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Short Reports

Short report: COVID-19-related anxiety is associated with mental health problems among adults with rare disorders

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ABSTRACT

Background: For adults with rare disorders, COVID-19 can be more severe and deadlier. This may lead to anxiety about COVID-19 among adults with rare disorders, including worries about being infected. COVID-19 anxiety is linked with mental health problems in the general population.

Aims: To examine the levels of mental health problems and COVID-19 anxiety, and their association, among adults with rare disorders.

Methods and procedures: Adults with rare disorders ($N = 58$, $M_{\text{age}} = 45.2$ years, $SD = 12.7$, 69.0 % females, 31.0 % males) answered standardized mental health and COVID-19 anxiety questionnaires online. Their scores were compared with samples without rare disorders.

Outcomes and results: Mental health problems were higher than in a sample without rare disorders (effect size $d = 1.14$), as was COVID-19 anxiety (effect size $d = 0.53$). COVID-19 anxiety correlated significantly with mental health problems ($r = 0.46$). Controlling for age, gender, and work status, COVID-19 anxiety explained 16.1 % of the variance in mental health problems ($\Delta R^2 = 0.161$, $p = 0.001$).

Conclusions and implications: COVID-19 anxiety is higher than norms and associated with mental health problems for adults with rare disorders. During the pandemic, clinicians are recommended to assess COVID-19 anxiety for patients with rare disorders.

What this paper adds

We show that persons with rare disorders had more mental health problems and COVID-19 anxiety than samples without rare disorders. There was a significant association between mental health problems and COVID-19 anxiety among adults with rare disorders. The implication is that during the pandemic, practitioners are recommended to examine mental health and COVID-19 anxiety among their patients with rare disorders. Interventions aimed at reducing either mental health problems or COVID-19 anxiety may be beneficial for both domains.

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1. Introduction

A disorder is defined as *rare* if it affects fewer than 1:2000 individuals (EURORDIS Rare Diseases Europe, 2020). More than 7000 rare disorders have been identified, so many individuals are affected. Whereas there is considerable variation in the medical impact of rare disorders, these disorders share some common associated psychosocial risk factors due to their rarity. Psychosocial risk factors associated with rare disorders include mental health problems, social isolation, and loneliness (Barnett et al., 2012; Sasseville et al., 2021). The psychosocial risk factors facing adults with rare disorders were exacerbated during the ongoing coronavirus disease 2019 (COVID-19) pandemic (Lampe et al., 2020; Zhou et al., 2020). The closure of organized daytime activities and home care services enhanced social isolation and loneliness among persons with rare disorders (Sasseville et al., 2021). The combination of medical risk due to the corona virus and the strain on health services added to the psychosocial stain for persons with rare disorders (EURORDIS Rare Diseases Europe, 2020; Zhou et al., 2020).

Given the unknown end of the pandemic and the restrictions, the current situation is detrimental for many persons with rare disorders. The situation brings considerable unpredictability, which is known to negatively affect mental health (Barnett et al., 2012). COVID-19 anxiety is associated with more general anxiety and psychological stress in the general population (Duong, 2021; Muñoz-Rodríguez, Caravaca-Sánchez, & Fernández-Prados, 2021). It is important to examine these associations also for persons with rare disorders, as providing such documentation is crucial to organize an appropriate response and to prioritize actions of healthcare providers in the coming years to minimize the COVID-19 impact on persons with rare disorders.

Our aim is to examine the level of mental health problems and COVID-19 anxiety in persons with rare disorders during the pandemic, and their association. To contextualize our findings, we compared the mental health and COVID-19 anxiety scores of persons with rare disorders with previously reported population data from persons without rare disorders. The current study took place in Norway. Therefore, Norwegian population data were used as comparison for mental health (Vassend, Lian, & Andersen, 1992) and COVID-19 anxiety scores (Lieven, 2021). We examined three research questions. One, are mental health problems higher for persons with rare disorders compared to persons without rare disorders? We expected yes. Second, is COVID-19 anxiety higher for persons with rare disorders compared with persons without rare disorders? We expected yes. Third, are COVID-19 anxiety and mental health problems associated among persons with rare disorders? We expected a moderate association. We controlled for three demographic factors, i.e., age, gender, and work status, since these factors are known to influence mental health (Twomey, Baldwin, Hopfe, & Cieza, 2015), and therefore may also influence COVID-19 anxiety.

2. Method

2.1. Participants and procedure

Adults with rare disorders ($N = 58$, $M_{\text{age}} = 45.2$ years, $SD = 12.7$, 69.0 % female, 31.0 % male) were recruited through the social media platforms of a national resource center for rare disorders in Norway. In terms of background variables, 46.6 % of participants reported regular salary as main income, 41.4 % reported disability benefits, 10.3 % reported other unemployment benefits, and 1.7 % reported no income. Participants were recruited between the end of July 2020 and February 2021, a period during which COVID-19 infections fluctuated, but mainly increased. Governmental measures towards social distancing were in place throughout this period, which was prior to vaccinations. More than 20 rare neurodevelopmental disorders were represented in the sample. The disorders with more than one participant included Charcot-Marie-Tooth disease (24.1 %), Morbus Osler disease (15.5 %), Hypogammaglobulinemia (5.2 %), Henoch-Schönlein purpura (3.4 %), Neurofibromatosis type 1 (3.4 %) Ehlers-Danlos syndrome (3.4 %), Limb-Girdle muscular dystrophies (3.4 %), and common variable immunodeficiency (3.4 %). The study was approved by the local review board for research ethics.

2.2. Measures

2.2.1. Hopkins Symptom Checklist

Hopkins Symptom Checklist (SCL-5; Strand, Dalgard, Tambs, & Rognerud, 2003) was used to measure mental health problems. The SCL-5 comprises five items tapping symptoms of mental health problems (e.g., *I feel hopeless about the future*) and is rated on a 5-point Likert-scale from 0 (not at all) to 4 (extremely). The SCL-5 has demonstrated alpha coefficients of 0.87 and convergent validity with other measures of mental health, including longer versions of the SCL (r 's 0.76–0.97; Strand et al., 2003). In the current study, the inter-item reliability for the SCL-5 was $\alpha = 0.90$. The official Norwegian version of the SCL-5 was used. The SCL-5 scores are presented as global severity index ranging from 0 to 4, with higher scores indicating more problems.

2.2.2. Coronavirus Anxiety Scale

Coronavirus Anxiety Scale (CAS; Lee, 2020) was used to measure COVID-19 anxiety. The CAS comprises four items tapping corona anxiety during the last 14 days (e.g., *I cannot stop thinking about the corona virus*) and is rated on a 5-point Likert-scale from 0 (not at all) to 5 (almost every day). The CAS has demonstrated alpha coefficients of 0.93 and convergent validity with measures of hopelessness, suicidality, adjustment, and coping (r 's 0.75–0.86; Lee, 2020). In the current study, the inter-item reliability for the CAS was $\alpha = 0.71$. The CAS was translated to Norwegian by the first author of this paper and a backtranslation was approved by the scale's developer (Lee). The CAS scores are presented on a scale ranging from 0 to 5, with higher scores indicating more problems.

2.3. Data analytic plan

In comparison analyses, Norwegian data were used for the SCL-5 ($n = 9735$ adults recruited from the general population; Vassend et al., 1992), and the CAS ($n = 408$ adults recruited online; Lieven, 2021). We calculated the effect size difference between the samples using the formula $M_{\text{rare}} - M_{\text{norms}}/SD_{\text{pooled}}$; with 0.30, 0.50, and 0.80 interpreted as small, moderate, and large, respectively (Cohen, 1988). The relationship between mental health and COVID-19 anxiety and was examined using Pearson's correlation, r , and hierarchical multiple regression analysis controlling for age, gender, and work status (i.e., employed vs. benefits/no income). For the linear regression, effect sizes were reported with standardized beta coefficients.

3. Results

The mean global severity index score for the SCL-5 mental health measure was 1.3 ($SD = 1.0$). This was higher than norm data ($M = 0.4$, $SD = 0.5$; Vassend et al., 1992); a large effect size difference ($d = 1.14$). The mean per item COVID-19 anxiety score was 1.2 ($SD = 0.4$). This was higher than Norwegian norm data ($M = 0.8$, $SD = 1.0$; Lieven, 2021); a medium effect size difference ($d = 0.53$).

Correlational analyses showed a positive correlation between mental health problems and COVID-19 anxiety ($r(57) = 0.46$, $p < 0.001$). In a regression model, COVID-19 anxiety was positively significantly associated with mental health problems ($B = 1.335$, $SE = 0.388$, 95% CI [0.562, 2.107], $\beta = 0.425$, $t = 3.465$, $p = 0.001$). Controlling for age, gender, and work status, COVID-19 anxiety significantly explained an additional 16.1% of the variance in mental health problems ($\Delta R^2 = 0.161$, $\Delta F = 12.007$, $p = 0.001$). We did not find evidence for significant correlations between age, gender, work status, and mental health (all p -values ≥ 0.101).

4. Discussion

The current study showed that adults with rare disorders reported more mental health problems than in a sample without rare disorders. The effect size difference was large. This was in line with our expectations, and with a number of studies showing higher psychosocial impairment and health worries for persons with rare disorders (e.g., Fjermestad, Runsjø, & Stokke, 2018; Lampe et al., 2020). We also found that adults with rare disorders reported more COVID-19 anxiety than a Norwegian norm sample. The effect size difference was medium. The social security and public health system is widely accessible in Norway and may reduce COVID-anxiety. The current findings indicate that despite this social welfare system, persons with rare disorders experience more fears than their countrymen without rare disorders.

Importantly, we found a moderate overlap between mental health problems and COVID-19 anxiety. Furthermore, COVID-19 anxiety explained a large amount of variance in mental health problems, above and beyond demographic variables. This finding has implications for health service providers. It means that COVID-19 anxiety should be addressed in consultations with patients with rare disorders. This may be important in itself, as COVID-19 anxiety negatively affects health-related quality of life (Zhou et al., 2020). However, addressing COVID-19 anxiety may also represent a potential mechanism to influence mental health. Studies are needed to identify how COVID-19 anxiety should best be addressed. Recently, advice has been provided to tailor mental health treatment for the aftermath of the pandemic, which include addressing potential collapses in routine (e.g., sleep, diet, physical activity), social connections and support, social media use, and acknowledging the crisis that the COVID-19 pandemic represents (Markowitz, 2021). The results of the current report suggest such advice may be particularly relevant for adults with rare disorders.

The current report has limitations that are inherent to some extent to the questions we are addressing. The sample size was small, which is a common challenge in rare disorders research. We only report cross-sectional findings because the timeline of the pandemic was unknown at the time of the study. Further studies are needed that examine COVID-anxiety for rare disorders, also over time.

The COVID-19 pandemic has caused a global crisis with unknown consequences for the unforeseeable future. The consequences involve risk for impaired mental health (e.g., anxiety, depression), social structures (e.g., loneliness), and economy (e.g., unemployment). Furthermore, there are consequences for health service use and policies (e.g., priorities). The current survey documents that for the already vulnerable group of adults with rare disorders, COVID-anxiety and mental health are clearly linked. We conclude that professionals working with adults with rare disorders should assess COVID-19 anxiety in their patients with rare disorders and discuss this issue with them.

Data availability

Data will be made available on request.

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