The powerless or the empowered? Stakeholders' experiences of diagnosis and treatment for attention-deficit hyperactivity disorder in Ireland

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Abstract

Introduction
In Ireland, attention-deficit hyperactivity disorder (ADHD) is the most commonly diagnosed condition in Child and Adolescent Mental Health Services (CAMHS). However, little is known about the experiences of stakeholders affected by ADHD in their pathways through care, especially in Ireland.

OBJECTIVES:
The aim of this stakeholder voice study was to explore stress and coping among parents and Children and Young People (C/YP) affected by ADHD in an Irish context, in order to contribute to knowledge about what works and what needs to change in practice from a service user perspective.

METHODS:
In total, 15 C/YP (7-18 years) with ADHD and their parents participated in semi-structured interviews, which were triangulated using other sources (e.g. visual methods), to contribute to a highly contextualised understanding of lived experiences. Transcribed interviews were analysed using a deductive approach to Thematic Analysis informed by a theoretical framework of stress and coping theory and Bronfenbrenner's bio-ecological model.

RESULTS:
Some degree of difficulty in their pathway through care was identified by participants in all case studies. Findings identified barriers to diagnosis, including delays in diagnosis, such as scepticism, stigma, and label avoidance from gatekeepers; poor multiagency working; and misdiagnosis. Once received, diagnosis may serve as an access to empowerment, providing knowledge, understanding, and support. However, C/YP and their parents also reported distressing experiences and a sense of powerlessness within CAMHS and with treatment; such as tensions around medical management, stigma, and a lack of child- and family-centred practice.

CONCLUSIONS:
Despite the professionals and the systematic supports available, stakeholders did not feel that they were fully understood, listened to, or participants in accessing diagnosis and care planning.