Physical and Psychological Health: The Nature and Extent of Social Support of the Cancer Patients in Institutional Settings

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Abstract

Cancer is the second most common cause of death in the developed world and a similar trend has emerged in the developing countries too (Goyal PK (2012). The study analyzes the understanding of the extent of social support among cancer patients in institutional settings. The study was conducted among the cancer patients in six palliative care clinics in Wayanad district, Kerala. It tries to pursue the two important research questions. (1) To identify the social support persons or groups who extend social support to the cancer patients. (2) Identify the various types of cancer occurring among the cancer patients in institutional settings. A descriptive research design was followed for conducting the study. The population which is included in this study was about 46 respondents who were under treatment in the six palliative care clinics in the district. The investigator conducted intuitional visits for data collection; informal consent was obtained from each respondent, followed by the distribution of socio economic data sheet and the Social Support Appraisal Questionnaire (Alan Vaux, 1987). Following the data collection, a data analysis was carried out. The findings of the study clearly revealed that most of the patients came out from the nuclear family and belonged to poor socio- economic status. The study pointed out the significance of psycho education among the family members and the society. This attempt will be helpful to the patient to ensure various kinds of social support towards the recovery from the disease.

Keywords: Social Support, Poor economic status, Psycho education, descriptive research

Introduction

Cancer is the second largest non-communicable disease and it has a sizable contribution in the total number of deaths. It is important for the public health professionals to understand the dynamics of cancer incidence for future strategies.

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The myth that cancer affects people mostly in the developed countries is being broken by the fact that, of the 10 million new cancer cases seen each year worldwide, nearly 5.5 million are in the less developed countries. Cancer is the second most common causes of death in the developed world and a similar trend has emerged in the developing countries too (Goyal PK (2012). The World Cancer Report documents that cancer rates are set to increase at an alarming rate globally and could increase by 50% in the years to come. The Cancer Atlas published by Indian Council of Medical Research (ICMR) indicates that the incidence of gall bladder cancer in women in New Delhi is 10.6 per 100,000 population which is the world's highest rate for women. From the same source it is reported that Thyroid cancer is more prevalent in the coastal areas of Kerala and Karnataka (Marimuthu, 2008). The recent increase in cancer rates is mainly attributed to urbanization, industrialization, lifestyle changes, population growth and increased life span (in turn leading to an increase in the elderly population). In India, the life expectancy has steadily risen from 45 years in 1971 to 62 years in 1991, indicating a shift in the demographic profile. It is estimated that life expectancy of the Indian population will increase to 70 years by 2021–25. This has caused a paradigm shift in the disease pattern from communicable diseases to non-communicable diseases like cancer, diabetes and hypertension (N.S Murthy and Aleyamma Mathew 2009).

According to epidemiological studies, 80-90% of all cancers are due to environmental factors of which, lifestyle related factors are the most important and preventable. The major risk factors for cancer are tobacco, alcohol consumption, infections, dietary habits and behavioral factors. Tobacco consumption, either by way of chewing or smoking, accounts for 50% of all cancers in men. Dietary practices, reproductive and sexual practices account for 20-30% of cancers. Studies have shown that appropriate changes in lifestyle will reduce the mortality and morbidity caused due to cancer. A trend analysis of the data on cancer incidence for the period 1964–96 has demonstrated that the overall occurrence of cancer is increasing among females. The greatest increase among females was for cancer of the breast and among males for cancer of the prostate. There was an increasing trend for lymphoma, urinary bladder, gall bladder and brain tumors in both sexes.

Cancer of the colon was increasing in females and that of the kidney in males. Esophageal and stomach cancers were decreasing in both sexes. Cervical cancer showed a decreasing trend.
Cancer prevalence in India is estimated to be around 2.5 million, with over 8,00,000 new cases and 5,50,000 deaths occurring each year due to this disease. More than 70% of the cases report for diagnostic and treatment services in the advanced stages of the disease, which has led to a poor survival and high mortality rate. In a report from India, roughly two-thirds of all patients with lung cancer were smokers, using cigarettes and/or bidis, hand-rolled tobacco. Among 54 female patients, only 5% were smokers, reflecting both the low prevalence of tobacco use among women and the cancer-causing effects of environmental tobacco smoke.

Studies reported that a number of tribal people were severely affected by cancer. In Kerala, Wayanad district is considered as one of the major tribal hamlets of the state. Looking into the causative aspects of the disease in the district, Wayanad, Alcohol and tobacco usage, extensive usage of pesticides, changes in life styles are the major factors which lead to the disease. It is significant to mention about the current cancer prevention and research programmes in Kerala. Dedicated cancer detection centres will be set up in five district hospitals of the state under National Rural Health Mission, NRHM, in the near future. Each hospital will be provided seven crore rupees under Non-communicable disease control scheme of the Centre. As per the latest data, the cases of cancer, especially breast cancer, are rising fast in a highly urbanised state like Kerala. AIR correspondent reports, Regional Cancer Centre, Thiruvananthapuram, a premier cancer institute of the country treats about 13000 cancer patients in a year. Fast increasing breast cancer cases are a matter of serious concern. Every year 1700 new breast cancer is detected in Kerala (NRHM Oct 2011).

Cancer is considered to be a period of stressful situations and patients who are affected with cancer are considered to be more vulnerable. During this situation patients can pass through several stressful situations and might think as to how one should survive in Social, Psychological and Economical stressful situations in life. The researcher feels that patients who receive strong and consistent social support will adjust more successfully over time in their life. Hence he wanted to understand the extent of social support among cancer patients in institutional settings.

Moreover the researcher also wanted to know about types of cancer which are prevalent in the area in which he studied. The outcome of the study could be useful in developing a comprehensive approach in social support activities and other useful social work interventions for this population.
For understanding the types of cancers and its impact on patient and the support groups, the researcher tried to understand the extent of social support among cancer patients in institutional settings. So this current study reveals that the level of social support achieved by the cancer patients in an institutional setting.

**Review of Literature**

Social support is defined as received assistance and support from others, particularly certain people. It has been suggested that social support has a mediating role in the effect on adaptability style. If social support can reduce the effect of life's difficult stress and incidence of mood disorder, cancer patients certainly need such supportive mechanisms. For years, scientists have identified the positive correlation between social support and health (Tan M, 2007). Past research indicates that social support is beneficial to cancer patients in adjusting to the stress of the disease. The author (Christine Dunkel-Schetter, 2010) in the article ‘Social Support and Cancer: Findings Based on Patient Interviews and Their Implications’ mentioned that the health care providers are particularly important sources of support to cancer patients; of several types, emotional support is seen as especially helpful; and the types of support seen as most helpful by those with cancer depends on who provides them with support. In addition, variability in stress among cancer patients mediated the frequency of interpersonal problems and the association between support and various indices of adjustment.

Research has shown social support to be effective in decreasing stress and enhancing coping in adolescents facing such demands. A review and critical analysis of studies of social support in adolescent cancer survivors was conducted. The seventeen studies were mainly descriptive and exploratory in nature with social support examined for a number of outcome variables in eight of the studies. Findings from this review indicate that support from parents (especially the mother) and friends were extremely important and that the adolescents were satisfied with family support. Support from friends was described as less satisfactory. Methodological concerns of the reviewed studies include small samples and a lack of consistency in the instruments used to assess social support.

Future studies of social support for adolescent cancer survivors should include larger samples to determine gender, age group, and ethnic differences and to allow the examination of social support theoretical models specific to the developmental and chronic illness situation of these adolescents (Decker C, L. 2006).
Psychosocial research examining the impact of cancer on adolescents and young adults has focused mostly on domains relating to family, psychological/emotional impact and social effects. Studies have identified various psychosocial challenges that adolescents and young adults experience when faced with cancer. Further research, incorporating the effects of treatment stage and developmental level of the patient on specific psychosocial dimensions of the cancer experience, is needed. Evidence-based information regarding the influence and interaction of family, psychological and emotional state, and social status of adolescents and young adults with cancer can aid clinicians when developing psychosocial assessment and treatment approaches for these patients (Evan EE1, Zeltzer LK, 2006). An informal or primary caregiver is an individual in a cancer patient’s life that provides unpaid assistance and cancer-related care [1]. Due to the typically late onset of cancer, caregivers are often the spouses and/or children of patients, but may also be parents, other family members, or close friends. Informal caregivers are a major form of support for the cancer patient because they provide most care outside of the hospital environment.

This support includes:

- Physical support: management of side effects and late effects of treatment and assistance with personal tasks such as bathing.
- Emotional support
- Financial assistance: helping cover the expenses associated with cancer treatment.
- Practical assistance: treatment monitoring, assistance with decision making and assistance with non-personal tasks such as grocery shopping and Spiritual support.

Descriptive studies suggest that emotional support is most desired by patients and correlational studies suggest that emotional support has the strongest associations with better adjustment. However, the evidence for the effectiveness of peer discussion groups aimed at providing emotional support is less than convincing.

Moreover educational groups aimed at providing informational support appear to be more effective than peer discussions (Population based Cancer registry report 1991-95). A diagnosis of cancer usually arouses fear of death. It seems that patients are often left alone with their anxieties.
Caring for an individual who is diagnosed with a severe illness like cancer can be a stressful experience. So the researcher tries to understand the extent of social support among cancer patients in institutional settings.

The social capital concept provides a structure for understanding how the organization and meaning of social contexts can potentially enhance or hinder end-of-life care. Research that identifies specificity in application of social capital concepts is fundamental to issues of access to services, sustaining levels of care, quality of life, and well-being. The importance of "bridged" social capital relations and networks for improved resource acquisition and information flow was identified in the literature and outlined within the palliative care social capital framework. Differential access to social capital by disadvantaged groups provides further impetus to engage a model of social capital for palliative care (Lewis JM et al, 2013).

**Materials and Methods**

The aim and objectives of the study are (1) To Understand the extent of social support among cancer patients in Institutional settings. (2) To identify the support persons or groups whom extends social support to the cancer patients. (3) To identify the types of cancer occurring in the targeted area. The research design of this study is descriptive and the researcher has taken samples of the cancer patients who are above 18 yrs of age and are under palliative care clinics in Wayanad district was the universe of this study. Simple random sampling is used for this study. The total number of patients coming in the palliative care clinic is at the range of 150-160. Throughe simple random sampling 47 samples were taken, thus sample size is 47. A socio demographic data sheet was specially designed for this study. The investigator used Social Support Appraisal Scale developed by Alan Vaux (1986). The major hypotheses of the study are (a) There is a significant relationship between cancer patients and the extent of social support (b) Social support and various socio economic factors are closely related.

The study is based on the data collected from institutions from Wayanad district such as Swami Vivekananda Medical Mission, Kripa Pain and Palliative clinic, Santhvanam Pain and Palliative clinic, Pain and Palliative clinic, Karunya Pain and Palliative clinic and Ashraya Pain and Palliative clinic. The data were analyzed using appropriate statistics with SPSS.
Major Findings

According to the study, most of the patients came from the nuclear family and had poor socioeconomic status. The remarkable findings towards the objective is that the following types of cancer diseases are common like brain tumor, blood cancer, mouth cancer, cancer at the lower lip, bone cancer and rectum. The minimum age of the respondent groups were 23 and maximum age is 105. The mean age corresponding to the respondent group is 59.85. This point shows that respondents above 18 years of age are vulnerable to cancer. The minimum income of the population is 100/- and the maximum income is 300/-. This shows the poor economic condition resulting from poor social support is alarming. The distribution of religion shows the trend in Wayanad district. Hindus (41.3%) being the dominated community followed by Muslims (34.8%) and Christians (23.9%) are the minority community. The community plays in general an important role in social support.

The gender distribution of this test shows that out of the total population, 41.3% were females and 58.7% were males. A vast majority of the respondents selected were married (76.1%). The remaining respondents can be grouped as single. In that single group 2.2% were unmarried, 19.6% were widowed/ widower and 2.2% were separated. None of the respondents were divorced. In the occupational distribution 91.3% were unemployed. This shows that the respondents lack the economic support which play a major role in the social support which play a major role in the severity of disease. Among the respondents 34.8% have reported 2 children. But the major respondents (73.9%) were childless. Majority of the couples had only one child. Parents are the second greatest support structures for treatment followed by children and siblings. Among the patient population, most of the respondents are from nuclear families.
Description of Extent of Social Support among Cancer Patients: The extent of social support among cancer patients in institutional settings has been analysed by using Social Support Appraisal Scale. The population (N) consists of 46 respondents each. The table shows that among the patient population 93.5% have poor social support.

Discussion

The general trend in Kerala’s population follows more to nuclear families, with increasing urbanization and gradual extinction of villages. This shows a current trend in the Kerala’s family life system. The tool used for the study was Social Support Appraisal Scale of Alan Vaux. According to the scoring method of SSA Scale, the higher the score obtained, the lower is the perceived social support. The extent of social support according to the analysis is as follows. 93.5% of the respondents was having poor social support. This depicts that the extent of social support among cancer patients in institutional settings is poor. This study also throws light about poor economic background of the patient population. Hence, hypothesis of the current study ie. The higher income family group gets more social support than lower income group could be accepted.

The poor economic background and nuclear type family which shows a vulnerable situation also paves the way for poor social support. Poor social support deteriorates the condition of cancer patients. Social Support and its perceived availability thus has become a crucial factor in the management of cancer in the Indian context. The findings imply that the Social support and various socio economic factors are closely related.
Thus the research indicated that the second hypothesis, ‘Social support and various socio economic factors are closely related’, could be accepted.

The results of this study showed that those who received low social support needed effective, long term care and support interventions in clinical and social environments for the welfare of the cancer patients. The improvement of friends and family networks, social interconnections, institutional building, research and capacity building in the area of cancer care and support is inevitable and it should be beneficial to the patient as well as the general community.

**Summary and Conclusion**

The study was aimed at understanding the extent of social support among cancer patients in institutional settings. The research design employed was the descriptive research. The necessary data was collected from 46 respondents who were undergoing treatment in 6 palliative care clinics in Wayanad district. Among the 160 respondents, 46 respondents were randomly selected using simple random sampling. Data collection for the patient population was done through institutional visits. Subsequent to the data collection, data analysis was done using SPSS version 13.0 for windows. The results obtained shows that the patient population experienced poor social support.

- Majority of the respondents were married.
- Most of the respondents’ families were nuclear families.
- Respondents were mostly from poor economic backgrounds.
- Significant numbers of respondents were unemployed.
- Most of the respondents had no parents.
- Almost all the respondents came from the Panchayat area.
- Most of the respondents belonged to Hindu faith.
- Nearly half of the patient populations were females.
- The patient population experienced poor social support.

The study elicits the understanding of the extent of social support among cancer patients in institutional settings and the fact that poor social support would lead to severe condition of patients’ life.
It points out the importance of imparting psycho education to the family members and friends of the cancer patients by social workers regarding the importance of familial and social support. It also depicts the importance of educating the patients about how to take the situation in a positive manner for coping up with such vulnerable situations. It also substantiates the need for giving skilled training to the patients to escape out of the grip of poor economic condition. The society in general should also be educated about the importance of social support towards cancer patients.

Nevertheless to say that, for maintaining social support among cancer patients, the role of family, community and institutional settings are considered one important arena to be worked upon further. It would be advantageous to carry out research studies with a bigger sample population, including more tribal population which is the peculiar feature in the Wayanad district so as to result in a much accurate result. Certain factors that have considerable effect on social support like establishing Rural Cancer Centers, Tribal Health Centres, Community Drug Banks, Medical detection camps could also be taken into account in future researches in the area. Multidisciplinary approaches are also to be looked into in a deeper angle. Suitable intervention packages that enhance the extent of social support could be studied further. Devising of such interventions and confirming their feasibility in the field is also an essential area.
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