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# QUALITY OF LIFE AND SOCIAL SUPPORT OF CANCER PATIENTS IN KERALA

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## *Abstract*

*The objective of this paper is to discuss the quality of life and social support of the cancer patients. It is based on the findings of an empirical study of 330 cancer patients undertaken in the Regional Cancer Centre, Thiruvananthapuram in 1997. Quality of life experienced by cancer patients and the social support received by them were measured in the study with the use of appropriate scales. The findings of the study showed that the cancer patients had a moderate level of quality of life and they received a relatively high level of social support from family, relatives and fiends.*

## INTRODUCTION

In recent years there has been new interest in research on cancer patients, especially on the social support they get and the quality of their life. This area of research could be of help in the rehabilitation of cancer patients as it highlights the nature of the social support system and the life of cancer patients. Treatment and care of cancer patients call for the utmost involvement of the family and social support which contribute to the quality of life they are experiencing. The psychosocial dynamics and the processes involved in cancer patients vary depending on their demographic profile, individual support system, personality characteristics etc. This article discusses the quality of life and social support appraisal of cancer patients in Kerala. It uses the findings of a study of cancer patients undertaken in 1997.

## QUALITY OF LIFE

Quality of life is a term heard frequently these days, particularly when issues of health, aging and economics are discussed. Individuals may have their own notion of just what a good quality of life means to them. For some, quality of life means having a job, a family and friends. To others, the measure of quality centres on the ability to afford travel, luxury cars, a "dream house" and a profitable stock portfolio. Still others would consider good health and grandchildren as essential to their idea of a good quality of life. We all have our dreams and needs that help to define quality in our lives. The World Health Organisation (WHO) defines quality of life as "(an) individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment" (WHO 2004). Quality of life refers to those aspects of life and human function considered essential for living fully (Mor et al. 1994). It is a person's appraisal of and satisfaction with their current levels of functioning compared to what they perceive to be possible or ideal (Cella and Cherin 1993).

## Dimensions of Quality of Life

Quality of life has several dimensions. People with illness, their families and their loved ones have every right to expect those dimensions of quality to continue in spite of their diagnosis and all that it can bring. Healthcare professionals generally agree that quality of life has four dimensions or domains: physical, psychological, social and spiritual. The physical dimension of quality of life includes comfort and mobility, among the many things that we take for granted in good health. The onset of disease and treatment related symptoms such as pain, weakness, fatigue, loss of appetite and changes in bowel or bladder function can drastically alter one's physical well-being. These symptoms may not occur in some people with certain diseases. However, those who develop physical problems and symptoms will need care and support to restore an acceptable quality of life.

While describing the psychological dimensions of quality of life, most healthcare professionals include such human needs as enjoyment and leisure activity, happiness, a sense of purpose and control over one's life. Any or all of these elements can be challenged when the diagnosis of a disease leads to uncertainty, anxiety, fear for the future or depression. Family and caregivers must be alert to any sign that psychological intervention is needed to address these concerns.

The social dimension of quality of life includes roles and relationships, financial concerns, burden on the family, affection and sexuality. It is not difficult to see how easily these elements of everyday life can be severely disrupted when a disease is diagnosed. Early intervention with understanding and social support can help to ease the social burdens that may accompany the diagnosis of a disease. Social dimension of quality of life rests on the fact that we are all part of a broad and complex social environment where decrease in the quality of life of a single individual can have a "ripple" effect on many others.

Spiritual well-being is considered by some as the most significant dimension of quality of life, and may also the least well understood. Until recently, the concept of spirituality was considered to be faith-based or religious in nature. Although religion may well be a part of the spiritual dimension of quality of life, there are many other aspects of this dimension to be considered. Spiritual well-being encompasses uncertainty, religiosity, the meaning of illness and suffering, the purpose of life, transcendence (lying beyond the limits of ordinary experience) and hopefulness. It is not difficult to see how diagnosis of a disease can lead to self-doubt and conflict with one's beliefs. In contrast, some will find meaning and solace through reliance on their strong spiritual foundation.

## SOCIAL SUPPORT

Development of a life-threatening and chronic disease like cancer has profound social consequences for both the patient and for those close to her/him. The onset of the disease tells upon various aspects of the patient’s life such as the activities of daily living, domestic life, social environments, working conditions and general outlook on life itself. It is in this context that a patient looks to others for their support in coping with the situation. Social support is commonly defined as the function performed for an individual under stress by significant others such as family members, friends, or professionals (Nelles et al. 1992). The function is generally classified into instrumental aid such as goods and services; expressive aid such as caring and listening; and informational aid such as education or advice concerning the disease or its treatment (Schaefer et al. 1981).

### Types of Social Support

Social support, or the various types of assistance/help that people receive from others, is generally classified into two (sometimes three) major categories: emotional, instrumental (and sometimes informational) support. Emotional support refers to the actions of people that make us feel loved and cared for, that bolster our sense of self-worth (e.g., talking over a problem, providing encouragement/positive feedback); such support frequently takes the form of non-tangible types of assistance. Emotional support involves providing encouragement, sympathy, appreciation, or otherwise interacting with people in ways that support them emotionally. By contrast, instrumental support refers to the various types of tangible help that others may provide. It includes help with childcare/housekeeping, provision of transportation, lending money, helping a friend to build a fence, or helping someone with problem in walking go up the stairs. Informational support represents a third type of social support (one that is sometimes included within the instrumental support category) and refers to the help that others may offer through the provision of information (John and Arthur 1998). Each form of support is traditionally thought of as a type of resource or social provision that can be exchanged between people. People who believe that they have access to these resources from others are expected to live healthier lives and to be able to cope more effectively with stress.

Though a patient expects support from several sources like peer groups, the most important source of support is the family. A patient’s perceived or actually received support from the family depends to a great deal upon the quality of communication he or she has with the family. Examination of the relationship between patient–family communication and psychosocial adjustment to cancer showed that interactions with immediate family members, especially spouse were important factor in determining psychosocial adjustment. Independently, emotional support was the most important predictor affecting global adjustment as well as domains of health care orientation, domestic adjustment and psychological distress. Thus family members are very important means of social support. Well-adjusted patients indicated that interpersonal interactions with the family members facilitated adjustment through emotional support, interest, reassurance, positive feedback and encouragement (Gotcher 1991).

## EMPIRICAL STUDY

The findings of the study, used in this paper, show the level of the quality of life experienced, and the kind of support expected and received by a patient with physical illness of cancer from the primary, secondary and tertiary social support systems available to him/her. The various possible emotional and behavioural reactions that the patient attributes to the significant others in his/her social environment in their interactions with him/her were measured in the study. It also measured how the person felt about himself/herself in relation to others in the social context. The research study also tried to find out how other factors influenced one's perception of social support appraisal and quality of life.

The study was conducted at the Regional Cancer Centre (RCC), Thiruvananthapuram. The RCC is the nodal cancer control agency for the state of Kerala. The Hospital Cancer Registry (HCR), managed by the RCC conforms to the standards set by the Indian Council of Medical Research (ICMR) for registering data reporting. As per the ICMR report, it was found that the maximum occurrence of cancer among males was oral, lung and pharynx, and breast, cervix and oral among females. Based on this information 165 female cancer patients with breast, cervix and oral cancer and 165 male cancer patients with oral, lung and pharynx cancer were selected from the HCR as the sample for the study. The distribution of the sample in each type of cancer is as follows:

**Table 1**
**Sample of the Study by Type of Cancer and by Sex**

| **Male Cancer Patients** | | **Female Cancer Patients** | |
|---|---|---|---|
| **Type of cancer** | **Number** | **Type of Cancer** | **Number** |
| Oral | 72 | Breast | 89 |
| Lung | 52 | Cervix | 42 |
| Pharynx | 41 | Oral | 34 |
| **Total** | **165** | **Total** | **165** |

## Operational Definitions

The central concepts of the empirical study - quality of life and social support - were operationally defined with appropriate scales adopted from earlier research studies. Social support experienced by the patient from his/her social environment in interaction with his/her friends and family was measured in the study by the social support appraisal prepared by the team of Alan Vaux and used by them in the year 1993 (Vaux et al. 1986). This instrument had 23 items to elicit the support perceived from three sources, namely family, friends and others. The items were based explicitly on Cobbs (1976) definition of social support and was designed to get the individual's belief that he/she is loved, esteemed and involved with family, friends and others. The items were found to be very simple and easily understandable to individuals of all backgrounds.

Quality of life in the study was derived from the patient's evaluation of his/her attitude towards himself/herself and the changes that the person perceived in the various aspects of his/her life. A set of questions for assessing quality of life, designed by S. Kaasa, A. Mastekaasa and S. Naess (1988), was used in this study. The psycho social well being questionnaire was composed of a 10 question scale and 2 global quality of life questions. The selection of questions was based on inventories of well being used in quality of life studies in general population. Five positive and five negative questions were used to correct the acquiescence response set, which has been joined to be a problem in some quality of life studies.

## Brief Description of the Sample

A brief description of the sampled patients on age, education, marital status, place of residence, occupation and income, religion and personal habits as well as on the clinical aspects like stage of illness, and frequency of hospitalisation is given below. Age-wise distribution of the patients showed that the single largest group of female cancer patients (32.6%) fell in the age group of 41-50 years, whereas among male patients the single largest group (34.3%) belonged to the 61-70 years age group. A relatively large number of the female (39.2%) and male (24.6%) cancer patients were illiterate. Only a small percentage (5%) of the patients had completed higher education. The vast majority of the patients were married/widowed. Just 4.5 per cent of the patients were unmarried. The majority of the respondents belonged to the rural areas - 80 per cent of males and 91.5 per cent of females. As many as 61 per cent of the male and 73 per cent of the female patients were Hindus. While looking into the employment it is noted that a considerable number of the male patients (40.9%) and a very large number of female patients (79.4%) were unemployed. However, while analysing the income status of the respondents, it was seen that 47.2 per cent of the male patients and 37.6 per cent of the female patients had a monthly income in the range of Rs.801-1000.

The habit of smoking developed by the respondents was also studied, since it is the main cause of some types of cancer. It was found that 90.3 per cent of the oral, 88.5 per cent of the lung, and 87.8 per cent of the pharynx cancer patients among the male respondents had smoking habit. In addition, drinking habit was found among majority (61.2%) of the male respondents.

During study data on some aspects of the health profile, the family history, stage of illness, type of treatment and frequency of hospitalisation were collected. It was found that majority of the patients (92 % of males and 74%of females) did not have a history of cancer in the family. The patients experienced various symptoms associated with cancer such as pain, discharge, swelling, cough, inflammation, ulcer, tumour, colour change and leucoplakia. Cancer patients in general need hospitalised treatment. Some of them undergo repeated hospitalisation. In the present sample male oral cancer patients had the largest number of repeated hospitalisation. The duration of hospitalisation varied according to the nature of the illness. The average duration of hospitalisation was three weeks. The hospitalisation process in itself calls for support from the family members, so that the patient is ensured with physical, social and emotional support, which in turn determines the quality of life. Majority of the cancer patients in this study were undergoing symptomatic treatment. Radiotherapy was generally administered to all types of cancer patients. The percentage of respondents who had surgery was highest (52.8 %) in the breast cancer group.

Regarding the stage of illness, a large percentage of the male (38.7%) and female (50.4%) cancer patients were in the middle stage. Those who were in the terminal stage constituted 12 per cent of the male and 10.5 per cent of the female patients. It was also found that 20 per cent of the male and 10.2 per cent of the female cancer patients were in the early stage and the remaining (29.4% of the male and 29% of the female) cancer patients were in the advanced stage of illness.

**Findings of the Study on Quality of Life**

Change in health status can disrupt what might be considered a normal, stable lifestyle. When that change is caused by a diagnosis of cancer, quality is certainly threatened or diminished, and often replaced by fear and uncertainty. The level of quality of life of cancer patients as perceived and experienced by them in the present study seemed relatively moderate. The average score in quality of life obtained by the cancer patients in the study was 33.93 out of the total of 64. The mean score in the total quality of life was 34.55 and 33.32 for males and females respectively. The difference between the male and female cancer patients in the scores in the quality of life was not significant (t = 1. 27; p>0.05). Thus the male and female cancer patients experienced more or less the same level of quality of life. In the Indian context it was expected that male cancer patients would enjoy better quality of life than female cancer patients due to the prevailing support system for males. But the findings of the present study do not support this hypothesis.

One would have thought that the nature of the cancer disease would affect the quality of life of the patients. But the results of the ANOVA test indicated that the different types of cancer patients had more or less the same level in quality of life. In other words, type of cancer did not make any significant difference in the level of the quality of life of the cancer patients.

**Table 2**

**Results of the ANOVA Test for Quality of Life**

| Male (165) | Oral (72) | Lung (52) | Pharynx (41) | Female (165) | Breast (89) | Cervix (42) | Oral (34) | Total (330) | F ratio | Stat result |
|---|---|---|---|---|---|---|---|---|---|---|
| Mean | 35.36 | 35.04 | 32.49 | Mean | 32.98 | 35.14 | 31.97 | 33.93 | 1.5 | p>0.05 |
| SD | 8.37 | 8.83 | 8.76 | SD | 8.89 | 8.57 | 8.92 | 8.75 | | |

The nature and extent of the treatment of cancer patients, especially frequency and duration of hospitalisation may differ according to the type of illness. Treatment to a great extent depends on the existing social support system that in turn may determine the level of quality of life. But analysis of the data in the study showed that perception and experience of quality of life among the patients was similar irrespective of the type of cancer they were suffering from and the nature of treatment they received.

### Findings of the Study on Social Support

One of the major consequences of cancer is the effect it has on the family and its structure. The burden of the care of the cancer patient, whether at home or in hospital falls mainly on the family. More often, there is a loss of family income on the part of a family member due to his or her own illness or to having no limit to working hours because of the illness of another family member. One of the direct effects of illness in the family is the change of roles within the family unit, which may be significant and sometimes permanent. This creates a heavy burden for many families.

Many cancer survivors tend to isolate themselves from the society for the fear of rejection or they are actually isolated by their family and friends due to the continued social stigma of cancer. Cancer patient and the family have to learn to cope and live with the reality of cancer disease and its implications, while trying to live together a friction free life and to derive satisfaction from what is left in life. For this, what they need is a lot of understanding and support from their relatives, friends and professionals.

#### *Source of Help*

The important aspects of social support of cancer patients that have been examined in the present study were source of support, concern of family members, expected behaviour from the family members, support from the family, relatives and friends, and the frequency of visit. The main sources of social support for the cancer patients are family, friends and relatives. Majority of the male respondents (74%) reported that they derived help from their spouses. For the female respondents, the main source of help was children (42%). The fact that 53 per cent of the female cancer patients in the study belonged to the category of widows probably explains the comparatively low percentage of female patients receiving help from spouses. Only a small percentage of the respondents received help from their parents (2.4% of males and 5.4% of females).

### ***Concern and Expected Behaviour of Family Members***

A high percentage of the male (91.5%) and female (83%) respondents reported that their family members became concerned towards them after the diagnosis. However, it may be noted that a few (4.5% of male and 6% of female) cancer patients did not attract any concern from the family, and another small group (4% of males and 10% of females) met with indifferent attitude of family members.

It was found that the vast majority of the cancer patients wanted their spouse/parents/siblings not to get anxious, but be normal. Irrespective of the nature of the illness, majority of the patients wanted their family members not to worry about them.

### ***Support from Family***

It was reported that over 97 per cent (98% male and 96.5% female) of the cancer patients received physical aid, emotional support and financial support from the family members. Around 60 per cent of the cancer patients received other forms of help from their family members.

Only 1.7 per cent of the male and 3.5 per cent of the female cancer patients reported that their family members were unhelpful. The family members in these cases exhibited their unhelpfulness by interfering in the patients' matters, considering the patients as burden, cursing God for the disease and creating impediments to treatment. Negative and unhelpful gestures from family members were problems faced by a very small number of patients. Of this small number, more lung and oral cancer patients experienced such reactions from the family. This is probably because these types of cancer are easily understood as largely caused by smoking and abuse of tobacco, which the patients probably were warned against by the family members.

### ***Support from Relatives***

The kind of help extended to the cancer patients by the relatives was in the order of emotional support, financial assistance, facilitation of treatment procedure and assistance during hospitalisation. The extent of support in these four areas of assistance was more or less the same. Similarly both the male and the female patients equally received from their relatives all the four types of support. They almost equally expected all the types of support (emotional support, financial helps, assistance during hospitalisation and facilitation of treatment procedure).

### *Support from Friends*

The help rendered by friends to the cancer patients were in the form of (a) giving opportunities to ventilate their feelings, (b) providing financial support, (c) facilitating financial assistance and (d) staying with them during hospitalisation. For many of the cancer patients, friends were a good source to ventilate their feelings and problems. Around 42 per cent of the male and 32 pr cent of the female cancer patients received financial support from friends. Friends facilitated financial assistance to around 44 per cent of the male and 26.7 per cent of the female cancer patients. Support from friends in the form of staying with the patients during hospitalisation was received by around 27 per cent of the male and 19.4 per cent of the female cancer patients.

### *Frequency of Relatives' Visit*

Majority of cancer patients reported that there was no change in the frequency of relatives' visit to their families after cancer was diagnosed. To the vast majority of the cancer patients, visits of the relatives were a source of consolation, relief and help, which proves the importance of social support. Only 3 per cent of the male and 1.8 per cent of the female cancer patients experienced tension or negative feeling out of the relatives' visits.

Despite the strong social support, many of the cancer patients have given up the battle for life and the reasons as reported by them are unbearable pain, fear of death, feelings of being a burden to the family, failure to fulfil ambitions and apprehension of social rejection. An equal number of the male (69.7%) and female (69%) cancer patients reported apprehension of social rejection and feelings of failure to fulfil ambitions.

### *Level of Social Support*

The maximum score in the scale used in the study for measuring social support was 92. The mean score in social support obtained by the cancer patients in the sample was 59.62. Thus the cancer patients experienced a level of social support from family, friends and others that can be considered as relatively high. The data further revealed that the male cancer patients with the average score of 61.46 experienced a higher level of social support than the female cancer patients (average score of 57.78). Results of the statistical test showed significant difference (t = 3.84; $p<0.05$) between the male and female cancer patients in the matter of social support from family, friends and others. The data of the present study are inadequate to explain this gender differentiation in social support.

**Table 3**

**Results of the ANOVA Test for Social Support**

| Male (165) | Oral (72) | Lung (52) | Pharynx (41) | Female (165) | Breast (89) | Cervix (42) | Oral (34) | Total (330) | F ratio | Stat result |
|---|---|---|---|---|---|---|---|---|---|---|
| Mean | 63.33 | 61.75 | 57.8 | Mean | 58.35 | 57.4 | 56.74 | 59.62 | 5.39 | $p<0.05$ |
| SD | 8.73 | 9.63 | 7.73 | SD | 8.55 | 8.79 | 7.52 | 8.89 | | |

While analysing the differences in social support among different types of cancer patients with the tests of ANOVA, it was found that there was significant difference in the level of social support experienced among the different types of cancer patients. The results of the test are given in Table 3. From the available data it is not possible to explain this difference.

## CONCLUSION

Cancer is an emotive word and for many, it spells grief, despair, bewilderment, fury, frustration and indeed the whole range of human emotions. A cancer patient is not merely an individual with a diseased body, he/she is also a person with a throbbing heart, a thinking mind, a stirring soul and one who lives in a small world of his/her own, surrounded by his/her family and friends. He/she has a physical disease that can be medically treated but he/she also has attitudes and aptitudes, interests and instincts, hopes and dreams of the future – which are all affected by the malady. Hence, it is imperative that all who have close contact with cancer patients should fasten out their own general philosophy – to be understanding, caring, accepting and willing to help. At the same time one should be practical, not to keep the patient in the dark, not to treat him/her as an outcast, or be hardhearted.

The patient will have to be made to understand his/her disease or disability, regain confidence and be inspired. Always make sure that fears and anxieties are dispelled and that social problems are solved. Also rehabilitation for the cancer patient is a team effort that requires the outstretched arms of the stakeholders. It needs to be remembered that total patient care and understanding is the essence for providing a better psychological and social adjustment of cancer patients.

Findings of the present study, it is hoped, will add to the existing knowledge about the psychosocial issues in oncology and prove beneficial to the professionals in the field of psycho-oncology. A more comprehensive research into the factors like family burden and psychological dimensions can be undertaken to understand the contours of factorial dynamics.

## REFERENCES

Cella, D.F., and Cherin, E.A., 1993, "Quality of Life in Cancer: Definition, Purpose and Method of Measurement', *Cancer Investigation*, Vol. 11, 327-336.

Cobb, S., 1976, "Social Support as a Moderator of Life Stress", *Psychosomatic Medicine,* Vol. 38, No.5, 300-314

Gotcher, J.M., 1991, "The Relationship between Family Communication and Psychosocial Adjustment of Cancer Patients", *Diseases Abstract International (A)*, Vol. 52, No.3, 738

John D. and Catherine T. Mac Arthur, 1998, website: www.macses.ucsf.edu/Research/Psychosocial/notebook/socsupp.html

Kaasa, S., Mastekasa, A. and Naes, S., 1988, "Quality of Life in Lung Cancer Patients in a Randomised Clinical Trial Evaluated by a Psychosocial Well-being Questionnaire", *Acta Oncologica*, Vol. 27, No.4, 335-342

Mor V., Allen S, and Malin, M., 1994, “The Psychosocial Impact of Cancer on Older Versus Younger Patients and Their Families”, *Cancer (Supplement)*, Vol. 74, No.7, 2118-27

Nelles, W.B., McCaffrey, R.J., Blanchard, C.G. and Ruckdeschel, J.C., 1992, “Social Supports and Breast Cancer: A Review”, *Journal of Psychosocial Oncology, Vol.* 9, 21-35

Schaefer, C., Coyne, J.C. and Lazarus, R.S., 1981, “The Health Related Functions of Social Support”, *Journal of Behavioural Medicine,* Vol. 4, 381-406

Vaux, A., Phillips, J., Thomson, B., Holly, L., Williams, D., and Stewart, D., 1986, “The Social Support Perceptions (SSA) Scale: Studies of Reliability and Validity”, *American Journal of Community Psychology*, Vol. 14, 195-220

WHO, 2004, *Mental Health: Evidence and Research*, Geneva, WHO Department of Mental Health and Substance Dependence

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