21,23,24,38,39]. Moreover, previous research has shown that major-life events, trauma, and stress can have a long-lasting impact on mental health in individuals with ASD [40], which leads to the expectation that the COVID-19 pandemic too will have long-term consequences for individuals with ASD and their families. In addition, relatives of individuals with ASD may be subject to significant stress as well, due to extra role confusion and the extra burdens put on them [17,28,29].

However, all but one of the beforementioned research studies lack a direct pre-COVID-19 baseline measure. Some studies *asked* participants if they experienced an increase in symptoms or difficulties as a result of the pandemic or its consequent measures [e.g. 17], or compared a subgroup to a larger cohort [e.g. 19], or compared different groups (e.g. neurotypicals with a group with neurodevelopmental disorders [e.g. 4]), but no direct baseline measure was available to compare during COVID-19 with pre-COVID-19. In addition, the

results depend on either quantitative [e.g. 18] or qualitative data [e.g. 30]. Given the limitations of these studies, it gives a limited understanding of the impact of the current pandemic as specific to individuals with ASD and their families. To date, no research has been conducted into the impact of a large-scale event in this target group using a baseline measure as well as a mixed-method design.

The aim of the current study is threefold; (1) to investigate the impact of the COVID-19 pandemic on overall functioning and autistic symptoms of the child/adolescent with ASD, as well as parental and family functioning (QUANT-QUAL), in both the short- and longer-term, and (2) to investigate risk and protective factors (in light of resilience) (QUANT-qual), and (3) to understand the care and information needs during such an event (QUAL-quant). The study will take place in collaboration with three mental health care institutions providing specialized care to families of children with ASD in South Holland.

This unique and state-of-the-art study design can inform and improve care in both the short- and long-term so that any negative impact of the pandemic for this group is minimized. Moreover, the information resulting from this project will allow for a better specification of guidelines for mental healthcare both during and after the COVID-19 pandemic, as well as other future impactful events, to better support individuals with ASD and their families and to minimize any long-term negative impact.

2. Methods

2.1. Study design

This study is a mixed-method multi-center cohort study involving parents/guardians/caregivers (referred to as "parents") of a child or adolescent with ASD (see Figure 1). The study will be conducted in the larger Rotterdam region of the Netherlands. Clinical data pre-COVID-19 (March 1, 2019, until March 1, 2020) of the participants will serve as baseline data (T0). Participants were invited to join the study during the second lockdown in the Netherlands between January 4, 2021, and May 31, 2021 (T1). Potential participants were invited to partake in the study through their clinical institution primarily via e-mail with an informational brochure including a consent form. Consent could be given either on paper or online. If no response was received for 1 week the research assistant did a follow-up via telephone. The quick turnaround was due to the time-sensitivity of COVID-19 research. Participants who did not want to partake were asked to answer a few questions on their motivation, to allow for some attrition analyses later. Active consent was acquired to share any unforeseen but relevant findings to medical

health professionals if needed. Participants were informed they could stop with the study at any point, without it impacting their care as usual and without providing a reason. In addition, they were informed that data collected up until the point that they indicated they no longer wanted to participate, will be used.

For the quantitative strand of the study, following informed consent, participants received an invitation link to an online survey. A second survey is tentatively planned for the Fall of 2021 (T2; expected to run from mid-September until December 1st, 2021) in a period with fewer COVID-19 infections and less restrictive public health measures.

For the qualitative strand of the study, participants who participated in the survey at T1 were invited to a semi-structured interview regarding family functioning, quality of life, and care, and informational needs. All interviewees at T1 will be invited again for an interview at T2. The semi-structured interview covers spontaneous reporting and prioritizing (A), adaptations experienced (B), emotional impact on the child (C) and the parent (D), information and care needs (E), role confusion (F), and experiences with the study and/or need for care post-study (G) (for more detail, see appendix A).

Participants receive financial compensation for their participation (T1 survey 10€; T2 survey 25€; T1 interview 25€; and T2 interview 50€). A graded compensation was set up to promote long-term participation and minimize drop-out.

< insert Figure 1. Study design here >

2.2. Participants

All parents with children diagnosed with ASD (4-21 years old) of whom clinical data, i.e., the Child Behavior Checklist (CBCL) and/or Social Responsiveness Scale (SRS-2), is available between March 2019 and March 2020 (pre-COVID-19) at one of the three collaborating mental healthcare institutions, were approached for participation ($n = 213$). In total 68 parents provided consent for gathering T0 data. At T1, 57 parents of children and adolescents with ASD participated in the survey. Sampling for the interview was open and voluntary (self-selection); in total 27 parents signed up for participation and participated in the interview. In all future publications for which quantitative and/or qualitative data is used, the demographic characteristics of that subsample will be reported. Exclusion criterium for the study is the participant does not provide active consent,.

Participants were informed that clinical follow-up, support, or referral by clinically trained team members was available in case of adverse effects of study participation.

2.3. Sample size calculation

The aim is to detect differences with a small to medium effect size ($d = 0.4 - 0.5$) with 95% power. When translating such effect size in terms of clinical impact, this would mean 25% of the surveyed group experiences a significant change [41].

For the quantitative data, aiming to investigate the impact of the COVID-19 pandemic as well as identify the risk/protective factors, data will be evaluated using t-tests, to identify impact (T0 vs T1/T2), and single- or multiple regression, to identify variables which may explain (a change in) functioning at T1/T2 compared to T0. As such, power calculations using G*Power indicate a sample size of $N = 34$-59 for correlations, and a sample of $N = 45 - 70$ for regression analyses should result in sufficient power.

For the qualitative data, no a priori power analysis is conducted. At the end of the survey at T1 participants were asked if they wanted to also participate with the interviews. In total 27 parents participated in the interviews. This sample size will allow for inductive analyses based on specific qualitatively oriented research questions, such as the experience of agency and family dynamics, role-confusion/change and parental burden due to the COVID-19 pandemic. For these questions, sub-samples will be used in which sample size will be determined based on the qualitative saturation principle [42] and the sample will be selected using the at random, purposive of critical sampling [43]. As an example, for the impact of COVID-19 on the families (research question 4) we will use a grounded theory framework to capture the development of experiences within families. For this question, we do not exclude participants a priori but analyze the full sample until saturation is reached (i.e., random sampling until saturation). For a research question on the parental burden, we entertain a mixed-method design in which we use quantitative data to select a sample with a score of xx or higher on questionnaire xx / "yes" on item xx (i.e., purposive selection).

2.4. Measures

2.4.1. Demographics (T0, T1, T2)

Age, gender, nationality, educational level, language skills, intelligence quotient (FSIQ, and if available other indices), medication use, and family composition are obtained from the surveys or from clinical records. Gender will be scored as female, male, or other. Nationality will be

extracted from the electronic patient files, based on parent nationalities the child's nationality will be determined. This will be divided into seven subgroups: Dutch, Surinamese, Turkish, Moroccan, Antillean, Cape Verdean, and other. Parents will be asked what type of education their child receives (e.g., primary or secondary, regular or special education) during the survey. Language skills of the child during the baseline measurement will be scored as fluent, telegraphic, no spoken language, or not specified, if available from clinical records. If an IQ test was conducted as part of the diagnostic or guidance procedure, this will be noted as well including the relevant outcome(s) of the IQ test. Lastly, the family composition will be obtained (e.g., single or partnered parenting, siblings, relation to the child in question).

2.4.2. Overall functioning (T0, T1, T2)

To determine overall functioning of the children with ASD, several Achenbach System of Empirically Based Assessment [ASEBA; 44] questionnaires will be used, which are commonly used in the clinical care institutions for youth (up to the age of 21). At baseline, overall functioning could be reported by a parent/guardian by filling out the Child Behavior Checklist [CBCL; 45], as part of standard care. Each item is scored on a 3-point Likert scale ranging from 1, Not at all to 3, Clearly to describe the behavior of the child during the last 6 months. The CBCL consists of an Internalizing (subscales: Anxious/Depressed, Somatic Complaints, and Withdrawn/Depressed) and an Externalizing domain (subscales: Rule-Breaking Behavior and Aggressive Behavior). A Total Problems score can also be determined, this score gives a general view of the extent of both behavioral and emotional problems based on the scores of the two domains and the three remaining syndrome scales: Thought Problems, Social Problems, and Attention Problems. The CBCL 6-18 parent-report has high test-retest reliability, internal consistency, and criterion validity [46].

Overall functioning during the pandemic (T1 & T2) will also be assessed, for which the Brief Problem Monitor – Parent form [BPM-P; 47], a shortened version of the CBCL. The BPM-P will be scored similar to the original CBCL on a 3-point Likert scale ranging from 1, Not at all to 3, Clearly. The internal consistency of the BPM was high, and the total score of the CBCL and the BPM-P highly correlate [48].

If the participant was ≥ 12 years at baseline, self-reported overall functioning will also be included if available, by means of the Youth Self Report [YSR; 49]. The CBCL and the YSR can be transformed into similar domains and syndrome scales. Good reliability and validity

have been confirmed for the Dutch version of the YSR in the Dutch population by Verhulst and colleagues [46].

2.4.3. ASD characteristics (T0,T1,T2)

To assess ASD characteristics within the children, the Dutch version of the parent-report Social Responsiveness Scale [SRS-2; 50], and if applicable the self-report Social Responsiveness Scale [SRS-A; 51] will be used, which can be part of baseline measurements as well. The SRS-2 will be filled out by the parent, the SRS-A is a self-report measure and will therefore be filled out by the adolescent (if $\geq$ 16 years old). The SRS-2 is comprised of six subscales: 1) Social Awareness, 2) Social Cognition, 3) Social Communication, 4) Social Motivation, 5) Restricted Interests, and 6) Repetitive Behavior. The SRS-2 parent report demonstrated good sensitivity, reliability, and validity [e.g., 52]. The SRS-A has satisfactory psychometric qualities [51], and consists of 64 items, which group into four dimensions: 1) Social awareness, 2) Social communication, 3) Social motivation, and 4) Restricted interests and repetitive behavior. Both on the SRS-2 and SRS-A each item is scored on a 4-point Likert scale (Not true, Sometimes true, Often true, Always true).

If other relevant diagnostic materials, for example, the Autism Diagnostic Observations Scale (ADOS), are administered in addition to the SRS-2, the results of both instruments will be documented.

2.4.4. Quality of Life (T1& T2)

To assess the quality of life of the child with ASD the Dutch version of the Pediatric Quality of Life Inventory [PedsQL; 53] will be used. The PedsQL will be completed as part of the survey at T1 and T2. It will be filled out by the parent/guardian, and if the child is $\geq$ 12 years old, by the child as well. The items are scored on a 5-point Likert scale, ranging from "Never a problem" to "Almost always a problem". The PedsQL is comprised of four subscales: 1) Physical, 2) Emotional, 3) Social, and 4) School functioning, as well as a psychosocial health summary and a total score. Satisfactory reliability and validity are reported for the Dutch translation of the PedsQL [53].

2.4.5. Parenting burden (T1& T2)

To assess the parenting burden during the pandemic the Parenting Stress Questionnaire (PSQ; in Dutch: *Opvoedingsbelastingvragenlijst*; OBVL) will be used [54]. The PSQ will be

completed by the parent/guardian as part of the survey at T1 and T2. The items are scored on a 4-point Likert scale, ranging from "not true' to "very true". The PSQ is comprised of five domains: 1) parent-child relationship problems, 2) parenting problems, 3) depressive mood, 4) parental role restriction, and 5) physical health problems. The instrument has good reliability and validity [55,56].

2.4.6. Parental functioning (T1& T2)

The subscales anxiety and depression of the Brief Symptom Inventory [BSI; 57,58] will be administered to gain insight into the functioning of parents at T1 and T2. The subscales consist of 6 items each which are scored on a 5-point Likert scale, ranging from "not at all" to "very much".

2.4.7. Impact of COVID-19 (T1& T2)

The impact of COVID-19 is explored using a variety of questions which provide important insights about elements that are expected to be impacted by COVID-19; e.g., general anxious/depressed feelings, the atmosphere at home, effect on the child's sleeping (e.g., nightmares and problems with sleeping), social problems (e.g., social isolation and loneliness), non-suicidal self-injury, suicidal thoughts, rumination, and specific COVID-19 elements like experience of infection, behavior, stress, and anxiety (e.g. has child/parent been infected, which preventative measures does the child/parent take, what is the level of confidence in the governmental approach to the pandemic, how worried is the child/parent about becoming sick, how has COVID-19 impacted the work/income of the parent, and any positive experiences related to the pandemic). Some of the questions concerning the impact of COVID-19 are based, for example, on the CoRonavIruS Health Impact Survey [CRISIS; 59] and national collaborations (e.g., Grow-it Study, Generation R), or are commonly used overall functioning instruments such as the CBCL (Achenbach, 1999). These questions have not all been validated (yet).

2.4.8. Informational and care needs (T1& T2)

The informational and care needs will be assed using questions regarding informational source for child and parents, as well as questions regarding use of care, adaptations made due to COVID-19 and the experience with care during COVID-19, specifically designed for the current study.

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2.4.9. *Semi-structured interview (T1& T2)*

Family functioning, parental load, and the informational and care needs will be assessed using a newly developed semi-structured interview for parents, specifically designed for the current study. The themes that will be discussed during this interview (see Appendix A) are: 1) spontaneously reported experiences of COVID-19 measures (A), experienced changes in daily life / symptoms /family life (B), emotional impact on the child (C) and the parent (D), information and care needs (E), role confusion (F) and experiences with the study and/or need for care post-study (G - validation & quality control). Interviewers will be trained by FT to ensure uniformity in the interviews. Interviews will be transcribed verbatim by a professional company. Interviews at T1 were administered over the phone or by video calling.

2.5. Analyses

As both the quantitative and qualitative strands (help) answer our research questions, they each carry equal weight in the umbrella/overall design yet will be entertained in various ways as appropriate per subquestion and integration of strands is done accordingly. The primary research questions we aim to answer: 1) what is the impact of the COVID-19 pandemic on the children and which risk factors can be identified (QUANT-qual); 2) what is the impact of COVID-19 on parenting/the parents including risk factors (QUANT-QUAL); 3) does COVID-19 impact children/adolescents with ASD differently from typically developing children/adolescents and are there risk/resilience factors (QUANT); 4) what is the impact of COVID-19 on the families (QUAL-quant); and 5) what are the care and informational needs of the participants (QUAL-QUANT). Depending on the research question, emphasis of the paradigm may differ as well as time order decisions [60]. Research integrity is monitored and reported in each study, following the guidelines of Levitt et al. [61] in line with the specific designs of each study.

For research questions which rely solely on quantitative data (QUANT) common quantitative analysis methods, including t-tests, single and multiple regression, repeated-measures ANOVA's, and correlations will be employed. For research questions for which quantitative data is supplemented with qualitative data (QUANT-qual) the design is sequential[62,63], where quantitative data is reported first, and qualitative data is used to support/deepen/illustrate/clarify the findings (deductive analyses). In this design, the relevant parts of the interview will be used from the entire sample (a priori sampling).

For research questions in which qualitative data only (QUAL) or substantiated with quantitative data (QUAL-quant), is used, inductive analyses are utilized until saturation based on grounded theory principles. Here, without pre-defined hypotheses, either overarching themes/dynamics are identified based on the qualitative data which for some questions can be substantiated/validated/compared to quantitative data. Alternatively, quantitative data may be used to identify a relevant subgroup (e.g. age - deductive/a priori sampling) after which qualitative data is used to answer the research question [64]. Qualitative data is therefore analyzed both deductively and inductively depending on the research question.

2.6. Patient and Public Involvement

Patients nor public parties were involved in the first design of the study given the urgency of the study. However, clinicians took part in the design of the study. In addition, after funding but prior to ethical approval was acquired several parents/patients (who were not participants) were involved to discuss the study and design as proposed. As soon as data collection has taken place and results have been processed, participants to the study will be informed of the study results via a study newsletter suitable for a non-specialist audience.

2.7. Ethics and dissemination

Medical ethical approval for the study was provided by the Medical Ethics Committee (METC) of the Erasmus MC (MEC-2020-0720). Informed (e-)consent will be obtained prior to participation.

The study was registered on The Open Science Framework platform prior to its start [osf.io/b6ghz]. Additionally, a data management plan was created.

The EUR data vault of the university will be used for data storage and backup of the data, supported by the Erasmus Data Service Centre. All personal data will be stored with care and the researchers will act within the limits of the General Data Protection Regulation (GDPR). Study data will be de-identified as much as possible and a master linking log with identifiers will be kept and stored separately from the data, either at the clinical institutions (for quantitative data) or at the Erasmus University Rotterdam vault (for qualitative data). The data will be kept for at least 15 years (in accordance with article 454, paragraph 3 of the Medical Treatment Contracts Act, WGBO).

Due to privacy reasons, there will be restricted access to the data for further research. A request needs to be submitted to the principal investigator (L. P. Dekker) after which the

Rotterdam Autism Consortium (R.A.C.; founding members are the authors on the current paper) decides if and how the data can be shared, based on ethical and privacy standards which will be defined in a Creative Commons license adapted to the requirements within the current study.

Outcomes of the study will be made available as soon as possible to participants and interested parties; to clinicians and other professionals working with families with children with ASD; the government; and Autism Associations and networks in the Netherlands and abroad, by means of for example newsletters, social media, white papers, scientific publications (including pre-prints), meetings, and in the education of students.

3. Discussion

The difficulties that often present with ASD [7] provides a challenge, as the COVID-19 pandemic has drastically changed the social and educational landscape, with social distancing, less face-to-face social contact, more online interaction, and difficulties interpreting social cues due to face masks. Due to their social-emotional difficulties, this could lead to increased tensions, which in turn may result in difficulties in behavioral regulations as well as emotional stress in children and adolescents with ASD [e.g., 18,19]. In addition, many individuals with ASD, children in particular, rely on clear structures and routines in order to function well on a day-to-day basis and minimize externalizing behavior [e.g., 65,66]. These structures and routines are rarely subject to change under normal conditions. However, the COVID-19 pandemic measures often included lockdowns, with school and day-care closings, limited social gatherings, and most of cultural, sporting or religious events cancelled. When schools and health care facilities re-open after lockdown, this often involves significant changes as well (e.g., different entrance and exit routes, online consultations, mandatory facemasks) rather than going back to business as usual, with a second wave of structure and routine disruptions as a result. In addition, there is variation in terms of how strict individuals adhere to the governmentally imposed rules and regulations [67], which can also lead to frustration and stress particularly for individuals with ASD. Lastly, as many individuals with ASD present with comorbid problems, particularly anxiety, depression, and externalizing behaviors, in varying rates [9,10], extra concerns may arise with the COVID-19 pandemic and related measures. Simultaneously, some individuals with ASD may thrive due to decreased typical stressors [e.g., 32]. The current study attempts to identify the impact of the public health measures on children with ASD and their families, both positive and negative, the relevant protective and risk factors,

and the care and informational needs of this population during these challenging times in a mixed-method design.

Although the project is still ongoing, there are two noteworthy limitations to our design. First, baseline measurements may vary within limits between the different institutions and participants. As an inclusion criterion is pre-COVID-19 (March 2019 – March 2020) availability of the Child Behavior Checklist (CBCL) and/or the Social Responsiveness Scale (SRS-2; see measures for details) some participants may only have 1 of the measures. However, as this is an inclusion criterion there will be sufficient data to compare pre-COVID-19 functioning to during COVID-19 functioning. Second, possible loss of follow-up data at T2. Given that T0 and T1 have already taken place, there will be at least the possibility of investigating T0 to T1 functioning. In addition, our team has extensive experience with long-term follow-up studies and will exert all efforts to minimize loss of follow-up data, such as the graded compensation. That said, there are also several noteworthy strengths to mention. First, having pre-COVID-19 data which can be compared to during COVID-19 data, we can more objectively determine the impact of the COVID-19 pandemic on the functioning of children with ASD and their families. Second, the mixed-method design allows for a comprehensive understanding as well as unique insight into the functioning of families with children with ASD during extremely challenging times. Third, a wide range of constructs is being assessed which allows for a comprehensive overview of functioning during the pandemic.

5. **Competing interests' statement**

All authors declare that they do not have conflict of interest.

6. **Authors contributions**

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LD & RVDH were responsible for conceptualizing the study. LD, LH, and RVDH drafted the manuscript. LD, RVDH, and FT revised the manuscript after reviewer feedback. AL, KV, DB, LTH, PDN, GD, WE provided access and assisted in drafting participants. LD, LH, AL, KV, DB, LTH, PDN, GD, WE, EVR, FT, and RVDH all participated and contributed to the design of the study and manuscript development.

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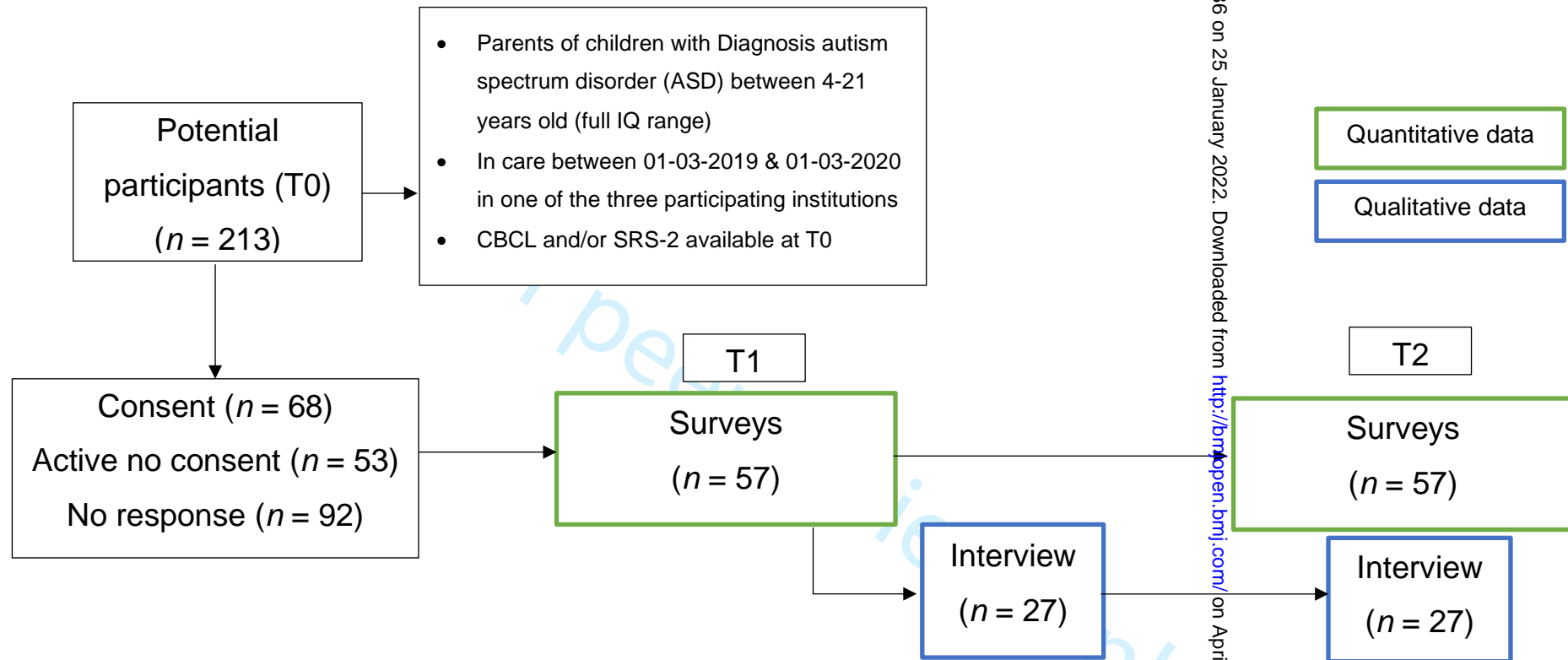54 Vermulst A, Kroes G, Meyer RD, *et al. Handleiding OBVL*. 2015.

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8. Figure Captions

Figure 1. Study Design

Potential participants (T0)

(n = 213)

- Parents of children with Diagnosis autism spectrum disorder (ASD) between 4-21 years old (full IQ range)
- In care between 01-03-2019 & 01-03-2020 in one of the three participating institutions
- CBCL and/or SRS-2 available at T0

Quantitative data

Qualitative data

Consent (n = 68)

Active no consent (n = 53)

No response (n = 92)

T1

Surveys

(n = 57)

T2

Surveys

(n = 57)

Interview

(n = 27)

Interview

(n = 27)

Interview Guide Autism & COVID-19

Welcome & Thank you for participating

In this interview we are curious about your experience of the Covid-19 measures. I usually use the word covid, but sometimes maybe corona. I always mean the situation that arose with the announcement of national measures due to the corona virus in March 2020.

We would like to ask you to tell us in your own words about the changes you have experienced in your situation, for example at home, at school, at work and in the care context of your child. It's about your experience, in your words and in your order. It doesn't have to be a well-developed story, you can just tell what comes to mind. There are no right and wrong answers and the interviewer is not surprised by anything.

The interviewer will continue to ask for explanations and details. If you do not understand a question or find it difficult, you can ask the interviewer for clarification. If you don't want to or can't answer a question, that's always okay. If you want to pause or finish, you can also indicate that.

Can I say you and you? (*in Dutch there is a more formal form of addressing individuals*)

Takes about an hour
Do you have any questions before we start?

Do you still agree to record this interview?
Then I start recording now.

(intro 5 min)

A. Spontaneous reporting & prioritization	(10 min)

Let's start with your experience of the corona crisis.

1. *Can you tell us how you experienced the Covid situation?*

   Points of attention interview-intro:
   • Intro at the **emotional level**!
   • Invite to speak **spontaneously**
   • Carefully probe for **prominence** of experiences: what weighed the most, which changes were the most disruptive?
   • General **tenor**: positive, negative, double, ambivalent?
   • Form an impression of **balance**: focus mainly on child? Where is parent in the story (present/absent)?

B. Perceived change - concrete & factual questioning   **(10 min)**

I would like to ask a few more concrete things, so that I have a good idea of how the corona crisis has changed the situation for you and your child.

2. *Can you outline what concrete things have changed in the Covid circumstances?*

Assess actual changes
   a. home situation & family dynamics
   b. care context child
      (Pay attention to multidisciplinary → per institution and relationship between institutions)
   c. school
   d. work
   e. political & social

3. *Can you explain how these things differ in concrete terms from the situation before Covid?*

   - **Ask per situation for a concrete comparison pre-post Covid**

   - **How would you characterize this change?**
     • Well-arranged to badly arranged
     • Well arranged to better arranged
     • Badly arranged to worse arranged
     • Badly arranged to better arranged
     • Not arranged to well arranged
     • Not arranged to badly arranged
     • Not settled & still not settled

C. Emotional impact child - feeling level   **(5 min)**

(refer to spontaneous speaking A for transition). You already said that…
I would like to know more about the impact of the corona crisis on your child's emotional life.)

4. *How has your child reacted to the Covid measures?*

   - *How has this affected your child's well-being?*

   Assess specifically:
   - Structure & Daily planning
   - Sleeping & Eating
   - Feeling Level:
     o General: emotion, emotion regulation
     o ASD-specific: symptomatic handling of emotions
     o Covid-specific: fear, (un)rest, (in)understanding?

o Comparison of brothers/sisters/nephews/neighbors? → compare

5. *Can you describe where and how your child normally feels safe/unsafe?*

Assess specifically:
• Indoor/outdoor
• Significant others

6. *Has the sense of indoor/outdoor security changed due to Covid?*
   - *Is this Covid-specific.. (eg fear of the virus)*
   - *…or response to Covid measures (eg response to uncertainty/grey area)*
   - *…or reaction to reaction of others (eg others are more difficult to gauge)*

D. D. Emotional impact parent(s): emotional level   **(5 min)**

(transition from C.)

7. *How are you?*

   - you as a person?
   - Your emotions/fears/concerns regarding the child?
   - Your emotions/fears/concerns regarding work (own/partner)?
   - Your emotions/fears/concerns about society/future?

8. *What is it like for you that these questions are being asked?*

   - *Who usually asks you this question?*
   - *Is there sufficient attention for you as a person?*
   - *Can you take care of yourself sufficiently in these circumstances?*

   Assess per answer:
   - *Would you specifically attribute these experiences to Covid?*
   - *If no: are they comparable to pre-Covid?*
   - *Or: have they become magnified/ are you more aware of it because of Covid?*

9. *How do the current circumstances affect your relationship with (important) others?*

   - *Wait for spontaneous reporting FIRST; WAIT to provide examples-others. Then assess:*
     o *Partner*
     o *Siblings → do they have diagnoses?*
     o *Family*
     o *Friends*
     o *Babysitter/nanny*

   - *Would you specifically attribute this to Covid?*

E. Information and care needs	(10 min)

I would like to ask you a few more things about the provision of information during the corona crisis, and the care you or your child received or would have liked to receive during this period.

10. *Did you miss care <u>due to</u> Covid measures?*
- *Were others involved besides formal care & nuclear family?*
  - ○ *For example: parents, babysitter..*

- *What care would have been helpful to you?*
  - i. *For child*
  - ii. *For parent/family*

- *How would you have liked to receive this care?*

11. *Did you receive care via (video) calling?*

- *If yes: how did you experience this?*
- *If yes: how did your child experience this?*

12. *How did you experience the information provided about Covid?*

Assess Specific:
- *From the government*
- *From institutions/school/care network*

13. *Did you miss information?*
- *Has your child indicated that he/she has missed information?*

- *Which information provision would have been helpful to you?*
  - i. *For child*
  - ii. *For parent/family*

- *How would you like to receive this information provision?*

F. Roleconfusion	(5 min)

(transition from E)

14. *As a parent, you were also an information provider to your child. How did you experience this?*

15. *How did you experience translating information provided from government/institutions to your child?*

16. Did you use the COVID-19 signpost sheet on the NVA (Dutch Autism Association) website?

17. What would have been helpful to you in this dual role?

18. These questions were about Covid. Are there things we can learn from this for more regular times and/or special circumstances?

- *What are the most important lessons for you to be learned from the Covid crisis with regard to ASD care and information provision?*

G. Survey experience (5 min)

19. Are there things I didn't ask, but that are important to understand your story?

20. How did you experience this interview?

21. How did you experience the questionnaires?

- *Did you request support?*
- *Has your child requested support?*

Thank you for your participation.

As agreed, you will receive a newsletter with our research findings as soon as the research has been completed.

If you still have questions after this interview, or if you want to add something, you can always send the researchers a message.

If you notice that this interview raises a new care need in you, please let the researchers know. We can always think along with you.

Thank you again for your participation

(closing 5 min)

The impact of the COVID-19 pandemic on children and adolescents with Autism Spectrum Disorder and their families: A mixed-methods study protocol

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The impact of the COVID-19 pandemic on children and adolescents with Autism Spectrum Disorder and their families: A mixed-methods study protocol

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Abstract

Background: The COVID-19 pandemic is a challenge for everyone, particularly for children and adolescents with autism spectrum disorder (ASD). ASD is a developmental disorder characterized by limitations in social communication, repetitive behavioral patterns, and limited interests, and activities. It is expected that many families with children with ASD will experience more problems due to the COVID-19 pandemic and the related public health restrictions. At the same time, some may experience improved functioning, due to fewer expectations and social demands.

Methods/design: In a mixed-method study to identify the impact of the COVID-19 pandemic, parents of children with ASD (ages 4-21) who were in care pre-COVID-19 at one of three large mental health care institutions in the region of Rotterdam participated (68 for T0, 57 for T1). The aims are (1) to investigate the impact of the COVID-19 pandemic on overall functioning and autistic symptoms of the child/adolescent with ASD, as well as parental and family functioning (QUANT-QUAL), in both the short- and longer-term, and (2) to investigate risk and protective factors (in light of resilience) (QUANT-qual), and (3) to investigate care and informational needs (QUAL-quant). Pre-COVID-19 baseline data will be retrieved from clinical records. Participants will fill out two surveys (one during a COVID-19 peak - January-May 2021 - and one thereafter). Survey participants were invited to participate in interviews ($n = 27$). Surveys include measures thar were included pre-COVID-19 (i.e., overall functioning and autism symptoms) as well as specific measures to identify family functioning and COVID-19 impact. The semi-structured interviews focus on child, parent and family functioning and care- and informational needs.

Ethics & Dissemination: The Medical Ethics Committee (METC) of the Erasmus MC has approved the study. Findings will be available to families of children with ASD, their care providers, the funders, autism societies, the government and other researchers.

Article summary

Strengths and limitations of this study:

1. As pre-COVID-19 clinical data is available, a natural experiment occurs in which direct comparisons in functioning can be made from pre-COVID-19 to during COVID-19 functioning of children/adolescents with ASD.

2. The mixed-method design allows a comparison between quantitative and qualitative data for clarification, nuancing, and validation (mixed methods research), as well as an exploration of unknown or unanticipated experiences and needs (qualitative research).

3. The primary limitation is the dependence on pre-COVID-19 data from three different clinical institutions, which may mean that not all participants have the same baseline measurement(s).

4. A potential limitation is the risk that less participants may be willing to partake than expected (both at T1 and T2).

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1. Introduction

While challenging to each and every one of us, the COVID-19 pandemic may be particularly challenging for children and adolescents with Autism Spectrum Disorder (ASD) and their families [1–6]. ASD is an early-onset neurodevelopmental condition characterized by a co-occurrence of impairments in social reciprocity and social communication, and rigid, repetitive patterns of behavior, interest, or activities [7]. Worldwide prevalence is estimated at 1% of the population [8], and many present with co-occurring conditions such as anxiety and depression [e.g., 9,10]. While ASD is best-known for its profound impact on the social-emotional domain, its impact on the non-social domain, which includes externalizing behavior, atypical responses to sensory input, difficulty processing non-verbal information, and anticipating the behavior of others, should not be overlooked [11,12]. The key diagnostic criteria, related to social-emotional challenges and rigid, repetitive patterns of behavior, interest, and activities, in addition to information processing difficulties and comorbid disorders (e.g. anxiety), could lead to both an increase as well as a decrease of problems given pandemic related measures that are taken such as nation-wide lockdowns, social distancing, less face-to-face and more online social contact, and the use of face masks.

Indeed, recent studies considering the impact of the COVID-19 pandemic and its associated public health measures on individuals with ASD and their close ones show mixed results. Several authors suggest that individuals with ASD may pose a particularly vulnerable population [e.g., 13–16], yet only a handful of empirical studies have investigated the impact of the COVID-19 pandemic on individuals with ASD. For instance, a recent study by Nonweiler and colleagues [4] showed that, during a COVID-19 related lockdown in the UK, children and young people with neurodevelopmental disorders ($n = 106$ with ASD) compared to neurotypicals ($n = 82$) experienced more emotional and behavioral problems and presented with less prosocial behavior. Moreover, two Italian studies [17,18] found increased problematic behavior and intensity of autistic symptoms in children with ASD as measured during a COVID-19 related lockdown in Italy spring 2020. In addition, a large cohort study in the U.S. [19] found that the pandemic led to significant disruptions in therapies, worsened ASD symptoms and family distress. In a broader sense, the Co-Space study [20] has found that children with special educational needs and/or neurodevelopmental difficulties (among whom children with ASD) have elevated levels of behavioral, emotional, and attentional difficulties, which have not subsided post-lockdown in this group contrary to neurotypicals. Along that line, a study by Mutluer et al. [21] revealed that special needs education was either partially or

completely suspended as during the COVID-19 pandemic, and noted more behavioral problems. Other authors have also suggested that school disruption may potentially result in frustration [22]. The increased complexity of social interaction with different social cues in online communication, a decrease in exposure to social situations, routines that have been broken, disrupted mental health care services, and information and public health restrictions which are constantly changing may all contribute to increases in behavioral and emotional problems, such as more restricted, repetitive behaviors, sleep problems, anxiety, depression and aggression [21,23,24].

Along with individuals with ASD, relatives of individuals with ASD, like their parents or siblings, may also find themselves particularly challenged during the pandemic. Most informal support and professional mental healthcare guidance were significantly reduced due to the pandemic measures, known to be important protective factors for parents and families under normal circumstances [25]. Informal support, particularly one's satisfaction with informal support, is known to predict family resilience [26], i.e., a lack thereof is likely to decrease such family resilience. Actually, during a school-closure period in the UK, it was found that a large portion of families with children with special educational needs (>80% ASD) experienced negative effects on their mental health, with more anxiety, stress, and lower mood [27]. Moreover, a recent COVID-19 study in Turkey found that mothers of children with ASD had more health anxiety, less dispositional hope, and less psychological well-being compared to mothers with neurotypical children [28]. Similarly, parents of children with ASD in Saudi Arabia were negatively impacted (i.e., more stress and less emotional well-being) by the COVID-19 pandemic [29]. It seems that particularly parents of school-aged children had an increase in overall distress, which may increase their risk of crises [19]. Relatives of individuals with ASD have to both assist their affected family members, and face other potential challenges such as work demands or financial worries [30]. Role confusion, i.e., having to navigate the role of parent, advocate, educator, spouse, and so on, is most likely increased as well [31]. Overall, the COVID-19 pandemic and corresponding measures seem to affect relatives of individuals with ASD by an increase in stress and decrease in overall well-being family resilience [1,17,19,26].

Interestingly, while the beforementioned ASD characteristics may thus leave individuals with ASD as well as their relatives at increased risk, some of these characteristics may also serve as a protective factor at the same time [32]. As the COVID-19 pandemic includes mandatory distancing, less-to-no exposure to group activities, and less social

interaction, some individuals with ASD may benefit from the measures related to the pandemic [33]. For example, they might feel less pressured by society to participate in everyday (social) life, typical sensory overstimulation might be reduced, or they may be able to engage more in the repetitive behaviors which soothe them and decrease anxiety [23]. Moreover, individuals with ASD may, all of a sudden, feel less different from neurotypicals, as during the pandemic most people spent their time alone at home with little-to-no social activities. As such, individuals with ASD may experience less rejection or bullying, feel less stigmatized or outside the norm, reducing so-called minority stress [27,34] and potentially improving overall functioning [35]. Lastly, individuals with ASD may benefit from more online compared to offline social interaction with friends as an online environment may elicit less anxiety, allowing friendships to blossom [36]. During the COVID-19 pandemic, parents to individuals with ASD may also have gained new, positive experiences in dealing with their child (e.g., maintaining a schedule for their children, learning new skills to their child and setting boundaries), resulting in potential positive long-term effects [33,37].

Taken together, previous research suggests that, while a pandemic may prove challenging to each and every individual, individuals with ASD and their relatives may prove particularly vulnerable [e.g., 3,15,16,18]. Individuals with ASD and their relatives present with characteristics that may limit coping and resilience in light of the COVID-19 pandemic as well as the continuously changing public health measures, putting them at risk for negative outcomes, such as stress, anxiety, depression, loneliness, a decline in general functioning, increase autistic symptoms, and confusion regarding the COVID-19 measures [e.g., 15,16,18,19,21,23,24,38,39]. Moreover, previous research has shown that major-life events, trauma, and stress can have a long-lasting impact on mental health in individuals with ASD [40], which leads to the expectation that the COVID-19 pandemic too will have long-term consequences for individuals with ASD and their families. In addition, relatives of individuals with ASD may be subject to significant stress as well, due to extra role confusion and the extra burdens put on them [17,28,29].

However, all but one of the beforementioned research studies lack a direct pre-COVID-19 baseline measure. Some studies *asked* participants if they experienced an increase in symptoms or difficulties as a result of the pandemic or its consequent measures [e.g. 17], or compared a subgroup to a larger cohort [e.g. 19], or compared different groups (e.g. neurotypicals with a group with neurodevelopmental disorders [e.g. 4]), but no direct baseline measure was available to compare during COVID-19 with pre-COVID-19. In addition, the

results depend on either quantitative [e.g. 18] or qualitative data [e.g. 30]. Given the limitations of these studies, it gives a limited understanding of the impact of the current pandemic as specific to individuals with ASD and their families. To date, no research has been conducted into the impact of a large-scale event in this target group using a baseline measure as well as a mixed-method design.

The aim of the current study is threefold; (1) to investigate the impact of the COVID-19 pandemic on overall functioning and autistic symptoms of the child/adolescent with ASD, as well as parental and family functioning (QUANT-QUAL), in both the short- and longer-term, and (2) to investigate risk and protective factors (in light of resilience) (QUANT-qual), and (3) to understand the care and information needs during such an event (QUAL-quant). The study will take place in collaboration with three mental health care institutions providing specialized care to families of children with ASD in South Holland.

This unique and robust study design can inform and improve care in both the short- and long-term so that any negative impact of the pandemic for this group is minimized. Moreover, the information resulting from this project will allow for a better specification of guidelines for mental healthcare both during and after the COVID-19 pandemic, as well as other future impactful events, to better support individuals with ASD and their families and to minimize any long-term negative impact.

2. Methods

2.1. Study design

This study is a mixed-method multi-center cohort study involving parents/guardians/caregivers (referred to as "parents") of a child or adolescent with ASD (see Figure 1). The study will be conducted in the larger Rotterdam region of the Netherlands. Clinical data pre-COVID-19 (March 1, 2019, until March 1, 2020) of the participants will serve as baseline data (T0). Participants were invited to join the study during the second lockdown in the Netherlands between January 4, 2021, and May 31, 2021 (T1). Potential participants were invited to partake in the study through their clinical institution primarily via e-mail with an informational brochure including a consent form. Consent could be given either on paper or online. If no response was received for 1 week the research assistant did a follow-up via telephone. The quick turnaround was due to the time-sensitivity of COVID-19 research. Participants who did not want to partake were asked to answer a few questions on their motivation, to allow for some attrition analyses later. Active consent was acquired to share any unforeseen but relevant findings to medical

health professionals if needed. Participants were informed they could stop with the study at any point, without it impacting their care as usual and without providing a reason. In addition, they were informed that data collected up until the point that they indicated they no longer wanted to participate, will be used.

For the quantitative strand of the study, following informed consent, participants received an invitation link to an online survey. A second survey is tentatively planned for the Fall of 2021 (T2; expected to run from mid-September until December 1st, 2021) in a period with fewer COVID-19 infections and less restrictive public health measures.

For the qualitative strand of the study, participants who participated in the survey at T1 were invited to a semi-structured interview regarding family functioning, quality of life, and care, and informational needs. All interviewees at T1 will be invited again for an interview at T2. The semi-structured interview covers spontaneous reporting and prioritizing (A), adaptations experienced (B), emotional impact on the child (C) and the parent (D), information and care needs (E), role confusion (F), and experiences with the study and/or need for care post-study (G) (for more detail, see appendix A).

Participants receive financial compensation for their participation (T1 survey 10€; T2 survey 25€; T1 interview 25€; and T2 interview 50€). A graded compensation was set up to promote long-term participation and minimize drop-out.

< insert Figure 1. Study design here >

2.2. Participants

All parents with children diagnosed with ASD (4-21 years old) of whom clinical data, i.e., the Child Behavior Checklist (CBCL) and/or Social Responsiveness Scale (SRS-2), is available between March 2019 and March 2020 (pre-COVID-19) at one of the three collaborating mental healthcare institutions, were approached for participation ($n = 213$). In total 68 parents provided consent for gathering T0 data. At T1, 57 parents of children and adolescents with ASD participated in the survey. Sampling for the interview was open and voluntary (self-selection); in total 27 parents signed up for participation and participated in the interview. In all future publications for which quantitative and/or qualitative data is used, the demographic characteristics of that subsample will be reported. Exclusion criterium for the study is the participant does not provide active consent,.

Participants were informed that clinical follow-up, support, or referral by clinically trained team members was available in case of adverse effects of study participation.

2.3. Sample size calculation

The aim is to detect differences with a small to medium effect size ($d = 0.4 - 0.5$) with 95% power. When translating such effect size in terms of clinical impact, this would mean 25% of the surveyed group experiences a significant change [41].

For the quantitative data, aiming to investigate the impact of the COVID-19 pandemic as well as identify the risk/protective factors, data will be evaluated using t-tests, to identify impact (T0 vs T1/T2), and single- or multiple regression, to identify variables which may explain (a change in) functioning at T1/T2 compared to T0. As such, power calculations using G*Power indicate a sample size of $N = 34$-59 for correlations, and a sample of $N = 45 - 70$ for regression analyses should result in sufficient power.

For the qualitative data, no a priori power analysis is conducted. At the end of the survey at T1 participants were asked if they wanted to also participate with the interviews. In total 27 parents participated in the interviews. This sample size will allow for both deductive and inductive analyses depending on specific qualitatively or mixed-method oriented research questions, such as the experience of agency and family dynamics, role-confusion/change and parental burden due to the COVID-19 pandemic. For these questions, sub-samples will be used in which sample size will be determined based on, for example, the qualitative saturation principle [42] or a mixed-method design in which we deductively deepen quantitative data. Samples will be selected either based on random sampling, purposive qualitative sampling, or purposive quantitative sampling. For instance, for research question 2 (parental burden) parents who score high on parental load on the Parenting Stress Questionnaire (PSQ; in Dutch: *Opvoedingsbelastingvragenlijst*; OBVL) may be selected. [43]. For the impact of COVID-19 on the families and the multiple roles parents may have to play (caregiver; informer, therapist; teacher; etc) (research question 5) we will use a grounded theory framework to capture the development of experiences within families and identify if parents experience role confusion due to the multiple roles they have play, more during the pandemic than normally. From previous literature it is known that chaos is particularly problematic in families with children with ASD [44,45], and parents can play a critical role in managing chaotic circumstances for their children with ASD. Given the challenges the pandemic puts on everyone, including additional stress for parents, no predefined hypothesis can be formulated,

but based on general theory one may expect this theme to be important. For this question, we do not exclude participants a priori but analyze the full sample until saturation is reached (i.e., random sampling until saturation). If, contrary to expectations, saturation is not reached within the current sample, additional funding will be applied for continued sampling. If this is not feasible due to practical limitations, such as the impossibility to return to a time frame with specific COVID-19 measures, the findings will be presented in open science framework for triangulation with other possible study findings.

2.4. Measures

2.4.1. *Demographics (T0, T1, T2)*

Age, gender, nationality, educational level, language skills, intelligence quotient (FSIQ, and if available other indices), medication use, and family composition are obtained from the surveys or from clinical records. Gender will be scored as female, male, or other. Nationality will be extracted from the electronic patient files, based on parent nationalities the child's nationality will be determined. This will be divided into seven subgroups: Dutch, Surinamese, Turkish, Moroccan, Antillean, Cape Verdean, and other. Parents will be asked what type of education their child receives (e.g., primary or secondary, regular or special education) during the survey. Language skills of the child during the baseline measurement will be scored as fluent, telegraphic, no spoken language, or not specified, if available from clinical records. If an IQ test was conducted as part of the diagnostic or guidance procedure, this will be noted as well including the relevant outcome(s) of the IQ test. Lastly, the family composition will be obtained (e.g., single or partnered parenting, siblings, relation to the child in question).

2.4.2. *Overall functioning (T0, T1, T2)*

To determine overall functioning of the children with ASD, several Achenbach System of Empirically Based Assessment [ASEBA; 46] questionnaires will be used, which are commonly used in the clinical care institutions for youth (up to the age of 21). At baseline, overall functioning could be reported by a parent/guardian by filling out the Child Behavior Checklist [CBCL; 47], as part of standard care. Each item is scored on a 3-point Likert scale ranging from 1, Not at all to 3, Clearly to describe the behavior of the child during the last 6 months. The CBCL consists of an Internalizing (subscales: Anxious/Depressed, Somatic Complaints, and Withdrawn/Depressed) and an Externalizing domain (subscales: Rule-Breaking Behavior and Aggressive Behavior). A Total Problems score can also be determined,

this score gives a general view of the extent of both behavioral and emotional problems based on the scores of the two domains and the three remaining syndrome scales: Thought Problems, Social Problems, and Attention Problems. The CBCL 6-18 parent-report has high test-retest reliability, internal consistency, and criterion validity [48].

Overall functioning during the pandemic (T1 & T2) will also be assessed, for which the Brief Problem Monitor – Parent form [BPM-P; 49], a shortened version of the CBCL. The BPM-P will be scored similar to the original CBCL on a 3-point Likert scale ranging from 1, Not at all to 3, Clearly. The internal consistency of the BPM was high, and the total score of the CBCL and the BPM-P highly correlate [50].

If the participant was ≥ 12 years at baseline, self-reported overall functioning will also be included if available, by means of the Youth Self Report [YSR; 51]. The CBCL and the YSR can be transformed into similar domains and syndrome scales. Good reliability and validity have been confirmed for the Dutch version of the YSR in the Dutch population by Verhulst and colleagues [48].

2.4.3. ASD characteristics (T0,T1,T2)

To assess ASD characteristics within the children, the Dutch version of the parent-report Social Responsiveness Scale [SRS-2; 52], and if applicable the self-report Social Responsiveness Scale [SRS-A; 53] will be used, which can be part of baseline measurements as well. The SRS-2 will be filled out by the parent, the SRS-A is a self-report measure and will therefore be filled out by the adolescent (if ≥ 16 years old). The SRS-2 is comprised of six subscales: 1) Social Awareness, 2) Social Cognition, 3) Social Communication, 4) Social Motivation, 5) Restricted Interests, and 6) Repetitive Behavior. The SRS-2 parent report demonstrated good sensitivity, reliability, and validity [e.g., 54]. The SRS-A has satisfactory psychometric qualities [53], and consists of 64 items, which group into four dimensions: 1) Social awareness, 2) Social communication, 3) Social motivation, and 4) Restricted interests and repetitive behavior. Both on the SRS-2 and SRS-A each item is scored on a 4-point Likert scale (Not true, Sometimes true, Often true, Always true).

If other relevant diagnostic materials, for example, the Autism Diagnostic Observations Scale (ADOS), are administered in addition to the SRS-2, the results of both instruments will be documented.

2.4.4. Quality of Life (T1& T2)

To assess the quality of life of the child with ASD the Dutch version of the Pediatric Quality of Life Inventory [PedsQL; 55] will be used. The PedsQL will be completed as part of the survey at T1 and T2. It will be filled out by the parent/guardian, and if the child is ≥ 12 years old, by the child as well. The items are scored on a 5-point Likert scale, ranging from "Never a problem" to "Almost always a problem". The PedsQL is comprised of four subscales: 1) Physical, 2) Emotional, 3) Social, and 4) School functioning, as well a psychosocial health summary and a total score. Satisfactory reliability and validity are reported for the Dutch translation of the PedsQL [55].

2.4.5. Parenting burden (T1& T2)

To assess the parenting burden during the pandemic the Parenting Stress Questionnaire (PSQ; in Dutch: *Opvoedingsbelastingvragenlijst*; OBVL) will be used [56]. The PSQ will be completed by the parent/guardian as part of the survey at T1 and T2. The items are scored on a 4-point Likert scale, ranging from "not true' to "very true". The PSQ is comprised of five domains: 1) parent-child relationship problems, 2) parenting problems, 3) depressive mood, 4) parental role restriction, and 5) physical health problems. The instrument has good reliability and validity [57,58].

2.4.6. Parental functioning (T1& T2)

The subscales anxiety and depression of the Brief Symptom Inventory [BSI; 59,60] will be administered to gain insight into the functioning of parents at T1 and T2. The subscales consist of 6 items each which are scored on a 5-point Likert scale, ranging from "not at all" to "very much".

2.4.7. Impact of COVID-19 (T1& T2)

The impact of COVID-19 is explored using a variety of questions which provide important insights about elements that are expected to be impacted by COVID-19; e.g., general anxious/depressed feelings, the atmosphere at home, effect on the child's sleeping (e.g., nightmares and problems with sleeping), social problems (e.g., social isolation and loneliness), non-suicidal self-injury, suicidal thoughts, rumination, and specific COVID-19 elements like experience of infection, behavior, stress, and anxiety (e.g. has child/parent been infected, which preventative measures does the child/parent take, what is the level of confidence in the governmental approach to the pandemic, how worried is the child/parent about becoming sick,

how has COVID-19 impacted the work/income of the parent, and any positive experiences related to the pandemic). Some of the questions concerning the impact of COVID-19 are based, for example, on the CoRonavIruS Health Impact Survey [CRISIS; 61] and national collaborations (e.g., Grow-it Study, Generation R), or are commonly used overall functioning instruments such as the CBCL (Achenbach, 1999). These questions have not all been validated (yet).

2.4.8. *Informational and care needs (T1& T2)*

The informational and care needs will be assed using questions regarding informational source for child and parents, as well as questions regarding use of care, adaptations made due to COVID-19 and the experience with care during COVID-19, specifically designed for the current study.

2.4.9. *Semi-structured interview (T1& T2)*

Family functioning, parental load, and the informational and care needs will be assessed using a newly developed semi-structured interview for parents, specifically designed for the current study. The themes that will be discussed during this interview (see Appendix A) are: 1) spontaneously reported experiences of COVID-19 measures (A), experienced changes in daily life / symptoms /family life (B), emotional impact on the child (C) and the parent (D), information and care needs (E), role confusion (F) and experiences with the study and/or need for care post-study (G - validation & quality control). Interviewers will be trained by FT to ensure uniformity in the interviews. Interviews will be transcribed verbatim by a professional company. Interviews at T1 were administered over the phone or by video calling.

2.5. Analyses

As both the quantitative and qualitative strands (help) answer our research questions, they each carry equal weight in the umbrella/overall design yet will be entertained in various ways as appropriate per subquestion and integration of strands is done accordingly. The primary research questions we aim to answer: 1) what is the impact of the COVID-19 pandemic on the children and which risk factors can be identified (QUANT-qual); 2) what is the impact of COVID-19 on parenting/the parents including risk factors (QUANT-QUAL); 3) does COVID-19 impact children/adolescents with ASD differently from typically developing children/adolescents and are there risk/resilience factors (QUANT); 4) what is the impact of

COVID-19 on the families (QUAL-quant); and 5) what are the care and informational needs of the participants (QUAL-QUANT). Depending on the research question, emphasis of the paradigm may differ as well as time order decisions [62]. Research integrity is monitored and reported in each study, following the guidelines of Levitt et al. [63] in line with the specific designs of each study.

For research questions which rely solely on quantitative data (QUANT) common quantitative analysis methods, including t-tests, single and multiple regression, repeated-measures ANOVA's, and correlations will be employed. For research questions for which quantitative data is supplemented with qualitative data (QUANT-qual) the design is sequential[64,65], where quantitative data is reported first, and qualitative data is used to support/deepen/illustrate/clarify the findings (deductive analyses). In this design, the relevant parts of the interview will be used from the entire sample (a priori sampling).

For research questions in which qualitative data only (QUAL) or substantiated with quantitative data (QUAL-quant), is used, inductive analyses are utilized until saturation based on grounded theory principles. Here, without pre-defined hypotheses, either overarching themes/dynamics are identified based on the qualitative data which for some questions can be substantiated/validated/compared to quantitative data. For example, the impact of having multiple roles within the family as a parent, as described earlier. Alternatively, quantitative data may be used to identify a relevant subgroup (e.g. age - deductive/a priori sampling) after which qualitative data is used to answer the research question [66]. Qualitative data is therefore analyzed both deductively and inductively depending on the research question.

2.6. Patient and Public Involvement

Patients nor public parties were involved in the first design of the study given the urgency of the study. However, clinicians took part in the design of the study. In addition, after funding but prior to ethical approval was acquired several parents/patients (who were not participants) were involved to discuss the study and design as proposed. As soon as data collection has taken place and results have been processed, participants to the study will be informed of the study results via a study newsletter suitable for a non-specialist audience.

2.7. Ethics and dissemination

Medical ethical approval for the study was provided by the Medical Ethics Committee (METC) of the Erasmus MC (MEC-2020-0720). Informed (e-)consent will be obtained prior to participation.

The study was registered on The Open Science Framework platform prior to its start [osf.io/b6ghz]. Additionally, a data management plan was created.

The EUR data vault of the university will be used for data storage and backup of the data, supported by the Erasmus Data Service Centre. All personal data will be stored with care and the researchers will act within the limits of the General Data Protection Regulation (GDPR). Study data will be de-identified as much as possible and a master linking log with identifiers will be kept and stored separately from the data, either at the clinical institutions (for quantitative data) or at the Erasmus University Rotterdam vault (for qualitative data). The data will be kept for at least 15 years (in accordance with article 454, paragraph 3 of the Medical Treatment Contracts Act, WGBO).

Due to privacy reasons, there will be restricted access to the data for further research. A request needs to be submitted to the principal investigator (L. P. Dekker) after which the Rotterdam Autism Consortium (R.A.C.; founding members are the authors on the current paper) decides if and how the data can be shared, based on ethical and privacy standards which will be defined in a Creative Commons license adapted to the requirements within the current study.

Outcomes of the study will be made available as soon as possible to participants and interested parties; to clinicians and other professionals working with families with children with ASD; the government; and Autism Associations and networks in the Netherlands and abroad, by means of for example newsletters, social media, white papers, scientific publications (including pre-prints), meetings, and in the education of students.

3. Discussion

The difficulties that often present with ASD [7] provides a challenge, as the COVID-19 pandemic has drastically changed the social and educational landscape, with social distancing, less face-to-face social contact, more online interaction, and difficulties interpreting social cues due to face masks. Due to their social-emotional difficulties, this could lead to increased tensions, which in turn may result in difficulties in behavioral regulations as well as emotional stress in children and adolescents with ASD [e.g., 18,19]. In addition, many individuals with ASD, children in particular, rely on clear structures and routines in order to function well on a

day-to-day basis and minimize externalizing behavior [e.g., 67,68]. These structures and routines are rarely subject to change under normal conditions. However, the COVID-19 pandemic measures often included lockdowns, with school and day-care closings, limited social gatherings, and most of cultural, sporting or religious events cancelled. When schools and health care facilities re-open after lockdown, this often involves significant changes as well (e.g., different entrance and exit routes, online consultations, mandatory facemasks) rather than going back to business as usual, with a second wave of structure and routine disruptions as a result. In addition, there is variation in terms of how strict individuals adhere to the governmentally imposed rules and regulations [69], which can also lead to frustration and stress particularly for individuals with ASD. Lastly, as many individuals with ASD present with comorbid problems, particularly anxiety, depression, and externalizing behaviors, in varying rates [9,10], extra concerns may arise with the COVID-19 pandemic and related measures. Simultaneously, some individuals with ASD may thrive due to decreased typical stressors [e.g., 32]. The current study attempts to identify the impact of the public health measures on children with ASD and their families, both positive and negative, the relevant protective and risk factors, and the care and informational needs of this population during these challenging times in a mixed-method design.

Although the project is still ongoing, there are two noteworthy limitations to our design. First, baseline measurements may vary within limits between the different institutions and participants. As an inclusion criterion is pre-COVID-19 (March 2019 – March 2020) availability of the Child Behavior Checklist (CBCL) and/or the Social Responsiveness Scale (SRS-2; see measures for details) some participants may only have 1 of the measures. However, as this is an inclusion criterion there will be sufficient data to compare pre-COVID-19 functioning to during COVID-19 functioning. Second, possible loss of follow-up data at T2. Given that T0 and T1 have already taken place, there will be at least the possibility of investigating T0 to T1 functioning. In addition, our team has extensive experience with long-term follow-up studies and will exert all efforts to minimize loss of follow-up data, such as the graded compensation. That said, there are also several noteworthy strengths to mention. First, having pre-COVID-19 data which can be compared to during COVID-19 data, we can more objectively determine the impact of the COVID-19 pandemic on the functioning of children with ASD and their families. Second, the mixed-method design allows for a comprehensive understanding as well as unique insight into the functioning of families with children with ASD

during extremely challenging times. Third, a wide range of constructs is being assessed which allows for a comprehensive overview of functioning during the pandemic.

4. Funding statement

5. Competing interests' statement

All authors declare that they do not have conflict of interest.

6. Authors contributions

LD & RVDH were responsible for conceptualizing the study. LD, LH, and RVDH drafted the manuscript. LD, RVDH, and FT revised the manuscript after reviewer feedback. AL, KV, DB, LTH, PDN, GD, WE provided access and assisted in drafting participants. LD, LH, AL, KV, DB, LTH, PDN, GD, WE, EVR, FT, and RVDH all participated and contributed to the design of the study and manuscript development.

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For peer review only

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8. Figure Captions

Figure 1. Study Design

Potential participants (T0)

(n = 213)

- Parents of children with Diagnosis autism spectrum disorder (ASD) between 4-21 years old (full IQ range)
- In care between 01-03-2019 & 01-03-2020 in one of the three participating institutions
- CBCL and/or SRS-2 available at T0

Quantitative data

Qualitative data

Consent (n = 68)

Active no consent (n = 53)

No response (n = 92)

T1

Surveys

(n = 57)

T2

Surveys

(n = 57)

Interview

(n = 27)

Interview

(n = 27)

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Interview Guide Autism & COVID-19   Rotterdam Autism Consortium

Interview Guide Autism & COVID-19

Welcome & Thank you for participating

In this interview we are curious about your experience of the Covid-19 measures. I usually use the word covid, but sometimes maybe corona. I always mean the situation that arose with the announcement of national measures due to the corona virus in March 2020.

We would like to ask you to tell us in your own words about the changes you have experienced in your situation, for example at home, at school, at work and in the care context of your child. It's about your experience, in your words and in your order. It doesn't have to be a well-developed story, you can just tell what comes to mind. There are no right and wrong answers and the interviewer is not surprised by anything.

The interviewer will continue to ask for explanations and details. If you do not understand a question or find it difficult, you can ask the interviewer for clarification. If you don't want to or can't answer a question, that's always okay. If you want to pause or finish, you can also indicate that.

Can I say you and you? (*in Dutch there is a more formal form of addressing individuals*)

Takes about an hour
Do you have any questions before we start?

Do you still agree to record this interview?
Then I start recording now.

(intro 5 min)

A. Spontaneous reporting & prioritization   **(10 min)**

Let's start with your experience of the corona crisis.

1. *Can you tell us how you experienced the Covid situation?*

   Points of attention interview-intro:
   • Intro at the **emotional level**!
   • Invite to speak **spontaneously**
   • Carefully probe for **prominence** of experiences: what weighed the most, which changes were the most disruptive?
   • General **tenor**: positive, negative, double, ambivalent?
   • Form an impression of **balance**: focus mainly on child? Where is parent in the story (present/absent)?

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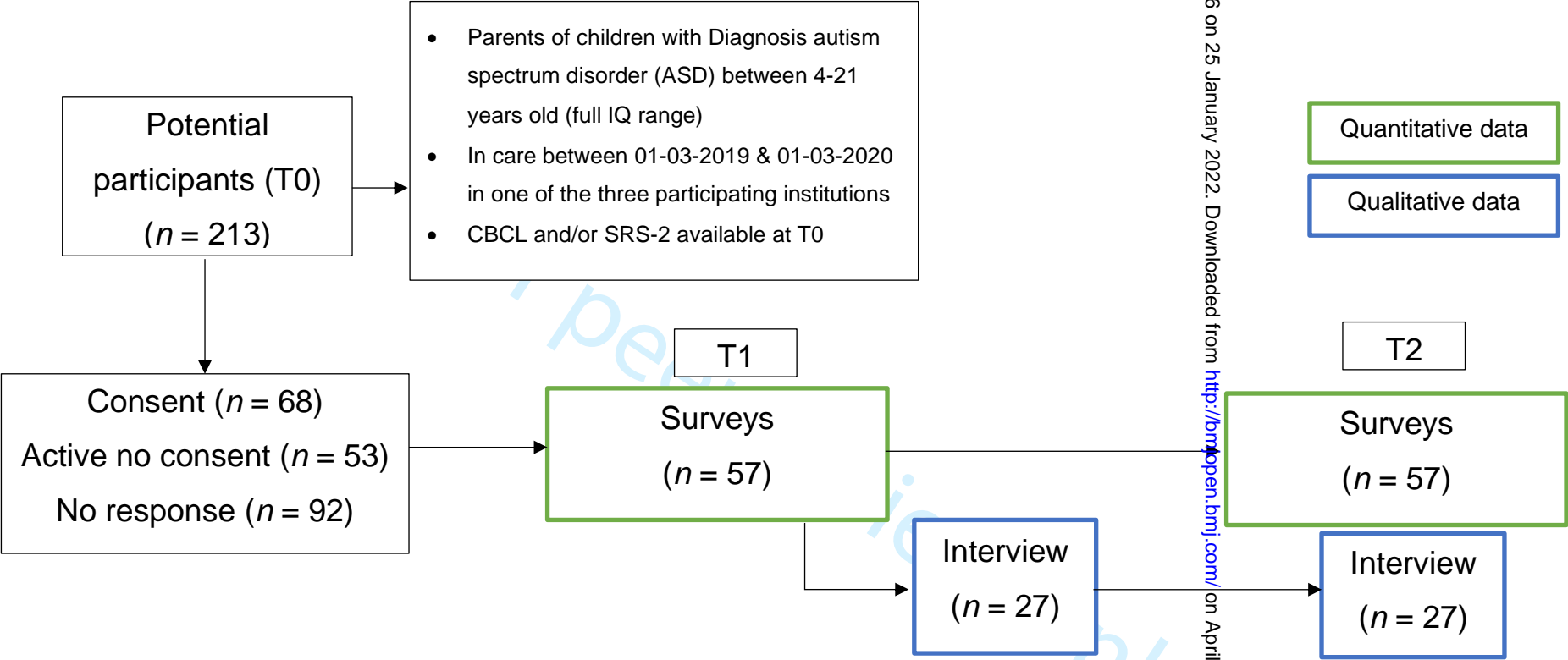46
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B. Perceived change - concrete & factual questioning   (10 min)

I would like to ask a few more concrete things, so that I have a good idea of how the corona crisis has changed the situation for you and your child.

  2. *Can you outline what concrete things have changed in the Covid circumstances?*

Assess actual changes
  a. home situation & family dynamics
  b. care context child
     (Pay attention to multidisciplinary → per institution and relationship between institutions)
  c. school
  d. work
  e. political & social

  3. *Can you explain how these things differ in concrete terms from the situation before Covid?*

  • **Ask per situation for a concrete comparison pre-post Covid**

  • **How would you characterize this change?**
    • Well-arranged to badly arranged
    • Well arranged to better arranged
    • Badly arranged to worse arranged
    • Badly arranged to better arranged
    • Not arranged to well arranged
    • Not arranged to badly arranged
    • Not settled & still not settled

C. Emotional impact child - feeling level   (5 min)

(refer to spontaneous speaking A for transition). You already said that…
I would like to know more about the impact of the corona crisis on your child's emotional life.)

  4. *How has your child reacted to the Covid measures?*

  • *How has this affected your child's well-being?*

  Assess specifically:
  • Structure & Daily planning
  • Sleeping & Eating
  • Feeling Level:
    o General: emotion, emotion regulation
    o ASD-specific: symptomatic handling of emotions
    o Covid-specific: fear, (un)rest, (in)understanding?

      o Comparison of brothers/sisters/nephews/neighbors? → compare

5. *Can you describe where and how your child normally feels safe/unsafe?*

    Assess specifically:
- Indoor/outdoor
- Significant others

6. *Has the sense of indoor/outdoor security changed due to Covid?*
   - *Is this Covid-specific.. (eg fear of the virus)*
   - *…or response to Covid measures (eg response to uncertainty/grey area)*
   - *…or reaction to reaction of others (eg others are more difficult to gauge)*

D. D. Emotional impact parent(s): emotional level	**(5 min)**

(transition from C.)

7. *How are you?*

   - you as a person?
   - Your emotions/fears/concerns regarding the child?
   - Your emotions/fears/concerns regarding work (own/partner)?
   - Your emotions/fears/concerns about society/future?

8. *What is it like for you that these questions are being asked?*

   - *Who usually asks you this question?*
   - *Is there sufficient attention for you as a person?*
   - *Can you take care of yourself sufficiently in these circumstances?*

   Assess per answer:
   - *Would you specifically attribute these experiences to Covid?*
   - *If no: are they comparable to pre-Covid?*
   - *Or: have they become magnified/ are you more aware of it because of Covid?*

9. *How do the current circumstances affect your relationship with (important) others?*

   - *Wait for spontaneous reporting FIRST; WAIT to provide examples-others. Then assess:*
     - *Partner*
     - *Siblings → do they have diagnoses?*
     - *Family*
     - *Friends*
     - *Babysitter/nanny*

   - *Would you specifically attribute this to Covid?*

E.	Information and care needs	(10 min)

I would like to ask you a few more things about the provision of information during the corona crisis, and the care you or your child received or would have liked to receive during this period.

10. *Did you miss care <u>due to</u> Covid measures?*
    - *Were others involved besides formal care & nuclear family?*
      - *For example: parents, babysitter..*

    - *What care would have been helpful to you?*
      i. *For child*
      ii. *For parent/family*

    - *How would you have liked to receive this care?*

11. *Did you receive care via (video) calling?*

    - *If yes: how did you experience this?*
    - *If yes: how did your child experience this?*

12. *How did you experience the information provided about Covid?*

Assess Specific:
    - *From the government*
    - *From institutions/school/care network*

13. *Did you miss information?*
    - *Has your child indicated that he/she has missed information?*

    - *Which information provision would have been helpful to you?*
      i. *For child*
      ii. *For parent/family*

    - *How would you like to receive this information provision?*

F.	Roleconfusion	(5 min)

(transition from E)

14. *As a parent, you were also an information provider to your child. How did you experience this?*

15. *How did you experience translating information provided from government/institutions to your child?*

16. *Did you use the COVID-19 signpost sheet on the NVA (Dutch Autism Association) website?*

17. *What would have been helpful to you in this dual role?*

18. *These questions were about Covid. Are there things we can learn from this for more regular times and/or special circumstances?*

- *What are the most important lessons for you to be learned from the Covid crisis with regard to ASD care and information provision?*

G. Survey experience **(5 min)**

19. *Are there things I didn't ask, but that are important to understand your story?*

20. *How did you experience this interview?*

21. *How did you experience the questionnaires?*

- *Did you request support?*
- *Has your child requested support?*

Thank you for your participation.

As agreed, you will receive a newsletter with our research findings as soon as the research has been completed.

If you still have questions after this interview, or if you want to add something, you can always send the researchers a message.

If you notice that this interview raises a new care need in you, please let the researchers know. We can always think along with you.

Thank you again for your participation

(closing 5 min)