A Longitudinal Study to Assess the Cognitive and Behavioral Changes in Patients with Intracranial Tumors and their Impact on Chosen Psychological Parameters of the Family Caregivers

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ABSTRACT

Background of the study: The caregivers of the patients with intracranial tumor go through physical and psychological challenges resulting in poor quality of life due to deep impact of complex nature of the disease from functional, cognitive to neuropsychological changes in patients with intracranial tumor and variability in treatment outcome.

Aim of the study: The present study was conducted to assess the cognitive and behavioural changes in patients of intracranial tumor till six months prospectively and its impact on family caregivers’ psychological well-being (general health, global functioning, self-esteem and dysthymia) at one month and again six months after the initial assessment before initiating any definitive treatment. Various factors influencing cognitive and behavioural changes of patients with intracranial tumor and psychological well-being of their family caregivers was also examined.

Materials and methods: A prospective cohort design was chosen to assess the cognitive and behavioral changes of patients with intracranial tumor and its impact on psychological variables of their family caregivers before any definitive treatment initiation and again post-treatment after one month and six months. The setting was neurosurgery outpatient department and wards of PGIMER, Chandigarh, during the period of March 2013 to May 2015. Patients having normal sensorium without any communication deficit and who were accompanied by their family caregiver were enrolled by consecutive sampling technique. Out of 150 patient-family caregiver pairs at initial assessment, 129 (150) were followed up at one month first follow up post-treatment and 109 (150) patients at six months second follow up. Thirteen standardized tools were used for the study. Post Graduate Institute-Battery for Brain Dysfunction-memory scale and Neuropsychiatry questionnaire were used to measure cognitive function and behavioral changes
in patients with intracranial tumor respectively. Glasgow Coma Scale was used to screen the patients. Tools used to measure selected variables of the patients with intracranial tumor included DS14 questionnaire to assess type ‘D’ personality, Karnofsky performance scale to measure the performance status, European organization for research and treatment of cancer quality of life questionnaire-Brain neoplasm-Hindi version to measure the quality of life, Glasgow outcome scale to measure the outcome status, Katz index of independence in activities of daily living and Lawton instrumental activities of daily living scale to measure the functional daily activities. Tools used for family caregivers included general health questionnaire to measure general health, modified global functioning scale-revised to measure global functioning, Rosenberg self-esteem questionnaire to measure self-esteem and Cornell dysthymia rating scale to measure dysthymia. Ethical clearance was obtained from Institutional ethics committee and permission to conduct the study from Director and Head of Department of Neurosurgery. Written consent was taken from the patients and caregivers at initial assessment. Verbal consent was taken every time from patient and caregivers as it is a longitudinal study i.e. at one month and six months post-treatment. Appropriate descriptive and inferential statistics were used for analysis depending on the normality of data. The level of significance was set as p<0.05.

Results: Mean age of patients with ICT was 43.41±13.58 years. Most of the patients were males. Most of the patients were diagnosed with supra-tentorial and axial tumors. More than half of the patients were having benign tumors. Maximum number of patients had undergone surgical intervention. Mean age of the family caregivers was 40.47±12.84 years. Most of the family caregivers were females and were married. Most of the family caregivers were spouses of the patients with ICT. Mean daily duration of time spent for caregiving by the family caregivers was 3.98±2.39 hours.

There was a significant reduction in the median cognitive dysfunction score of the patients with intracranial tumor from first assessment (pre-treatment) i.e. 19 (14.5) to first follow up at one month (post treatment) i.e. 14 (14) and to second follow up at 6 months (post treatment) i.e. 9 (14.5) (p<0.001). The symptoms of cognitive function of patients improved in remote memory (p=0.005), recent memory (p<0.001), mental balance (p<0.001), attention and concentration (p=0.001), delayed recall (p<0.001), immediate recall (p<0.001), verbal retention to similar pairs (p<0.001), verbal retention to dissimilar pairs (p<0.001), visual retention
There was a reduction of number (p<0.001) as well as severity (p<0.001) of behavioral changes of the patients from initial assessment (pre-treatment) to first follow up at one month and second follow up at six months (post-treatment). The common behavioral changes present in patients with intracranial tumor assessed using NPI-Q were anxiety, depression, irritability, sleep disturbances, agitation, appetite disorder and disinhibition. The prevalence of each behavioral change reduced from first assessment (pre-treatment) to first follow up at one month and second follow up at six months (post-treatment).

Higher cognitive dysfunction score was seen in patients who were married (p=0.03), having less than secondary education (p=0.026), patients from higher age group (p<0.001), patients with supra-tentorial (p=0.03), high grade (p<0.001) intracranial tumors and patients who are left handed (p=0.044). More number of behavioral changes were seen in patients who are married (p=0.002), having less than secondary education (p=0.03) and higher age group (p=0.007), patients with intracranial tumor who are left handed (p=0.04), patients with axial (p<0.001), high grade tumors (p<0.001), type ‘D’ personality (p=0.002) and patients who underwent radiotherapy (p=0.004). Severity of behavioral symptoms was significantly higher in patients who are married (p=0.017), patients from higher age group (p=0.02), patients with axial (p=0.018) high grade tumor (p=0.035), type ‘D’ personality (p=0.003), focal neurological deficits (p=0.025), radiotherapy (p=0.005) and absence of surgical intervention (p=0.03).

There was improvement in general health (p<0.001), global functioning (p<0.001), self-esteem (p<0.001) and dysthymia scores (p<0.001) of the family caregivers of the patients with intracranial tumor from initial assessment, first follow up at one month and second follow up at six months. Though after surgery patients continued to improve in terms of cognitive function and behavioral changes, the caregivers however were still impaired in terms of general health, global functioning, self-esteem and dysthymia.

Cognitive changes of patients with intracranial tumors had impact on impaired psychological well-being score on general health (p<0.001), global functioning (p<0.001) and dysthymia (p<0.001) of their family caregivers. Similarly, number (p<0.001) as well as severity (p<0.001) of behavioral changes in patients with intracranial tumors also had impact on impaired psychological well-being (score on general health, global functioning, self-esteem and dysthymia) of their family caregivers.
Low general health of family caregivers of the patients with intracranial tumors was reported by family caregivers of male patients (p=0.03), patients with increased duration of illness (p=0.002), high grade (p<0.001), axial tumor (p=0.005), low Glasgow Outcome Score (p=0.006), low Karnofsky Performance Scale score means high functional impairment (p<0.001), low quality of life score (p<0.001), decreased ability to perform activities of daily living (p<0.001) as well as instrumental activities of daily living (p<0.001), absence of surgical intervention (p=0.008) and patients underwent radiotherapy (p=0.002). Low global functioning in family caregivers of the patients with intracranial tumor was reported by those who had patients with higher age (p<0.001), male gender (p=0.004), type ‘D’ personality (p=0.01), high grade tumor (p=0.01), low Glasgow Outcome Score (p=0.015), low Karnofsky Performance Scale score (p<0.001), low quality of life score (p<0.001), decreased ability to perform activities of daily living (p<0.001) as well as instrumental activities of daily living (p<0.001) and absence of surgery (p=0.045). Low self-esteem was reported by family caregivers of the patients who were male (p=0.038), had type ‘D’ personality (p=0.026), high grade (p<0.001) axial (p=0.001) tumors, low Glasgow Outcome Score (p=0.048), low Karnofsky Performance Scale score (p=0.025), low quality of life score (p<0.001) and their decreased ability to perform activities of daily living (p=0.008) as well as instrumental activities of daily living (p=0.001), radiotherapy (p=0.028) and absence of surgical intervention (p=0.001). High score on dysthymia was reported by family caregivers of the patients with type ‘D’ personality (p=0.034), high grade (p<0.001) axial (p=0.003) intracranial tumors, neurological deficits (p=0.003), low Glasgow Outcome Score (p<0.001), low Karnofsky Performance Scale score (performance status) (p<0.001), low quality of life score (p<0.001), their decreased ability to perform activities of daily living (p<0.001) as well as instrumental activities of daily living (p<0.001), radiotherapy (p=0.03) and absence of surgical intervention (p=0.01).

On analysis of influence of caregiver related variables, low general health in family caregivers of the patients with intracranial tumor was associated with gender of caregivers (females) (p=0.018), low educational status (p=0.013), longer duration of caregiving more than six months (p=0.002), longer hours of caregiving (p<0.001) and lack of helper at home (p<0.001). Low global functioning in caregivers was associated with their marital status (married) (p=0.05) and longer hours of caregiving (p<0.001). Low self-esteem of family caregivers was associated with higher age (p=0.02), gender (females) (p=0.01), low educational
status (p=0.024), habitat (rural and suburban) (0.026), unemployment (p<0.001), longer hours of caregiving (p<0.001), lack of helper at home (p=0.007) and relationship of family caregiver with patient (parents, spouses and siblings) (p=0.007). High score of dysthymia in family caregivers of the patients with intracranial tumors was associated with their gender (females) (p=0.048), unemployment(p=0.008), low per capita income (p=0.047), longer hours of caregiving (p<0.001), inability to meet the household needs (p=0.025), presence of external financial support (p=0.019) and absence of helper at home (p=0.01).

**Conclusion:** Patients with intracranial tumor have substantial cognitive dysfunction score before any definite treatment was initiated. There was significant improvement in cognitive function and decrease in number and severity of behavioural changes at six months post definitive treatment, though deficits persisting in some domains. There was improvement in caregivers’ psychological well-being in specific areas, though dysfunction persisted in psychological parameters (general health, global functioning, self-esteem and dysthymia) at six months due to chronic nature of the problems of patients with intracranial tumor.

There is definite psychological impact on caregiver due to labour intensive and emotion intensive caregiving role of patients with ICT. Though after surgery patients continued to improve in terms of cognitive function and behavioral changes, the caregivers however continued to be impaired in terms of general health, global functioning, self-esteem and dysthymia, so appropriate health care provider initiated interventions along with caregiver empowerment programs are necessary to improve the quality of life of patients and caregivers. Nurses need to be specially trained to address various issues faced by patients with intracranial tumors and their caregivers at nurse-led clinics. These interventions can be planned only if there is a protocol of assessing variables of caregivers as they are potential patients in the health delivery system.

**Keywords:** Intra-cranial tumors, Cognitive changes, Behavioral changes, Family caregiver, Caregiver psychological distress, General health, Global functioning, Self-esteem, Dysthymia