



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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DOI Number: <https://doi.org/10.4088/PCC.22r03474>

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* >>