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Inequalities in access to neuro-oncology supportive care and rehabilitation: A survey of healthcare professionals' perspectives

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Abstract

Background: Neuro-oncology patients and caregivers should have equitable access to rehabilitation, supportive-, and palliative care. To investigate existing issues and potential solutions, we surveyed neuro-oncology professionals to explore current barriers and facilitators to screening patients' needs and referral to services.

Methods: Members of the European Association of Neuro-Oncology and the European Organisation for Research and Treatment of Cancer Brain Tumor Group (EORTC-BTG) were invited to complete a 39item online questionnaire covering the availability of services, screening, and referral practice. Responses were analyzed descriptively; associations between sociodemographic/clinical variables and screening/referral practice were explored.

Results: In total, 103 participants completed the survey (67% women and 57% medical doctors). Fifteen professions from 23 countries were represented. Various rehabilitation, supportive-, and palliative care services were available yet rated "inadequate" by 21-37% of participants. Most respondents with a clinical role (n = 94) declare to screen (78%) and to refer (83%) their patients routinely for physical/cognitive/emotional issues. Survey completers (n = 103) indicated the main reasons for not screening/referring were (1) lack of suitable referral options (50%); (2) shortage of healthcare professionals (48%); and (3) long waiting lists (42%). To improve service provision, respondents suggested there is a need for education about neuro-oncology-specific issues (75%), improving the availability of services (65%) and staff (64%), developing international guidelines (64%), and strengthening the existing evidence-base for rehabilitation (60%).

Conclusions: Detecting and managing neuro-oncology patients' and caregivers' rehabilitation, supportive,- and palliative care needs can be improved. Better international collaboration can help address healthcare disparities.

Keywords: brain tumor; disparity; inequalities; rehabilitation; supportive/palliative care.

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