

A Qualitative Evaluation of Providers' Perspectives on Current Tools Used to Assess Adults with Down Syndrome Presenting with Cognitive Decline

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OBJECTIVE: Down syndrome (DS) is a genetic disorder diagnosed in about 1 in 600 live births. Advances in medical management have led to an increased life span for the DS population and decreases in mortality and morbidity have presented new challenges for health care providers. One of these challenges is the diagnosis and management of Alzheimer's disease (AD), a form of dementia. This study aimed to explore health care providers' experiences regarding the process of diagnosing AD in an individual with DS. **METHODS:** Qualitative semi-structured interviews were carried out with health care providers to assess the pros and cons of the tools they currently use to diagnose AD in their patients with DS, and to provide suggestions for improvements for future diagnostic tools. **RESULTS:** Qualitative analysis of the interviews revealed three major themes expressed by the participants, each with identifiable sub-themes. The themes and their sub-themes are: Barriers to diagnosis (continuity of care, awareness, and diagnosis of exclusion), Appreciating the patient (qualifying change and differing symptoms), and Practice guidelines (use of tools and making the diagnosis thoughtfully). **CONCLUSIONS:** The participants spoke about their experiences in making the diagnosis of AD in their patients with DS. The results of these interviews have articulated the need for a more formalized set of guidelines, which can aid in improving the diagnostic process.