Do parents of children with attention-deficit/hyperactivity disorder (ADhD) receive adequate information about the disorder and its treatments? A qualitative investigation

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Background: Attention-deficit/hyperactivity disorder (ADHD) is the most prevalent pediatric neurodevelopmental condition, commonly treated using pharmacological agents such as stimulant medicines. The use of these agents remains contentious, placing parents in a difficult position when deciding to initiate and/or continue their child’s treatment. Parents refer to a range of information sources to assist with their treatment decision-making. This qualitative study aimed to investigate 1) parents’ ADHD-related knowledge pre- and post-diagnosis, 2) the information sources accessed by parents, 3) whether parents’ information needs were met post-diagnosis, and 4) parents’ views about strategies to meet their information needs.

Methods: Three focus groups (n=16 parents), each lasting 1.0–1.5 hours were conducted. Focus groups were audio-recorded and transcribed verbatim. Transcripts were analyzed using the framework method, coded, and categorized into themes.

Results: Generally, parents had limited ADHD-related knowledge prior to their child’s diagnosis and perceived prescription medicines indicated for ADHD in a negative context. Parents reported improved knowledge after their child’s diagnosis; however, they expressed dissatisfaction with information that they accessed, which was often technical and not tailored to their child’s needs. Verbal information sought from health care professionals was viewed to be reliable but generally medicine-focused and not necessarily comprehensive. Parents identified a need for concise, tailored information about ADHD, the medicines used for its treatment, and changes to their child’s medication needs with age. They also expressed a desire for increased availability of support groups and tools to assist them in sourcing information from health care professionals during consultations, such as question prompt lists.

Conclusion: There are gaps in parents’ knowledge about ADHD and its treatment, and an expressed need for tailored and reliable information. Future research needs to focus on providing parents with avenues to access concise, reliable, and relevant information and support in order to empower them to make the best treatment decision for their child.