

MINOR RESEARCH PROJECT REPORT

ON

PSYCHO SOCIAL IMPACT OF CANCER ON THE FAMILY MEMBERS – A STUDY IN SOUTH CANARA, KARNATAKA

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Introduction:

When a person develops cancer, it is family members who provide the care, but they themselves are often profoundly affected by the disease. Families of cancer patients are susceptible to same amount of stress as cancer survivors themselves and in some cases, suffer more quality of life-related effects than the survivors. Care giver issues are often the last to be attended by the family members as well as the treating team and the hospital staff. A considerable amount of researchers have documented negative physical, emotional and social consequences for both patients and family members.

Methodology:

The aim of the current study was to explore the repercussions of cancer on the psychological, economic and social conditions of care takers. The universe of the study comprised of Mangalore taluq of south Canara district Karnataka. The care takers of cancer patients were the respondents of the study. A care taker here would mean one who spends time and energy looking after a friend, relative, or a spouse who is terminally ill cancer patient. Multi stage sampling was the method adopted in the present study. Hospitals which were the sources of data collection were selected based on purposive sampling. Availability of doctors specialized in Oncology and density of patients approaching the hospitals was considered for selection of hospitals. A sample of 100 was covered in the study using the systematic random sampling method. Informed consent was obtained from each respondent before the inclusion in the study. Respondents were informed about the strict confidentiality of their personal data. Participation was voluntary and that the respondent was allowed to refuse to give information at any time.

Findings:

Respondents belonged to the middle age (36 to 50 yrs) contributed to 49%. Seventy six per cent were of the respondents were female with only 34% male. Respondents who are married constituted 68% and 14% were unmarried. Respondents who lost their spouses constituted about 18% who still carried on the care taking responsibility of either their children or relatives. Occupational status of the respondents after the diagnosis of cancer to their family member was studied to understand the care takers employability as an indicator of the impact of having a cancer patient to be cared for. The result revealed that 5% of the care takers had to leave their job as care taking requires time, patients were dependent on them and they wanted personal care from their family members. This also shows extra burden on the family's financial status. As far as the respondents relationship to the cancer patient is concerned it was found that majority constituting 39% had to care for their spouses who had cancer. Thirty percent had their parents with cancer and 14% of the parents were caring for their children suffering from cancer. Breast cancer, abdominal and oral cancer cases were found in family members of many of the respondents i.e., 16%, 22% and 15% respectively. It is 83% of the respondents who knew that smoking is the risk factor for lung cancer and 67% were aware that tobacco chewing can lead to cancer, but 33% remained unaware. But out of these respondents many of them also reported that they were told about the causative factor after the diagnosis of the illness. Early awareness on the causative factors can prevent such deadly diseases.

In spite of the advanced technologies the diagnosis at the early stage is not happening just because people do not suspect cancer and take minor treatments to cure the initial symptoms. The study showed that nearly 38% were diagnosed at the middle stage. Most striking statistics is that 28% were detected at the very last stage where in prognosis becomes very slow and often the treatment fails. The stress will be definitely more in the families where the cases were detected at the later stage.

Larger portion of the respondents [61%] were shocked at the diagnosis as it was unexpected news to them. It is 15% who were depressed soon after the results were shown to them as the very word 'cancer' spells doom and disaster for the family, 14% felt disrupted or felt helpless. Even a simple individual can understand that cancer is rarely curable and can imagine the overall impact of it. Fear of anticipated problems was reported by 10% of the care takers. But at the later on period a very small portion of the respondents that is 8% have accepted the illness of their loved one and rest of them continued to be stressed, depressed and frustrated. A large majority constituting 70% report that their ability to concentrate has deteriorated considerably. At the same time 90% care takers ability to take decision has weakened but interestingly 6% state that it has improved. It is 33% of care takers ability to overcome difficult situations has remained same as usual, whereas 62% report to be less than usual.

As per the results majority of the care givers feel that care giving task makes them feel exhausted. They get tired, worried, tensed easily. Complaint of poor appetite is evident among

72%. It is very significant to note that 38% have had the feeling of ending their life. Concern about the future and practical difficulties with regard to daily care were the most common psycho social issues raised by the care takers of cancer patients. Need for more information on the illness has identified to be an important need by 98% families. Concerns regarding the arrangements to be made for patients in terms of physical environment modification were considered a significant area for 38% while 78% care givers raised financial implications as an issue of their worry. 48% families considered themselves to have inadequate social support to deal with the implications of their loved ones illness.

Cancer diagnosis and treatment is phenomenally expensive. Unless the family is favorably wealthy they are probably devastated financially.

The above table shows that the majority of respondents [37] have spent between Rs 25000-45000 per month on Cancer treatment. Out of these respondents nearly 50% are earning up to Rs 15000 and one third of the respondents earn below Rs 5000 only.

Another 30% of respondents have spent between Rs 5000 –Rs 25000, and among those 75% being majority are earning below Rs 5000. This shows that the expenses for treatment are crossing the range of total income of the family. At the same time we can also find that economically stable respondents have gone for the more costly cancer treatment facilities. Majority of 70 respondents say that they anticipate an expenditure of Rs 5000-25000 per month for treatment. Among this portion of the respondents nearly 75% are gaining up to 15000 only. These findings strengthens the fact that cancer treatment being highly expensive causing more stress, as it puts the people in a condition where they have to spend more than what they earn. The financial burden can be as stressful as the disease and the financial impact sometimes lasts longer than the disease itself. In order to meet these expenses only 19% of respondents are using their savings. Striking statistics it is 24% who have gone into deep debt for providing treatment to their loved one and 35% had to sell their moveable or immoveable property to meet their expenses. Which member in the family is a source of support to the respondent at the time of stress? Large percentage of respondents [30%] is supported by spouse. When nearly 20% children support their parents during a stressful situation, a good number of parents support their children. The analysis also shows that a noticeable portion of the respondents are not supported by any one. Investigator while interacting has found out that broken family relations, physical distance, and nuclear family structure as the factors for the same. Almost all the respondents constituting 96% are saying that the illness has affected the daily routine of the family. Working over time for the patient, accompanying them to hospitals, attending visitors are few of the new tasks the family or care taker should accept in the daily life. Majority constituting 64% avoided all social gatherings and 21% were found abstaining from going to family functions and 15% avoided meeting friends. This reveals that their social life has been affected and it is shown by them in various ways.

Cancer affects not only the Quality Of Life (QOL) of individuals with the disease but also that of their family members and close friends. The impact on various aspects of the family caregivers' QOL is significant throughout the trajectory of the illness. Caregiving often is associated with multiple rewards, yet the diversity and intensity of caregiving roles also can result in caregiver strain and burden. Using interventions to reduce the strain and burden on caregivers of patients with cancer is the need of the hour.