The Experience of Adults With Attention-Deficit/Hyperactivity Disorder in 2021 During the COVID-19 Pandemic: The UNCOVER Study

Subhara Raveendran, PhD; Mary C. Burke, MD; Karen Klahn, MBA; Maggie McCue, MS, RD; Anit Roy, BS; Michael Martin, MD, MBA; and Sara Sarkey, PhD

ABSTRACT

Background: This study surveyed adults with attention-deficit/hyperactivity disorder (ADHD) to understand the impact of the COVID-19 pandemic on aspects of their disorder, quality of life, and treatment experience.

Methods: A cross-sectional survey of US-resident members of PatientsLikeMe (PLM) was conducted through the PLM health tracking platform between March 10 and April 2, 2021. Adult participants with self-reported ADHD currently taking prescription medication (treated) and those not taking medication (untreated) were enrolled.

Results: The study included 93 adults, of whom 48 patients were taking medication for ADHD. Most of the 45 untreated patients were not taking medication for reasons unrelated to the pandemic. Of the 47 treated patients who also completed the survey, 22 patients had ≥ 1 switch in ADHD medication type, and nearly half had a dosage change during the pandemic. Further, 29 treated patients reported a negative impact of the pandemic on their daily ADHD medication routine, primarily due to a "lack of schedule" and "changes to structured routine," and 16 patients reported "increased difficulty" adhering to prescribed ADHD medication during the pandemic compared with before the pandemic. Of the total study population, 52 patients reported having a telehealth visit during the pandemic, and 38 patients had an ADHD management goal. All but 1 patient with an ADHD management goal reported a negative impact of the pandemic on progress toward their goal. More treated patients than untreated adults reported having control over bothersome ADHD symptoms.

Conclusions: Adults with ADHD reported increased difficulty in managing their symptoms during the COVID-19 pandemic.

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Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterized by inattention, hyperactivity, and impulsivity.[1] ADHD often begins in childhood, but it persists into adulthood for many individuals.[1,2] The prevalence of ADHD in adults was estimated to be 4.4% in a US national survey.[3]

The core symptoms of ADHD (inattention, hyperactivity, and impulsivity) tend to endure throughout life, but their clinical presentation may change over time.[4–6] In adults, inattention can be expressed through difficulties organizing and prioritizing work, lack of concentration, and trouble completing tasks.[5,6] Hyperactivity can be characterized by feelings of restlessness or agitation, excessive talking, and the inability to rest, relax, or sleep.[6,7] Impulsivity can manifest as frequent job changes, interrupting, acting without forethought, and blurting out thoughts that can cause distress to others.[5,6] Adults with ADHD are also more likely to engage in sensation-seeking behavior, risk taking, and unhealthy practices such as smoking or alcohol or drug misuse.[6,7]

ADHD has a negative impact on long-term outcomes (including educational attainment and employability) among adults, as well as on their self-esteem and social functioning.[8–10] A recent (2019) cross-sectional study by Quintero et al[11] found that, compared with control populations, adults with ADHD reported significantly lower (ie, worse) total scores and scores on all subscales of life outlook, relationships, psychological health, and life productivity on the Adult ADHD Quality of Life rating scale. Long-term ADHD can result in a variety of burdensome socioeconomic costs such as loss of work productivity, increased health care expenditures, and higher spending on social services.[9,12,13] Other impacts are more difficult to quantify, such as high emotional burden, impaired goal attainment, and poor quality of life for both the individual with ADHD and other family members.[9]

PatientsLikeMe (PLM) is an online, integrated community that offers health management and a real-world data platform through which patients with diverse medical conditions support one another and share personal information about their health, symptoms, and treatments.[14] The PLM platform provides real-world data on a wide range of conditions and their management by tracking symptoms, quality of life, and other important health data. As of early 2020, the PLM community consisted of approximately 830,000 members, sharing their experiences managing over 2,800 conditions, including ADHD.

The ongoing COVID-19 pandemic has resulted in widespread shifts in social interactions and access to effective treatment since early 2020. School and workplace closures leading to impaired social

Clinical Points

- Adult patients with attention-deficit/hyperactivity disorder (ADHD) found it more difficult to manage their symptoms during the COVID-19 pandemic than before.
- The COVID-19 pandemic led to disruptions in daily routine, fewer in-person interactions with health care providers and peers, and employment-related stress, all of which caused issues with adherence to ADHD treatment regimens among patients.
- As patients with ADHD have diverse treatment and disease management goals, health care providers should aim to provide support tailored to the individual needs of every patient to facilitate achievement of these goals.

interactions and financial uncertainties, telehealth services without in-person support and interaction, and other pandemic-related stressors may be especially challenging for patients with psychiatric and neurodevelopmental disorders, including adults with ADHD.[15,16] These changes have the potential to worsen ADHD symptoms and increase the burden of disease. The UNCOVER study (**Un**derstanding the patient experience during the **COV**ID-19 pandemic, **e**ffects on **r**eal world quality of life, symptom management and clinical outcomes in patients treated and untreated for ADHD) surveyed adult patients with ADHD in the US who are members of PLM to better understand the impact of the COVID-19 pandemic on aspects of their disorder and quality of life.

METHODS

Study Design

In the UNCOVER study, a 36-question cross-sectional survey was conducted between March 10 and April 2, 2021, via the PLM health tracking platform. The study included adult patients (aged ≥ 18 years) with ADHD in the US who were taking prescribed medication for ADHD (treated) or were not taking any ADHD management drugs (untreated). Study participants were PLM members with self-reported ADHD who provided written informed consent. No additional exclusion criteria were applied. The UNCOVER study protocol was approved by the WIRB-Copernicus Group Institutional Review Board on February 23, 2021. Questions that captured the experience with ADHD are listed in Supplementary Appendix 1.

Data and Statistical Analyses

The survey collected data related to the impact on treatment, access to medical care, symptoms, and ADHD management goals. Descriptive statistics were calculated for demographics and individual survey items. Summary statistics for continuous variables included the number of respondents and mean value. Categorical variables were reported as frequencies and proportions. Categorical variables were compared using the χ^2 test, and continuous variables were compared between groups using 2-sample *t* tests.

RESULTS

Study Participants and Impact of the COVID-19 Pandemic on Employment and Insurance

The 39-question survey was completed by 93 adults (Table 1). The majority of respondents were female and aged ≥ 40 years. Of the 93 participants, 32 individuals (34%) reported a change in employment status during the COVID-19 pandemic, and 8 of them had lost their jobs and were still unemployed at the time of this study. Twenty participants (22%) had a change in their medical insurance during the pandemic, including 6 individuals who reported loss of medical insurance coverage during the study period.

Impact of the COVID-19 Pandemic on Medication Management for ADHD

Of the entire study population, 45 patients (48%) were not taking prescription drugs for the treatment of ADHD at the time of the study, and the remaining 48 patients (52%) were taking prescribed medication for ADHD. Of the 45 patients not on any prescribed ADHD medication at the time of the study, 4 patients reported that they were regularly taking prescribed medication for ADHD prior to the pandemic. Only 3 (7%) of the 45 patients in this group reported difficulties accessing treatment (due to loss of employment or insurance coverage) during the pandemic as their reason for not taking ADHD medication. Most patients in this group (27/45, 60%) stated their reason for not taking prescribed ADHD medication was unrelated to the pandemic, and 7 patients (16%) reported they were not taking ADHD medication due to side effects.

Of the 48 participants who were taking prescription drugs for ADHD (such as amphetamine, lisdexamfetamine dimesylate, and methylphenidate) at the time of the study, 1 respondent did not complete additional follow-up questions on ADHD management. Of the 47 patients who completed the survey, one-quarter (23%) had at least 1 switch in their prescribed medication, and nearly half of the patients (47%) had their medication dosage changed by their physicians since the beginning of the COVID-19 pandemic (Figures 1A and B). In addition, one-third of the patients in this group (34%) reported greater difficulty in adhering to their ADHD medication during the pandemic than before (Figure 1C). Nearly two-thirds of treated patients reported that pandemic-related difficulties negatively impacted their daily medication routine, primarily due to "lack of schedule" (n = 20) and "changes to routine structure" (n = 17, Figure 1D). Fewer patients without a change in employment status reported difficulty adhering to their medication regimen, compared with those who had a change in employment, although this difference was not statistically significant ($P = .08$) (Figure 1E).

Management of ADHD Symptoms and Treatment Goals During the COVID-19 Pandemic

Of the 93 survey participants, 86 patients (44 patients taking medication for ADHD and 42 untreated patients)

Table 1. Patient Demographics and Impact of COVID-19 on Employment and Insurance Since the Start of the Pandemic

Parameter	Patient Cohort, % (n) (N = 93)
Demographics	
Gender	
Female	71 (66)
Male	29 (27)
Age, y	
18–24	1 (1)
25–39	13 (12)
40–64	57 (53)
≥65	29 (27)
Taking prescription medication for ADHD	52 (48)
Current prescription medications for ADHD	(n = 47)
Adderall XR (extended release) [amphetamine, dextroamphetamine mixed salts]	23 (11)
Adderall IR (immediate release) [amphetamine/dextroamphetamine]	21 (10)
Vyvanse [lisdexamfetamine dimesylate]	15 (7)
Ritalin XR (extended release) [methylphenidate HCl]	9 (4)
Concerta [methylphenidate extended release]	6 (3)
Ritalin IR (immediate release) [methylphenidate HCl]	6 (3)
Strattera [atomoxetine HCl]	4 (2)
Focalin IR (immediate release) [dexmethylphenidate HCl]	2 (1)
Other (modafinil [2-[(diphenylmethyl)sulfinyl] acetamide] Mydayis [mixed salts of a single-entity amphetamine product], venlafaxine HCl)	13 (6)
Comorbidities[a]	
Depression	71 (61)
Anxiety	69 (59)
Bipolar disorder	22 (19)
Obsessive-compulsive disorder	12 (10)
None of the above	12 (10)
Self-Reported Impact of COVID-19 on Employment/Insurance	
Changed employment status[b]	34 (32)
Lost job and still unemployed[c]	31 (8)
Shifted to home/remote working[c]	23 (6)
Took leave of absence for health or family reasons[c]	8 (2)
Lost job but now employed[c]	8 (2)
Working hours have increased[c]	4 (1)
Other changes[c]	27 (7)
Changed insurance status[b]	22 (20)
Loss of insurance[d]	30 (6)
Switched/added to Medicare[d]	20 (4)
Increase in premium[d]	10 (2)
Other changes[d]	40 (8)

[a]n = 86.
[b]N = 93.
[c]Among those who shared insights into their changed employment status (n = 26).
[d]Among those who changed insurance status (n = 20).
Abbreviation: ADHD = attention-deficit/hyperactivity disorder.

further described the management of their ADHD symptoms and treatment goals during the COVID-19 pandemic. Of these 86 patients, 34 patients (39%) either "disagreed" or "strongly disagreed" that their symptoms were well managed during the pandemic, citing "difficulty following through on tasks and instructions" (n = 28), "easily distracted" (n = 25), and lack of "organizational skills" (n = 21) as the most difficult symptoms to manage (Figures 2A and 2B). Most patients who "agreed" or "strongly agreed" that their symptoms were well managed during the pandemic (22/33, 67%) were taking prescribed medications (Figure 2A). Patients receiving medication for ADHD also appeared to have better control in managing the most problematic symptoms of ADHD than those not taking any medication for ADHD, although this comparison was not statistically significant ($P = .056$, Figure 2A).

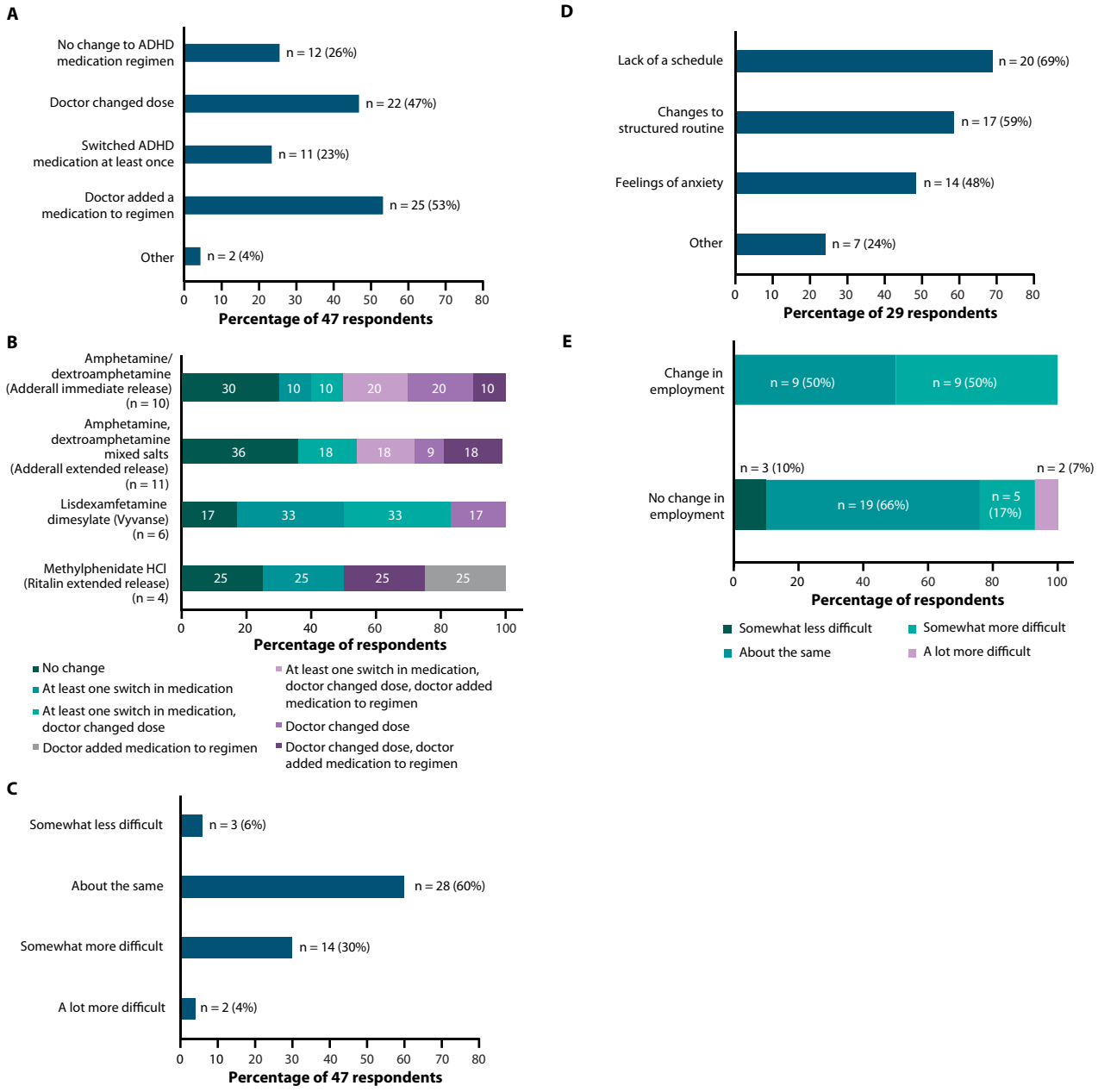
More than half of the patients (52/86, 60%) reported having at least 1 telehealth visit related to ADHD (Figure 3A). While 47 of 86 patients said that the pandemic did not affect the medical care they received for ADHD at all (Figure 3B), 15 others reported a pandemic-related negative impact on their level of medical care, including 7 patients who stated a preference for in-person care that was not easily available during the pandemic (Figure 3C).

Regardless of treatment status, 38 patients had goals for managing their ADHD during the pandemic, including management of mental health, organization, and a positive attitude (Figures 4A and 4B). However, 37 of those 38 patients reported a negative impact of the pandemic on progress toward their goal (Figure 4C).

DISCUSSION

ADHD is a pervasive disorder that can affect multiple areas of life, including employment and work productivity,

Figure 1. ADHD Medication Management During the COVID-19 Pandemic[a]

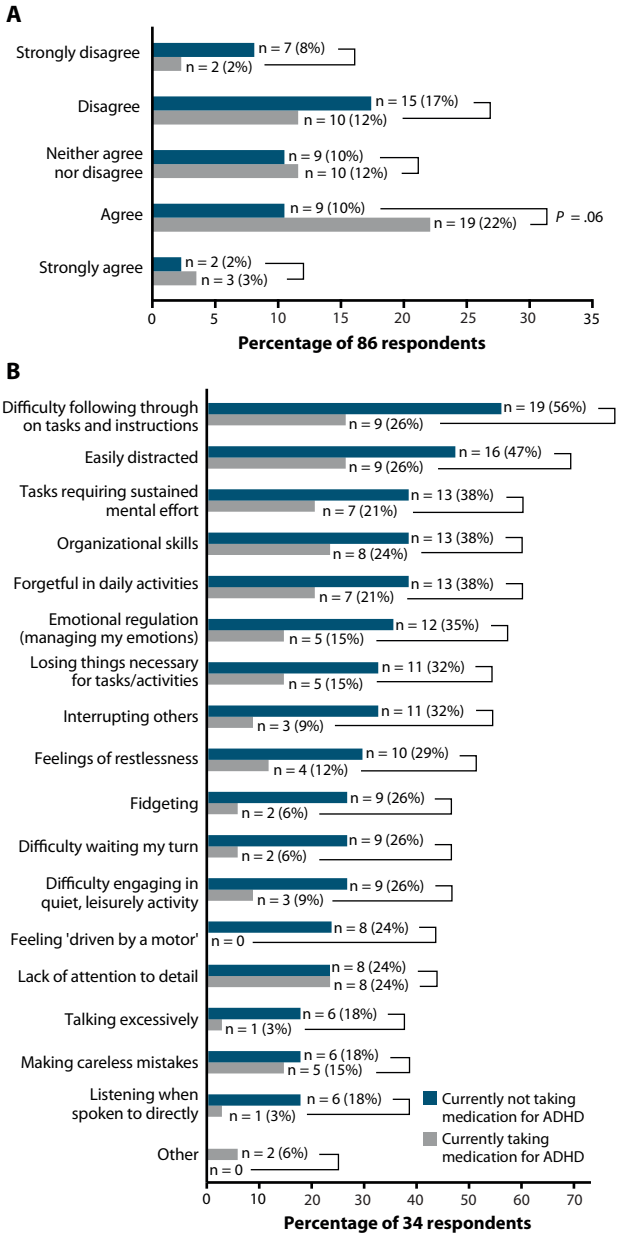


[a]The following are shown in the figure: (A) changes to prescribed medications during the pandemic among 47 survey respondents, (B) changes in prescribed dosage for the 4 most frequently prescribed ADHD drugs, (C) difficulty of adherence to prescribed medication regimen among 47 survey respondents with ADHD, (D) reasons for difficulty in medication adherence during the pandemic provided by 29 survey respondents with ADHD, and (E) impact of change in employment status on adherence to prescribed medication among patients with ADHD.
Abbreviation: ADHD = attention-deficit/hyperactivity disorder.

as well as social and family relationships. While the current COVID-19 pandemic has created unprecedented challenges at every level of society, many clinicians have recognized that individuals with ADHD may be especially vulnerable to stresses caused by the pandemic.[15] In the UNCOVER study, we aimed to understand the impact of the pandemic on patients with ADHD with respect to their quality of life, symptom management, and goal attainment and to determine the role played by their treatment status and health care interactions on that impact.

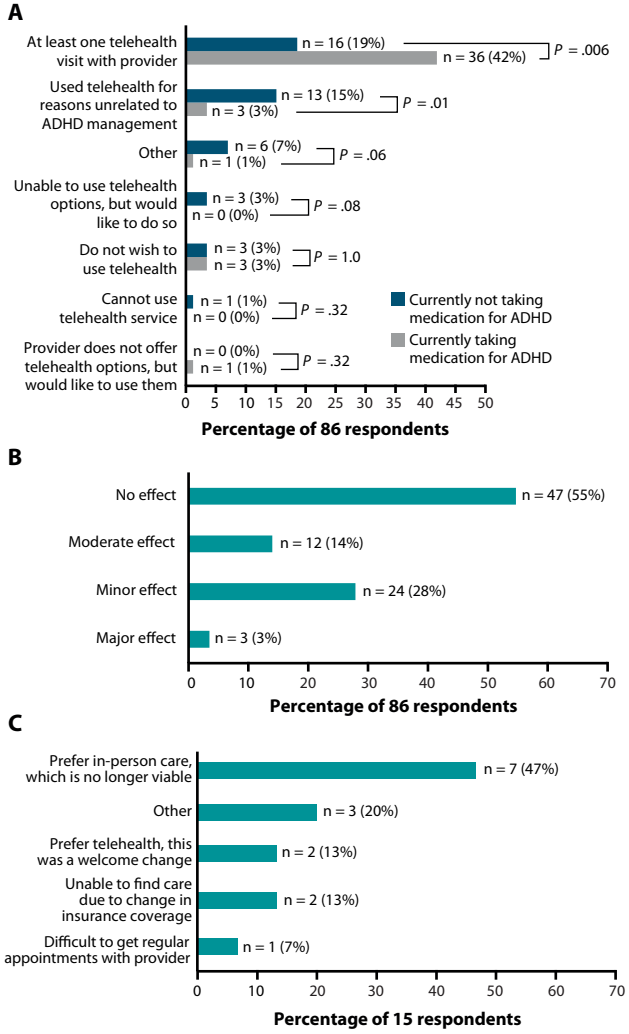
The main finding of this study was that patients with ADHD reported greater difficulty in managing their symptoms during the COVID-19 pandemic than before. Patients with ADHD experienced a wide range of behavioral symptoms that were self-reported as bothersome during the pandemic, including "difficulty following through on tasks and instructions" and being "easily distracted." Fewer patients who were taking prescription medications for ADHD reported difficulties with symptom management than those who were not being treated with medication,

Figure 2. ADHD Symptom Management During the COVID-19 Pandemic Among Patients With and Without Prescribed ADHD Medication[a]



[a]The following are shown in the figure: (A) survey responses from 86 patients with ADHD on whether their ADHD symptoms were well managed during the pandemic and (B) management of most problematic symptoms of ADHD during the pandemic among 34 survey respondents.
Abbreviation: ADHD = attention-deficit/hyperactivity disorder.

Figure 3. Medical Care for ADHD Received During the COVID-19 Pandemic Among Patients With and Without Prescribed ADHD Medication[a]

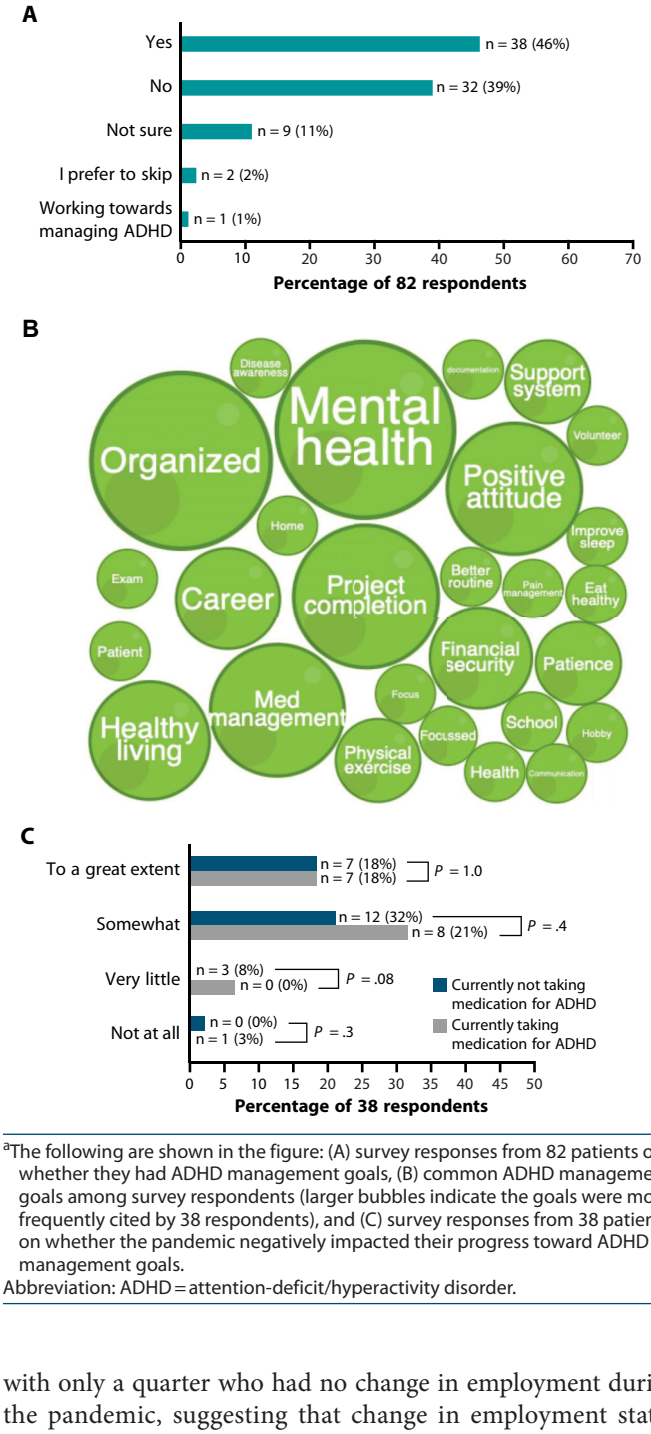


[a]The following are shown in the figure: (A) use of telehealth services among 86 survey respondents, (B) effect of the pandemic on medical care for ADHD received by 86 survey respondents, and (C) negative impact of the pandemic on medical care received by 15 survey respondents with ADHD.
Abbreviation: ADHD = attention-deficit/hyperactivity disorder.

suggesting that everyday functioning associated with ADHD was better managed in patients treated with medication.

Many patients treated with an ADHD medication reported a change in medication, dosage, or medication routine during the pandemic. In this study, 23% of treated adult patients reported a switch in prescribed medication, and 47% had a change of dose, including those taking amphetamine, lisdexamfetamine dimesylate, and methylphenidate. In this study, we do not know how long patients were on their current/previous treatment. By comparison, in a study conducted primarily in the pre-pandemic period (January 2015–October 2020),[17] 24% of treatment-naive patients switched medication within 2 months after treatment initiation, and 25% required a formulation change or another medication for anxiety or depression. The European ADHD Guidance Group[15] highlights that individuals with ADHD may be more susceptible to stresses caused by the pandemic. Pandemic-associated stress may underlie the relatively high rates of ADHD medication regimen changes reported by our survey respondents. Further, many patients in our study found it difficult to adhere to their ADHD medication during the pandemic, attributing this to pandemic-related disruptions to daily medication routine structure. Half of the patients who had a change in employment status found it difficult to adhere to their ADHD medication, compared

Figure 4. Impact of the COVID-19 Pandemic on ADHD Management Goals[a]



[a]The following are shown in the figure: (A) survey responses from 82 patients on whether they had ADHD management goals, (B) common ADHD management goals among survey respondents (larger bubbles indicate the goals were more frequently cited by 38 respondents), and (C) survey responses from 38 patients on whether the pandemic negatively impacted their progress toward ADHD management goals.
Abbreviation: ADHD = attention-deficit/hyperactivity disorder.

with only a quarter who had no change in employment during the pandemic, suggesting that change in employment status is an added stressor affecting patients with ADHD. These observations reiterated the impact of the unique circumstances of the pandemic on adult patients with ADHD.

The reduced availability of face-to-face consultations, coupled with state- and federal-level policy changes, has led to a dramatic increase in the availability of telehealth services in the United States.[16,18] In this study, 60% of respondents had at least 1 telehealth visit. The proportion of patients who had a telehealth visit was higher among those receiving ADHD medication than in untreated patients. The widespread availability of telehealth visits may partially account for the finding that over half of patients reported that the pandemic did not negatively impact the medical care received for ADHD. Nonetheless, 7 of 15 survey respondents who indicated that their ADHD-related treatment was affected by the pandemic expressed a preference for in-person care. Many respondents reported working toward a goal as a self-care strategy to better manage their ADHD. The ADHD goals of these patients were diverse, but improvement in mental health, lifestyle, and home and work environments was important. This suggests that consistent support—that is tailored to the individual needs of patients and that facilitates achievement of treatment goals—is warranted.

The current pandemic has increased the demand for health care services, which has tested the resources and resilience of health care systems.[18] Pandemic-associated stress factors, such as social isolation, financial anxieties, and health concerns, can worsen mental health issues and increase the need for clinical services.[16] Our data suggest this is especially true of patients with ADHD, who thrive under consistency and structured routines.[19] Behavioral issues of patients with ADHD can be effectively managed with medication, access to health care services tailored to individual preferences, and consistent peer support. Enhanced training to improve virtual patient-clinician interactions, design of adapted digital tools for patients with ADHD, and creation of virtual peer support groups such as PLM may compensate for the lack of face-to-face interaction and increase support for patients with ADHD using telehealth services.[16] Goal attainment training and digital tools to help track symptoms, set goals, and monitor progress (like PLM) could be helpful to further support patients in their care journey.[20]

This study is limited by the selection of participants who, as members and contributors to the PLM platform, may be particularly invested in trying to understand and manage their condition. This limits the generalizability of the findings to the overall population of patients with ADHD. In general, the PLM population is also more biased toward middle-aged women. As such, the participants in this study were also more likely to be female and aged ≥ 40 years. The small sample size restricts interpretation of the data. The cross-sectional design of the study did not capture changes in patient experiences over the course of the pandemic; for example, whether symptoms improved or deteriorated. Comparisons of patient experiences with the pre-pandemic period were not possible. The results presented in this study were merely descriptive and are not causal.

Results of this survey show that the COVID-19 pandemic potentially had deleterious effects on adults with ADHD. Patients with ADHD reported more difficulties in managing their ADHD during the COVID-19 era than before the start of the pandemic.

The proportion of patients reporting a negative impact of COVID-19 on ADHD symptom and treatment management was higher among patients not taking any ADHD medication compared with those who were taking prescription drugs for ADHD; however, these findings were not significant. More patients taking prescribed medication for ADHD reported having control over the most bothersome symptoms of ADHD than those not taking any medication for ADHD.

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Supplementary Material: See accompanying pages.

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Supplementary material follows this article.

THE PRIMARY CARE COMPANION
FOR CNS DISORDERS

Supplementary Material

Article Title: The Experience of Adults With Attention-Deficit/Hyperactivity Disorder in 2021 During the COVID-19 Pandemic: The UNCOVER Study

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List of Supplementary Material for the article

1. **Appendix 1** Study Questionnaire

Disclaimer

This Supplementary Material has been provided by the author(s) as an enhancement to the published article. It has been approved by peer review; however, it has undergone neither editing nor formatting by in-house editorial staff. The material is presented in the manner supplied by the author.

SUPPLEMENTARY MATERIAL

Appendix 1. Study Questionnaire

Section 1: Introduction

Welcome to the UNCOVER Study Understanding the patient experience during the COVID-19 pandemic, effects on real world quality of life, symptom management and clinical outcomes in patients treated and untreated for ADHD.

This survey is part of our research collaboration between PatientsLikeMe and Takeda. We appreciate your time and willingness to share your experiences with us. The goal of this study is to better understand your symptoms of ADHD and which ones are most troublesome and hardest to resolve. During this study we will ask a variety of questions related to your experience with ADHD.

Section 2: Demographic Characteristics

Intro: First, we would like to ask you some background questions about you

1. What is your age?
    - Date picker

2. What is your country of residence?
    - U.S.
    - Not U.S. **[SCREEN OUT]**

    Logic→ if respondent indicates non-U.S. residence, end module and present thank you language.

3. What state do you live in?
    - Dropdown

4. What is your sex?
    - Female
    - Male
    - I prefer not to answer

5. Has your employment status changed during the COVID-19 pandemic?
    - Yes
    - No

    Skip→ if respondent answers Yes present question 6 else skip to question 7

6. You indicated your employment status changed during the COVID-19 pandemic. Which of the following most closely describes your situation?

    - My job shifted to remote/working from home
    - I lost my job and am still unemployed
    - I lost my job but am now employed
    - My hours have been reduced
    - My hours have increased
    - I took a leave of absence due to health or other family reasons
    - None of these describes my employment situation during the COVID-19 pandemic

    Skip→ if respondent answers "None of these" present a follow-up open text in Q7 else skip to Q8

7. Please describe the change in employment status you have experienced during the COVID-19 pandemic. [OPEN TEXT]

8. Has your insurance coverage changed during the COVID-19 pandemic?
    - Yes
    - No

    Skip→ if select yes present question to ask in what ways/reasons in Q9 else skip to Q10

9. Which of the following best describes the change in insurance coverage you have experienced during the COVID-19 pandemic? (***Select all that apply***)

    - Loss of insurance
    - Change in insurance policy resulting in a decrease of coverage
    - Increase in premiums
    - Increase in deductibles / copays
    - Loss of prescription coverage
    - Reduction in prescription coverage
    - Other (specify)

10. Are you a parent or guardian of a child below age 18 years with ADHD?
    - **No**
    - Yes

    Skip → If selected **No**, module branches to survey **Version A**
    Skip → If selected Yes, module branches to survey Version B

Survey Version A: written for adults with ADHD of the appropriate age (ie 18+)
Survey Version B:written for parents/guardians of children/adolescents below age 18

Below are the questions for Survey **Version A**

Section 3: Diagnosis

Transition language: Next, we would like to know a little more about your experience living with ADHD during the COVID-19 pandemic. This helps us understand where in your journey you are and enables us to compare experiences.

11. How old were you when you were first diagnosed with ADHD?
    - Please enter a whole number. [age]
    - I have not been diagnosed with ADHD [**SCREEN OUT**]
    - I do not remember how old I was when I was diagnosed with ADHD

Logic→ if indicate they have not been diagnosed, end module and present thank you language.

Section 4: Patient experience with treatment

12. Are you currently taking prescribed medication for ADHD?
    - Yes
    - No

Skip→ If selected No, then present Q13 - Q14; and skip to Q21
Skip→ If selected Yes, present Q15 through Q19 (note, Q19 has skip logic for presenting Q20)

13. Which of the following best describes your reason(s) for not taking prescribed medication for ADHD during the COVID-19 pandemic? (***Select all that apply)***
    - I had issues with accessing treatment during the pandemic that have not resolved (such as loss of employment and/or change in my insurance)
    - I began experiencing side effects
    - My reason is not related to the COVID-19 pandemic
    - Other reasons [please describe]

14. Prior to the COVID-19 pandemic, were you taking prescribed medication for ADHD? *Please answer thinking about the time period immediately prior to when the pandemic impacted your area (ie, lockdown or other changes due to the pandemic)*
    - Yes
    - No
    - Does not apply
    - I prefer to skip

15. You mentioned you *are currently* taking prescribed medication for ADHD. What changes have you experienced with the ADHD medication during the COVID-19 pandemic? *(**Select all that apply**)*
    - I have switched ADHD medications at least once
    - My doctor has changed my dose
    - My doctor has added a medication to my regimen
    - I have had no changes to my ADHD medication regimen
    - Other [specify]

16. Which of the following prescribed medications are you currently taking for your ADHD?
    - Adderall IR (immediate release) [amphetamine/dextroamphetamine]
    - Adderall XR (extended release) [amphetamine, dextroamphetamine mixed salts]
    - Concerta [methylphenidate extended-release]
    - Dexedrine [Dextroamphetamine]
    - Evekeo [amphetamine sulfate]
    - Focalin IR (immediate release) [dexmethylphenidate HCL]
    - Focalin XR (extended release) [dexmethylphenidate HCL]
    - Intuniv [guanfacine]
    - Quillivant XR [methylphenidate hydrochloride]
    - Ritalin IR (immediate release) [methylphenidate hcl]
    - Ritalin XR (extended release) [methylphenidate hcl]
    - Strattera [atomoxetine hcl]
    - Vyvanse [lisdexamfetamine dimesylate]
    - I do not know which one but am taking medicine for my ADHD
    - Other [Specify]

17. Compared to before the COVID-19 pandemic, how difficult is it to adhere to taking your ADHD medication as prescribed?
    - A lot more difficult
    - Somewhat more difficult
    - About the same
    - Somewhat less difficult
    - A lot less difficult

Skip→ If selected any response other than “About the same” present follow-up open text question Q17

18. Could you tell us more about what has been easy or difficult about adhering to your ADHD medication during the pandemic? [OPEN TEXT]

19. Due to the COVID-19 pandemic, to what extent has your daily routine for taking ADHD medication been interfered with?
    - To a great extent
    - Somewhat
    - A very little
    - Not at all

Skip→ If selected any option other than "not at all" present Q20 else skip to Q21

20. The pandemic has impacted my daily ADHD medication routine due to … (***Select all that apply***)
    - Feelings of anxiety
    - Lack of a schedule
    - Changes to my structured routine
    - Challenges with childcare
    - Other [please specify]

Section 5: Standard of care

Transition language: Next, we would like to ask some questions about your care experiences over the last several months during the COVID-19 pandemic

21. When was your last annual primary care physician (PCP) visit (e.g., in-person visit or telehealth)?
    - During this past year (1/1/2020 through 1/1/2021)
    - Within the past two years
    - Three years or more
    - Appointment is scheduled but have not had it yet
    - I do not have a primary care physician

22. What type of health care provider/professional are you currently seeing for managing your ADHD? (***Select all that apply)***.
    - Primary care physician
    - Psychologist
    - Psychiatrist
    - Social worker
    - Nurse practitioner
    - Physician assistant
    - I am not currently seeing a health care professional for ADHD

- Other [specify]

23. How would you describe your use of telehealth/video chat during the COVID-19 pandemic for managing your ADHD?
    - I have had at least one telehealth visit with my provider
    - I would like to use telehealth but my health care provider has not offered it
    - I would like to use telehealth but have not been able to (for example, could not find a provider with my insurance)
    - I was offered telehealth but then I had to switch back to in-person
    - I do not have the working technology or problems with Internet/Wi-Fi exist and I cannot use telehealth
    - I have used telehealth for other reasons, but not for ADHD
    - I do not wish to use telehealth
    - Other [please describe]

24. To what extent has the COVID-19 pandemic affected the medical care you receive for ADHD?
    - 1. No effect
    - 2. Minor effect
    - 3. Moderate effect
    - 4. Major effect

Skip → If respond with 3 or 4, present Q25 else, skip to Q26.

25. You mentioned the pandemic has affected the care you receive for ADHD. How has it impacted your care?

    - It is harder to access my health care provider for regular appointments
    - I prefer in-person care, but it is no longer a viable option for me to see my therapist in person
    - I prefer telehealth/video chat for my care and this was a welcome change
    - The frequency of visits to my therapist have decreased
    - The frequency of visits to my therapist have increased
    - Other [specify]

Section 6: Symptom experience and impact on functioning and productivity

Transition language: Next, we would like to ask some questions about your mental health and symptom experiences and impact on daily life over the last several months (since March 2020) during the COVID-19 pandemic.

26. Have you ever been diagnosed with any of the following? (***Select all that apply***)
    - Anxiety
    - Bipolar disorder
    - Depression
    - Obsessive Compulsive disorder (OCD)
    - None of the above

27. What is your agreement with the following statement:

    During the pandemic, my ADHD symptoms have been well-managed

    - Strongly agree
    - Agree
    - Neither agree nor disagree
    - Disagree
    - Strongly disagree

    Skip → If answer Strongly disagree or disagree, present question Q28, else skip to Q29

28. During the COVID-19 pandemic, which symptoms have been most problematic to manage? (***Select all that apply***)
    - Making careless mistakes
    - Lack of attention to detail
    - Emotional regulation (managing my emotions)
    - Listening when spoken to directly
    - Difficulty following through on tasks and instructions
    - Organizational skills
    - Tasks requiring sustained mental effort
    - Losing things necessary for tasks/activities
    - Easily distracted
    - Forgetful in daily activities
    - Fidgeting
    - Feelings of restlessness
    - Difficulty engaging in quiet, leisurely activity
    - Feeling “driven by a motor”
    - Talking excessively
    - Interrupting others
    - Difficulty waiting my turn
    - Other [specify]

29. Have your ADHD symptoms changed during the pandemic or have new symptoms emerged? Please describe [OPEN TEXT]

30. What is your agreement with the following statement

During the pandemic, I have been receiving the support I need to manage my life.

- Strongly agree
- Agree
- Neither agree nor disagree
  Disagree

31. During the pandemic, how much has your ADHD affected your life?

- A lot
- Some
- A little
- Not at all

32. Have you been working toward any goals for managing your ADHD during the COVID-19 pandemic (for example, goals to improve symptoms, to feel better, improve social aspects of life, improve functioning at work)?

- Yes
- No
- Not sure
- I prefer to skip

Skip → If replied Yes, present Q33-34 else skip to Q35

33. [OPEN TEXT] Please describe the top goals (1-3) that matter most to you.

34. To what extent has the pandemic impacted your ability to make progress toward these goals?

- To a great extent
- Somewhat
- A very little
- Not at all

35. Are you currently enrolled in school?

- No
- Yes, college (undergraduate)
- Yes, graduate school
- Other

36. Do you have primary caregiving responsibilities for: (***Select all that apply***)

- A child/dependent
- A parent(s)

- Other relatives or family members
- None of the above
- I prefer to skip

<< ***End survey and present thank you language*** >>