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Original Research Article

Quality of life in gynaecologic cancer subjects attending a tertiary care centre

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ABSTRACT

Background: As newer treatment modalities improve survival; quality of life issues takes on increasing importance for survivors. An adequate knowledge is required for psychosocial interventions and designing programs aimed at improving the quality of life of the cancer patients. The purpose of the study is to assess quality of life among gynaecological cancer subjects and its association with duration since diagnosis, type of cancer, mode of treatment and socio-demographic variables.
Methods: This is an interview based cross sectional study involving 131 patients diagnosed to have gynaecological cancer who were evaluated using WHOQOL-BREF Questionnaire. The gynaecological and socio-demographic data was analysed for any significant difference in QOL scores using one-way ANOVA.
Results: Social domain scored high with median score 50 ± 22.82. Environmental domain scored least with median score 28 ± 24.91. Based on domain scores it was found that only 2.3% subjects had better quality of life. Physical (55.7 ± 7.43) and psychological (57.95 ± 22.85) domain mean score was statistically significantly higher among subjects with cancer for more than 12 months. Subjects who had radiotherapy and chemotherapy scored least (44.52 ± 9.8) and subjects who had surgery and chemotherapy scored highest (59.43 ± 8.8) in physical domain.
Conclusions: As cancer incidence is increasing and post treatment survival is improving among cancer patients, two factors are gaining importance. One is early detection and prevention of cancer and the other is improving quality of life of survivors. In clinical practice the QOL instruments may be used with other forms of assessment, giving valuable information that can indicate areas in which a person is most affected and help the practitioner in making the best choices in patient care.

Keywords: Gynaecological cancer, Quality of life, WHOQOL-BREF

INTRODUCTION

Gynaecological cancers include cervical cancer, endometrial cancer, gestational trophoblastic tumour, ovarian epithelial cancer, ovarian germ cell tumour, uterine sarcoma, vaginal cancer and vulvar cancer.[1] It is estimated that about 9 million new cancer cases are diagnosed every year and over 4.5 million people die from cancer each year in the world. Cervical cancer is one of the most prevalent cancers that afflict women and that lead to deaths worldwide. The estimated number of new cancers in India per year is about 7 lakhs and over 3.5 lakhs people die of cancer each year. Out of these 7 lakhs new cancers about 2.3 lakhs (33%) cancers are tobacco related.[2] More than 4,70,000 new cases per year, of about 2,30,000 deaths every year are due to cervical cancer[3]. The data from HBCRs of India has shown that Cancer of Cervix (28%) and Breast (16%) in women are most common and cancer of Head and Neck region constitute about 30 % of all cancer in males and females.[1]

Other common cancers in women are those of Breast, Oral cavity, Ovary, Oesophagus and Stomach. More than 3-8% of ovarian, 0.5-4.8% of corpus uteri, 1-3% of vulvar and gestational trophoblastic tumours are reported in India every year.[1] There would be about 1.5 lakhs cancer cases at any given time in Karnataka and about 35,000 new cancer cases are added to this pool each year.[2]

The diagnosis of cancer affects patients and their families physically, financially and emotionally. Cancer is still considered synonymous to death, pain and suffering.[4] The common psychological and emotional responses to cancer arise from knowledge of life- threatening diagnosis, its prognostic uncertainty and fears about death and dying. The stigma due to cancer and its consequences adds to the negative reactions to the disease.[5] Various factors contribute to changes in the quality of life of women with gynecological cancers, functional damage secondary to treatment such as pelvic surgery, chemotherapy and radiation therapy as nausea, vomiting, diarrhea, constipation, mucositis, weight changes and hormonal changes, psychological factors including erroneous beliefs about the origin of cancer, change in self -image and self- esteem, marital tensions, fears and worries.[6]

The World Health Organization (WHO) defined quality of life as "an individual perception of their own position in life within the context of the cultural and value system in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1996); this concept is consistent with the definition of health in the same organization, incorporating physical, psychological, level of independence, social relationships, environmental, and spiritual areas. This definition means that the quality of life is a subjective assessment and stresses that it can only be improved if incorporated into the cultural, social and environment life of that person. So, the quality of life is the sense of well-being that can be experienced by people and represents the sum of objective and subjective personal feelings. Because there is no single definition of QOL, the operational definition in this study is based on the four domains of the WHO-BREF instrument.[7]

The survival rate of cancer patients has improved and focus has shifted to improve the quality of life of the survivors. gynaecological cancer received much less attention than breast cancer in terms of creating public awareness regarding risk factors and importance of screening. Therefore, this study will help in reconsidering our preventive approach and improving women access to screening programs and vaccination. An adequate knowledge is required for psychosocial interventions and designing programs aimed at improving the quality of life of the cancer patients. The purpose of the study is to assess quality of life among gynaecological cancer subjects and its association with duration since diagnosis, type of cancer, mode of treatment and socio-demographic variables.

METHODS

This is a cross sectional study involving systematic evaluation of quality of life. As a result, a primary source of information technique with Direct interview method using a predefined and structured questionnaire used on the referred inpatients to collect the necessary information. Written informed consent was obtained from the willing patients to participate in the study. Patients visiting K. R. Hospital for radiotherapy during May 2013 to June 2014 were considered. Non probability sampling technique was utilized to draw a convenient sample of 131 Gynaecological cancer patients undergoing treatment in KR Hospital. Patients who were >18yrs and gave consent were included in the study. Patients with gross cognitive deficits and too sick or distressed to participate, prior history of psychiatric illness, with major medical problems and who refused consent excluded from the study.

Population seeking treatment here represents the community. Study was planned after literature review and discussion with psychiatrist. Following ethical committee clearance permission was taken from radiotherapy department and informed written consent was taken from subjects who were eligible for the study. Predefined and structured questionnaire was used to collect socio-demographic details and MMSE (Mini Mental State Examination) scale was used to rule out cognitive impairment. Patients scoring >24 were considered for study and for illiterates' cutoff was taken as 21. Selected subjects were administered Kannada version of WHOQOL-BREF Questionnaire. Total of 150 patients reported to radiotherapy unit during study period, among them 12 did not give consent, five were on ART and two had CVA.

The World Health Organization quality of life – brief version (WHOQOL-BREF) designed to examine domain level profiles assessing quality of life. It includes four domains: physical health; psychological; social relationships; environment scored on five point Likert scale with varying anchors. Instrument contains two questions from the overall quality of life and general health, and one question from each of the 24 facets included in the WHOQOL-100. Self-administered questionnaire (estimated 15-20 minutes) assesses past two weeks. Reliability ranged from 0.66 to 0.84. Similar alphas have been shown for test-retest reliability ranging from 0.66 to 0.87.[7]

Data was analyzed using SPSS version 20 software. One-way analysis of variance test was done to find the significant difference between groups. Fisher's least significant difference (LSD) post hoc test was used to find out which group differed significantly. Probability

value less than 5% was considered as statistically significant.

RESULTS

Most of the patients (42.7%) in the study group were in the 46-55 age groups and were married (80.2%). More subjects (70%) were found to have low educational status, only up to high school education; majority of them (67.2%) were from nuclear family. Most of the sample population belonged to lower socioeconomic strata (70.2%), (70.2%) were from the rural area belonging to Hindu religion 101 (77%). Majority of patients (97.7%) had no health hazardous habits. Cancer cervix (66.4%) was found to be the highest among the individual cancer type and 100% patients knew about the cancer diagnosis what they are suffering. In this study majority (61.8%) had no associated co-morbidities like hypertension and diabetes mellitus. Majority of the patients (86.3%) had government insurance like Vajpayee Arogyashree and were below poverty line card holders. In this study maximum number of patients had cancer of three to six months' duration (61.1%). Radiotherapy and chemotherapy (64.9%) was found to be the mode of treatment in majority of subjects.

Table 1: Descriptive statistics of all domains.

	Domains			
	Physical	**Psychological**	**Social**	**Environmental**
Mean	46.53	41.61	49.92	32.29
Median	46.00	38.00	50.00	28.00
Standard deviation	11.051	19.449	28.826	24.910

Table 2: Comparison of means of QOL domains between duration since diagnosis, type of cancer and treatment groups.

Domains of QOL	Physical		Psychological		Social		Environmental	
	F	P value	F	P value	F	P value	F	P value
Duration since diagnosis	9.821	0.000*	7.054	0.000*	0.213	0.887	2.372	0.074
Type of cancer	8.704	0.000*	0.381	0.767	2.282	0.082	2.377	0.073
Type of treatment	8.641	0.000*	0.368	0.776	2.516	0.061	0.288	0.834

* indicates significance.

It was found that gynecologic cancer subjects have an equal perception of the general quality of life and general health satisfaction with a median value of 3 for both. 42.7% of them felt that the quality of their life was neither good nor bad. 21.4% perceived they had poor quality of life and 43% as good. 56.5% subjects are neither satisfied nor dissatisfied with their health. Almost equal numbers are satisfied (20%) and not satisfied (23%) with their health. Based on domain scores it was found that only 2.3% subjects had better quality of life. Physical health domain median score is 46±11.05. The median score for psychological domain is 38±19.45. Social domain median score is 50±22.82. Environmental domain: the median score is 28±24.91. Overall environmental domain had least score with only 21% scoring 50 and above indicating financial constraints, poor health care access, difficult transport and bad home environment. Higher scores meant better quality of life but in this study only social domain scored high with 56% subjects having scores 50 and above indicating good social support and better personal relationship (Table 1).

QOL and cancer types, duration, treatment

There was a statistically significant difference in physical domain scores among cancer types as determined by one-way ANOVA with p-value <0.01. A LSD post hoc test revealed that the physical domain score was statistically significantly higher among chorio-carcinoma subjects (59.43 ± 8.82) compared to other types with p-value ≤0.02. Chorio-carcinoma subjects had significantly least social domain scores (33.29 ± 24.57) compared to other types with p-value <0.05. The mean difference was significant with p-value 0.01 for environmental domain of cancer cervix and cancer endometrium with mean score of 29.07 ± 23.35 and 43.7 ± 26.8 respectively (Table 2).

Physical (55.7 ± 7.43) and psychological (57.95 ± 22.85) domain mean score was statistically significantly higher among subjects with cancer for more than 12 months compared to other groups with p-value <0.01. Physical domain mean score was least (38.7 ± 9.7) in subjects with duration three to six months and psychological domain score (36.38 ± 15.5) was least among subjects with duration six to twelve months. There was no statistically significant difference between other groups. There was a statistically significant difference in physical domain scores among treatment types with p-value <0.01. Subjects who had radiotherapy and chemotherapy scored least (44.52 ± 9.8) and subjects who had surgery and chemotherapy scored highest (59.43 ± 8.8) (Table 2).

QOL and socio-demographic variables

Significant difference existed between age groups in physical and social domain scores with p-value <0.01. Mean physical domain scores were high in 26-35 years' age group (56.58 ± 11.06) and low in 46-55 years' age group (42.8 ± 11.59). Mean social domain scores was higher in 36-45 years' age group (65.07 ± 26.74) and least in 26-35 years' age group (27.67 ± 21.9) (Table 3).

Table 3: Comparison of means of QOL domains between the socio-demographic variables.

Socio demographic variables	Total (%)	Domains				
		Physical	Psychological	Social	Environmental	
Age category						
<=25	6[4.6]					
26 – 35	12[9.2]	5.954	0.209	4.851	1.371	F
36 – 45	27[20.6]					
46 – 55	56[42.7]					
>=56	30[22.9]	0.000*	0.933	0.001*	0.248	P
Total	131 [100]					
Marital status						
Single	3[2.3]	0.914	0.991	20.571	0.642	F
Married	105[80.2]					
Divorce	3[2.3]	0.436	0.399	0.00*	0.59	P
Widow	20[15.3]					
Total	131 [100]					
Education						
Illiterate	52[39.7]	5.459	0.540	1.051	0.638	F
Primary school	40[30.5]					
High school	31[23.7]	0.001*	0.655	0.372	0.592	P
Degree	8[6.1]					
Total	131 [100]					
Family type						
Joint family	30[22.9]	1.474	0.709	3.701	1.036	F
Nuclear family	88[67.2]					
Extended family	13[9.9]	0.233	0.494	0.027*	0.358	P
Total	131 [100]					
Socio-economic status						
Lower	92[70.2]	0.631	0.231	1.120	29.908	F
Middle	38[29.0]					
Upper	1[0.8]	0.534	0.794	0.329	0.000*	P
Total	131 [100]					
Locality						
Rural	92[70.2]	2.592	0.416	0.057	0.027*	F
Urban	39[29.8]	0.11	0.52	0.811	0.86	P
Total	131 [100]					
Religion						
Hindu	101[77.1]	2.667	1.264	4.648	0.746	F
Muslim	27[20.6]					
Christian	3[2.3]	0.073	0.286	0.011*	0.476	P
Total	131 [100]					
Habits						
None	128[97.7]	0.305	0.668	1.15	0.477	F
Alcohol	2[1.5]					
Smoking	1[0.8]	0.738	0.515	0.320	0.621	P
Total	131 [100]					

* indicates significance.

There was a statistically significant difference in social domain scores among groups based on marital status with p-value <0.01. Married women had statistically significant high mean scores (58 ± 25.16) than others

with p-value <0.05. Physical domain score difference between groups based on education is significant with p-value <0.01. Subjects studied till high school had better physical domain mean score (52.65 ± 10.74) compared to illiterates and primary school groups. The difference in means of social domain scores between groups of family type was significant with p-value 0.02. Women from extended families had significantly higher social domain scores (67.38 ± 17.78) compared to women from nuclear families (45.9 ± 30.3) (Table 3).

Environmental domain scores differed significantly between socio-economic groups with p-value <0.01. Woman of upper socio-economic status had better environmental domain score (23.18 ± 21.2) compared to lower socio-economic status women. Muslim women had significantly higher social domain mean scores (64.52 ± 27) compared to Hindu women (46.26 ± 28.4) with p-value <0.01. No difference in any mean scores between groups based on locality and habits (Table 3).

DISCUSSION

Physical domain integrated seven items relating to activities of daily living, dependence on medications, energy and fatigue, mobility, pain and discomfort, sleep and rest, and work capacity. It scored second high among all domains with 45% women having scores 50 and above. Women with cancer for three to six months and who were on chemotherapy and radiotherapy had scored less indicating the impact of nausea, vomiting, diarrhoea, constipation, mucositis, myelosuppression, neutropenia, thrombocytopenia, anaemia and pain caused by cancer and its treatment. Women frequently must adjust to physical changes after treatment including loss of ovarian function, hot flashes, vaginal dryness, hair and skin changes, and mood changes. Surgical scarring may be another hurdle to adjustment, as are the need for urostomy or colostomy.[8] The scores were high among women aged 26 to 35 years and having chorio-carcinoma showing that young age women could withstand the physical symptoms in a better way.

Women studied till high school had adjusted for physical distress compared to illiterates and primary school groups in a better way. In a study among gynaecologic cancer women in Turkey, physical scores were found higher in women who had graduated from secondary school or above similar to this study results. Global, physical, role function, cognitive and social scores were found higher in women who had been treated with surgery in common with this study where women who had surgery and chemotherapy scored highest in physical domain.[9] In a study of quality of life of cancer patients in South India the results showed that the disease condition had moderately affected the physical condition of the major percentage of the population. Almost 50% of study population felt that they needed more rest. The results clearly indicate that proper nutritional supplement should be provided to patients, which could increase their working capacity.[10]

Psychological domain was made up of six items: body image and appearance, negative feeling, positive feelings, self-esteem, spiritual beliefs/religion/personal beliefs and thinking, learning, memory and concentration. 33% subjects had scores of 50 and above. Subjects with cancer for duration six to twelve months had less score showing higher prevalence of distress caused from feelings of vulnerability, sadness and fear, anxiety, panic, social isolation and spiritual crisis, affecting the way people deal with cancer and their changes. Over the course of the first year following diagnosis, gynecologic patients reported significant increases in emotional and functional wellbeing and total QOL in a prospective study of gynecologic cancer women done using the Functional Assessment of Cancer Therapy (FACT-G). In this study subjects with duration more than 12 months scored more than 50 in all domains except environmental domain indicating overall better quality of life.[11]

Among four domains social domain scored highest with 56% subjects having scores 50 and above, demonstrating that social support greatly influences the quality of life of women. This study found that social support principally from family plays a very important role, creating significant relationships with all aspects of women's quality of life and positively impacting the long term cancer survivor's mental health. Married Muslim women of age group 36 to 45 years from extended families had high social domain scores showing better personal relationships, social support, and sexual activity. Young women of age 26 to 35 years with choriocarcinoma from nuclear families scored less in social domain indicating social relationships are beneficial to improve quality of life of these patients and those who receive help and support from others cope well with the disease. But in a study at Turkey, role function scores were found lower, and emotional and social scores were found to be higher in single women than in married women. Women with endometrial cancer were found to have better role function, and social well-being than those with vulvar, cervical or ovarian cancer.[9]

In this study 75% women with cancer for more than 12 months had scored 50 and above in social domain. Similar to this, the study of patients with regionally advanced cancers reported better social well-being at one year suggesting that these patients may preferentially value or invest energy into social relationships. Results of one more study among women with gynaecologic and breast cancer, undergoing antineoplastic chemotherapy and attended by the Unified Health System, revealed that the most compromised domains were the physical and psychological domains, and the most preserved was the social sector consistent with this study results.[12]

Only socio-economic status had effect on environmental domain scores in this study**.** Domain items were related to financial resources, freedom, physical safety and security, health and social care, home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation (leisure activities), physical environment (pollution, noise, traffic, climate), and transportation. Overall it was the domain which scored least with only 21% scoring 50 and above. Women with cancer endometrium had better scores in this domain and it was significant. 73% of endometrial cancer patients are diagnosed at early stages as they present with symptoms early and treatment cost burden is less.[13] So this may be the reason for better scores. Lack of financial resources hinders accessibility to health care centres, thus compromising living and safety conditions, and it also affects the adherence to treatment. Therefore, health professionals should help these patients and refer them to assistance services when needed.

Capelli et al studied 115 women with gynecologic cancer and found that women with primary gynecologic cancer scored lower than healthy women on scales measuring emotional and physical role functioning. Patients undergoing palliative chemotherapy treatment had the lowest scores overall, as would be expected. Results also showed that the poorest QOL scores were reported by the youngest women with cervical cancer.[14] Sarikapan Wilailak et al concluded that treatment modalities appeared to have some effect on quality of life. Patients who underwent radiation therapy had lower FACT-G scores after treatment, while patients who underwent surgery had higher FACT-G scores, especially in the physical sub scores, similar to this study. The effect of treatment might explain why cervical cancer patients, who were treated mostly by radiation therapy alone, reported slightly lower QOL than patients with other types of gynaecologic cancer in this study. However, the results varied in the present study.[15]

Wenzel et al studied the QOL of long-term survivors of ovarian cancer and the results indicated that disease-free early stage sample enjoyed a good QOL with physical, emotional, and social well-being compared to other cancer survivors and non-cancer cohorts. However, 20% of survivors reported significant long-term treatment related side effects, including abdominal, gynecologic and neurologic toxicity. Furthermore, greater than half of the women surveyed indicated that they would have attended a support group if one were available to them at the time of diagnosis and treatment. This information provides some insight into the complex survivorship relationships between quality of life, long-term physical and sexual sequelae, and factors of resilience and growth which appear to promote a sense of well-being as a result of the cancer experience.[16]

Miller, Pittman, Case and McQuellon compared QOL in gynecologic cancer patients to that of healthy women. Patients treated with surgery only had better overall QOL, probably due to short treatment time and less advanced disease. Their study revealed significantly lower total QOL scores in patients with the following characteristics: ovarian cancer diagnosis, treatment with radiation therapy or multi-modality therapy, less than high school education, and lack of help at home.[17] A longitudinal study by Chan and colleagues assessed 144 women with newly diagnosed gynecologic cancer and concluded overall QOL improved after the completion of treatment but remained the same throughout the 2 years after treatment. The individual patient's QOL before treatment was insignificant while the impact of treatment on the individual patient was significant in determining QOL after treatment. The scores on overall QOL were lower for younger patients and for patients treated with chemotherapy than for patients treated with surgery. Site and stage of disease had no significant effect on QOL after treatment.[18]

Greimel and colleagues prospectively assessed women with gynecologic or breast cancer. QOL data was collected in female cancer patients, global QOL and emotional functioning are mostly affected during the course of disease, independent of their diagnosis. Overall, the researchers concluded that during active treatment patients with gynecologic cancer are significantly more physically impaired compared to breast cancer patients. However, QOL is comparable between groups at one-year follow-up, suggesting that gynecologic cancer survivors experience significant improvement in QOL following treatment. Predictors of long-term QOL included pre-treatment performance status and severity of surgery. Not predictive was family support, number of treatments, age, stage or site of disease.[19]

In another study, Lutgendorf and colleagues investigated quality of life and mood among women who had received intensive chemotherapy for at least one year for advanced gynaecologic cancers. Extensively treated women reported substantial, lasting decrements in physical, functional and emotional well-being. Patients using avoidant coping reported poorer physical and emotional well-being, along with greater anxiety, depression, fatigue, and total mood disturbance. Those using active coping reported better social well-being, better relationships with their doctors, and less overall distress.[20] Of all the demographic and clinical characteristics, younger age, greater education, early stage disease, and newly diagnosed were highly correlated with various QOL measures.[21]

As cancer incidence is increasing and post treatment survival is improving among cancer patients, two factors are gaining importance. One is early detection and prevention of cancer and the other is improving quality of life of survivors. Risk factors for maladjustment include treatment with radiotherapy or multi-modality treatment, increased length of treatment, younger age, psychiatric morbidity and coping using a disengaged style. Lower levels of education, poverty and spiritual/religious belief,

as well as lack of help at home, are also risk factors for poor QOL. Counselling patients regarding healthy coping techniques. Early detection of psychiatric morbidity can be done by screening of cancer patients using questionnaires at oncology unit/ gynaecology OPD by the counsellor. Minor illnesses can be treated by radiotherapists/ gynaecologists and others referred to psychiatry.

Finally, all higher socioeconomic indicators (higher income and educational level, and having a job) as well as having greater levels of spiritual belief produce positive influences on QOL. Financial assistance is provided by means of Vajpayee Arogyashree yojana for below poverty line card holders, but cancer treatment is costly that cannot be bared by middle class families. Many families end up in debts by the end of cancer treatment, especially when a bread earner has cancer. So financial assistance must be extended to all irrespective of their socio-economic status, concession in travelling fares, free medicines for co-morbidities must be provided to all. Support principally from family and friends plays a very important role in all aspects of QOL, impacting positively the long term cancer survivor's mental health. Creation of cancer survivor groups which is a ray of hope for patients, where healthy survivors can boost the self-confidence of other suffering women. Organizing educational support groups which provide peer support, education and specific information about danger signals of recurrence and exercise activities. Age appropriate interventions might need to be designed for effective management of limited resources, such as preparing older women for the social, physical, functional and treatment related effects of breast cancer, or involving partners and families in patient consultation may be helpful.

An adequate knowledge of cancer related symptoms and psychosocial issues are necessary for designing any intervention program aimed at improving the quality of life of these patients. In clinical practice the QOL instruments may be used with other forms of assessment, giving valuable information that can indicate areas in which a person is most affected and help the practitioner in making the best choices in patient care. In addition, they may be used to measure change in quality of life over the course of treatment. By increasing the physician's understanding of how disease affects a patient's quality of life, the interaction between patient and doctor will change and improve. This gives more meaning and fulfilment to the work of the doctor and leads to the patient being provided with more comprehensive health care. Because a more complete form of assessment covering different aspects of patients' functioning is being carried out, patients themselves may find their health care more meaningful. Palliative care in terminal stage cancer and community based rehabilitation of cancer treated patients is equally important to improve the quality of life.

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