Mental health outcomes and experiences of family caregivers of children with disabilities during the COVID-19 pandemic in Bolivia

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Abstract
This study examined whether certain demographic characteristics, caregiver strain, and coping behaviors were associated with the mental health outcomes of family caregivers of children with disabilities in Bolivia during the COVID-19 pandemic. A mixed-methods convergent study design was used with virtual interviews to quantitatively assess caregivers' demographic characteristics, caregiver strain, coping behaviors, and mental health outcomes, as well as qualitatively assess how the pandemic affected their family. Approximately 32%–71% of caregivers experienced poor mental health outcomes (stress, anxiety, and depression), especially among those experiencing poor health, high caregiver strain, and those using maladaptive coping strategies. Qualitative responses revealed that they experienced several unique stressors during the pandemic that affected them and their children. These findings highlight the need for culturally tailored prevention and treatment interventions to help offset the adverse effects of the COVID-19 pandemic on the mental health outcomes of this at-risk population.

Keywords
Bolivia, caregiver strain, children with disabilities, coping, COVID-19, mental health, mixed methods
1 | INTRODUCTION

It is estimated that there are 93–150 million children living with moderate to severe disabilities (e.g., physical, mental, intellectual, and/or sensory impairments) worldwide and is most common in low-income countries, such as Bolivia (Kuper et al., 2014; UNICEF, 2005; World Health Organization (WHO), 2011). Bolivia is a land-locked country located in western-central South America that has historically been classified as being one of the poorest countries in Latin America with 60% of the population living below the poverty line (Programa de las Naciones Unidas para el Desarrollo, 2013). Proper nourishment is a constant struggle for many Bolivians with 19% of children under the age of three and 23% of the entire population suffering from chronic malnutrition (Encuesta de Evaluación de Salud y Nutrición, 2014). These high malnutrition rates, as well as high rates of birth complications (Moloney, 2009), have contributed to approximately 15% of the Bolivian population (~1.5 million) having a developmental disability, 35% of whom are children and adolescents (Disabled World, 2017; Sistema de Información del Programa de Registro Único Nacional de Personas con Discapacidad (SIPRUNPCD), 2017). The most common types of disabilities in Bolivia for this age group consist of those with physical/motor (38%), intellectual (29%), or multiple impairments (15%), with 34% of disabilities being classified as mild to moderate, 51% as severe, and 15% as very severe (SIPRUNPCD, 2019). Several of these genetic and neurodevelopmental disorders (e.g., Down syndrome, cerebral palsy, and autism spectrum disorders) significantly impact children’s ability to engage in activities of daily living, such as being able to independently feed themselves, walk, or communicate with others, and can, therefore, have a lasting effect on the quality of life of these children and their families.

Children with disabilities are one of the most marginalized and disadvantaged social groups in Bolivia as there are limited healthcare resources for this population, with 50% not being able to afford the health services that are available (Tejerina et al., 2014). Furthermore, certain health professionals and teachers often lack the specialized training to care for and teach children with disabilities, resulting in them seldomly receiving the medical attention and education needed, with only 38% attending school compared to 98% of children without disabilities (WHO, 2011). As such, a greater burden has been placed on the families of these children to provide the day-to-day support needed. These ongoing caregiving responsibilities can have a major impact on the entire family as many search for affordable therapeutic options or rehabilitation interventions (e.g., physiotherapy, occupational therapy, speech and language therapy, behavioral therapy, and/or special education) for their child, while coordinating follow-up evaluations with hospitals or clinics to minimize the long-term effects that the disability may have on the child’s development (Kandel & Merrick, 2003). Consequently, parents in Bolivia are typically expected to take on this caregiver role and often find themselves unprepared for the responsibilities involved in caring for their child, which can lead to caregiver strain.

Caregiver strain refers to the process by which the demands and responsibilities associated with caring for one’s child exceed their resources to cope with those demands, thereby resulting in the caregiver often feeling overwhelmed and unable to perform their role to the best of their ability (Raina et al., 2004). The accumulation of these caregiving demands over time can lead many parents of children with disabilities to experience poor mental health outcomes. Indeed, studies have demonstrated parents of children with disabilities to experience higher levels of stress, anxiety, and depression than parents of children without disabilities (J. Lee, 2013; Masefield et al., 2020; Singer & Floyd, 2006), which is concerning given the detrimental effects that poor caregiver health can have on the quality of care that is provided for their child. Therefore, studies are needed to identify factors associated with increased caregiver strain and poor mental health outcomes in this at-risk population.

One theoretical model that has been used to better understand factors associated with increased caregiver strain and mental health outcomes is the caregiver burden model. According to this model, variations in how caregivers adapt to their caregiver demands are largely dependent on contextual factors, such as the presence of certain demographic characteristics (e.g., low socioeconomic status, marital status, severity of child disability, caregivers’ physical health), the level of caregiver strain experienced, and the coping strategies used to offset caregiving demands (Raina et al., 2004). Studies have supported this multidimensional model demonstrating that
caregivers from low-income households, those who are single, those caring for children with severe and multiple developmental disabilities, those with worse physical health, and those with higher caregiver strain experience elevated levels of anxiety and depression (Gallagher et al., 2008; Masefield et al., 2020; Miodrag & Hodapp, 2010; Raina et al., 2005; Woodman & Hauser-Cram, 2013). Coping responses, which involve the use of several cognitive and behavioral strategies to manage stressful situations (Sears et al., 2000), can also play a major role in caregivers’ psychological well-being. Results from several studies generally suggest that lower use of adaptive coping strategies (e.g., use of positive reframing, seeking social support) and greater use of maladaptive coping strategies (e.g., denial, self-blame) are associated with worse psychological (e.g., depression) health outcomes in caregivers (Fairfax et al., 2019; Woodman & Hauser-Cram, 2013). However, mixed results have been found between the use of these coping strategies and caregivers’ anxiety levels (Fairfax et al., 2019; Guillamón et al., 2013). Another understudied contextual factor that may strongly impact the mental health of caregivers is the added demands associated with living through a worldwide pandemic.

Since the WHO declared the spread of the COVID-19 virus as a global pandemic in March 2020, preventive health campaigns, such as social distancing, were implemented to contain the spread of the virus in many countries. In Bolivia, a country-wide lockdown of schools, workplaces, and international borders was posed by the government in March 2020 (Hummel et al., 2021). While the distribution of vaccines for COVID-19 increased substantially since December 2020 in wealthier countries, such as the U.S. (42% fully vaccinated), smaller countries like Bolivia have struggled to obtain vaccinations for their residents during this same time period (3.5% fully vaccinated; Ritchie et al., 2020). Consequently, the percentage of COVID-19 cases (21% increase) and deaths (44% increase) have substantially increased in Bolivia in June 2021 compared to the U.S. (42% decrease in the number of cases and 8% decrease in deaths; Ritchie et al., 2020). This surge in COVID-19 cases and deaths has strongly impacted Bolivia’s already weak economy, leaving hundreds of thousands of people unemployed, as workplaces have continued to be locked down and curfews have been enforced to slow the spread of the virus (Comisión Económica para América Latina y el Caribe (CEPAL), 2020). This country-wide lockdown has also left many parents and their children with disabilities struggling as face-to-face education has been suspended in schools and special education and rehabilitation programs have been closed during the pandemic, placing added responsibility on parents to financially support their families while also sustaining their child’s education and rehabilitation goals at home with very little knowledge or training (Pérez-de la Cruz & Ramírez, 2020). In turn, recent studies have shown the mental well-being and caregiver strain of parents of children with disabilities to have significantly worsened during the pandemic compared to prepandemic levels (Cankurtaran et al., 2021; Dhiman et al., 2020; Pecor et al., 2021), with a significant percentage of caregivers in countries such as India and Iran experiencing elevated stress (36%), anxiety (21%–41%), and depression (45%–63%) during the pandemic (Dhiman et al., 2020; Farajzadeh et al., 2021). Yet, few studies have examined which factors are associated with the mental health outcomes of family caregivers of children with disabilities during the COVID-19 pandemic, particularly in low-income countries such as Bolivia.

1.1 Present study

The purpose of the current mixed-methods study was to describe the mental health status and perceived strain experienced by family caregivers of children with disabilities in Bolivia during the COVID-19 pandemic, as well as to identify whether certain factors (i.e., demographic characteristics, caregiver strain, the impact of the pandemic, and coping strategies used) were associated with mental health outcomes in this population. Specifically, we hypothesized that family caregivers who experienced more caregiver strain, were more strongly impacted by the COVID-19 pandemic, and who used more maladaptive coping strategies would experience worse mental health outcomes (i.e., elevated levels of stress, anxiety, and depression). Qualitative interviews were also administered to
provide more in-depth information on the stressors that family caregivers experienced, as well as how the COVID-19 pandemic affected them and their children.

2 | METHODS

2.1 | Participants

Family caregivers were recruited between July and September 2020 from the Department of Chuquisaca, Neurodevelopment Research Institute for Children With Disabilities (Sucre, Bolivia) that serves low-income parents and their children. Recruitment occurred by mailing a letter to the caregivers of the children who received rehabilitation and therapy services at the neurodevelopment research institute during the previous year (2019) that explained the purpose of the study and included an informed consent form. After mailing these letters, research staff from the institute called these caregivers to provide an overview of study requirements, determine their level of interest in participating in the study, and help answer any questions they may have had. Caregivers who were interested in the study then signed the consent form that was sent to them (which they mailed back to the research staff using a self-addressed, stamped envelope) to determine their study eligibility and to participate in the study. Eligibility criteria included being 18 years of age or older, having a child with a disability (physical/motor, intellectual, sensory, or multiple impairments) who was under 18 years of age, being the primary caregiver for the child, living with the child, being a native Spanish speaker who could read in Spanish, and having access to Zoom through a phone or computer to participate in a virtual interview. Of note, most families that received services through the neurodevelopment research institute had already been connecting with their child’s clinician during the pandemic virtually via Zoom to receive guidance on therapy exercises and activities that they could do with their child at home.

2.2 | Procedures

Eligible caregivers were sent a Zoom link via WhatsApp or their email to participate in a 1-h virtual health interview (using a mixed-methods, convergent, cross-sectional study design). Each one-on-one interview was conducted in Spanish by a trained research staff member (team of 10 undergraduates majoring in psychology or kinesiology). Members of the research team had received extensive training by a licensed clinical psychologist to administer these mixed-methods assessments by reading each item to participants while sharing the response options for each questionnaire on their screen to facilitate study participation and to ensure accuracy of the data. Participants were administered questionnaires that assessed their demographic characteristics, level of caregiver strain, the impact of the COVID-19 pandemic, use of different coping strategies, and level of stress, anxiety, and depression. They were also asked open-ended questions to obtain more in-depth information on the types of stressors they experienced and how the COVID-19 pandemic affected them and their child. All health interviews were videotaped through Zoom to verify the scoring of each questionnaire and to transcribe the qualitative responses.

Of 100 caregivers who were originally contacted by mail and a follow-up phone call to determine their study interest and eligibility, 77 participated in the study. Of the 23 caregivers who did not participate, 10 were lost to contact, eight declined to participate, and five did not have access to Zoom to complete the virtual interviews. Participants did not differ from nonparticipants by demographic characteristics or the type of disability that their child had ($p > 0.05$). All study procedures were approved by the Research Bioethics Committee of the Faculty of Health Sciences and Technologies at the University of San Francisco Xavier de Chuquisaca.
2.3 Measures

2.3.1 Sociodemographic characteristics

The sociodemographic questionnaire assessed for caregiver characteristics, such as caregiver age (in years), relationship to child (mother, father, other relative), total years of education, marital status (single, married/living with a partner). Caregivers also indicated the degree to which they had difficulty living on their annual family income on a 4-point Likert scale of 1 ("Not difficult at all") to 4 ("Very difficult"). Additionally, they were asked to rate their physical health on a 5-point Likert scale of 1 ("Excellent") to 5 ("Poor"). Child characteristics were also assessed and included the child's gender (girl, boy), age, and a number of siblings. The child's type of disability (physical/motor, intellectual, sensory, language, multiple) and severity of the disability (mild, moderate, severe/very severe) were also assessed and confirmed by a review of the child's medical records.

2.3.2 Caregiver strain

Caregiver strain was assessed using the 7-item short-form version of the Caregiver Strain Questionnaire (CGSQ-SF7; Brannan et al., 2012). The CGSQ-SF7 assesses the extent to which certain occurrences, events, or feelings have been a problem for the caregiver over the past month due to their child's behavior. These seven items are separated into two distinct subscales including a subjective internalized strain subscale (three items; e.g., worry, guilt, fatigue) and an objective strain subscale (four items; e.g., work interruptions, disrupted family relations). Items for both subscales are rated on a 5-point scale of 1 ("Not at all a problem") to 5 ("Very much a problem"). A total caregiver strain score is calculated by averaging the responses for each subscale and then summing those average subscale scores together, with higher scores (range = 1–10) representing greater caregiver strain. A cutoff score of 7 represents high caregiver strain (Brannan et al., 2012). The CGSQ-SF7 has been shown to have good reliability and validity in Spanish-speaking populations (Fawley-King et al., 2020). Cronbach's α for the current study was 0.84.

2.3.3 Impact of COVID-19 pandemic

The impact of the COVID-19 pandemic on the lives of caregivers was assessed by using one item from the Pandemic Stress Index (PSI; Harkness, 2020). Specifically, participants were asked to rate "How much is/did COVID-19 (coronavirus) impact your day-to-day life?" on a 5-point scale of 1 ("Not at all") to 5 ("Extremely"), with higher scores representing the COVID-19 pandemic having a greater impact on caregivers' lives.

2.3.4 Coping strategies

Coping was assessed using the 28-item short-form version of the Coping Orientation to Problems Experienced Inventory (Brief-COPE; Carver, 1997). The Brief-COPE assesses the extent to which people use different coping strategies under stressful situations. These 28 items are separated into 14 distinct coping subscales (two items each) with each item being rated on a 4-point scale of 1 ("I usually don't do this at all") to 4 ("I usually do this a lot"). Although each of the 14 coping subscales can be evaluated on its own, studies have also combined eight of the subscales as a measure of adaptive coping (i.e., active coping, planning, use of emotional support, use of instrumental support, positive reframing, acceptance, religion, and humor) and six of the subscales as a measure of maladaptive coping (i.e., venting, denial, substance use, behavioral disengagement, self-distraction, and self-blame), with these adaptive and maladaptive coping subscales being associated with distinct health outcomes (Meyer, 2001). Therefore, these
two subscales were used in the current study. Adaptive coping was calculated by summing the responses for the 16 items of this subscale, with higher scores (range = 16–64) representing greater use of adaptive coping strategies. Similarly, maladaptive coping was calculated by summing the responses for the 12 items of this subscale, with higher scores (range = 12–48) representing greater use of maladaptive coping strategies. The Brief-COPE has been shown to have good reliability and validity in Spanish-speaking populations (García et al., 2018). Cronbach’s α for the current study was 0.70.

2.3.5 | Stress

Stress was assessed using the four-item version of the Perceived Stress Scale (PSS-4; Cohen & Williamson, 1988). The PSS-4 measures the extent to which situations in one's life were perceived as stressful over the past month, with items detecting how unpredictable, uncontrollable, and overloaded respondents find their lives. Items are rated on a 5-point scale of 0 (“Never”) to 4 (“Very often”). A total score is calculated by reverse-coding two of the positively worded items and then summing all four items, with higher scores (range = 0–16) representing higher levels of stress. A cutoff score of 8 represents high stress (Vallejo et al., 2018). The PSS-4 has been shown to have good internal consistency in Spanish-speaking populations (Vallejo et al., 2018). Cronbach’s α for the current study was 0.73.

2.3.6 | Anxiety

Anxiety was assessed using the state anxiety subscale of the 8-item version of the State-Trait Anxiety Inventory (STAI-8; Buela-Casal & Guillén-Riquelme, 2017). The four items of this subscale measure the level of anxious feelings experienced at the present moment. Items are rated on a 4-point scale of 0 (“Not at all”) to 3 (“Very much”). A total score is calculated by reverse-coding one of the positively worded items and then summing all four items, with higher scores (range = 0–12) representing greater anxiety. A cutoff score of 7 was used to represent high anxiety (one standard deviation above the mean). The state subscale of the STAI-8 has been shown to have good reliability and validity in Spanish-speaking populations (Buela-Casal & Guillén-Riquelme, 2017). Cronbach’s α for the current study was 0.74.

2.3.7 | Depression

Depression was measured using the 10-item version of the Center for Epidemiologic Studies Depression Scale (CESD-10; Cole et al., 2004). The CESD-10 assesses for affective and somatic symptoms of depression during the past week. Items are rated on a 4-point scale of 0 (“Rarely or None of the time”) to 3 (“A majority of the time or All of the time”). A total score is calculated by reverse-coding two of the positively worded items and then summing all 10 items, with higher scores (range = 0–30) reflecting greater symptoms of depression. A cutoff score of 10 represents significant depressive symptoms (Cole et al., 2004). The CESD-10 has demonstrated good internal consistency in Spanish-speaking populations (Urizar et al., 2019). Cronbach’s α for the current study was 0.79.

2.3.8 | Qualitative interview

During the health interview, participants were asked the following three open-ended questions to gather contextual information on the types of stressors that family caregivers experienced, as well as how the COVID-19 pandemic affected them and their children:
1. What are your major stressors?
2. How has the COVID-19 pandemic affected you?
3. How has the COVID-19 pandemic affected your child?

2.4 | Statistical analyses

A power analysis was performed a priori using G*Power to determine the sample size needed for the current study (Faul et al., 2009). On the basis of findings from previous studies that reported medium to large effect sizes when examining the association between caregiver strain, coping strategies, and mental health outcomes (Raina et al., 2005; Woodman & Hauser-Cram, 2013), it was estimated that approximately 78 caregivers would result in statistical power at the recommended 0.80 level with an $\alpha$ level of 0.05.

2.4.1 | Quantitative analyses

Possible covariates affecting study outcomes (i.e., caregiver age, relationship to the child, education, marital status, financial strain, physical health status, child gender, child age, number of siblings, child’s type of disability, severity of child’s disability) were identified using Pearson correlations and analysis of variances. Only marital status, financial strain, physical health status, and severity of child’s disability were significantly associated with caregivers’ mental health outcomes ($p < 0.05$) and were included as covariates in subsequent analyses. Hierarchical regression models were tested to identify whether certain factors (i.e., demographic characteristics, caregiver strain, the impact of the pandemic, and coping strategies used) were associated with mental health outcomes among family caregivers of children with disabilities during the COVID-19 pandemic. Three separate regression models were tested for each mental health outcome (i.e., stress, anxiety, and depression). For each regression model, demographic characteristics (i.e., marital status, financial strain, physical health status, and severity of child’s disability) were entered first followed by caregiver strain, the impact of the pandemic, and type of coping strategies used (i.e., adaptive and maladaptive coping). The effect sizes for these associations were presented as Cohen’s $f^2$ with values of 0.02, 0.15, and 0.35 representing a small, medium, and large effect size, respectively (Cohen, 1988). Hierarchical regression models were also used to test for two-way interactions (i.e., caregiver strain by coping) on mental health outcomes.

2.4.2 | Qualitative analyses

Interview transcripts were examined using inductive thematic analysis (Braun & Clarke, 2006). First, marginal coding was used to identify potential themes and subthemes and to develop a codebook. Two research staff members pilot tested the codebook independently using half of the qualitative transcripts. Thematic codes and their definitions were then revised further through group discussions to portray caregivers’ experiences more accurately. Second, two coders were paired to independently apply codes to excerpts using the codebook that was developed earlier. Group discussions were used to resolve any differences in how codes were applied until there was a consensus. Cohen’s $\kappa$ was used to report the level of agreement found between coders using the remaining 50% of transcripts. Interrater reliability was strong ($\kappa = 0.80$).
3 | RESULTS

3.1 | Participants

Participants were approximately 37 years of age (SD = 7.99; range = 23–59 years), with most being married or living with a partner (69%) and having a high school education or less (48%; 31% were college graduates and 21% had professional degrees). Approximately three-fourths of participants (73%) found it somewhat or very difficult to live on their combined family income and had two children on average (SD = 1.19; range = 1–5 children). Most family caregivers were mothers (84%), followed by fathers (12%) and other relatives (4%; grandmother, aunt). On average, their children were 7 years of age (SD = 4.34; range = 1–17 years; 49% 1–5 years old, 31% 6–10 years old, and 20% 11–17 years old) and were mostly boys (77%). The most common types of disabilities that children had were multiple impairments (36%), followed by language/communication (33%), intellectual (17%), sensory (9%), and motor delays (5%). Furthermore, 36% of children’s disabilities were classified as mild, 48% as moderate, and 16% as severe or very severe.

Approximately one-third of family caregivers (31%) reported their physical health as being average to poor (49% experiencing muscular pain, 48% having sleep difficulties, 44% with headaches), with 94% indicating that they had been greatly affected by the COVID-19 pandemic. Furthermore, 35% reported experiencing high caregiver strain (CGSQ-SF7 score ≥ 7). The most common adaptive coping strategies used by family caregivers included accepting the situation (M = 6.58, SD = 1.26), using active coping to do something about the situation they are in (M = 6.43, SD = 1.26), and planning steps to deal with the situation (M = 6.35, SD = 1.41). In turn, the most common maladaptive coping strategies reported included using self-distraction to take their mind off things (M = 5.23, SD = 1.42), blaming themselves for things that happened (M = 4.70, SD = 1.76), and venting their negative feelings towards others (M = 4.69, SD = 1.32). Results also showed that 32% of family caregivers had elevated stress levels (PSS-4 score ≥ 8), 32% had high anxiety (STAI-8 score ≥ 7), and 71% had high depressive symptoms (CESD-10 score ≥ 10). See Table 1 for Pearson correlation analyses between study variables.

3.2 | Factors associated with caregivers’ mental health outcomes

3.2.1 | Stress

Regression analyses revealed that financial strain, caregivers’ physical health status, caregiver strain, and maladaptive coping were significantly associated with stress (see Table 2). Caregivers’ physical health status accounted for the greatest increment of variance for stress, with 13% explained by its entry into the model; poorer caregiver health was associated with higher stress (p = 0.004). Caregiver strain accounted for the next greatest increment of variance for stress, with 12% explained by its entry into the model; higher caregiver strain was associated with higher stress (p = 0.003). Caregivers with higher financial strain (p = 0.005) and those who used more maladaptive coping strategies (p = 0.025) were also associated with higher stress, accounting for 10% and 4% of the variance, respectively. More specifically, Pearson correlation analyses revealed that the maladaptive coping strategies of denial (r = 0.376, p = 0.001) and self-blame (r = 0.389, p < 0.001) were associated with higher stress levels (see Table 3). The overall variance explained by the final model was 46% (f² = 0.85). Marital status, severity of the child’s disability, the impact of the pandemic, and adaptive coping strategies were not significantly associated with stress. Coping was not found to moderate the relationship between caregiver strain and stress (R² = 0.0002, β = 0.005, p = 0.902).
TABLE 1  Pearson correlation analyses (with means and standard deviations) between caregiver characteristics and mental health outcomes among family caregivers of children with disabilities in Bolivia during the COVID-19 pandemic (N = 77)

|                | 1   | 2   | 3   | 4   | 5   | 6   | 7   | 8   | 9   | 10  | 11  | M   | SD  |
|----------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| 1. Marital status |    | -   |     |     |     |     |     |     |     |     |     |     |     |
| 2. Financial strain | -0.28* | -   |     |     |     |     |     |     |     |     |     |     | 2.81 | 0.89 |
| 3. Physical health status<sup>a</sup> | -0.08 | 0.06 | -   |     |     |     |     |     |     |     |     |     |     | 3.19 | 0.78 |
| 4. Severity of child's disability | -0.04 | 0.23* | 0.27* | -   |     |     |     |     |     |     |     | 1.79 | 0.70 |
| 5. Caregiver strain | -0.06 | 0.38** | 0.03 | 0.16 | -   |     |     |     |     |     |     |     | 6.10 | 1.57 |
| 6. Impact COVID-19 pandemic | -0.15 | 0.22 | 0.01 | 0.01 | 0.35** | -   |     |     |     |     |     | 3.91 | 1.01 |
| 7. Adaptive coping | 0.01 | -0.11 | -0.39** | -0.01 | -0.09 | -0.11 | -   |     |     |     |     | 45.31 | 6.93 |
| 8. Maladaptive coping | -0.13 | 0.09 | 0.02 | 0.12 | 0.33** | 0.22 | 0.03 | -   |     |     |     | 25.03 | 4.16 |
| 9. Stress | -0.24* | 0.37** | 0.37** | 0.20 | 0.48*** | 0.17 | -0.23* | 0.37** | -   |     |     | 6.88 | 2.88 |
| 10. Anxiety | -0.08 | 0.18 | 0.37** | 0.06 | 0.44*** | 0.30** | -0.29* | 0.28 | 0.66*** | -   |     | 5.23 | 2.53 |
| 11. Depression | -0.24* | 0.27* | 0.38** | 0.12 | 0.36** | 0.20 | -0.22 | 0.30** | 0.69*** | 0.65*** | -   | 13.16 | 5.97 |

<sup>a</sup>Higher scores for physical health status reflect poorer health.

*<i>p < 0.05</i>; **<i>p < 0.01</i>; ***<i>p < 0.001</i>. 
| Variables                        | Stress          | Anxiety        | Depression       |
|---------------------------------|-----------------|----------------|-----------------|
|                                 | $R^2$ Standard β | $R^2$ Standard β | $R^2$ Standard β |
|                                 | β                | β              | β               |
|                                 | Standard error   | Standard error | Standard error  |
| **Marital status**              |                 | -0.14          | 0.60            | 0.39***         | 0.34*** |
| Financial strain                | 0.31**          | 0.35           | -0.01           | 0.32            | 0.10   | 0.77   |
| Physical health statusa         | 0.31**          | 0.38           | 0.34**          | 0.36            | 0.34** | 0.87   |
| Severity of child’s disability  | -0.01           | 0.41           | -0.11           | 0.38            | -0.06  | 0.93   |
| Caregiver strain                | 0.32**          | 0.20           | 0.34**          | 0.18            | 0.28*  | 0.44   |
| Impact of COVID-19 pandemic      | -0.06           | 0.28           | 0.14            | 0.26            | 0.03   | 0.64   |
| Adaptive coping                 | -0.09           | 0.04           | -0.11           | 0.04            | -0.05  | 0.10   |
| Maladaptive coping              | 0.22*           | 0.07           | 0.14            | 0.07            | 0.19*  | 0.16   |

aHigher scores for physical health status reflect poorer health.

*p < 0.05; **p < 0.01; ***p < 0.001.
### TABLE 3  Pearson correlation analyses between types of coping strategies and mental health outcomes among family caregivers of children with disabilities in Bolivia during the COVID-19 pandemic (N = 77)

|                      | 1       | 2       | 3       | 4       | 5       | 6       | 7       | 8       | 9       | 10      | 11      | 12      | 13      | 14      | 15      | 16      | 17      |
|----------------------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|---------|
| 1. Active coping     |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |
| 2. Planning         | 0.49*** |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |
| 3. Emotional support| 0.24*   | 0.25*   |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |
| 4. Instrumental support | 0.26*   | 0.23*   | 0.59*** |         |         |         |         |         |         |         |         |         |         |         |         |         |         |         |
| 5. Positive reframing | 0.43*** | 0.58*** | 0.24*   | 0.20   |         |         |         |         |         |         |         |         |         |         |         |         |         |         |
| 6. Acceptance       | 0.45**  | 0.71*** | 0.33**  | 0.30**  | 0.43*** |         |         |         |         |         |         |         |         |         |         |         |         |         |
| 7. Religion         | 0.10    | 0.19    | 0.29*   | 0.21    | 0.08    | 0.13    |         |         |         |         |         |         |         |         |         |         |         |
| 8. Humor            | 0.21    | 0.31**  | -0.01   | 0.07    | 0.08    | 0.15    | 0.18    |         |         |         |         |         |         |         |         |         |         |
| 9. Venting          | 0.14    | 0.19    | 0.11    | 0.25*   | 0.15    | 0.02    | 0.18    | 0.19    |         |         |         |         |         |         |         |         |         |
| 10. Denial          | -0.23*  | -0.37** | -0.01   | -0.07   | -0.31** | -0.47***| 0.15    | -0.11   | 0.13    |         |         |         |         |         |         |         |         |         |
| 11. Substance use   | -0.29*  | -0.22*  | -0.07   | -0.07   | -0.21   | -0.13   | 0.02    | -0.03   | 0.02    | 0.07    |         |         |         |         |         |         |         |         |
| 12. Behavioral disengagement | -0.14   | -0.04   | 0.18    | 0.02    | 0.06    | -0.14   | 0.11    | -0.04   | 0.15    | 0.18    | 0.09    |         |         |         |         |         |         |
| 13. Self-distraction | 0.32**  | 0.19    | 0.18    | 0.31**  | 0.16    | 0.25*   | 0.02    | 0.11    | 0.26*   | -0.17   | -0.15   | -0.04   |         |         |         |         |         |
| 14. Self-blame      | 0.05    | -0.09   | -0.13   | 0.03    | -0.18   | -0.25*  | 0.12    | 0.06    | 0.35**  | 0.30**  | 0.11    | -0.01   | -0.01   |         |         |         |         |
| 15. Stress          | -0.10   | -0.19   | -0.28*  | -0.12   | -0.26*  | -0.38** | 0.17    | -0.03   | 0.14    | 0.38**  | -0.05   | 0.15    | -0.07   | 0.39*** |         |         |         |
| 16. Anxiety         | -0.09   | -0.22   | -0.34** | -0.13   | -0.29*  | -0.34** | 0.03    | -0.01   | 0.12    | 0.39**  | -0.07   | -0.01   | -0.11   | 0.34*** | 0.66*** |         |         |
| 17. Depression      | -0.03   | -0.17   | -0.29*  | -0.06   | -0.39*** | -0.23*  | 0.13    | -0.04   | 0.11    | 0.38**  | 0.06    | 0.05    | -0.07   | 0.28*   | 0.69*** | 0.65*** |         |

*a*Adaptive coping strategies.

*b*Maladaptive coping strategies.

*p < 0.05; **p < 0.01; ***p < 0.001.
3.2.2 | Anxiety

Caregivers' physical health status and caregiver strain were significantly associated with anxiety (see Table 2). Caregivers reporting poorer physical health \( (p = 0.003) \) and higher caregiver strain \( (p = 0.004) \) were associated with having higher anxiety, accounting for 13% and 16% of the variance, respectively. The overall variance explained by the final model was 39% \( (f^2 = 0.63) \). Marital status, financial strain, severity of the child's disability, the impact of the pandemic, and adaptive and maladaptive coping strategies were not significantly associated with anxiety. Coping was not found to moderate the relationship between caregiver strain and anxiety \( (R^2 = 0.006, \beta = -0.015, p = 0.465) \).

3.2.3 | Depression

Caregivers' physical health status, caregiver strain, and maladaptive coping were significantly associated with depression (see Table 2). Caregivers' physical health status accounted for the greatest increment of variance for depression, with 13% explained by its entry into the model; poorer caregiver health was associated with higher depression \( (p = 0.004) \). Higher caregiver strain \( (p = 0.017) \) and those who used more maladaptive coping strategies \( (p = 0.045) \) were also associated with higher depression, accounting for 8% and 3% of the variance, respectively. More specifically, Pearson correlation analyses revealed that the maladaptive coping strategies of denial \( (r = 0.378, p = 0.001) \) and self-blame \( (r = 0.277, p = 0.015) \) were associated with higher depression (see Table 3). The overall variance explained by the final model was 34% \( (f^2 = 0.52) \). Marital status, financial strain, severity of child's disability, the impact of the pandemic, and adaptive coping strategies were not significantly associated with depression. Coping was not found to moderate the relationship between caregiver strain and depression \( (R^2 = 0.026, \beta = -0.076, p = 0.132) \).

3.3 | Qualitative results

Qualitative interviews revealed that family caregivers and their children experienced several stressors during the COVID-19 pandemic including stressors related to their child's well-being, financial stressors, emotional responses to COVID-19, social isolation/lack of support, time management, marital issues, and political stressors. Definitions for major themes and subthemes, quote examples, and the frequency by which the theme/subtheme was discussed by caregivers are presented below and in Table 4 (see Figure 1 for a word cloud representation of the stressors that caregivers experienced).

3.3.1 | Child's well-being

The most common stressor reported by caregivers was having concerns about their child's well-being and how the pandemic affected their child. These included caregivers being worried about how their child would function in school, whether they would be bullied by other kids because of their disability, and steps caregivers could be taking now to help their child be safe and be able to care for themselves when they are older in the scenario that the caregivers are no longer alive to take care of them. Several caregivers also reported being fearful of their child contracting the COVID-19 virus and being concerned about how the country's lockdown during the pandemic created a socially isolated home environment that strongly impacted their child's behaviors. In particular, one mother discussed the notable restlessness her child had displayed throughout his confinement at home.
| Main theme, subtheme                  | N  | Definition                                                                                                                                 |
|--------------------------------------|----|------------------------------------------------------------------------------------------------------------------------------------------|
| Current stressors                    | 303| Participants mentioned various forms of stress affecting their current lives                                                            |
| Child's well being                   | 130| Participants mentioned current stressors as child's overall well-being or stressors in child's life                                        |
| Financial stressors                  | 62 | Participants mentioned current stressors regarding financial difficulties                                                              |
| Emotional responses to COVID-19      | 53 | Participants mentioned current stressors as various emotional reactions to COVID-19                                                    |
| Social isolation/lack of support     | 29 | Participants mentioned current stressors as the absence of support from others or not being able to provide support for others and not being able to leave the house or socialize |
| Time management                      | 16 | Participants mentioned current stressors as lack of time to complete all fulfillments/responsibilities                                  |
| Marital issues                       | 10 | Participants mentioned issues with spouse as a current stressor                                                                         |
| Political stressors                  | 3  | Participants mentioned concerns surrounding the political climate of Bolivia and its potential impact on its citizens                   |

Numbers represent the number of instances that a code was discussed by participants.

**Table 4** Qualitative themes for the stressors experienced by family caregivers and their children in Bolivia during the COVID-19 pandemic (N = 77)

**Figure 1** Word cloud of most common stressors experienced by family caregivers and their children in Bolivia during the COVID-19 pandemic
[Being in quarantine] has stressed him in a certain way. The fact of not performing his daily scheduled activities [going to therapy], understanding that my child is a child of habits and schedules, so when they get used to a routine they are waiting for it. They know at what times and how it moves, so altering these cycles causes them some stress in such a way that they do not discharge that energy and accumulate it...

He asks me every day when [will] it end, when [will] the quarantine end? I do not know what to say to him because I do not know when it will end.

3.3.2 | Financial stressors

The second most common stressor was increased financial strain experienced due to the pandemic. More specifically, several caregivers mentioned losing their jobs or that the money they earned from their family-owned business was significantly reduced due to the country's lockdown, resulting in food insecurity for their families. One mother even discussed not having the funds to pay for the internet connection that her child needed to participate in school since her bakery was shut down.

We don't have money for food. I didn't have my child go to school because he's not at the level of the other kids and he didn't have the [internet] resources to participate in Zoom. We make bread for a living but haven't been able to make any.

3.3.3 | Emotional responses to COVID-19

Several caregivers also reported being in constant fear about them and their family members contracting the COVID-19 virus, which led to increased feelings of terror, depression, stress, and guilt. Due to this fear, one parent discussed the different measures she took to prevent her and her family from contracting COVID-19.

I have tried to be careful. I have taken ivermectin, I have two types of chlorine hydroxide in my refrigerator. I have not taken them, I didn't want to take them, but if I need them. I have bought medicines [Aspirin] in the time when medicines were a luxury. I have the most expensive azithromycin. I was shopping and tried to buy everything in case something happened [at] home. I had never washed so many things in my house or cleaned [so much before]. I was disinfecting [everything]... I was afraid for my mother to grab COVID and [her not] surviving because my mother is already 71 years old and I had that same terror, that concern and a guilt.

3.3.4 | Social isolation/lack of support

Caregivers also discussed having a very difficult time being socially isolated from their friends and family during quarantine and feeling "locked" in their house. This isolation made it difficult for them to receive support from others at home, as well as provide support to their loved ones during difficult situations. One caregiver expressed the emotional pain he experienced as a result of not being able to offer support to his loved ones who had died during the pandemic.

I have this pain because I have lost friends, family, people I have known and not being able to be there, not giving support to the family, watching over them, or not being able to visit them. They passed away and I never saw them again.
3.3.5 | Time management

Caregivers also mentioned having difficulty splitting their time effectively to manage all their responsibilities and demands associated with financially supporting their families while caring for their child, often feeling as if they did not have the time to give their child the attention they need.

*Because of my work, I can't dedicate as much time as I would like to my daughter. Because my employer sometimes makes me stay longer than agreed. Even though it is a little extra money for us, it is time I would like to give to my little girl.*

3.3.6 | Marital issues

Some caregivers reported experiencing marital strain before the pandemic that was made worse during quarantine, such as experiencing domestic violence, verbal abuse, and infidelity. These experiences have led some caregivers to leave their spouses or get divorced.

*The relationship was not so good, but with this quarantine, the confinement and all that has affected [our marriage] a lot. We are now in the middle of a divorce.*

3.3.7 | Political stressors

Some caregivers also discussed being stressed due to the political climate in Bolivia, with the upcoming presidential election causing worry and uncertainty of what the future holds for its citizens. Specifically, one caregiver discussed the implications of the election on being able to safely travel from one city in Bolivia to another due to political tensions and disagreements in different areas of the country.

*Due to the elections, depending on that, I know that La Paz is a city that has several conflicts due to the political issue, so there is a bit of uncertainty. I hope that everything goes well to be able to travel calmly for the next month.*

4 | DISCUSSION

The current study is the first to describe the mental health status and perceived strain experienced by family caregivers of children with disabilities in Bolivia during the COVID-19 pandemic. Results demonstrated that 32% of our sample experienced elevated stress and anxiety, and 71% had high depressive symptoms. These rates are much higher than those found for parents of children without disabilities in the U.S. during the outset of the pandemic (Russell et al., 2020) and are consistent with results of recent studies demonstrating that the mental well-being of parents of children with disabilities has significantly worsened during the pandemic compared to pre-pandemic levels (Cankurtaran et al., 2021; Pecor et al., 2021). With regard to stress and anxiety, our rates are similar to those found for family caregivers of children with disabilities in India and Iran (36% with elevated stress, 21%–41% with high anxiety; Dhiman et al., 2020; Farajzadeh et al., 2021). However, depression rates in the current study (71%) were much higher than that found in any previous studies of family caregivers during the pandemic (45%–63%; Dhiman et al., 2020; Farajzadeh et al., 2021). The relatively lower rates of stress and anxiety, when compared to depression, maybe due to caregivers being assessed later in the pandemic, where they had time to
process and be better informed about the COVID-19 virus and the precautionary measures (e.g., social distancing and wearing masks) needed to stay safe. Yet, the chronic effects of being in lockdown since March 2020 and the subsequent interruptions in their ability to financially support their families and care for their children, as well as Bolivia having been in a state of political upheaval during this time, may have contributed to the high rates of depression observed in the current sample.

Indeed, 94% of family caregivers reported being greatly affected by the COVID-19 pandemic, having experienced several major stressors during this time such as feeling depressed or fearful about contracting the virus, being blamed for getting infected, and witnessing the death of loved ones due to the virus. Several caregivers also described having difficulty balancing the demands of taking care of their child and their own health, with little support during the lockdown as they had to isolate themselves from family and friends. This also had a significant impact on the well-being of their child as they were no longer able to attend therapy during lockdown (facilities were shut down), thus limiting their developmental progress and leading to more behavior problems at home as they were isolated from family/friends. Compounding these effects were financial stressors as many caregivers lost their jobs during the pandemic, leading to food insecurity for their families and marital strain, with about three-fourths of caregivers finding it very difficult to live off of their combined family income. Finally, some caregivers discussed the political climate in Bolivia as being very stressful during the pandemic, as a transitional government was in power due to controversies over a fraudulent election taking place in November 2019 resulting in the ousting of then-President Evo Morales. Several attempts to hold general elections to elect a new president were postponed due to safety concerns related to the COVID-19 pandemic, which left many voters in Bolivia upset and unsure which political party would be in power until November 2020 when a new president was finally elected (Zilla & Aguilar Andrade, 2020). However, at the time this study was being conducted (July–September 2020), there was still much uncertainty and stress experienced by many family caregivers on the political future of Bolivia and its impact on them and their families.

Results from the current study provide some insight into factors associated with mental health outcomes among family caregivers in Bolivia during the COVID-19 pandemic. In general, caregivers who experienced more physical health problems, had high caregiver strain, and who used more maladaptive coping strategies demonstrated worse mental health outcomes. Caregivers’ physical health and caregiver strain were strongly associated with all three mental health outcomes (stress, depression, and anxiety), with 31% of our sample reporting poor physical health and 35% experiencing high caregiver strain. The most common physical health complaints experienced were muscular pain (49%), difficulty sleeping (48%), and headaches (44%). These results are similar to the higher rates of physical health problems observed among caregivers of children with disabilities when compared to caregivers of children without disabilities (Lee et al., 2017; Masefield et al., 2020; Miodrag & Hodapp, 2010) and have been attributed to the chronic demands associated with caring for a child exhibiting developmental delays or behavior problems that leave little time for the caregiver to engage in self-care behaviors (e.g., sleep, exercise). Over time, the chronic nature of these caregiving responsibilities can lead to elevated levels of stress, anxiety, and depression that can have detrimental consequences on the health of caregivers and their children. As demonstrated in our qualitative findings, this is particularly true during the pandemic, where many families are caring for their child in isolation with limited knowledge or training in how to support their child's developmental goals at home. Indeed, a study by Dhiman et al. (2020) demonstrated that caregiver strain has worsened during the pandemic with higher caregiver strain being associated with poorer mental health outcomes among family caregivers of children with disabilities (Farajzadeh et al., 2021). Therefore, studies are needed to examine the mechanisms by which these unique caregiving demands and contexts lead to adverse physical and mental health outcomes in this population.

Our results also revealed that caregivers who used more maladaptive coping strategies, such as denial and self-blame, experienced elevated levels of stress and depression. Denial has been characterized as a form of cognitive avoidance where one minimizes or ignores stressors in their life, whereas self-blame refers to criticizing oneself for being responsible for a stressful life event they experienced (Carver, 1997). Although denial can serve a protective function in helping one to cope in the short-term, particularly for stressors perceived to be outside one's control
(Woodman & Hauser-Cram, 2013), it has generally been associated with worse mental health outcomes among family caregivers (Silva et al., 2015; Whittingham et al., 2013). Similarly, self-blame has been examined in the context of some parents believing that they somehow contributed to their child having a disability and are being punished, especially in the absence of a medical explanation for their child’s condition, or that they could be doing more for their child (Čolić & Milačić-Vidojević, 2019), with one study showing parents’ self-blame to be associated with higher levels of caregiver burden, hopelessness, and depression (Moses, 2010). Interestingly, our results also showed that the use of specific adaptive coping strategies (i.e., emotional support, positive reframing, and acceptance) was associated with lower levels of stress, anxiety, and depression during the pandemic, although these associations were no longer significant when adjusting for other caregiver factors. Nevertheless, these results may help to inform the development of interventions that can help support these families through psychoeducation and implementation of these coping behaviors to minimize the impact that social isolation and negative cognitive appraisals (e.g., self-blame, guilt), may have on the mental health outcomes of caregivers and their children during the pandemic.

5 | STUDY LIMITATIONS

Several limitations should be considered when interpreting these findings. First, although our sample was largely representative of family caregivers in Bolivia (SIPRUNPCD, 2019), our results may not be generalizable or represent the experiences of caregivers from other socioeconomic/ethnic backgrounds or other parts of the world. In particular, the percentage of COVID-19 cases and deaths have substantially increased in Bolivia since December 2020 when compared to more economically developed countries, such as the U.S. (Ritchie et al., 2020), leaving many caregivers struggling to obtain vaccinations and continuing to experience financial strain and social isolation as workplaces and businesses remain locked down to help slow the spread of the virus (CEPAL, 2020). Therefore, results from the current study provide important data on the chronic effects of the COVID-19 pandemic on mental health outcomes among caregivers and their children in low-income countries that are being severely impacted by the peak of the pandemic in South America. Similarly, because of the virtual administration of the health interview, study participation was limited to those families who had already been receiving services from a neurodevelopment research institute in Bolivia who also had a phone or internet connection to participate in the interview. Therefore, these results may not be generalizable to caregivers who could not afford or have access to these services. Third, our sample represented caregivers of children with a wide age range (i.e., under 18 years of age) and diverse types of disabilities. These diverse characteristics in care recipients have been shown to affect the degree of caregiver strain experienced, particularly for those caring for children and adolescents who display more behavior problems over a longer time period (Masefield et al., 2020). Therefore, additional studies with larger sample sizes, would further our understanding of potential mediators (e.g., cortisol and self-efficacy) and moderators (e.g., type of child disability and coping) that may influence caregiver strain effects on mental health outcomes. Finally, information collected from this survey was cross-sectional by design, and therefore, any predictive interpretations between demographic characteristics, caregiver strain, the impact of the pandemic, coping strategies used, and caregivers’ mental health outcomes were not feasible. Longitudinal studies that capture pre-, current, and post-pandemic assessments of caregiver strain and mental health outcomes are recommended to assess the effects of the pandemic more thoroughly on caregivers’ levels of stress, anxiety, and depression.

6 | CONCLUSION AND IMPLICATIONS

In sum, our findings indicate that a substantial proportion of family caregivers in Bolivia (32%–71%) are displaying elevated levels of stress, anxiety, and depression while experiencing several unique stressors during the COVID-19 pandemic that are adversely affecting them and their children. Specifically, caregivers in poor health, with high
caregiver strain and use of maladaptive coping strategies (i.e., denial and self-blame) are particularly at risk for poor mental health outcomes. Given the detrimental effects that caregivers’ mental health can have on the quality of care that is provided for their child, preventive and treatment interventions are needed to help caregivers balance the responsibilities and demands that come with caring for their child, financially supporting their families, and managing the new challenges associated with living through a life-threatening pandemic. These interventions should be culturally tailored to integrate the strengths that caregivers and their community have to cope with the stressors they face, including the sharing of information and resources between families to expand their support network (Buell & Chadwick, 2017). In addition, coordination between policymakers and health services are highly needed to address the additional barriers that many families in low-income countries are now facing to access therapy services for their child (Gupta et al., 2020). This coordination of care can help identify resources to help ease the financial strain and social isolation that many caregivers and their families are experiencing during the pandemic. Finally, additional training is needed to support health care and community workers in the delivery of virtual interventions shown to be effective in reducing stress, anxiety, and depression among caregivers (Urizar et al., 2021). Such interventions can be implemented using a family-centered approach that simultaneously teaches caregivers effective coping strategies for stress management and structured routines they could use at home to help manage their child’s behaviors while promoting their development. Studies are now needed to test the effectiveness of these interventions during the pandemic and identify the intervention components associated with improved health outcomes in caregivers and their families.

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DATA AVAILABILITY STATEMENT
Data are available on request due to privacy/ethical restrictions.

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REFERENCES
Brannan, A. M., Athay, M. M., & de Andrade, A. R. (2012). Measurement quality of the caregiver strain questionnaire-short form 7 (CGSQ-SF7). Administration and Policy in Mental Health, 39(1–2), 51–59. https://doi.org/10.1007/s10488-012-0412-1
Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa
Buela-Casal, G., & Guillén-Riquelme, A. (2017). Short form of the Spanish adaptation of the state-trait anxiety inventory. International Journal of Clinical and Health Psychology, 17(3), 261–268. https://doi.org/10.1016/j.ijchp.2017.07.003
Buell, S., & Chadwick, D. (2017). Meeting the communication support needs of children and young people with intellectual disabilities in the Bolivian Andes. Journal of Intellectual Disabilities, 21(3), 220–234. https://doi.org/10.1177/1744629517707086
Cankurtaran, D., Tezel, N., Yildiz, S. Y., Celik, G., & Unlu Akyuz, E. (2021). Evaluation of the effects of the COVID-19 pandemic on children with cerebral palsy, caregivers' quality of life, and caregivers' fear of COVID-19 with telemedicine. *Irish Journal of Medical Science*, 190, 1473-1480. https://doi.org/10.1007/s11845-021-02622-2

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92–100. https://doi.org/10.1207/s15327558ijbm0401_6

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Lawrence Erlbaum Associates.

Cohen, S., & Williamson, G. (1988). Perceived stress in a probability sample of the United States. In Spacapan, S. & Oskamp, S. (Eds.), *The social psychology of health: Claremont Symposium on applied social psychology*. Sage.

Cole, J. C., Rabin, A. S., Smith, T. L., & Kaufman, A. S. (2004). Development and validation of a Rasch-derived CES-D short form. *Psychological Assessment*, 16(4), 360–372. https://doi.org/10.1037/1040-3590.16.4.360

Čolić, M., & Milačić-Vidojević, I. (2019). Self-blame in parents of children with autism spectrum disorder and children with physical disabilities: The role of a child's problem behavior and personality traits. *Specijalna Edukacija i Rehabilitacija*, 18(4), 391–417. https://doi.org/10.5937/specedreh18-24824

Comisión Económica para América Latina y el Caribe (CEPAL) (2020). *El desafío social en tiempos de Covid-19. Informe especial*. Economic Commission for Latin America and the Caribbean. https://repositorio.cepal.org/bitstream/handle/11362/45527/5/S2000325_es.pdf

Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Research in Developmental Disabilities*, 107, 103970. https://doi.org/10.1016/j.ridd.2020.103970

Disabled World (2017). *Disability in South American countries*. https://www.disabled-world.com/disability/dsa.php

Encuesta de Evaluación de Salud y Nutrición (ESNUT) (2014). https://www.udeape.gob.bo/portales_html/docsociales/LIBROESNUT.pdf

Fairfax, A., Brehaut, J., Colman, I., Sikora, L., Kazakova, A., Chakraborty, P., & Potter, B. K., & Canadian Inherited Metabolic Diseases Research Network. (2019). A systematic review of the association between coping strategies and quality of life among caregivers of children with chronic illness and/or disability. *BMC Pediatrics*, 19(1), 215. https://doi.org/10.1186/s12887-019-1587-3

Farajzadeh, A., Dehghanizadeh, M., Maroufizadeh, S., Amini, M., & Shamili, A. (2021). Predictors of mental health among parents of children with cerebral palsy during the COVID-19 pandemic in Iran: A web-based cross-sectional study. *Research in Developmental Disabilities*, 112, 103890. https://doi.org/10.1016/j.ridd.2021.103890

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G*Power 3.1: Test for correlation and regression analyses. *Behavior Research Methods*, 41(4), 1149–1160. https://doi.org/10.3758/BRM.41.4.1149

Fawley-King, K., Trask, E. V., Ferrand, J., & Aarons, G. A. (2020). Caregiver strain among biological, foster, and adoptive caregivers caring for youth receiving outpatient care in a public mental health system. *Children and Youth Services Review*, 111, 104874. https://doi.org/10.1016/j.childyouth.2020.104874

Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, 33(10), 1129–1136. https://doi.org/10.1093/jpepsy/jsn040

García, F. E., Barraza-Peña, C. G., Włodarczyk, A., Alvear-Carrasco, M., & Reyes-Reyes, A. (2018). Psychometric properties of the Brief-COPE for the evaluation of coping strategies in the Chilean population. *Psicologia, Reflexao e Critica*, 31(1), 22. https://doi.org/10.1186/s41155-018-0102-3

Guillamón, N., Nieto, R., Pousada, M., Redolar, D., Muñoz, E., Hernández, E., Boixadós, M., & Gómez-Zúñiga, B. (2013). Quality of life and mental health among parents of children with cerebral palsy: The influence of self-efficacy and coping strategies. *Journal of Clinical Nursing*, 22(11-12), 1579–1590. https://doi.org/10.1111/jcn.12124

Gupta, J., Madaan, P., & Gulati, S. (2020). COVID-19: Implications for children with special needs. *Journal for ReAttach Therapy and Developmental Diversities*, 3(1), 1–3. https://doi.org/10.26407/2020jrtdd.1.31

Harkness, A. (2020). *The pandemic stress index*. University of Miami. https://elcentro.sonhs.miami.edu/research/measures-library/psi/psi-spanish/index.html

Hummel, C., Knaul, F. M., Touchton, M., Guachalla, V., Nelson-Nuñez, J., & Boulding, C. (2021). Poverty, precarious work, and the COVID-19 pandemic: Lessons from Bolivia. *The Lancet. Global Health*, 9(5), e579–e581. https://doi.org/10.1016/S2214-109X(21)00001-2

Kandell, I., & Merrick, J. (2003). The birth of a child with disability. Coping by parents and siblings. *The Scientific World Journal*, 3, 741–750. https://doi.org/10.1100/tsw.2003.63

Kuper, H., Monteath-van Dok, A., Wing, K., Danquah, L., Evans, J., Zuurmond, M., & Gallinetti, J. (2014). The impact of disability on the lives of children; cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries. *PLoS One*, 9(9), e107300. https://doi.org/10.1371/journal.pone.0107300

Lee, J. (2013). Maternal stress, well-being, and impaired sleep in mothers of children with developmentald disabilities: A literature review. *Research in Developmental Disabilities*, 34(11), 4255–4273. https://doi.org/10.1016/j.ridd.2013.09.008
Lee, M. H., Park, C., Matthews, A. K., & Hsieh, K. (2017). Differences in physical health, and health behaviors between family caregivers of children with and without disabilities. Disability and Health Journal, 10(4), 565–570. https://doi.org/10.1016/j.dhjo.2017.03.007

Masefield, S. C., Prady, S. L., Sheldon, T. A., Small, N., Jarvis, S., & Pickett, K. E. (2020). The caregiver health effects of caring for young children with developmental disabilities: A meta-analysis. Maternal and Child Health Journal, 24(5), 561–574. https://doi.org/10.1007/s10995-020-02896-5

Meyer, B. (2001). Coping with severe mental illness: Relations of the Brief COPE with symptoms, functioning, and well-being. Journal of psychopathology and behavioral assessment, 23, 265–277. https://doi.org/10.1023/A:1012731520781

Miodrag, N., & Hodapp, R. M. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. Current Opinion in Psychiatry, 23(5), 407–411. https://doi.org/10.1097/YCO.0b013e3283a8796

Moloney, A. (2009). Bolivia tackles maternal and child deaths. Lancet, 374(9688), 442. https://doi.org/10.1016/s0140-6736(09)61438-0

Moses, T. (2010). Exploring parents’ self-Blame in relation to adolescents’ mental disorders. Family Relations, 59(2), 103–120. https://doi.org/10.1111/j.1741-3729.2010.00589.x

Pecor, K. W., Barbyannis, G., Yang, M., Johnson, J., Materasso, S., Borda, M., Garcia, D., Garla, V., & Ming, X. (2021). Quality of life changes during the COVID-19 pandemic for caregivers of children with ADHD and/or ASD. International Journal of Environmental Research and Public Health, 18(7), 3667. https://doi.org/10.3390/ijerph18073667

Pérez-de la Cruz, S., & Ramirez, I. (2020). Parents’ perceptions regarding the implementation of a physical therapy stimulation program for children with disabilities in Bolivia: A qualitative study. International Journal of Environmental Research and Public Health, 17(17), 6409. https://doi.org/10.3390/ijerph17176409

Programa de las Naciones Unidas para el Desarrollo (PNUD) (2013). Informe sobre desarrollo humano 2013. El ascenso del Sur: Progreso humano en un mundo diverso.

Raina, P., O’Donnell, M., Rosenbaum, P., Brehart, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. Pediatrics, 115(6), e626–e636. https://doi.org/10.1542/peds.2004-1689

Raina, P., O’Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehart, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D., & Wood, E. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. BMC Pediatrics, 4, 1. https://doi.org/10.1186/1471-2431-4-1

Ritchie, H., Ortiz-Ospina, E., Beltekian, D., Mathieu, E., Hasell, J., Macdonald, B., Giattino, C., Appel, C., Rodés-Guirao, L. & Roser, M. (2020). Coronavirus pandemic (COVID-19). https://ourworldindata.org/coronavirus

Russell, B. S., Hutchison, M., Tambling, R., Tomkunas, A. J., Horton, A. L. (2020). Initial challenges of caregiving during COVID-19: Caregiver burden, mental health, and the parent-child relationship. Child Psychiatry & Human Development, 51(5), 671–682. http://doi.org/10.1007/s10578-020-01037-x

Sears, S. F., Jr Urizar, Jr, G. G., & Evans, G. D. (2000). Examining a stress intervention of comparative studies of depression in mothers of children with and without developmental disabilities. American Association on Intellectual and Developmental Disabilities, 111(3), 155–169.

Sistema de Información del Programa de Registro Único Nacional de Personas con Discapacidad (SIPRUNPCD). (2017). La Paz, Bolivia.

Sistema de Información del Programa de Registro Único Nacional de Personas con Discapacidad (SIPRUNPCD). (2019). La Paz, Bolivia.

Tejerina, H., Closon, M. C., Paepe, P. D., Darras, C., Dessel, P. V., & Unger, J. P. (2014). Forty years of USAID health cooperation in Bolivia. A lose-lose game? The International Journal of Health Planning and Management, 29(1), 90–107. https://doi.org/10.1002/hpm.2149

UNICEF. (2005). The state of the world’s children 2006: Excluded and invisible.

Urizar, G. G., Jr., Miller, K., Saldua, K. S., Garovoy, N., Sweet, C., & King, A. C. (2021). Effects of health behavior interventions on psychosocial outcomes and cortisol regulation among chronically stressed midlife and older adults. International Journal of Behavioral Medicine, 28, 627–640. https://doi.org/10.1007/s12529-021-09957-1

Urizar, G. G., Jr., Yim, I. S., Kofman, Y. B., Tilk, N., Miller, K., Freche, R., & Johnson, A. (2019). Ethnic differences in stress-induced cortisol responses: Increased risk for depression during pregnancy. Biological Psychology, 147, 107630. https://doi.org/10.1016/j.biopsycho.2018.12.005
Vallejo, M. A., Vallejo-Slocker, L., Fernández-Abascal, E. G., & Mañanes, G. (2018). Determining factors for stress perception assessed with the Perceived Stress Scale (PSS-4) in Spanish and other European samples. *Frontiers in Psychology*, 9, 37. https://doi.org/10.3389/fpsyg.2018.00037

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child: Care, Health and Development*, 39(3), 366–373. https://doi.org/10.1111/j.1365-2214.2012.01396.x

Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research*, 57(6), 513–530. https://doi.org/10.1111/j.1365-2788.2012.01555.x

World Health Organization (WHO). (2011). *World report on disability*.

Zilla, C., & Aguilar Andrade, M. (2020). Bolivia after the 2020 general elections. Despite the return to power of the MAS, a new political era could be about to begin. Stiftung Wissenschaft und Politik (SWP Comment 2020/C 55). https://doi.org/10.18449/2020C55

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