

## **Mental health outcomes among parents of children with a chronic disease during the COVID-19 pandemic: The role of parental burn-out**

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**ABSTRACT OBJECTIVE:** The COVID-19 pandemic and associated quarantine measures highly impacted parental psychological well-being. Parents of children with chronic diseases might be specifically vulnerable as they already face multiple challenges to provide adequate care for their child. The research questions of the current study were twofold: 1) to examine whether parents of children with a chronic disease experienced more anxiety and depression compared to parents of healthy children and 2) to examine a series of risk factors for worsened well-being (i.e., depression, anxiety and sleep problems), such as sociodemographic variables, COVID-19 specific variables (i.e., financial worries, living space and perceived quality of health care) and parental psychological experiences (i.e., parental burn-out and less positive parenting experiences). **METHODS:** Parents of children with a chronic disease (i.e., the clinical sample;  $N = 599$  and  $507$  for research questions 1 and 2, respectively) and parents of healthy children (i.e., the reference sample;  $N = 417$ ) filled out an online survey. **RESULTS:** Findings demonstrated that the parents in the clinical sample reported higher levels of anxiety than parents in the reference sample. Analyses within the clinical sample indicated that COVID-19 specific stressors and parental psychological experiences were associated with higher levels of anxiety, depression and sleep problems. Mediation analyses furthermore indicated that the association of COVID-19 specific stressors with all outcome measures was mediated by parental burn-out. **CONCLUSIONS:** Parents of children with a chronic disease constitute a vulnerable group for worse well-being during the current pandemic. Findings suggest interventions directly targeting parental burn-out are warranted.

**INTRODUCTION.** The COVID-19 pandemic and the measures taken to contain the pandemic have increased pressure on families and reduced their access to support services (Marchetti et al., 2020). Parents have been struggling with the increased caregiving burden, finding it hard to balance individual and shared needs (Russell et al., 2020; Günther-Bel et al., 2020). Consequently, parents worldwide have reported symptoms of anxiety, depression,

stress, poor sleep and more negative affect during the pandemic (Russell et al., 2020; Brown et al., 2020; Prime et al., 2020). Greater COVID-19 stressors (i.e., stay at home restrictions, school and childcare closures) are associated with higher parental stress (Brown et al., 2020). Parents also reported worsened parental functioning and more negative experiences specifically in their role as a parent (Günther-Bel et al., 2020). Parents particularly experienced parenting-related exhaustion (Marchetti et al., 2020) and feelings of parental burn-out, a severe condition resulting from high parenting demands that are not sufficiently met by available resources (Griffith et al., 2020; see Roskam et al., 2017). They furthermore reported less closeness and greater conflict with their child during the pandemic (Russell et al., 2020), which might indicate a decrease in positive parenting experiences.

Parents of children suffering from chronic diseases are generally particularly vulnerable for experiencing psychological distress (i.e., depressive symptoms and anxiety) and parenting distress (e.g., Bassi et al., 2021; Kelada et al., 2020; Ljungman et al., 2014; Jones et al., 2016). These parents also report lower overall parental quality of life than parents of healthy children (Goldbeck et al., 2006). Moreover, mothers of children with chronic diseases display more distress in their parental role and have significantly higher burn-out scores than mothers of healthy children (Norberg, 2007). Especially parents of children with chronic diseases who experience low social support, a lack of leisure time and financial concerns, are prone to develop parental burn-out (Lindström et al., 2011). Considered from a cumulative risk perspective (Evans et al., 2013), these parents were already vulnerable to maladjustment prior to the pandemic and may be particularly susceptible to the challenges and risks associated with the COVID-19 crisis. While to the best of our knowledge, only one study has examined experiences of parents with children with chronic diseases during the COVID-19 lockdown (Darlington et al., 2020), no study has investigated if parents of children with chronic diseases encounter significantly more psychosocial difficulties than parents of healthy children during

the current pandemic and if so, what specific variables are associated with these negative parental outcomes.

Drawing from preliminary evidence obtained among parents of healthy children, several variables can be considered as risk factors for worsened mental well-being during the COVID-19 pandemic. First, several personal and sociodemographic variables (e.g., maternal parental role, single parent status,...) have been shown to be associated with parental well-being (Russell et al., 2020). Second, COVID-19 specific stressors have also been shown to contribute to worsened parental outcomes (Brown et al., 2020; but see Marchetti et al., 2020; Janssen et al., 2020). Such COVID-19 specific stressors may comprise, amongst others, financial worries (Russell et al., 2020), home confinement and crowding (see Prime et al., 2020), and parental worries concerning the quality of health care for their children (Darlington et al., 2020). Third, psychological experiences in the parental role are likely to affect parents' general mental well-being. As parents report feelings of parental burn-out and exhaustion during the pandemic (Griffith et al., 2020; Marchetti et al., 2020) and possibly less positive parenting experiences (Russell et al., 2020), they are more likely to display more general mental health problems. Because the parental role is quite central to most adults' identity (Fadjukoff et al., 2016), it can indeed be assumed that experiences in the parental role have carry-over effects on parents' mental health. Therefore, in accordance with Marchetti et al. (2020), three categories of possible parental risk factors for worsened parental mental health were examined in the current study : (1) personal and sociodemographic characteristics, (2) COVID-19 specific stressors (i.e., financial worries, living space and current health care experience, and (3) psychological experiences in the parental role (i.e., parental burn-out and positive parenting experiences).

Two research questions were addressed in the current study. First, we examined whether parents of children with chronic diseases (i.e., the clinical sample) experienced more anxiety or depression than parents of healthy children (i.e., the reference sample). We

hypothesized that parents of children with chronic diseases would report more depressive symptoms and anxiety compared to parents of healthy children. Second, we identified key variables associated with mental health problems (i.e., anxiety, depression and sleep problems) among parents of children with chronic diseases. We hypothesized that variables from each of the three categories of risk variables (assessed only in the clinical sample) would relate to mental health problems among parents of children with chronic diseases. As such, we assumed that specific experiences in the parental role (i.e., burn-out and a lack of positive experiences) would be associated with parents' general mental health problems above and beyond the personal and sociodemographic factors and the COVID-19 specific stressors. An additional and more exploratory research question was to examine whether parental burn-out and (a lack of) positive parenting experiences would mediate associations between the COVID-19 specific stressors and parents' general mental health outcomes. We hypothesized that associations between COVID-19 specific stressors and parental mental health problems, if any, would be mediated by parental burn-out and a lack of positive parenting experiences.

**METHOD. Participants and Procedure.** To address Research Question 1 (RQ1), a mean-level comparison between parents of a child with a chronic disease (i.e., clinical sample) and parents of healthy children (i.e., reference sample) was performed. Research question 2 (RQ2) was addressed within the clinical sample only.

*Clinical sample.* Participants were parents of child patients recruited from the pediatric departments (nephrology, neurology, pneumology, hemato-oncology and endocrinology) of the Ghent University Hospital in Belgium. The inclusion criteria were: (a) being at least 18 years old and (b) being the parent of at least one child (0-18 years old) with a chronic disease. Eligible parents ( $N = 1856$ ) were recruited from patient lists of children with a diagnosed medical and tertiary pathology treated in the University Hospital. Parents were informed about the current study by the research team by email only and were invited to participate in the study.

If parents came to the hospital, they were reminded of the study. If they agreed to participate, the online survey link was provided on the REDCap® (Research Electronic Data Capture) platform, a secure web-based software platform designed to support data capture for research studies. The survey was available from June 29, 2020 to July 15, 2020 and took approximately 30 min to complete. Eventually, data of 599 parents (for RQ1) and 507 parents (for RQ2) was used as we only included participants without missing data on relevant questionnaire variables. This study was approved by the Ethics Committee of the Ghent University Hospital (B6702020000259). Written informed consent was obtained from all parents. Participation was voluntary and no payments or other rewards were provided.

*Reference sample.* Participants (cfr. RQ1) consisted of 417 parents recruited via a larger follow-up survey ( $N=4730$ ) to a previous survey conducted in the general population ( $N=19269$ ; Schrooyen et al., 2021). This larger survey ( $N = 19269$ ) dealt with individuals' motivation for adhering to the COVID-related measures and with their overall mental health (<https://motivationbarometer.com/>). If participants indicated that they were willing to participate in a follow-up assessment, they received a follow-up questionnaire ( $N = 4730$ ). Only the survey specifically aimed at parents (i.e., participants who indicated they were a parent and had at least one child under 18 who lived at home) was used in the current study ( $N = 492$ ). The final sample used for analyses included 417 parents, as 75 participants were not included in the final analyses because they indicated that their child had a chronic disease. Parents of children with a physical disability ( $N=8$ ), emotional problem ( $N=82$ ), behavioral problem ( $N=52$ ) or intellectual disability ( $N=15$ ) were included. This study was approved by the Psychology and Educational Sciences Ethical Committee of Ghent University (nr.2020/37). All participants provided informed consent before filling out the online questionnaire.

Sample characteristics of both samples are reported in Table 1. Mean age of participants was 43.60 years in the reference sample ( $SD = 7.50$ ) and 40.74 years ( $SD = 6.60$ ) for the clinical

sample used for RQ1 and 41.5 years ( $SD = 6.3$ ) for the clinical sample used for RQ2. Data on ethnicity, number of children and medical diagnosis was only assessed in the clinical sample and thus not used for research question 1. -- INSERT TABLE 1 ABOUT HERE --

**Measures.** An ad hoc questionnaire was used to gather *demographic information* from the reference and clinical sample assessing parents' age, parental role (mother/father), educational degree and marital status. Additional variables that were assessed in the clinical sample only were ethnicity of the parent, number of children and the medical diagnosis of the child. *Anxiety and depression* (RQ1 & 2). In the *clinical sample*, anxiety and depression were measured with the self-report 4-item short forms of the PROMIS item bank (Patient-Reported Outcomes Measurement Information System; [www.healthmeasures.net](http://www.healthmeasures.net)). The PROMIS scales have been found to be reliable and valid to use in general populations as well as in populations with chronic health conditions (e.g., Cella et al., 2010) and were psychometrically evaluated for use in Dutch populations (Flens et al., 2017). For *anxiety*, the PROMIS Item Bank v1.0 Emotional Distress-Anxiety (Short Form-4a; Dutch version by Terwee et al., 2014) was used (e.g., "I felt anxious"). For *depression*, the PROMIS Item Bank v1.0 Emotional Distress-Depression (Short Form-4a; Dutch version by Terwee et al., 2014) was used (e.g., "I felt depressed"). Parents were asked to rate statements on both scales about the last 7 days on a 5-point Likert Scale, with answers ranging from 1 (= "Never") to 5 (= "Always"). Cronbach's alpha for anxiety and depression was excellent (i.e.,  $\alpha = .91$  and  $.94$ , respectively). Total scores for anxiety and depression were used, with higher scores indicating more anxiety and depression. In the *reference group*, parental anxiety and depression were assessed with the single item that had direct overlap with the items used in the clinical sample. Parents rated the face valid items "I felt anxious" and "I felt depressed" on a 5-point Likert Scale with answers ranging from 1 (= "Never") to 5 (= "Always"). Previous studies have supported the assessment of anxiety and depression by a single item (e.g., Turon et al., 2019).

*Sleep quality* (RQ2) was assessed in the clinical sample only with the Insomnia Severity Index (ISI; Morin, 1993; Dutch version), a 7-item self-report questionnaire to assess the severity of both nighttime and daytime components of insomnia (e.g., “how much trouble did you have with falling asleep?”). Parents were asked to rate each item for the last two weeks on a 5-point Likert scale, with answers ranging from 0 (e.g., “no trouble” or “no impact”) to 4 (e.g., “very severe trouble” or “very severe negative impact”). Total scores were used with higher scores indicating more sleep problems. Previous studies have reported good psychometric properties for the ISI (Bastien et al., 2001). Internal consistency of the questionnaire was excellent in the clinical sample (i.e., Cronbach’s  $\alpha=.90$ ).

*COVID-19 specific stressors* (RQ2) were assessed in the clinical sample with an ad hoc questionnaire investigating financial worries, living space and perceived quality of health care for the child. The questionnaire was developed by the research team in consultation with the hospital clinicians, as no validated COVID-19 specific items were yet available. Financial worries were assessed with one face valid item (i.e., “to what extent are you worried about your financial situation during the COVID-19 pandemic”) and rated on a 4-point Likert Scale with answers ranging from 1 (=“not at all”) to 4 (=“very much”). To assess perceived quality of health care, 4 face valid items were developed by the research team, investigating the extent to which parents felt that their child was supported and listened to by health care workers (e.g., “The health care worker (doctor, nurse, physiotherapist, psychologist) contributed enough time to my child”). Items were rated on a 5-point Likert Scale with answers ranging from 1 (=“never”) to 5 (=“always”). Items of the questionnaire showed excellent internal consistency (Cronbach’s  $\alpha=.91$ ). Living space was assessed with 5 items assessing how much space the family has at home (e.g., “everyone has a space at home where he/she can work in silence”). Parents checked if the items were applicable, with unchecked items scored as 0 and checked items scored as 1. Items of the questionnaire showed adequate internal consistency (Cronbach’s



$\alpha=.73$ ). Total scores for each variable were used, with higher scores indicating more financial worries, more living space and higher perceived quality of health care.

*Parental burn-out* (RQ2). Participants in the clinical sample rated their levels of parental burn-out with three items from the Parental Burnout Assessment (Roskam et al., 2018; e.g., “I feel like I can’t take any more as a parent”: also used in Schrooyen et al., 2021). Items were scored on a 5-point Likert scale ranging from 1 (=“Totally don’t agree”) to 5 (=“Totally agree”). Items of the questionnaire showed good internal consistency (Cronbach’s  $\alpha=.87$ ). Total scores were used with higher scores indicating more parental burn-out.

*Positive parenting experiences* was measured with three face valid items in the clinical sample to tap into positive feelings parents may experience when spending time with their children (e.g., “I can really enjoy spending more time than before with my children”; also used in Schrooyen et al., (2021)). Items were scored on a 5-point Likert scale ranging from 1 (=“Totally don’t agree”) to 5 (=“Totally agree”). Items of the questionnaire showed good internal consistency (Cronbach’s  $\alpha = .82$ ). Total scores were used with higher scores indicating more positive parenting experiences.

**Statistical Analyses.** Correlational and regression analyses were conducted with the statistical software SPSS version 26 (SPSS IBM, New York City, NY). Significance levels were set at .05. Pearson correlation analyses assessed bivariate relationships between variables of interest. To investigate RQ1, hierarchical regression analyses were conducted to examine whether parents of children with chronic diseases reported higher levels of anxiety and depression compared to parents of healthy children. To match the outcomes with the reference sample, only the identical items for anxiety and depression from the PROMIS short-form of the clinical sample were included. Within this regression analysis, parental age, parental role (fathers coded ‘1’, mothers coded ‘2’), educational degree (higher education coded ‘1’; highest degree secondary school or lower ‘0’) and marital status (single/living alone coded ‘0’,

married/cohabiting coded '1') were entered in step 1; group (reference sample coded '0'; clinical sample coded '1') was entered in step 2. To investigate RQ2, a series of three hierarchical regression analyses were conducted within the clinical sample to examine the role of sociodemographic variables, COVID-19 specific stressors and parental experiences in their association with parents' general mental health outcomes. Specifically, in each of these regression analyses, parental age, parental role, marital status, ethnicity (white coded '0', other ethnicities coded '1'), educational degree (higher education coded '1'; highest degree secondary school or lower '0'), number of children and child diagnosis (14 different categories, see Table 1) were entered in Step 1. Step 2 included the COVID-19 specific stressors during the past 6 months. In Step 3, parental burn-out and positive parenting experiences were added. Following the regression analyses, multiple mediation analyses were conducted within the clinical sample to examine whether parental burn-out and positive parenting experiences mediated the relationship between each of the COVID-19 specific variables and each of the parental outcome measures<sup>1</sup>. A bootstrapping method was used with 5000 resamples with weights being calculated for each path of the model, using the PROCESS macro for SPSS (Hayes, 2013). First, the total effect of each COVID-19 specific variable on each outcome measure was assigned weight  $c$ . This total effect consists of the direct effect of the independent variable on the outcome measure (weight  $c'$ ) plus the indirect effect of the independent variable on the outcome measure through the potential mediators (weight  $ab$ ). This indirect effect  $ab$  is partialled out by calculating the effects of the independent variable on the potential mediator variables (weight  $a$ ) and the mediator variable on the outcome measure (weight  $b$ ). The model assessed the indirect effect of all mediators (i.e., total indirect effect), but also the effect of each mediator separately (i.e., specific indirect effects;  $a^1b^1$  and  $a^2b^2$ ) while controlling for the other

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<sup>1</sup> This model was compared with an alternative model where anxiety, depression and sleep were the mediators and burn-out and parenting positive experiences were considered the outcomes. All fit indices (AIC, BIC and a Chi-squared test) showed a significant difference in the fit between both models, favorizing the original model and strengthening theoretical assumptions about the ordering of effects.

mediator. Furthermore, the effect of the mediators on each other, controlled for predictors, was also assessed (d). The presence of an indirect effect is considered the only condition to establish mediation, even in the absence of total or direct effects (Zhao et al., 2010). Given the cross-sectional nature of this study, all causal paths remain speculative and alternative directions of effects are equally plausible. No problems of multicollinearity were detected (all VIF <1.54).

**RESULTS. RQ 1: Do parents of children with chronic diseases report more depressive symptoms and anxiety compared to parents of healthy children?** Means (M), standard deviations (SD) and correlations between study variables are shown in Table 2. Correlation analyses indicated that, within both samples, parental anxiety and depression levels were significantly positively correlated (both  $r \geq .46, p < .001$ ).-INSERT TABLE 2 ABOUT HERE- Results of the *hierarchical regression analyses* examining differences in parental anxiety and depression as a function of group (i.e., clinical sample vs. reference sample; cfr. RQ1) whilst controlling for age, parental role, education and marital status are reported in Table 3. Findings indicated that *parental anxiety* was significantly higher for younger parents and for mothers, but results suggest a small effect<sup>2</sup>. There was also a significant medium effect of group such that parents in the clinical sample reported significantly higher levels of anxiety compared to parents of the reference sample. Results furthermore indicated a rather small effect for higher *parental depression* amongst younger parents and parents living alone or being single. There was no statistically significant difference in depression levels between parents of youth with and without a chronic disease. --- INSERT TABLE 3 ABOUT HERE ---

**RQ 2: What are key variables associated with mental health problems in parents of children with chronic diseases?** Means (M), standard deviations (SD) and correlations amongst all variables are shown in Table 4. Correlation analyses indicated that, except for the

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<sup>2</sup> In this paper the following indicators for effect sizes were administered: Effect sizes for correlations:  $r$  around .50 = large effect;  $r$  around .30 = moderate effect;  $r$  around .10 = small effect. For regressions,  $F^2$  values were computed per individual predictor with values around .02 = small effect; .15 = medium effect and .35 = large effect (Cohen, 1988).

relationship between living space and parental anxiety, all COVID-19 specific variables were significantly correlated with each of the three parental outcome variables and parental burn-out, such that more financial worries (moderate effect), less living space (small effect) and lower perceived quality of health care (small to moderate effect) were associated with worse parental outcomes and higher parental burn-out. Conversely, more living space, lower financial worries and higher perceived quality of health care were associated with more positive parenting experiences, but effect sizes were smaller. Finally, correlation analyses indicated significantly positive large correlations between parental burn-out and parental anxiety, depression and sleep problems and significantly negative moderate correlations between positive parenting experiences and all three mental health outcomes.

-INSERT TABLE 4 ABOUT HERE-

***Hierarchical Regression Analyses.*** The results of the hierarchical regression analyses are reported in Table 5. The regression analysis with *parental anxiety* as a dependent variable indicated that mothers, parents with a non-white ethnicity and parents with fewer children experienced more parental anxiety. Results further indicated that anxiety was also higher when parents reported more financial worries and lower levels of perceived quality of health care during the past 6 months. Above and beyond the sociodemographic and COVID-19 specific variables, results indicated that higher levels of parental burn-out and lower levels of positive parenting experiences were associated significantly with higher levels of parental anxiety. The regression analysis with *parental depression* as a dependent variable revealed largely comparable findings. In particular, higher levels of depression were observed for mothers, for parents reporting higher levels of financial worries, reporting lower levels of perceived quality of health care and reporting higher levels of burn-out. Additionally, there was also a significant effect of living space and education indicating that less living space and lower education is associated with higher levels of parental depression. Positive parenting experiences were not

associated with parents' levels of depression. The analysis with *parental sleep problems* as a dependent variable indicated that sleep problems were enhanced for older parents, parents with a non-white ethnicity, parents reporting more financial worries, parents with lower perceived quality of health care and parents indicating higher levels of parental burn-out. Positive parenting experiences were not significantly associated with parental sleep problems. It must be noted that parental burn-out and financial worries seem most strongly associated with parental mental health outcomes (medium to large effects), while the remaining effects suggest rather small associations. --- INSERT TABLE 5 ABOUT HERE---

**Mediation analyses.** Results of mediation analyses with *parental burn-out* and *positive parenting experiences* as mediators can be found in Figure 1. More *financial worries* were related to higher anxiety (total effect  $c=1.63$ ,  $SE=.17$ ,  $p<.001$ ) and higher parental burn-out ( $a^{1x}$ ), but not to positive parenting experiences ( $a^{2x}$ ). Higher parental burn-out was related to more anxiety ( $b^1$ ), while positive parenting experiences was not ( $b^2$ ). Analyses showed the total indirect effect to be positive ( $ab^{1x}$ ) and significant as the bootstrapped confidence interval excluded zero (95% CI) indicating that parental burn-out and positive parenting experiences mediated the association between higher financial worries and higher anxiety. Specific indirect effects showed that only parental burn-out, but not positive parenting experiences, was a mediator. Similar findings were observed for parental depression and sleep problems as outcomes. Specifically, the total indirect effects of financial worries via parental burn-out and positive parenting experiences ( $ab^{2x}$  and  $ab^{3x}$ ) were all significant such that parental burn-out and positive parenting experiences mediated the association between higher financial worries and higher depression and sleep problems, respectively. Analyses also demonstrated the mediating role of parental burn-out and positive parenting experiences in the relationship between less *living space* and higher parental anxiety (total indirect effect  $ab^{1y}$ ) as well as higher depression ( $ab^{2y}$ ) and more sleep problems ( $ab^{3y}$ ). Analyses likewise demonstrated the

mediating role of higher parental burn-out and positive parenting experiences in the relationship between *perceived quality of health care* and parental anxiety ( $ab^{1z}$ ), as well as higher depression ( $ab^{2z}$ ) and more sleep problems ( $ab^{3z}$ ). In all analyses, an inspection of the specific indirect effects showed that only parental burn-out, but not positive parenting experiences, was a mediator. In all analyses, parental burn-out was strongly negatively associated with positive parenting experiences ( $d=-.32$ ,  $SE=.03$ ,  $p<.001$ ).

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**DISCUSSION.** This study was the first to investigate mental health problems among parents with children with chronic diseases during the COVID-19 pandemic. Partially in line with our hypotheses, parents of children with chronic diseases reported significantly more anxiety, but not more depressive symptoms, compared to parents of healthy children. These findings are in line with other studies reporting high anxiety scores in parents of children with chronic diseases (e.g., Jones et al., 2016; Kelada et al., 2020; Bassi et al., 2021). However, literature on the topic of parental well-being of children with chronic diseases is not univocal (e.g., Kelada et al., 2020; Ljungman et al., 2014). This study is the first to compare mental health outcomes between parents of children with chronic diseases and parents of healthy children specifically during the COVID-19 pandemic. Although we have no pre-pandemic data as a comparison basis, results underscore our hypothesis that the pandemic might be an additional source of stress for parents of children with chronic diseases, who already constitute a vulnerable group for worsened mental health outcomes. Because the COVID-19 pandemic entails an immediate threat to individuals' health and safety, it is logical that anxiety was particularly elevated among parents of children with chronic diseases. Depression may reflect a more chronic response to the pandemic occurring after a longer period of time.

Results in both samples furthermore suggest that certain groups of parents are particularly vulnerable for worsened well-being outcomes. Results corroborate the growing

evidence that mothers (but note that mothers were overrepresented in our sample) and single parents (i.e., mothers and fathers) constitute a high-risk group for which special attention might be warranted during the COVID-19 pandemic. The multiple roles that women and single parents had to take on during the pandemic as the often primary caregiver, in combination with drastically decreased social support, led to a heavier parenting burden and might explain enhanced vulnerability (Marchetti et al., 2020; Norberg, 2007). Younger parents also reported worse well-being, which might be due to the challenging novelty of both parenthood and the COVID-19 pandemic. Of further interest, parents of Arabic, Asian, Black, or Mixed ethnicity reported more anxiety and sleep problems, corroborating preliminary results of Brown et al. (2020) which suggest that parents of Black, Asian, American Indian, Latinx and Mixed ethnicity might be disproportionately impacted by COVID-19 stressors. However, as this group of parents in the current sample was rather small and the effect size was rather small, findings must be interpreted with caution.

Given that mental health problems, and anxiety in particular, were elevated among parents of children with chronic diseases, a second research question aimed to identify possible variables associated with these mental health problems. This study is, to the best of our knowledge, the first to demonstrate the association of those COVID-19 specific stressors with the mental health of parents of children with chronic diseases. Furthermore, parents' experiences in their parental role (i.e., parental burn-out and positive parenting experiences) were uniquely related to most general mental health outcomes above and beyond the effects of the COVID-19 specific stressors. Feelings of exhaustion and depletion in the parental role radiate towards parents' general mental health, (Marchetti et al., 2020; Mikolajczak et al., 2020; Roskam et al., 2017), with the current pandemic representing an additional stressor for parents as they are being asked to combine multiple roles (e.g., professional role, teaching role and parenting role). Positive parenting experiences were significantly related to lower parental

anxiety, but were not associated with parental depression and sleep problems. Parents who experience the increased time spent with their children as an opportunity might be protected against COVID-19 related anxiety, while depression and sleep problems might be caused more strongly by vulnerability factors existing already prior to the pandemic. Future research would do well to rely on diary designs (see e.g., Neubauer et al., 2020), thereby examining whether a daily increase in positive parenting experiences suffices to ameliorate parents' mental health (i.e., at within-person level), even when parents display dispositionally high levels of ill-being (i.e., at between-person level). A recent study furthermore suggests that interventions targeting parental identity (i.e., having a clear view of who you are as a parent) and parental need satisfaction (i.e., need for autonomy, competence and relatedness) might lead to more positive parenting experiences and more parental well-being in general, thereby protecting against feelings of parental burn-out (Schrooyen et al., 2021). In the current study, parents' positive parenting experiences might have also been impacted by the health status of their children, as worries about the virus and its implications for the health (care) of their child (Darlington et al., 2020) might have reduced feelings of shared enjoyment when spending time together.

Results from exploratory mediation analyses suggest that different COVID-19 related stressors affect parents' mental health (at least partially) through their experiences in the parental role. Parents feel worn out in their parental role, with these feelings of exhaustion (and perhaps also guilt about not fulfilling the parental role adequately) in turn undermining their mental health. Whereas COVID-19 specific stressors might be hard to tackle in psychological interventions, our findings attest to the opportunity for interventions to specifically target parental burn-out, a more modifiable psychological variable. As parents with high levels of distress and burn-out might be less available and responsive to their child's needs (Abidin, 1922), children's well-being might also be threatened (Marchetti et al., 2020). Parental burn-out even increases child neglect and parental violence (Mikolajczak et al., 2019; Mikolajczak



et al., 2020). A recent study showed that an intervention for parental burn-out that aimed to restore the balance between parental stressors and resources as well as an intervention where parents were offered a setting wherein they can share their difficulties with someone actively listening to them, significantly decreased symptoms of parental burn-out (Brianda et al., 2020). Results of this study also implied that psychologists do not need to be experts in parental burn-out to deliver effective support for parents. Health professionals in integrated pediatric primary care settings are in a unique and important position to assess parents' emotional exhaustion and need for additional support. They can furthermore provide parents with clear health-related additional information during the pandemic and address worries about reduced (quality of) health care (Darlington et al., 2020). Interventions should ideally be tailored to specific risk factors for the parent (e.g., having a child with chronic pain during the COVID-19 pandemic; see Mikolajczak et al., 2019). However, more research on interventions for parental burn-out in the context of pediatric chronic diseases is needed.

The current study has several limitations. Primarily, the cross-sectional nature of this study does not allow for causal inferences or firm conclusions regarding the directionality of associations between study variables (see Maxwell & Cole, 2007). Additional longitudinal research is warranted to examine bidirectional associations between the variables central in this study. Second, because the risk factors for worsened mental health outcomes were only assessed in the clinical sample, but not in the reference sample, it remains unclear whether the difference in mental health outcomes between both samples is due to the COVID-19 pandemic or due to pre-existing disparities between both samples. The study design did not allow for examining whether the strength of associations between the risk factors and the mental health outcomes is similar or different between these two groups of parents. Future research should therefore investigate if parents of children with a chronic disease experience more impact of COVID-19 stressors than parents of healthy children. Third, only parental self-report measures

were included and mothers were overrepresented in this sample. Fourth, for the first research question, parental anxiety and depression were measured with a single item. Fifth, due to the online recruitment of participants in both samples, it was not possible to identify potential differences between participants and non-participants on certain demographic or clinical variables. Sixth, the absence of measures examining racism and discrimination limits the understanding of the study's findings regarding race and ethnicity. More research on this topic is therefore warranted.

In conclusion, the current findings highlight that parents of children with chronic diseases constitute a vulnerable group for worse well-being during the current pandemic. Feelings of parental burn-out are associated with parents' mental health problems and should be targeted by specific interventions.

**Figure Legends.** Figure 1: Multiple mediation analysis paths with financial worries, living space and perceived quality of health care as independent variables, parental burn-out and positive parenting experiences as mediators, and parental anxiety, depression and sleep problems as dependent variables. Listed in order are weights, SEs, and either the p-value or the 95% CI. \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

**Keywords:** parents, children with a chronic diseases, parental burn-out, positive parenting experiences, parental well-being, COVID-19

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