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The Psychological Impact of Adult-Onset Craniopharyngioma: The Experience of Patients and Clinicians

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Introduction: Individuals who experience social and emotional difficulties struggle to maintain successful social relationships and incur an increased risk of developing mood disorders. These, in turn, have been found to have a significant impact on both psychological and physical wellbeing. A small number of medical studies suggest that patients with adult-onset craniopharyngioma (AoC) report a poorer quality of life, however, no psychological research has been carried out. The present study aimed to capture, for the first time, a detailed description of AoC patients' lives outside the clinic. Specifically, whether they experience a psychological impact from their diagnosis and whether psychological factors may contribute to a poorer quality of life. **Methods:** Both patients with AoC and clinicians with experience of working with patients with AoC were invited to take part in a semi-structured interview. Clinicians were recruited with the view to providing an alternative viewpoint and the possibility to assess potential (mis) matches in perceptions of AoC patients' social strengths and difficulties. Participants were recruited from three geographically disperse NHS units across the UK. Eight patients and 11 clinicians took part in the study. Interviews were analysed using inductive thematic analysis whereby codes are identified which represent statements centring on a similar topic that are endorsed by multiple participants. Codes that are frequently used are compiled into larger

themes, reflecting broader topics. **Results:** The central theme of 'symptoms' was consistent across patients and clinicians and consisted of three sub-themes: physical symptoms, psychological symptoms, and the tendency for patients to hide symptoms. Both cohorts stated that weight gain and fatigue were the most common physical symptoms, but these were also closely related to psychological symptoms, such as changing lifestyle patterns and a shrinking social network. Crucially, both cohorts stated that low mood, anxiety, and low self-esteem were common and significant experiences. Both cohorts discussed instances of specific mental health disorders. Conversely, some patients tried to hide symptoms with diminishing or contradictory statements or acknowledged that others had encouraged them to seek help, a theme that was also found with clinicians. In addition to these similarities there were also important differences in perceptions. Firstly, while clinicians believed they were open to or actively discussed a patient's psychological wellbeing during consultations, many patients felt they had never been asked about this. Secondly, while some clinicians were very clear on the extreme negative impact of the condition, patients also described more subtle social impacts. Finally, clinicians felt a sense of frustration regarding poor, unspecialised, under resourced psychological support, a feeling that was not common among patients. **Conclusion:** In conclusion, both patients and clinicians recognised significant psychological impact as a result of AoC. Further research is planned to quantitatively assess the topics raised in the present study.

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