

# Delay in Presentation of Cancer Patients for Diagnosis and Management: An Institutional Report

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## Abstract

**Introduction:** Cancer is a public health problem world-wide affecting all categories of persons and there is rising incidence in developing countries. Most cancer patients in developing countries present late with associated high mortality. Identifying causes of late presentation can assist in designing programs to minimize such.

**Objectives:** This study was undertaken to measure total delays for presentation and to identify factors responsible for late presentation in patients with cancer. In addition, common places where patients with cancer related symptoms first seek help were identified.

**Methods:** This was a cross-sectional survey of consecutive patients with advance staged cancer at the Radiotherapy Department of University College Hospital, Ibadan, Nigeria. Participants were patients with advance cancer (stages III & IV) who were seen at the department between June 2014 and May 2015. Information relevant to the study were collected using semi structured questionnaire.

**Results:** A total of Two hundred and eighteen respondents participated in the study. Out of this number, 51 (23.4%) and 167 (76.6%) sought medical care within 3 months and over 3 months respectively after the discovery of first symptom of their cancer. The respondents gave multiple and varied reasons for presenting late for proper medical care, top on the list are lack of awareness of cancer symptoms as recorded for 134(61%) of the respondents., seeking after alternative care (48.2%), fear of diagnosis (45%) and the challenges of distance to available centers of treatment. Most responders 126 (58%) visited general practitioners first for consultation following onset of symptoms.

**Conclusion:** The outcome of this study shows that most of our cancer patients (77%) experience significant total delays from time of symptoms to diagnosis and treatment. Prominent among the factors responsible for late delay is lack of awareness of cancer symptoms. Most of the patients sought initial help from their General Practitioners /Private Health Centers.

## INTRODUCTION

Cancer is a public health problem world-wide affecting all categories of persons. According to the World Health Organization (WHO 2006), cancer is one of the leading causes of death worldwide, the second common cause of death in developed countries and the third leading cause of death in developing countries. Deaths from cancer are projected to continue rising and an estimated 19.3 million people will have cancer in 2025 (Gulland, 2014)

Cancer is assuming epidemic proportions with rising incidence worldwide and over 60% of new cases have been estimated to occur in less developed parts of the world.

Currently in Nigeria, there are about two million people suffering from cancer and at least 100,000 new cases occur every year. With respect to breast cancer, which is the most common cancer worldwide, more than 70% of patients in high-income countries are diagnosed in early stages (I and II). However, only 20%-50% patients in the majority of low- and middle-income countries are diagnosed in these earlier stages (Unger-Saldaña, 2014). In most developing countries such as Nigeria, most cancer patients (about 70%) present in late stages (stages III and IV). Campbell and colleagues in a review of 5,000 cancer cases in Ibadan South West Nigeria reported that majority presented at first visit in advanced stages (Campbell OB, Agwimah R, 1998) while Ketiku and

colleagues reported that 66% of cancer patients in Lagos, South West Nigeria presented late in stages III and IV (Ketiku, 1986). In another report from North Western Nigeria it was found that that over 60% of cancer patients presented late (Kene et al., 2010).

Early detection of cancer is important because of the established association between stage at diagnosis and survival rate. Late stage cancer has poorer prognosis and most time the main stay of treatment offer is palliative Radiotherapy and Chemotherapy. Survival from cancer in the United Kingdom is reported to be poorer than that of other European countries and it has been attributed to more advanced disease stage at presentation (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009). A report by Richards and colleagues observed that longer delays have an impact on survival of breast cancer patients (Richards, Smith, Ramirez, Fentiman, & Rubens, 1999).

Delay with respect to cancer management has been defined as having symptoms for 12 or more weeks before diagnosis and treatment (Richards, Smith, et al., 1999). This delay has been described in three phases: First is the patient delay which is the interval between the patient's initial symptom and first consultation with a doctor. Second is doctor or practitioner delay, which is the interval between first consultation and referral by a practitioner to a center where diagnosis and management can be carried out and thirdly, hospital or system delay which is the interval between referral and diagnosis (Nichols, Waters, Fraser, Wheeller, & Ingham, 1981). Delays of more than 12 weeks between symptom discovery and treatment start is known as total delay (Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999). Delay of more than 12 to 26 weeks may be described as prolonged delay (Richards, Smith, et al., 1999). Delays may increase the proportion of patients with advanced stages thereby leading to negative impact on prognosis and quality of life (Mwaka et al., 2016). The higher cancer mortality rates in LMICs are thought to be due to diagnosis in advanced stages and poor access to medical care (Anderson & Jakesz, 2008).

Late presentation leading to advanced stage at diagnosis may contribute to poor treatment outcome and survival. Many factors have been adjudged to be responsible for increased time to presentation and treatment. Almuammar et al (2010) in their study "Factors associated with late presentation of cancer", identified factors associated with patients delay to include patients' knowledge, stress and fear, and nature of the disease. Other factors were attributed to health providers

such as general practitioner (GP) experience, referral delay, and a younger age group being considered as low risk, therefore symptoms were missed (Almuammar, Dryden, & Burr, 2010).

According to Mbuka-Ongona et al, a lack of awareness and knowledge and use of screening practices were identified as the major reasons for late presentation (Mbuka-Ongona & Tumbo, 2013).

Anorlu RI et al revealed that patients' delay in seeking healthcare and care providers' delay in referring patients to tertiary hospitals contributed to late presentation (Anorlu RI, Orakwue CO, Oyeneyin L, 2004).

According to Ezeome E.R, institutional or physician induced delays accounts for 46.2% of the late presentation, while patient related delays accounts for 79.2% of cases (Ezeome, 2010).

This study is therefore essential to increase our understanding of the factors associated with delay in presentation of cancer patients. Such understanding will assist in facilitating the development of effective strategies to reduce the time lag.

### **OBJECTIVES**

This study was undertaken to measure total delays for presentation and to identify factors responsible for late presentation in patients with cancer. In addition, common places where patients with cancer related symptoms first seek help were identified.

### **MATERIAL AND METHODS**

This was a cross-sectional survey of patients with late stage cancer seen at the Radiotherapy Department of the University College Hospital (UCH), Ibadan, between June 2014 and May 2015. The hospital offers comprehensive cancer services and is a major referral center for cancer care. Participants were patients with advance cancer (stages III & IV), who gave consent to participate in the study were recruited and were interviewed with aid of questionnaire administered by the investigators. The questionnaire included demographic data, such as age, sex, marital status, tribe, socioeconomic status, occupation, religious, area of domicile (address), and education level. Information on the diagnosis and stage of the disease was obtained from the hospital case records. Other information obtained were symptoms present, how the disease was noticed, the first point patient went for treatment, the lag time between the

onset of symptoms and the first point of presentation for orthodox medical treatment, the reasons for delay in presenting to the first point of treatment. Other information included the duration and reasons for delay between the first point of treatment and presentation at a tertiary center for treatment.

The patients were classified into those without significant delays (less than 3 months delay) and those with significant delays (more than 3 months delay). Those with significant delay were further classified as significant delay 12-26 weeks and prolonged delay (more than 26 weeks). The data was analyzed using SPSS software version 20.0

### RESULTS

There were two hundred and eighteen (218) respondents, with age range from 21 to 83 years.

Most respondents presented with cancer of the uterine cervix (Figure 1) while 13.7 % of responders had other cancers made up of sarcomas, bronchogenic urogenital and CNS cancers.

The spread of patients cuts across the six geopolitical zones in the country. The total number of respondents with stage III disease was 119 (54.6%) while those with stage IV disease were 99 (45.4%). The total number of respondents with significant delay (sought medical care after 12 weeks of first symptom) was 167(76.6%) (Table 1)

General practitioners (GP) / private medical centers were the first port of call for 126 (57.8%) of respondents, while 72 (33%) presented at tertiary hospitals. Others, 20 (9.2%) consulted either primary health care center, local chemist shop or complementary alternative medical practitioners such as traditional healers or spiritualists (Table 2).

Definitive treatments (surgery, chemotherapy & hormonal) were offered at the primary center of presentation in about 15% of the patients and 40% were offered diagnostic biopsy only before being referred. Others received various therapies such as antibiotics, herbs or prayers (Table 3).

The number of participants that were formally referred to our center (a tertiary setting) was 184 (84.4%). Out of these, only 81 (44%) presented at our center within 12 weeks of referral. The remaining 56% again delayed in reporting at the referral center (secondary delay). Other patients 4 (1.8%) reported to the center through self-referrals and 30 (13.8%) came through information from acquaintances. At the referral center, 209 (95.9%) patients who needed surgery or

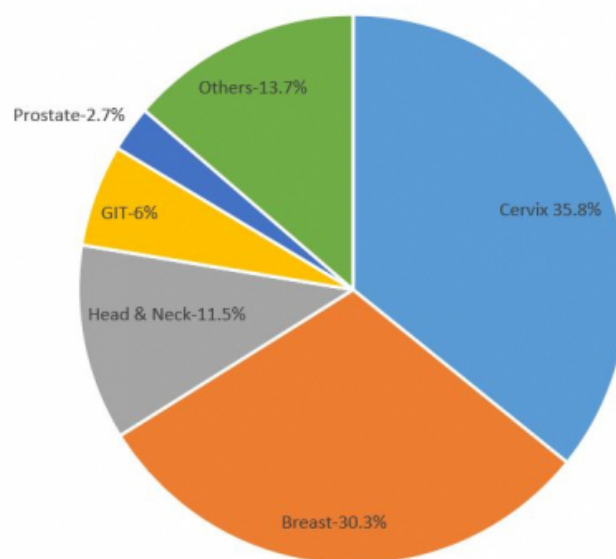
adjuvant radiation therapy did not commence treatment immediately due to inadequate facility (tertiary delay) as they were given long booking periods (more than 12 weeks) for commencement of treatment.

Various reasons were given by the participants for late presentation. Prominent among these was ignorance or lack of awareness about cancer as reported by 133 (61%) of the participants. Some of them (26.1%) claimed it was because of financial constraints while about 33% did not present early because the disease was not painful. The various reasons for late presentation are presented in Table 4

Prior to presentation, most patients sought alternative therapies for their symptoms. The identified therapies included spiritual/faith healing by 61 (58%) and herbal medications by 26 (25%) of the respondents. Fifteen (14%) of the respondents sought both forms of therapies before presentation while 3 (3%) participants did not seek any form of therapy.

**Figure 1**

Proportion of patients with various cancer sites.



**Table 1**

Duration of symptoms in cancer patients before presentation for orthodox medical care

Duration	Frequency	Percent	Cumulative Percent
≤12 weeks	51	23.4	23.4
>12-26 weeks	26	11.9	35.3
>26- 36 weeks	64	29.4	64.7
>36-52 weeks	50	22.9	87.6
1-5 years	18	8.3	95.9
>5 years	9	4.1	100.0
<b>Total</b>	<b>218</b>	<b>100.0</b>	

**Table 2**

First point of presentation of cancer patients following occurrence of symptoms

First Point of Presentation	Frequency	Percent
GP/Private Health Center	126	57.8
Tertiary Hospital	72	33.0
Spiritualist/Traditional Healer	10	4.6
Paramedics	6	2.8
Primary Health Center	4	1.8
<b>Total</b>	<b>218</b>	<b>100.0</b>

**Table 3**

Treatment received by cancer patients at point of first presentation

	Frequency	Percent	Cumulative Percent
Biopsy (only)	89	40.82	40.8
Antibiotics	74	33.94	74.8
Surgery	28	12.84	87.6
Chemotherapy and hormone therapy	8	3.7	91.3
Herbal Medicine	7	3.2	94.8
Spiritual care (Prayers)	2	0.9	95.7
None	10	4.6	100
<b>Total</b>	<b>218</b>	<b>100.0</b>	

**Table 4**

Reasons for late presentation of cancer patients for diagnosis and treatment.

	Yes	No
Lack of awareness about cancer symptoms	133 (61.0%)	85 (39.0%)
Seeking Alternative Therapy	105 (48.2%)	113 (51.8%)
Fear of diagnosis of cancer	101 (46.3%)	117 (53.7%)
Challenges of distance to treatment center	99 (45.4%)	119 (54.6)
Fear of treatment side effects	97 (44.5%)	121 (55.5%)
Financial constraint	57 (26.1%)	161 (73.9%)
Lack of family support	12 (5.5%)	206 (94.5%)
Using food supplements	9 (4.1%)	209 (95.9%)

## DISCUSSION

Delay in presentation leading to advanced stage at diagnosis contributes significantly to poor cancer survival, and most patients in Nigeria (70% patients) present in late stages III and IV. Many factors have been adjudged to be responsible for increased time to presentation and treatment. From the study it is observed that majority of patients treated for advanced cancer experienced all forms of delay namely primary delay (period between the onsets of symptoms to contacting the first medical person), secondary delay (period from the first medical contact to confirmed diagnosis), and tertiary delay (period from the confirmation of diagnosis to treatment initiation). All these constitute significant delay and 167 (67.6%) of the participants experienced significant delay in this study. In a review on challenges to early diagnosis and treatment of breast cancer in developing countries Karla Unger-Saldaña reported that while more than 70% of breast cancer patients in most high-income countries are diagnosed in early stages (stages 1 and II) the comparative figure for developing countries was, only 20%-50%. (Karla Unger-Saldaña, 2014). The report also gave evidence that the median of time to presentation was 30-48 days in high-income countries but 3-8 months in low- and middle-income countries. In this study the median time to presentation was 4-9 months recorded for 29% of respondents.

Access barriers and quality deficiencies in cancer care are determinants of provider delay in low- and middle-income countries. The report from this study shows that majority of the respondents 209 (95.9%) had tertiary delay as they had to be delayed while waiting for surgery/radiation therapy. Access to surgical care has been identified as a major barrier to cancer care in low income countries. This is due to the inadequate infrastructure and cancer surgery has also been

noted to consist mostly of palliative procedures due to late presentation (Gyorki, et al., 2012).

Also observed are various reason why patients delayed in presenting at the hospital and the factors identified include lack of knowledge of cancer awareness, stress and fear, and financial constraints, this is similar to the findings by Almummar and colleagues. Other factors were attributed to health providers such as general practitioner (GP) experience whom more than half of the patient presented to first who also delay in referring patients to a tertiary hospital contributed to the late presentation.

About 48% of the patients (Table 4) claimed they have tried Complementary and Alternative Medicines (CAM) (Complementary and Alternative Medicines are defined as medical and health care systems, practices, and products that are not currently considered an integral part of conventional medicine) before presented somewhere else which reflects the cultural belief of the majority of the patients. Ezeome and colleagues in their study titled “Use of complementary and alternative medicine by cancer patients at the University of Nigeria Teaching Hospital, Enugu, Nigeria” revealed that the prevalence of CAM use in cancer patients in Nigeria is one of the highest in the world and it is not affected by age, marital status, socioeconomic status, or level of education. They also observed that herbs and faith healing/prayer house healing are the most common forms of CAM (Ezeome & Anarado, 2007).

Several studies have also shown that delay in presentation of the patients are multifactorial; Anorlu and colleagues report revealed that patients' delay in seeking healthcare in addition to care providers' delay in referring patients to a tertiary hospital contributed to the late (Anorlu RI, Orakwue CO, Oyeneyin L, 2004) while Ezeome and colleague's report from Enugu, Nigeria; revealed that institutional or physician induced delays accounted for 46.2% of the late presentation, while patient related delays accounted for 79.2% of delay (Ezeome, 2010).

Lack of awareness of cancer symptoms was responsible for delay in most patients. (61.0%). In a previous this has been given as the most common patient related reason for delay in presentation even in developed countries (Macleod 2009).

The time to travel to the hospital, distance from the patient's home to the hospital as well as long waiting times for medical appointments at a cancer hospital reflect different dimensions of access to care (Penchansky et al., 1981).

These factors were established in this study as contributing to delay in presentation as 99 (45.4%) of respondents had delay due to long distance from hospital (Table 4). Family physicians play a crucial role in the early diagnosis of cancer. The proportion of patients in this study that presented first to their family physicians was 57%. They are therefore important concerning early presentation of cancer. This position is supported by earlier report by Fisher and colleagues who found out that General Practitioners play a great role in early diagnosis of breast cancer (Fisher, Redman, & Bollen, 1994). The outcome of this study agrees with the submissions of Price and colleagues in their study titled cancer care challenges in developing countries that cancer patients experienced numerous geographic and health care system challenges, resulting in significant delays in receiving diagnosis and treatment, even for cancers highly amenable to early intervention. This situation is likely explained by limited knowledge about cancer among patients and health care professionals, government neglect, poverty, and reliance on traditional healers (Price et. al 2012).

### **CONCLUSION:**

The outcome of this study shows that most of our cancer patients (77%) experience total significant delays from time of symptoms to diagnosis and treatment. Prominent among the factors responsible for delay is lack of awareness of cancer symptoms. Most of the patients sought initial help from their General Practitioners /Private Health Centers.

### **RECOMMENDATION**

Approaches to promote early presentation should aim to increase awareness of the significance of cancer symptoms and should be designed to work for people of the lowest socioeconomic status. Further and regular Continuing Medical Education (CME) in Oncology for the general practitioners (GP) should be encouraged. In addition, provision of more & modern treatment facilities and training of more cancer specialists to attend to the increasing population of cancer patients in the country should be seen as a matter of urgency

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