



Impact of COVID-19 on Mental Health of Adults with Autism in India- A case series

Abstract:

Background:

This study focuses on the direct and indirect implications of the COVID-19 pandemic on adults with Autism in India. This study took into account the social isolation during the global pandemic in 2020 and its effect on the emotional well-being of the community.

Methods:

We designed a survey involving Indian residents. Part I involved questionnaires for different cohorts: 1) educated, 2) employed and 3) unemployed. The questions were based on proposed life models to maintain the heterogeneity according to the preferences of the target group. Part II of involved online interviews conducted in English. Qualitative and quantitative analyses were performed.

Findings:

The analyses of participants' responses (N=10) stipulated that the impact of the COVID-19 pandemic on autistic people's mental health has been variable. Participants encountered both positive and negative emotions. Factors such as disrupted schedules, fear of job loss, poor domestic support system and inconsistency in transition were important. These were associated with development of new or worsening of pre-existing psychological as well as behavioural conditions including depression, anxiety, panic attacks and high-stress levels. At the same time, reduced interactions with decreased social insistence led to an improvement for some participants.

Interpretation:

Our results illustrate the deterioration of mental health and well-being for Autistic adults due to the impact of the COVID-19 pandemic. These findings emphasise the need for the development of innovative approaches and investment in the creation of support systems to address mental distress in this population.

Keywords: Coronavirus, COVID-19, Autism spectrum disorder, Neuropsychiatric presentations, Mental Health, India

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1. Introduction:

In the last two decades, several viral epidemics such as the severe acute respiratory syndrome coronavirus (SARS-CoV-1) from 2002 to 2003, and H1N1 influenza in 2009, have been recorded (1). Since December 2019 the entire world has been affected by the SARS-CoV-2 infection that emerged in Wuhan, China, leading to huge afflictions on health and lives. To date (May 22nd, 2021), the total number of confirmed cases is more than 166 million, and the number of deaths ascribed to the disease is more than 3 million (2).

Various studies have reported an increase in psychological distress and most relevant psychological presentations as uncertainties and fears (3), pervasive anxiety (4), and disabling loneliness (5). Long-term isolation/quarantine, with mass lockdowns and economic recession, is predicted to lead to increases in suicide as well as mental health conditions (6). Studies have also correlated the positive rate of incidence of restrictions on movement, inconvenient routine screening, and medical treatments with high rates of depression and anxiety (7). Not just the general population but also healthcare professionals and front-line workers have been displaying a higher risk of mental health problems due to work under extreme pressure to diagnose, treat, and care for COVID-19 patients (8).

While this pandemic has affected all groups of people in society, little has been done to highlight the disproportionate vulnerabilities of certain groups especially people with neurodevelopmental conditions like autism spectrum disorder (ASD) (9). The term includes Autism, Pervasive Developmental Disorder (PDD), and Asperger's syndrome which have been characterised as displaying social and communication awkwardness with barriers and/or repetitive sensory-motor behaviours (10).

For individuals with Autism, the published data suggests amplification of mental health changes like depression, personality change (11), abnormal behaviour (12), symptoms of post-traumatic stress disorder (13), post-intensive care syndrome (PICS) (14). These changes are attributed to the classic characteristics of the syndrome i.e., inflexibility, insistence on sameness, and loathe change (15). Despite a large Indian population being affected by Autism, little data is available on mental health exacerbations due to COVID-19 in the population having autism.

Additionally, India is one of the largest exceptions to the list of countries that lacks an estimate of autism prevalence and there exists a massive underreporting of this disorder among both adults and children (16). Only small-scale studies involving local hospital settings have been reported which estimate the prevalence of autism spectrum disorders, varying widely from 2.9% to 62.5% (17).

This study aims to analyse the correlation between the development and exacerbation of mental health disorders and COVID-19 in individuals with Autism. These correlations are speculated and associated with COVID-19 due to multifarious factors like limitations in understanding, personal relationships involving resilience and social support, employment/education status, long term isolation/quarantine.

We hypothesize that COVID-19 exacerbated the pre-existing mental health conditions or resulted in the development of other neuropsychiatric presentations in individuals with Autism. We hope to create awareness amongst the healthcare professionals and policymakers to manage and encompass the needs of individuals with Autism to prevent misdiagnosis, adopt behavioural strategies to reduce the burden, and limit long-term sequelae.

2. Methodology

2.1. Sample

We designed a pan India survey involving only Indian residents. An invitation describing expression of interest with a description of the study was shared on various platforms including universities, organizations, and NGOs requesting to share the description with their contacts. This study was directed towards adults (18+) with ASD living in India during the COVID-19 pandemic. The respondents were from the cities of Mumbai, Kolkata, Bangalore, Delhi, Amritsar, and Ooty. In accordance with the principles of the Declaration of Helsinki, consent was included in the survey and was accompanied by a description of the study describing the aims, methods and other relevant aspects of this study.

2.3. Data collection

The consent for participation in questionnaires, interviews, and recordings was obtained along with assuring them confidentiality. To ensure anonymity the participants were coded as P1-P10. The data collection for the study consisted of two parts. Part I involved independent questionnaires, which were prepared for different cohorts:

1) educated, 2) employed and 3) unemployed.

The questions were based on various proposed life models that can be to maintain the heterogeneity according to the preferences of the target group. Once the questionnaire was deemed appropriate to be used for examination of the quality of life, the final set of questions was finalised (18–21). These questionnaires apart from the participants’ journey since diagnosis, included sections on the impact of the COVID-19 on daily routines, variations between present and pre-COVID mental health with exacerbations if any, social relationships, and the transition to online classes/work-from-home hybrid model. Part II of this study involved extensive online interviews which were conducted in English. Additionally, the audio-recorded interviews were transcribed into electronic format. Qualitative and quantitative analyses were

performed for the assessed variables and divided into profuse segments following the precedence of the study.

2.4. Statistical Analysis

The analyses were conducted using Microsoft Excel 2019 where the quantitative data was presented by frequencies and percentages while qualitative data was presented using inter-rater reliability. We used the critical realism thematic approach to analyse the responses (22). We analysed the content and identified themes across the participants’ responses to broadly organize the causes of exacerbation of mental health presentations. Figure 1 consists of broad themes on how COVID-19 could have exacerbated mental health.

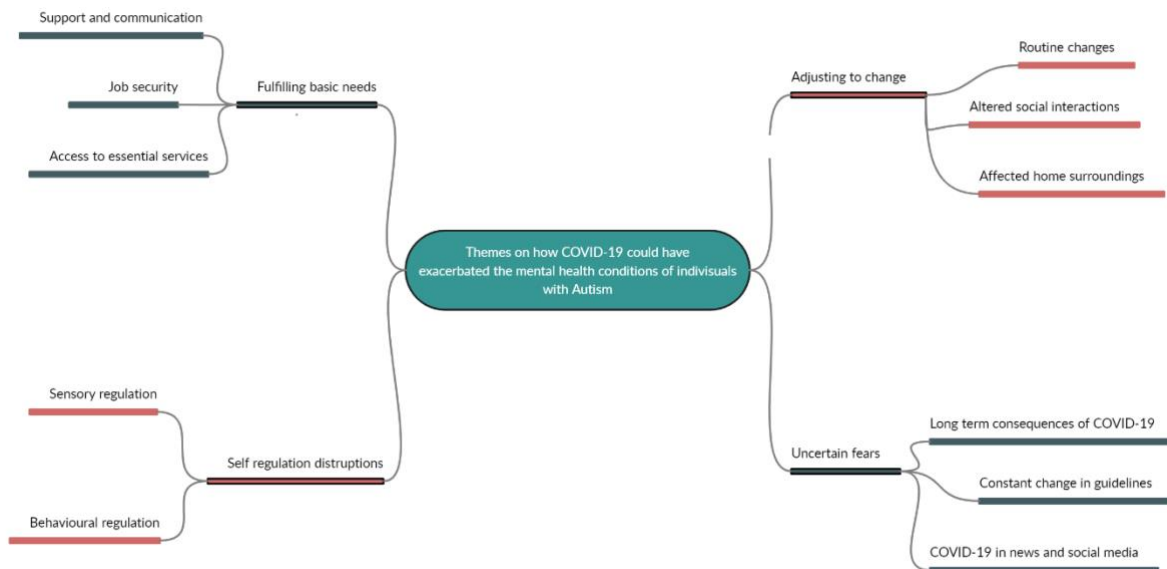


Figure 1: Major factors deduced to exacerbated the mental health condition in our target group.

To minimize the risk of bias and expand the extent of the accurate representation of data we calculated interrater reliability using Cohen’s Kappa Coefficient. The quality of agreement was defined as follows: values ≤ 0 as indicating no agreement and 0.01–0.20 as none to slight, 0.21–0.40 as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement. Perfect agreement (0.81–1.00) was reached for 96.5% of the variables (23). Table 1 consists of categories and percentages of response in addition to interrater reliability.

3.0. Results

All participants reported having received information about the coronavirus, where the sources of information were COVID-19 websites (50%), social media (50%), News Channels (40%), Newspapers (20%), and family and friends (1%). One participant reported refraining from all the news.

A significant number of participants reported a sufficient level of comfort in adhering to lockdown rules (80%) and staying indoors (60%) during the pandemic.

The participants reported experiencing negative emotions: low moods (90%), depression (60%), panic attacks (50%), and overthinking (50%) during the nationwide COVID lockdown.

higher intensity (70% high and 30% medium) of negative emotions.

All candidates reported worsening of mental health in comparison with pre-lockdown states with higher frequency (60% high and 40% medium) and

The reported levels of anxiety at home were: Non-Existent (10%), Low (20%), High (30%), and Unbearable (40%).

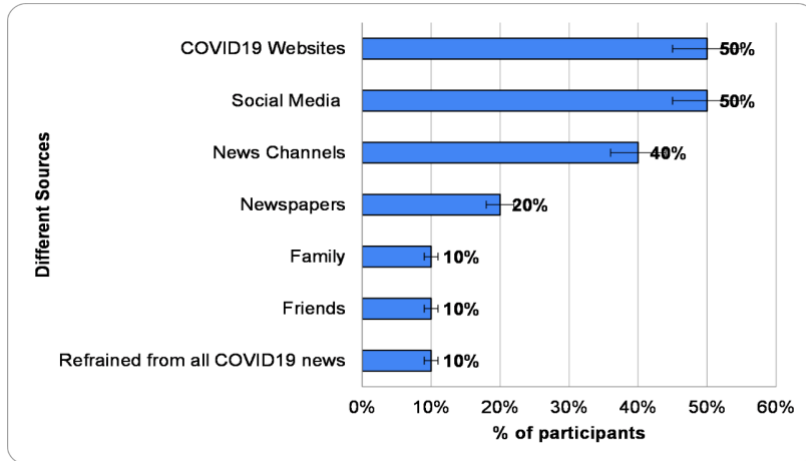


Figure 2: Major sources of information concerning COVID-19 pandemic for the participants

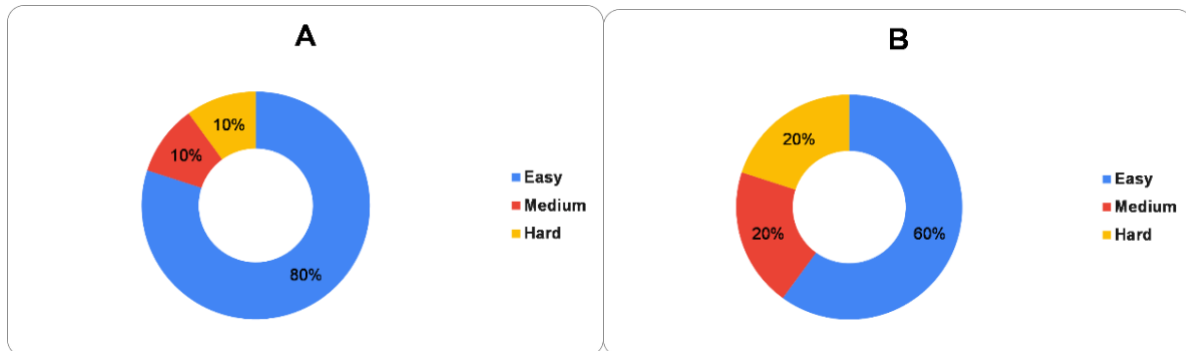


Figure 3: A: Comfort level adhering to lockdown rules, B: Comfort levels staying indoors

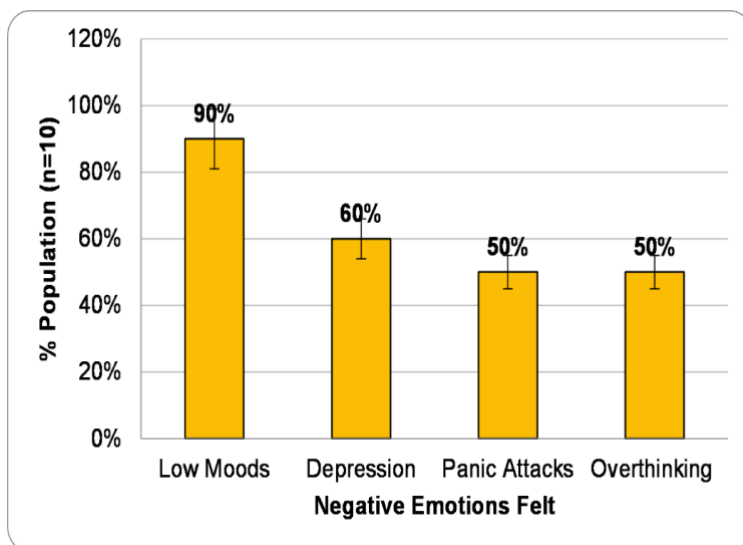


Figure 4: Percentage of participants experiencing negative emotions

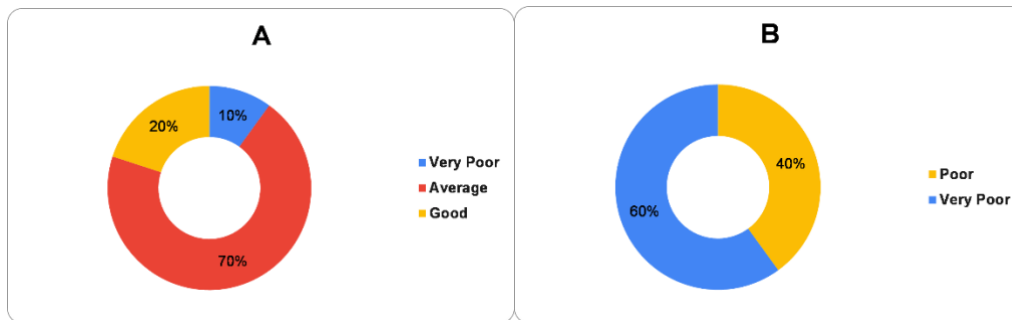


Figure 5: Comparison of mental health. A: Before lockdown, B: After lockdown

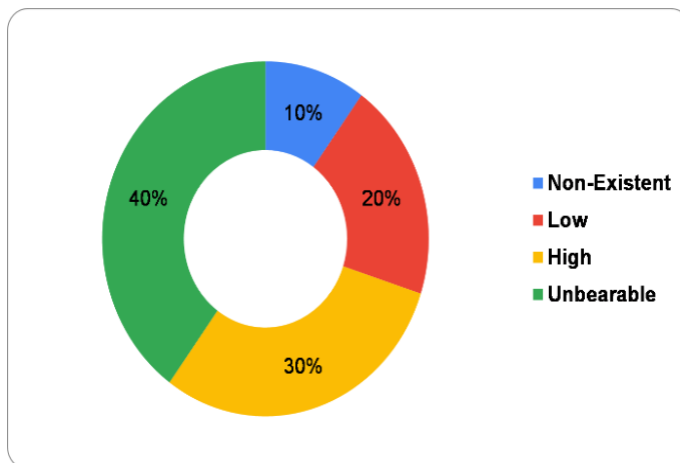


Figure 6: Anxiety levels at home

From the analyses of the responses, the most common factors that were found to affect mental health were: affected social relationships, sensory overload, loud home surroundings. The reported factors to have supported mental health were: discovering their strategies to help them during meltdowns (50%), staying at home with minimal interaction with new people (60%). Participants described how the initial preference to avoid social interactions became difficult after a few months.

P1 reported:

“Initially, I was happy - I didn’t have to talk to new people, so stress decreased. Initially, my mental health was good. Became worse with progressive months. By the third month, I craved human contact. That impacted my mental health negatively.”

50% of the participants were perturbed about loved ones becoming infected with SARS-CoV 2, and how they now had more burden and responsibilities.

P5 reported about supplementary competence:

“Day-care for my son was gone, so added responsibilities, husband is very social so he was losing his mind, we started fighting.”

However, at the same time, more time spent with family was followed by misunderstandings and disagreements: increased time spent together resulted in disagreements and misunderstandings.

For example, P9 reported:

“Misunderstanding with parents, parents’ relationship is fragile, they are not going for divorce, they used to fight a lot, this impacted me, and each other’s anger was put on me.”

Another contributor to the soaring stress levels was unreliability and uncertainty over job security and access to healthcare facilities. Those who were employed (n=7) reported difficulty in transition to work from a home-based setup.

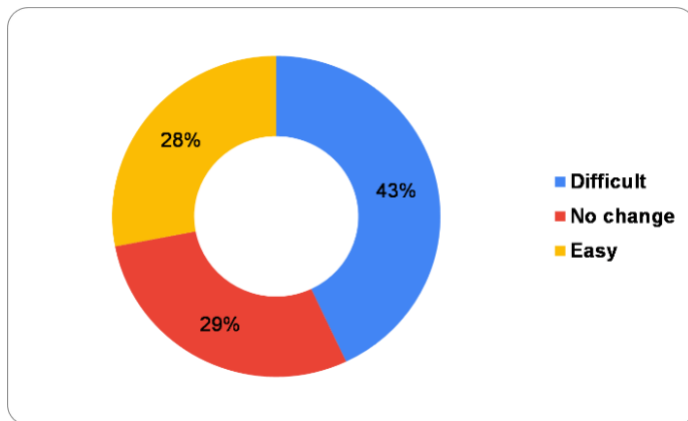


Figure 7: Difficulty in transition to work from home-based setup

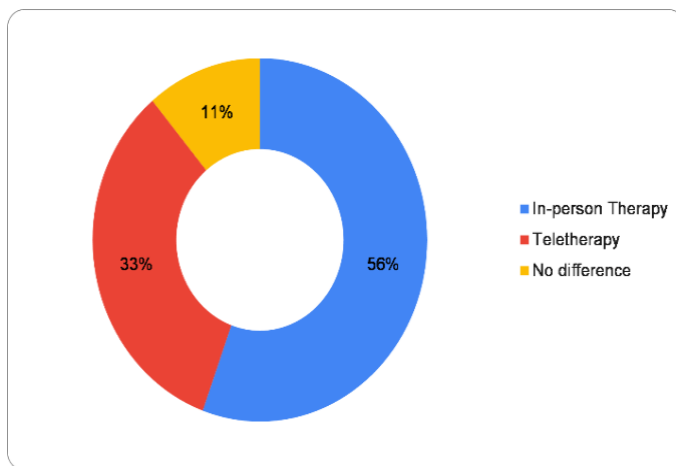


Figure 8: Therapy preference during the pandemic and nationwide lockdown

Additionally, participants devised strategies and ways to help them during meltdowns.

For example, P2 reported about managing the multifaceted stressors of the pandemic: “Set personal boundaries, changed philosophies, morality on certain behaviours, all that shifted in the lockdown, I don’t want to set unrealistic expectations of myself, realistic expectations from myself, Learnt more about different things”.

Among all interviewed adults, regardless of age or gender, the living circumstances appear to be appreciably associated with specific support sources. Those who were employed and living an independent life had a lack of a natural support system, while those who were students lived with their families and particularly depended on the support provided by the family. Since all services and activities were moved online teletherapy became the new normal and the counsellors/therapists/ practitioners spoke to

their clients over tele sessions. 56% preferred in-person therapy, 33% preferred teletherapy while 11% found therapy ineffective.

4.0 Discussion

Adults belonging to the range of autism spectrum disorders are one of the clinical groups at the highest risk of being affected by COVID-19. This study analysed the impact that COVID-19 had on autistic adults living in India. The escalated risk of exposure in this population can be elucidated by a variety of factors including necessary daily care requiring regular contact, shared transportation, etc. It’s worth highlighting the importance of the internet and the effect it has on minds in providing easy-to-understand information.

Overall, the analyses of the participants’ responses stipulated that the reverberation of the COVID-19 pandemic on autistic people's mental health has been variable. Participants encountered both

positive and negative emotions, not, particularly at the extremes. Factors like disrupted routine schedules, fear of job loss, poor domestic support system and inconsistency in transition were associated with development and worsening of pre-existing psychological and behavioural conditions like depression, anxiety, panic attacks and high-stress levels. At the same time, reduced interactions with decreased social insistence led to an improvement for some participants.

Unfortunately, the magnified risk of negatives outweighs this benefit. Irrespective of age, gender, and financial stability, fortification by family and friends played an important role to reduce anxiety. The other encouraging factor to be accentuated was recreational and leisure activities, in addition to discovering new ways to adapt to the new routine. Auxiliary efforts were required especially by the employed individuals to make their family and work-life compatible.

There is a critical requirement of studies to highlight how the pandemic has affected the employment of people with Autism as they are frequently only recognized as the recipient of services. Hardly any importance is given to the role that the individuals with Autism play for the support of surrounding members. Other needs expressed by autistic adults were related to access to appropriate and affordable healthcare services. Before the pandemic, accessibility was a huge problem for autistic people and this appears to have been amplified over this period. There was variability in participants' experiences of therapy. While a small proportion found it ineffective, a significant number of participants found in-person and teletherapy effective.

5.0. Conclusion

Based on our above findings it is amiable to deduce the direct and indirect implications of the COVID-19 pandemic on adults with autism spectrum disorders in India. The analyses of the participants' responses and perspectives exemplify the significant decline of mental well-being. The findings of this study emphasize the need for the development of innovative approaches and the creation of multifaceted support systems to address mental distress in this population.

A set of recommendations have been curated to ensure better support and therapy resources are available to the neurodiverse community:

- 1) Enhanced availability and accessibility of therapists, counsellors and practitioners.
- 2) Virtual helplines to cater to the emotional well-being and mental health concerns.
- 3) Multidisciplinary centres with therapists, doctors and support staff could actively provide real-time support and toolkits for safe mental well-being. Further studies can investigate the real-world application of early interventions, provision of full-time support via support groups and neurodiverse specific helplines; to address the mental health concerns and mitigate the effects of prolonged quarantine as a result of the COVID-19 lockdown in this population.

6.0 Limitations of the study

The selection of the participants was randomised with variations in their demography. Due to time and financial constraints the sample size was relatively small to draw any conclusive judgments, lacking geographical and socioeconomic diversity. Sampling biases could have led to a skewed understanding of the issues examined, for example, participants varied in their verbal expressions of feelings, either being extremely verbose or too laconic (being a part of the spectrum).

Therefore, findings may only be characteristic of the segments of the population represented. The questionnaires used were created by the authors working on this project and no standard tools were used to assess the mental well-being of the participants. To enable more consistency in the future, we would recommend the use standard questionnaires, look into a larger sample size of the participants and document their strategies for verifying diagnoses and eligibility.

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Table 1: Summary of responses and relevant causes of exacerbation of mental health presentations.

Question	Categories	Result (n=10)	Kappa
How difficult was it for you to understand the lockdown rules and adhere to it, staying indoors?	Easy Medium Hard	80% (8) 10% (1) 10% (1)	0.972 1.00 1.00
How difficult was it for you to stay indoors?	Easy Medium Hard	60% (6) 20% (2) 20% (2)	0.667 0.967 0.967
How were you updating yourself about COVID19 during the pandemic? (news, friends, family, social media)	COVID-19 websites Social media News Channels Newspapers Family Friends Refrained from all news	50% (5) 50% (5) 40% (4) 20% (2) 1% (1) 1% (1) 1% (1)	0.980 0.817 0.980 0.960 1.00 1.00 1.00
Mental health? (SCALE: Excellent, Good, Average, Poor, Very Poor)	Before pandemic Good Average Very poor During pandemic Poor Very poor	20% (2) 70% (2) 10% (2) 40% (4) 60% (6)	0.940 0.712 0.840 0.980 0.980
How was your mental health after the pandemic? (SCALE: Better, Same, Worse)	Better Same Worse	60% (6) 30% (3) 10% (1)	0.847 0.960 1.00
How were your anxiety levels at home? (SCALE: Non-Existent, Low, Medium, High, Unbearable)	Non-Existent Low High Unbearable	10% (1) 20% (2) 30% (3) 40% (4)	1.00 1.00 0.980 0.860
Did you feel any of the following: Panic attacks, Depression, Low Moods, Overthinking	Low Moods Depression Panic Attacks Overthinking	90% (9) 60% (6) 50% (5) 50% (5)	0.860 0.960 0.960 0.960