

## A STUDY TO ASSESS THE EFFICACY OF PSYCHOSOCIAL INTERVENTIONS IN PRIMARY CAREGIVERS OF MALIGNANT BRAIN TUMOR PATIENTS IN SELECTED HOSPITALS BHARATPUR, RAJASTHAN

**Author Name:** <sup>1</sup>Mr. Tara Chand, <sup>2</sup> Dr. Rajasudhakar

**Affiliation:** <sup>1</sup> PhD Scholar, Himalayan University, Itanagar, Arunachal Pradesh & Vice-Principal Shree Digamber Degree college of nursing Bharatpur, Rajasthan, India.

<sup>2</sup>Professor, Himalayan University, Itanagar, Arunachal Pradesh, India

**E-Mail:** tarachandch@gmail.com

### Abstract

Brain tumors present much of the anguish like that of any other terminal illness. level. Both patients and family members would face various Bio-psycho social problems such as Physical, Emotional, Cognitive, Social, Behavioral, and Vocational. Providing essential psychosocial support to patients and family is much important to prevent the personal and family disorganization, which might arise due to significant medical crisis. A mixed approach is used in this research study. The researcher decided the sample size for pilot study of 10 caregivers of malignant brain tumor patients. The caregivers will be first interviewed with the help of selected tools, and then assigned to the experimental or control group then researcher identified that tools are valid and reliable suitable to use for obtaining data. The impact of illness is not only restricted to the patient but also extends at the family.

**Keywords :** Efficacy, psychosocial intervention, brain tumor, primary caregivers.

### INTRODUCTION

The human brain is a complex organ that allows us to think, move, feel, see, hear, taste, smell, talk and does many other complex activities. The brain directs not only a person's physical, cognitive, and emotional functions, but also their personality, sense of identity and the essence of who they are. Growth of a tumor in the brain can have a devastating effect on an individual. The repercussions of a brain tumor significantly impact quality of life for both patients and loved ones. However, patients facing a brain tumor diagnosis (whether malignant or benign), as well as their health care team, may not identify with this definition of survivorship. There has been a tendency for the focus on the acute control of the tumor to overshadow addressing the many long-term and sub-acute quality of life issues that affect brain tumor survivors used the word 'shock' when explaining their feelings upon hearing the diagnosis. The data reflect that the diagnosis of a primary malignant brain tumor and subsequent treatment results in family role changes for both the patient and the caregiver. The effect of caring for a family member with a primary malignant brain tumor results in psychosocial effects for the caregiver, his or her family, and the patient. It is not unusual for caregivers to develop mild or more serious depression as a result of the constant demands they face in providing care. When giving care for patients during a stressful illness such as cancer, caregivers often become anxious. "Caregiver burden" to describe this type of stress. Many factors influence the amount of caregiving burden felt. The caregivers of patients with malignant brain tumors are at risk for negative health outcomes similar to those of caregivers for persons with other types of cancer. Social support is

the physical and emotional comfort given to individuals by their family, friends, co-workers and others. Many patients and their families poorly understand about brain tumors and the nature of illness. Hence, education of patients and family members is an important component of psychosocial care, Supportive Therapy needs to be provided to the patient and their family members who are significantly distressed due to the illness.

### **NEED FOR THE STUDY**

One of the important aspects of providing better care for terminally patients and their caregivers is to understand their experiences, symptoms, and concerns about life. It requires research into what patients and their caregivers perceive to be the greatest problems with the illness process, the care they receive from the health system, and other issues.

Very few studies have examined factors that lead to role strain for caregivers of patients with both oncological and neurological illnesses (P. Sherwood et al., 2004). There is a lack of prospective studies concerning how both patients and spouses deal with the serious facts of cancer (Salander&Spetz, 2002). Hospitalization for the patient and families is in itself a stressful event in the lifetime; added to its psychological distress are the social and economic constraints. These take toll on the health and well being of the caregiver and the family on the whole.

### **STATEMENT OF THE PROBLEM:-**

**“A study to assess the efficacy of psychosocial interventions in primary caregivers of malignant brain tumor patients in selected hospitals Bharatpur Rajasthan”**

### **OBJECTIVES OF THE STUDY:-**

- To study the psychosocial needs of the caregivers
- To measure the level of Family burden experienced by the caregivers
- To measure the level of depression experienced by the caregivers.
- To study the level of anxiety experienced by the caregivers.
- To measure the level of stress experienced by the caregivers
- To understand the coping types adopted by the caregivers
- To study the level of perceived social support available for caregivers.
- To develop and check the efficacy of a feasible psychosocial intervention package for caregivers to overcome distress.

### HYPOTHESIS:-

H1: Psychosocial intervention is effective in dealing with Caregiver Burden

H2: Psychosocial intervention is effective in dealing with distress

H3: Psychosocial intervention is effective in improving the social support

H4: Psychosocial intervention is effective in improving the coping patterns of the caregivers

### MATERIALS AND METHODS:-

**Research Design: mixed research design used in research**

#### Research Designs Used in the Study

Objectives	Research Design Used
To assess the psycho-social needs of the caregivers	Exploratory Research Design
To study the level of burden, distress, social support and coping among caregivers	Descriptive Research/ ex post facto research design
To study the efficacy of intervention programme	Quasi-Experimental Design with Control Group

#### Research setting (universe) :

The present study will be carried out in selected neuroscience hospitals in Bharatpur.

#### Sample

The overall sample for the study consisted of 57 caregivers of malignant brain tumor patients. The sample will be randomly assigned to experimental and control groups. Thirty caregivers constituted control group and twenty-seven will be included in the experimental group.

#### Method of Data Collection

Structured clinical interview method will be used to collect data. Various factors led the researcher to adopt this method. First of all, the researcher will be dealing with a sensitive issue, which required a clinical approach. Second reason will be that all the caregivers could not read or write. Third reason will be the nature of the research design itself; in this psychosocial interventions will be provided individually. Each interview (both during pre-test and post-test) lasted for 45 to 60 minutes.

**Tools for Data Collection:**

**Summary of tools used in the present study**

Sl. No.	Tool	Purpose	Type
1	<i>Structured Interview Schedule</i>	Gather personal data and socio-demographic profile of the respondents	Qualitative –Prepared by researcher
2	<i>Interview Schedule to Assess Family Burden (Pai&amp;Kapur, 1981)</i>	Measure the level of Family burden experienced by the caregivers	Quantitative- Standardized Instrument
3	<i>Depression Anxiety and Stress Scale (DASS-21) (Lovibond&amp;Lovibond, 1995)</i>	Measure the level of distress (Depression, Anxiety and Stress) experienced by the caregivers	Quantitative- Standardized Instrument
4	<i>Multidimensional Scale of Perceived Social Support [MSPSS] (Zimet, Dahlem, Zimet, &amp; Farley, 1988)</i>	Study the level of perceived social support available for caregivers	Quantitative- Standardized Instrument
5	<i>Brief COPE (Carver, 1997)</i>	Understand the coping patterns adopted by the caregivers	Quantitative- Standardized Instrument

**CONCLUSION :-**

Many research studies shows that psychosocial intervention are effective in caregiver of brain cancer patients The purposes of this study were (1) to identify the caregiver characteristics and their unmet needs; (2) to examine the association between caregiver unmet needs, caregiver burden, and caregiver satisfaction; and (3) to identify the independent predictors of different caregiver outcomes. One hundred caregivers completed three caregiver outcomes instruments: Family Inventory of Needs, Care Strain Index, and Family Satisfaction with Advanced Cancer Care. Most of unmet needs were related to information needs (needing more information related to home care, finding

help with the problems at home, and disease prognosis) and symptom management. The majority of caregivers were satisfied or very satisfied by the care patients received. Spouse caregivers (N=60, 60%) were significantly older ( $p=0.006$ ) with higher unemployment rates ( $p = 0.001$ ), higher depression scores ( $p = 0.04$ ), and lower social support scores ( $p < 0.001$ ) than non-spouse caregivers (N = 40, 40%). The Psychosocial unmet needs predicted caregiver burden and the presence of caregiver unmet needs independently. The presence of caregiver unmet needs was the only independent predictor of caregiver satisfaction. Caregivers with a high Psychosocial unmet needs and higher depression score experienced a higher burden.

Researchers from University of Groningen, Netherlands organized a study to get insight in the needs of the caregivers of patients with palliative cancer and how to address those needs with a support program (Jansma, Schure, & de Jong, 2005). A questionnaire developed on the basis of 26 interviews was sent to 65 caregivers. The respondents indicate that they do need support, that communication is considered the most important factor followed by practical information about nursing skills, the caregivers' own health and finally social network. The respondents also expressed a need for support after the patient died during bereavement. Most respondents stated they wanted to participate in a support program at least partly together with the patient, at the patient's home and guided by a supporter who has experience with loss and is a professional.

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