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Prevalence of and Factors Associated with Depression, Anxiety, Stress, and Perceived Family QOL Among Primary Caregivers of Children With Intellectual Disabilities in Bagmati Province, Nepal

Master's thesis in Department of Global Health

Supervisor: Gørill Haugan

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ABSTRACT

Introduction: Ill mental health and low quality of life among caregivers of children with intellectual disabilities have been associated with lack of financial stability, the severity of disability of the child, and inadequate health care facilities, amongst other factors. While increased stress, anxiety, and depression among such caregivers is evident globally, it is higher in low-income countries (LICs) because of lack of government relief for caregivers, life stressors related to impoverishment, stigma associated with disability and mental health, etc. Data on caregivers and their health, in general, is scarce in Nepal. We aimed to estimate the prevalence of anxiety, depression, stress, and perceived family quality of life (FQOL) in a population of primary caregivers of children with intellectual disability (CWID) in urban and rural areas of Province 3 in Nepal.

Methods: A total of 215 primary caregivers of CWID, who send their children to daycare centers, participated in this cross-sectional study. Socio-demographic and health-related data were collected through phone interviews. The health-related data included the prevalence of symptoms of anxiety and depression, assessed using the Hopkins Symptoms Checklist-25 (HSCL-25). The caregivers' level of stress and satisfaction of their quality of life were calculated using the Perceived Stress Scale (PSS) and Beach Centre Family Quality of Life (FQOL) scale, respectively. A correlation matrix was tabulated using Cramer's V to estimate the associations between mental distress and several covariates such as family income, severity of disability, employment, and more.

Results: The prevalence of anxiety and depression was 6% (N=13) and 5.6% (N=12), respectively. 98.1% (N=211) of the caregivers experienced stress, and 3.7% (N=8) reported having less than acceptable family life satisfaction. Strong associations were not observed between the dependent variables and covariates. Anxiety and depression had associations with the residency of caregivers (rural or urban), employment status, family income, and the caregivers' health conditions. Association between FQOL and stress of caregivers was also observed while there was no association between FQOL and stress with any covariates.

Conclusion: The findings suggest low anxiety and depression, high levels of stress, and satisfaction with their FQOL among the caregivers. Given that associations between FQOL and perceived stress were observed, prevalence of stress and broader impacts of mental illness should be dealt with targeted interventions. A larger study with caregivers of CWID who do not attend schools may be warranted to capture prevalences in a population more representative

of the entire country. Additionally, it seems important to explore the factors that seem to be protective against anxiety and depression despite stress in this particular population.

Keywords: caregivers; mental health; depression; anxiety; stress; family quality of life

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ABBREVIATIONS

ASD	autism spectrum disorder
CWD	children with disabilities
CWID	children with intellectual disabilities
CBS	Central Bureau of Statistics
FQOL	family quality of life
HIC	high-income country
HSCL	Hopkin's Symptom Checklist
LIC	low-income country
LMIC	low and middle-income country
NGO	non-governmental organization
NHRC	Nepal Health Research Council
PSS	Perceived Stress Scale
RA	research assistant
REC	Regional Committee for Medical Research Ethics
WHO	World Health Organization

1. INTRODUCTION

1.1 Background

1.1.1 Global Burden of Disability

The World Health Organization (WHO) estimates that around 15% of people worldwide live with disabilities (1). People with disabilities may suffer from social exclusion and discrimination related to their disability. In addition, they are more likely to be exposed to poor socioeconomic conditions, such as higher poverty rates and lower levels of education and employment, affecting health. People with intellectual disabilities suffer similarly. The American Association of Intellectual and Developmental Disabilities characterizes intellectual disability by significant limitations in intellectual functioning and adaptive behavior expressed in conceptual, social, and practical adaptive skills (2). Deficits can cause these disorders in the brain due to metabolic, perinatal, prenatal, or other factors. Culture must be considered when evaluating intellectual disabilities for the proper administration of assessment equipment and interpretation of the empirical data (3).

1.1.2 Disability in Nepal

Disability data in Nepal is scarce. According to the Nepali Central Bureau of Statistics (CBS), the total population prevalence of all types of disability in Nepal was 1.9% in 2011 (4), which is likely a severe underestimate in light of the lack of studies and the prevalence of disability globally in the same year, which was reported to be 15% (1).

A SINTEF study in Nepal in 2016 estimated a prevalence of all types of disability of 3.1% among 4213 participants (4). According to this study, the total prevalence of disability in children and young adults (0-19 years) was 1.06% (1.18% in males and 0.94% in females). The Disability Research Center of Kathmandu University reported 5.64% children (0-14 years) with intellectual disability in Nepal in 2016 (5). The number is reported to be the highest in the Terai region, followed by the Hilly region. Dhading, Kathmandu, Chitwan, Banke, Udaypur districts have the highest number of children with intellectual disability (CWID) with 14.63%, 13.07%, 10.54%, 10.80%, and 11.85% out of 10,000 children, respectively. The actual prevalence of disability in Nepal is likely to be significantly higher but has been underestimated due to inadequate or inconsistent data collection methods and definitions of disability (4).

In Nepal, people with disabilities are given disability identity cards from the smallest unit of local governance, the local ward office, following a doctor's recommendation. The cards relate to the severity of the disability, classified by the Ministry of Women, Children and Senior Citizens (6). Four color cards are provided based on the disability severity; red, blue, yellow, and white for persons with complete disability, severe disability, moderate disability, and general disability, respectively (7). Based on Nepal's government policy, people holding red and blue cards can receive disability allowances. Those with red cards get NRs 2,000 per month (about 17-19 USD), and those with blue cards receive NRs 600 per month (about 5-6 USD) (8).

In 2015, the Nepali Constitution promulgated that children with disabilities (CWD) get free education with the required assistance. For instance, children with speech or hearing disabilities are assisted with sign language and visually impaired children with brail (9). However, a lack of practical implementation of these policies has resulted in the continued exclusion of CWD from formal education settings.

At the time of writing, a global pandemic of coronavirus disease 2019 (COVID-19), caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), is ongoing. The pandemic has impacted the health and livelihoods of people worldwide, and people with disabilities are affected in several areas, notably health, education, social support, and transportation. For instance, the underlying health conditions or disability-related health needs of people with disabilities may make them more vulnerable to COVID-19 symptoms (10). Due to COVID-19 prevention and infection control measures, many CWD do not have access to schools, day-care centers, assistive teaching, and other extracurricular activities. Lack of public transportation services during the pandemic may hinder healthcare access, such as visits to hospitals and clinics (10).

1.1.3 Mental Health in Nepali Context

Mental health policies and services are under-developed in Nepal. The first national policy mentioning mental health was developed in 1997 (11). It led to the establishment of a separate mental health division, but it lacked proper implementation. The constitution of 2006 marked the government's first attention to ensuring equal human rights for people with mental illness, but it has yet to be fully implemented (11).

In terms of health services, the percentage of the total national health budget dedicated to mental health is 0.7%-1% (12, 13). In addition, there is a severe shortage of mental health professionals (14, 15). To address the severe limitations of public mental health services and the absence of

mental health professionals, many mental health services are provided by non-governmental organizations (NGOs) such as WHO filling needs for specific populations affected by violence, trafficking, displacement, and civil unrest. Formal mental health services were introduced in Nepal by the WHO in 1980 (13). The first NGOs for mental health were established in the 1990s for people affected by the Maoist insurgency when the country was in civil uprising, and Bhutanese refugees (13) to address the need for more mental health services.

Until 2019 Nepal had no national-level data regarding mental health. In 2019, the Nepal Health Research Council (NHRC) conducted a National Mental Health Survey throughout the country (16). The study (N = 1371) reported a point prevalence of 3.4% depression and 1.4% anxiety (17). Before this date, smaller population studies showed prevalences of depression ranging from 4.2% to 33.7% and anxiety ranging from 16.1% to 27.7% (14, 18).

1.1.4 Link between Mental Health and Caregiving for Children with Intellectual Disabilities

In prior studies in the South Asia region, it has been established that caregivers of CWD suffer disproportionately high burdens of physical and mental ill-health (19). The caregivers of people with all types of disabilities have been shown to suffer from stress, low back pain (LBP), isolation (20), and other physical and mental health concerns. The relationships between these factors and associations are complex. For example, Tong et al. (22) assessed the prevalence of LBP among caregivers of children with physical disabilities and suggested that LBP is higher among caregivers with children who need physical assistance. LBP also has psychological health origins (21). Almansour observed a higher depression and anxiety score among caregivers of children with autism (9.52 and 10.54 respectively) than those with healthy children (4.98 and 3.93 respectively) (22). However, other studies show mixed results and unclear correlations regarding the relationships between age, disability, and caregiving (23-25).

Prior studies found that several factors consistently contribute to the poor mental health of caregivers of CWD – most of which are connected to the child they look after, while some are related to the caregivers' characteristics. Mbugua et al. suggested a list of five factors that negatively impact the caregiver's health: lack of social support, low self-esteem, the severity of the disability, child's temper, and child's behavior (26). A systematic review noted that the majority (79%) of the caregivers of CWID are women in low-income countries (LICs) (27). Many women in these settings have limited support from their family members and spouses, which may increase their susceptibility to physical and psychological ill-health. Moreover, the overwhelming burden of unpaid care and other domestic work for women in these contexts

(typically unshared with their male partners) can act as stressors. Many of these women also work physically demanding jobs in agricultural settings too, especially in rural areas, contributing to poor mental health.

Depression and anxiety disorders are widely seen in family members and the primary caregivers of CWID compared to family members of children without disabilities (27). For example, a study conducted in rural Bangladesh compared the outcomes in two groups – one consisting of 154 caregivers of children with cerebral palsy and 173 caregivers of children without disability (28). This study reported significantly higher depression (effect size .13) and stress (effect size .17) among the first comparison group, illustrating the link between ill-mental health and caregiving.

Only two Nepalese studies, both conducted in urban settings, are available to assess the mental health of caregivers of CWD (29, 30). Pandey and Sharma used the Zarit Burden Interview and the Hopkin's Symptom Checklist-25 (HSCL-25) in 2016 (29), while Maridal et al. used the General Health Questionnaire-12 in 2021 (30). In both studies, mothers made up 95% of participants and reported a high prevalence of caregiver burden and distress. Pandey and Sharma found that 33% of 61 caregivers of children with autism reported anxiety symptoms, while 24.6% had depressive symptoms. Maridal et al. reported 90% of 63 caregivers of CWD with mental distress. However, the sample sizes are small and thus require caution when generalizing for a larger population.

In other low and middle-income countries (LMICs), caregivers suffer from a high level of mental stress due to family income, inadequate health systems, limited or inefficient transportation services, and stigma surrounding mental illness. A recent scoping review by Nuri et al. assessed relationships between family support and family- and child-related outcomes among families affected by disabilities in LMICs (19). The majority of the studies included in this review were from China and African countries. Parental stress was found to be negatively associated with parent's perceived support from the community members, family, friends, and especially from immediate family. The review highlighted that caregivers who received support were more satisfied than those who received little or no support. This study reported that caregivers in LICs suffered more parental stress than those in HICs.

Furthermore, a study from Kenya reported that 79% of caregivers of CWID had the risk of severe depression; the primary risk factor was lack of financial stability, followed by social isolation and stigma related to being a caregiver of a child with intellectual disabilities (26). Studies from India in three cities (Delhi, Chennai, and Gujarat) reported that the majority of the

caregivers of CWID were women (58%-97%), and most caregivers were the parents of the child with a disability (31-33). The study from Delhi found that 39% of the caregivers of CWID had symptoms of depression, and 38% of the caregivers had symptoms of anxiety. The Chennai study found severe stress among 89.6% of the participant below the age of 35 years, and the Gujarat study found that over 85.7% of the caregivers aged <35 years had anxiety, and 95.2% had depression.

1.1.5 Link Between Family Quality of Life (FQOL) and Caregiving

Quality of life (QOL) is a multidimensional concept – encompassing social, mental, spiritual, and physical health (34). Fumincelli et al. suggested that QOL comprises the values, perspectives, satisfaction, living conditions, accomplishments, functionality, cultural contexts, and spirituality (34). Perceived QOL includes an individual's subjective assessment and satisfaction with various domains of their life; relationships with family, environment, or friends (35).

Studies have shown associations between low household income and low QOL among caregivers for people with physical disabilities (36, 37). In Nepal, caregiving for people with spinal cord injury was associated with low QOL (38). Many caregivers in the study had low monthly income, and people with spinal cord injury received no financial aid from the government. It has also been noted that the longer a caregiver cares for a stroke survivor, their health status becomes poorer, and their social participation decreases (36).

A study in Nepal, among 244 caregivers of CWD, used the WHO Quality of Life-Brief Questionnaire and found that caregivers with higher education had a better QOL on all domains presented in the questionnaire (environmental, social, psychosocial, physical) (39) .

The severity of disability is a predictor of satisfaction with FQOL among parents with young children, along with coping mechanisms in families, child's age, depression, family cohesion, and parenting knowledge (40). A study in China indicated that families with CWID living in different housing conditions perceive satisfaction with FQOL significantly differently (40). Their results indicate that the factors influencing family QOL and satisfaction in Chinese families with CWID include crowded housing conditions, access to own transportation, the severity of the disabilities, and family income.

1.1.6 Scientific Gaps this Study Aims to Fill

Scientific research on the mental health of daily caregivers of CWID highlights inconsistencies such as overrepresentation of mothers, lack of focus on spiritual wellbeing and individual characteristics such as ‘hardiness’ as coping strategies, lack of focus on the association between child’s characteristics and the parent’s difficulties and burdens (41). It is evident that mothers globally take more responsibility for CWD and spend more time with their children than fathers, even when both parents have equal availability (42, 43). Furthermore, research in this field is more focused on high income countries (HICs), with a slowly growing literature emerging from LICs (19, 26, 31). Studies in HICs and LICs have shown that simple, low-cost interventions, such as training programs or focus group discussions for exchanging experiences and concerns, can positively change the caregivers’ lives (44, 45). These changes occur especially in their understanding of their child’s disability and positive changes in the caregiver’s attitude. Hence, it is crucial to gain better baseline data in Nepal through additional prevalence studies to identify and assess the characteristics of caregivers of CWID, their mental health, feelings, thoughts, FQOL, and well-being. This knowledge can provide a foundation for future intervention and implementation studies.

Studies conducted in Nepal assessing the prevalence of mental distress among caregivers of CWID are scarce (29, 30). The two prior studies explored the caregiver burden and its association with depression and anxiety in the Kathmandu valley, highlighting the importance of larger-scale studies assessing caregivers’ health concerning different factors in Nepal (29, 30). This current study encompasses a different population of caregivers whose children have access to support in the form of daycare centers. Notably, no prior study in Nepal has fully explored the prevalence of stress and perceived FQOL in such a population of caregivers of CWD. Prior assessments of FQOL in Nepal are mainly among the elderly (39).

1.2 Rationale

1.2.1 Rationale for the Study

This study aims to contribute to building a scientific foundation upon which to enhance mental health among caregivers of CWID, and consequently, the health and QOL of individuals affected by disabilities in Nepal. This master thesis involves a baseline survey assessing the mental health of a population of these caregivers in Nepal. The survey will provide needed knowledge, currently lacking, which is helpful to prevent and reduce mental distress and

facilitate health and wellbeing among parents of CWIDs in Nepal. It is especially important to consider caregivers of CWID as opposed to children with physical disabilities as CWID due to the lack of social welfare and support for this population. An important reason for working with this population is that the research team had already collaborated with the parent organization working for parents of CWID, and built an efficient network. The results will be assessed and potentially developed further into a family-centered health-promoting intervention for parents of CWID.

1.2.2 Study Aim and Objectives

1. Primary Aim

The primary aim of this study is to estimate the prevalence of anxiety, depression, stress (collectively referred to as indicators of mental distress), and perceived FQOL, among the primary caregivers (mainly parents and close relatives) of children with intellectual disabilities in urban and rural areas of the Bagmati Province in Nepal.

2. Secondary Objectives

- To describe the factors associated with an increased risk of indicators of mental distress and poorer perceived FQOL.
- To assess associations between indicators of mental distress and perceived FQOL.

1.2.3 Research Questions

1. Are perceived stress, anxiety, depression, and FQOL among parents of CWID in Nepal associated with sociodemographic characteristics?
2. Which factors characterize FQOL among families with a CWID?

2. METHODOLOGY

2.1 Study Design

This is a cross-sectional study among caregivers of CWID who send their child to daycare centers in Bagmati province. Daycare centers, in this context, provide care, informal education, and physical activity to CWID. A cross-sectional study design helps gain baseline information about a cohort (46, 47); for example, for evaluating associations between sociodemographic variables and perceived anxiety, depression, stress, and FQOL in caregivers of CWID, as well as estimating the prevalence of indicators of mental distress and odds ratios for these variables in this population.

2.2 Study Setting & Sites

Caregivers of CWID were recruited from day-care centers in Bagmati province. Bagmati province has the highest population in the country and comprises 12 districts (Sindhuli, Ramechhap, Dolakha, Bhaktapur, Dhading, Kavrepalanchowk, Nuwakot, Lalitpur, Rasuwa, Sindhupalchowk, Chitwan, Makwanpur), as shown in Figure 1. The first part of the figure shows the location of Bagmati province in Nepal, and the second half illustrates the districts, and neighboring districts and countries. The day-care centers are situated across the province. Each provides daily activities for approximately 15-25 individuals, including children, adolescents, and young adults - typically ranging from 5 years up to 30 years of age.



Figure 1. Recruitment districts of Bagmati province (Province 3) (48)

2.3 Study Participants – Population and Sample:

The target population for the study was primary caregivers of CWID from day-care centers in Bagmati province. All parents, other family caregivers, and guardians with primary caregiving responsibilities for a CWID were invited to participate in the study. The formal eligibility criteria for participants were as follows:

- Primary caregiver or guardian of a CWID aged 5-18 years
- Caregiver aged ≥ 19 years
- Caregiver willing to be phoned for the study

Before commencing recruitment into the study, a required sample size of 200 participants was estimated based on assessments of the psychometric properties of the study questionnaire using confirmatory factor analyses (CFA) (49, 50). A total of 220 participants were invited to participate in this study, among whom 215 participated. The five who did not participate did not have their own phone through which they could be contacted for the study's data collection.

2.4 Data Collection Processes, Instruments, and Outcome Variables

2.4.1 Recruitment

Below is a list of the steps taken to share the study information with potential research participants, assess and determine their eligibility for the study, and obtain their informed consent:

1. A woman in Nepal, who works as a program coordinator at Down Syndrome Society Nepal, was selected as a research assistant (RA). The RA collated a list of all eligible caregivers (that is, the primary caregivers for CWID attending the day-care centers in the province); she telephoned them to explain the study's purpose verbally. Following the explanation, the RA asked if the caregiver was willing to provide their name and telephone number to the master student in Norway who would telephone them later. In this process, the RA assessed willingness to participate in the study.
2. The participant's verbal consent (either accepted or denied being telephoned to participate) was registered on a list by the local RA.
3. The RA sent this list, including names, Facebook messenger names/IDs, and telephone numbers, to the master's student in Norway by email.
4. The master's student in Norway sent written information and the study consent form in the Nepali language individually to parents (who had access to internet) to their Facebook Messenger accounts. This information was sent in two formats – both as written information (a pdf file) and a voice recording of the same information. The RA contacted the participants who could not be contacted via social media and read aloud the consent form in the Nepali language.
5. Participants were asked to answer “yes” or “no” verbally or in writing through Facebook Messenger accounts. The “yes” was an agreement to be contacted to participate in the study. The participants were also informed that they could ask the master student any other study-related questions before deciding to participate or not.

2.4.2 Processes

1. Due to the COVID-19 pandemic, the telephone was the most appropriate means for data collection for this study. After informed consent was collected, the master's student in Norway and two local RAs in Nepal - a parent of a CWID and a student - telephoned the participants to administer the study questionnaire verbally. The interviewers read

the questions to the caregivers with possible answer options. The interviewers used the same script while conducting the interview and strayed from it as little as possible. At this point, the interviewers provided an opportunity for caregivers to ask questions about the study and opt-out if they had changed their minds about participation. The interviews took a minimum of 40 minutes and a maximum of one and a half hour due to the problem with phone connectivity.

2. A professional psychiatrist had previously trained all three data collectors, including the master student, on conducting interviews in a manner as similar to each other as possible. The structured interviews followed a standardized procedure, including a short presentation of the interviewer, gratitude for the interviewee being willing to participate, and asking if the interviewee has received information about the study. The participants were notified again of the voluntary and anonymous participation.
3. The participants' answers to the study questionnaire were recorded anonymously in an electronic spreadsheet (MS Excel file), saved on a password-protected computer. The answers to the open-ended questions were collected in a separate word processing document (MS word file). The anonymous data collected by the two RAs based in Nepal was shared with the master's student via Microsoft Teams. The data was anonymous and could not be traced back to the participants.

2.4.3 Instruments

The study questionnaire included the validated Nepali-language version of the Hopkins Symptoms Checklist-25 scale (HSCL-25), Beach Center Family Quality of Life Scale (FQOL Scale), the Perceived Stress Scale (PSS), and questions about the participant's socio-demographic and health characteristics.

Hopkins Symptoms Checklist-25 scale (HSCL-25)

The HSCL-25 scale was used to assess the primary outcome, namely, indicators of mental distress (anxiety and depression scores). The HSCL-25 comprises 25 items, 10 items assessing anxiety symptoms and 15 assessing depression symptoms. Each question includes four response categories – 'not at all,' 'a little,' 'quite a bit,' and 'extremely,' which are rated 1-4, respectively. The instrument has been tested among various populations, such as special primary care populations in Tanzania and Afghanistan (51, 52), people in conflict-affected areas in Sri Lanka (53), and more.

The HSCL-25 has also been previously validated for use in the Nepali context. It was translated and adapted in Nepali among Bhutanese refugees who speak Nepali (54) and has been used to identify depression and anxiety in this population (55-57). The Nepali-language HSCL-25 has also been used to assess the prevalence of depression and anxiety among female survivors of human trafficking taking shelter in Kathmandu (58), among multi-drug resistant tuberculosis patients (59), widows (60), and the general population living in earthquake-affected areas (15). The lowest prevalence reported from these mentioned studies was among tuberculosis patients (22.2% and 15.6% depression and anxiety, respectively) (59).

The Beach Center FQOL Scale

The Beach Center FQOL Scale was developed by the Beach Center on Disability (a multidisciplinary American research institute at the University of Kansas (61) to assess caregiver satisfaction with several life domains. The FQOL component of the scale comprises 25 items and five domains (used as sub-scales) of FQOL; (1) family interaction (FI) (six items), (2) parenting (PA) (six items), (3) emotional well-being (EWB) (four items), (4) physical well-being (PWB) (five items), and (5) disability-related support (DRS) (four items) (62). The Beach Center FQOL scale employs a 5-point Likert scale where participants express their satisfaction with and the importance of the item (1 = very dissatisfied, 3 = neither satisfied nor dissatisfied and 5 = very satisfied). The total score for satisfaction with their FQOL ranges from 25-125 (62), while the total score for the domains ranges from 6-30 (FI, PA), 40-20 (EWB, DRS), and 5-25 (PWB).

McFelea and Raver state the absence of a scoring system for this scale (63). Hence, based on a method developed by Raphael, Brown, Renwick, and Rootman (63, 64), the FQOL score (average score of 25 items) is interpreted in the following way: < 1.37 as very problematic, 1.37 to 2.11 as problematic, 2.12 to 2.86 as adequate, 2.87 to 3.61 as very acceptable, and 3.61 as exemplary.

The Beach Center scale has been tested in HICs and LMICs (65, 66). Two studies in China and Malaysia presented the results of families of children with intellectual and developmental disabilities (40, 67).

The Beach Center FQOL Scale has not been validated in Nepal. However, the scale has been translated to Nepali, and it has been validated in neighboring China (Cronbach's alpha of .91) (40).

The Perceived Stress Scale (PSS)

The Perceived Stress Scale (PSS), developed by Sheldon Cohen and his colleagues in 1983, consists of 14 items rated on a 5-points Likert Scale (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often) (68). The tool was shortened from 14 items to 10 by the original developers (68). There are 4 positively stated items (items 4, 5, 7, 8); the scores for these items were reversed for analysis: 0 was reversed to 4, 1 to 3, 2 was the same, 3 to 1, and 4 to 0 (69). The total score for the PSS ranges from 0 to 40 (70). A person's score ranging from 0-13 indicates low stress, scores from 14-26 indicate moderate stress, and 27-40 designate high perceived stress (70). In a systematic review of the psychometric evidence of the PSS, Cronbach's alpha always passed the 0.7 thresholds, with the internal consistency ranging from 0.74 to 0.91 (71, 72).

The PSS has been translated from the original English-language version to more than 25 languages: Japanese, Spanish, Turkish, Portuguese, Chinese, Thai, Arabic, Greek, French, and more (72). The tool has been used in general populations (for example, college students in Ethiopia and the US, pregnant women in Brazil) and among clinical patients (patients with chronic headache in Iran, Multiple Sclerosis patients in the US, systemic lupus erythematosus in China, and more) (68, 73-77). It has been used among parents of children with developmental delay in countries such as Australia (78), Turkey (79), Jordan (80), and the USA (81). However, the scale has not been validated in Nepal, although it has been used in several studies among Nepali nursing and medical students (82-84), former sex workers with HIV (85), and among the general population during the COVID-19 pandemic (86).

Sociodemographic characteristics

In addition to the three scales presented above, questions about sociodemographic characteristics were included in the questionnaire to control confounders and explore potential associations. The sociodemographic variables were included based on a thorough literature review and consultation with project advisors and topic experts. The assessed sociodemographic characteristics are as follows:

About the caregivers:

1. Gender: Male/female
2. Age: marked in scale and categorized into groups of 19-35, 36-55, and 56 and above
3. Residence: Metropolitan/municipality/rural municipality
4. Ethnicity: (Brahmin, Chhetri, Thakuri)/Indigenous/Dalit/Others
5. Marital status: Married or in a relationship/divorced or widowed/never married/other

6. Education: Illiterate/Literate (knows how to read and write)
7. Employment status: Employed/unemployed
8. Total monthly income of the family: marked in scale and categorized into groups of average and below average (\leq NRs 26894), and above average (\geq NRs 26894) (87)
9. Number of family members: marked in scale and categorized into groups of 1-4, 5-7 and >7
10. Accessibility (access to nearest public transportation, and health service): marked in scale in minutes and categorized into groups: less than 30 minutes/ more than 30 minutes
11. Effect of COVID 19 on personal and family health and daily life: marked in Likert scale of extremely positive (1) to extremely negative (5) with a neutral value of 3
12. Self-reported health problems: High blood pressure/heart problems/diabetes/physical discomfort/disturbed sleep/emotional distress or discomfort

About the children with intellectual disabilities:

1. Gender: Male/female
2. Age: marked in scale and stratified into groups of 5-9, 10-14, and 15-18 years old
3. Formal diagnosis: Down syndrome/fragile x syndrome/autism spectrum disorder/apert syndrome/williams syndrome/prader-willis syndrome/phenylketonuria (PKU)/cerebral palsy/fetal alcohol spectrum disorder/intellectual disability/not sure/other
4. Severity of disability: Mild/moderate/severe/profound
5. Multiple disabilities (comorbidity): autism/emotional or behavioral disorder/developmental delay/hearing impairment including deafness/vision impairment including blindness/learning disability/physical disability/speech or language impairment/traumatic brain injury/intellectual disability/other disabilities/no specific diagnosis

The caste system in Nepal is hierarchically divided, with Dalits considered to be at the lowest level. There have been many movements to eradicate caste-based untouchability and discrimination in Nepal. However, the idea of a country free of untouchability has not been implemented practically. Due to the social exclusion Dalits face, these groups are poor in education and health (88). For instance, their literacy rate in the 2001 census was only 38%, while the national literacy rate was 53.7% (89). The castes considered to be the purest, Brahmins and Chhetris, had much higher literacy rates (74.9% and 82%, respectively). Dalits also face a high incidence of poverty. They lie in the lowest ranks of all the indicators of the

Human Development Index, such as lowest per income capita (89). Hence, ethnicity has been included in the questionnaire as it can be used to understand its relationship with poor health conditions.

In addition, the COVID-19 pandemic starting in the spring of 2020 resulted in lockdowns and prohibitions on citizens traveling far from their homes. The consequences of the pandemic made it necessary and warranted to include a few questions about the influence of the pandemic on the participants' mental health and situation, such as its effect on the participants' and their families' health, stress, their income, accessibility to daycare centers, and external help.

Translation and adaptation of instruments

To enhance the face validity and reliability of the Nepali version of The Beach Center FQOL scale, PSS, and the socioeconomic questionnaire, the entire questionnaire was translated and adapted to the Nepali culture based on WHO's 'Process of translation and adaptation of instruments' (90). The procedure involved the following steps:

1. Forward translation
2. Expert panel back-translation
3. Pre-testing and cognitive interviewing
4. Final version

A translator with a Nepali mother tongue and fluent in English translated the questionnaire from English to Nepali. The translator tried to avoid using jargon and use language that was understood by a broad Nepali population. Then, the questionnaire was sent to four Nepali friends and colleagues fluent in English, and edits were made according to their suggestions. Since they were not experts in the research field, they commented on the primary language and understanding of the questionnaire. The edits were made by the master student and a Ph.D. candidate who is conducting a larger research project on caregivers of CWID, in which this master thesis is a part.

Next, we sent the questionnaire to four experts who had not seen the questionnaire before: a teacher at one of the daycare centers, a pedagogue and language expert, a researcher and language expert, and a researcher and psychiatrist. These experts identified some mistakes in the language and the accuracy and cultural appropriateness of the wordings. Some words or concepts that did not match the Nepali context were identified and replaced with relevant phrases and words. After necessary edits, the questionnaire was back-translated by another Nepali fluent in English. Then, we conducted a pre-test among six caregivers who acted as

representatives of the research participants. The six representatives were also parents who brought their children to the day-care centers, but were not included in the study since they helped with the pre-testing. The six respondents were briefed on the research and then interviewed informally, drawing from techniques used in cognitive interviewing. Specifically, they were asked to comment on and share thoughts about the items in the questionnaire. We interviewed six respondents because their comments reached a saturation point at six, meaning the respondents started sharing similar comments. We then prepared the final version of the questionnaire after changing the questionnaire based on the respondents' feedback.

2.5 Outcome Variables

Four dependent variables were included in this study: depression, anxiety, stress, and FQOL. The cut-offs to measure these variables are presented in Table 1.

Table 1. *Dependent variables and their measures*

Study variables (Dependent variables)	Measures
Depression	Mean score: ≥ 1.55 - symptoms ≥ 1.75 - symptoms requiring treatment
Anxiety	Mean score: ≥ 1.55 - symptoms ≥ 1.75 - symptoms requiring treatment
Stress	Total score: 0-13 - low stress 14-26 - moderate stress 27-40 - high perceived stress
Family quality of life (FQOL)	Mean score: < 2.87 - not acceptable > 2.87 - acceptable

2.6 Data Management and Analysis

2.6.1 Data Management

After receiving the data from the two RAs in Nepal, the master's student imported it to SPSS and coded it as required. Variables such as age, income, time taken to access public transportation or hospital were recoded into categories for more straightforward analysis. Some continuous variables were stratified and categorized into groups.

The variables urban and rural areas of the province were generated by placing participants residing in metropolitan areas and municipalities into the same variable (urban area) and those in rural municipalities into another variable (rural area). The variable 'accessibility' was created by grouping all the caregivers who took less than 30 minutes to reach public transport and a health facility, in one group and the rest in another. Only two groups were created for employment status by placing full-time, part-time, and daily wage workers into one group (employed) and the unemployed, homemakers, and students into another (unemployed).

Mean scores were calculated for the variables that used Likert scales, such as the mean score for the HSCL-25 items and its depression and anxiety subscales, PSS items, and the questions about the effects of COVID-19. Total and mean scores were calculated for the items in the Beach Centre FQOL Scale and its five domains: FI, PA, EWB, PWB, and DRS.

2.6.2 Data Analysis

All the analyses were performed with SPSS version 27.0. The independent variables were stratified accordingly, and descriptive statistics were calculated for all the parents and the children. We first carried out Chi-square tests, followed by logistic regression to adjust for possible confounders. However, the results were not meaningful since the number of cases was too small. Therefore, to explore the correlations between categorical parent and child variables and the outcome variables, we created a correlation matrix with Cramer's V with statistical significance set at $p < .05$. While correlation measures associations (strength and direction), it does not explain the association; hence, the association cannot explain a causal relationship between the variables (91). Cramer's V was used to measure the strength of association of two categorical variables in tables larger than 2x2 tabulations (92). Cramer's V does not show direction, only the strength; values greater than .30 is a moderate correlation, and greater than .50 is a strong association (93, 94).

2.7 Ethical Considerations

We obtained verbal informed consent from all the participants before conducting the interviews. We conducted the study under the approval of the Regional Committee for Medical Research Ethics (REK) (134579 REK sør-øst A) in Norway and the Nepal Health Research Committee (590-2020). Data were collected anonymously as no personal names nor identification numbers were recorded. Personal information used for telephone calls, such as names and telephone numbers, were deleted after the interviews and never linked to the questionnaire items or study database.

3. RESULTS

3.1 Socio-demographic Characteristics of the Study Population

The characteristics of the study participants, primary caregivers of CWID, are presented in Table 2, while Table 3 lists these caregivers' child characteristics. The majority (67.4%) of the caregiver participants were female, and most (56.7%) were mothers of the child. The majority of the females were married (81.8%) and homemakers (62.2%) (those who stayed home and managed their household). Of the 14 study participants who were divorced, separated, or widowed, almost all were women. Additionally, 71.7% of the total number of females were unemployed, while only 21% of the total males were unemployed.

Table 3 shows that the caregivers' children suffered predominantly from down syndrome (41.5%) and had multiple disabilities, including speech or language impairments (60.5%). The majority had severe disabilities (47.8%), as classified by the caregivers.

Table 2. Characteristics of caregivers

N=215		
Characteristic	n	%
Female	145	67.4
Male	70	32.6
Age group		
19-35	86	40.0
36-55	123	57.2
≥ 56	4	1.9
Number of family members		
1-4	117	54.4
5-7	84	39.1
>7	11	5.1
Relationship with child		
Mother	122	56.7
Father	45	20.9
Other relatives	48	22.3
Ethnicity		
Brahmin/Chettri/Thakuri	95	44.2
Indigenous	107	49.8

	Dalit and others	11	5.1
Education			
	Illiterate	48	22.3
	Literate	167	77.7
Employment status			
	Employed	90	41.9
	Unemployed	117	54.4
Monthly family income in NRs			
	≥ 26894	110	51.2
	<26894	104	48.4
Relationship status			
	Married	177	82.3
	Unmarried	23	10.7
	Divorced/Separated/ Widowed	14	6.5
Residence			
	Urban	165	76.7
	Rural	50	23.3

Table 3. Characteristics of the caregivers' child

N=215			
Characteristic	n	%	
Male	126	58.6	
Female	87	40.5	
Age group			
	5-9	31	14.4
	10-14	90	41.9
	15-18	93	43.3
Formal diagnosis of disability			
	Down syndrome	89	41.5
	Intellectual disability	50	23.3
	Autism spectrum disorder	24	11.2
	Cerebral Palsy	9	4.2
	Others	6	2.8

	Don't know	36	16.8
Severity of disability			
	Mild	19	8.8
	Moderate	73	34.0
	Severe	102	47.4
	Profound	21	9.8
Multiple diagnoses			
	Autism spectrum disorder	23	10.7
	Emotional or behavioural disorder	27	12.6
	Developmental delay/early childhood disability disorder	97	45.1
	Hearing impairment including deafness	33	15.3
	Vision impairment including blindness	16	7.9
	Learning disability	95	44.2
	Physical disability	56	26.0
	Speech or language impairment	130	60.5
	Traumatic brain injury	13	6.0
	Intellectual disability	17	7.9
	No specific diagnosis	6	2.8
Comorbidity			
	No	5	2.3
	Yes	210	97.7

3.2 Reliability of Scales

After assessing the HSCL-25 scale by Cronbach's alpha, its reliability was found to be 0.92, which corresponds well with previous findings (95, 96). The internal consistency of the HSCL-25 anxiety subscale measured by Cronbach's alpha was 0.84, while the internal consistency for the HSCL-25 depression subscale was 0.88, which is a strong correlation between the questionnaire items.

Assessing the Beach Center FQOL Scale by Cronbach’s alpha, the reliability was found to be 0.94 while it ranged from .71 to .79 for the domains. The reliability scores suggest good internal consistency and thus reliability of the scale in this sample, while the Cronbach’s alpha for PSS was 0.94.

3.3 Prevalence of Anxiety, Depression, Stress, and FQOL Among the Caregivers

The prevalence estimates for indicators of mental distress were as follows: 6% (N=13) of the caregivers reported symptoms of anxiety, 5.6% (N=12) depression, 98.1% (N=211) reported stress, and 3.7% (N=8) reported having less than acceptable family life satisfaction, as reported in Table 4.

Table 4. Prevalence of mental distress among the caregivers

Outcome	Prevalence N (%)
Anxiety	
No symptoms	203 (94.4%)
Probable symptoms	12 (5.6%)
Total	215
Depression	
No symptoms	204 (94.9%)
Probable symptoms	11 (5.1%)
Total	215
Stress	
Low	3 (1.4%)
Moderate	203 (94.4%)
High	8 (3.7%)
Total	214 (99.5%)
FQOL	
Below acceptable	8 (3.7%)
Acceptable	207 (96.3%)
Total	215

3.4 Correlation Between Independent Variables and Dependent Variables

We evaluated pairwise associations between the dependent and independent variables. As demonstrated in Table 5, we considered relationships among several variables. Among the dependent variables, FQOL was significantly correlated with stress ($V=.18, p<.01$). Anxiety/depression showed significant and weak correlations with four variables: residence ($V=.14, p<.05$), employment ($V=.15, p<.05$), income ($V=.20, p<.01$), and caregivers' health issues ($V=.15, p<.05$).

Among the independent variables, gender revealed a strong significant correlation with employment ($V=.46, p<.01$). Family income exhibited a moderately significant correlation with severity of disability ($V=.24, p<.01$), effects of COVID-19 ($V=.31, p<.01$), and caregivers' residence ($V=.30, p<.01$). In addition, moderate associations were observed between age and marital status ($V=.28, p<.01$) and education ($V=.35, p<.01$). Finally, there was a weak but significant association between severity of disability and the effect of COVID-19 ($V=.20, p<.05$).

Table 5. Correlation Matrix (Cramer's V) of Independent and Dependent Variables

Variables	FQOL	Stress	Anxiety/ depression	Sex	Age	Marital status	Education	Residence	Employ ment	Income	Severity	Health issues	Covid-19 effects
FQOL	1												
Stress	.18**	1											
Anxiety/depression	.04	.02	1										
Sex	.02	.00	.10	1									
Age	.16	.02	.05	.15	1								
Marital status	.10	.04	.04	.02	.28**	1							
Education	.04	.06	.11	.07	.35**	.13	1						
Residence	.10	.06	.14*	.05	.10	.00	.10	1					
Employment	.07	.05	.15*	.46**	.08	.11	.14*	.15*	1				
Income	.04	.03	.20**	.11	.09	.18**	.03	.30**	.07	1			
Severity	.02	.05	.05	.03	.10	.01	.10	.23**	.06	.24**	1		
Health issues	.08	.03	.15*	.05	.12	.02	.11	.14*	.06	.04	.00	1	
Covid-19 effects	.11	.07	.03	.05	.01	.03	.08	.10	.05	.31**	.20**	.10	1

***. Correlation is significant at the 0.01 level (2-tailed)*

**. Correlation is significant at the 0.05 level (2-tailed)*

4. DISCUSSION

The overall aim was to assess the prevalence of indicators of mental distress among caregivers of CWID and the factors associated with these symptoms. The findings illustrate that caregivers experienced stress (99.5%), while only a few experienced the symptoms of depression (5.1%) and anxiety (5.6%). Moreover, the majority were satisfied with their FQOL (96.3%).

4.1 Comparison to Prior Studies

4.1.1 Participant Characteristics

Some of the characteristics of the present participants were inconsistent with that of the Nepal's Demographic and Health Survey, 2016 (16). This comparison reflects on the potential uniqueness of our study sample compared to the general population of Nepal, or comparable LICs. In our study, the proportion of illiterate male participants was almost three times higher than the average population. In contrast, the illiterate female participants were reflective of the norm, which may reflect the regions where interviews took place. The proportion of widowed, separated, or divorced participants in our study was double than that of the general population. One possible reason for their number to be twice as much in our study is being a caregiver itself. Caregiving is stressful and may hinder the caregiver's relationship, which leads to the separation of caregivers (97).

4.1.2 Prevalence of Mental Distress

Numerous studies evaluate the prevalence of mental illness among caregivers in both LICs and HICs. Similar studies from LICs have reported both corresponding and varying prevalences of stress among caregivers of CWID; a study in India reported 89.6% (33), and another study in Pakistan reported 70% severe and 4% profound stress (98). The differences in the prevalences can be attributed to disparities and differences in healthcare systems, culture and variation in instruments used and methods of collecting data (99). The level of severe stress among the female caregivers in this study (75% of the total reporting severe stress) was consistent with a study in urban India which reported clinically significant stress of 77% among caregiving mothers (100). Our study provides additional support for the prevalence of severe stress among female caregivers. However, no significant correlation was observed between stress and the sex of the caregiver in our study.

Conversely, the results of this study suggest a low prevalence of symptoms of depression and anxiety, which contradicted prior studies with caregivers of CWID in Nepal and globally. However, the prevalences reported in our study are higher than the general population averages (3.4% with depression symptoms and 1.4% with anxiety symptoms) (17). Since our study was conducted during a pandemic, comparing our results to a comparable study conducted during a similar time shows mostly disparities rather than similarities. The prevalences in our study are low compared to a study conducted among the caregivers of CWID (N=1871) in India during the COVID-19 lockdown, which reported 20.5%, 62.5% and 36.4% of the total study population suffering from anxiety symptoms, depression symptoms, and stress symptoms, respectively (101). The prevalence of mental distress in their study is high compared to previous studies which can be credited to the lockdown period and the pandemic's media coverage, which constantly illustrated negative impacts of the pandemic, which was the condition for Nepal too. Nevertheless, a substantial disagreement is evident as the prevalence is low in our study.

One potential reason for the low prevalence of mental distress (anxiety and depression) in this study may be that the sample of caregivers experiences social support through the daycare centers, as well as related parents' organizations, friends, and families. Support acts as a buffer towards mental distress, reducing depression (102, 103). Women tend to receive help mainly from networks of similar women, whereas men have more diverse connections, including work colleagues and professionals (104). A systematic review by Peer and Hillman states that social support mediates the effects of mental distress and should be included in practices across various disciplines to promote the mental health of caregivers (103). In the Beach Center FQOL scale in this study, the mean score for the question regarding the availability of external help was above average for both males and females. Also, the mean score for support from the family and external help (daycare centers and medical officers or doctors) was above average. However, our study did not find a significant association between FQOL, and anxiety and depression.

Another possible reason for the low depression and anxiety may be more positive answers given by the male participants compared to the females (Table S2). Fathers are generally less involved with the household chores and caring practices of their children (105). Barriers related to cultural norms, professions, and institutions prevent fathers from getting involved in child care (106). Due to their work and societal expectations of gender roles, for example, since males or fathers are comparatively less involved in caring for children, they may not be aware of the

challenges that females or mothers face daily. Also, mothers usually feel more responsible for their children, especially when they are the primary caregiver; accordingly, they spend more time with their children (42, 43, 107). As a result, males or fathers in this study may have been relieved of household duties and reported better mental health than females.

Furthermore, mental health is a stigmatized and controversial topic in Nepal. Public stigma and self-stigma are widespread among people with psychiatric problems in Nepal (108). With negative social attitudes towards disability, PWD and their families can face social exclusion in their communities or even within their families (109). Thus, they may show less enthusiasm or truthfulness in answering questions about this sensitive topic. Vulnerable populations such as the participants in this study, recruited voluntarily, are prone to avoid questions about ill health or may answer positively about their mental health (108). Among several other characteristics, vulnerable populations may have high unemployment, underinsurance, and social or cultural differences that create difficulty accessing healthcare (110).

Also, when responding to sensitive issues, response bias such as social desirability bias may appear (111, 112). Socially desirability bias occurs when participants change their answers according to social norms (111). According to Krumpal, if there is a possibility of participants facing a loss (for example, embarrassment or judgment) when answering, responding truthfully may be a risk for them. Talking about suffering from mental health problems can be stigmatized, or the participants can be judged. Hence, despite the interviewers' best efforts to assure confidentiality, it is possible participants in this study underreported symptoms of depression and anxiety, considering such answers to be undesirable (113). Also, the participants may have faced difficulty in conceptualising the HSCL-25 items, although a validated Nepalese-language version of the questionnaire was used.

Another reason for the low prevalence of mental distress might relate to the fact that the interviewers were female; studies highlight the effect of the gender of the interviewer on the findings, influencing the dynamics of the interview (114-117). The difference in age and sex of interviewers and interviewees may reproduce different cultural and societal stereotypes and norms, influencing the participant's opinions and answers (117). Hyman et al. have illustrated how participants provide different answers to interviewers based on their gender (116). Our study participants may have answered according to the stereotypes generated by their perceptions of a female interviewer. One interviewer was a mother of a CWID herself. Salazar states that choosing the staff as an interviewer may not result in accurate data as some participants may know them personally, creating a bias. However, Salazar also writes that

interviewers with similar characteristics of the target population may help create rapport more effortlessly, resulting in a collection of more precise data (118), which is the reason why this mother was selected as an interviewer.

4.1.3 Family Quality of Life (FQOL) Domains

Our study results showed that the majority of caregivers were satisfied with their FQOL. This is in disagreement with several similar studies that claim poor FQOL among caregivers of CWID in India and China (119, 120), and in HICs as presented in a systematic review (121). Possible reasons for high satisfaction are similar to that of low mental distress – social support for the caregivers, positive answers from the males, and stigma attached to ill mental health leading them to present more positive answers to the interviewers. Furthermore, a population with above average FQOL is expected to report a lower prevalence of anxiety and depressive symptoms (122, 123), which is reported in our study.

The EWB domain of the FQOL scale revealed the lowest score among the five domains, while parenting domain had the highest score (Table S1). Although EWB score is the lowest in our study, it is still higher compared to a similar study in Taiwan which also had the lowest score in EWB (124). Previous studies show an inverse relationship between anxiety and depression, and EWB (125, 126) - as depression increases, EWB decreases. On the other hand, our study showed that caregivers with low prevalence of depression had average EWB, but with weak and non-significant association. One reason for a low EWB score in our study is that the caregivers did not have enough time to invest in themselves, and to pursue their goals and interest, as presented in Table S3 (caregivers scored comparatively less in the question asking them about investing time for themselves).

4.1.4 Association between Mental Distress, FQOL, and Covariates

Mental distress such as stress, depression, suicidal ideation and attempt seem to worsen QOL (124). To better understand factors that contributed to the mental distress of caregivers, the correlation between such factors was evaluated. Our study shows a significant correlation of stress with FQOL, although Cramer's V does not reveal the direction of the relationship. Our finding is consistent with Hsiao et al. (127), who found a significant negative association between FQOL and perceived stress among parents of children with Autism Spectrum Disorder, as well as with Lee et al. (122), showing the negative impact of perceived stress on anxiety and depression, affecting the overall FQOL (128).

Apart from the dependent variables, the strongest correlation between family income and the effects of COVID-19 on the family illustrates that the pandemic has created an enormous financial burden on the caregivers. Various studies focusing on COVID-19 have noticed an inverse relationship between income and mental health; with a decrease in financial stability, there is an increase in mental illness (129, 130). Hertz-Palmor et al. found the abrupt loss in income due to the pandemic associated with increasing anxiety and depression in a general Israeli and American population (130).

We found that anxiety and depression are strongly related to family income, which substantiates findings in previous studies (19, 27), illustrating the decrease in symptoms of mental illness with an increase in family income and financial stability. Higher income allows caregivers access to daycare services, providing them a temporary break from caring for their child (128). They can manage time to meet friends or groups that act as their support system, reducing their mental distress (127). In addition, Kola et al. discuss the possibility of an increase in mental health problems in LMICs because of poverty and social inequalities (131). Brazil is used as an example of disease transmission among poor communities (132), demonstrating the importance of financial stability. Apart from financial difficulties, caregivers may have difficulty managing and accessing in-home care of their child as they face challenges in seeking help from their daycare centers and health providers.

Although one would expect females, mostly mothers, to have a higher proportion of distress, there was no significant association between mental illnesses and the sex of caregivers. This finding concurs well with previous findings that did not observe a significant association between the sex of caregivers and satisfaction with their FQOL (123). However, this is contrary to the literature exhibiting disparities in the mental health of different sexes. During the pandemic, single females have a higher risk of getting affected mentally than males in Nepal (133) and thus in LICs. Women are affected more due to the lack of economic freedom, lack of access to health and education services, and the spread of societal and cultural gender norms (134). A similar study in Bangladesh specified that women were at a higher risk of stress (135). This contradiction with our study might explain the small number of caregivers suffering from anxiety and depression.

However, the strongest association was observed between the sex of the caregivers and their status of employment. We observed a higher number of unemployed females (undertaking unpaid labor as homemakers) in comparison to males in our study. A considerable gender gap in employment in Nepal has been identified by CBS, who found that only 59 females were

employed for every 100 males in 2017/18 (136). Our findings show a much higher proportion of illiterate and unemployed women in comparison to men. Unemployment among women leads to economic instability and scarce decision-making authority concerning their children (137).

4.2 Strengths and Limitations

To our knowledge, no previous studies on caregivers of CWID in Nepal have covered a large part of Nepal. It is a strength that our study was conducted in 13 out of the 77 districts. Additionally, the relation between FQOL and perceived stress has not been assessed in similar studies in Nepal. While previous studies show a vast majority of females or mothers (29, 30), this cross-sectional study includes a comparatively more significant proportion of males or fathers.

This study is not without limitations. Due to COVID-19, face-to-face interviews could not be collected. Since data were collected through phone interviews, information bias may have occurred. As a result of phone interviews and frequent disruption of phone connectivity, participants may have understood the questions differently, and thus given varying answers. In addition, the master's student could not reach many participants due to the logistic difficulty of phone connectivity. This limitation highlights the difficulty of collecting data during a pandemic.

Furthermore, we interviewed caregivers who had admitted their children at the daycare centers. However, caregivers who were unable or did not wish to send their children to daycare centers could not be interviewed. There is a scope of missing the poorest or inaccessible caregivers and children. Hence, the results should not be generalized but suggested when considering a larger population. In addition, the caregivers needed to recall situations a month earlier to answer some of the questions. As they are a population already affected by stress, it might have been difficult for them to remember all events clearly, leading to recall bias.

A significant source of unreliability is that although we had a sample size of 215, there were only 13, 12, and 8 cases for anxiety, depression, and low FQOL. It is difficult to entirely estimate the association between mental distress and the predictors because of few events due to which the results should be interpreted with caution. Our findings need to be confirmed by larger sample size.

While we used HSCL-25, which was already validated for use in Nepal, the other two instruments, Beach Center FQOL and PSS, were not validated. We did not explore these tools' construct validity, which may have led to inaccurate interpretations of findings (138). However, we explored the face validity and internal consistency of these tools, ensuring the tools were reliable for use among caregivers and that the questions were meaningful for caregivers to answer (138). Despite the limitations, this study contributes to the evidence of prevalence and association of anxiety, depression, stress, and FQOL among caregivers of CWID.

4.3 Public Health Implications and Future Research

There is an absence of mental health care providers and health care services that focus on caregivers. Our findings provide important baseline information which can be utilized by future researchers, policy makers, and caregivers for implementation of feasible actions. Getting informed about our results may help caregivers intervene and seek help for themselves. Future researchers should focus on analyses of factors associated with mental distress, conducted in larger sample size, including analyses of associations among mental illnesses. Further studies are necessary to identify factors that challenge community and health care providers in supporting caregivers and identify ways to boost multisector engagement of health, education, social services, and disability service providers.

In addition, public health literature suggests that support systems and interventions (even short and brief) can mediate the high levels of mental distress. Thus, training interventions to engage not only the caregivers but those around them - including their spouses or family, friends, and community - on ways to support caregivers to develop long-term care plans for their child could help reduce their distress. Community interventions can be beneficial and feasible in countries like Nepal that emphasizes groups, cohesiveness. As the data suggest higher distress among females, employing a gendered perception of intervention is critical to decreasing females' added burden.

5. CONCLUSION

The present study provides evidence of a low level of anxiety and depression, high level of stress, and high satisfaction with their FQOL among caregivers of CWID in Province 3 of Nepal. FQOL correlated with perceived stress, while the pandemic created a financially hostile environment for caregivers. The data specify higher distress in females than males and thus suggest the potential effectiveness of interventions targeted at female caregivers in the future. In addition to professional help, formal and informal support systems are essential in mediating the high level of perceived stress found in this study. Our study highlights the need of a larger study for caregivers of CWID who do not attend daycare centers to capture prevalences in a population more representative of the entire country. Additionally, it is essential to explore the protective factors against anxiety and depression despite stress in this particular population.

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7. APPENDICES

APPENDIX A: SUPPLEMENTARY TABLES

Table S1. Mean of FQOL and its domains

Covariates of FQOL	Mean (SD)
FQOL overall	3.77 (.47)
Family Interaction	3.82 (.55)
Parenting	3.88 (.52)
Emotional Well-being	3.70 (.59)
Physical Well-being	3.72 (.48)
Disability related support	3.74 (.53)

Table S2. Mean of HSCL-25 items

	Male		Female	
	Mean	SD	Mean	SD
Suddenly scared for no reason	1.08	.319	1.18	.452
Feeling fearful	1.11	.434	1.18	.477
Faintness, dizziness or weakness	1.06	.295	1.14	.432
Nervousness or shakiness inside	1.03	.171	1.06	.315
Heart pounding or racing	1.04	.272	1.08	.343
Trembling	1.00	.000	1.04	.259
Feeling tense or keyed up	1.48	.503	1.51	.591
Headaches	1.69	.467	1.81	.501
Spells of terror or panic	1.00	.000	1.10	.359
Feeling restless and can't sit still	1.01	.122	1.06	.294
Feeling low in energy, slowed down	1.26	.474	1.30	.543
Blaming yourself for things	1.03	.171	1.12	.362
Crying easily	1.00	.000	1.12	.397
Loss of sexual interest or pleasure	1.33	.543	1.60	.744
Poor appetite	1.03	.173	1.10	.394
Difficulty falling asleep, staying asleep	1.04	.272	1.10	.394
Feeling helpless about the future	1.07	.317	1.12	.420
Feeling blue	1.23	.422	1.34	.566
Feeling lonely	1.03	.173	1.11	.423
Thoughts of ending your life	1.04	.272	1.07	.323
Feeling of being trapped or caught	1.03	.173	1.06	.314
Worrying too much about things	1.09	.288	1.24	.486
Feeling no interest in things	1.01	.122	1.10	.382
Feeling everything is an effort	1.06	.239	1.14	.421
Feeling of worthlessness	1.03	.173	1.07	.352

Table S 3. Mean of Beach Centre FQOL items

	Male		Female	
	Mean	SD	Mean	SD
My family enjoys spending time together.	4.24	.525	4.26	.576
My family members help the children learn to be independent.	4.00	.603	3.96	.671
My family has the support we need to relieve stress.	3.61	.969	3.46	1.157
My family members have friends or others who provide support.	3.97	.627	3.87	.749
My family members help the children with schoolwork and activities.	4.07	.502	3.96	.627
My family members have transportation to get to the places they need to be.	3.48	.959	3.26	1.080
My family members talk openly with each other.	3.97	.577	3.89	.701
My family members teach the children how to get along with others.	4.04	.475	4.01	.600
My family members have some time to pursue our own interests.	3.52	.990	3.32	1.051
Our family solves problems together.	4.06	.385	3.95	.599
My family members support each other to accomplish goals.	4.00	.522	3.89	.705
My family members show that they love and care for each other.	4.07	.502	4.07	.584
My family has outside help available to us to take care of special needs of all family members.	3.57	.973	3.40	1.015
Adults in our family teach the children to make good decisions.	4.04	.475	3.97	.564
My family gets medical care when needed.	3.67	.842	3.55	.936
My family has a way to take care of our expenses.	3.91	.621	3.74	.775
Adults in my family know other people in the children's lives.	3.97	.491	3.93	.569
My family is able to handle life's ups and downs.	3.99	.507	3.87	.673
Adults in my family have time to take care of the individual needs of every child.	3.94	.574	3.95	.557
My family gets dental care when needed.	2.90	1.075	2.87	1.025
My family feels safe at home, work, school, and in our neighbourhood.	3.91	.668	3.97	.496
My family member with a disability has support to accomplish goals at school or at workplace.	3.87	.694	3.86	.624
My family member with a disability has support to accomplish goals at home.	3.93	.611	3.90	.589
My family member with a disability has support to make friends.	3.93	.559	3.86	.615
My family has good relationships with the service providers who provide services and support to our family member with a disability.	3.37	1.085	3.28	1.088

Table S4. Mean of PSS items

	Male		Female	
	Mean	SD	Mean	SD
how often have you been upset because of something that happened unexpectedly?	1.85	1.091	1.98	.884
how often have you felt that you were unable to control the important things in your life?	1.76	1.129	1.81	1.127
how often have you felt nervous and “stressed”?	1.61	1.058	1.60	.847
how often have you felt confident about your ability to handle your personal problems?	2.03	1.073	2.00	.969
how often have you felt that things were going your way?	2.27	.931	2.23	.842
how often have you found that you could not cope with all the things that you had to do?	1.82	1.072	1.94	1.029
how often have you been able to control irritations in your life?	1.99	1.135	1.95	1.016
how often have you felt that you were on top of things?	2.21	1.081	2.20	.827
how often have you been angered because of things that were outside of your control?	1.90	1.195	1.88	1.057
how often have you felt difficulties were piling up so high that you could not overcome them?	1.88	1.135	1.90	.927

APPENDIX B: APPROVAL LETTERS FROM ETHICS COMMITTEES

B.1 Approval from Regional Committee for Medical Research Ethics

9/22/2020

Mental helse blant omsorgsgivere for barn med funksjonsnedsettelse i Nepal - Kommunikasjon - REK PORTALEN

✉ COPY of decision

Reply letter

Date: 14.09.2020
From: REK
To: Gørill Haugan
Applies: [Mental health among caregivers of children with disabilities in Nepal](#)



Region:	Case manager:	Phone:	Our date:	Our reference:
REK south-east A	Tove Irene Kløkk	22845522	14.09.2020	134579
Their reference:				

REK south-east A

Visiting address : Gullhaugveien 1-3, 0484 Oslo
Gørill Haugan

Phone : 22 84 55 11 | Email : rek-sorost@medisin.uio.no
Web : <https://rekportalen.no>

134579 Mental health care for children with disabilities in Nepal

Responsible for research : Norwegian University of Science and Technology

Applicant : Gørill Haugan

REK's assessment

We refer to the application for project change dated 10.09.2020 for the above research project. The application has been processed by the leader of REK south-east on delegated authority from REK south-east A, pursuant to the Health Research Act § 11.

The protocol has changed as a result of the covid-19 pandemic. Due to travel restrictions, data collection must take place by telephone, and consent must also be obtained orally. Participants receive information about the study both in writing and orally, and will have several opportunities to ask questions and possibly withdraw from the study. Changed procedures for recruitment, data collection and obtaining consent are described in the revised research protocol.

The questionnaire has been revised with some questions about how the covid-19 pandemic has affected the participants, and the revised questionnaire is attached to the change notification.

The chair of the committee has assessed the changes, and finds that these are justifiable to implement. The changes are approved as described in the application for project change and revised protocol.

Decision

Approved

Pursuant to section 11, second paragraph, of the Health Research Act, the committee approves that the project is continued in accordance with what appears from the application for project change and in accordance with the provisions that follow from the Health Research Act with regulations.

At the same time, we point out that according to the new Personal Data Act, there must also be a basis for processing in accordance with the Privacy Ordinance. It must be anchored in its own institution.

The approval is valid until 01.08.2021.

If further changes are to be made to the project in relation to the information provided in the application, the project manager must send a new change notification to REK.

Av dokumentasjonshensyn skal opplysningene oppbevares i 5 år etter prosjektslutt. Opplysningene skal oppbevares avidentifisert, dvs. atskilt i en nøkkel- og en datafil. Opplysningene skal deretter slettes eller anonymiseres.

Prosjektet skal sende sluttmelding til REK, se helseforskningsloven § 12, senest 6 måneder etter at prosjektet er avsluttet.

Vennlig hilsen

Knut Engedal
Professor dr. med.
Leder REK sør-øst A

Tove Irene Klokk
Seniorrådgiver
REK sør-øst

Kopi til forskningsansvarlig institusjoner(er) og medbruker(e).

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK sør-øst A. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst A, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag (NEM) for endelig vurdering.

B.2 Approval from Nepal Health Research Council



Government of Nepal
Nepal Health Research Council (NHRC)
Estd. 1991

Ref. No.: 1279

20 October 2020

Ms. Susan Sitoula
Principal Investigator
Norwegian University of Science and Technology

Ref: Approval of thesis proposal

* Dear Ms. Sitoula,

This is to certify that the following protocol and related documents have been granted approval by the Ethical Review Board, NHRC for implementation.

If the researcher requires transfer of the bio-samples to other countries, the investigator should apply to the NHRC for the permission. The researchers will not be allowed to ship any raw/crude human biomaterial outside the country, only extracted and amplified samples can be taken to laboratories outside of Nepal for specific study, as per the protocol submitted and approved by the NHRC. The remaining samples of the lab should be destroyed as per standard operating procedure and the process should be documented and informed to the NHRC timely.

ERB Protocol No	590/2020 MT	Sponsor Protocol No	NA
Principal Investigator/s	Ms. Susan Sitoula	Sponsor	NA
Title	Prevalence of and factors associated with of anxiety, depression, stress, and perceived family QOL among primary caregivers of children with neurodevelopmental disabilities in Bagmati Province, Nepal		
Protocol Version No	NA	Version Date	NA
Other Documents	1. Data collection tools		
Members of research team	Prof. Gørill Haugan		
Study Site	Province 3		
Type of Review	<input type="checkbox"/>	Expedited	Duration of Approval 20 October 2020 to 20 October 2021 Frequency of continuing review
	<input checked="" type="checkbox"/>	Full Board	
	Meeting Date: 14 October 2020		

Tel: +977 1 4254220, Fax: +977 1 4262469, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: <http://www.nhrc.gov.np>, E-mail: nhrc@nhrc.gov.np



Government of Nepal
Nepal Health Research Council (NHRC)
Estd. 1991



Ref. No.: 1279

Total budget of research	NRs 76,000.00
Ethical review processing fee	NRs 10,000.00
Investigator Responsibilities <ul style="list-style-type: none">• Any amendments shall be approved from the ERB before implementing them• Submit Serious Adverse Events (SAE) and Suspected Unexpected Serious Adverse Reaction (SUSAR) reports to the ERB within 48hours• Submit progress report every 3 months• Submit final report after completion of protocol procedures at the study site• Report protocol deviation / violation within 7 days• Comply with all relevant international and NHRC guidelines• Abide by the principles of Good Clinical Practice and ethical conduct of the research	

If you have any questions, please contact the Ethical Review M & E Section at NHRC.

Thanking you,

Dr. Pradip Gyanwali
Member-Secretary
Executive Chief

APPENDIX C: QUESTIONNAIRE AND INFORMED CONSENT

C.1 Questionnaire for Caregivers of Children With Intellectual Disabilities in Nepal

SECTION A: INFORMATION ABOUT YOU

The questions in this section will help us to identify trends in responses based on child and family characteristics.

Please fill in the correct answers for you by marking with a tick [✓] unless other instructions are given.

1. What is your relationship with the child with a disability whom you care for daily?

Mother Father Sibling Grandfather Grandmother

Uncle Aunt Cousin Other (please specify): _____

2. How long have you cared for the child?

3. What is your age in years?

4. What is your gender?

Male Female Other

5. What is your ethnicity/caste?

Brahmin/Chhetri/Thakuri Indegenous Dalit

Other please specify): _____

6. In which district do you live?

Kathmandu Lalitpur Bhaktapur Chitwan Dolakha

Kavrepalanchowk Nuwakot Sindhuli Makwanpur

Ramechhap Rasuwa Sindhupalchowk

7. How long have you lived here? (according to months or years)

8. Which kind of municipality do you reside in?

Metropolitan

Municipality

Rural municipality

9. What is your religion? (mark one or several answers, as relevant)

Hinduism Buddhism Kirat Islam

Christian Other (please specify): _____

10. Can you read and write?

Not at all (go directly to question 10)

Yes, a little bit

Yes, quite well but with some difficulties

Very well/highly literate

11. How many years of formal education have you completed in years?

12. What is your employment status?

Full time employed Part time employed Unemployed

On call/casual employment/daily wage based Homemaker

Other (please specify): _____

13. If employed, what is your occupation? Please specify (for example, farmer, teacher, cleaner)

14. What is the average total monthly income (in rupees) of your household? Please consider all your household resources in addition to salary (for example, selling farming products, animals, or rent, etc.)

15. How many household members are dependent on this income? Please write the number of members in the given box below.

16. What is your marital status?

Married/cohabiting Widowed Divorced/separated/never married

Temporarily separated due to employment

Other (please specify): _____

17. How many minutes or hours does it take for you to access any form of public transportation from your home? (in minutes or hours)

18. How many minutes or hours does it take from your home to the nearest government/public health services? (in minutes or hours)

19. Overall, how has the COVID-19 pandemic impacted your personal health and your family's health?

- Extremely positive Moderately positive No impact
- Moderately negative Extremely negative

20. How has the COVID-19 pandemic impacted your personal stress level?

- Extremely positive Moderately positive No impact
- Moderately negative Extremely negative

21. How has the COVID-19 pandemic impacted your access to other caregivers for support?

- Extremely positive Moderately positive No impact
- Moderately negative Extremely negative

22. How has the COVID-19 pandemic impacted your access to day care centers?

- Extremely positive Moderately positive No impact
- Moderately negative Extremely negative

23. How has the COVID-19 pandemic impacted your income?

- Extremely positive Moderately positive No impact
- Moderately negative Extremely negative

SECTION B: Information about the child you are caring for

Please fill in the correct answers by marking with a tick mark [✓] or as otherwise instructed.

24. What is the age of the child you care for in years?

25. What is the gender of the child?

Male Female

26. Has your child been given any formal diagnosis for his/her intellectual disability by a health professional? Tick all the answers that applies.

Down syndrome Fragile x syndrome Autism Spectrum disorder

Apert syndrome Williams syndrome Fragile x syndrome

Prader-Willi syndrome Phenylketonouria (PKU) Cerebral palsy

Fetal alcohol syndrome/FASDs

Don't Know/Not sure

Other (please specify): _____

27. How would you classify the severity of your child's disability based on his/her ability to perform personal day-to-day activities and to participate in social activities?

Mild disability (Child can regularly participate in activities)

Moderate disability (Child can regularly participate in daily activities and social activities with training or with assistive devices or without any environmental barriers)

Severe disability (Child needs continuous support to perform daily activities)

Profound disability (Child has difficulty performing daily activities even with continuous support)

28. Has your child's disability been more severe than before?

Yes No

1. If yes, how long has the child's condition been severe?

29. Has your child's disability been better than before?

Yes No

1. If yes, how long has the child's condition been better?

30. Has your child with an intellectual disability been given any additional disability, health or behavioral diagnoses by a health or other professional? Please tick all that apply.

Attention deficit hyperactivity disorder/ADHD Autism spectrum disorder

Emotional or behavioral disorder Developmental delay/early childhood disability

disorder Hearing impairment including deafness

Vision impairment including blindness Learning disability

Physical disability Speech or language impairment Traumatic brain injury

Other disability (please specify): _____

Other health challenge or impairment (please specify): _____

No specific diagnosis

31. Does your child have a disability identity card from the government?

Yes No (go directly to section C)

I don't know (go directly to section C)

If yes, please specify the type/color of the card: _____

32. Does your child receive any government benefits as a disability identity card holder?

Yes No (*go directly to section C*)

33. Which of the following benefits does the child receive from his/her disability identity card?

Monetary benefit Free health services Free public transportation

Free education All of the above None

Others (please specify): _____

SECTION C: INFORMATION ABOUT YOUR HEALTH, FEELINGS, AND THOUGHTS

Daily caregiving for a child with an intellectual disability can affect the physical and emotional health of the caregiver. In this section, we ask you about some of your feelings and thoughts.

C1. Information about your feelings and thoughts

34. These questions are about your feelings and thoughts in the last two weeks. Please tick the appropriate box [✓] for you. Checking the first box means you have felt nothing at all whereas the last box means you have felt it extremely.

		Not at all	Slightly	A good deal	Extremely
	In the last two weeks, how often have you felt or thought:				
C1	Suddenly scared for no reason	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C2	Feeling fearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C3	Faintness, dizziness, or weakness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C4	Nervousness or shakiness inside	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C5	Heart pounding or racing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Not at all	Slightly	A good deal	Extremely
In the last two weeks, how often have you felt or thought:					
C6	Trembling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C7	Feeling tense or keyed up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C8	Headaches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C9	Spell of terror or panic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C10	Feeling restless or can't sit still	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C11	Feeling low in energy, slowed down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C12	Blaming yourself for things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C13	Crying easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C14	Loss of sexual interest or pleasure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C15	Poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>					
C16	Difficulty falling asleep, staying asleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C17	Feeling hopeless about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C18	Feeling blue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C19	Feeling lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C20	Thought of ending your life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C21	Feeling of being trapped or caught	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not at all	Slightly	A good deal	Extremely
In the last two weeks, how often have you felt or thought:				
C22 Worrying too much about things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C23 Feeling no interest in things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C24 Feeling everything is an effort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C25 Feeling of worthlessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. For the next set of questions, please indicate how often you felt or thought a certain way in the last two weeks by ticking the most accurate box:

0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Fairly Often; 4 = Very Often

	Never	Almost Never	Sometimes	Fairly often	Very often
In the last 4 weeks/1 month	0	1	2	3	4
C26 how often have you been upset because of something that happened unexpectedly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C27 how often have you felt that you were unable to control the important things in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C28 how often have you felt nervous and “stressed”?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C29 how often have you felt confident about your ability to handle your personal problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C30 how often have you felt that things were going your way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C31 how often have you found that you could not cope with all the things that you had to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C32 how often have you been able to control irritations in your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Almost Never	Sometimes	Fairly often	Very often
	0	1	2	3	4
In the last 4 weeks/1 month					
C33 how often have you felt that you were on top of things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C34 how often have you been angered because of things that were outside of your control?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C35 how often have you felt difficulties were piling up so high that you could not overcome them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C 1.2. General information about your health

Here, we would like to know about your personal health. Please fill in the correct answers by marking with a tick [✓].

36. Do you have any of the below health problem/s that you are being treated for or for which you are taking medication?

- High blood pressure Cardiac problems Diabetes
 Lung disease Cancer Physical discomfort Disturbed sleep/sleeplessness
 Emotional discomfort or distress (stress, anxious, depression)
 None Other (please specify):

37. Please provide information regarding your use of medicine during the past year by putting a tick [✓] on the appropriate box

In the last year, how often have you used:	Never	Occasionally	Short period	Long period	Always
Sleeping tablet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain killers tablets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Calming medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Medicine for depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other medicine for psychological problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION D: INFORMATION ON HOW YOU FEEL ABOUT YOUR LIFE TOGETHER

Now some final few questions about how you feel about your life together as a family. Your answers to these questions will help us to better understand the quality of life of your family as a unit.

38. Please place a tick [✓] on the most accurate answer for you. The answers to the questions are about how satisfied you are with the given statement in the table are below. The first square means you are very dissatisfied, and the last square means you are very satisfied.

		Very dissatisfied	Dissatisfied	Neither	Satisfied	Very satisfied
D1	My family enjoys spending time together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D2	My family members help the children learn to be independent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D3	My family has the support we need to relieve stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D4	My family members have friends or others who provide support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D5	My family members help the children with schoolwork and activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D6	My family members have transportation to get to the places they need to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D7	My family members talk openly with each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Very dissatisfied	Dissatisfied	Neither	Satisfied	Very satisfied
D8	My family members teach children how to get along with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D9	My family members have some time to pursue our own interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D10	Our family solves problem together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D11	My family members support each other to accomplish goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D12	My family members show that they love and care for each other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D13	My family has outside help available to us to take care of special needs of all family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D14	Adults in our family teach the children to make good decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D15	My family gets medical care when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D16	My family has a way to take care of our expenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D17	Adults in my family know other people in the children's lives (friends, teachers etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D18	My family is able to handle life's ups and downs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D19	Adults in my family have time to take care of the individual needs of every child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D20	My family gets dental care when needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D21	My family feels safe at home, work school, and in our neighborhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D22	My family member with a disability has support to accomplish goals at the school or at workplace	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D23	My family member with disability has support to accomplish goals at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Very dissatisfied	Dissatisfied	Neither	Satisfied	Very satisfied
D24	My family member with a disability has the support to make friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D25	My family has the good relationship with the service providers who provide services and support to our family member with a disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. In general, would you say your health is:

Excellent Very good Fair Poor

40. Is there anything else you would like to tell us or anything that you feel our questions have not addressed (for instance, experiences regarding caring for your child, or your own health, or about the child and his/her health, or your own feelings and thoughts)? Please feel free to add comments and to use the other pages too.

C.2 Informed Consent

Invitation to Participate in a Research Project

PREVALENCE OF AND FACTORS ASSOCIATED WITH MENTAL DISTRESS AMONG PRIMARY CAREGIVERS OF CHILDREN NEURODEVELOPMENTAL DISABILITIES IN NEPAL

You are invited to participate in a research project which aims to find the prevalence and factors associated with the mental health of family caregivers of children with neurodevelopmental disabilities in Nepal. To achieve this goal, the research team is working closely with the daycare centres for children with neurodevelopmental disability inside the Kathmandu Valley.

Participating in this project is voluntary. We want to inform you about what participation would mean for you before you decide if you want to participate. Please take the time to read the information in this document carefully before making your decision about participating in this study. You are welcome to contact us if anything is unclear in this document, or if you would like any additional information about the project.

What is the project about?

The purpose of this project is to estimate the prevalence of anxiety, depression, stress, and family quality of life of caregivers of children with disabilities in urban and rural areas of the Kathmandu Valley in Nepal. We will explore the factors associated with an increased risk of mental distress and perceived family quality of life.

All the caregivers who agree to participate in the project will be asked to complete a questionnaire. The questionnaire will include questions about how your mental health has been affected after becoming a caregiver, how satisfied you are with different aspects of family quality of life, some specific information about you and your child's background, such as your address and health conditions. We expect the questionnaire will take approximately 20 minutes to complete, but you can spend as much time as you need on it. Choosing to participate in the study will not change your health care in any way.

Apart from the information you provide by completing the questionnaire, the project will not collect any more personal information about you.

Possible benefits and predictable risks/burden of taking part in the project

The project has no direct benefits for you as a participant, but we hope the study will help us learn from your experiences of caregiving for a child/children with intellectual disability. This will benefit the scientific community and stakeholders, such as government officials and non-profit organizations, to better understand the situation and ideally take actions to improve the quality of life of caregivers in similar situations to you.

However, we expect that some participants may relive potentially distressing past experiences which could cause some discomfort or anxiety. If any participant is upset or distressed, the researcher will stop the study, and can also offer to refer participants to counselling services if they want to talk to someone with relevant professional training.

Voluntary participation and the possibility to withdraw consent

Participation in the project is voluntary. If you wish to take part, you will need to sign the declaration of consent on the last page. You can, at any given time and without reason withdraw your consent.

If you decide to withdraw participation in the project, you can demand that personal data concerning health be deleted, unless however, the personal data concerning health have already been analysed or used in scientific publications. If you at a later point, wish to withdraw consent or have questions regarding the project, you can contact Susan Sitoula (telephone: +9779823662653, email: susansitoula1@gmail.com).

What will happen to your information?

Any personal data concerning health that has been recorded about you will only be used as described in the purpose of the project. You have the right to access information that has been recorded about you and the right to stipulate that any error(s) in the information that is recorded is/are corrected. You also have the right to know which security measures have been/will be taken when your personal data concerning health is processed.

All information will be processed and used without your name or personal identification number, or any other information that is directly identifiable to you. A code links you and your personal data concerning health via an identifier list. Only Susan Sitoula (primary researcher), Gørill Haugen (project supervisor), Jennifer Infanti (project co-supervisor), and Samita Giri (project co-supervisor) will have access to this list.

Information about you will be anonymised or deleted five years after the project has ended.

Sharing of personal data and transfer of personal data abroad

By agreeing to participate in the study, you are also consenting to that your data from the questionnaire can be transferred to another country as a part of research collaboration and publication. In Nepal, your data will be stored on an encrypted USB drive accessible only to the student researcher and will not be disclosed to anyone. The drive will be password protected and stored in a locked location at the researcher's residence. After completion of data collection, the USB drive will be taken from Nepal to NTNU, Norway by Ms. Susan Sitoula for data analysis. It will be therefore ensured that your answers for the questionnaire will be kept safe.

The code that connects you and your personal data concerning health will not be released.

Finance

This project is funded by the Global Health department in Health and Nursing Department of NTNU. Participants will not receive any financial support to participate in this project.

Approval

The Regional Committee for Medical and Health Research Ethics has reviewed and approved the Research Project 134579 REK sør-øst A.

In accordance with the General Data Protection Regulation the controller Norwegian University of Science and Technology (NTNU), and the project manager Susan Sitoula, are independently responsible to ensure that the processing of your personal data concerning health has a legal basis. This project has legal basis in accordance with the EUs General Data Protection Regulation, article 6 no. 1a, article 9 no. 2a and your consent.

You have the right to submit a complaint on the processing of your personal health data concerning health to the Norwegian Data Inspectorate.

Contact Information

If you have any questions regarding the research project, you can get in touch with:

- Susan Sitoula, Primary researcher, Phone number +977 9823662653, +47 96756231, susansitoula1@gmail.com
- Gørill Haugen, Project co-supervisor, Phone number +477341258, gorill.haugen@ntnu.no
- Jennifer Infanti, Project supervisor, Phone number +47 73598782, jennifer.infanti@ntnu.no
- Samita Giri, Project co-supervisor, Phone number +47 47740102, samita.giri@ntnu.no

I consent to participating in the research project and that my personal data concerning health can be used as described above

City/Town and date

Participant's Signature

Participant's Name (in BLOCK LETTERS)

Consent on behalf of a representative

As next of kin for _____ (Full name) I hereby consent to that he/she can participate in the research project.

Place and date

Next of kin signature

Next of kin name (IN BLOCK LETTERS)

I confirm that I have given information about the research project.

Place and date

Signature

Role in the research project

