The “Silent Disability”- Examining Patient Perspectives on the Diagnosis, Management and the Long-term Implications of Cauda Equina Syndrome

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INTRODUCTION: Cauda Equina Syndrome (CES) is a serious neurological condition marked by red flag symptoms such as saddle anaesthesia, bowel and bladder dysfunction, and lower limb weakness. While early diagnosis and intervention are crucial, long-term patient outcomes remain underexplored.

METHODS: A 34-question survey was distributed to 130 individuals with a CES diagnosis via the registered charity Spinal Injuries Ireland, with 93 responses included in the analysis. The survey assessed initial presentation, diagnosis and treatment timelines, access to post-surgical rehabilitation, and the long-term physical, psychological, and socioeconomic impacts of CES.

RESULTS: A 72% response rate was achieved. A significant proportion (16.7%) delayed seeking care after symptom onset for over a month, highlighting gaps in lay person awareness. Poor resolution of CES symptoms was common, with respondents reporting ongoing frequent to major distress caused by radicular pain (43%), urinary (40.1%), bowel (44%) and sexual (54.8%) symptoms respectively. Despite prevalence of ongoing issues, only 28.2% of respondents had been offered access to sexual therapy. Effects on mental health were stark, with 96% reporting associated mood disorders and 33.3% requiring pharmacological intervention for these. Employment rates post-diagnosis dropped from 78.5% to 24.7%, with pain (38%), continence issues (30%), and mobility challenges (36%) as primary barriers to returning. Free text feedback emphasized the “silent” nature of CES, poor information dissemination from healthcare providers at diagnosis, and inadequate access to long-term rehabilitation services.

DISCUSSION AND CONCLUSION: CES presents significant long-term challenges, with high rates of unresolved symptoms and poor return to work. Our study highlights the under reported and resourced reality of associated sexual dysfunction and psychological burden, as well as the impact of poor information giving by health providers. This highlights areas of significant unmet needs to target for improvement in this patient cohort.