PSYCHOSOCIAL WELLBEING AND NEEDS OF CERVICAL CANCER PATIENTS IN WESTERN KENYA

Jane A. Owenga*

Yaw Afrane*

Peter O. Odada**

ABSTRACT

Cervical cancer is a public health problem in Kenya and a major cause of morbidity and mortality and have an impact on the health related quality of life. In Kenya cervical cancer is the leading female cancer in both incidence and mortality rates at 40.1 and 21.8 respectively.Eighty percent of reported cases of cervical cancer in Kenya are diagnosed at advanced stages, leading to many patients who need palliative care services to improve their quality of life. This study was conducted at Jaramogi Oginga Odinga teaching and referral hospital in western Kenya. The objective of this study was to determine Perception of cervical cancer patients on their psychosocial wellbeing status and needs in western Kenya.

* School of Health sciences- Jaramogi Oginga Odinga University of Science and Technology

** Kenya Medical Research Institute, Public Health Department.

INTRODUCTION

Palliative care is an urgent humanitarian need worldwide for people with cancer and other life threatening diseases. Palliative care is particularly needed where a high proportion of patients present at advanced stages like in Kenya. Ideally, palliative care services should be provided from the time of diagnosis of life threatening illness, adapting to the increasing needs of cancer patients and their families as the disease progresses into the terminal phase.

Palliative care policy in Kenya is largely exotic. According to the Kenya human rights charter, patients have a right to participate in decision making and designing healthcare services appropriate for them. They also have a right to complain about healthcare services that they consume. This requirement so far is not provided for in Kenyan palliative care, there is no evidence that cervical cancer patients have been given an opportunity to participate in articulating their palliative care needs.Among cervical cancer patients in western Kenya, no study has previously investigated and established their quality of life and palliative care needs.

This study therefore hope to fill this gap of information by allowing the patients to evaluate their own psychosocial wellbeing status and identifying their psychosocial needs this will give them an opportunity to participate in designing their cancer site specific palliative care needs. This will go a long way in providing appropriate care that will ensure improved quality of life. (WHO, Strengthening palliative care: Policy and strategic directions, 2011–2015; Kenya National Palliative Care Training Curriculum for HIV/AIDs, Cancer and other Life Threatening Illnesses Trainer's Manual, 2013)

METHODOLOGY

Across-sectional survey using purposive sampling of 334 cervical cancer patients and 7 healthcare providers was conducted in Jaramogi Oginga Odinga Teaching and Referral Hospital in western Kenya. Data was collected using structured questionnaire, focus group discussion guide and in-depth interview guide. Statistical analysis was done using Chi-square and regression analysis and qualitative data were audio recorded, transcribed verbatim and the content analyzed in emerging themes.

RESULTS

Respondents reported psychological concerns which included being very much bothered by bleeding or discharge 250(74.9%) and odor from vagina 199(59.6%); being very much afraid to have sex 272(81.4%). Though only 31(9.3%) were very much worried about death. Patients mainly lacked access to professional counselling 281(84.1%) and counselling on sexual matters 252**(75.4%).**Majority 293(87.7%) did not have support groups.Most respondents reported getting inadequate support from their friends 190(56.9%), getting inadequate emotional support from their families 156(46.7%) and only 20(6.0%) were satisfied with their family communication about their illness.Majority of the respondents had high spiritual needs.

Further Regression analysis showed that spiritual status hada negative influence on overall quality of life. The P-values **>0.011** and **>0.047**inbold were greater than 0.05 implying there was no statistically significant relationship between spiritual status and overall quality of life at $P \leq 0.05$

Table 1 Psychological concerns

Variable	Not at all	A little bit	Somewhat	Quite a bit	Very much	Total
I am bothered by discharge or bleeding from my vagina	42 (12.6%)	32 (9.6%)		10 (3.0%)	250 (74.9%)	334 (100%)
I am bothered by odor coming from my vagina		63 (18.9%)	21 (6.3%)	51 (15.3%)	199 (59.6%)	334 (100%)
I feel sad	21 (6.3%)	83 (24.9%)	11 (3.3%)	124 (37.1%)	95 (28.4%)	334 (100%)
I worry about dying	168 (50.3%)	52 (15.6%)	61 (18.3%)	22 (6.6%)	31 (9.3%)	334 (100%)
I feel nervous	63 (18.9%)	133 (39.8%)	106 (31.7%)	11 (3.3%)	21 (6.3%)	334 (100%)
I am afraid to have sex		10 (3.0%)	41 (12.3%)	11 (3.3%)	272 (81.4%)	334 (100%)

Most of the respondents were very much bothered by bleeding or discharge 250(74.9%) and odor from vagina 199(59.6%).From the FGD discussions a patients said that *''I bleed a lot and when bleeding starts it goes even for six hours nonstop and when it stops I even faint, this has made me develop severe anaemia. This is usually followed by dirty creamish, whitish discharge with a bad odor'' (37 year old cervical cancer patient).*

In contrast only 31(9.3%) were very much worried about death. This result was justified from FGD discussion where most respondents said that their life is in the hand of God a patient said that "*God has been very good to me this far, I should have died long time ago but due to his protection I am still alive and trust that I will be well soon, He never fails his people." (46 year old cervical cancer patient).*

Majority of the patients were very much afraid to have sex 272(81.4%). In an in- depth interview a patient said that "*I feel a lot of pain during sexual intercourse, and bleed a lot after sex. This has made me develop intense fear for sex until I no longer feel like sex. I have them freed my Husband to marry or seek Sexual satisfaction elsewhere to preserve my health*" *(37 year old cervical cancer patient).* In another interview a patient said that *"my husband forces me to have sex even if I complain of pain and bleeding, he doesn't understand he thinks that I just refuse to have sex with him and accuse me of having other sexual partners that satisfy me elsewhere so I don't know how to convince him". (29 year old cervical cancer patient).*

Table 2 Psychosocial concerns

Variables	Not at all	A Little bit	Somewhat	Quite abit	Very much	Total
Have access to professional counselling (e.g., psychologist, social worker, counselor,)	281(84.1%)	33(3.3%)	10(3.0%)	----	10(3.0%)	334(100%)
Counselled on sexual matters	252(75.4%)	51(15.3%)	11(3.3%)	10(3.0%)	10(3.0%)	334(100%)
Treated with dignity	53(15.9%)	85(25.4%)	84(25.1%)	32(9.6%)	80(24.0%)	334(100%)
Informed about support groups in my area	293(87.7%)	21(6.3%)		10(3.0%)	10(3.0%)	334(100%)

Patients majorly lacked access to professional counselling at all 281(84.1%). Further interview with care provider at the palliative care unit revealed that, the facility lacks professional counsellors. "*We don't have professional counsellors in the unit, nowadays VCT counsellors has neutralized professional counselling, most providers only attend in- service VCT counselling and are considered qualified……so we need counsellors for our patients"* (HCP1)

Majority of the respondents reported not counselled on sexual matters at all 252**(75.4%).** Most of the patients studied were in the age groups of 18-35 and 36-46 which comprised 93 (27.8%) and 114 (34.1%) respectively. This is the prime age in reproductive health and sexual matters are key for life of the families. In the FGD discussions most of the patients said they are experiencing difficulties in handling their sexual matters since sexuality is also handled with a lot of secrecy in their culture. More often they are viewed as suffering from Sexually Transmitted Infections' and therefore not clean sexually and are abandoned by their husbands or "inheritors", most of them are forced to kill their sex life for not having way forward.

In another interview a patient said that *"my husband forces me to have sex even if I complain of pain and bleeding, he doesn't understand he thinks that I just refuse to have sex with him and accuse me of having other sexual partners that satisfy me elsewhere so I don't know how to convince him". (29 year old cervical cancer patient).*

As regards support groups, 293 (87.7%) were not informed of support groups at all. The health care providers reported that they do try to form support groups for the patients but it has not worked due to lack of support with logistics like T.V, snacks, space and fare reimbursement. They don't have any funding and that most patients are too sick to attend the meetings and worst of all the patients die quite fast after diagnosis since most of them cannot afford treatments of late stage.

Table 3 Professional counselling by Emotional wellbeing

Have access to professional counselling	**Emotional wellbeing**				
	Poor n=42	**Fair n=112**	**Moderate n=148**	**Good n=32**	**P-value**
Not at alln=281	42(100%)	102(91.07%)	116(78.37%)	21(65.62%)	**<0.0000***
A little bit n=33	0	0	22(14.86%)	11(34.37%)	
Somewhat n=10	0	0	10(6.75%)	0	

Very muchn=10	0	10 (8.92%)	0	0
	42	112	148	32

Analyses performed by Chi-square tests. *Statistically significant at P≤0.05.

Table 3 presents the proportion of respondents who experienced different levels of emotional wellbeing by access to professional counselling. Results revealed that emotional wellbeing was the best lived as compared to other three domains of wellbeing and overall wellbeing of the respondents. Almost half of the respondents 148(44.3%) experienced moderate emotional wellbeing while 32(9.6%) experienced good emotional wellbeing and only 42 (12.6%) experienced poor emotional wellbeing. Due to lack of professional counsellors in the Public health facilities most patients do not access professional counselling at all. Among those who accessed a little bit of professional counselling 11(34.37%) had good emotional wellbeing.

There is statistically significant relationships between cervical cancer stage and emotional wellbeing of cervical cancer patients P<0.0000

Table 4 Social concerns

Variable	Not at all	A little bit	Somewhat	Quite a bit	Very much	Total
I get support from my friends	31 (9.3%)	190 (56.9%)	42 (12.6%)	40 (12.0%)	20 (6.0%)	334 (100%)
I feel close to my friends	30 (9.0%)	139 (41.6%)	53 (15.9%)	72 (21.6%)	40 (12.0%)	334 (100%)
I get emotional support from my family	11 (3.3%)	42 (12.6%)	156 (46.7%)	105 (31.4%)	20 (6.0%)	334 (100%)
My family has accepted my illness	74 (22.2%)	83 (24.9%)	106 (31.7%)	41 (12.3%)	30 (9.0%)	334 (100%)
I am satisfied with family communication about my illness	106 (31.7%)	72 (21.6%)	136 (40.7%)		20 (6.0%)	334 (100%)

Most respondents reported receiving a little support from their friends 190(56.9%), getting some emotional support from their families 156(46.7%) and only 20(6.0%) were satisfied with their family communication about their illness. From the Focus Group discussions the patients said that their friends, church members and family members visit them and talk with them so they are not so lonely. They also assist them with home and child care. Most of them though said that their illness is not really accepted and that communication about their illness is not pleasant, they also reported being secretive about it since it concerns private parts and in their culture talking about this is difficult.

Table 5 Spiritual concerns of patients

variables	Not at all	A Little bit	Somewhat	Quite abit	Very much	**Total**
I feel God's presence	10(**3.0%**)	10(**3.0%**)	----	75(**22.5%**)	239(**71.6%**)	334(100%)
I find strength and comfort in my religion or spirituality	-----	20(**6.0%**)	20(**6.0%**)	52(**15.6%**)	242(**72.5%**)	334(100%)
I ask for God's help in the midst of daily activities	-----	20(**6.0%**)	-----	31	283(**84.7%**)	334(100%)
I feel God's love for me directly.	-----	-----	21(**6.3%**)	52(**15.6%**)	261(**78.1%**)	334(100%)
I desire to be closer to God or in union with Him	-----	-----	10(**3.0%**)	52(**15.6%**)	272(**81.4%**)	334(100%)
I need church members to visit me	-----	62(**18.6%**)	------	52(**15.6%**)	220(**65.9%**)	334(100%)
I need spiritual group members to pray for me	-----	10(**3.0%**)	11(**3.3%**)	63(**18.9%**)	250(**74.9 %**)	334(100%)
I need to listen to gospel music	-----	------	------	63(**18.9%**)	271(**81.1%**)	334(100%)

The study revealed how important spirituality is to patients with chronic conditions like cervical cancer. Amidst pain and difficulties associated with illness, most patients reported feeling Gods presence in their lives 304(94.1%) and finding strength and comfort in their spirituality 294(88.1%). Majority of the patients said that He is their closest friend available at every point in their lives. In an in-depth interview a patient said that ''*I constantly pray and talk to God even in my hospital bed, sometimes people think that I am asleep but just communing with God and praising Him in my heart, I find relief from that*.''(42 year old cervical cancer patient).

The findings indicated that most 250**(74.9 %)** patients very much need their church and spiritual group members to visit them and that they 271**(81.1%)** also need to listen to gospel music in their hospital beds. In an interview with the care providers it was reported that the hospital liaises with some spiritual groups who wish to minister to the patients and they allow them to come to the wards to meet the patients for spiritual nourishment.

Table 6 Influence of spiritual status on overall quality of life

Independent variables	B	Std. Error	t	P-value
(Constant)	-0.305	0.332	-0.920	**>0.358**
I feel God`s presence	-0.128	0.050	-2.554	**>0.011**
I feel inner peace or harmony	-0.072	0.036	-1.997	**>0.047**

a. Dependent Variable: Overall quality of life

Regression analysis between independent and dependent variables was used to identify whether **spiritual status had** influence on overall quality of life had. The P-values **>0.011** and **>0.047**inbold were greater than 0.05 implying there was no statistically significant relationship between spiritual status and overall quality of life at P≤0.05

spiritual status showed a negative influence on overall quality of life, this is evident from the fact that majority of the respondents expressed good spiritual status yet their quality of life were poor or at best fair.

Table 7 Influence of age, marital status, level of education and religion onspiritual needs of cervical cancer patients

Independent variables	B	Std. Error	t	P-value
(Constant)	4.283	0.150	28.465	0.000
Age	0.010	0.023	0.427	0.670
Marital status	-0.039	0.023	-1.682	0.094
level of education	0.109	0.029	3.773	0.000
religion	0.141	0.035	4.013	0.000

Dependent Variable: According to your experience how would you describe your spiritual needs?

Regression analysis between independent and dependent variables was used to identify whether **age, marital status, level of education and religion** had influence on spiritual needs. All the independent variables showed positive influence on spiritual needs except marital status that had a negative influence.

The P-values for level of education and religion were less than 0.05 indicating that these variables had statistically significant relationship with spiritual needs. Whereas age and marital status had P- value more than 0.05 indicating that they did not have statistically significant relationship with spiritual needs**P=0.670** and **P=0.094** respectively.

Discussions

The study revealed a wide distribution of age of the respondents, 18-35 (27.8%), 36-46 (34.1%) 47-57 (15.6%) and 58 and above (22.5%) reinforcing the fact that cervical cancer can occur across the life cycle, though age group of 36-46 constituted the highest number this finding agreed with Kim Hobbs (2008).

Puchalski (2012), asserted that Chaplains and other spiritual care professionals need to be recognized as experts in spiritual care and should be integral members of the healthcare team. Integrating spirituality as an essential domain of care will result in better health outcomes,

particularly quality of life for patients across the trajectory of cancer care. The current study fully concurs with this as majority of respondents revealed how important spirituality is to them. Amidst pain and difficulties associated with illness, most patients reported feeling Gods presence in their lives 304(94.1%) and finding strength and comfort in their spirituality 294(88.1%). Majority of the patients said that God is their closest friend available at every point in their lives. In an in-depth interview, a patient said that ''*I constantly pray and talk to God even in my hospital bed, sometimes people think that I am asleep but just communing with God and praising Him in my heart, I find relief from that*.''(42 year old cervical cancer patient).

Gioiella et.al (1998) and Taylor (2001) affirms that spiritual and religious well-being are associated with an improved quality of life because of reduced anxiety, depression, and discomfort; reduced sense of isolation; better adjustment to the effects of cancer and treatment; a feeling of personal growth as a result of living with cancer and overall improved health outcomes. The current study contrasts these findings in that however much the patients displayed satisfactory spirituality and high need for spiritual care, this did not impact much in their overall quality of life. This may be explained by other factors like health system constraints that were largely reported in this study.

The current study confirms Selman, et al. (2011) in a study of Patients receiving palliative care in South Africa and Uganda who exhibited significantly poorer QOL compared to similar populations in the USA. Feeling at peace and having a sense of meaning in life were more important to patients than being active or physical comfort, and spiritual wellbeing correlated most highly with overall QOL. The study concluded that it is vital to identify and meet the psychological and spiritual care needs of patients, as well as to assess and treat pain and other symptoms.

Bergmark et al. (1999) asserts that cervical cancer, regardless of the stage at presentation, may cause difficulties with sexuality, intimacy, and fertility. Cervical cancer patients also tend to have additional, premenopausal issues. This concurs with the current study where majority 283(84.7%) of the patients were not satisfied with their sexual life at all; 252**(75.4%)** respondents reported not counselled on sexual matters and 272(81.4%) were very much afraid to have sex.

The patients in this study lacked support groups, 293(87.7%) and access to professional counselling 281(84.1%). This agrees with Toubassi et al. (2006); Klee, Thranov, and Machin

2000); (Hawighorst-Knapstein et al. 2004) who also reiterated need for psychosocial support to cancer patients.

Abrahamson et al. (2010), identified Four types of system-level barriers to the meeting of patient psychosocial and information-based needs these included under identification of needs due to inadequate assessment, time constraints on cancer care providers, lack of adequate reimbursement for psychosocial and information services, and barriers related to communication of disease-related information. He also discovered that unmet need, especially unmet information need, is related to the level of patient health literacy. This concurs with the current study where level of education attained showed a positive influence on care and informational needs, regression analysis showed that 34.8% (0.348) of increase in care and informational needs is explained or predicted by level of education attained. This study also revealed system level barriers which included lack of relevant skills among staff, inadequate staff who were overwhelmed with work and therefore could not get time for proper counselling, lack of psychosocial needs assessment and inadequate resources for palliative care services in general.

CONCLUSION

The study identified wholesome professional counselling inclusive of sexual counselling and spiritual nourishment as major needs for cervical cancer patients.

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