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Article

Diagnosis and treatment delay in patients with OCD in the United States over the past three decades

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SUMMARY

Obsessive-compulsive disorder is a mental health disorder that can lead to significant functional impairment and profound disability. Studies have shown that delayed diagnosis and treatment and prolonged duration of illness (DI, onset of symptoms to treatment) led to poorer patient outcomes. The purposes of this study are to investigate whether these time frames have improved over time and to identify reasons for delays. Our main hypothesis was that diagnosis delay, treatment delay, and DI have all improved over the past three decades. We grouped 182 participants into three epochs based on their onset of symptoms (epoch 1: 1992 – 2002, epoch 2: 2003 – 2012, epoch 3: 2013 – 2023). There were statistically significant findings across all epochs for mean diagnosis delay (14.3 years in epoch 1, 10.7 in epoch 2, and 2.0 in epoch 3, $p < 0.001$) and mean DI (15.6 years in epoch 1, 11.6 in epoch 2, and 2.4 in epoch 3, $p < 0.001$). Mean treatment delay was significant between epochs 2 (0.9 years) and 3 (0.4 years, $p < 0.003$). Participants' responses showed that perceived social stigma, limited access to care, and inability to afford care were statistically significant reasons for diagnosis delay across all epochs ($p < 0.05$), and limited access to care was a statistically significant reason for treatment delay across all epochs ($p < 0.005$). These findings demonstrate an ongoing need for timely diagnosis and treatment and improvements in access to and affordability of care in the United States.

INTRODUCTION

Obsessive-compulsive disorder (OCD) is a mental health condition characterized by obsessions, defined as thoughts or images, and compulsions, defined as repeated behaviors (1). For instance, an OCD patient may be compelled to repeatedly wash his or her hands due to obsessive thoughts of contamination. In this example, the thoughts of contamination are the obsessions, and hand washing is the compulsion. Some patients feel compelled to repeatedly check certain things, such as the stove being turned off, while others feel the need to make sure everything is symmetrical. OCD affects approximately 2.3% of the population in the United States (US) and often causes significant disability (1). As a result, there are significant direct and indirect costs to society (2). In the US, the indirect costs related to OCD due to decreased productivity were estimated at $6.2 billion, and the total costs related to OCD were estimated at $8.4 billion in 1990 (2).

Duration of illness (DI, the time from onset of symptoms to treatment) and duration of untreated illness (DUI, the time from diagnosis to treatment) are both significantly prolonged for patients with OCD (3, 4). Longer DI has been associated with higher rates of hospitalization and is directly correlated with higher disability in work, social, and family life (3). In addition, patients with OCD have significantly greater DUI values than patients with other mental disorders (5, 6). For example, the mean DUI for patients with panic disorder is 3.3 – 3.7 years, compared to 7.6 – 7.9 years for patients with OCD (5, 6). Prolonged DUI has been associated with poorer response rates to medications, whereas earlier treatment is associated with a faster onset of remission (7, 8).

Nonetheless, significant delays persist. Studies in Italy (2015), Turkey (2015), and Brazil (2019) have documented mean DI values of 12.7 – 19.3 years and mean DUI values of 7.0 – 7.7 years (9, 10, 11). However, these studies did not investigate whether there have been improvements in DI or DUI over time; the mean DI and DUI values included their entire sample sizes. A different Italian study in 2016 separated patients into three epochs and found a statistically significant decrease in mean DUI across the epochs: 16.0 years for onset before 1978, 6.4 years for onset between 1978 – 2000, and 1.6 years for onset after 2000 (12). The authors attributed the improvement in DUI to improved diagnostic and treatment algorithms and improved psychiatric services after Italian legislation abolished custodial psychiatry in 1978 (12). However, this study included patients with schizophrenia spectrum disorder, mood disorders, and anxiety disorders (including OCD) but did not report findings specific to the subset of patients with OCD (12). As a result, the findings of this study may not accurately represent the DUI of OCD patients over the years.

In the US, a 1994 – 1995 survey conducted by the Obsessive-Compulsive Foundation found a mean DI of 17.2 years (13). A more recent study, conducted in 2022 focused on the time from onset of symptoms to diagnosis (14). This time frame, referred to as the delay to diagnosis, was found to be 11.4 years (14). These persistent delays to diagnosis and prolonged DI have been attributed to various factors, such as social stigma, impaired access to treatment, and poor insight (15).

We conducted this study to investigate diagnosis delay, treatment delay, and DI in the US to determine whether these time frames have improved from 1992 to 2023. In our study, *diagnosis delay* refers to the time between the onset of symptoms and diagnosis, and *treatment delay*, or DUI, refers to the time between diagnosis and treatment (**Figure 1**). As such, diagnosis delay plus treatment delay equals DI. We hypothesized that all three parameters have improved in the US during this time frame, especially since there has been

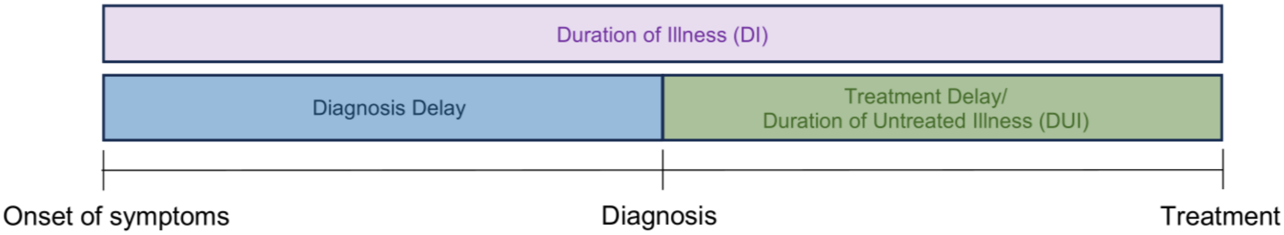

Figure 1: Definition of terms. Diagnosis delay is defined as the time from onset of symptoms to diagnosis. Treatment delay and duration of untreated illness (DUI) are defined as the time from diagnosis to treatment. Duration of illness (DI) is defined as the time from onset of symptoms to treatment or diagnosis delay plus treatment delay.

an increase in mental health awareness among the general public (16). In addition, due to this increased awareness, we hypothesized that perceived social stigma would be less associated with patients deciding to delay diagnosis or treatment. However, due to persistent obstacles within the US healthcare system, we hypothesized that access to care or affordability of care may still be significant contributing factors for delays in diagnosis and treatment.

Participants who met all three inclusion criteria (at least 18 years old, diagnosed with OCD by a mental health professional in the US, and onset of OCD symptoms within the past 30 years) completed an online survey that we created for this study. We grouped the participants into three epochs based on the onset of symptoms: epoch 1 (1993 – 2002), epoch 2 (2003 – 2012) and epoch 3 (2013 – 2023). We compared mean values for diagnosis delay, treatment delay, and DI among the three epochs. In addition, the data was analyzed to identify statistically significant reasons associated with diagnosis delay and treatment delay across all three epochs. We found a statistically significant improvement in diagnosis delay and DI across all three epochs as well as a significant improvement in treatment delay between epochs 2 and 3. In addition, statistically significant reasons associated with diagnosis delay were perceived social stigma, limited access to care, and inability to afford care. The only statistically significant reason associated with treatment delay was access to care. In summary, while diagnosis delay, treatment delay, and DI have significantly improved over time, there remains potential for future improvements in perceived social stigma, limited access to care, and the ability to afford care.

RESULTS

Participants completed an online survey if they met the inclusion criteria for the study. We recruited participants by contacting OCD support groups online and in person at an OCD conference. Survey questions included demographic questions, age at onset, diagnosis, and treatment for OCD as well as reasons for diagnosis and treatment delay. A total of 182 survey responses were included in the analysis. Participants were between the ages of 18 and 69, with a mean age of 31.2 ± 7.1, years and consisted of 78 males (42.9%), 101 females (55.5%), 2 non-binary individuals (1.1%), and 1 transgender individual (0.5%) (**Table 1**, **Table 2**). We grouped the participants into three epochs based on the onset of symptoms: epoch 1 (1993 – 2002), epoch 2 (2003 – 2012) and epoch 3 (2013 – 2023). The mean age at onset of symptoms was 12.7 ± 7.0 (epoch 1), 12.8 ± 4.3 (epoch 2), and 24.0 ± 7.3 (epoch 3) (**Table 1**).

Mean diagnosis delay (14.3 ± 6.8 years, epoch 1; 10.7 ± 4.9 years, epoch 2; and 2.0 ± 2.1 years, epoch 3; p < 0.001) and mean DI (15.6 ± 7.3 years, epoch 1; 11.6 ± 5.1 years, epoch 2; and 2.4 ± 2.9 years, epoch 3; p < 0.001) were statistically significant across all three epochs using the Kruskal-Wallis test (**Table 1**). Mean treatment delay (1.3 ± 2.4 years, epoch 1; 0.9 ± 1.7 years, epoch 2; and 0.4 ± 1.3 years, epoch 3) was significant between epochs 2 and 3 (Wilcoxon rank sum

Epochs of onset		Epoch 1 1993-2002 n = 52 (29%)	Epoch 2 2003-2012 n = 84 (46%)	Epoch 3 2013-2023 n = 46 (25%)	Total n = 182 (100%)
Age		37.0 (± 7.4)	28.6 (± 4.6)	29.1 (± 6.7)	31.2 (± 7.1)
Age at onset		12.7 (± 7.0)	12.8 (± 4.3)	24.0 (± 7.3)	15.6 (± 7.7)
Diagnosis Delay	Mean	14.3^{*} (± 6.8)	10.7^{*} (± 4.9)	2.0^{*} (± 2.1)	9.5 (± 6.9)
	Median	17.0	12.5	0.5	10.5
Treatment Delay	Mean	$1.3^{\dagger}$ (± 2.4)	$0.9^{\dagger}$ (± 1.7)	$0.4^{\dagger}$ (± 1.3)	0.9 (± 1.9)
	Median	1.0	1.0	0.0	0.5
DI	Mean	15.6^{*} (± 7.3)	11.6^{*} (± 5.1)	2.4^{*} (± 2.9)	10.4 (± 7.4)
	Median	18.0	13.0	1.0	11.0

Table 1: Diagnosis and treatment delay. Mean age and age at onset (+/- standard deviation) for participants in each epoch as well as total. Mean and median values for diagnosis delay, treatment delay, and DI for each epoch as well as total are also displayed. All values are in years. * = p < 0.001 across all epochs. † = p < 0.003 for epochs 2 and 3 and p < 0.001 for epochs 1 and 3.

Gender	Male	78 (42.9%)
	Female	101 (55.5%)
Race	White	126 (69.2%)
	Black	30 (16.5%)
	Asian	10 (5.5%)
Education	High school	56 (30.8%)
	College	92 (50.5%)
	Graduate degree	31 (17.0%)
Employment	Unemployed	45 (24.7%)
	Part-time	43 (23.6%)
	Full-time	94 (51.6%)
Health insurance provided by employer	Yes	94 (51.6%)
	No	88 (48.4%)

Table 2: Demographic information. Demographic information for all of the participants in the study. Categories that represented less than 5.0% of respondents were not included in the table.

post-hoc test, $p < 0.003$) and between epochs 1 and 3 ($p < 0.001$) (**Table 1**). There were no significant differences in mean diagnosis or treatment delays associated with race, education, employment status, or whether health insurance was provided by the employer ($p > 0.05$ for all comparisons). Participants' responses demonstrated that there was a statistically significant difference in the percentage of participants reporting perceived social stigma, limited access to care, and inability to afford care as reasons for diagnosis delay over the three epochs. There was a statistically significant increase in participants reporting perceived social stigma as a reason for diagnosis delay across epochs, from 13% (epoch 1) to 25% (epoch 2) and 37% (epoch 3) (Chi-square Test of Homogeneity, $p < 0.05$) (**Figure 2**). There was also a statistically significant increase in participants reporting access to care as a reason for diagnosis delay from 6% (epoch 1) to 8 % (epoch 2) and 22% (epoch 3) ($p < 0.05$) (**Figure 2**). Finally, there was a statistically significant increase in participants reporting inability to afford care as a reason for diagnosis delay from 0% (epoch 1) to 6% (epoch 2) and 11% (epoch 3) (Fisher's exact test, $p < 0.05$) (**Figure 2**). Factors that were not statistically significant with diagnosis delay were trying to 'fix' it themselves, having symptoms that did not greatly affect daily life, and having symptoms that did not last long. Based on the participants' responses, there was a statistically significant increase in access to care as a reason for treatment delay from 17% (epoch 1) to 14% (epoch 2) and 39% (epoch 3) (Chi-square Test of Homogeneity, $p < 0.005$) (**Figure 3**). Factors that were not statistically significant with treatment delay were trying to 'fix' it themselves, having symptoms that did not greatly affect daily life, having symptoms that did not last long, perceived social stigma, and affordability of care.

We also asked participants to specify the amount of time that they experienced obsessions or compulsions each day at the time of diagnosis and treatment. 22.0% of all participants experienced symptoms for less than 1 hour per day at the time they were diagnosed with OCD, compared to 16.5% at the time they began treatment (**Figure 4, Figure 5**). 36.3% of all participants experienced symptoms for 2 – 3 hours per day at the time they were diagnosed compared to 29.1% at the time they began treatment (**Figure 4, Figure 5**). 22.0% of all participants experienced symptoms for more than 4 hours per day at the time they were diagnosed compared to 28.6% at the time they began treatment (**Figure 4, Figure 5**).

DISCUSSION

OCD continues to affect millions of Americans, resulting in significant disability and healthcare costs (1, 2). Since prolonged DI and delayed treatment are both known to lead

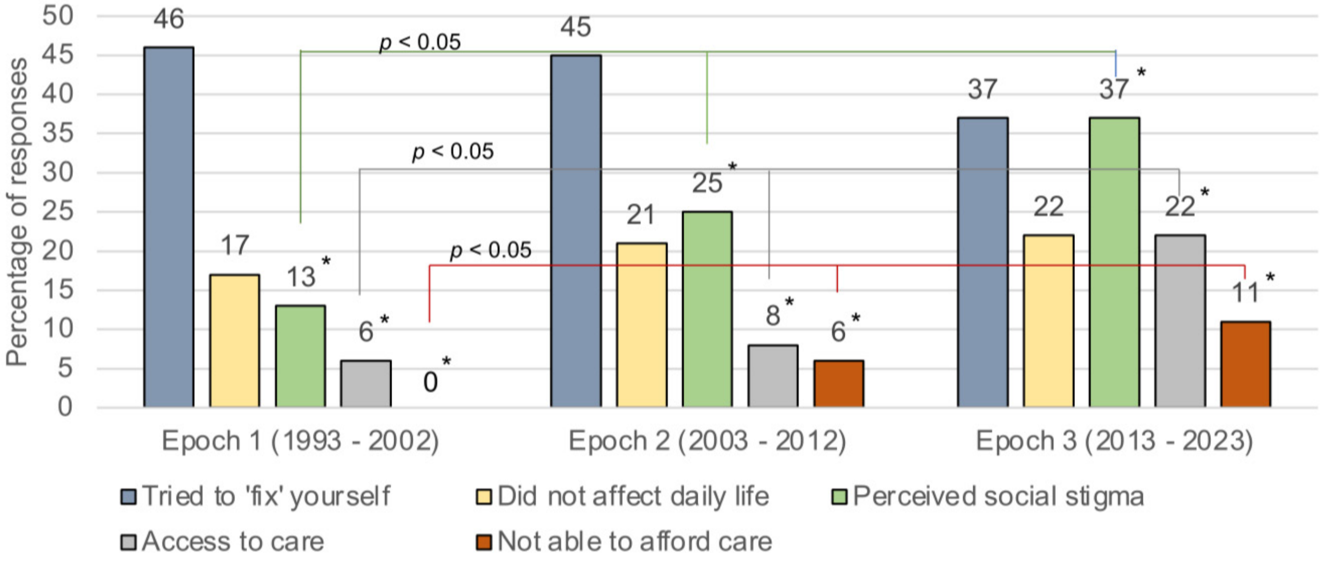

Figure 2: Reasons for diagnosis delay. The percentage of all responses reported by participants as reasons for diagnosis delay. Perceived social stigma, access to care, and not able to afford care were statistically significant over the three epochs using the Chi-square Test of Homogeneity. Only responses which demonstrated at least a 5% difference in percentage among epochs are included. Diagnosis not delayed is not included. * = $p < 0.05$ across all epochs.

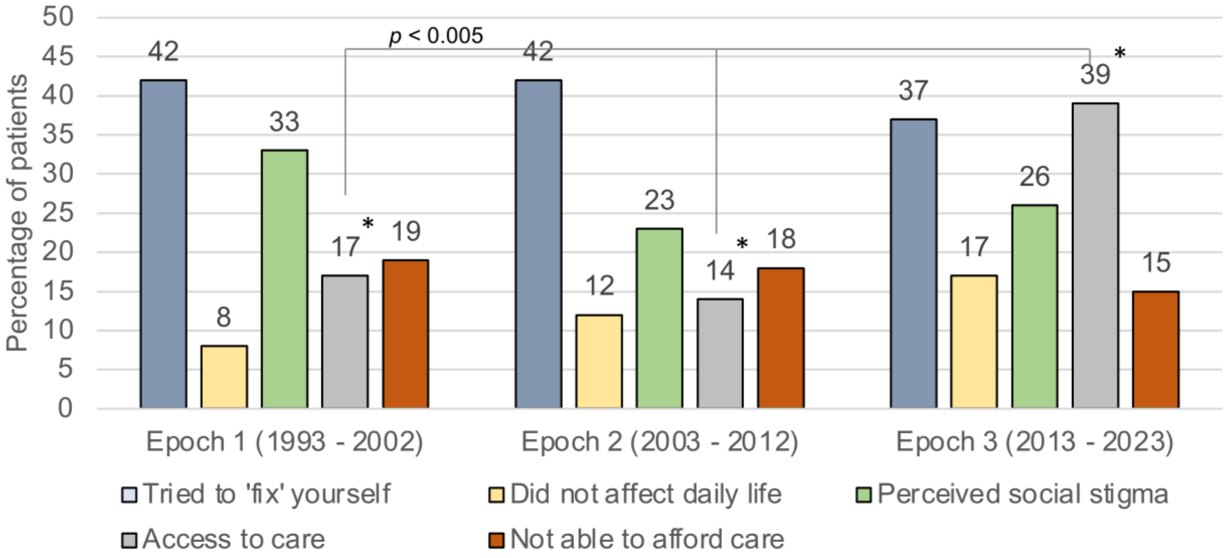

Figure 3: Reasons for treatment delay. The percentage of all responses reported by participants as reasons for treatment delay. Access to care was statistically significant over the three epochs using the Chi-square Test of Homogeneity. Only responses which demonstrated at least a 4% difference in percentage among epochs are included. Treatment not delayed is not included. * = $p < 0.005$ across all epochs.

to poorer patient outcomes, timely diagnosis and treatment are essential (3, 7, 8). Our study found a progressive and statistically significant decrease in both diagnosis delay and DI in the US over the past three decades**.** For participants whose symptoms began between 1993 and 2003, diagnosis delay was 14.3 years, which is consistent with a prior study that found a diagnosis delay of 15.9 years in the US between 1994 and 1995 (13). Diagnosis delay improved to 10.7 years for patients with symptom onset between 2003 and 2012 and further decreased to 2.0 years for patients with symptom onset between 2013 and 2023. The 1994 - 1995 US survey found a treatment delay of 1.3 years (13). Similarly, our study found a treatment delay of 1.3 years for participants with symptom onset between 1993 and 2002. In the third epoch (2013 – 2023), treatment delay improved to 0.4 years, which was statistically significant compared to the first epoch.

In this study, three reasons for diagnosis delay were statistically significant: perceived social stigma, access to care, and the ability to afford care. Contrary to our hypothesis that perceived social stigma has improved over the past three decades, the percentage of participants in this study reporting perceived social stigma as a reason for diagnosis delay increased from 13% (epoch 1) to 25% (epoch 2) and 37% (epoch 3). In 2019, the American Psychological Association (APA) reported the results of a survey conducted by The Harris Poll which found that 87% of Americans “agreed that having a mental health disorder is nothing to be ashamed of” (16). However, 33% of respondents in the survey agreed that “people with mental health disorders scare” them, and 39% said “they would view someone differently if they knew that person had a mental health disorder” (16). In addition, a more recent survey conducted by The West Health – Gallup Poll in February of 2024 found that seven out of ten Americans believe that society views individuals with mental health conditions “very negatively” (13%) or “somewhat negatively” (57%) (17). Unfortunately, social stigma persists.

The second statistically significant reason for diagnosis delay and the only statistically significant reason for treatment delay was access to care. In 2022, the Research and Action Institute, a think tank of the Association of American Medical Colleges, published a brief, noting that access to care and treatment for mental health disorders were unavailable for most of the US population, in part due to a lack of providers (18). From 2008 to 2019, the number of adults diagnosed with any mental illness increased by almost 30% in the US (18). However, as of September 2021, almost 130 million people lived in federally-designated mental health care Health Professional Shortage Areas, and more than half (51%) of counties in the US had no practicing psychiatrists (18). This lack of qualified providers coupled with the increase in adults diagnosed with any mental illness in recent years, may have contributed to access to care being a reason for diagnosis delay that tripled between epochs 2 (8%) and 3 (22%) and more than doubled between epochs 1 (17%) and epoch 3 (39%) as a reason for treatment delay. These findings suggest that access to care is still a substantial barrier for OCD patients.

The third statistically significant reason for diagnosis delay was affordability of care which increased from 0% (epoch 1) to 6% (epoch 2) and 11% (epoch 3). The number of people with health insurance in the US has steadily increased from 1993 to 2023 (19). Nonetheless, affordability of care remains a barrier to diagnosis. This may be because many insurance companies do not provide as much coverage for mental health as they do for other medical or surgical reasons (20). To minimize this disparity, the federal government enacted the Mental Health Parity and Addiction Equity Act, which states that insurance coverage for mental health benefits must match physical health benefits, in 2008 (20). Despite this legislation, the gap between out-of-network coverage

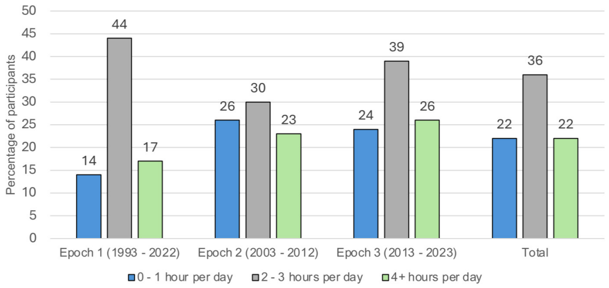

Figure 4: Time spent per day on OCD at time of diagnosis. The percentage of participants who spent 0 – 1 hour, 2 – 3 hours, and more than 4 hours per day on their obsessions or compulsions at the time of diagnosis for each epoch and total.

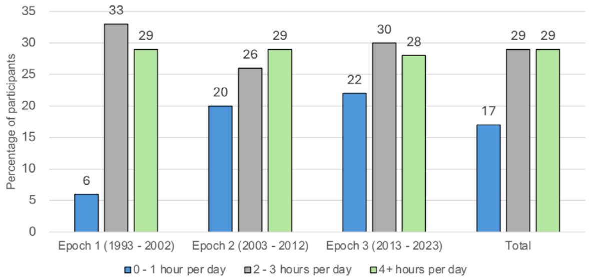

Figure 5: Time spent per day on OCD at time of treatment. The percentage of participants who spent 0 – 1 hour, 2 – 3 hours, and more than 4 hours per day on their obsessions or compulsions at the time of treatment for each epoch and total.

for mental health issues versus physical health issues has increased 85% in recent years (20). This gap in coverage may be contributing to the increase in affordability of care as a reason for diagnosis delay.

Meanwhile, it is encouraging that 22.0% of participants were diagnosed with OCD before their symptomatology met the time criteria for an OCD diagnosis, which requires symptoms that take up more than one hour per day. In addition, 16.5% of participants began treatment before their symptomatology met this time criteria. These results indicate that clinicians may be aware of or are factoring in the second consideration in making an OCD diagnosis - whether symptoms were causing significant distress or functional impairment.

At the same time, it is important to note that OCD symptoms took up 2 – 3 hours every day for 36.3% of all participants by the time they were diagnosed and 29.1% of participants by the time they were treated. In addition, OCD symptomatology took up more than 4 hours per day for 22.0% of all participants by the time they were diagnosed and 28.6% of participants by the time they initiated treatment. Given that the minimum time requirement for an OCD diagnosis is one hour spent on symptoms per day, patients should ideally not have to wait until their symptomatology occupies such a substantial portion of their daily lives before being diagnosed or treated. Since earlier diagnosis and treatment are correlated with more positive outcomes, mental health awareness campaigns may benefit from including information about timely diagnosis treatment.

The greatest limitation of this study is that it is a retrospective, self-reported study. However, prior studies have shown that participants are likely to remember the onset of their symptoms, and numerous studies have used self-reported dates for symptom onset (4, 14, 21). Potential recall bias regarding the dates of diagnosis and treatment should be taken into consideration since responses were not corroborated with medical records. Future studies utilizing a retrospective chart review would mitigate this limitation.

Overall, our study found significant improvements in diagnosis delay, treatment delay, and DI over the past three decades, and our findings were consistent with prior studies in the US for diagnosis delay and treatment delay in epoch 1. Comparing our results to findings from foreign countries may or may not show similar results. In addition, future studies abroad comparing epochs may or may not show similar improvements. Our study demonstrated a significant increase in perceived social stigma, access to care, and the inability to afford care as reasons for diagnosis delay and a significant increase in access to care as a reason for treatment delay. Since identifying reasons for diagnosis delay and treatment delay are one step towards reducing these latencies, studies more closely examining reasons for diagnosis and treatment delay may be useful for ongoing efforts to reduce these barriers. For example, it may be useful to investigate how great an influence each reason for diagnosis and treatment delay has in the decision-making process and what ultimately leads patients to being diagnosed or treated despite these barriers. Based on our findings, social awareness campaigns and policy changes may further reduce diagnosis and treatment delays in the US. Finally, a substantial percentage of participants experienced daily obsessions and compulsions for more than 2 hours per day prior to diagnosis or treatment. Mental health awareness campaigns emphasizing the importance of timely diagnosis and treatment may aid in reducing the percentage of patients spending over an hour on their symptoms every day before diagnosis or treatment.

MATERIALS AND METHODS

This study received an IRB exemption determination in April 2023. Participants were recruited using social media and email requests sent to OCD support groups and practitioners found on the International OCD Foundation (IOCDF) website. In addition, patients were recruited at the IOCDF conference in July 2023. Inclusion criteria were as follows: (1) at least 18 years old, (2) diagnosed with OCD by a mental health professional in the US, and (3) onset of OCD symptoms within the past thirty years. Those who met all three inclusion criteria were asked to complete an online survey.

The survey was created on a Google Form, began with obtaining informed consent, and consisted of 37 questions (**Appendix**). Responses were accepted between April and August of 2023. There were a total of 198 survey responses. Of these, 16 responses were not included in the analysis due to not meeting all of the inclusion criteria or clear errors in data entry (e.g., symptom onset, diagnosis, and treatment all occurred on the same day). The survey responses were separated into three groups based on symptom onset: onset 1993 – 2002 (epoch 1), onset 2003 – 2012 (epoch 2), and onset 2013 – 2023 (epoch 3).

R Version 4.3.1 was used to analyze the data. For analyzing diagnosis delay, treatment delay, and DI, a Kruskal-Wallis omnibus test followed by Wilcoxon rank sum post-hoc tests were used to compare the epochs. Finally, the *p* values were Bonferroni-corrected for three comparisons. For both reasons for diagnosis delay and treatment delay, questions 25 and 32 of the survey, respectively, asked participants to check all of the reasons that applied. The reasons for diagnosis delay and treatment delay were the same: symptoms did not last long, tried to 'fix' by yourself, symptoms did not greatly affect daily life, perceived social stigma, access to care, not able to afford care, diagnosis/treatment was not delayed, and other. Participants were asked to check all of the reasons that contributed to delayed diagnosis and delayed treatment. For analyzing reasons for diagnosis delay and treatment delay, a Chi-square Test of Homogeneity was used. Due to the small sample size for "not able to afford care", Fisher's exact test was used to analyze this factor.

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REFERENCES

1. Ruscio, Ayelet, et al. "The epidemiology of obsessive-compulsive disorder in the National Comorbidity Survey Replication." *Molecular psychiatry*, vol. 15, no. 1, 2010, pp. 53-63. https://doi.org/10.1038/mp.2008.94.
2. DuPont, Robert, et al. "Economic costs of obsessive-compulsive disorder." *Medical interface,* vol. 8, no. 4, 1995, pp. 102-9.
3. Dell'Osso, Bernardo, et al. "The influence of age at onset and duration of illness on long-term outcome in patients with obsessive-compulsive disorder: a report from the International College of Obsessive Compulsive Spectrum Disorders (ICOCS)." *European neuropsychopharmacology : the journal of the European College of Neuropsychopharmacology,* vol. 23, no. 8, 2013, pp. 865-71. https://doi.org/10.1016/j.euroneuro.2013.05.004.
4. Ziegler, Sina, et al. "Long durations from symptom onset to diagnosis and from diagnosis to treatment in obsessive-compulsive disorder: A retrospective self-report study." *PloS one,* vol. 16, no. 12, 2021, e0261169. https://doi.org/10.1371/journal.pone.0261169.
5. Dell'Osso, Bernardo, et al. "Differences in latency to first pharmacological treatment (duration of untreated illness) in anxiety disorders: a study on patients with panic disorder, generalized anxiety disorder and obsessive-compulsive disorder." *Early intervention in psychiatry*, vol. 7, no. 4, 2013, pp. 374-80. https://doi.org/10.1111/eip.12016.
6. Altamura, Alfredo Carlo, et al. "Age at onset and latency to treatment (duration of untreated illness) in patients with mood and anxiety disorders: a naturalistic study." *International clinical psychopharmacology,* vol. 25, no. 3, 2010, pp. 172-9. https://doi.org/10.1097/YIC.0b013e3283384c74.
7. Albert, Umberto, et al. "Duration of untreated illness and response to SRI treatment in Obsessive-Compulsive Disorder." *European psychiatry: the journal of the Association of European Psychiatrists,* vol. 58, 2019, pp. 19-26. https://doi.org/10.1016/j.eurpsy.2019.01.017.
8. Mancebo, Maria C., et al. "Long-term course of pediatric obsessive-compulsive disorder: 3 years of prospective follow-up." *Comprehensive psychiatry,* vol. 55, no. 7, 2014, pp. 1498-504. https://doi.org/10.1016/j.comppsych.2014.04.010.
9. Dell'Osso, Bernardo, et al. "Differences in duration of untreated illness, duration, and severity of illness among clinical phenotypes of obsessive-compulsive disorder." *CNS spectrums,* vol. 20, no. 5, 2015, pp. 474-8. https://doi.org/10.1017/S1092852914000339.
10. Poyraz, Cana Aksoy, et al. "Factors associated with the duration of untreated illness among patients with obsessive compulsive disorder." *Comprehensive psychiatry*, vol. 58, 2015, pp. 88-93. https://doi.org/10.1016/j.comppsych.2014.12.019.
11. Vigne, Paula, et al. "Duration of Untreated Illness in a Cross-Diagnostic Sample of Obsessive-Compulsive Disorder, Panic Disorder, and Social Anxiety Disorder." *CNS Spectrums*, vol. 24, no. 5, 2019, pp. 526–532. https://doi.org/10.1017/S1092852918001281.
12. Dell'Osso, Bernardo, et al. "Reduced duration of untreated illness over time in patients with schizophrenia spectrum, mood and anxiety disorders." *Psychiatry and clinical neurosciences,* vol. 70, no. 5, 2016, pp. 202-10. https://doi.org/10.1111/pcn.12380.
13. Hollander, Eric, et al. "Psychosocial Function and Economic Costs of Obsessive-Compulsive Disoder." *CNS Spectrums*, vol. 2, no. 10, 1997, pp. 16-25. https://doi.org/10.1017/S1092852900011068.
14. Hezel, Dianne M., et al. "Delay to diagnosis in OCD." *Journal of Obsessive-Compulsive and Related Disorder*, vol. 32, no. 100709, 2022. https://doi.org/10.1016/j.jocrd.2022.100709.
15. García-Soriano, Gemma, et al. "Factors associated with non-treatment or delayed treatment seeking in OCD sufferers: a review of the literature." *Psychiatry research,* vol. 220, no. 1-2, 2014, pp. 1-10. https://doi.org/10.1016/j.psychres.2014.07.009.
16. "Americans Becoming More Open About Mental Health." *American Psychological Association*, May 2019, www.apa.org/news/press/releases/apa-mental-health-report.pdf. Accessed 3 July 2024.
17. "Americans Perceive Gaps in Mental, Physical Healthcare." *Gallup*, 1 May 2024, news.gallup.com/poll/644144/americans-perceive-gaps-mental-physical-healthcare.aspx#:~:text=Many%20See%20Mental%20Health%20Stigma,all%20negatively%E2%80%9D%20(6%25). Accessed 3 July 2024.
18. Modi, Hemangi, et al. "Exploring Barriers to Mental Health Care in the U.S." *Research and Action Institute*, 2022, www.aamcresearchinstitute.org/our-work/issue-brief/exploring-barriers-mental-health-care-us. Accessed 20 Sept. 2023.
19. Vankar, Preeti. "Health Insured Number U.S. 1990-2022." *Statista*, 2023, www.statista.com/statistics/200946/americans-with-health-insurance/. Accessed 21 Sept. 2023.
20. Ettner, Susan L., et al. "The Mental Health Parity and Addiction Equity Act evaluation study: Impact on specialty behavioral health utilization and expenditures among "carve-out" enrollees." *Journal of health economics,* vol.

50, 2016, pp. 131-143. https://doi.org/10.1016/j.jhealeco.2016.09.009.

21. Taylor, Steven. "Early versus late onset obsessive-compulsive disorder: evidence for distinct subtypes." *Clinical psychology review,* vol. 31, no. 7, 2011, pp. 1083-100. https://doi.org/10.1016/j.cpr.2011.06.007.

Appendix (Survey used for this study)

Duration of Illness and Duration of Untreated Illness in Patients with OCD in the United States Over the Past Three Decades: A Retrospective Self-Report Study

Informed Consent

You are invited to participate in a research study that investigates the duration of illness (DI) and duration of untreated illness (DUI) in patients diagnosed with obsessive compulsive disorder (OCD) in the United States over the past three decades. DI is defined as the time between the onset of symptoms and the onset of treatment. DUI is defined as the time between diagnosis and the onset of treatment. The goal of the proposed study is to examine potential differences in DI and DUI over the past three decades (onset of symptoms within the past 10 years, past 11-20 years, and past 21-30 years).

There are three qualifications to participate in this study: (1) you must be at least 18 years of age; (2) you must have received a diagnosis of OCD by a medical professional in the United States; and (3) your initial symptoms must have started within the past 30 years.

Participation in this study is voluntary. If you agree to participate in this study, you will be asked about your OCD and other mental health problems. The survey includes questions about gender, education, employment, health insurance, race, dates concerning OCD development, OCD symptoms, severity of symptoms, other psychiatric diagnoses, possible contributing factors, and reasons for delayed treatment.

Participating in this study may not benefit you directly, but it will help us learn the differences in DI and DUI across three different decades. You may find answering some of the question uncomfortable, but we expect that this would not be different from the kinds of things you discuss with family or friends. You may end the survey at any time.

The information you share with us, if you participate in this study, will be kept completely confidential to the full extent of the law.

In this self-reported study, patient's names, email addresses, and IP addressed will not be collected nor required. Your information will be kept in a locked file and only the researchers involved in this study will be able to the see the survey responses. While the investigators(s) will keep your information confidential, there are some risks of data breaches when sending information over the internet that are beyond the control of the investigators(s).

By completing this survey, you are consenting to participate in this study.

1. Mark only one oval. *
    - I consent. I am at least 18 years old, was diagnosed with OCD by a medical professional in the US, and my symptoms started within the past 30 years.
    - I do not consent.

2. Date of Birth *

3. Gender (Mark only one oval.) *
    - Male

- Female
- Transgender
- Non-binary
- Non-conforming
- Prefer not to respond

4. Education level (Mark only one oval.) *
    - Did not complete high school
    - Completed high school (GED or equivalent)
    - Completed college/ university
    - Completed graduate level education

5. Employment status (Mark only one oval.) *
    - Full-time
    - Part-time
    - Un-employed
    - Retired

6. Health insurance provided by employer (Mark only one oval.) *
    - Yes
    - No

7. Health insurance (Mark only one oval.) *
    - PPO
    - HMO
    - POS
    - EPO
    - Medicare
    - Medicaid
    - None
    - Other:

8. Annual household income level (Mark only one oval.) *
    - $0-$50,000
    - $50,000 – $100,000
    - $100,000 – $250,000
    - $250,000 +

9. Race (Check all that apply.) *
    - White
    - Black/ African American
    - American Indian/ Alaska Native
    - Asian
    - Native American/ Other Pacific Islander
    - Prefer not to respond

10. Are you Hispanic or Latino (Mark only one oval.) *
    - Yes
    - No

11. Marital Status (Mark only one oval.) *
    - Married
    - Not married
    - Divorced

12. Have you been diagnosed with OCD by a medical professional in the United States? (Mark only one oval.) *
    - Yes
    - No

13. Did your initial symptoms occur within the past 30 years? (Mark only one oval.) *
    - Yes
    - No

14. Date when initial OCD symptoms occurred (e.g. when you first noticed symptoms) *

15. Date of OCD diagnosis by a medical professional *

16. Medical professional who made the diagnosis (Mark only one oval.) *
    - General practitioner
    - Psychologist
    - Psychiatrist
    - Other

17. Date that treatment began (therapy, medication, etc) *

18. Prior to formal diagnosis, had you heard of OCD? (Mark only one oval.) *
    - Yes
    - No

19. Prior to formal diagnosis, did you research any of your symptoms? (Mark only one oval.) *
    - Yes
    - No

20. If yes, how? (Check all that apply.)
    - Internet
    - Friends
    - Family
    - Social media/ You tube
    - Medical professional
    - Other:

21. What was your **initial** OCD symptom? (Mark only one oval.) *
    - Cleaning and hand washing
    - Checking (door, stove, etc)
    - Counting/ special numbers
    - Ordering and arranging
    - Hoarding

- Asking for reassurance
- Repeating words in your head
- Thinking ‘neutralizing’ thoughts to counter the obsessive thoughts
- Avoiding places and situations that could trigger obsessive thoughts
- Doings things in a certain order
- Aggressive, sexual, or religious obsessions and related compulsions
- Other:

22. How much time (per day) did you spend on your **initial** OCD symptom? (Mark only one oval.) *
    - 0-30 minutes
    - 30-60 minutes
    - 1-2 hours
    - 2-3 hours
    - 3-4 hours
    - 4+

23. What symptom specifically led you to seed a **professional diagnosis**? (Mark only one oval.) *
    - Cleaning and hand washing
    - Checking (door, stove, etc)
    - Counting/ special numbers
    - Ordering and arranging
    - Hoarding
    - Asking for reassurance
    - Repeating words in your head
    - Thinking ‘neutralizing’ thoughts to counter the obsessive thoughts
    - Avoiding places and situations that could trigger obsessive thoughts
    - Doings things in a certain order
    - Aggressive, sexual, or religious obsessions and related compulsions
    - Other:

24. How much time (per day) did you spend on the symptom that specifically led you to seek a **professional diagnosis**? (Mark only one oval.) *
    - 0-30 minutes
    - 30-60 minutes
    - 1-2 hours
    - 2-3 hours
    - 3-4 hours
    - 4+

25. Reasons for delayed **diagnosis** (if delayed) (Check all that apply.) *
    - Symptoms did not last long
    - Tried to ‘fix’ by yourself
    - Symptoms did not greatly affect daily life
    - Perceived social stigma
    - Access to care (availability of health services, wi-fi/ cellular, device for telehealth)
    - Not able to afford care
    - Diagnosis was not delayed

- Other

26. What symptom specifically led you to seek **treatment**? (Mark only one oval.) *
    - Cleaning and hand washing
    - Checking (door, stove, etc)
    - Counting/ special numbers
    - Ordering and arranging
    - Hoarding
    - Asking for reassurance
    - Repeating words in your head
    - Thinking ‘neutralizing’ thoughts to counter the obsessive thoughts
    - Avoiding places and situations that could trigger obsessive thoughts
    - Doings things in a certain order
    - Aggressive, sexual, or religious obsessions and related compulsions
    - Other:

27. How much time (per day) did you spend on the symptom that specifically led you to seek **treatment**? (Mark only one oval.) *
    - 0-30 minutes
    - 30-60 minutes
    - 1-2 hours
    - 2-3 hours
    - 3-4 hours
    - 4+

28. Check all of the OCD symptoms you have experienced since onset of symptoms (Check all that apply.) *
    - Cleaning and hand washing
    - Checking (door, stove, etc)
    - Counting/ special numbers
    - Ordering and arranging
    - Hoarding
    - Asking for reassurance
    - Repeating words in your head
    - Thinking ‘neutralizing’ thoughts to counter the obsessive thoughts
    - Avoiding places and situations that could trigger obsessive thoughts
    - Doings things in a certain order
    - Aggressive, sexual, or religious obsessions and related compulsions
    - Other:

29. Any other formal psychiatric diagnosis or self-reported disorders (Check all that apply.) *
    - Schizophrenia
    - Generalized anxiety
    - Social anxiety disorder
    - Depression
    - Bipolar disorder
    - Panic disorder
    - Body dysmorphic disorder

- Eating disorder
- Trichotillomania (hair pulling)
- Hoarding disorder
- Excoriation disorder (skin picking)
- Tic disorder
- ADHD
- Substance abuse
- None
- Other:

30. Any family history of psychiatric disorders? (Mark only one oval.) *
    - Yes
    - No

31. If yes, what psychiatric disorders?

32. Reasons for delayed **treatment** (if delayed) (Check all that apply.) *
    - Symptoms did not last long
    - Tried to 'fix' by yourself
    - Symptoms did not greatly affect daily life
    - Perceived social stigma
    - Access to care (availability of health services, wi-fi/ cellular, device for telehealth)
    - Not able to afford care
    - Diagnosis was not delayed
    - Other

33. Is your treatment for OCD covered by your insurance? (Mark only one oval.) *
    - Yes
    - No
    - Partially

34. Do you use any OCD apps? If yes, which ones?

35. If you use a OCD app, how helpful has it been? (Mark only one oval.)
    - 1 Not helpful
    - 2 Somewhat helpful
    - 3 Moderately helpful
    - 4 Very helpful
    - 5 Very helpful

36. Are you in a social media support group for OCD? (Mark only one oval.) *
    - Yes
    - No

37. If you are in a support group on social media for OCD, how helpful has it been? (Mark only one oval.)
    - 1 Not helpful

- 2 Somewhat helpful
- 3 Moderately helpful
- 4 Very helpful
- 5 Very helpful