

## Home-based Carers' General Cancer Knowledge: A Case Study of One Rural Village in Vhembe District, South Africa

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**ABSTRACT** This paper assessed the general cancer knowledge amongst home-based carers of a selected rural village in Vhembe district, South Africa. The study adopted a qualitative descriptive design collecting data from eight members of a selected home based care group between 30 to 45 years who were conveniently recruited and interviewed using unstructured interview guide. Permission to enter the village was obtained from the local chief. Informed consent was obtained from individual participants. Participants' rights to anonymity and privacy were observed. Data was analysed through content analysis. The results revealed that though the majority of participants knew the importance of screening for cancer, their cancer knowledge was inadequate. This paper concluded that home-based carers of the selected rural village possess inadequate general knowledge of cancer; and recommended that nationally collaborated projects regarding cancer training be intensified amongst rural home based care workers.

### INTRODUCTION

Cancer is the second leading cause of death world-wide from non-communicable diseases, only exceeded by heart diseases and accounting for nearly 1 of every 4 deaths. In 2014, about 585 720 of Americans are expected to die of cancer, which amount to almost 1 600 people per day (White et al. 2013). A total of 1 665 540 new cancer cases are projected to occur in the United States (US) in 2014.

During the most recent years for which there are data (2006-2010), delay-adjusted cancer incidence rates declined slightly in men (by 0.6 % per year) and were stable in women, while cancer death rates decreased by 1.8 percent per year in men and by 1.4 percent per year in women (White et al. 2013). The combined cancer death rate (deaths per 100,000 populations) has been continuously declining for 2 decades, from a peak of 215.1 in 1991 to 171.8 in 2010. According to White et al. (2013), this 20 percent decline translates to the avoidance of approximately 1 340 400 cancer deaths (952 700 among men and 387 700 among women) during this time period. The magnitude of the decline in cancer death rates from 1991 to 2010 varies substantially by age, race, and sex, ranging from no decline among white women aged 80 years and older to a 55 percent decline among black men aged 40 years to 49 years. Notably, black men experienced the largest drop within every 10-year age group (White et al. 2013). Ap-

proximately 681 000 new cancer cases and 512 400 cancer deaths were reported in Africa in 2008. These numbers are projected to nearly double to 1.28 million new cancer cases and 970 000 cancer deaths by 2030, due to ageing and growth in the population. The five-year survival rate for breast cancer is less than 50 percent in Gambia, Uganda and Algeria, compared to nearly 90 percent in the US (Holman et al. 2013).

In South Africa, the top six types of cancer found in men that were diagnosed histologically in 2007 includes Basal Cell Carcinoma (BCC), prostate, Squamous Cell Carcinoma (SCC) of skin, primary site unknown, lung and colorectal. On the other hand, the top seven in women were breast, cervix, BCC, primary site unknown, SCC of skin, Kaposi sarcoma and colorectal (National institute for occupational Health 2013).

On the contrary, in the US the three most common prevalent cancer types among males are prostate cancer (43%), colorectal cancer (9%), and melanoma (8%), and those among females are cancer of the breast (41%), uterine corpus (8%), and colon and rectum (8%). This means that world-wide, the top common cancer types among men is prostate while in women is breast cancer.

However, it is interesting to note that the number of cancer survivors continues to increase due to improvements in early detection and treatment. Thus, nearly 14.5 million Americans with a history of cancer were alive on Jan-

uary 1, 2014 excluding carcinoma in situ of any site. According to Holman et al. (2013), by January 1, 2024, it is estimated that the population of cancer survivors will increase to nearly 19 million individuals (9.3 million males and 9.6 million females) with the distribution of prevalent cancers expected to remain largely unchanged.

Ward et al. (2014) states that after the completion of primary cancer treatment, survivors often return to their primary care provider for medical care. A number of organizations have begun to produce guidelines to assist primary care physicians in the provision of care for patients with a history of cancer. These guidelines focus on on-going surveillance and cancer screening, as well as the assessment and management of long-term and late effects of cancer and its treatment. There is also increasing emphasis on improving the overall well-being and quality of life of cancer survivors through the application of principles of disease self-management and the promotion of healthy lifestyles, such as avoiding tobacco, maintaining a healthy body weight, and being physically active throughout life.

Ward et al. (2014) warns that despite increasing awareness of survivorship issues, many challenges remain, which include fractured health care systems; poor integration of survivorship care in the oncology and primary care settings; lack of strong evidence-based guidelines for post-treatment care (although some have begun to emerge); financial challenges and other barriers to quality care, particularly among the medically under-served. Ward et al. (2014) believes that in order to address these challenges, ongoing efforts to identify best practices for the delivery of quality post-treatment cancer care are needed. For example, it is not yet clear who should provide survivorship care services and how they will be reimbursed.

However, in South Africa, locals with basic training (also called community health workers (CHWs)/ home based care workers) are becoming increasingly central to the provision of healthcare and drugs (Storer 2013). According to Storer (2013), these community-based workers were initiated to offer a pragmatic solution to shortages of medical professionals. Storer (2013) believes that while it takes six years to train a nurse, a community health worker can be trained within several weeks and is much cheaper; and that CHWs have the advantage of being more closely embedded at the local level. The use of community health workers has led to consider-

able improvements in terms of patients continuing with their treatment as problems associated with clinics such as transport costs and long waiting times are by-passed.

Research by Medicines Sans Frontiers (MSF), who set up Community Adherence Clubs in the township of Khayelitsha found that the use of CHWs reduced loss to follow-up by two thirds and nearly halved the proportion with virologic rebound or breaks in monitoring compared with patients who remained in clinic-based care. Thus, the retention in care rose to 97 percent for patients enrolled in adherence CHWs, compared to 85 percent for those in clinical-based care (Storer 2013).

Given these initial successes, and the affordability of this category of health worker, it was not surprising that South Africa's '2012 Primary Healthcare Re-Engineering Framework' explicitly placed CHWs at the core of delivering life-saving ART in "resource-limited settings". Whilst CHWs have historically been volunteers, according to Storer (2013), the 2012 Re-engineering Framework marks an attempt to coordinate on-the-ground efforts with formal channels of state funding. Storer (2013) however, asserts that as care becomes increasingly local, it is essential that community workers are trained to detect early symptoms of diseases including cancer. Equally, inadequate or inappropriate training may mean that health workers fail to understand the local community health and care needs regarding cancer. It is against this background that this study emerged. The study assessed home-based carers' general knowledge of cancer since they are also responsible for providing local cancer survivorship home-based care services in South Africa.

### Objectives of the Study

- To assess home-based carers' knowledge of:
  - ♦ The signs and symptoms of cancer
  - ♦ The causes or risk factors for cancer
  - ♦ The importance of screening for cancer
  - ♦ General cancer treatment

## METHODOLOGY

### Study Design

In line with the purpose, this study adopted a qualitative approach using a cross-sectional exploratory design. Blanche et al. (2006) advises that in situations where it is difficult to identify

and measure the important variables, researchers may engage in open-ended, inductive exploration that is possible by means of qualitative research.

### **Study Setting**

This study was conducted at Nweli rural village of Vhembe district, Limpopo Province of South Africa. The rationale behind choosing this village was that the department of public health (with which the author is affiliated to) has entered into an agreement with the local chief to use the village for University community engagement projects.

### **Population, Sample and Sampling Procedure**

The target population for this study was all home-based carers serving Nweli Village. Convenience sampling was used to identify eight home-based carers who were available at the time of data collection (one male and seven females between the ages of 30 and 45 years). Being a member of Nweli home based care group was a recruitment criterion.

### **Data Collection Tool**

An unstructured interview guide was developed comprised of one central question namely, "what do you know about cancer?" The probing questions assessed knowledge regarding home-based carers' knowledge of signs and symptoms; causes or risk factors of cancer; screening tests and cancer treatment options.

### **Pre-test of the Interview Guide**

A pre-test of the interview guide was conducted using three home-based carers who did not participate in the in-depth interviews. Thereafter, the interview guide was re-adjusted accordingly.

### **Ethical Consideration**

Permission to enter the village was obtained through the memorandum of understanding signed between the University of Venda and Nweli village authorities. Written informed consent was obtained from each participant. Partici-

pants were allocated codes *P1 to P8* to ensure anonymity. Participants were assured of their right to withdraw anytime whenever a feeling of discomfort arise.

### **Data Collection**

Members of Nweli home based care group were met at the community engagement meeting that was organized by the Department of Public Health. In-depth interviews were conducted in Tshivenda and an office was used to interview members individually. Data was recorded as field notes.

### **Data Analysis**

Analysis of the data was guided by Tesch's (1984) open-coding method, as discussed in Creswell (2009) where by the researcher read through all of the field notes from the unstructured interviews, and interpreted them carefully in order to obtain an overall sense of the notes. The interpretations were written as themes.

### **Measures to Ensure Trustworthiness of the Study Findings**

Trustworthiness of the results was ensured through the use of Lincoln and Guba's (1985) criteria, as outlined in Creswell (2009) namely credibility, transferability, confirm ability and dependability. Credibility was ensured through prolonged engagement with the participants, which lasted from forty-five minutes to one hour. Transferability was ensured through the provision of a complete description of the research method and interpretation of the research findings in the study report (Babbie 2010).

## **RESULTS**

### **Characteristics of the Participants**

Eight home based carers, seven females and one male participated in this study. The level of education of participants was grade 12 certificate. These home-based carers also received further training called ancillary nursing. Participants are employed by government as carers. Home-based carers are attached to non-governmental organisations.

### Home Based Carers' General Knowledge about Cancer

Majority of the participants (seven) had poor knowledge about cancer. Only one participant (p4) responded and said "*ndipfuko*" (a Tshivenda term for cancer).

### Home Based Carers' General Knowledge of the Signs and Symptoms of Cancer

The participants also showed lack of knowledge regarding the signs and symptoms. Only two participants responded by naming only one symptom each.

One participant said "*a sore that does not heal*" (p3)

The other one said "*lump on the breast or anywhere in the body*" (p1)

The eighth participant said "*a sore*" (p8), without specifying it, which makes it an incorrect answer.

### Home Based Carers' General Knowledge of the Causes or Risk Factor for Cancer

In response to the probing question "what are the causes or risk factors for cancer you know" The majority of participants could not answer this question. Only one participant (p6) listed the following:

"*Obesity*"

"*Age*"

"*Prolonged exposure to sunlight*"

"*Early sexual intercourse*"

### Home Based Carers' General Knowledge of the Importance of Screening for Cancer

In response to the probing question "why do you think it is important to be screened for cancer" The majority of the participants (p1, p2, p4, p6 and p7) stated one reason each as follows:

"*Because you know that with early detection one can be cured*"(P1)

"*You can get treatment early*" (2 participants) (P2 and 4)

"*So that you know where you stand*"(P7)

"*To know your health status*" (P1)

### Home Based Carers' General Knowledge of Cancer Treatment

In response to the probing question "name any form of cancer treatment you know" the

majority of participants (p3, p4, p5, p6, p7 and p8) could not answer the question. Only one participant mentioned one form of treatment correctly and said "*radiation*" (p2). The other participant who attempted this question, answered it wrongly and wrote "*breast*" (p1).

## DISCUSSION

This study discovered that home based carers in a selected rural village possess inadequate general knowledge of cancer. Thus, they do not know what cancer is; they do not know the symptoms of cancer; they do not know the causes or risk factors of cancer; and they do not know the cancer treatment options. This level of cancer knowledge makes one wonder how these home based carers are educating the communities about cancer regarding self-screening and medical screening for early detection; and how are they managing cancer survivors.

The results of this study were really amazing since the study was conducted during the time when Paul's wife- Joyce (in South African most watched local soapy, Muvhango) was playing a cancer sufferer, treatment receiver and a cancer survivor, which was educating the public about cancer in general (South African Broadcasting Corporation 2014). This observation confirmed what the researchers from Johns Hopkins Bloomberg School of Public Health and the University Of Maryland School Of Public Health discovered that about 75 per cent of Americans were aware that the Oscar-winning actress Angelina Jolie had mastectomy done after she discovered she had the BRCA gene variant that raises risk for breast cancer disease. But, less than 10 per cent of those surveyed knew what the risk of breast cancer was for a woman who did not have a genetic risk for breast cancer (Agus 2013).

Similarly, a study that tested a priori hypothesis that "self-perceived and real presences of risks for colorectal cancer (CRC) are associated with better knowledge of the symptoms and risk factors for CRC, respectively" in Hong Kong by Wong et al. (2013) revealed that only family history of CRC was associated with better knowledge when compared to TV and other forms of media news.

On the contrary, in a knowledge and beliefs of children and young people study conducted in the United Kingdom (UK) by Oakley et al.



(1995), children and young people were found to possess considerable knowledge about cancer, especially about lung cancer and smoking, and they showed considerable awareness of predominant health education messages from television; and the media was found to be the most important sources of information.

The results of this study are related to those of a study conducted to analyse patients' knowledge of symptoms and diagnostic possibilities of cancer diseases in the Provincial Hospital in Bydgoszcz by Kozłowska et al. (2011), which revealed that those most aware of their condition were patients from small towns (below 50,000), while subjects living in villages were the least aware.

Another study that was conducted to examine and compare awareness of lifestyle risk factors for cancer and heart disease in a single UK representative sample by Sanderson (2009) suggested that public awareness of the impact of lifestyle on commonly feared diseases, especially cancer, is low, which is similar to home based carers' lack of knowledge of causes or risk factors of cancer in this study.

The results of this study are exactly similar to those of a study conducted in the UK to investigate the influence of culture on attitude and knowledge about breast cancer and preventive measures by Karbani et al. (2012), which revealed that most patients were unfamiliar with the subject of cancer; they expressed lack of knowledge of cancer as a disease and its symptoms. They identified a painless lump in the breast as sign of abnormality, but not cancer.

A study to investigate cervical cancer knowledge and prevention among college women in Nova South-Eastern University, USA by Wolwa et al. (2013) highlighted that cervical cancer knowledge and preventive practices are variable among women and that significant differences exist among college and community women.

### CONCLUSION

Home based carers from the selected village of South Africa possessed inadequate general knowledge of cancer. This level of cancer knowledge on the part of home based carers might lead to misinformation of the community members and mismanagement of cancer survivors in rural villages and ultimately undesired consequences.

### RECOMMENDATIONS

A nationally collaborated project to intensify the training of home based carers regarding cancer is needed, where the content to be covered should include the description of cancer and the symptoms of different cancers, the importance of referrals for cancer screening and various treatment options; and the home-based care of cancer survivors. In addition, cancer awareness campaigns through bill boards along the roads and adverts on TV would increase cancer knowledge of many home based carers.

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