

The COVID-19 Pandemic's Impact on Obsessive-Compulsive Disorder: Survey of Online Peer Support Community Users

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Table of Contents

Original Manuscript..... 5

Supplementary Files..... 13

 Figures 14

 Figure 1..... 15

 Figure 2..... 16

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Abstract

Background: People with obsessive-compulsive disorder (OCD) have faced unique challenges during the COVID-19 pandemic. Research from the first two months of the pandemic suggested that between 7% and 37% of people with OCD experienced worsening in their OCD symptoms since the pandemic began, while the rest experienced either no change or an improvement in their symptoms. However, as society-level factors relating to the pandemic have evolved, the pandemic's impacts on people with OCD have likely changed as well, in complex and population-specific ways. Therefore, this work contributes to a growing body of knowledge on the COVID-19 pandemic's impact on people, and demonstrates how differences across studies might emerge when studying specific populations and at specific timepoints.

Objective: Our study aimed to learn how members of online OCD peer support communities felt the COVID-19 pandemic had impacted their OCD symptoms, 3-4 months after the pandemic began.

Methods: We recruited participants from online OCD peer support communities for our brief survey. Participants indicated how much they felt their OCD symptoms had changed since the pandemic began, and how much they felt that having OCD was making it harder to deal with the pandemic.

Results: 196 people responded to our survey, although some participants skipped some questions. Among non-missing data, 65.9% (108/164) of respondents were from the United States and 90.5% (152/168) had been subjected to a stay-at-home order. 92.9% (182/196) of respondents said they experienced worsening of their OCD symptoms since the pandemic began, although the extent to which symptoms worsened differed across dimensions of OCD, with symmetry and completeness symptoms less likely than others to have worsened. 95.5% (171/179) of respondents felt that having OCD made it harder to deal with the pandemic.

Conclusions: Our study of online OCD peer support community members found a considerably higher rate of OCD symptom worsening than did other studies of people with OCD during the pandemic. Factors such as quarantine length, location, overlapping society-level challenges, and differing measurement and sampling choices may help to explain this difference across studies.

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Original Manuscript

Short Paper

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Conclusions: Our study of online OCD support community members found a much higher rate of OCD symptom worsening than did other studies of people with OCD during the pandemic. Factors such as quarantine length, location, overlapping society-level challenges, and differing measurement and sampling choices may help to explain this difference across studies.

Keywords: Obsessive-Compulsive Disorder; COVID-19 pandemic; Online Support Communities; Mental health

Introduction

The COVID-19 pandemic has led to population-level decreases in psychological well-being globally

[1]. However, people with obsessive-compulsive disorder (OCD) may experience distinct pandemic-related stressors, compared to the general population. While many people with OCD might be particularly sensitive to pandemic-related stressors (e.g., related to contamination fears), social distancing measures might also provide a welcome respite from typical OCD triggers outside of one's home. Research across various populations and timepoints is needed to learn how people with OCD have experienced the COVID-19 pandemic.

Online OCD support communities are a useful sample to consider as people seek support from online mental health communities for various reasons [6]. Online support communities may provide some unique advantages to traditional forms of support, including anonymity and use of access, that may enable greater self-disclosure and social support [7]. These communities may also be especially relevant to a pandemic context, in which many in-person support sources may be lacking. Thus, exploring the COVID-19 pandemic's impact among individuals who go to online support communities may be useful to understand the impact of the pandemic on help-seeking populations.

Several surveys of people with OCD were conducted between April and May of 2020 in Israel [2], Italy [3], India [4], and Japan [5] to explore how OCD symptoms had changed since the onset of the pandemic. 7%-37% of respondents to these surveys experienced worsening in their OCD symptoms since the COVID-19 pandemic began. Although our survey used a highly-similar methodology to these studies, we found a much higher rate of OCD symptom worsening – 92.9% (182/196). Here, we describe our study of online OCD support community users and discuss possible reasons for our differing patterns of results.

Methods

We recruited the vast majority of our study participants from three anonymous online OCD peer support communities and the rest via posts on OCD-related social media pages. Respondents indicated how much their symptoms in each of four OCD symptom dimensions (“unacceptable thoughts”, “symmetry and completeness”, “responsibility for harm”, and “contamination”), as evaluated by the Dimensional Obsessive-Compulsive Scale (DOCS) [8], had changed since the pandemic began (-3 [much worse] to 3 [much better]). Respondents also indicated how much their OCD symptoms made living during the pandemic more difficult (0 [not at all more difficult] to 4 [much more difficult]). Our pre-registered study materials and analysis plan, as well as the survey data and R code used for analyses, are available online (see Supplementary Files).

Results

We received 196 survey responses between June 28 and August 10, 2020 from individuals who stated they were professionally diagnosed with OCD, self-diagnosed, or suspected they had OCD. Not all participants answered all demographics questions. Most respondents were young ($M=24.77$, $SD=5.96$, $N=163$), female (71.4% [115/161], 21.8% [35/161] male, 6.8% [11/161] other gender identity), Caucasian (74.1% [123/166]), lived in the United States (65.9% [108/164]), and had their daily life impacted by a stay-at-home order (90.5% [152/168]). We also excluded from analyses an additional 134 individuals who left the survey before completing the main OCD measure.

We found that 92.9% (182/196) of respondents experienced worsening of their OCD symptoms since the COVID-19 pandemic began ($\text{mean}_{\text{change}}=-1.10$, $95\%CI=(-1.21, -0.99)$, $t(195)=-19.35$, $P<.001$, $d=1.38$). Notably, however, symmetry and completeness symptoms worsened considerably less ($d=0.38$) than did other dimensions of OCD ($ds>0.94$), and comparisons between symmetry and exactness symptoms and other symptom dimensions were large and significant, $Ps<0.001$. See Figure 1 and Figure 2. Also, 95.5% (171/179) of respondents felt that having OCD made it more

difficult to deal with the pandemic, and the greatest proportion of respondents (36.3% [65/179]) indicated that having OCD made it much more difficult ($\text{mean}_{\text{more difficult}}=2.79$, $\text{SD}_{\text{more difficult}}=1.16$). Results were roughly the same when including only those participants who stated they had been professionally diagnosed with OCD in analyses ($N=142$).

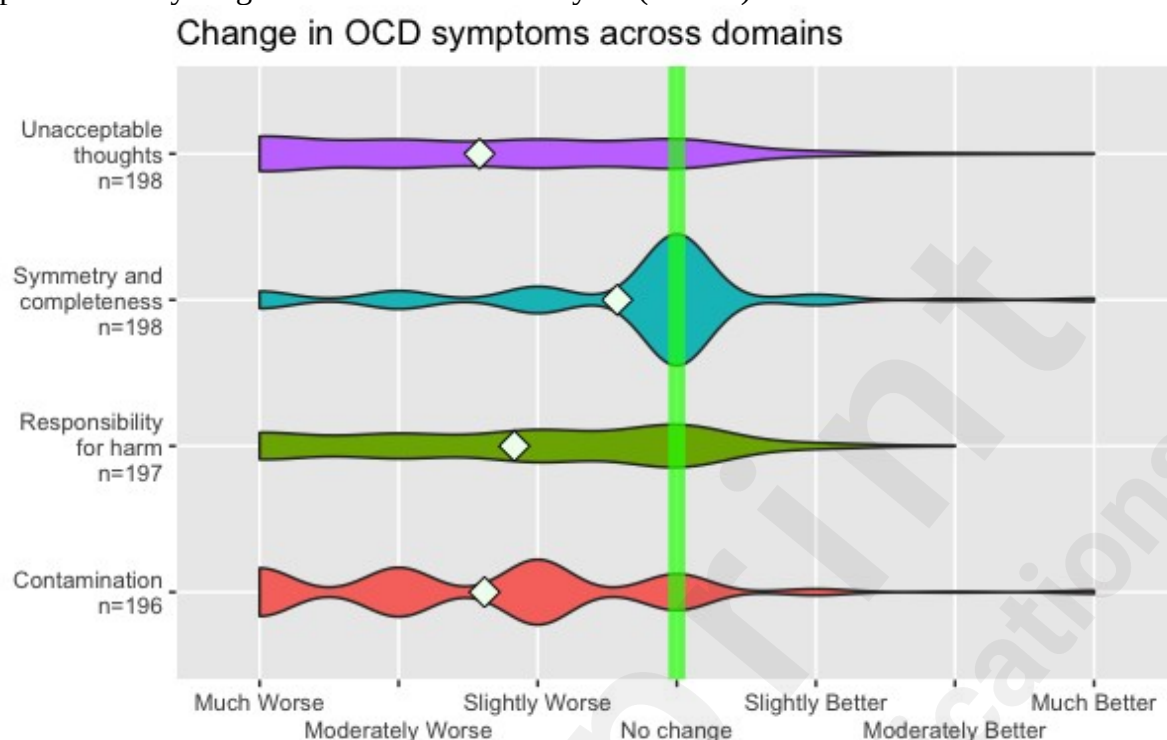


Figure 1: Changes in OCD symptom severity across dimensions, as evaluated by the Dimensional Obsessive-Compulsive Scale (DOCS). The white diamonds correspond to sample means. Respondents indicated the extents to which their symptoms across four dimensions of OCD (“unacceptable thoughts”, “symmetry and completeness”, “responsibility for harm”, and “contamination”), changed since the onset of the pandemic (-3 [much worse] to 3 [much better]).

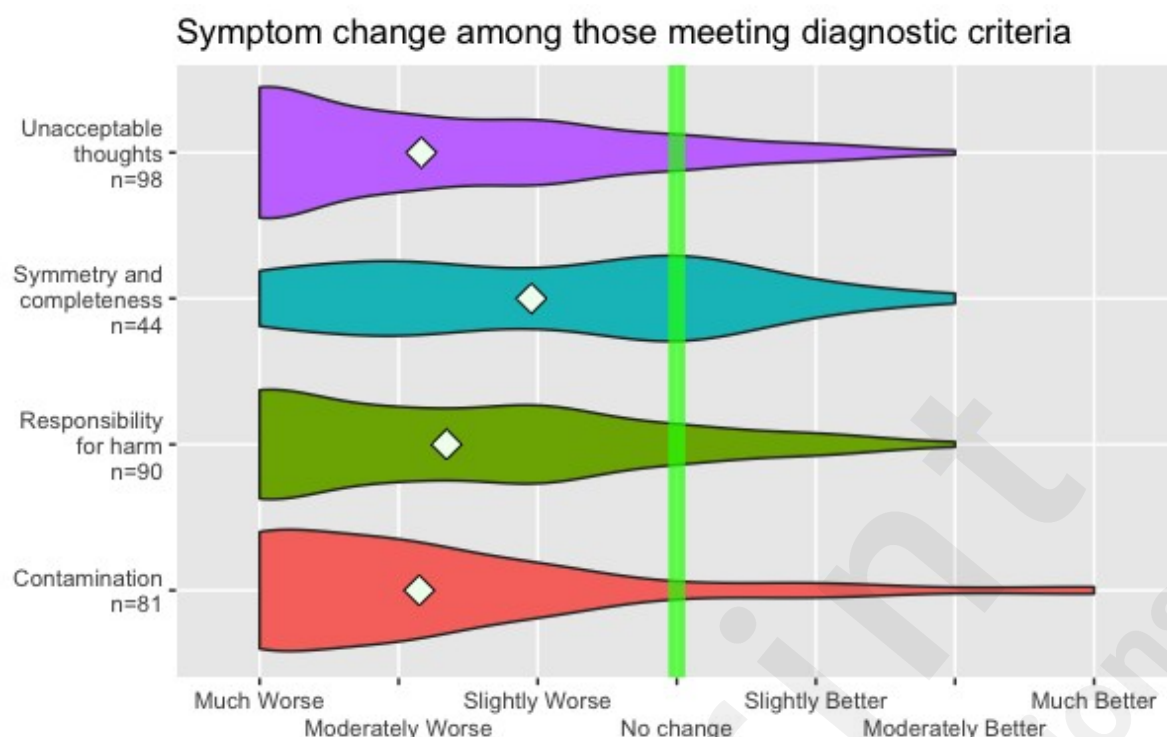


Figure 2: Changes in OCD symptom severity across dimensions, only among respondents with clinically elevated symptoms for a given dimension of OCD, as evaluated by the Dimensional Obsessive-Compulsive Scale (DOCS). We considered respondents to have clinically elevated symptoms in a given symptom dimension if they scored an average of 2 (0-4) across each item in that symptom dimension – which corresponds to moderate symptoms. The white diamonds correspond to sample means. Respondents indicated the extents to which their symptoms across four dimensions of OCD (“unacceptable thoughts”, “symmetry and completeness”, “responsibility for harm”, and “contamination”), changed since the onset of the pandemic (-3 [much worse] to 3 [much better]).

Discussion

Our results align with those of similar studies in some regards but differ importantly in other ways [2-5]. Like those of Littman et al. [2], our results indicate that symmetry and completeness symptoms were less likely to worsen during the pandemic than symptom dimensions typically associated with harm. Overall, however, a much higher proportion of our participants than of other studies’

participants reported worsening OCD severity during the pandemic, and we believe that several factors may explain why.

Comparison with Prior Work

First, the other studies were conducted in April and May of 2020, only a few weeks after quarantine measures were first instituted in their respective participants' communities, while we collected surveys between June 28 and August 10, roughly three months after quarantine measures began for most Americans. The mental health toll of pandemics may increase over time as anxiety, boredom, and frustration compound (reviewed in [9]). Indeed, in the United States, symptoms of anxiety and depressive disorders increased considerably more between April and June of 2020 compared to April and June of 2019 [10].

Second, the other studies were conducted in Israel [2], Italy [3], India [4], and Japan [5], whereas most respondents to our survey were from the United States. The mental health toll of COVID-19 is inextricable from location-specific factors; these include government decisions about the pandemic, media reports that might influence beliefs and reduce or increase psychological distress [11], and co-occurring collective challenges such as political unrest [12].

Third, online OCD support communities are likely disproportionately used by people seeking help during periods of elevated symptoms. As a result, the communities we surveyed might have had higher proportions of people who felt their symptoms worsened since the pandemic began, compared to in-person populations (such as patients of an OCD clinic). Although Littman et al. [2] also recruited a majority of their study's participants from online OCD support groups, the communities they studied may have differed from the ones we studied in the proportion of people seeking help on them.

Limitations

We must note some limitations to our study. First, because we recruited our sample by posting advertisements on online OCD support communities and we do not know who chose not to take the survey, our sample is not representative of any population of people with OCD. Second, our measure of OCD symptom change relied on retrospective self-report about the pandemic's impact, asking participants how much their symptoms changed since the pandemic began; comparable studies did not mention the pandemic when asking respondents about their symptom change or directly compared OCD measures before and after the pandemic using longitudinal data. As such, it might be most accurate to describe our findings as perceived worsening of symptoms. Despite these important limitations, we believe the extremely high rate of OCD symptom worsening among our survey respondents remains noteworthy.

Conclusions

Intersecting moderator variables such as quarantine length, location, overlapping society-level challenges, and public sentiment about quarantine measures complicate efforts to identify how the COVID-19 pandemic has affected people with OCD. Further, subjects recruited from online support communities might be more likely to be experiencing elevated symptoms at the time of data collection than typical in-person samples. The marked difference in results between our study and other studies with similar goals and methodologies highlights the importance of considering these variables. As more studies on this topic are published, future work should use meta-analysis to investigate which sociocultural variables (e.g., healthcare availability and trust in government) and researcher variables (e.g., sampling and measurement choices) predict observed changes in OCD symptom severity during the COVID-19 pandemic.

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Conflicts of Interest

Mr. Kaveladze has nothing to disclose. Ms. Chang has nothing to disclose. Dr. Siev has nothing to disclose. Dr. Schueller reports personal consulting fees from Otsuka Pharmaceuticals, outside the submitted work.

Abbreviations

OCD: Obsessive-Compulsive Disorder

DOCS: Dimensional Obsessive-Compulsive Scale

Multimedia Appendix

Our analysis plan, data, and study materials are available at <https://osf.io/3hs6a/>.

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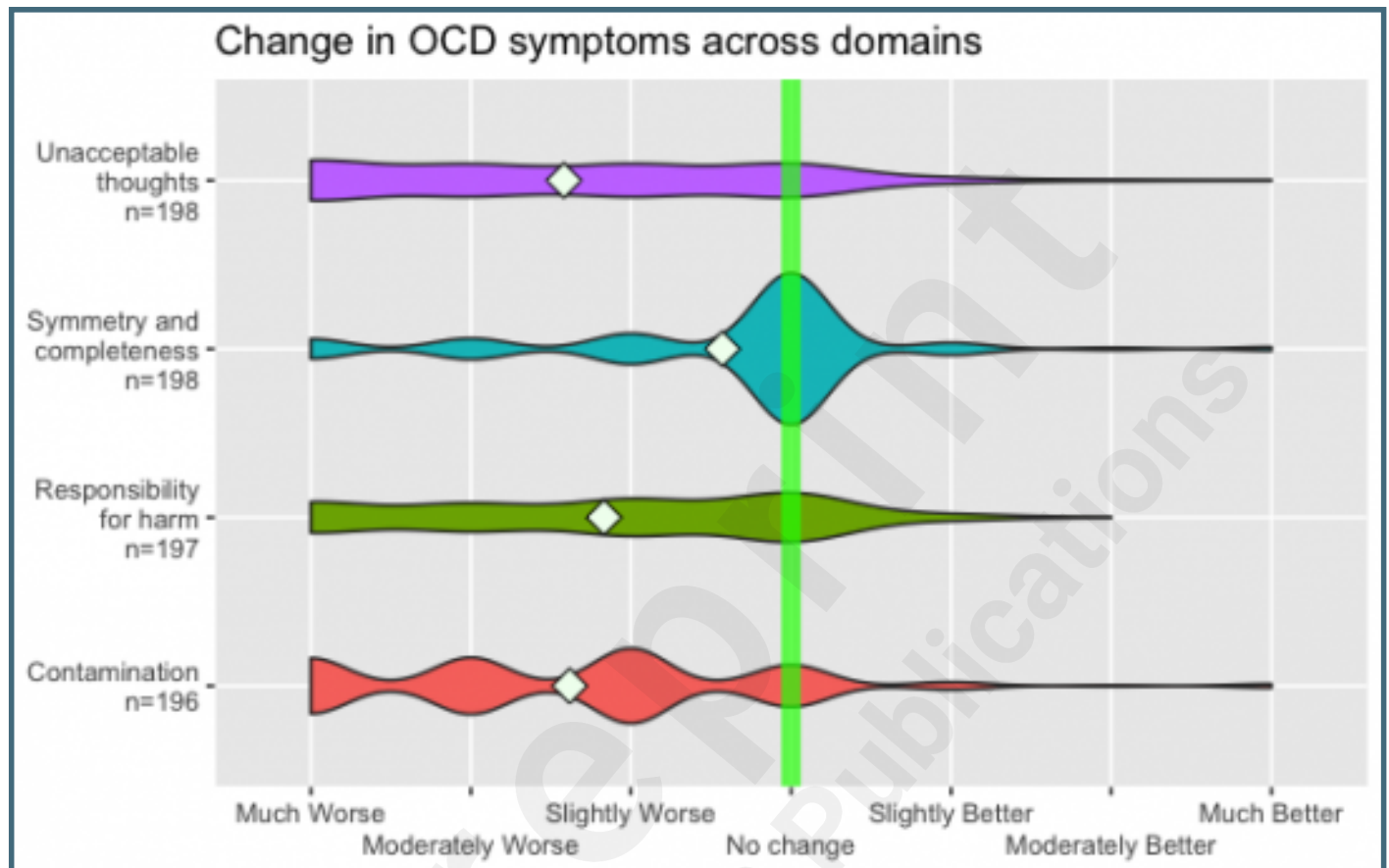
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Supplementary Files

Figures

Changes in OCD symptom severity across dimensions, as evaluated by the Dimensional Obsessive-Compulsive Scale (DOCS). The white diamonds correspond to sample means. Respondents indicated the extents to which their symptoms across four dimensions of OCD (“unacceptable thoughts”, “symmetry and completeness”, “responsibility for harm”, and “contamination”), changed since the onset of the pandemic (-3 [much worse] to 3 [much better]).



Changes in OCD symptom severity across dimensions, only among respondents with clinically elevated symptoms for a given dimension of OCD, as evaluated by the Dimensional Obsessive-Compulsive Scale (DOCS). We considered respondents to have clinically elevated symptoms in a given symptom dimension if they scored an average of 2 (0-4) across each item in that symptom dimension – which corresponds to moderate symptoms. The white diamonds correspond to sample means. Respondents indicated the extents to which their symptoms across four dimensions of OCD (“unacceptable thoughts”, “symmetry and completeness”, “responsibility for harm”, and “contamination”), changed since the onset of the pandemic (-3 [much worse] to 3 [much better]).

