

# Stress Levels and Coping Strategies of Families of Adults With Intellectual Disability and Challenging Behaviours During the COVID-19 Pandemic in Qatar

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**Abstract**

This study investigated the perceived stress levels and coping strategies of caregivers of adults with intellectual disability and challenging behaviours during the COVID-19 pandemic in Qatar. A cross-sectional survey was conducted from June 7 to September 7, 2020 for caregivers of adults diagnosed with intellectual disability and challenging behaviours. Perceived stress levels and coping strategies were assessed using the Perceived Stress Scale and Brief Coping Orientation to Problems Experienced inventory. Results showed moderate to high perceived stress levels in most caregivers (69%). The most frequent coping strategy was religion, followed by acceptance and active coping. Substance use and self-blame were less frequently used. The study revealed that emotional support, informational support and venting coping strategies were significant predictors of perceived stress levels. Restrictions on physical activity and social mobility caused by pandemic-related lockdowns have placed tremendous pressure on caregivers. Appropriate supportive measures should be implemented for the caregivers.

**Keywords**

caregiver, coping strategies, COVID-19, intellectual disability, perceived stress

**Introduction**

It is commonly recognised that caregivers of individuals with intellectual disability are at greater risk of developing mental health issues than caregivers of typically developing children (Singer & Floyd, 2006). Studies have demonstrated that the pressure associated with caring for adult sons or daughters with disabilities are cumulative (Patrick & Hayden, 1999).

The measures used to control the coronavirus disease 2019 (COVID-19) pandemic may increase the necessity for care for people with intellectual disabilities, increasing stress levels and leading to burnout (Panicker & Ramesh, 2019; Patton et al., 2018; Rose, 2011; Willner & Goldstein, 2001). During pandemic-related lockdowns, caregivers have faced increased challenges due to limited access to professional help, leading to a dilution of social supports (Mind Organisation, 2020).

People with intellectual disability are at particular risk during the COVID-19 pandemic because of multiple comorbidities arising from their mental and physical health (Cuypers et al., 2020; Turk et al., 2020). In addition, the social-distancing measures and movement restrictions used to curb the pandemic are known to affect mental health (Brooks et al., 2020; Torales et al., 2020). This, in turn, puts increased care demands on caregivers who are already facing pandemic-related worries and logistical challenges (Alexander et al., 2020).

Adults with intellectual disability and challenging behaviours in Qatar access their main health providers through the Mental Health Service of Hamad Medical Corporation (HMC) and its newly launched intellectual disability team. Unfortunately, pandemic response measures have reallocated many staff nurses to front-line emergency services and have limited access to regular clinics and outreach services. Therefore, individuals with intellectual disability and challenging behaviours have been more likely to remain at home under the care of their own families or other caregivers and receiving phone call consultations when needed. Challenging behaviour definition, as proposed by Emmerson, is widely used in clinical practice and research and includes behaviours with sufficient intensity, frequency or duration that is likely to place the physical safety of the person and/or others in serious jeopardy or is likely to seriously limit or delay access to and use of ordinary community facilities (Emerson et al., 1988).

This study's primary goal was to assess the stress levels in families of adults with intellectual disability and challenging behaviours during the period of total lockdown due to the COVID-19 pandemic in the state of Qatar as well as to evaluate common coping strategies used by these families to manage the pressures of complying with quarantine restrictions. Stress is an adaptive psychophysiological response to a physical, social or psychological stimulus called a stressor (McEwen, 2017). The COVID-19 outbreak can certainly be considered a serious stressor as it is a unique and unforeseen situation with potentially serious health effects (Huremovi'c, 2019).

To our knowledge, this is the first study to investigate caregiver stress in this region, and we believe that the characterisation of coping strategies in this population will help guide future public health mitigation strategies.

## **Material and methods**

A cross-sectional survey was conducted between June 7 and September 7, 2020, at the peak of the COVID-19 pandemic in Qatar.

### *Participants*

The database for the Mental Health and Intellectual Disability service of HMC was reviewed to identify all adults with intellectual disability and coexisting challenging behaviours. A total of 277 adults diagnosed with intellectual disability were identified through this database search. Subsequently, 120 candidates were selected based on documented diagnoses of both intellectual disability and challenging behaviours. All caregivers of these 120 patients were contacted for enrolment in the study. Non-responders or those who did not choose to participate (20 caregivers) were excluded. The resulting 100 caregivers who provided consent and completed the questionnaires were included. Therefore, the response rate was 83.3% of the total sample. Each caregiver answered the questionnaires only once to avoid duplication. The callers were two doctors and two senior nurses. Gender: two males and two females and they called roughly equal number of respondents. They underwent training together to use a consistent interview. The four callers worked in the hospital but did not have direct clinical working contact with the cases selected to ensure that their previous knowledge did not influence the interview.

### *Ethical statement*

This study obtained ethical approval from the Medical Research Centre (MRC) at HMC (approval number: MRC 01 20 777). All procedures involved in this study complied with the relevant national and institutional committees' ethical standards on human experimentation and the Helsinki Declaration of 1975, as revised in 2008.

### *Informed consent*

Participation in this study was voluntary, and anonymity was assured. All participants provided written informed consent.

## Measures

This study involved responding to several survey questionnaires administered over the telephone by callers trained together to standardise data collection. The questionnaires were available in both English and Arabic, and the callers were able to speak both languages.

*Brief coping orientation to problems experienced inventory (Brief-COPE).* The Brief-COPE is a 28-item, self-reported questionnaire designed to measure efficient and inefficient strategies of coping with stressful life events. The scale is also used to measure how people deal with various adversities, including a cancer diagnosis, cardiac disease, accidents, natural disasters and financial stress. This scale can distinguish between approach and avoidance coping styles as the primary coping style. The following subscales are included in the Brief-COPE inventory: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame (Carver et al., 1989 – Brief-COPE, Carver, C. S. (1997). Validated Arabic version is also used (Alghamdi, 2020).

*Perceived stress scale (PSS).* The PSS is a classic stress assessment instrument (Cohen et al., 1983). Individual scores on the PSS range from 0 to 40, with higher scores indicating higher perceived stress. (Kelly and Percival, 2010) Validated Arabic version is also used (Chaaya et al., 2010)

## Sociodemographic questionnaire

A sociodemographic questionnaire was used to record the age, gender, marital status, employment status, educational level and availability of social supports of caregivers, as well as the number of adults with intellectual disability at home, the caregiver's relationship with the adult with intellectual disability and the number of services attended by the adult with intellectual disability before the pandemic. This information was gathered to contextualise the data and to examine socio-demographic correlates of stress and coping.

## Statistical analysis

Data analysis was conducted using IBM SPSS 22.0 (IBM Corp., USA). Descriptive analyses were used to describe sociodemographic information, disability-related variables, perceived stress levels and coping styles. Results are presented as means with standard deviations (SD) for normally distributed data. For categorical data, results are presented as frequencies with percentages (%). Independent *t*-tests were used to compare mean perceived stress scores between variables with two groups, such as gender. Pearson's correlation or Spearman's correlation analyses were used to describe associations between total perceived stress scores, independent numerical variables and Brief-COPE subscales.

Multiple linear regression analysis was performed to determine the predictors of perceived stress. Clinically relevant variables with *p*-values less than 0.05 in the univariable analysis were included in the variable selection method of the multiple linear regression analysis. The significance level was set at two-tailed. The scales were assessed for internal reliability using Cronbach's alpha

**Table 1.** Sociodemographic Characteristics of Caregivers.

Variables		Percentage, %
Gender	Men	48
	Women	52
Age group	18–49	37
	50 and above	63
Marital status	Divorced	5
	Married	84
	Single	6
	Widowed	5
Employment status	Employed	48
	Unemployed	52
Educational level	No formal education	8
	Primary/secondary	41
	2-year college level course	14
	University and above	37
Relationship to the ID relative	Father	42
	Mother	38
	Sibling	20
Level of ID severity	Mild	22
	Moderate	43
	Severe	35
Autism spectrum disorder	Yes	44
Chronic illness among caregiver	Yes	37
Availability of social support	Yes	41
Number intellectual disability cases in family	More than one	10
	One	90
Number of ID services attended before the pandemic	1 service	73.0
	2 services	12.0

## Results

### *Profiles of caregivers of adults with intellectual disability and challenging behaviours*

Most participants were the biological parents of the ill relative (78%) and were married (84%), with 48% of caregivers were employed. More than a third of caregivers had received higher education (37%). Sociodemographic data and psychiatric characteristics related to caregivers are presented in [Table 1](#).

In this study, 10% of caregivers indicated that they had more than one child with intellectual disability, and 37% of caregivers reported having a chronic illness, such as diabetes mellitus, hypertension or heart disease. In terms of the intellectual disability level, most of the caregivers (65%) were caring for adults with mild to moderate intellectual disability, while the remaining (35%) were responsible for adults with severe intellectual disability. [Table 1](#) also presents the health characteristics of adults with intellectual disability and challenging behaviours, as well as their caregivers.

**Table 2.** Brief-COPE and Perceived Stress Scale.

	Mean	Standard Deviation
Total score on the Perceived Stress Scale	16.70	6.24
<b>Brief-COPE</b>		
Behavioural disengagement	2.82	1.32
Denial	2.69	1.31
Self-distraction	4.91	1.61
Self-blame	2.73	1.20
Substance use	2.07	0.41
Venting	3.30	1.31
<b>Avoidant subscale</b>	<b>18.52</b>	<b>3.98</b>
Active coping	5.63	1.51
Acceptance	6.19	1.35
Emotional support	4.93	1.91
Informational support	4.38	1.79
Planning	5.00	1.73
Positive reframing	4.98	1.66
<b>Approach subscale</b>	<b>31.11</b>	<b>6.36</b>
Religion	6.72	1.35
Humour	2.99	1.42

Brief-COPE, Brief Coping Orientation to Problems Experienced inventory.

### *Perceived stress and coping styles of caregivers*

The mean PSS-10 score for all 100 caregivers was 16.7 (SD = 6.24), with a minimum score of 0 and a maximum score of 33. According to the PSS-10 scoring system, the mean total perceived stress score of these caregivers was considered slightly higher than average, and the health concern level was high (total scores ranging from 0 to 40). Only 31% of the sample had a low stress level while 61% had moderate and 8% high perceived stress. Hence, 69% of our sample had moderate to high perceived stress.

The most frequently used coping style was religion (mean = 6.72, SD = 1.35), followed by acceptance (mean = 6.19, SD = 1.35) and active coping (mean = 5.63, SD = 1.51). Substance use (mean = 2.07, SD = 0.41) and self-blame (mean = 2.73, SD = 1.20) were less frequently used by caregivers. Table 2 presents descriptive statistics of perceived stress and coping styles of the caregivers.

### *Associations between perceived stress and sociodemographic variables*

*T*-tests were conducted to identify significant differences in sociodemographic variables between groups. There were no significant differences on pre-exiting medical conditions and availability of social support or use of services on the perceived stress of the caregivers. There were no significant differences in total PSS scores between men and women ( $p > 0.05$ ) or between those who were married and those who were single/divorced/widowed.

**Table 3.** Multiple Regression Analysis of Correlations between Coping Styles and Perceived Stress Levels in Caregivers of Adults with ID.

Coefficients <sup>a</sup>	Standardised Coefficients	
	Beta	p-Value
Self-distraction	0.02	0.823
Active coping	-0.13	0.273
Denial	0.02	0.862
Substance use	-0.17	0.104
Emotional support	-0.35*	0.006
Informational support	0.26*	0.028
Behavioural disengagement	-0.11	0.296
Venting	0.32*	0.006
Positive reframing	0.03	0.829
Planning	0.12	0.372
Humour	0.23	0.054
Acceptance	-0.18	0.093
Religion	0.08	0.426
Self-blame	-0.03	0.766

\* $p < .05$ .

### Reliability analysis

The psychometrics of the utilised scales were good. The PSS had a Cronbach's alpha value of 0.83. For the Brief-COPE, the approach subscale had a Cronbach's alpha value of 0.78, and the avoidant subscale had a 0.59 score for reliability.

### Bivariate correlations between the PSS and Brief-COPE

Religion and an approach coping style ( $r = 0.32, p < 0.05$ ) and avoidant and approach coping styles ( $r = 0.43, p < 0.05$ ) were significantly correlated. Pearson's correlation showed that humour and the PSS score were significantly correlated ( $r = 0.28, p < 0.05$ ). Neither approach nor avoidant coping styles showed significant correlations with the PSS score ( $p > 0.05$ ). The PSS score was, however, correlated with venting ( $r = 0.27, p < 0.05$ ). For the approach coping style, the educational level was significant ( $p < 0.05$ ), with post-hoc testing showing that those with a university or higher education level were significantly more likely to use this style than caregivers without a formal education ( $p < 0.05$ ).

### Predictors of perceived stress

Since no sociodemographic variables were significantly correlated with caregiver PSS scores, we opted not to include them in the multivariate analysis. Multiple linear regression analysis, with coping styles as an independent variable and PSS as a dependent variable, showed that the model was significant ( $F = 2.53, p < 0.05$ ). The variance explained ( $R^2$ ) was 29.5% of the total variance in the PSS scale. The analyses revealed that emotional support, informational support and venting

coping strategies were significant predictors of perceived stress levels. Table 3 presents the results of the final regression analysis.

The final regression model showed that the perceived stress level was best predicted by low emotional support ( $\beta = -0.35, p 0.006$ ). The results also indicated that caregivers with higher use of informational supports and venting had increased perceived stress levels ( $p < 0.05$ ).

## Discussion

Our study showed that caregivers of individuals with intellectual disability and challenging behaviours experienced moderate to high stress levels during the COVID-19 pandemic in Qatar. Our findings mirror those of previous studies, which have found that caregivers are under considerable stress (Dabrowska & Pisula, 2010; Merkaj et al., 2013). In turn, these high levels of stress have been suggested to increase caregiver susceptibility to illness and to affect the adaptability required while caring for an adult with intellectual disability (Kline, 2014; Rao & Beidel, 2009). However, when comparing the mean of this sample on PSS-10 scale with samples from previous studies, we found that it is slightly lower than scores in caregivers of patients with Alzheimer's disease (Rusowics, 2021), schizophrenia, bipolar, major depressive disorder and anxiety disorder (Masa'Deh 2017). Hence, the caregivers in this study had used coping strategies to reduce their perceived stress. Since the pandemic has increased stress levels in the general population (Xiong et al., 2020), we hypothesised that caregivers of adults with intellectual disability and challenging behaviours experienced even higher stress levels due to the increased care needs created by caregiving during lockdowns.

The population surveyed in this study consisted of caregivers of adults with a wide spectrum of intellectual disability severity, ranging from mild to more severe. It is noteworthy that many of the adults with intellectual disability were considered to have a moderate disability, and all had associated challenging behaviours, with 43% experiencing referral to mental health services in Qatar according to the ID team database. A diagnosis of autism spectrum disorder was also overrepresented in this population, possibly because these patients tend to exhibit more challenging behaviours. Many of the adults in this study had attended at least one service before the pandemic; however, there were no significant differences identified in the stress levels of those who had attended one or more services during the pandemic as all services had been stopped during the lockdown.

Caregivers experiencing moderate to high stress levels and those experiencing low stress levels were similar in their sociodemographic characteristics. A small number of caregivers had chronic health conditions, which did not significantly affect their perceived stress levels. We also found that neither gender nor marital status was associated with a caregiver's perceived stress levels in the home setting. In fact, our study showed no significant associations between any of the sociodemographic variables and the perceived stress levels of caregivers.

Furthermore, there were no significant differences in perceived stress levels based on whether the adults with intellectual disability had comorbid autism spectrum disorder or an increased intellectual disability severity. In contrast, other studies have shown positive associations between the number of children with intellectual disability and the levels of stress and anxiety (Bumin et al., 2008; Dabrowska & Pisula, 2010), while our data did not show association between number of children with ID and stress level. This could be explained by the small number of families with more than one child with ID enrolled. The present findings, therefore, require further exploration in the context of our society and culture.



Coping strategies are psychological patterns that people use to manage their thoughts, feelings and behaviours when under stress. Avoidant coping styles are used when people avoid thinking, feeling or the actual cause of stress, while approach coping styles are used when people focus on the problem causing stress and actively seeking its management (Roth, S., and Cohen, L. J. 1986)

Caregivers who used humour or venting as coping strategies were more likely to have higher stress levels, while those who used an emotional support coping strategy had lower perceived stress levels. In addition, our results demonstrated that caregivers seeking informational support, such as information from the internet, social media or other resources, had higher stress levels, possibly because they have more exposure to news about the current events. This study showed that most caregivers reported moderate to high stress levels and used a variety of coping strategies, including religion, which was the most common. Other common coping strategies included active coping, planning, acceptance, self-distraction, humour and positive reframing. The least common coping strategy was substance use, possibly for cultural reasons. In addition, denial, self-blame and behavioural disengagement were not commonly used as caregiver coping strategies.

In our study, those who relied on religion as a coping strategy were more likely to use an approach coping style. Furthermore, the approach coping style was used more frequently than the avoidant coping style. Interestingly, the avoidant and approach coping styles were significantly correlated with one another. In other words, caregivers in our study relied on various coping strategies that could not strictly be split into two different styles. Instead, the caregivers used a mix of coping strategies, representing both approach and avoidant styles at the same time. The present study showed that caregivers used several coping strategies concurrently and were most likely to use religion, acceptance and active coping styles in relation to their perceived stress. Although a recent study in Qatar looked at prescription patterns among adults with intellectual disabilities and challenging behaviour (Elhusein et al., 2021), however, this is the first study to examine the perceived stress levels and coping strategies of caregivers of adults with intellectual disability and challenging behaviours in the state of Qatar, there were no similar studies for comparison.

Self-blame and substance use were least commonly seen in our caregivers, possibly due to strong religious convictions and social values. Unfortunately, the present research did not look at all the potential factors that may have led to coping strategy choices. This study found three significant predictors of perceived stress levels in caregivers of adults with intellectual disability and challenging behaviour. The results of multiple linear regression analysis revealed that emotional support, informational support and venting coping strategies were significant predictors of perceived stress levels.

Caregivers who used emotional support and religion coping strategies more often displayed lower levels of stress, which was expected. Previous studies have shown that negative effects on the mental health of parents are minimised when they receive more supportive reinforcement from family members (Ha et al., 2011). People may also turn to religion because it can serve as a source of emotional support, as well as a vessel for positive reinterpretation, development and a technique to actively cope with a stressor (Carver et al., 1989). Moreover, religion plays an integral part in the local culture in Qatar, and the support provided to a disabled child is considered to be a part of a caregiver's religious beliefs and represents a way to foster family bonds and show loyalty and dedication to religion and God. All adults with intellectual disability in this study lived at home with their families and were cared for by a family member, even when their parents had died. The main caregiver was, therefore, a family member, which is consistent with the local society's cultures and values.

### **Limitations**

There were some shortcomings in this study that should be addressed. First, although the study included a considerable number of caregivers, they were only recruited from a list of adults with intellectual disability registered with the Mental Health Service at HMC, which is the primary mental health provider in the state of Qatar. However, caregivers of patients who were being followed within the private sector were not included, limiting the generalisability of this study. We also did not include caregivers of adults with intellectual disability and other mental health diagnoses for comparison with caregivers of adults with intellectual disability and challenging behaviours. However, regardless of the presence of other diagnoses, the COVID-19 pandemic and the quarantine situation are likely to have significantly increased the level of care required for ID relatives, as well as the impact on caregivers. Our study response rate was high (80%), but we did not have data on the remaining 20% to compare and this could be considered a limitation.

It would be reasonable for future work to involve a broader range of participants for improved external validity. Future studies should also consider other variables, evaluating the level of care necessary for carers, financial pressure and employment stability.

### **Conclusions**

The COVID-19 pandemic and its associated quarantine restrictions have placed considerable stress on the caregivers of individuals with intellectual disability and challenging behaviours in Qatar. This study found that caregivers used coping styles related to their cultural beliefs and available resources. Healthcare authorities need to be aware that this pandemic-related stress affects not only individuals with intellectual disability but also adversely affects the mental health and well-being of their caregivers. Support for these caregivers during this highly stressful time is needed. Based on the relevant coping strategies, easy access to professionals and information may help improve coping.

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### **Author contributions**

M.E. is the principle investigator who designed the study and participated in manuscript writing, data analysis and literature review. B.E. performed the literature review, results analysis and manuscript writing. HE-HB and S.A. performed data collection and literature review. H.R. performed the literature review and participated in manuscript writing. S.R. contributed to data analysis, interpretation of the results and manuscript writing. M.A. performed the literature review and contributed in writing the manuscript and final approval of the article.

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