

This is a self-archived version of the original publication

The self-archived version is a publisher's pdf of the original publication. Please note that the self-archived version may differ from the original in pagination, typographical details and illustrations.

Danielson, J., Nafiseh, M., & Espinosa-Leal, L. (2024). Attention Deficit Hyperactivity Disorder: trends and themes of information seeking and needs. *Informaatiotutkimus*, 43(3-4), 74-80.

DOI: 10.23978/inf.148580

All material supplied via Arcada's self-archived publications collection in Theseus repository is protected by copyright laws. Use of all or part of any of the repository collections is permitted only for personal non-commercial, research or educational purposes in digital and print form. You must obtain permission for any other use.

INFORMATION STUDIES DAYS 2024



Attention Deficit Hyperactivity Disorder: trends and themes of information seeking and needs

Jonas Danielson

Arcada University of Applied Sciences

jonas.danielson@arcada.fi

<https://orcid.org/0000-0002-6821-1571>

Nafiseh Mohammadi

Arcada University of Applied Sciences

nafiseh.mohammadi@arcada.fi

<https://orcid.org/0009-0006-2710-7213>

Leonardo Espinosa-Leal

Arcada University of Applied Sciences

leonardo.espinosaleal@arcada.fi

<https://orcid.org/0000-0001-6861-8024>

Keywords: ADHD, information need, information behavior

Pysyvä osoite: <https://doi.org/10.23978/inf.148580>

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterized by hyperactivity, impulsivity, inattention, and deficits in executive functions. Symptom severity and presentation vary widely (Eagle & Ringland, 2023). In recent years, the number of diagnoses of ADHD have been increasing in Finland, especially in children and adolescents. The prevalence of ADHD diagnoses among boys aged 7–17 was 8.3% in 2022, compared to 2.9% in 2015. For girls, there was an increase in prevalence from 0.7% to 3.3% during the same period (Finnish Institute for Health and Welfare, 2024). For the adult population, the estimated prevalence is between 2.5 and 3.4% (Duodecim, 2019). The diagnostic process and the management of ADHD is complex as well as multifaceted and associated with uncertainty and a heightened need for information (Ahmed, 2014; Eagle & Ringland, 2023). Information needs have been said to arise from the recognition that there is a knowledge gap or knowledge insufficiencies in an individual to meet or satisfy a specific goal or underlying purpose (Ormandy, 2010). For individuals or their relatives either diagnosed or suffering from ADHD symptoms, this knowledge deficit appears to be a common occurrence both before and after diagnosis (Eagle & Ringland, 2023; Sciberras et al., 2010). Information is a vital component in understanding, adjusting, managing and coping to neurological diversity (Sciberras et al., 2010). The fact that ADHD is a stigmatized condition, with many negative associations and prejudices, can act as a barrier to seek professional help. Previous research has suggested that individuals seek out alternative support systems and self-management solutions and prefer to turn to online sources to help fulfil information needs about ADHD (Bussing et al., 2012; Scholze et al., 2023). These include social media or online forums, that allow individuals to gain support from people in similar situations, experiences or diagnoses (Eagle & Ringland, 2023; Lundin, 2020).

The rising prevalence combined with the fact that there is limited research on ADHD related information behaviour (Scholze et al., 2023) is fruitful research setting that needs further exploration. Deeper knowledge on this issue can have substantial impact on information and communication intervention planning. The aim of this pilot study is to investigate online health information seeking behaviour, as well as expressed information needs in relation to ADHD.

Methodology

To explore patterns of information seeking in relation to ADHD we utilized the Google Health Trends Application Programming Interface (GHT-API) to collect daily search volume

data for the term "ADHD" in Finland from 2013 to 2023. The data was analysed using Python with libraries such as "pandas" and "seaborn". To explore information needs, we downloaded/scraped threads from the ADHD subcategory of the Finnish discussion forum Suomi24 for the years 2012 to 2022. This resulted in 2306 posts included for the content analysis to identify expressed information needs. For the development of an inductive coding scheme, we utilised a large language model (Microsoft Copilot), as these have been found reliable in assisting with qualitative analysis (Bijker et al., 2024). The posts in Suomi24 are openly available and considered to be in the public domain, thus permitted for research purposes (Lundin, 2020). Therefore, no consent or research permit was necessary.

Results

Only a few preliminary results will be presented here in this initial stage of analysis, as a more thorough presentation of the results will be published in an upcoming article. Regarding information seeking, ADHD related searches have during the last 10 years shown a significant increase, as can be seen in Figure 1. The increase is especially visible for the last three years. On a yearly level, the pattern of ADHD related searches follows a bimodal curve, with higher values during spring and autumn, and lower values during summer and Christmas (see Figure 2).

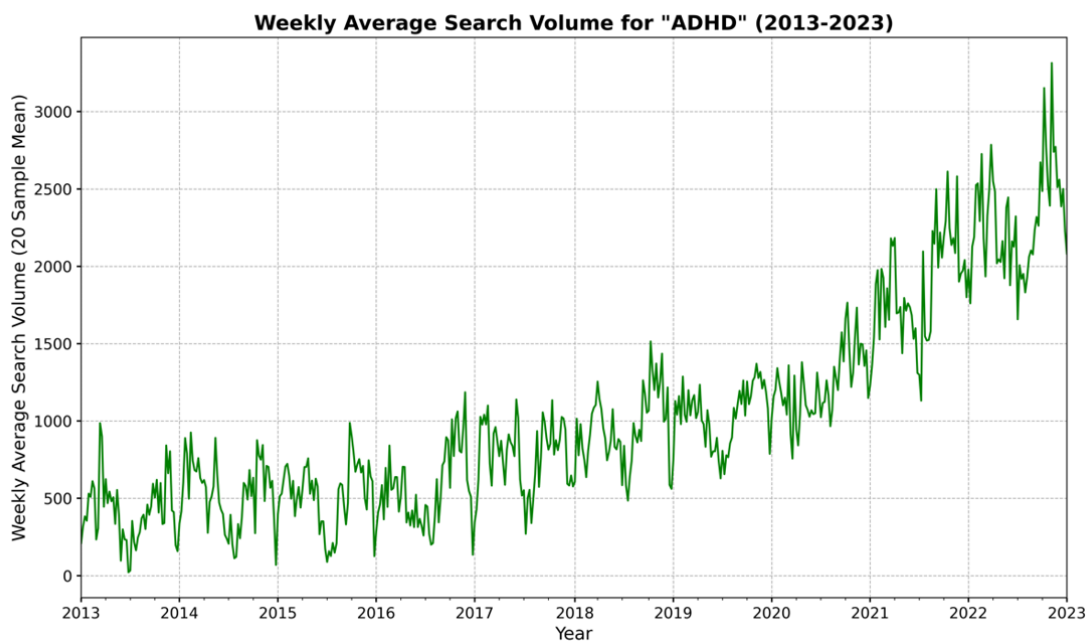


Figure 1: Weekly Average Search Volumes for the Term "ADHD" in Finland (2013-2023).

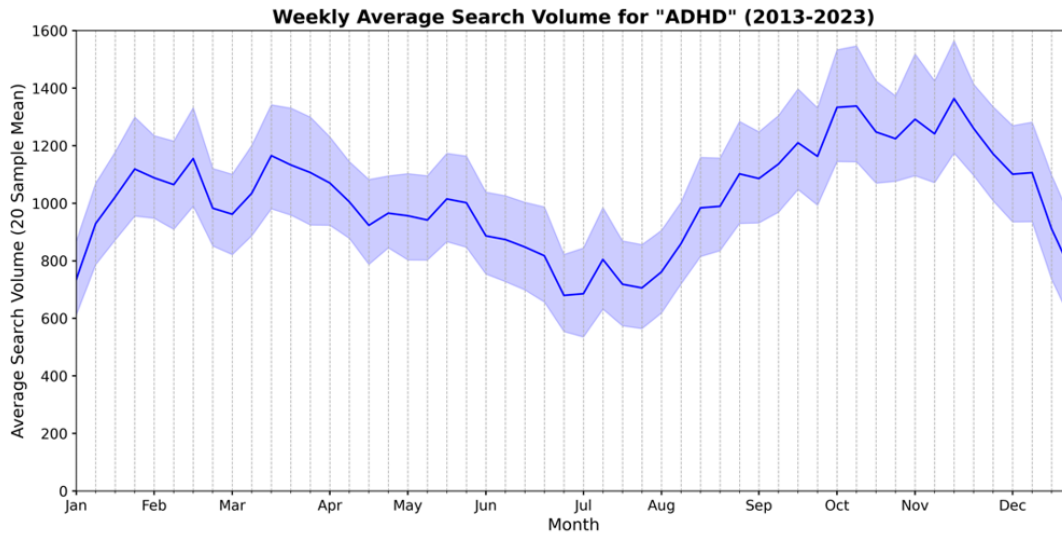


Figure 2: Average seasonal search volumes for the term “ADHD” in Google during the years 2013-2023.

The preliminary content analysis of the discussion forum posts reveals that information needs are mostly expressed in relation to six different categories: 1) diagnosis and symptoms, 2) treatment and medication, 3) coping strategies and lifestyle adjustments, 4) educational and occupational challenges, 5) emotional and social impact as well as 6) support and resources (Table 1). Within these categories, common questions were also identified, as can be seen in Table 1.

Table 1: Identified categories and common questions related to them in the Suomi 24 ADHD discussion forum threads.

Category	Common questions
Diagnosis and Symptoms	<ul style="list-style-type: none"> • How do I know if I have ADHD? • What are the common symptoms of ADHD in adults? • Can ADHD be diagnosed in adulthood?
Treatment and Medication	<ul style="list-style-type: none"> • What medications are available for ADHD? • Are there any side effects of ADHD medications? • How effective are ADHD medications?

Coping Strategies and Lifestyle Adjustments	<ul style="list-style-type: none"> • What lifestyle changes can help manage ADHD symptoms? • Are there any dietary recommendations for ADHD? • How can exercise impact ADHD symptoms?
Educational and Occupational Challenges	<ul style="list-style-type: none"> • How can ADHD affect academic performance? • What accommodations can be made in the workplace for someone with ADHD? • How can I improve my focus and productivity at work or school?
Emotional and Social Impact	<ul style="list-style-type: none"> • How does ADHD affect relationships? • What are some common emotional challenges faced by people with ADHD? • How can I explain my ADHD to friends and family?
Support and Resources	<ul style="list-style-type: none"> • Where can I find support groups for ADHD? • Are there any online resources or communities for people with ADHD? • How can I find a specialist who understands ADHD?

Discussion

What these preliminary findings reveal, is that there is a rising demand for information on ADHD. This increase in demand correlates with the rising amount of ADHD diagnoses. Considering information needs, our findings show that information needs in regard to ADHD are related to diagnosis and symptoms, treatment and medication, coping strategies and lifestyle adjustments, educational and occupational challenges, emotional and social impact as well as support and resources. This is in accordance with previous research, which has found similar categories of information needs (Ahmed et al., 2014; Bisset et al., 2023; Scholze et al., 2023). However, a more thorough analysis will reveal more detailed results, not only regarding nuances of the different categories of information needs, but also which information needs are more emphasized during the identified periods, autumn and spring, of heightened information seeking activity.

As the amount of ADHD diagnosis keep rising, and as there is an upsurge in demand for information in relation to this, detailed knowledge on not only what kind of information needs individuals have, but also when these needs arise, is important. Being able to provide

the right kind of information at the right time may aid in how people manage and cope with, as well as regain a sense of control over ADHD and related symptoms. It can also promote self-acceptance and empowerment, help raise awareness and reduce stigma (Ahmed et al., 2014). As the Internet is increasingly utilized as a source of health information, insights about these online behaviours can provide us with completely new knowledge about ADHD.

References

- Ahmed, R., Borst, J. M., Yong, C. W., & Aslani, P. (2014). Do parents of children with attention-deficit/hyperactivity disorder (ADHD) receive adequate information about the disorder and its treatments? A qualitative investigation. *Patient Preference and Adherence*, 8, 661–670. <https://doi.org/10.2147/PPA.S60164>
- Bijker, R., Merkouris, S. S., Dowling, N. A., & Rodda, S. N. (2024). ChatGPT for Automated Qualitative Research: Content Analysis. *Journal of Medical Internet Research*, 26, e59050. <https://doi.org/10.2196/59050>
- Bisset, M., Brown, L. E., Bhide, S., Patel, P., Zendarski, N., Coghill, D., ... & Sciberras, E. (2023). Practitioner review: It's time to bridge the gap—understanding the unmet needs of consumers with attention-deficit/hyperactivity disorder—a systematic review and recommendations. *Journal of Child Psychology and Psychiatry*, 64(6), 848–858. <https://doi.org/10.1111/jcpp.13752>
- Bussing, R., Zima, B. T., Mason, D. M., Meyer, J. M., White, K., & Garvan, C. W. (2012). ADHD knowledge, perceptions, and information sources: Perspectives from a community sample of adolescents and their parents. *Journal of Adolescent Health*, 51(6), 593–600. <https://doi.org/10.1016/j.jadohealth.2012.03.004>
- Duodecim. (2019). ADHD (aktiivisuuden ja tarkkaavuuden häiriö). Käypä Hoito -suositus. Suomalaisen Lääkäriseuran Duodecimin, Suomen Lastenneurologinen yhdistys ry:n, Suomen Nuorisopsykiatrisen yhdistyksen ja Suomen Lastenpsykiatriyhdistyksen asettama työryhmä. Helsinki: Suomalainen Lääkäriseura Duodecim. <https://www.kaypa-hoito.fi/xmedia/khp/khp00071.pdf>
- Eagle, T., & Ringland, K. E. (2023). “You Can't Possibly Have ADHD”: Exploring Validation and Tensions around Diagnosis within Unbounded ADHD Social Media Communities. In *Proceedings of the 25th International ACM SIGACCESS Conference on Computers and Accessibility* (pp. 1-17). <https://doi.org/10.1145/3597638.3608400>

- Finnish Institute for Health and Welfare (2024). Lasten ja nuorten ADHD-diagnoosien yleisyys 2022 ADHD-diagnoosit yleistyvät tasaisesti: sukupuoli- ja alue-erot ovat melko suuria (Tilastoraportti 1/2024). <https://urn.fi/URN:NBN:fi-fe202401183216>
- Lundin, L. (2020). Parental narratives online about ADHD. *Social Work in Mental Health*, 18(6), 684–703. <https://doi.org/10.1080/15332985.2020.183803>
- Scholze, D. A., Gosdin, M. M., Perez, S. L., & Schweitzer, J. B. (2023). Identifying the Information Needs and Format Preferences for Web-Based Content Among Adults With or Parents of Children With Attention-Deficit/Hyperactivity Disorder: Three-Stage Qualitative Analysis. *JMIR formative research*, 7(1), e47409. <https://doi.org/10.2196/47409>
- Sciberras, E., Iyer, S., Efron, D., & Green, J. (2010). Information needs of parents of children with attention-deficit/hyperactivity disorder. *Clinical Pediatrics*, 49(2), 150–157. <https://doi.org/10.1177/0009922809346730>