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A Study on the Burden of Caretakers of Cancer Patients

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ABSTRACT

According to the WHO studies millions of world population suffer from cancer. The fact that so many families are actively assisting their patient relative on a day to day basis. The lack of acceptance of the patients in the family, and the negative attitude towards patient in the community leads to create many problems of the patient both physically and psychologically which in term increase burden on the family. So it is necessary to study the burden of family and to suggest measures to improve the situations.

Cancer is a deadly disease. In the modem world cancer is the leading cause of morbidity and mortality if affects every parts of human system. Changes in the life styles habits and living standards have contributed much to this phenomena.

During the past several years there have been some developments in professional and public awareness about the diverse methods of diagnosis and treatment of cancer. 'Recently physicians have realized that therapeutic success is also depends on the functional, psychological and social well being of the patients. Physicians along with the psychologist and social workers can help the patient in order to overcome and face all the unpleasant experiences they have to face during the time of treatment and also during the rest of their life time.

Cancer is derived from the Latin word meaning 'crab'. It is termed as cancer, due to spreading nature of it. Cancer is the abnormal growth and spread of malignant cells. If not controlled it usually cause death but if treated early it frequently can be cured.

It has been existed in India since Vedic periods and it has affected people throughout the ages. It affect all age group especially over 50 years of age. Overall men experience higher incidence than women. It is higher in advanced, industrialized nations than the underdeveloped, developing nations.

Cancer is a non-communicable disease. Cancer in all forms is causing 9% of deaths throughout the world. In the developed countries it is the second leading cause of death. There are number of reasons for it increase diet, tobacco, alcohol and smoking infections.

In India it is the one of the ten leading causes of death and twenty lakhs of people are affected by it. Among the higher classes the disease is diagnosed at the primary stage. The middle class people are mostly diagnosed at the middle stage and among the lower class people it is diagnosed at the end stages.

CARETAKERS BURDEN WITH REFERENCE TO CANCER

Cancer the dreadful disease is equally feared by patient affected and his then family members. Its effect thus is not restricted to the physique of the person affected alone, but extends his family member and their mental makeup.

The wrong notion and fear of the disease such as contagious can make the family members ill treat, disregard and even alienate the patient. Added to this, economical burden and social stigma or constrain can be another disturbing factor. Social changes after cancer are often first experienced within the family unit.

The burden of caring for a person with chronic cancer is considerably greater. Families continuous to serve as the principal caregivers for cancer patients. while the burden of providing emotional, social and instrumental support for cancer patients has always fallen mainly on the patients' relatives.

The diagnosis of cancer may provoke various emotional disturbances among patients, spouses and other members of the family and anxiety is the common among all. The family experiences an increased burden of care especially, the spouses as they find it difficult to cope with the stress when their beloved ones are undergoing investigations and consultations and when their partners complaints of intolerable pain.

Families coping with a member with cancer for an extended period of time may find that social networks and supports are overwhelmed, leading to social death before the death of the patient. Terminal illness such as cancer poses a major burden for families who may become socially isolated. Communication within the family members is a crucial issue. The onset of life threatening cancer causes emotional and physical burdens to the family and when it becomes multi fold, anxiety arises which jeopardizes emotional stability between the family members.

AREAS OF BURDEN

The presence of a cancer patient disturbs many aspects of daily life.

Traditionally the family has been serving as the major support system for the cancer patients. For those who believe in modem treatment, the resources are inadequate to suffice the needs of the patients and it is the family, as a major support system that has to bear the heavy burden of caring for the affected member.

1. Financial Burden

Financial burden is likely to be experienced by the families due to the loss of patients income especially when the patient happens to be the sole bread winner of the family. Incertain cases, in order to look after the patient, the other members may not be able to go to work, Treatments are sometimes very expensive because of that financial burden increases.

2. Effect of Family Routine

A normal routine is very badly affected. The family members need to accommodate the disease by adjusting the daily routine of the household to it. The patient may not go to work. Female patient may not be in a position to help in household duties. The whole family may also need to change its routine.

3. Effect on Family leisure

In families of chronic patients, there will be a stopping of the normal recreational activities. The family members are expected to extra duties, which lessen their leisure hours. Other family members have to sacrifice their holidays and leisure time in order to look after the patient.

4. Effect on Family interaction

The presence of a cancer patient in the family has a severe negative impact on the general family atmosphere. Due to some social stigma attached, there will be a reduction of interaction with friend, relatives and neighbours. This eventually leads to the family becoming isolated in the community.

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5. Effect of Mental Health of other Members
The stress and strain associated with caring patient, caretaker often has a disruptive effect on the mental health of other family members.

REVIEW OF LITERATURE: Some of the reviews the researcher made on the study are presented below
Sumi Moon(2004) studied on Cancer and Mental Health Patients are not only the one who suffer when they diagnosed with cancer spouses/ family members with significant relation to the patient are often feel the same intensity of bereavements as the patient but with different dimensions. They are the second under patients. it is important for the patient and their family members to be aware that professional help is available to assist them in handling difficult situations.

Greers (1983) expressed his opinion after studying the Cancer and Mind of Patients' Relatives, that, the psychiatric morbidity observed in the family members of cancer patients are enuresis, school phobia and depression in siblings, conversion, reactions, psycho-somatic psycho-sexual and psycho social problems in the parents and anxiety and depression in the spouses. In his study on psychiatric aspects he shows that the terminal phases of cancer are frequently complicated with psychiatric disturbances possibly because of physical symptoms and a fear of painful death. The disease process can cause organic brain syndrome through metastasis and paraneoplastic syndromes.

RESEARCH METHODOLGY
RESEARCH DESIGN
The researcher adopted descriptive research design, which includes fact finding investigation with adequate interpretation of facts about the problems. The study tries to identify various aspects of problems. The researcher adopted the descriptive design for describing the objective of the study.

SAMPLING PROCEDURE
A sample design is a definite plane for obtaining a sample from a given population. The researcher adopted purposive sampling method.60 respondents were selected by the researcher by using purposive sampling method. Universe of the study is Coimbatore cancer foundation in Coimbatore. Interview schedule method was used to collect the data. The well structured questionnaire consists of age, sex, educational qualification and other relevant questions related to the burden of caretakers of cancer patients.

FINDINGS
- The majority (50%) of the respondents belong to the age group of 41-60.
- The majority (54%) of the respondents were females.
- The majority (54%) of the respondents belong to Hindu religion.
- The majority (68%) of the respondents were married.
- The majority (28%) of the respondents were House wives.
- The majority (34%) of the respondents have studied up to primary level.
- The majority (66%) of the respondents were from nuclear families.
- The majority (36%) of the respondents were living in rural areas
- The majority (46%) of the respondents have monthly income of rupees 3000-6000.
- The majority (76%) of the patients have cancer for below 8 months.
- The majority 50% of the respondent rarely embarrassed the relative behavior.
- The majority (40%) of the respondent rarely feel angry when they are around their relative.
- The majority (52%) of the respondent sometimes feel strained when they are around their relative.
- The majority (38%) of the respondents quite frequently feel that your relative ask more help than he needs.
- The majority (38%) of respondents are rarely stressed, 36% of respondents are quite frequently stressed.
- The majority (50%) of the respondent sometimes tried to satisfy the desire of the patient.
- The majority (38%) of the respondent sometimes time they spend their relatives.
- The majority (38%) of the respondent sometimes feel that their relative is dependent on them.
- The majority (34%) of the respondent sometimes afraid what the future holds for their relative.
- The majority (40%) of the respondent rarely feel their health has affected because of their involvement with their relative.
- The majority (42%) of the respondent sometimes feel that they don't have privacy because of their relative.
- The majority (58%) of the respondent sometimes feel that their social life has suffered because they are caring for their relative.
- The majority (58%) of the respondent sometimes feel uncomfortable about having friends over because of their relative.
- The majority (40%) of the respondent rarely feel that they don't have enough money to care of their relative in addition to rest of your expenses.
- The majority (48%) of the respondent rarely feel that they will not be able to take care of their relative much longer.
- The majority (42%) of the respondent sometimes feel they have lost control of their life since their relative illness.
- The majority (38%) of the respondent rarely they could just leave the ease of their relative to someone else.
- The majority (56%) of the respondent sometimes feel uncertain about what to do about their relative.
- The majority (40%) of the respondent sometimes feel they should be doing more for their relative.
- The majority (62%) of the respondent sometimes feel they could do a better job instead of caring their relative.

SUGGESTION
- Educating the family is essential to handle the more immediate operational problems in the family by making adjustment in their role.
- Voluntary agencies can play a vital role in providing vocational rehabilitation services to the patients and make them productive member of the society. This would also help the family to lessen its financial burden.
- Counselor can play an important role among the cancer patient and their family members to reduce their depression.
- Early detection of cancer to some extent reduces the severity of disease. So awareness programs should be organized for the public.

CONCLUSION
Cancer still remains as a major cause for death of the majority of the people in the world. Every year huge number of poor innocent people from child to old has died due to this chronic disease. Most of the people believed that it is an incurable type of disease and it affects and leads person to a slow and painful death. Because of this disease the patient and their family members face many difficulties in their life. Most of the time they will be in depressed or hopeless stage.

The study conducted by the researcher to find out the burden level of caretakers cancer patient reveals that burden level of each caretakers is high.

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