



Quality of Life of People Living with Cancer Under Institutionalized Palliative Care and Community Based Palliative Care in Kerala

Kiirii Aniljoy¹, Jona V.²

ABSTRACT: This study compares the Quality of Life (QoL) of Cancer Patients under Institutionalized Palliative Care (IPC) and Community Based Palliative Care (CBPC) in Kerala. A Comparative and descriptive research designed was adopted for the study. The universe of the study included two IPC centers in Thiruvananthapuram district and two CBPC centers in Malappuram district. A total of 100 respondents (50 respondents each from IPC & CBPC) drawn up using purposive sampling technique was the sample of the study. Data for the research was collected using a semi-structured interview schedule and WHO Quality of Life (WHOQOL) Assessment scale of 26 items (2001) for assessing the QoL. Statistical Analysis was performed using statistical analysis software SPSS version 11.5. T-test was performed for finding out significance difference between domain scores. The findings suggest that the QoL of cancer patients under IPC is lower compared to the QoL of cancer patients under CBPC. A vital issue underpinning this study is the choice of location of care, which depends on a range of factors. Although the research was conducted in Kerala, the findings are relevant to the attention of terminally ill cancer patients worldwide.

Keywords: Quality of Life, Cancer Patients, Institutionalized Palliative Care, Community Based Palliative Care



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1. Introduction

Cancer has been identified as a major health issue in the world, causing six million deaths annually, and 10 million new cases are reported annually. The disease has an immense impact on almost all facets of life like physical, psychological, social and spiritual. Even though medicine plays an important role in the diagnosis and treatment of the disease, the suffering of the patients has no end. In recent years, the improvements in cancer treatment have emphasized the importance of not only of the short term but the long-term implications of therapy. Because of the psychological and cultural overtones associated with cancer, assessing the quality of life (QoL) of cancer patients has gained more importance.

WHO has defined QoL as an individuals' perception of their position in life in the context of the culture and value system in which they live and about their goals, expectations, standards and concerns (WHO QoL group 1995). The definition highlights QoL as a subjective self-report from the individual, which is not based on reports or judgment from others. (E.g. family members,

¹ Research Scholar, Department of Social Work, Jamia Milia Islamia, New Delhi, India

² Medical Social Worker, NEIGRIHMS, Shillong, India

clinicians). QoL is also multidimensional incorporating positive (e.g. feeling happy, energetic) as well as negative aspects (e.g. not having pain, sadness, sexual difficulties).

Cancer affects not only the quantity of life but also the quality of patients' lives. Palliative care is the only possible humane option for patients suffering from a life-threatening illness like cancer. It is an approach that improves the quality of life of patients and their families associated with a life-threatening disease like cancer through the prevention and relief of suffering using early identification and impeccable assessment and treatment of pain and other problems; physical, psychological and spiritual. The objective of such services is to improve the symptom control and QoL of patients with terminal illnesses and to coordinate the care of the patient and support for the family.

In Kerala, palliative care is functioning under two different settings; institutionalized palliative care (IPC) and community-based palliative care (CBPC). Institutionalized palliative care is a conventional palliative care unit attached to hospitals or independent clinics. It mainly addresses the immediate needs of the patients. But the latter is a community-based service led by self-motivated community volunteers, which addresses almost all requirements of the patient as well as a family through home care. Though IPC exists in all parts of the world, CBPC is a new revolution in the field of palliative care. In Kerala, it got worldwide attention, and it is functioning as a model project of the WHO in Calicut and Malappuram District of Kerala state. Although the two settings are based on the same philosophy and principles, which is humanitarian, and the clients are all having almost same sufferings, the mobilization and utilization of resources and delivery of services are entirely different. Since palliative care aims for the total well-being of the patients, an assessment of the patients' perspective about QoL is crucial. This paper, therefore, seeks to compare the QoL of patients under the two different settings operational in the state of Kerala.

2. Review of Literature

Peter et al. (2006) study of QoL of cancer patients receiving in-patient and home-based palliative care found that most prevalent symptoms were weaknesses, fatigue, sleeping during the day and pain. Patients receiving home-based services had statistically significantly less symptom severity and distress (Mean symptom severity=1.90, Symptom Distress= 1 .16), lower depression scores, and better physical health and QoL than those receiving in-patient care. Home-care patients also reported statistically significantly more control over the effects of their illness,

medical care and treatment received, and the course of the disease. Multiple regression analyses showed that better global physical health, greater control over the effects of cancer and lower depression scores (Institution based=10.3% Home Based= 4.67) were statistically significant predictors of higher QoL.

A 1994 QoL study showed that hospice patients with cancer ranked support of family and friends fourth in importance, following (1) their relationship with God, (2) physical care they were receiving, and (3) support from the hospice interdisciplinary team (McMillan & Mahon, 1994).

Another study on QoL in lung cancer patients (Montazeri et al., 2003) found that the patients of lower socioeconomic status had more health problems, less functioning and global QoL, and a higher degree of symptoms at baseline assessment. The general findings suggested that QoL is not only the outcome of the disease, but is also highly dependent on each patient's socioeconomic characteristics. The results also indicated the need for more investigation on the socioeconomic status as the same play an essential role in patients' perceptions of QoL.

A study by Saini et al. (2006) compares the QoL and symptoms in cancer patients and patients at the end-stage renal disease. The study showed that there was no significant difference between the two groups in the symptom profile overall. Both groups reported similar levels of distress. Most symptoms reported by both groups were causing a little bit of distress (39% renal group, 36% cancer group). Pain and lack of energy were the most frequent distress symptoms. The level of psychological distress caused by these symptoms was similar for both groups. As per the study, the QoL scores were remarkably similar for the two groups.

Weitzner Michael et al. (2000) study on QoL in patients with cancer at the end of life revealed that patients receiving end-of-life care had the most problems in the area of functional abilities such as activities of daily living, feeling independent, and maintaining a social life and other enjoyable activities. The study found that patients were more worried about family and friends than what was happening to them, although this also was of concern to them. As per the study, patients reported the most significant level of well-being in the social/spiritual domain, with a relationship with God receiving the highest mean score. The study suggested that in the face of overwhelming physical problems, patients were able to maintain satisfactory social

Thomas et al. (2007) conducted a study on gender differences in perceived health-related quality of life among persons living with HIV. The WHOQOL Bref scale was used to assess the quality of life. The findings revealed that men reported a poor QoL in the psychological domain ($p < 0.01$) while women reported a poor QoL in the sociological domain ($p = 0.03$). The stage of

illness did not seem to influence the quality of life among women and men. The findings emphasize the need for health providers to assess the QoL among people living with HIV/AIDS.

Nirmal et al. (2008) cross-sectional survey on QoL among HIV/AIDS patients in south India revealed that the environmental domain had the maximum QoL score of the four domains. This suggested that the patients who had relatively better QoL scores had a linear relationship with the CD 4 count. When the study population was divided into men and women, and their CD 4 counts were compared, women in the study had better CD4 count compared to their male counterparts. However, they had a lower quality of life scores as opposed to males despite having less advanced disease. This was because women were more likely to sacrifice their health for the welfare of their family and postpone treatment or because they had low income or perhaps they dropped out of school early. As the education of the patient increased, they had better psychological domain scores. Family support significantly influenced the environmental domain in HIV/AIDS patients.

Brazil et al. (2005) study on preference for place of care and place of death among informal caregivers of the terminally ill showed that among the 214 respondents significantly higher preference was given for (63.1%) to die at home. Only 4.7 percent preferred the institution and 32.2 percent had no preference.

3. Methodology

This study aims at comparing the Quality of Life (QoL) of Cancer Patients under Institutionalized Palliative Care (IPC) and Community Based Palliative Care (CBPC) in Kerala.

Hypothesis

1. There is a significant difference between the QoL of cancer patients under IPC and CBPC.
2. There is a difference in the QoL of cancer patients about different socioeconomic status in IPC and CBPC

The research design used in the study was comparative and descriptive. The universe of the study included two IPC centers in Thiruvananthapuram district, namely; Krithudeva Hospice and Swanthanam Palliative Care and two CBPC centers in Malappuram district, namely; Areekode Palliative Care Clinic and Edakkara Palliative Care Clinic. The sample size for the study was 100 respondents (50 respondents each from IPC & CBPC), which were drawn up using purposive sampling technique. Data for the study was collected using semi-structured interview schedule developed in consultation with palliative centre doctors, psycho-oncology social worker and

community volunteers and WHO Quality of Life (WHOQOL) Assessment scale of 26 items (2001) for assessing the QoL.

4. Results

Table 1: Total QoL Vs. Type of Palliative Care

Groups	N	Mean	Std. Deviation	Test of significance
IPC	50	140.89	33.41	t-test= -12.49 df = 98 P= .00
CBPC	50	211.16	21.57	

Hypothesis: There is a significant difference between the Quality of Life of the cancer patients under Institutionalized Palliative Care and Community Based Palliative Care.

The above table shows the total QoL of cancer patients under IPC and CBPC. T-test was applied to find out whether there is any difference in the QoL of patients under IPC and CBPC. The group CBPC respondents had higher QoL as compared to group IPC respondents. On the quality assessment scale, the mean QoL score for IPC group was 140.89 with a standard deviation of 33.41 and for CBPC was 211.16 with a standard deviation of 21.57. The t-test value obtained was -12.49 and the mean difference was significant at 1% level. There was a vast difference in the actual means, and t-test also revealed a statistically significant difference between the means. This revealed that both groups have a difference in the QoL. Therefore, the hypothesis is accepted with a big significant difference.

Total QoL assessment included four domains; physical domains, psychological domains, social domains and environmental domains. The physical problems of the patients were immediately addressed by the CBPC team through home care and outpatient unit and had adequate pain management facilities than IPC. The psychological problems were not at all managed in IPC and majority of them depended on spiritual ways to reduce their problems. But in CBPC, these problems were managed through more professional ways like counselling.

Table 2: Physical QoL Vs. Type of Palliative Care

Groups	N	Mean	Std. Deviation	Test of significance
IPC	50	39.64	8.72	t-test= -4.257 df = 98 P= .00
CBPC	50	46.64	7.68	

Physical health and well being in WHOQOL scale meant patient is free of pain, having energy, feel restful sleep and free of dependence on medicine and treatment. The patient's ability to move around, engage in daily living activities and work is also considered as the physical well being of the individuals. The t-test showed that CBPC patients had higher physical QoL than the IPC. The mean value of IPC on physical QoL was 39.64 with a standard deviation of 8.72 and for CBPC was 46.64 with a standard deviation of 7.68. The t-test value was -4.257 at 1% level of significance. This showed that there was a statistically significant difference between IPC and CBPC respondents with regards to physical QoL.

Table 3: Psychological QoL Vs. Type of Palliative Care

Groups	N	Mean	Std. Deviation	Test of significance
IPC	50	27.50	12.87	t-test= -6.593 df = 98 P= .000
CBPC	50	43.33	11.07	

Psychological health and well-being of the individuals were mainly reflected through the individuals' happiness and enjoyment of life, ability to concentrate, feeling positive about him/her self, bodily image and appearance, free of negative feelings and personal belief. The t-test proved that CBPC patients had a higher psychological quality of life than the IPC. The mean value of IPC on psychological QoL was 27.50 with a standard deviation of 12.87 and for CBPC was 43.33 with a standard deviation of 11.07. The t-test value was -6.593 and was statistically significant at 1% level. This showed that there was a significant difference between IPC and CBPC group with regards to psychological QoL.

Table 4: Social QoL Vs. Type of Palliative Care

Groups	N	Mean	Std. Deviation	Test of significance
IPC	50	42	14.38	t-test= -10.504 df = 98 P= .000
CBPC	50	67	8.74	

Social relations include a relationship with other people, support from others and individual's sexual life. The result showed that CBPC patients had higher social QoL than IPC patients. The mean value of IPC on social QoL was 42 with a standard deviation of 14.38 and for CBPC was 67 with a standard deviation of 8.74. The t-test value was -10.504 at 0.00 level (1%) of significance. This showed that there was a significant difference between IPC and CBPC group with regards to social QoL. In CBPC, the patients were looked after by the community. Among CBPC patients, tertiary support was also found to be very high.

Table 5: Environmental QoL Vs. Type of Palliative Care

Groups	N	Mean	Std. Deviation	Test of significance
IPC	50	31.75	12.94	t-test= -10.855 df = 98 P= .000
CBPC	50	54.18	6.78	

According to WHOQOL, Environmental well-being of the individual means the individual feels physically safe and secure, pleasant home environment, having financial resources, to be able to get adequate health care, changes of getting new information and knowledge, relaxation and leisure and availability of adequate transport in everyday life.

The CBPC patients had higher environmental QoL than the IPC. The mean value of IPC on environmental QoL was 31.75 with a standard deviation of 12.94 and for CBPC was 54.18 with a standard deviation of 6.78. The t-test value was -10.855 at 0.00 level (1%) of significance. This showed that there was a significant difference between IPC and CBPC group with regards to environmental QoL.

Table 6: Sex Vs. QoL

Groups	Sex	N	Mean	SD	Test of Significance
IPC	Male	17	148.48	30.23	t-test = 1.157 df = 48 p > .05
	Female	33	136.98	34.73	
CBPC	Male	29	217.21	22.09	t-test = 2.445 df = 48 p < .05
	Female	21	202.81	18.17	

Hypothesis: There is a difference in Quality of Life with regard to different Socioeconomic Status in both settings

The quality of life of patients with regard to the sex of the respondents in two different settings was analyzed in the above table. In IPC, the mean score for male was 148.48 with a standard deviation of 30.23 and for females was 136.98 with a standard deviation of 34.73. The t-test value obtained was 1.157 and was not significant at 0.05 levels. The result showed that the quality of life of male and female respondents was equal in IPC.

In CBPC, the mean score received by the male was 217.21 with a standard deviation of 22.09, and for female, the mean score was 202.81 with a standard deviation of 18.17. The t-test value obtained was 2.445 and was significant at 0.05 levels. The mean score showed that male patients experienced a better quality of life as compared to female patients in CBPC. The reason for this was that the type of diseases female patients suffered from was mainly breast and gynecological related cancer resulting in loss of organs. And also, female patients were more worried about their family than their male counterparts. These were reflected in the psychological health of the patients. In CBPC, there was no special attention given to the female patients.

Table 7: Age Vs. QoL

Groups	Age	N	Mean	SD	Test of Significance
IPC	Up to 40 yrs	15	141.52	37.70	t-test = .087
	Above 40 yrs	35	140.62	31.99	df = 48 p > .05
CBPC	Upto 40 yrs	7	209.27	19.38	t-test = -0.248
	Above 40 yrs	43	211.47	22.10	df = 48 p > .05

For IPC age vs. QoL the mean score for age group up to 40 years was 141.75 with a standard deviation of 37.7 and above 40 years was 140.62 with a standard deviation 31.99. The t-test value attained was .087, and the mean difference was not significant at 0.05 levels.

In CBPC age vs. QoL assessment scale the mean score for age group up to 40 age was 209.27 with a standard deviation of 19.38, and for above 40 years mean score was 211.47 with a standard deviation of 22.10. The t-test value obtained was -0.248 and the mean difference was not significant at 0.05 levels.

For both the groups, there was a lesser number of patients in the age group of up to 40 years as compared with patients in the age group of above 40 years. On the other hand, the mean score was more or less similar in both the groups indicating that the total quality of life was almost similar in two age groups.

Table 8: Educational Status Vs. QoL

Groups	Education	N	Mean	SD	Test of Significance
IPC	Up to Middle school	27	134.56	31.16	t-test = -1.468
	High school and above	23	148.32	35.10	df = 48 p > .05
CBPC	Up to Middle school	31	212.82	21.45	t-test = .690
	High school and above	19	208.46	22.07	df = 48 p > .05

For IPC education vs. QoL, the mean score for up to middle school was 134.56 with a standard deviation of 31.16 and high school and above was 148.62 with a standard deviation of 35.10. The t-test value attained was -1.468 and the mean difference was not significant at 0.05 levels.

In CBPC education vs. QoL assessment scale, the mean score for up to middle school, was 212.82 with a standard deviation of 21.45 and for high school and above was 208.46 with a standard deviation of 22.07. The t-test value obtained was .690, and the mean difference was not significant at 0.05 levels. This statistical analysis showed that there was no significant difference in total QoL of cancer patients under IPC and CBPC with regard to education.

Table 9: Marital Status Vs. QoL

Groups	Marital status	N	Mean	SD	Test of Significance
IPC	Married	19	136.42	40.75	t-test = -.736 df = 48 p >.05
	Others	31	143.63	28.40	
CBPC	Married	37	215.13	21.84	t-test = 2.289 df = 48 p < .05
	Others	13	199.86	16.79	

For IPC marital status vs. QoL, the mean score for married patients was 136.42 with a standard deviation of 40.75 and unmarried and widows was 143.63 with a standard deviation of 28.40. The t-test value attained was -.736, and the mean difference was not significant at 0.05 levels. In CBPC marital status vs. QoL assessment scale, the mean score for married patients was 215.13 with a standard deviation of 21.84, and for unmarried and widows was 199.86 with a standard deviation of 16.79. The t-test value obtained was 2.289, and the mean difference was significant at 0.05 levels.

The total QoL of patients with regard to marital status was significant in CBPC at .05 levels. The data revealed that there is a substantial difference in married and unmarried patients in QoL. The married patients had good QoL than unmarried and divorced ones. The married patients often feel physical security, enjoy the right home environment and receive financial support from their spouses or children.

Table 10
Occupation Vs. QoL

Groups	Occupation	N	Mean	SD	Test of Significance
IPC	Employed	15	156.60	28.40	t-test = 2.267
	Unemployed	35	134.16	28.39	df = 48 p < .05
CBPC	Employed	12	225.53	28.22	t-test = 2.445
	Unemployed	38	206.63	17.06	df = 48 p < .05

The mean value of IPC for employed patients was 156.60 with a standard deviation of 28.40, and for unemployed patients was 134.16 with a standard deviation of 28.39. The t-test value obtained was 2.267, not significant at .05 levels. For CBPC, the mean value for employed patients was 225.53 with a standard deviation of 28.22, and for unemployed patients was 206.63 with 17.06 standard as a deviation. The t-test value was 2.445, significant at .05 levels. This showed that there was a statistically significant difference between IPC and CBPC groups with regards to the occupation.

The test value in both groups revealed that there was a significant difference in QoL between the employed and unemployed respondents. The QoL was low in unemployed patients. The reason being, though the majority of the patients was in the middle age group, they lost their jobs due to their illness. This directly affected their financial condition and led to some psychological problems. So, occupation is one of the critical factors in assessing the QoL.

Table 11
Family Monthly Income Vs. QoL

Group	Family monthly Income	N	Mean	SD	Test of Significance
IPC	Up to Rs. 3000/-	39	138.36	29.72	t-test = -1.01 df = 48 p > .05
	Above Rs. 3000/-	11	149.87	44.70	
CBPC	Upto Rs. 3000/-	37	209.44	21.12	t-test = -.950 df = 48 p >.05
	Above Rs. 3000/-	13	216.06	22.93	

For IPC monthly income vs. QoL the mean score for income up to Rs. 3000/- was 138.36 with a standard deviation of 29.72 and for income above Rs. 3000/- was 149.87 with a standard deviation of 44.70. The t-test value attained was -1.01 and the mean difference was not significant at 0.05 levels.

In CBPC monthly income vs. QoL assessment scales the mean score for income up to Rs. 3000/- was 209.44 with a standard deviation of 21.12 and for income above Rs. 3000/- was 216.06 with a standard deviation of 22.93. The t-test value obtained was -.950 and the mean difference was not significant at 0.05 levels. This statistical analysis showed that there was no significant difference in QoL among cancer patients with regard to their family monthly income.

5. Conclusion

Helping patients to achieve optimal QoL is the primary goal of palliative care regardless of whether this is provided at home or in an institution. In this study, IPC patients reported more negative effects of their symptoms, social life, treatment expenses and psychological condition. The impact of pain on QoL was a particular problem for the IPC patients, which, together with poorer health, may explain restriction on their physical and social activities. IPC patients experiencing higher

financial expense implied that hospital care is more expensive than home care. Higher QoL for the patients under CBPC could reflect freedom from pain, adequate psychological support and enjoy some measure of social life – factors that play an essential part in defining QoL. The home-based care patients had higher QoL supported by McMillan (1996) and in accordance with that finding patients receiving home-based palliative care had better QoL than those receiving institutionalized care.

Although the study is conducted in Kerala, the findings are relevant to the care of terminally ill cancer patients worldwide. A vital issue underpinning this study is the choice of location of care; a decision that depends on a range of factors, particularly the health status of the patient and availability of support. The results suggest that home-based care may be preferred (90% of patients preferred) option for the patients who are in better health and have a support network at home. In CBPC setting, community volunteers were actively involved in the patients' care. So the burden was shared between various sources and was never felt as a severe encumbrance. This total sharing of the burden resulted in the overall wellbeing of the patients. In-patient care on the contrary, particularly in a hospice is a more likely choice for patients who are very ill or require intensive symptom management or when the family is unable to cope with the burden of care. The main implication for the role of the caregivers and community volunteers are the need for early detection and management of both physical and psychological symptoms and the need to use strategies that will improve the QoL of the patient and to have a greater sense of control over their illness, treatment and life.

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