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EFFECT OF DIAGNOSIS AND TREATMENT OF INOPERABLE CERVICAL CANCER ON QUALITY OF LIFE AMONG WOMEN RECEIVING RADIOTHERAPY AT KENYATTA NATIONAL HOSPITAL

R.K. Kamau, MBChB (Nbi), MMed, Obs/Gyn (Nbi), Chairman and Senior Lecturer, Department of Obstetrics and Gynaecology, College of Health Sciences, University of Nairobi, P.O. Box 19676-00202, Nairobi, Kenya, Also Chairman, Division of Obstetrics and Gynaecology, Nairobi Hospital, P.O. Box 3006-00100, Nairobi, Kenya, A.O. Osoti, MBChB (Nbi), MMed Obs/Gyn (Nbi), Consultant Obstetrician / Gynaecologist, AIC Kijabe Hospital, P.O. Box 20, Kijabe, Kiambu and E.M Njuguna MBChB (Nbi), Cert. Oncol. (Israel), Dip. Palmed (UK). Ag Head, Cancer Treatment Centre, Kenyatta National Hospital, P.O. Box 207230-00202, Nairobi, Kenya

Request for reprints to: Dr. R.K. Kamau, Department of Obstetrics and Gynaecology, College of Health Sciences, University of Nairobi, P.O. Box 19676-00202, Nairobi, Kenya

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R.K. KAMAU, A.O. OSOTI and E.M. NJUGUNA

ABSTRACT

Background: **Cancer of the uterine cervix is the most common female cancer in Kenya. Despite being preventable, it is often diagnosed when it is already late. For this reason, only palliative therapy is provided. Hence, it is expected that their daily routines and that of their caregivers are severely disrupted.**

Objectives: **To determine the extent to which diagnosis and treatment of inoperable cervical carcinoma affects quality of life (QOL).**

Design: **Cross-sectional descriptive study.**

Setting: **Radiotherapy Department at the Kenyatta National Hospital.**

Subjects: **Women undergoing radiotherapy for inoperable cervical cancer.**

Results: **There is high prevalence of profound disruptions in nearly all domains of QOL. In the social domain, between 33% and 44% had the perception that family members and friends had withdrawn social support. Reduction in various economic facets was reported by 47.4% – 52.6%, with 44.7% reporting a fall in the overall living standards. There were significant changes in the sexual domain, as a result in which 28.3% reported marital discordance. In the personality domain, decreased self-esteem and self-projection in life occurred in 30.9% and 36.2% respectively. On functional outcomes (EORTC QLQ-C30), only 32% – 41% reported not being affected in the various facets of emotional function. Physical functions were affected in 19% – 79%, role functions in 69% – 75%; symptoms in 49% – 80%; cognitive functions in 46% – 56%; social functions in 63% – 71% and financial aspects by 63%. On global QOL, 53% and 47% respectively reported high level disruption in overall physical health and overall QOL.**

Conclusion: **Severe deterioration of QOL occurs as a result of diagnosis of inoperable cervical cancer and subsequent therapies. For this reason there is need to establish severe disease and end-of-life research and management services that would ensure better coping with cancer for patients and for home-based caregivers.**

INTRODUCTION

The need to incorporate management of quality of life (QOL) outcomes in provision of care to cancer patients has recently been discerned (1). This need emanates from the observation that cancer therapy profoundly impacts on QOL, with resultant long-term disruption of life routines and emotional distress (2). Among the important deterrents towards achieving this goal have been difficulties in defining what constitutes QOL. In broad terms, QOL can be considered as a multidimensional concept that encompasses physical, social and psychological domains (3). The extent to which QOL in the various domains is affected is influenced by patient characteristics, type and extent of affliction (4). Among the indicators of the extent to which QOL has been affected is the appraisal of, and satisfaction with, the patient's current level of functioning as compared to the perceived ideal *(5)*. Based on these observations, many definitions of QOL have been advanced (1), but Gotey *et al* (6) appears to capture most of the elements that encompass the concept of QOL in relation to disease that *"QOL constitutes a state of well-being which is a composite of physical, psychological and social well-being on one hand, and the patient's satisfaction with the level of functioning, control of disease and treatment related symptoms on the other".* Calman *et al* (7) adds that *"QOL is appropriate or at its best if the hopes and expectations are matched and fulfilled by experience".*

Le *et al* (1), in a comprehensive review of QOL issues in ovarian cancer patients, notes the existence of serious paucity of data. This inadequacy of evidence-based information creates a hiatus of need that deters development of objective universal policies on interventional measures that would ameliorate QOL in cancer patients. On the other hand, Gleimel *et al* (2) has shown that most female cancer patients have high level of impairment of QOL domains as a result of both diagnosis and treatment, with global QOL and emotional functioning being the most affected. In addition, global QOL is significantly predicted by pre-treatment status and severity of surgery. Hence the challenge to achieve globalisation of management directed towards QOL outcomes within the concept of Quality in Continuum of Cancer Care (QCCC) model (8).

Diagnosis of cancer and the treatment processes also substantially affect QOL of home-based caregivers, who are often close relatives (9). Their daily routines are invariably disrupted and have to adapt to new lifestyles. These experiences often cause significant emotional and physical impact, which may be manifested as depression, psychosomatic symptoms, restriction of roles and activities, strains in marital relationships, as well as diminished physical health (9,10). Thus, preparation of home-based caregivers for their roles in providing care for cancer patients is another area of commonly unmet needs in cancer therapy.

Worldwide, gynaecologic malignancies account for a third of all female malignancies (2). In Kenya, as in most developing world, cervical cancer is the most common female cancer and diagnosis is often made when the disease is advanced (11). Hence, a majority receive only palliative radiotherapy. In circumstances such as these, it is useful to carry out needs assessment on QOL interventions as adjunctive measures in management of patients with advanced cancer. Studies elsewhere have ascertained the benefits accrued from QOL-based interventions in advanced disease and in long-term cancer survivors (4,12,13).

This study was carried out with the objective of determining self-assessed extent to which diagnosis of inoperable cervical cancer and radiotherapy affects QOL. The study focused on four main QOL domains and functional assessment using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - EORTC QLQ-C30 (15).

MATERIALS AND METHODS

The study population consisted of women with inoperable cancer of the cervix, all of who were in the process of receiving the required 20 courses of radiotherapy. All of them were aware that the treatment was palliative. There were no special sampling procedures as a total population was studied. The study period was from 10th January to 30th April 2005. The subjects were admitted into the study after receiving the latest course of radiotherapy. Data collectors were two nurse counselors, who were trained on the questionnaire. The study instrument was a structured questionnaire that focused on the main domains of QOL and the EORTC QLQ-C30 functional assessment questionnaire. Each subject was invited into a private room where she was explained about the study and a verbal consent obtained before administering the questionnaire. Analysis was done using EPI INFO Program. For comparative data, χ^2 was applied at 5% level of significance.

RESULTS

The study population comprised of 152 patients who were in the process of undergoing 20 courses of radiotherapy for treatment of advanced inoperable cervical cancer.

Table 1 shows the socio-demographic characteristics of the study population. The modal age group of patients receiving radiotherapy was 50 – 59 years, constituting 30.9% of the study population. There were 70 (46.1%) who were less than 50 years, with the age group 40 – 49 years contributing to 29.6%, while the rest (53.1%) were over 50 years of age. Only 16.4% were less than 40 years.

On parity, 50% had at least five previous deliveries. Only one (0.7%) was nullipara. Those who were currently married constituted 67.1% and 86.2% were either currently married or had a previous marriage. One-fifth of the patients had no education at all and only 46.2% had secondary education and above. Just over one-third had no gainful employment which, together with those employed as domestic servants contributed to 55.2% of the study population. Only 8.6% of patients had what could be considered as professional employment such as teaching.

Table 2 shows the perception of the respondents on the effect of diagnosis and treatment of inoperable cervical cancer on four major domains of life – social support, economic functions, sexual life and personality.

A majority of the patients felt that they still received social support from those closely associated with them (56.6% from the spouse, and between 63-71% from children, siblings, family and friends). Although the perception that social support was still available was generally lower among those aged 50 years and above as compared to those less than 50 years of age, significant difference found only in relation to social support from the family as a whole (71.4% as compared to 56.1%, $p<0.05$).

Regarding the domain of economic functions, reduction in income generation was the most affected (52.6%), followed by the ability to purchase drugs (47.4%), ability to provide basic needs (46%) and perception that the overall living standards have fallen (44.7%). There were no significant differences between those below and above 50 years of age.

On the domain of sexual function, 13.8% of the respondents reported that despite the diagnosis of inoperable cervical cancer, they were still interested with coitus. This interest was expressed by a significantly large population of those aged <50 years compared to those ≥ 50 years (24.3%, and 4.4% respectively, $p<0.001$). In spite of diagnosis of inoperable cervical cancer, 11.3% were still sexually active, 18.6% of the ones below 50 years of age being still sexually active as compared to 4.9% among those ≥ 50 years old ($p<0.01$). A total of 28.3% of the subjects reported sexual-related changes in relationship with the spouse.

Table 1

Socio-demographic characteristics of the study population (No. = 152)

Characteristic	No.	(%)
Age group (years)		
20–29	7	4.6
30–39	18	11.8
40–49	45	29.6
50–59	47	30.9
60–69	26	17.1
≥70	9	5.9
Parity		
Nullipara	1	0.7
Parous (1–4)	75	49.3
Grandmultipara (≥ 5)	76	50.0
Marital status		
Single	21	13.8
Married	102	67.1
Separated/divorced	6	3.6
Widowed	23	15.1
Educational level		
None	33	21.7
Primary	64	42.1
Secondary	44	28.9
Post-secondary	11	7.3
Occupation		
Unemployed	56	36.8
Domestic servant	28	18.4
Business	34	22.4
Professional	13	8.6
Others	21	13.8

Two aspects of personality were examined; self-esteem and self-projection in life. On self-esteem, 30.9% reported a perception that it was decreased, while 36.2% reported a decreased perception of self-projection in life. Perception on decrease in these parameters of personality was not significantly affected by whether the patients were below 50 years of age or 50 years and above.

Table 3 shows the effect of diagnosis and treatment of inoperable cervical cancer on daily functions as based on European Organization Research and Treatment of Cancer Quality Life Questionnaire (EORTC QLQ-C30). On physical functions, 81% did not need help with daily activities and 54% did not need to stay in bed or on the chair during the day. However, only 21% did not have trouble with strenuous activity, 19% did not have trouble with a short walk and 42% did not have trouble with taking a long walk.

On role functions, 25% and 31% reported that they were not limited in daily activities/work and leisure activities/hobbies respectively. On the same note, 61% and 53% reported "quite a bit" to "very much" affection in daily work/activities and leisure activities/hobbies respectively.

A majority of the patients experienced the various symptoms except diarrhoea, dyspnoea and constipation which were not experienced at all by 50%, 51% and 51% respectively. Direct symptoms least not experienced at all by less than 50% of the patients were the following: feeling weak (22%), tiredness (27%), pain (28%) and insomnia (37%). The corollaries are also true — that these symptoms were most commonly under the category "quite a bit" to "very much" as follows: feeling weak (59%), tiredness (58%), pain (60%) and insomnia (60%).

On cognitive functions, 54% and 44% reported no affection of concentration and memory respectively. Only 31% and 30% respectively reported "quite a bit" to "very much" affection of this domain.

The domain of emotional functions, consisting of the elements of tension, worry, irritability and depression, was not affected at all in 21-27% of the patients. The distribution of the proportions remained more or less the same among those who reported the degree of affection as "a little bit", "quite a bit" and "very much".

Table 2

Perception on effect of diagnosis and treatment of inoperable cervical cancer on some aspects of QOL by age

Aspect of QOL	Overall (n = 152)		By age (years) <50 (n = 70)		50+ (n = 82)		P-value
	No.	(%)	No.	(%)	No.	(%)	
Social support still available							
Spouse	86	56.6	44	66.7	42	56.0	NS
Children	97	63.8	49	70.0	48	58.5	NS
Siblings	98	64.5	50	71.4	48	58.5	NS
Family	96	63.2	50	71.4	46	56.1	<0.05
Friends	102	67.1	51	72.9	51	62.2	NS
Reduction in economic functions							
Income generation	80	52.6	36	51.4	44	53.7	NS
Provision for basic needs	70	46.0	30	42.9	40	48.8	NS
Purchase of drugs	72	47.4	33	47.1	39	47.6	NS
Overall living standards	68	44.7	30	42.9	38	46.3	NS
Sexual life							
Still interested	21	13.8	17	24.3	4	4.4	<0.001
Still sexually active	17	11.2	13	18.6	4	4.9	<0.01
Relation with spouse affected	43	28.3	23	39.9	20	24.4	NS
Aspects of personality							
Decreased self-esteem	47	30.9	20	28.6	27	32.9	NS
Decreased self-projection in life	55	36.2	24	34.3	31	37.8	NS

NS = Not significant

Table 3

Effect of diagnosis and treatment of inoperable cervical cancer on functions, based on EORTC QLQ-C30 scoring (No. = 152)

Aspect of function	Not at all		A little bit		Quite a bit		Very much	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Physical functions								
Trouble with strenuous activity	32	21	29	19	42	28	49	32
Trouble taking a short walk	29	19	36	24	41	27	46	30
Trouble taking a long walk	64	42	36	24	28	18	24	16
Need to stay in bed/on chair during the day	82	54	18	12	29	19	23	15
Needs help with daily activities	123	81	12	8	5	3	12	8
Role Functions								
Limited in daily work/activities	38	25	21	14	41	27	52	34
Limited in leisure activities/hobbies	47	31	24	16	37	24	44	29
Symptoms								
Needed rest	30	20	29	19	24	16	68	45
Felt weak	33	22	29	19	23	15	67	44
Felt tired	41	27	23	15	26	17	62	41
Dyspnoea	78	51	21	14	26	17	27	18
Pain	43	28	18	12	26	17	65	43
Pain interfered with daily activity	44	29	23	15	27	18	58	38
Insomnia	56	37	24	16	20	13	52	34
Lacked appetite	50	33	20	13	21	14	61	40
Nausea	64	42	20	13	18	12	50	33
Vomiting	72	48	21	14	14	9	44	29
Constipation	78	51	11	7	20	13	44	29
Diarrhoea	76	50	20	13	14	19	43	28
Cognitive functions								
Difficulties in concentration	82	54	23	15	23	15	24	16
Difficulty in remembering/memory	67	44	40	26	23	15	23	15
Emotional functions								
Tension	41	27	40	26	35	23	36	24
Worry	33	22	38	25	41	27	40	26
Irritability	35	23	33	22	47	31	36	24
Depression	32	21	43	28	36	24	43	28
Social functions								
Family life functions/roles affected	44	29	21	14	20	20	56	37
Social activities limited	32	37	27	18	27	18	65	43
Financial aspects								
Financial difficulties encountered	56	37	21	14	29	19	46	30

In the domain of social functions, family life functions and social activities were not affected at all in only 29% and 37%, while those reporting the degree of affection as "quite a bit" to "very much" were 57% and 61% on family life functions and social activities respectively.

The proportion that reported that they had not experienced financial difficulties as a result of diagnosis and treatment of inoperable cervical cancer was 37%, while 49% were in the combined categories of "quite a bit" to "very much" self-assessed degree of affection.

Table 4 shows the effect of diagnosis and treatment of cervical cancer on the two components that constitute global QOL self-assessment — overall physical health and overall QOL — measured from a least score of one point for "very poor" self-assessment to a maximum score of seven points for "excellent" self-assessment. Only 11% and 14% perceived that their overall physical health and overall QOL was excellent, while approximately one-third in each instance self-scored six or seven points. Those who assessed themselves as very poor in both aspects that constitute global QOL were 9% in each instance. On overall health, 53% indicated a score of four or less, while 47% indicated the same scores under overall QOL.

Table 4

Effect of diagnosis and treatment of cervical cancer on global QOL, based on EORTC QLQ-C30 scoring (No. = 150)

QOL self score		Aspect of global QOL	
		Overall physical health No. (%)	Overall QOL No. (%)
Very poor	1	14 9)	14 9
	2	13 8	17 11
	3	23 15	18 12
	4	32 21	23 15
	5	26 17	29 19
	6	29 19	30 20
Excellent	7	17 11	21 14

DISCUSSION

The results of this observational study reveal high prevalence of profound self-reported perception on disruptions in nearly all aspects of QOL as a result of diagnosis and treatment of inoperable cervical cancer. Adverse impact of diagnosis and treatment processes of cancer is not unique to this population (1,2), but may differ in severity depending on the type of cancer, extent of the disease and the ability of the patient to adapt and cope with disease (2). The socio-demographic characteristics depict a population that is economically meek, with 50% aged more than 50 years and a majority with little or no education and over 50% being highly parous (≥5). It is then apt to assume that they are likely to seek medical advice when the disease is already advanced (11). In addition, QOL prior to disease occurrence may have been sub-optimal (based on their socio-demographic characteristics), making adaptation to the advanced disease and palliative therapy more difficult (2).

In the social domain, a third or more of the patients had the perception that social support had become less available from all the categories of people who are normally considered to be close to the patient. It has been shown that poor social support is associated with less coping with the disease, and hence significantly greater distress (13). Closely related to this is the impact on the various arms of the economic domain, which were even more adversely affected in the sense that just around 50% of the subjects reported reduction in economic functions and a perception of a fall in overall living standards (44.7%). In the sexual domain, the changes were more subtle, but significantly affected by age. Of significance is that 28.3% reported that diagnosis and treatment of cervical cancer affected sexual relationship with the spouse, an observation that has been found to be very significant in other QOL studies (12,15). The possible relationship between declining economic abilities and perception of neglect from people who are normally considered as close is easy to discern, and may lead to the reported decrease in self-esteem and self-projection in life by 30.9% and 36.2% respectively. Hawighorst-Knapstein *et al* (15) have also noted that adverse personality disorders are common in cancer patients during treatment.

The responses on changes based on EORTC QLQ-C30 also depict that interrelated aspects of QOL — limitation of activities, role functions, symptoms, cognitive functions, emotional functions, social functions as well as financial aspects — are all adversely affected to a great extent. These deranged functions and symptoms are also surrogates of the extent of the disease and adversities generated by therapies that are administered. The extent of impact of diagnosis and therapy was most commonly manifested in the emotional domain where the various elements (tension, worry, irritability and depression) were reported 73 - 79%, an observation that is also described in other populations (2,4). The level or frequency of emotional derangement is also influenced by socio-economic status among cervical cancer survivors (4). This is not surprising, given the severe derangement of functions within all the domains considered in the EORTC QLQ-C30, the culmination of which should be overall derangement of emotional functions. The implication of this scenario is the need for increased dependence on care-takers, which in turn results in disruptions of their routines and economic activities — and hence affecting their QOL as well (1, 9). In a scenario such as this one, in which the population is economically meek, it is an expected outcome that the affected patients report a perception of neglect from the care takers, as a result of which there may be further disturbances in emotional aspects of their lives, as well as personality derangements.

Global QOL is the summation of changes in the various facets that constitute QOL. Both aspects that constitute global QOL — overall physical health and overall QOL — depict poor self-assessment towards deterioration in around 50% of the study population. Similar studies have also shown that global and emotional functions are the most affected aspects on QOL (2,4). These outcomes and observations depict the need to appreciate that QOL outcomes are as important as other measures of treatment (14).

On the whole, it can be concluded that this study has revealed that there is severe deterioration of QOL as a result of diagnosis of inoperable cervical cancer, as well as during palliative radiotherapy. For this reason, it is recommended that counseling on QOL issues should be integrated in management of cancer patients as well as their relatives in order to enhance better coping with the disease at all stages of the continuum of cancer care. In addition, there is need to carry out further research in this area.

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