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Title: **CAN IEC BE PART OF ROUTINE CARE TO CANCER
PATIENTS IN ZAMBIA**

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INTRODUCTION

Information Education and Communication “IEC” refers to a public health approach aiming at changing or reinforcing health-related behaviors’ in a target audience, concerning a specific problem and within a pre-defined period of time, through communication methods and principles (Cliff, 2001).

IEC is of paramount importance in the care of oncology patients because cancer is not a single disease with a single cause; rather it is a group of distinct diseases with different causes, manifestations, treatments and prognoses (Smeltzer et al, 2008). People with chronic illness need IEC in order to participate actively in and assume responsibility for their care. Moreover, IEC is important to prepare patients and their families through a wide range of physical, emotional, socio-cultural and spiritual crises that they may face (Smeltzer et al, 2008). IEC remains crucial in the cancer setting as patients have to deal with stress, uncertainty, complex information and life altering medical decisions (Epstein and Street, 2010).

The author was attached to an oncology ward at a Central Hospital in Norway for a period of six weeks during which, IEC was given to the patients as part of routine care. The author would like to know the importance of IEC to patients with cancer. What are the benefits of giving IEC to patients with cancer? Is it of benefit to the nurse if patients have information? How is IEC given to patients with cancer in Zambia? What are the challenges of giving IEC to patients with cancer in Zambia? A conclusion will be drawn and recommendation for the Zambian system will be made.

Description

A diagnosis of cancer is a stressful life experience, the nature of the disease requires patients to learn about the illness, make difficult decisions regarding the ensuing treatment and cope with the consequences of the illness. (Ankem, 2006) Providing patients with IEC at all stages of the cancer trajectory is extremely important as result of the complex issues

that surround cancer and its treatment (Wells, in Corner and Bailey, 2008 and Ankem, 2006).

In Norway, care of patients with cancer is provided in various hospitals around the country. The common cancers that were nursed on the cancer ward included; leukaemia, lymphomas, prostate, myeloma, breast, pancreatic, colorectal and stomach cancer. The stages of cancer also varied among the patients. Most of the patients were above the age of 65 although a few were less than 40. The patients were grouped into three categories namely organs cancers, hematological and palliative care. Provision of information was an important component of the nursing care to the patients with cancer.

IEC was given using information packs, brochures, leaflets, one on one nurse-patient discussions, and family meetings with the nurse and oncologist. The telephone line of the ward was also open for patients to call whenever they had a concern. The nurses also had a checklist to ensure that they gave the patient the information required.

During my practice, a team of experienced and specialized nurses cared for these patients. The ward was generally well staffed with not less than eight nurses on an early shift which helped to ensure that patients received holistic care. The author participated in the care of the patients. During the period of admission, patients were given *IEC* tailored to their needs. Some patients came for chemotherapy treatment while others were admitted for treatment of infection and other complications. Patients also asked for information about the blood tests and the nurses printed out the results and had discussions with the patient.

In Norway, *IEC* involves giving information about the:

- 1) Nature of disease, its process and prognosis,
- 2) Cancer treatments,
- 3) Investigative tests,
- 4) Preventive, restorative, maintenance, physical care, nutrition
- 5) Information about pain management in cancer

6) Information about morphine and cancer

7) Patient's or family's psychosocial concerns, palliative care and other patient support

Networks (Helse-Førde)

8) Use of the Edmonton Symptom Assessment System (ESAS) which is a tool designed to assist in the assessment of: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing, and shortness of breath. In Norway, the ESAS has been modified to include a question about oral dryness and a second question about pain at movement supplementing the item on pain at rest (Bergh et al, 2011). The ESAS was designed so that the patient, or his/her family caregiver, could self-administer the tool. So IEC includes teaching patients how to complete this form (Bruera et al 1991 and cancer care Ontario, 2003).

The commonest cancers in Zambia are cervical, breast, prostate and hematological. Most the patients are above 55years although some are less than 40. The number of young patients especially women is growing due to HIV/AIDS related cervical cancer (Bourke and Bomela, 2009). There is one Cancer Diseases Hospital which caters for the whole country and one cancer ward mostly for female patients the rest of the patients are cared for in the surgical wards. Most patients in Zambia bewail the non-availability of information on lifestyle effects of cancer as well as self-care (Nyirenda, 2011).

The average number of nurses is normally two nurses to thirty patients on an early and afternoon shift while only one nurse works during the night shift. IEC is mostly given in small group discussions due to high number of patients. Most IEC programs are targeted at awareness and diagnosis while patients mostly desire information about treatment, side effects as well as lifestyle related changes. There are leaflets and brochures which are mostly on the signs and symptoms of the common cancers such as breast and cervical cancer but there is generally very little information on treatments and side effects. Most of this information is given by nurses after the treatment sessions.

Analysis

What are the benefits of IEC to the cancer patients?

The benefits of giving IEC to the patients include the following;

Helps patients make informed decisions about treatment: Ankem 2006, found that providing IEC to patients with cancer is crucial to facilitate informed decision making. For patients to participate fully in the decision making process they need information about the disease, and treatment options. Adequate information, advice and support around treatment are an important component of care, in which nurses play an important role.

Helps patients cope with side effects of treatment: Providing IEC about various aspects of information about cancer provides a very important coping mechanism for patients. Not having adequate information may lead to negative coping and contribute to anxiety among the patients (McLaughlin and Oosthuizen, 1996 and Ankem, 2006).

IEC reduces anxiety; anxiety is one of the problems that patients with cancer face and lack or inadequate information about the disease, prognosis and treatments may be a contributing factor. A study conducted by Norwegian oncology nurses found that anxiety was one of the major patient problems (Rustøen et al 2003). The benefits of good patient education for cancer patients may include greater satisfaction with treatment choices, improved ability to cope during the diagnosis, treatment, and post-treatment phases, and reductions in anxiety and mood disturbances (Posma et al, 2009). Giving information has been found to be beneficial in reducing anxiety among cancer patients (Ankem, 2005).

Cope with side effects of treatment; IEC can promote patients' ability to manage side effects themselves and seek appropriate care when needed by educating them and giving them suitable recommendations (Jansen et al, 2009). Thus IEC prevents emergencies which may arise if patients had no information. The importance of good patient education about chemotherapy, immunotherapy and other treatments is underscored by the fact that people with cancer express a strong desire for information on self-care (Posma et al, 2009).

IEC enables patients to live with cancer: IEC enables patients to live with the cancer as it provides them with useful information for their day to day living. For example Kelly 2007

in her article about myeloma patients found that providing patient information and ensuring they understand the disease, its complications and the aims of treatment is important to minimize risks of complications and help reduce life-threatening complications such as renal impairment, infections and spinal cord compression in myeloma patients. During practice, a myeloma patient who was given information about the various aspects of myeloma was able to comply with the need for isolation because he understood the meaning of low white blood cell counts.

IEC is beneficial to help patients regain control over their lives: Yabro, wujcik and Goble 2010, also found that IEC is beneficial in helping patients and family understand the self-care measures they need to take in the case of side effects at home. Furthermore it provides support and knowledge to empower the patient, reduces fear and enhances confidence and participation in care. Informed patients are able to make a difference in oncology care as they can use the information and their own experience to teach or encourage other patients (Ankem, 2006).

Contributes to patient satisfaction and adherence; in evaluating the long-term effect of patient education, Spath 2001, found that IEC was contributing to patients' satisfaction with the health care provider through communication. Patients provided with IEC are more likely to provide timely reports of their illness symptoms or adverse reactions. This minimizes the likelihood that the patient will discontinue therapy without first contacting their physician.

Impacts on health related quality of life: providing patients with adequate information about their disease contributes to the positive impact on health related quality of life. In many cases improvements in health-related quality of life are a natural result of improved clinical outcomes. However, patients' perception of their quality of life is also improved when they are empowered by well-designed educational programs. Empowered patients tend to feel more personally capable of positively impacting their outcomes. For patients with chronic conditions such as cancer, health-related quality of life can improve significantly when they are trained in self-management techniques and empowered with education (Spath, 2001).

Providing patient information using booklets, brochures is helpful to clients as it helps them to recall information and it also provides as an information source for future reference (Iconoumou et al, 2006).

Helps patient psychosocially; it is important that the nurses and other members of the health care team are cognizant of the patient's need for information therefore providing information is a key tool in the psychosocial management of the cancer patient. (McPalarnd, 2009).

Is it of benefit to the nurses if patients have information about cancer?

Provision of information is beneficial to the nurse in the following ways;

Provision of IEC also helps the nurses to identify information gaps in their interaction with the patient and hence help them focus on the patients information need. An understanding of the informational needs from the patients' perspective enables nurses to provide specific and practical information. (Lei et al, 2011).

Providing patient information facilitates compliance with treatment, life style changes and growth of relationships within the family and health management. If patients are not informed, it becomes difficult for the nurse and health care providers to plan for the patient as he/she is not able to make decisions (Ankem, 2006). IEC also 'eases' the work of the nurses as patient are able to understand nursing procedures being carried out on them. For example during my practice, a patient who knew about the toxic effects of cisplatin was able to remind the nurse about urine bottles for the monitoring of the renal function. On the other hand if the patient had no information, he/she would not have understood the importance of monitoring urine output.

Providing information to the patient is beneficial to the nurse as it enables compliance with treatment programs and life-style changes. In Norway and Zambia, at times patients stay for a short time at the hospital and return home after treatment, IEC is helpful because the patients are able to report any adverse effects they may experience. IEC also contributes to reduced hospital stays since patients are able to monitor side effects at home. Without

patient information, the hospital stays would be prolonged for the nurses to monitor the patients (Ankem, 2006).

How is IEC given to patients with cancer in Zambia?

Patients from 73 districts in Zambia all get treatment from one hospital in Lusaka where they are attended to by a handful of oncology nurses and other members of the team. Most of them receive the confirmation of the diagnosis from there. Patients are given information about the disease, the treatment which includes radiotherapy or chemotherapy. They are also told about the importance of blood samples. Patient information is also provided through leaflets which are mostly very few and printed in English. At times patient information is given in small group discussions and individual patient counseling where patients have to wait for the nurse due to staff shortages. Family meetings are also held once or twice in a month especially for patients requiring palliative care. Most of the information available is on prevention and is based on the western perspective which is usually difficult for most people to apply to their day to day living (Maliti, 2011). Information is also provided by support groups such as the Breakthrough Cancer Trust (BCT) which is a dedicated support group comprising cancer survivors. The BCT provides information to patients with breast and cervical cancer. This means that patients with other types of cancer are left out on information (Breakthrough cancer trust, 2011).

Challenges of giving IEC to patients with cancer in Zambia

Shortage of human resource: there are only five nurses trained in oncology nursing at the CDH out of fourteen nurses at the Hospital. Another five (5) out of fourteen are trained in diagnostic mammography and are mostly involved in awareness campaigns which makes it difficult for the few remaining nurses to give one-on-one patient information. Being the only hospital in the country makes the challenge even worse due to high number of patients seeking care (Maliti, 2011).

Language: most of the information materials are written in English and which most people are not able to read so nurses are limited on what brochures to give patients to take home. Kingsley and Bandolin, 2011, also noted language as one of the factors in the access of cancer services and information in their study of Latina population in the United States.

Limited patient information about cancer: there are very few IEC materials about cancer which makes it difficult for nurses to teach while information about HIV/AIDS is in many local languages and on various aspects of the disease. This confirms the findings of a study conducted in Tanzania which showed how a lot of resources have been channeled to the control of communicable diseases such as HIV/AIDS while non-communicable diseases like cancer continue increasing and impact on the population (Timothy and Kangolle, 2010).

Lack of standard steps: there are no standardized information packs which elaborate what steps a patient can follow once they are diagnosed with cancer. In Norway because information is part of routine health care system, its easier for an oncology nurse to give step by step information about what the patient should do.

There is a lack of local mentors in oncology nursing, as this is a new specialty for Zambia. Therefore nurses at Cancer Diseases Hospital rely on websites such as Oncology Nursing Society, Canadian Association of Nurses in Oncology/ Association des Canadienne des Infirmiers en Oncologie and International Society of Nurses in Cancer Care for resources to solve emerging clinical issues and safe practice guidelines (Maliti, 2011). McParland 2009 also recognized that lack of knowledge/comprehension on the part of frontline health care workers dealing with the patient seriously impedes information provision to cancer patients. Provider knowledge is important to ensure that high quality, reliable and evidence based information is routinely provided as an integral part of care. (Dougherty and Lister, 2011)

There are inadequate palliative care services for cancer patients in Zambia although the system for home-based care for HIV/AIDS patients is well defined. More than half of the patients with cancer require palliative care as they are usually having advanced disease. Family meetings are only scheduled once or twice a month. There is also a paucity of trained palliative care providers (Maliti, 2011)

Inadequate palliative care services for cancer patients: there is no proper follow up of cancer patients when they go back home, due to the ambulatory set up and lack of oncology

trained personnel in the rest of the country. Consequently, patients have to travel hundreds of kilometers back to Lusaka for medication refills and follow up care.

Fund allocation by government- a lot of resources has been channeled towards the control of communicable diseases such as tuberculosis and HIV/AIDS as a result Non-communicable diseases such as cancer have not been allocated adequate resources to meet the patients' information needs. Not until 2010 has the Zambian Government planned for the non-communicable diseases in the 6th national development plan (Zambia Ministry of finance, 2011)

Conclusion

Information Education and Communication is a key factor in the care of patients with cancer. It should be imbedded within the routine care of the patients. IEC is beneficial to both the patient and the nurse and it should be provided using variety of means and in a way in which the patient can easily understand. Cancer remains a complex disease with ever advancing treatments and information therefore oncology nurses in resource limited countries like Zambia should rise above the challenge and use every means and opportunity to provide high quality care to the patients through provision of information.

Recommendations for Zambia

- There is need to train more oncology nurses to meet the overwhelming number of patients. Training of more nurses will improve knowledge base for the nurses and contribute to cancer prevention and screening. It will also help to maintain a sustainable pool of qualified staff to offer care that is effective and efficient in meeting the many needs of cancer patients and their families
- There is need for more IEC materials to be made available in the common local languages so that as many patients as possible can have access. The information should be tailored to the needs of the people with examples which people can easily relate to. Examples about local cancer prevention activities, information about nutrition with a combination of locally available foods as well as how to protect others from the harmful effects of chemotherapy the first few days after treatment.

- Since Cancer Diseases Hospital is the only cancer treatment facility in Zambia it should have as much information as possible to help both patients with cancer and the general public
- Nurses should have a standardized information pack and check list which can be used during IEC sessions to ensure that patients are given the necessary information about their diagnosis, treatment options.
- Since patients travel to Lusaka from different places, hospitals should be linked and proper referral systems developed to improve follow-up of patient care as well as treatment of infection or side effects of treatments.
- Training sessions should be planned to enlighten nurses in various district hospitals about cancer so that they can be able to attend to patients found in their care.
- Awareness programs should continue so that case detection is improved.
- The CDH should collaborate with various cancer associations in the country to ensure that patients are provided with quality information education materials.
- Organizations such as the Health Communication Program should also collaborate with cancer hospital in order to provide information about various aspects of cancer using different approaches such as printed materials and drama activities.

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