

Communication Challenges of Culture and Stigma in the Control of Cervical Cancer among Rural Women in Kenya.

Victoria Chepkemai Kutto,

Moi University, School of Human Resource Development
Communication Studies. P.O Box 3900, Eldoret, Code 30100

Dr. Abraham Mulwo

Moi University, School of Human Resource Development
Communication Studies. P.O Box 3900, Eldoret, Code 30100

Abstract

The paper is part of the literature review of an ongoing doctorate research on communication challenges in the control of cervical cancer among rural women in Kenya. The paper looks at communication challenges arising from culture and stigma, which contribute to setbacks in the control of cervical cancer among rural women. Culture and stigma are discussed in this paper because they address some of the concerns of the research questions in the study. Cervical cancer is preventable and also treatable at early stages, but statistics from various credible sources worldwide indicate that it is one of the cancers that is high in morbidity rates especially in sub-Saharan Africa. This paper interrogates how culture and stigma pose communication challenges that prevent women from seeking the necessary healthcare in order to achieve the four components of cancer control which are: prevention, detection, treatment and palliative care. The paper uses a qualitative approach in its methodology because the main research takes an interpretivist –constructivist philosophical stance. Recommendations and conclusions made are hoped to contribute knowledge to the field of cervical cancer control especially in rural communities.

Key words: cervical cancer, culture, stigma, communication, and qualitative research

INTRODUCTION

Cancer control is fast becoming a global issue of concern, as the disease is still a phenomenal challenge to humanity. According to International Agency for Cancer Research (IARC) (2013), cervical cancer is an avoidable cause of death among women in sub-Saharan Africa, but with 528000 new cases every year, control measures need to be put in place and implemented. This paper looks at the role that communication can play by first attempting to bring out some of the communication challenges that abound, and thus singles out for the purpose of this paper, culture and stigma. By discussing culture and stigma as brought out in the literature reviewed, the research puts into perspective the perception of cervical cancer by rural women. This will give an opportunity for debunking myths and beliefs that have been a setback to open communication about cervical cancer, consequently enabling rural women to appreciate the need to seek information, embrace preventive practices, and attend screening for cervical cancer.

MATERIALS AND METHODS

The paper collected most of the materials from literature reviewed on culture and stigma as far as cervical cancer communication is concerned. Focus was mainly on research and publications done on developing countries especially in sub-Saharan Africa which is most affected by

cervical cancer morbidity. The literature was reviewed from a qualitative perspective with an aim of bringing to focus the perceptions of rural women about a disease that is categorized under reproductive health, an area that is largely affected by culture and considered a taboo subject in rural African communities.

CULTURE AND CERVICAL CANCER COMMUNICATION

The influence of culture on communication of cervical cancer in rural communities is an important aspect of this research. Rural women to a great extent live lives that are guided by cultural norms and beliefs. Discussing personal matters like a disease of the reproductive system in public is taboo in most rural communities.

According to Katrak (2006), traditions most oppressive to women are located within the arena of female sexuality. The normative forms of objectification according to Katrak include customs like dowry, multiple childbearing and fulfilling traditionally expected roles as a daughter, wife and mother. These expectations make women desire to aim at perfecting their roles to keep their places in the home. A woman who is diagnosed with a reproductive disease like cervical cancer will want to hide it from the spouse in order to try and remain relevant. Most rural folk quickly replace a woman who cannot bear children or is incapacitated as not to perform day-to-day chores. According to Dunleavy (2009) a case study in Uganda with two Hospice Ugandan nurses, revealed that culture plays a major role in cervical cancer communication. Culturally the patients still feel obliged to fulfill their duty as women in matrimony, which according to Dunleavy is a real problem for the women as the ordeal is physically punitive. In the event that the woman is unable to play her role as a wife, she is eventually replaced. In Dunleavy's case study, cervical cancer communication faces challenges from a cultural perspective because of taboo and belief in witchcraft. There is the question "why me?" Some patients would think they are bewitched and a lot of money is spent in looking for the witch, and the patient will also seek all forms of divine intervention, but not information on cervical cancer that can aid prevention, detection, treatment, or palliative care.

Another aspect of culture that poses a communication challenge in the battle against cervical cancer is the issue of disclosure. According to Moore and Spiegel (2004) most cultural communities find disclosure of cancer a very sensitive issue. To many it is seen as cruel because it robs the patient of hope and is likely to provoke rapid decline and death. In a preliminary interview with a prospective participant, this study discovered that disclosure was an issue of concern. A young man preferred not to disclose to his mother and siblings the fact that their mother was ailing from cervical cancer, and he was proud that she lived peacefully until her time of death. Moore and Spiegel (2004) also note that in most rural communities, families are often made up of many members from immediate family to extended relations. Cancer disclosure is seen as having the potential of impacting negatively on so many people that it is found better to keep it secret even from the patient. Being largely patriarchal, African communities leave all decisions to the male head of the household. This includes disclosure of a terminal illness. In the case of cervical cancer, a man may not be in a position to understand a woman's illness and decisions hurtful to the woman may be made. This could include decisions that prevent her from seeking treatment or care and hence suffer in silence (Ibid)

Dunleavy (2009) and Moore et al (2004) observe that in spite of apparent advances in medical science that have led to prevention, detection and treatment of cancer, myths and beliefs about causation, expectations regarding the meaning and the cause of illness pose communication challenges. These serve as barriers to early detection, treatment and recovery. Reinforcing these points are negative attitudes towards cancer and its treatment. This can also

perpetuate a cultural barrier to communication between patients and clinicians and may influence decision-making about referrals and treatment. In many rural communities people are averse to surgical treatment for cancer claiming that once a cancer patient is surgically operated, they will die (Moore et al, 2004).

Issues of gender and body politics were explored in this research study to find out how they influence the challenges of communicating cervical cancer among rural women. In this literature review factors that have influenced how women communicate about their bodies were interrogated. These included what causes women to avoid talking about and/or displaying their bodies even if for medical purpose, consequently refusing to consume positively, information about attending well being women's clinics for screening.

As much as the modern world wishes to close in on the gender gap between men and women in various aspects of society, various differences in communication still exist. This is even more pronounced among rural women. Kramarae (1981) in Griffin (2000) maintains that language is literally a man made construction. She insists that the language of a particular culture does not serve all its speakers equally, for not all speakers contribute in an equal fashion to its formulation. Women and other subordinate groups are not as free or as able as men are, to say what they wish because the dominant group (men) has constructed the words and the general names for their use. (Kramarae, 1981).

According to Kramarae and other feminist theorists, what women say in most societies is discounted and their thoughts are often devalued or ignored. In a situation where women attempt to overcome this inequality, the masculine control of communication puts women in a great disadvantage. Man-made language "aids in defining, depreciating and excluding women" (Thorne, Kramarae & Henley, 1983). Thus according to Kramarae, women are a silent group and this is the basis of the Muted Group Theory. Communication challenges arising from the muted nature of women as far as communicating cervical cancer is concerned is explored in this review of literature. To a great extent women in rural communities do not often speak for themselves and will often seek authority from their husbands or whoever is the head of the family in order to do most of the things in their daily lives. This is seen overtly when women are unable to take contraception to plan their families even when they desire to do so. If their spouse does not allow, then they will not do so. Dunleavy (2009) in a research for a guide for nurses who handle cervical cancer patients in a Ugandan hospice, notes the importance of including decision makers of the households in cervical cancer communication. Dunleavy finds it necessary that husbands need to be involved, as they are often the decision makers in most homes in developing countries. Through them the caregivers will reach to the ailing woman. Kramarae (1981) in Griffin (2000) however does not see a dead end in the muted group theory. In this theory she contests the masculine agenda by proposing a reformist agenda in which she advocates for women to become less muted in order to increase control over their own lives. This study aims to investigate whether rural women are truly muted and how they can help their situation to communicate more openly about cervical cancer.

Harding and Wood (1997) in Griffin (2000: 447) however do not view women as a monolith whose nature is simply one entity. Instead they are of the view that one's situation is often dependent on one's perspective, or outlook in life, hence the Standpoint Theory. According to Wood et al (1997) our standpoint affects our worldview. Harding and Wood see the gender difference between men and women, not as a biological difference but mostly as a result of cultural expectations and treatment that each group receives from the other. In relation to this

study, rural women have probably been socialized according to cultural norms to leave issues to the family decision maker. African families are largely patriarchal and therefore the man is often the decision maker. Since men may not understand issues of women's sexual health, understanding and speaking for a woman suffering from cervical cancer may not be possible. It would be justified in the view of the Standpoint Theory to classify women as a marginalized group if they cannot communicate about their health and therefore suffer and die in silence, a silence that Kramarae and Trelchler (1992) define as 'not golden' in their Feminist Dictionary. They note that there is no agony like bearing an untold story inside oneself. In a world where language and naming are power, silence is oppressive, is violence.

According to Ellingson and Buzzanell (1999), physician-patient communication is critical to quality healthcare for women. They note that research demonstrates that physicians do not listen to women carefully. They claim that physicians will often take women's concerns less seriously than men's concerns. An asymmetrical relationship places physicians in authority over patients, a power dynamic that is exacerbated further when the doctor is male and the patient is female (Borges and Waitzkin, 1995). Physicians have a tendency to often get distrustful and dismissive of women with vague and chronic symptoms. The fact that cervical cancer is an intrusive disease lodged in a woman's most private part of the body makes it even more vague for the woman to understand and explain the disease. Deborah Tannen's Genderlect Theory (Griffin, 2000) brings out to some extent, why there is trivialization of women's health concerns. In this theory, women's way of talking is not understood in the society, particularly by men. In general socialization to language use, Tannen notes that women are taught to use language in ways that end up making women diminutive. Language used on women is characterized with triviality. This could be the reason why women will often be heard saying 'you just don't understand' as Tannen's text is titled. Men and women have different language codes. According to Wear (1997) women's experiences are marginalized in all aspects of conventional healthcare. Research education and practice of diagnosis, treatment and illness management have focused on the bodies and experiences of men (Ibid). This could be the reason why women shun their health issues, more so, if it is to do with invasive disease like cervical cancer.

This research also looked at some African feminists and writers, and the outlook they give to feminism, and communication. This was explored in the light of challenges and opportunities that African women have in communicating cervical cancer from their perspective as African women. This should also broaden the opportunities for caregivers to approach cervical cancer communication from the African women's point of view. Nfah-Abbenyi (1997) notes that in as much as African women are pulled down by tradition in largely patriarchal societies, they are not necessarily totally muted. She expounds on the many ways in which women in many African communities come together in various gatherings that are purely female and no men are allowed. These are some of the opportunities which women can take advantage of, to discuss among other issues, matters on health such as cervical cancer screening.

According to Shapiro (1999) the female body is a private issue, a fact that is quite pronounced in the societies of most developing countries. Katrak (2006), in politics of the female body notes that in third world countries, there is 'this loud silence around issues of sexuality' (Katrak 2006:12). When it is mentioned, sexuality in third world societies is 'equated often rather narrowly with lesbianism' (Katrak, 2006:12) and any other negative notions around sexuality. In Kenya for example, after the Beijing Women's conference of 1996, the president at that time dismissed the outcomes of the conference insinuating that the women have come to propagate homosexuality and lesbianism.

Shapiro (1999) notes that human beings view disease as a failure of the body to function as it is supposed to. This becomes more complicated for women who have reproductive disease such as cervical cancer. According to Shapiro, the female body is subjected to policing by the male gaze. Consequently the female body is objectified so that it has always been “remade and reshaped into an ornament of desire for the male’s image.” (Shapiro, 1999:16). The policing gaze of the female anatomy has been with humanity for centuries. In South Africa in the early nineteenth century, two Boers; a farmer and a doctor, tricked a voluptuous native South African woman to a trip to France. There, the woman Saartje Baartman was subjected to treatment akin to an animal in a circus, caged and taken around for displaying her naked body. Even in death her genitals were bottled and preserved in a museum for viewing (Hall 1997). This reduction of women to an aspect of their anatomy only serves to discourage them from coming out publicly about an ailment of their reproductive system yet cervical cancer can only be treated if detected early.

The rejection of imperfect bodies is evident in all human culture, (Couser 1997). The rejection is evidenced in popular media and manifested in attitude towards disabilities, disfigurements and other aspects deemed unattractive by social standards. According to Buzzanell et al (2004) women who survive cancer, have to live most of the time with chronic illness, impairments and disfigurements caused either directly by cancer or as side effects of invasive medical treatments. The picture in the rural set up could be worse because as Katrak (2006) puts it, women’s bodies in third world are a site of oppression in a largely patriarchal society. A girl or a wife’s sexuality is sanctioned and restricted through carefully codified behavior and roles, such that in an event of illness such as cervical cancer, a woman feels incapacitated. For fear of being seen as a failure such a woman will keep silent about her illness. The objectification of the female body has consequently contributed to the silence around a disease like cervical cancer. This situation is aggravated by the fact that schooling and education does not have in its curriculum, sound issues on female bodies or sexuality (Katrak 2006). This silence about female sexuality will most likely contribute to communication challenges in the control of cervical cancer.

It is difficult for women in rural communities to communicate about the complex issues about cervical cancer, such as the foul smell, leaking bowels and general discomfort in their lower abdomen (Dunleavey 2009). Most literature and studies on cervical cancer in developing countries dwell majorly on limited resources (Dunleavey 2009), but leave out communication challenges. Although it may be linked to resources, communication carries its own strength. Rural communication on cervical cancer and how it affects a woman’s body is shallow and women are often left to their own devices.

CERVICAL CANCER AND STIGMA

One of the issues of concern in communication of cervical cancer lies in the domain of stigma. This literature review looks at how stigmatization of cancer in public sphere contributes to health communication challenges in the control of cervical cancer. In a study in Recife, Brazil on sexual strategies and cervical cancer Gregg (2003) found that cervical cancer is stigmatized particularly because it is often regarded in most rural societies as a sexually transmitted disease. Further, the diseased are often isolated because of layers of metaphors. Society distinguishes the diseases, but unfortunately also distinguishes the diseased. Thus they are made different from, and less desirable than the rest of the population. The diseased person becomes, ‘reduced in our minds from a whole and usual person to a tainted, discounted one’

(Goffman 1963:3) and the condition becomes a master status that overshadows all other personal attributes.

According to Gregg (2003) cancer is metaphorically loaded. The patients suffer not only the physical effects of the disease, but also from the isolating effects of stigma surrounding cancer. Terrified by the notion that cancer is perhaps incurable and often unpredictable, people despise and fear it, leading to a lot of silence around the ailment. In rural settings, Gregg noted that cervical cancer and its association with sexually transmitted disease, reduces women with cervical cancer to being blamed for being promiscuous. They consequently become embarrassed and therefore even if unwell, such women will keep silent about their condition instead of seeking treatment. In one case study Gregg noted that the patients will always have written themselves off and any treatment procedures are treated with suspicion of being ridiculed. One woman who refused to continue with treatment said 'it is like someone putting a finger in an open wound and messing it up.'

Mason (2001) on stigma and social exclusion in healthcare observes that until recently, cancer was discussed in hushed terms. The word itself carried a powerful emotional message promoting feelings of anxiety, fear and dread. According to Mason cancer is mysterious to humanity in general, it is a silent killer, its origin is unknown and the facts available are both ominous and terrifying. Cancer challenges not only a person's resilience to withstand disabling and invasive disease and disruptive and disagreeable treatment, but also confronts an individual with a tenuous hold upon life itself. Cancer forces a person to look into the face of death against our reflective instinct to look away (Ibid). Cervical cancer faces more challenges than all other types of cancer because its nature and treatment is most invasive and the stigmatization is more profound.

Buzzanell et al (2004) looks into the lives of women cancer survivors and how they make meaning of chronic illness, and disability. Stigma stands out as a communication challenge because the rejection of imperfect bodies and a disease they hardly comprehend leaves them feeling isolated. Cancer survivors with persistent physical and/or emotional effects of the disease and treatment are stigmatized and dehumanized by society in the way they are handled. Female cancer survivors who have chronic impairments are often not easily categorized by self or others. These women occupy the boundary areas between health and illness; ability and disability; wholeness and loss; femininity and 'damaged goods' (Harrison 1999). In the society there is always the assumption that people are either completely able or healthy, or they are completely disabled and are an object of charity. There is still not enough middle ground (Wendel, 1992). In this light rural women are in a more complex situation because their setting often leaves them much more disadvantaged as they are mostly illiterate and are often addressed on various issues about their lives by authorities that do not allow them to participate in their own development issues.

CONCLUSION

Culture and stigma have largely contributed to the silence with which rural women have chosen to suffer the ravages of cervical cancer. This is brought out from the literature reviewed in this paper. IARC (2013) recommends the need to implement the available tools and methods of cervical cancer control, citing for example, the HPV vaccines available, the less invasive and affordable easy to administer screening and treatment procedures, in order to curb the upward morbidity trends of cervical cancer. This paper however is of the recommendation that until myths and beliefs about cervical cancer and reproductive health in general, are debunked, it is still going to be an uphill task for cervical cancer control to be achieved as rural communities

will still be barred by cultural and stigmatization factors from seeking the necessary healthcare for cervical cancer control. By seeking amicable participatory communication, rural communities will be able to embrace and participate in the implementation processes of advocacy and campaigns as they will feel they are part of the process, and consequently identify with, and own decisions made.

References

- Borges, S., & Waitzkin, H. (1995). *Women's narratives in primary states, 1946-1974*, Los Angeles: University of California DHEW publication.
- Couser, T. (1997). *Recovering bodies: illness, disability and life writing*. London: University of Wisconsin Press.
- Dunleavy, R. (2009) *Cervical cancer: A guide for nurses*. UK: John and Sons.
- Ellingson, L.L., Buzzanell, P.M. (1999). Listening to women's narratives of breast cancer treatment: A feminist approach to patient satisfaction with physician – patient communication. *Health Communication* 11, 153-183
- Goffman, E. (1963). *Stigma: notes on the management of spoiled identity* NY: Simon & Schuster, inc.
- Gregg, J. (2003). *Virtually Virgins: Sexuality strategies and cervical cancer in Recife, Brazil*. California: Stanford University Press.
- Griffin E.M. (2000). *A first look at communication theory 4th ed* USA: McGraw-Hill, Higher Education.
- Hall, S. (1989). "Ideology and communication Theory" in *Rethinking Communication Theory*, Vol 1, p.52
- Harding, S
- IARC World Health Organization Press Release No: 223 12, December, 2013
- Katrak K.H. (2006). *Politics of the female body*. N.J: Rutgers University Press.
- Kramarae, C. (1981). *Women and Men Speaking*. Rowley: Newbury House publishers
- Kramarae, C. and Trechler, P (1992). *Amazons, Blue Stockings and Crones: A feminist Dictionary*, 2nd Ed. London: Pandora.
- Mason T. (2001). *Stigma and social exclusion in healthcare*. London: Routledge.
- Moore R.J. and Spiegel D. (2004). *Cancer, Culture and communication*. NY: Kluwer Academica Publishers.
- Nfah-Abbenyi, J.K. (1997). *Gender in African Women's Writing: Identity sexuality and difference*, USA; Indiana University Press.
- Shapiro. S. (1999). *Pedagogy and the politics of the female body*. USA: Routledge
- Thorne, B., Kramarae, C., and Menley, N. (eds) (1983). *Language, Gender and Society*, Rowley: Newbury House.
- Wear, D. (1997). *Privilege in the medical academy: A feminist examines gender, race and power*. USA: Teachers College Press.