



MEDICATION-TAKING BEHAVIOUR IN ATTENTION-DEFICIT HYPERACTIVITY DISORDER (ADHD): A QUALITATIVE ANALYSIS OF SOCIAL MEDIA DATA

Introduction

- Adherence to ADHD medications is widely considered sub-optimal^{1,2}
 - Understanding the reasons for suboptimal adherence is important as effective treatment is linked to better symptom control, safety, and functional outcomes³
- While adherence is often operationalized as a binary concept,⁴ real-world patterns of medication use are more nuanced⁵
 - In addition, many adherence studies rely on self-report, which can be biased;⁶ or administrative databases, which cannot provide information on how medication is taken, or other contextual factors⁴
- Social media forums may provide a rich source of real-world data on how and why people take their medications in the way they do⁷
 - To our knowledge, these data have not been used to explore medication-taking behaviour in ADHD
- Objective:** To explore how individuals with ADHD describe and discuss their intentional medication-taking behaviours, including the personal, social and structural contexts that drive decision-making

Methods

We conducted a reflexive thematic analysis⁸ of publicly-available data from Reddit



Reddit users (known as 'redditors') post anonymously, allowing more open discussion of topics than on platforms lacking this level of privacy⁹

Posts were primarily identified from the r/ADHD subreddit, using a search strategy including keywords for adherence and ADHD

- Included threads contained posts discussing personal experiences of taking one's ADHD medication, with a focus on behaviours differing from regular daily use
- Posts related to how people without a prescription use ADHD medication were not included

In this interim analysis, data within the first set of posts identified were analyzed using NVivo 14 (QSR International)

Given our use of publicly-available anonymous social network data, ethical review was not required

Results

43 threads identified for screening

23 selected for analysis

Threads discussed situations in which individuals engaged in different medication taking behaviours and the reasons for these; while some reported taking their medications regularly as directed, many others described altering doses, and skipping or sharing medications

Drivers of medication-taking behaviour in ADHD



THEME #1: DAILY DECISION-MAKING IN CONTEXT

- Redditors discussed the day-to-day situations that prompted skipping medication or altering doses
 - "There have been several days I missed my dose at first and when I remembered it was too late in the day (was worried it would affect sleep)" - R1*
 - "this might sound like a bad way to do it, but my 'breaks' are any days that I accidentally sleep in (I can have a hard time going to bed if I take my XR in the mid- to late- morning) or if I plan to drink or smoke that day. I'm usually pretty good at estimating and staying within my limits for the night, but stimulants make it way harder and I don't really like that feeling." - R2*
- Common contexts included sleep concerns, illness, or when consuming alcohol or other substances that could interact with ADHD medication
- Productivity demands were the most common reason for taking more than the prescribed dose. While some individuals doubled their dose on long or demanding days, others were prescribed an as-needed booster dose
 - "My doctor (who also has ADHD) gives me an RX for 10 short-acting ritalin per month to use as a booster on long days. I almost never need the 10, but I've learned my lesson that I absolutely need to take it on days when take the later jiu jitsu class instead of the earlier and the Concerta has worn off. Otherwise I get distracted and injured, so no thank you" - R3*
- A small number of posts described over-using medication in the context of a desire to always feel productive, which could lead to running out of medication early
 - "sometimes I double up on extra hard days :(I'm still finding the right dosage so I feel like my current dosage is too low" - R4*
- In some cases, taking more than prescribed was driven by dose experimentation or inadequate effect of one's current dose



THEME #2: STRUCTURAL BARRIERS CAN SHAPE MEDICATION-TAKING STRATEGIES

- Redditors valued having a surplus of medication to account for barriers such as supply chain-related medication shortages, pharmacy dispensing policies or prescription processing delays, insurance provider requirements (e.g., refill timing and reauthorizations), and difficulty accessing timely provider appointments for prescription renewals
- Individuals described strategically skipping medication on days when they could manage without, to ensure they had a surplus
 - "I even hoard mine, strategically skipping doses just to have an emergency supply in case my doctor is on vacation or there is a shortage" - R5*
- In addition, individuals without insurance, or with limited coverage, described rationing medications due to their prohibitive cost
 - "meds are expensive so if its a weekend day and I know I've got nothing important going on, I might decide not to take it to stretch my script a little longer or save a couple backup pills." - R6*



THEME #3: HELPING EACH OTHER OUT

- While Redditors generally expressed opposition to selling or sharing medication, a notable exception was sharing with friends or family members who also had ADHD
- Most who admitted to sharing expressed they limited to individuals with their own prescription, and often to a specific person with the same prescription
- The context of medication sharing described was almost always altruistic:
 - To help friends or family who have a prescription but had forgotten their own medication; or in cases of medication shortages or barriers to timely refills
 - For individuals without their own prescription; while less frequent, some posts disclosed sharing based on an understanding of the long wait times or other barriers to obtaining a diagnosis
- "The only time I have ever shared my medication was with my sister who has the exact same prescription as me. Same dosage and brand." - R7*
- "I've had it happen a couple times from people who don't have adhd and want to buy it to study. NO. However, I have lots of adhd friends who take the same meds I do and if there's a shortage on one of our ends we do help each other out. That's the only exception." - R8*



THEME #4: TAKING MEDICATION TO LIVE, NOT JUST TO SURVIVE

- Beyond individual, social and structural factors that drove day-to-day decisions, individuals differed in their beliefs about how best to take their ADHD medication
- Some valued taking breaks from their medication on weekends or taking them 'as needed', and the reasons provided for these behaviours varied greatly
- These included that they were following their prescriber's guidance, or concerns about developing tolerance or dependence
- Others sought breaks from medication side effects, or felt that breaks allowed them to experience positive aspects of their personality suppressed by medication
 - "My doctor is one of those 'it's good to give your body a break to prevent a tolerance, just be,' kinda guys, so he encourages this. He says it's good to let my body function (or not function) without adderall." - R9*
 - "I always do skip days to make sure my meds keep working. I'm way more functional if I only take it 3-5 times a week, as opposed to every day. Plus I never have to worry about physiological dependence or reduced efficacy." - R10*
 - "In my case it's because I'm more fun I think when I'm off it. More wild and crazy maybe, too much energy, but it's fun." - R11*
- In contrast, many felt that taking medication daily was critical to supporting their quality of life; resisting the idea that medication should only support productivity during the work week
 - "I need it to live instead of survive, so on my days off I need it even more to live a full life." - R12*
 - "I take it daily - but ultimately, that's because I need it every day. I only work Mon-Fri but I need my medication to do household tasks and to enjoy my leisure time. My symptoms would prevent me from enjoying video games or paying attention to my friends, or from cleaning my room, so not taking meds just because I'm not working isn't gonna work." - R13*

Discussion

Our findings highlight the variability in ADHD medication-taking behaviour, and the reasons underlying it. Redditors with ADHD described:

- Individualized approaches shaped by both patient and prescriber preferences, sometimes with flexibility in how patients take their medication from day to day
- The contextual and structural factors influencing their access to their necessary medication, and their views on medication sharing



These insights are important as they reveal factors necessary to understanding whether someone is 'adherent', that may be overlooked in assessments lacking contextual data



Strengths include the large sample of posts reviewed and the anonymous nature that would encourage honest and unfiltered reflections on medication-taking behaviours



However, anonymity may not eliminate reluctance to disclose behaviours that may conflict with community norms and values

Though beyond the scope of this analysis, characterizing the impact of unintentional behaviours (e.g. missing or double dosing due to forgetfulness) is also important for understanding how people take ADHD medication



Ideally, these findings will help clinicians better understand their patients' motivations, and researchers understand how people take ADHD medications in real-world settings



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