

**DELAYS IN PROVISION OF BREAST CANCER CARE IN PATIENTS SEEN AT
A DISTRICT HOSPITAL DIAGNOSTIC BREAST UNIT IN SOUTH AFRICA**

by

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CHAPTER 1: PROTOCOL

PART A: PROTOCOL

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SEEN AT A DISTRICT HOSPITAL DIAGNOSTIC BREAST UNIT IN SOUTH
AFRICA**

Personal declaration:

I declare that the work I am submitting for assessment contains no section copied in whole or in part from any other source unless explicitly identified in quotation marks and with detailed, complete and accurate referencing.

TITLE: A retrospective study into the delays in provision of breast cancer care in patients seen at a diagnostic breast unit at a district hospital in Cape Town, South Africa

1. INTRODUCTION

Breast cancer is the second most common cancer in the world and, the most frequent cancer among women. It ranks as the fifth cause of death from cancer overall with 1.67 million new cancer cases diagnosed in 2012 according to Breast Health Global Initiative (2011) data ^{1,8}. It is the most common cancer in South African women (except amongst the black population where cervical cancer is more predominant) ².

It is the most frequent cause of cancer death in women in less developed regions and the second cause of cancer death in more developed regions after lung cancer.

The higher incidence of deaths in developing countries is due to late diagnosis stemming from the population's lack of awareness of presenting symptoms and signs⁶, deficient coverage of screening programs and hospital or provider delays upon diagnosis ^{1,2,6}.

Other confounding factors include socioeconomic disparities and patient comorbidities.

Breast Cancer

STATISTICS

Table 1 Estimated Incidence, Mortality and Prevalence of breast cancer Worldwide in 2012			
Estimated numbers (thousands)	Cases	Deaths	5-year prev.
World	1671	522	6232
More developed regions	788	198	3201
Less developed regions	883	324	3032
WHO Africa region (AFRO)	100	49	318
WHO Americas region (PAHO)	408	92	1618
WHO East Mediterranean region (EMRO)	99	42	348
WHO Europe region (EURO)	494	143	1936
WHO South-East Asia region (SEARO)	240	110	735
WHO Western Pacific region (WPRO)	330	86	1276
IARC membership (24 countries)	935	257	3591
United States of America	233	44	971
China	187	48	697
India	145	70	397
European Union (EU-28)	362	92	1444

World Health Organization: International Agency for Cancer research. GLOBOCAN Report 2012 - Breast Cancer: Estimated Incidence, Mortality and Prevalence Worldwide in 2012 http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx (accessed 21 January 2016)⁸

Table 2: Top Ten Most Common Cancers of Women in South Africa

Type of Cancer for All Women	No of Cases 2009	Lifetime Risk 2009
Breast Cancer	6 224	1:33
Cervical Cancer	5 270	1:42
Cancer of Unknown Primary (CUP)*	1 536	1:125
Kaposi Sarcoma	1 136	1:304
Colorectal Cancer	1 075	1:182
Cancer of the Uterus	1 073	1:160
Non-Hodgkin's Lymphoma	799	1:314
Cancer of the Oesophagus	764	1:239
Lung Cancer	685	1:254
Malignant Melanoma	635	1:391
All Cancers	29 891	1:9

National Cancer Registry: Summary statistics of cancer diagnosed histologically in 2009: All Females http://www.cansa.org.za/files/2015/03/NCR_2009_FINAL.pdf(accessed 21 January 2016)⁷

The research problem

Breast cancer delays are thought to contribute to the morbidity and mortality related to the disease ^{1,2}. This study investigates the delays in provision of cancer care in patients who present at a diagnostic breast unit at the Mitchell's Plain District Hospital.

Definition and classification of Breast cancer delay:

a) Patient delay

Patient delay is defined as the time lag between the onset of symptoms and the first contact with a health care provider.

b) Provider delay

Provider delay refers to the period of time between the initial medical consultation and the beginning of definitive treatment. Provider delay is also known as 'system' or 'doctor' delay.

Provider delay can further be divided into:

Referral delay: time elapsed between first consultation to a primary care service and referral to a hospital with a dedicated breast clinic

Diagnosis delay: time between the first consultation at the breast clinic and cancer diagnosis

Treatment delay: time between diagnosis and beginning of treatment.

Total Delay:

Total delay in cancer care is defined as the time lag between onset of symptoms and the start of definitive therapy (either surgical or oncological).

Total delay is usually divided into patient delay and provider delay. These types of delay were first described by Pack and Gallo in 1938⁹.

Overall, provider delay is a measure of efficiency with which any given health care system delivers timely services.

The maximum acceptable time period defined by Pack and Gallo for a physician to act after initial medical consultation was one month. This time period was chosen arbitrarily. This first definition was given by Pack and Gallo and has been surprisingly preserved for over 75 years in most studies of patient delay, even though the time threshold was not based on objective clinical evidence of harm, in cases of longer delays.

The impact of breast cancer provider delay

Provider delay may adversely affect survival due to disease progression. Advanced clinical stage, large tumor sizes and regional node involvement are all factors which have been found to have adverse prognosis in breast cancer patients⁵.

In addition, delays in cancer care also result in the patient requiring much more aggressive forms of therapy. Most importantly provider delay is a cause of major anxiety and distress in patients awaiting diagnosis and intervention⁶.

1.1 The purpose of the study

The purpose of this study is to record the time delays incurred by patients diagnosed with breast cancer in Mitchells Plain District Hospital breast clinic, and document the causes of such delay in order to try and improve the overall service provision at the clinic.

1.2 The objectives of the study

- Document the causes of delay in breast cancer care at the hospital
- Evaluate if the delays are acceptable
- Find out if they are preventable
- Investigate if there are certain pathways of the cancer care pathway that are contributing to delays more than others.
- Investigate if there are any measures that can be taken to make the provision of services more efficient.

1.3 The research questions

Primary outcome.

- Document and describe the delays in breast cancer management in patients presenting to a breast clinic at Mitchells Plain Hospital.

Secondary outcomes

If any delays are identified:

- Are there any patient factors that contribute to this delay?
- What are the causes of provider delay at the hospital?
- Are they preventable?
- Which departments (if any) are contributing to this delay?
- What measures can be taken to reduce this delay and make

the running of this clinic more efficient.

2. PROPOSED METHODOLOGY

2.1 Research design

This study is cross-sectional and has both quantitative and qualitative elements. It will look at the duration of time taken to access breast cancer care and the reason behind any delays with an aim of identifying ways to eliminate any areas of inefficiency. Period under study: Jan 2015-Dec 2015

2.2 Data sources

Main source of information will be a retrospective review of patient folders.

2.3 Data collection techniques

Data will be collected from folders of patients seen at Mitchells Plain District Hospital during the period stated and document the time taken for the various steps of the treatment process to be completed. A data collection form will aid in consolidation of the information.

2.4 Issues of reliability and validity

Upon completion of data collection, statistical analysis will be performed on the data from which conclusions can then be made.

2.5 Sampling techniques

Selective methods (purposive sampling) will be used for my study. Given that the subjects of the study all have similar characteristics (breast cancer patients in a secondary level hospital).

2.6 Data analysis and interpretation

The study is quantitative and data collection will be via forms to be filled in by reviewing patient folders.

2.7 Ethical considerations

The study has been approved by the University of Cape Town Human Research Ethics Committee. The investigators are part of the surgical team managing the study population ensuring no breach of confidentiality. This study has no bearing on clinical management decisions during the duration of the study period.

There are no conflicts of interest, and no funding from any source to disclose.

2.7.1 Confidentiality

The patient's information shall be kept confidential with no use of patient name or identification documents for the study.

2.7.2 Informed consent

Given that the study is retrospective, there will be no need for consent for patient folder review. The Breast Clinic team and the hospital administration will, however, be informed of the study and the information/ data being assessed.

2.7.3 Provision of additional information/debriefing

If any additional information is required from either patient or clinic staff, they will be given full disclosure about the study and the reason for the request for detailed information.

2.8 *Pre-test/Pilot Study:*

None to be done

3. REFERENCES

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Benjamin O Anderson, Eduardo Cazap, Nagi S El Saghir, Cheng-Har Yip, Hussein M Khaled, Isabel V Otero, Clement A Adebamowo, Rajendra A Badwe, Joe B Harford (*Lancet Oncol* 2011; 12: 387-98)
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9. G.T. Pack, J.S. Gallo The culpability for delay in the treatment of cancer
American Journal of Cancer, 33 (1938), p. 443e462

CHAPTER 2: LITERATURE REVIEW

1. INTRODUCTION

Breast cancer is a global concern and rapid access to health care services has been a major challenge in developing nations such as South Africa. Delays in breast cancer care are known to happen at both patient and provider levels. There is consensus amongst breast cancer treatment providers that delays have a negative influence on outcome¹⁻². This literature review will investigate if any guidelines exist on minimum delays in breast cancer care and will interrogate available data on delays in breast cancer care. It will specifically look at the influence that delays in care have on eventual outcome. The review includes and will report on studies done in low and middle income countries with resource constraints (similar to South Africa) and high income countries without resource constraints separately³. It will also investigate if any literature regarding intervention programs to improve treatment delays exists.

2. LITERATURE REVIEW

2.1 METHOD

An integrative literature review of breast cancer care delay associated was conducted. The research methodology was performed according to established criteria. The literature reviewed was sourced from MEDLINE and PUBMED databases. Initial search looked for all studies related to breast cancer delays. This was then progressively narrowed down to studies that took into account both patient and provider delay and the economic status of the country in which the study was carried out. (Figure 1)

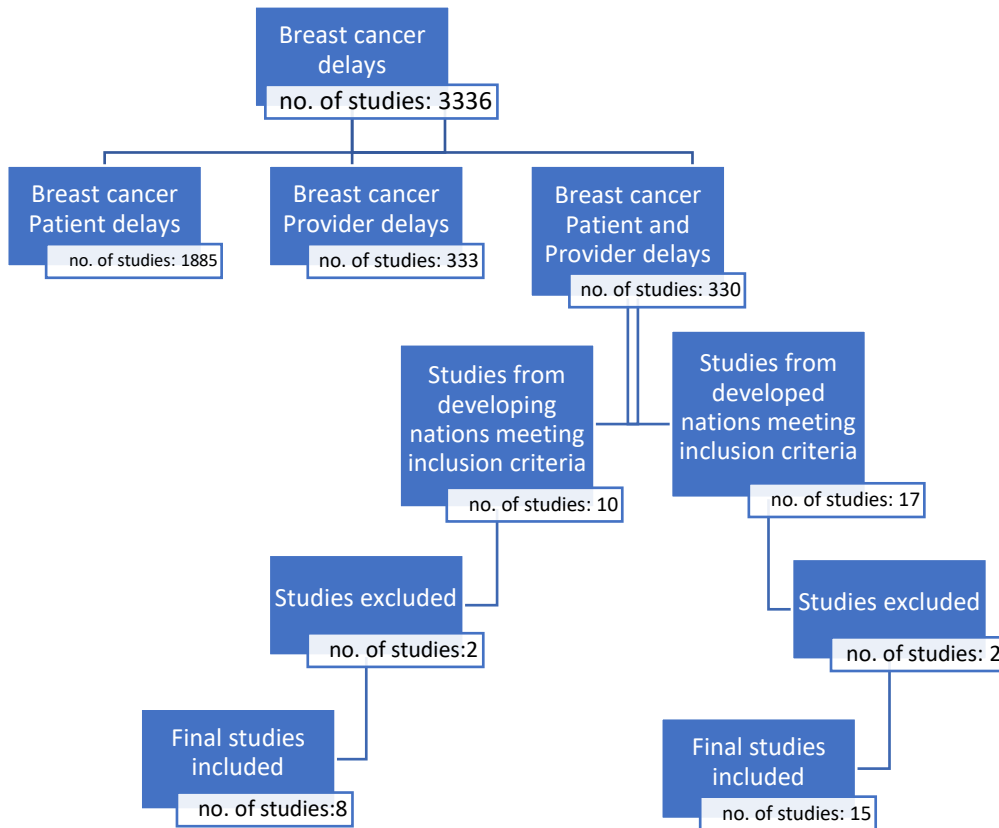


Figure 1: Literature review

PICOTTS eligibility criteria

Population	Patients experiencing breast cancer care delays
Intervention	Questionnaire, folder review
Control	Patients with no delay (however, control Not required)
Outcomes	A patient or provider breast cancer delay of more than 3 months
Time allowed for interventions effect (follow up)	Not applicable
Time into the past for the search	Studies dating back to 2010 were included in the literature for the search
Study designs allowed	Cohort studies; RCTs; observational studies; case series; cross sectional studies

Table 1: Population, intervention, control, outcome, time allowed for outcomes, time of search of the literature, study designs allowed (PICOTTS)

Exclusion criteria

- Non-English studies
- Studies done before 2010
- Studies that did not define possible variables contributing to the cancer care delay.

2.2 METHODOLOGICAL BACKGROUND OF STUDIES

The following studies have been evaluated in this literature review.

Author	Country	Year	Design of study	Data analysis	Number of participants (n)	Factors relating to patient delay	Factors relating to provider delay
Otieno et al	Kenya	2010	Retrospective descriptive	Multivariate	500	Socioeconomic, age	Diagnostic delays, hospital booking systems
Pace et al	Rwanda	2015	Prospective, cross sectional	Multivariate	144	Use of alternative medicine, socioeconomic	Diagnostic delays
Norsa'adah et al	Malaysia	2011	Cross sectional	Multivariate	328	Use of alternative medicine	Diagnostic delays
Ibrahim et al	Nigeria	2012	Prospective, cross sectional	Multivariate and univariate	201	Sociodemographic, use of alternative medicine	
Karla Unger-Saldana et al	Mexico	2015	Cross sectional	Multivariate	886	Sociodemographic	Diagnostic delays
Maghous et al	Morocco	2016	Cross sectional	Multivariate	137	Sociodemographic, use of alternative medicine	Diagnostic delays
Chintamani et al	India	2011	Prospective Cross sectional	Multivariate	100	Sociodemographic	Presence of unregistered doctors
Khan et al	Pakistan	2015	Cross sectional	Multivariate	315	Sociodemographic	
Poum et al	Thailand	2014	Prospective, Cross sectional	Multivariate	180	Socioeconomic	Diagnostic delay, distance to hospital
Mousaa et al	Egypt	2011	Cross sectional	Multivariate	163	Disease factors	Initial review by specialist

Abu- Helalah et al	Jordan	2016	Cross sectional	Multivariate	327	Patient awareness	Diagnostic and treatment delay
Odongo et al	Uganda	2015	Cross sectional	Multivariate	162	Sociodemographic	
Ozmen et al	Turkey	2014	Cross sectional	Multivariate	1031	Hospital mistrust, Sociodemographic	Availability of screening
Dalwai et al	South Africa	2015	Retrospective descriptive	Multivariate	45		Diagnostic delay
Ezeome et al	Nigeria	2010	Prospective, Cross sectional	Multivariate	164	Sociodemographic, use of alternative medicine	Diagnostic delay
Hansen et al	Denmark	2011	Cohort	Multivariate	2212	Patient awareness	Diagnostic delay
Innos et al	Estonia	2013	Cross sectional	Multivariate	703	Sociodemographic	
Huo et al	China	2015	Cross sectional	Multivariate	1431	Disease factors, sociodemographic	Diagnosis delay
Beattie et al	Australia	2009	Retrospective descriptive	Multivariate	30	Lack of a screening program	Diagnostic delay
Jassem et al	Mixed Nationalities	2013	Cross sectional	Multivariate Cluster	6588 (12 countries)	Socioeconomic, disease factors	Access to specialist, diagnostic delay

Table 2: summary of study backgrounds

3. TREATMENT AND REFERRAL SYSTEM IN SOUTH AFRICA

Most breast cancer patients are initially seen by primary health care providers (general practitioners, medical officers and nurse practitioners,) located at primary healthcare clinics and private practice centres. Some primary care providers are able to perform diagnostic investigations, but the majority of patients with symptoms and signs of breast cancer will be referred to a surgical clinic located in a secondary or regional hospital where all diagnostic and some staging investigations will be performed.

There are very few dedicated rapid access breast clinics in South Africa. After a diagnosis of breast cancer is made, the patient is then referred to a multi-disciplinary team which includes surgeons, oncologists, radiologists and pathologists. The multi-disciplinary team clinics in South Africa is based mainly in the big tertiary academic hospitals. This team determines the best management strategy for each patient on an individual basis.

3.1 MANAGEMENT OF BREAST CANCER

Most patients with early breast cancer are candidates for breast conserving therapy. This process involves removing the cancerous lesion and a rim of healthy tissue around it. This is often followed with radiotherapy. If breast conservation is not possible (either due to tumour or patient factors), the patient is offered a mastectomy (removal of the entire breast with or without removal of axillary lymph nodes).

Patients with locally advanced breast cancer usually require some form of neoadjuvant systemic therapy prior to surgery.

Patients with distant spread of the tumour (metastasis) are usually offered systemic therapy only. Occasionally, surgery is offered for patients with destructive infected breast cancers.

Management algorithm for breast cancer

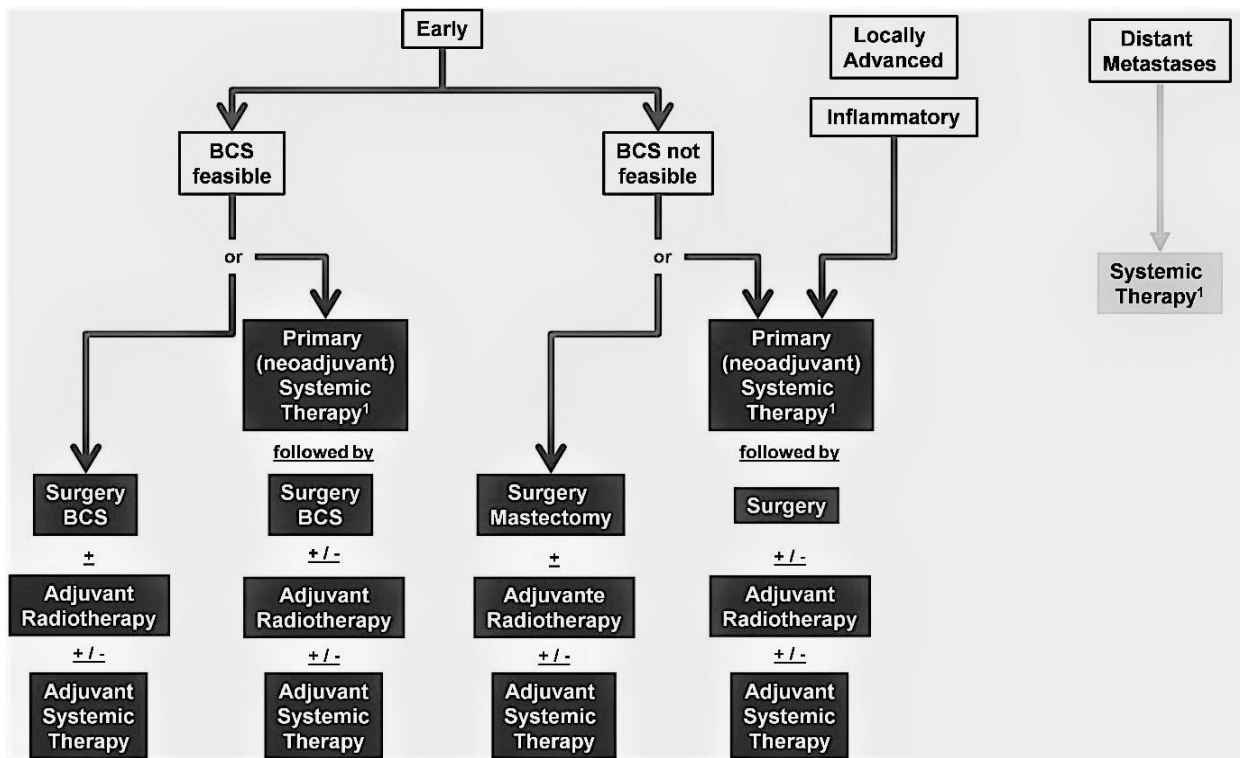


Figure 2: Onkopedia Guidelines 2012: Algorithm for primary therapy <https://www.onkopedia-guidelines.info/en/onkopedia/guidelines/breast-cancer-in-women/@@view/html/index.html> (accessed 18 April 2017) BCS: breast conserving therapy Systemic therapy includes endocrine therapy and / or chemotherapy and / or monoclonal antibodies

3.2 GUIDELINES ON ACCEPTABLE DELAY

There is limited consensus about what constitutes acceptable 'patient' and 'provider' delay.

Patient delay is generally considered to be a result of a complex interplay between patient awareness/education regarding a particular health condition, socioeconomic factors and accessibility to health care facilities. A 6 weeks delay was suggested as acceptable patient delay by the European Society of breast specialist in 2010 in their quality of care indicators¹⁶.

Provider delay is a measure of efficiency with which any given health care system delivers its services. The European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis were published in 2006⁴ to try and offer acceptable

time frames during which breast cancer patients should have had access to definitive treatment.

There is currently no published guidelines regarding what constitutes an acceptable breast cancer treatment delay for patients living in low and middle income countries¹³

European guidelines for quality assurance in breast cancer screening and diagnosis. Fourth edition⁴

These were put in place as a measure of reducing provider delay. Targets were set in terms of working days at every stage where delay may arise.

Targets:

- 95% of women should receive full and adequate assessment in three appointments or less.
- 90% of women with symptoms and signs strongly suggesting the presence of breast cancer should be seen within two weeks of referral, and agreed protocols should be in place to facilitate this.

Time (in working days / wd) between		
Performance indicator	Acceptable	Desirable level
Screening mammography and result	15 wd	10 wd
Symptomatic mammography and result	5 wd	
Result of screening mammography and offered assessment	5 wd	3 wd
Result of diagnostic mammography and offered assessment	5 wd	
Assessment and issuing of results	5 wd	3 wd
Decision to operate and date offered for surgery	15 wd	10 wd
Performance indices (% of patients the system expects to get done based on the guidelines)	acceptable	desirable
Time (in wd) between		
Screening mammography and results		
≤15 wd	95%	>95%
≤10 wd	90%	<90%
Symptomatic mammography and result		
≤5 wd	90%	>90%
Result of screening mammography and offered assessment		
≤5 wd	90%	>90%
≤3 wd	70%	>70%
Result of symptomatic mammography and offered assessment		
≤5 wd	90%	>90%
Assessment and issuing of results		
≤5 wd	90%	>90%
Decision to operate and date offered for surgery		
≤15 wd	90%	>90%
≤10 wd	70%	>70%

Table 3: European guidelines for quality assurance in breast cancer screening and diagnosis. Fourth edition--summary document: key table of performance indicators <https://academic.oup.com/annonc/article-lookup/doi/10.1093/annonc/mdm481> (accessed 7 Feb 2017)⁴

3.3 DELAYS: DEVELOPED VS DEVELOPING NATIONS

The World Bank categorizes countries according to their gross national income per capita into low income, lower middle income, upper middle income and high income countries. South Africa is considered an upper middle income country. Countries in the low and middle income countries are often referred to as

‘developing’ nations whilst high income countries are referred to as ‘developed’ nations. This is the categorization used in this literature review.

There are significant differences in delay intervals seen between developed and developing nations in the various studies reviewed^{3,16}. This is particularly true for studies assessing health care system delays^{1,3,12}.

The economic status of a country probably was an independent factor in the outcome of breast cancer because although the highest incidence of breast cancer was found in developed nations, the highest mortality was in developing nations¹⁸.

Global breast cancer incidence and mortality rates¹⁷

World region	Incidence	Mortality rate
World	43.3	12.9
Developed nations	74.1	14.9
Developing nations	31.3	11.5
Africa	36.2	17.3
Americas	67.6	14.0
Asia	29.1	10.2
Europe	71.1	16.1

Table 4: Incidence and mortality rates are number of cases and number of deaths, respectively, per 100,000 women. (GLOBOCAN 2012)¹⁷

3.3.1 DELAYS IN BREAST CANCER TREATMENT IN DEVELOPED NATIONS

The United States

Bleicher et al (2015)⁶ analysed two independent population-based studies conducted on prospectively collected national data from the Surveillance, Epidemiology, and End Results (SEER)-Medicare-linked database and the National Cancer Database

(NCDB). They were trying to determine if delay to surgery had an impact on outcome. In this study, they found that 77.7% (SEER group) and 69.5% (NCDB group) of patients received their surgical intervention within 30 days of presentation. Delays in access to definitive surgery were associated with worse overall outcome.

The United Kingdom

The UK Cancer Waiting Times Annual Report, 2015-16⁵ reviewed 313,786 suspected breast cancer cases to assess if they were managing to reach the targets set out by the European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis. Their end-points were:

- Review by specialist
- First definitive Therapy

They found that in 2015-16, 93.2% of patients urgently referred by their GP with exhibited breast symptoms were seen by a specialist within 14 days of referral.

98.8% of patients receiving first definitive treatment for breast cancer in 2015-16 began their treatment within 31 days of diagnosis.

Denmark

Hansen et al ²⁵ (2011) reviewed cancer registries and found that the median total delay was for all cancer was 98 days (IQI 57-168). Most of the total delay stemmed from patient (median 21 days (7-56)) and system delay (median 55 days (32-93)). Median GP delay was 0 (0-2) days. Total delay was shortest among patients with ovarian (median 60 days (45-112)) and breast cancer (median 65 days (39-106)). In their series, system delay accounted for a substantial part of the total delay experienced by cancer patients.

Australia

Beanie et al²⁶ in 2009 reviewed a breast cancer clinical database of a general practitioner spanning over a 20 year period. He found that the mean time interval

between women noting symptoms and consulting the GP was 84 days and the mean time interval from first presentation to final diagnosis was 54 days.

Estonia

In Estonia, Kaire Innos et al²² in 2013 found that seventeen percent of the patients had their first medical consultation more than three months after self-detection of symptoms. In multivariate analysis, the risk of prolonged delay was significantly associated with age 65 years and over (OR 2.27, 95% CI 1.23–4.20), current smoking (OR 2.09, 95% CI 1.21–3.61), symptoms other than painless breast lump or breast pain (OR 1.84, 95% CI 1.08–3.16), no history of mammograms (OR 1.83, 95% CI 1.13–2.95), having received no information on breast cancer during past year (OR 1.77, 95% CI 1.05–2.99), and previous benign breast problems (OR 1.65, 95% CI 1.01–2.67). Non-significant risk increase was seen with lower education.

China

Qiang Huo et al²⁴ in 2015 found that delays in diagnosis and treatment were correlated with larger tumour size, lymph node metastasis, late tumour stage, and worse disease-free survival. Patient residential status, initial symptom, menopausal status, and history of breast disease were independent predictors of delay

Japan

A unique concern reviewed by Ozaki et al²³ was the effect that isolation after catastrophic events such as earthquakes had on breast cancer delay. They found that these events contributed to both patient and provider delay.

Multinational analysis

Jassem et al (2013)²⁸ surveyed a total of 6588 female breast cancer patients from 12 countries (from both developing and developed nations). The average patient-related delay time and total delay time were 4.7 (range: 3.4–6.2) weeks and 14.4 (range: 11.5–29.4) weeks, respectively. The average system-related delay time was 11.1 (range: 8.3–24.7) weeks. Cancer diagnosis made by an oncologist versus another physician, higher education level, older age, family history of female cancers and

having a breast lump as the first cancer sign were associated with shorter system-related delay times. Longer patient-related delay times and higher levels of distrust and disregard were predictors of longer system-related delay times.

3.3.2 DELAYS IN BREAST CANCER TREATMENT IN DEVELOPING NATIONS

Thailand

Thailand is a middle income nation in Asia which provides free of charge basic health care services through its national health insurance system. Amornsak et. al. (2014)⁷ conducted a study at 3 tertiary level hospitals in Thailand and found that the median patient delay was 12 days, and median doctor delay was 21 days. Factors contributing to delay included previous breast symptoms, self-treatment, long distance or travel time to hospital, younger age at first birth, and increased number of consultations with a surgeon before diagnosis.

Nigeria

Nigeria has one of the most populous countries in the world and has one of the strongest economies in Africa. Ibrahim et al (2012)⁸ looked at socioeconomic factors that lead to delay in Nigerian women accessing breast cancer care at a large university teaching hospital. They found that the mean duration of symptoms was 12.12 months. Delay for more than 3 months before initial medical consultation was observed in 81.6% of the population studied. Ignorance of the nature of illness, belief in spiritual healing, fear of mastectomy and belief in herbal treatment were the leading reasons for delay.

Rwanda

Rwanda is one of the smallest countries in Africa but its economy and health sector has grown tremendously in the past 2 decades. Pace et al (2015)⁹ assessed 2 major rural hospitals providing breast cancer care in Rwanda and found that the median total delay was 15 months, and median patient and system delays were both 5 months. The significant patient delays were mainly due to lack of breast cancer awareness, financial constraint, low education levels and use of alternative health

therapy (traditional healers). The main reason for system delay was related to challenges experienced due to the healthcare referral system.

Kenya

Kenya has the strongest economy in eastern Africa and has a health system very similar to South Africa. Otieno et al (2010)¹⁰ carried out a study in the largest tertiary level hospital in the country and found that the mean overall provider delay (time lapse between the patients' first hospital visit date to time definitive anti-cancer treatment was started) was 87.9 days (range 1 to 1683 days) and a median of 21.5 days. Mean delay with regard to confirmatory laboratory diagnostic test was 56.2 days (range 1 to 985 days) with a median of 17.0 days. In this study, they found that contributing factors to delay were the patient's level of education, presentation with breast symptoms other than a lump, family history of breast cancer, employment status and diagnostic challenges. Interestingly, patient non-compliance was found common in the more educated and professional woman, probably related to time constraints.

South Africa

A retrospective study on provider delays done by Dalwai et al (2015)¹¹ at a tertiary institute in South Africa found that with a mean system delay was 70.1 days or 10 weeks with an interquartile range of 48 - 82 days. This was almost double the international recommendations of 6 weeks. They proposed that local guidelines be developed with an aim of improving service delivery.

Proposed Guidelines for breast cancer delays¹¹

	Time	Total Delay
Surgical clinic	1 wk	
Diagnosis		
Radiology and pathology delay	4 wk	5 wk
Definitive management		
Neo-adjuvant chemotherapy or surgery	3 wk	8 wk

Egypt

Breast cancer accounts for 37.6% of tumors amongst Egyptian women, and is often diagnosed at later stages. In 2010, Mousaa et al ¹⁹investigated breast cancer patient navigation through the health care system in the Nile Delta. Interviews were conducted with 163 newly diagnosed breast cancer patients at a major cancer center of the region. Patients described their medical care pathway from the initial symptom experienced until their arrival at the centre. Patients whose initial contact was with a general surgeon (OR: 7.6, 95% CI: 2.1, 27.6), primary care provider (OR: 12.2, 95% CI: 2.9, 51.0), or gynaecologist (OR: 8.6, 95% CI: 1.4, 53.4) were significantly more likely to experience a delay in reaching the centre as compared to those visiting a surgical oncologist. They concluded that overcoming health care system and patient navigation barriers in developing countries may reduce the time for breast cancer patients to reach a cancer centre for early management.

India

In 2011, Chintamani et al ²⁰ found that the use of unregistered medical practitioners or quacks contributed significantly to the delays. The average time lapse before diagnosis for rural patients was higher (67.5 days) compared to urban patients (53.7 days). The delay in illiterate women was 60.6 days compared to 49.5 days for literate ones.

Mexico

In 2015, Unger-Saldana et al ²¹ reviewed breast cancer patients from 4 major health facilities and found that the majority of patients with breast cancer began treatment after a delay. Both patient delays and provider delays were associated with advanced disease. The median time between problem identification and the beginning of treatment was 7 months.

Uganda

Omamo et al³⁰ (2014) assessed patients in a tertiary hospital in Uganda. In total 162 patients were recruited, the mean patient delay in months was 22.6 (SD = 26.4), median delay was 13 months and range was 1-127 months. 139 (89 %) patients

delayed by more than 3 months after noticing symptoms of breast anomaly. Patients who had no social support from their families were more likely to delay.

Morocco

Maghous et al.²⁷ (2016) reviewed breast cancer patients seen at a tertiary level institution and found that the median of consultation time was 6[4,12] months and the median of diagnosis time was 1[1,3] months. Diagnosis delay was associated to a personal reason in 96 (70.1 %) patients and to a medical reason in 19 (13.9 %) patients.

Jordan

Abu-Helalah et al²⁹ conducted a cross-sectional study on female breast cancer patients in Jordan. The total number of participants was 327. The proportion of patients with presentation delay, diagnosis delay, and treatment delay was 32.2%, 49.1%, or 32.4%, respectively. The main reported reasons for delay in presentation were ignorance of the nature of the problem (65.6%), limited/lack of knowledge that symptoms were suggestive of cancer diagnosis (16.7%), and misdiagnosis (16.7%).

Pakistan

Khan et al³¹ (2014) found that a significant percentage of women with breast cancer in North Pakistan (39%) is experiencing presentation delay due to their misconceptions about the disease. Education and socioeconomic status were two independent variables related to the delayed presentation after adjustment for others [odds ratios (OR) of 2.26, 2.29 and 95% confidence intervals (CI) was 1.25-4.10, 1.06-4.94 respectively].

Turkey

In 2010, Ozmen et al³², sampled 1031 breast cancer from 13 medical institutions in Turkey. They found that the mean patient delay time, system delay time and total were 4.8, 10.5 and 13.8 weeks, respectively. In all, 42% of the patients had a TDT >12 weeks. Shorter patient delay time was characteristic of patients who: had stronger self-examination habits, received more support from family and friends and had at

least secondary education. Patients who were diagnosed during a periodic check-up or opportunistic mammography displayed shorter system delay time compared with those who had symptomatic breast cancer.

Malaysia

Norsa'adah et al³³(2011) reviewed breast cancer patients presenting in 5 medical centres in Malaysia. The median time to consultation was 2 months and the median time to diagnosis was 5.5 months. The frequency of diagnosis delay of more than 3 months was 72.6% and delay of more than 6 months occurred in 45.5% of the cases. The factors associated with diagnosis delay included the use of alternative therapy (odds ratio (OR) 1.77; 95% confidence interval (CI): 1.06, 2.94), breast ulcer (OR 5.71; 95% CI: 1.59, 20.47), palpable axillary lymph nodes (OR 2.19; 95% CI: 1.23, 3.90), false-negative diagnostic test (OR 5.32; 95% CI: 2.32, 12.21), non-cancer interpretation (OR 1.68; 95% CI: 1.01, 2.78) and negative attitude toward treatment (OR 2.09; 95% CI: 1.15, 3.82).

Nigeria

In 2010, Ezeome et al³⁴ reviewed 164 patients presenting at a tertiary institute in Nigeria. They found that institutional or physician induced delays were present in 46.2% of the cases while patient related delays were present in 79.2% of cases. Only use of alternative practitioners for initial treatment was significantly related to delays of more than three months before presentation ($p = 0.017$).

3.4 EFFECTS OF DELAY ON PATIENT OUTCOME

Studies into the effects of breast cancer delays on outcome have almost invariably shown that delays are associated with poorer outcomes. In the American study by Bleicher et al (2015)⁶ analysed two independent population-based studies conducted on prospectively collected national data from the Surveillance, Epidemiology, and End Results (SEER)-Medicare-linked database and the National Cancer Database (NCDB). They were trying to determine if delay to surgery had an impact on

outcome. They found that with each interval of delay increase, overall survival was lower overall (hazard ratio [HR], 1.09; 95% CI, 1.06-1.13; P < .001).

McLaughlin et al³⁵ (2012) found that delay in initiation of breast cancer treatment was associated with increased risk of overall and breast cancer-related death.

Disease factors such as tumour biology can be associated with poor outcomes even in cases where there is no cancer care delay².

3.5 INTERVENTION POINTS

3.5.1 Patient delays:

Lack of patient breast cancer awareness is a major challenge in developing countries. It is, therefore, important to develop aggressive breast cancer awareness programs¹⁵ – especially in the rural areas⁹. The use of local media stations, religious organizations and community health workers would be useful in this endeavour.

3.5.2 System delays:

Accelerated referral programs: The majority of patients in the developing nations were initially seen by a primary health care worker (often a nurse) at the local clinic before getting access to a secondary level centre. Often diagnosis and treatment of the cancer was made at tertiary centres. Often, patients with breast cancer suspicion only got to see a specialist several months after presenting to the health care system. There is a need to introduce the concept of accelerated referral systems for all women suspected of having breast cancer. ¹⁵

Training programs:

Community health workers: Developing nations such as Rwanda and Kenya have a pool of community leaders known as community health workers whose primary role is to form a bridge between the community and the health care system. Often, these workers do not receive conventional medical training and come from all

spheres of life. They are usually get basic training about common health problems and are used to educate the community about them. In the past, that training has mainly targeted communicable diseases and very little attention has been given to non-communicable problems. Training these community health workers on the signs and symptoms of breast cancer and using them to educate and encourage the community to seek health care services would be a good way to try and improve our health care services.^{15,12}

Specialist health worker training: In most of the centres reviewed, there were major challenges in getting accurate and timely diagnosis. Training of dedicated breast health workers in fields such as biopsy and imaging would markedly reduce these challenges. ^{14,15}

Use of online record keeping and tracking systems: this would particularly be useful in ensuring that all women documented at a primary health care facility as having features suspicious for breast cancer get rapid access to specialist care. It would also allow for any diagnostic procedures be made accessible to all health workers interacting with the patient (prevents repetition of procedures). It is also crucial to establish breast cancer registries. ¹⁵

Development of breast cancer diagnostic centres in peripheral hospitals

The development of breast cancer care centres of excellence have been advocated as a pathway of improving availability of service¹⁵. These centres should provide rapid breast cancer diagnosis and specialist care.

4. CONCLUSION

Delays in the provision of breast cancer care are largely preventable and can be reduced even in resource scarce nations. The burden of disease in some of the developing nations was largely unknown due to lack of breast cancer registries. Resources in these countries are still mainly channelled to tackling communicable diseases due to better awareness of disease prevalence. Establishment of these registries would allow for governments to rationally re-distribute resources to

services such as breast cancer care which would inevitably lead to reduced delays and hopefully better outcomes.

Patient awareness programs and improvement of access to breast cancer care centres would help reduce delay. Provider delay can be reduced by the development of rapid access breast cancer diagnostic centres of excellence in peripheral hospitals. Guidelines on acceptable standards of care in these centres and training of staff would further work to reduce delay and improve the level of service in developing nations.

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CHAPTER 2: PUBLICATION READY MANUSCRIPT

Delays in provision of breast cancer care in patients seen at a district hospital diagnostic breast unit in South Africa

ABSTRACT

Objective: To determine the extent and nature of patient and system delay in breast cancer management at a district hospital in Cape Town, South Africa.

Background: There is evidence to show that delays in breast cancer management are detrimental to patient outcome. The aim of this study was to determine time trends and causes of delay in a newly established diagnostic breast clinic based at a district hospital in South Africa.

Method: All patients who presented to Mitchells Plain District Hospital Breast Clinic from January to December 2015 and had a diagnosis of breast cancer were included in this study. The intervals between the time she first noted her symptoms to initial contact with a health professional and delivery of definitive therapy was documented. Patient delay referred to the interval from when the patient first noted her symptoms to her initial contact with a health care provider. Provider delay referred to the interval between the first hospital visit and onset of therapy.

Result: A total of 33 patients were enrolled in this study. The median overall total delay (time lapse between the moment the patient first noticed her symptoms to time definitive anti-cancer treatment was started) was 157 days, (range 29 to 839 days). Median patient delay (time lapse between the moment the patient first noticed her symptoms and the visit to a health professional) was 56 days, (range 7 to 730 days). Median overall provider delay (time lapse between the patients' first encounter with a clinician to time definitive anti-cancer treatment was started) was 84 days, (range 22 to 338 days). Median Referral delay was 11 days (range 4 to 39 days). Median Diagnostic delay was 15 days (range 9 to 135 days) and median treatment delay was 45 days (range 5 to 246 days).

Conclusion: The median overall total delay for patients diagnosed with breast cancer at Mitchells Plain District Hospital does not compare well with institutions in developed nations but it is similar to studies done in developing nations. The largest contributor to this delay was patient delay. The main contributors to provider

delay was related to diagnosis (almost exclusively related to tissue diagnosis) and treatment (mainly patients who received surgery as their first definitive therapy).

INTRODUCTION

Breast cancer is the most frequent cancer amongst South African women. The lifetime risk of South African women developing breast cancer is 1:33 (National Cancer Registry, 2009). There is a higher incidence of death in developing countries as compared to more developed nations¹² and this is due to late diagnosis, lack of screening programs and hospital/provider delays after diagnosis³. In South Africa, there is no nationwide breast cancer screening program in place, and a significant number of patients present with advanced disease. Furthermore many clinical facilities are inefficient in the evaluation of such cases, and cause further delays in access to therapeutic interventions.

The breast unit at Mitchell's Plain hospital was established in 2014 to provide rapid access to comprehensive evaluation of breast complaints for patients in the Mitchells Plain area of Cape Town. The purpose of this study is to record the time delays incurred by patients diagnosed with breast cancer in Mitchells Plain District Hospital breast clinic, and document the causes of cancer care delay in order to try and improve the overall service provision at the clinic.

Breast cancer delays can be defined as either patient delays or provider delays.

Patient delay refers to a prolonged period between discovery of symptoms and a visit to a physician. Patient delay in South African patients is thought to stem from a combination of the population's lack of awareness of the condition, use of alternative medicine and limited access to health care facilities.

Provider delay refers to the time period between the initial medical consultation and the beginning of definitive treatment. It is a measure of the efficiency with which a health care system delivers its services. The maximum time period defined by Pack and Gallo for a physician to act after initial medical consultation was arbitrarily

selected to be one month. Provider delay can further be divided into '*referral delay*' (time elapsed between first consultation with a primary care service and referral to a breast diagnostic centre), '*diagnosis delay*' (time between the first clinical consultation at a breast diagnostic centre and cancer diagnosis) and '*treatment delay*' (time between diagnosis and beginning of definitive cancer treatment), Breast cancer care delays adversely affect survival due to disease progression. Advanced clinical stage has been found to be associated with higher recurrence rates, poor survival outcomes and the use of more aggressive forms of therapy in cancer patients. ^{1-2, 5}

METHOD

Data source and study settings

All patients who presented to Mitchells Plain District Hospital Breast clinic during the period of January 2015 to December 2015 were considered. Data was collected retrospectively through review of patient folders. Mitchells Plain District Hospital is a secondary level hospital in Cape Town, South Africa. It has a dedicated weekly rapid access breast unit where patients are evaluated after either referral by a primary health provider or on a 'walk in' basis. The Mitchells Plain District Hospital breast unit has access to both mammography and biopsy services. Although it is the first point of care where breast patients are evaluated, the patients who are diagnosed with breast cancer are referred to Groote Schuur Hospital (a tertiary teaching centre) for multi-disciplinary evaluation and a definitive treatment plan. All chemotherapy, radiotherapy and endocrine therapy is done at Groote Schuur Hospital. The surgical workload is shared between Groote Schuur Hospital and several secondary level hospitals in the western part of Cape Town of which Mitchells Plain Hospital is one.

REFERRAL PATHWAYS FOR MITCHELLS PLAIN HOSPITAL RAPID ACCESS BREAST UNIT

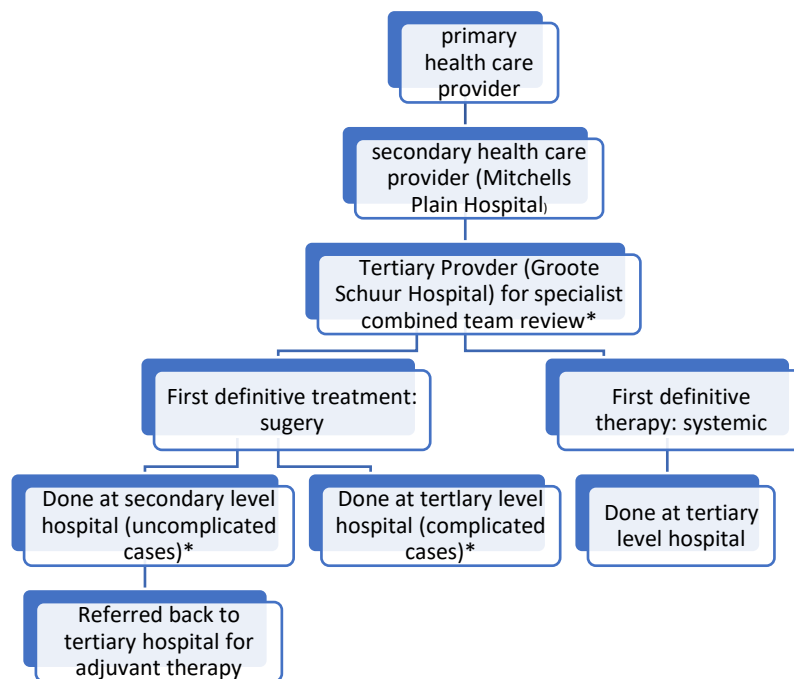


Figure 1: Referral and Treatment algorithm

*specialist team: breast surgeons, oncologists, radiologists, pathologist

*uncomplicated cases: no reconstructive therapy to be done, low anaesthetic risk

*complicated cases: patients requiring reconstructive therapy, high anaesthetic risk

Patient selection

All patients seen at Mitchells Plain District Hospital breast clinic with histologically confirmed breast cancer (both invasive and in situ) were included in this study.

Patients with recurrent disease and those whose diagnosis of cancer was made at another institution were excluded from this study. The study was approved by the University of Cape Town Research Health Science Faculty Research Ethics Committee.

Data collection

All patients who met this criteria had both their demographic and clinical information consolidated using a data collection sheet. Demographic data included factors which could influence patient delay such as employment/economic status,

age and distance between the patient's residence and the hospital. Clinical data included referral date (when the patient was initially seen at the primary health centre or by the general practitioner), date when they were seen at Mitchells Plain, biopsy and imaging dates (including repeat biopsies and additional imaging which was done prior to definitive therapy). A timeline was established as to when the patients were seen at Groote Schuur Hospital breast clinics and combined clinics with oncologists, radiologists and pathologists. The data endpoint was when the patients received their first definitive therapy (either surgery, chemotherapy, endocrine therapy or palliative treatment).

Statistical analysis

Demographic data captured during the folder review included age, gender, employment, marital status and distance from the patient's home to the hospital. A timeline was generated for each case by capturing dates of the consultations with the primary health care provider, referral date to the Mitchells Plain District hospital and review by the breast multidisciplinary team at the tertiary hospital (Groote Schuur Hospital). A timeline was also drawn delineating the dates of histology, imaging and initiation of definitive therapy. The individual step delays were quantified and any reasons sought to explain excessive delays were noted during the folder review. Quantitative data including time in days between dates of entry and exit from the cohort and between intermediate dates have been summarised using median, mean delay and interquartile range. A multivariate logistic analysis of patient socioeconomic status, disease presentation and hospital systems was done to review the factors predictive of delay.

RESULTS

During the 12 months reviewed, 34 cases were identified for the study. 1 case was excluded (she had part of her investigation done in the preceding year). The entire population studied was female. The age of the population studied ranged from 26-87 years (mean 55.5years)

Total delay

The median overall total delay (time lapse between the moment the patient first noticed her symptoms to time definitive anti-cancer treatment was started) was 157 days, (range 29 to 839 days). Review of the data revealed that both patient and provider factors contributed to this delay.

Patient delay factors

Median patient delay (time lapse between the moment the patient first noticed her symptoms and the visit to a health professional) was 56 days, (mean 104 days: range 7 to 730 days). The study reviewed various patient factors to see how they contributed to breast cancer care delay.

Age

In this study, we found that older women sought treatment earlier than their younger counterparts. The mean time taken women under the age of 50 years to seek therapy was 142 days as compared to the mean 77 days observed in women above 50 years ($p= 0.468149$).

Marital status

Unmarried women sought treatment earlier than married women. 36% of the patients studied were married whilst the remainder 64% were non-married (single, divorced or widowed). The mean time taken for married women to seek treatment was 156 days as compared to 71 days for the non-married group ($p= 0.33728$).

Employment status

24.2% of patients studied were employed whilst 75.8% were not employed (including pensioners) at time of study. The mean time taken for employed women to seek treatment was 146 days as compared to 92 days for the non-employed group ($p= 0.981025$).

Characteristic	Time to present to health facility (days - mean)	p value
Age (mean = 55.5 years)		
<50 years old	142	(p= 0.468149)
>50 years old	77	
Marital status		
Married	156	(p= 0.33728)
Non-married	71	
Employment status		
Employed	146	(p= 0.981025).
Non-employed	92	
Distance to hospital		
<5kilometers	141	(p=0.843692)
>5kilometers	90	
Family history of breast cancer		
Yes	89	(p= 0.568125)
No	109	
Stage		
Early breast cancer	95	(p= 0.173442)
Late breast cancer	101	

Table 1: Socioeconomic factors related to patient delay

Travel distance

To assess whether distance between patient residence and the hospital we used 5 kilometres as a cut off for which the health facility would be accessible to women on foot. Surprisingly, the mean time taken for women who lived less than 5 kilometres

to present to the health facility was 141 days as compared to 90 days for women who travelled longer distances ($p=0.843692$).

Family history

Patients with a family history of breast cancer are thought to have a greater awareness of the disease as compared to the rest of the population. In our series, the mean time for taken for women with a family history of breast cancer to present to a health facility was 89 days as compared to 109 days for those without ($p= 0.568125$)

Stage of disease

42.4% of women presented with early breast cancer (stage 1). The mean time for these women to present to the hospital was 95 days as compared to 101 days in those who presented in later stages of the disease ($p= 0.173442$).

Provider delay:

The median provider delay was 84 days (mean 86; range 22-338 days). This was further divided into referral, diagnostic and treatment delay.

Referral delay

In this study, the mean referral delay was 11 days (mean 13 days; range 4 to 39 days). It did not contribute significantly to delay and was comparable to standards set up in most developed nations.

Diagnosis delays

Tissue and radiological diagnosis is mandatory in the confirmation of breast cancer. The overall median diagnostic delay was 15 days (mean 21 days: range 9 to 135 days). All patients had a fine needle aspiration and a core biopsy at initial contact with the district hospital breast cancer care team. The fine needle aspiration biopsy was done to obtain cytology which was immediately assessed by onsite cytologists. This allowed for patients to be fast tracked for review by an oncology team if there are any cytological features of malignancy. The core biopsy was done to obtain tissue

samples required for further characterisation of the tumour. In 48% of cases, the patients needed multiple core biopsies as initial specimens taken were inadequate due to either technical difficulties or clinician inexperience. We compared the time to definitive therapy for women who required 3 or more biopsies as compared to the routine 2 described above. Patients who received less than 3 biopsies took a mean time of 15 days to get therapy as compared to a mean of 26 days for those who needed a larger number of biopsies ($p=0.0772286$). The histological characteristics (invasive malignancy vs carcinoma in situ) did not appear to contribute to diagnostic delays ($p=0.531403$).

All patients in the breast cancer program received a mammogram. A breast ultrasound was performed in women with very dense breast tissue. In this set up a chest radiograph was part of routine imaging. In cases where there were concerns of distant spread of disease (metastasis), further imaging was performed. Index imaging was done on first presentation at the Mitchell's plain breast clinic in 94% of patients.

First Definitive treatment

The first definitive treatment was taken to either be surgery, systemic therapy (chemotherapy or endocrine) or palliation. Choice of treatment was determined by the stage of the disease, tumour biology and patient suitability for a particular mode of therapy. The median treatment delay was 45 days (mean 52 days; range 5 to 246 days). The group whose first definitive treatment was non-surgical received treatment earlier than their counterparts whose first intervention was surgery {mean 41 vs 66 days (non-surgical group range 5-154 days vs surgical range 20-139days) $p=0.026159$ }. The location of the surgery also played a role in how fast a woman got her intervention. Women who got their surgery done at secondary level hospitals tended to get it within a shorter time frame than those done in tertiary hospital. The mean time for a woman to access surgery at the tertiary hospital was 67 days vs 51 days for the secondary level hospital group ($p=0.411541$). The main causes for treatment delay was lack of theatre time or patients' not coming in for their operation (some

opted for alternative therapy, defaulted on appointed clinic or surgery dates or by refused to proceed without family approval for their treatment).

Characteristic	Time between presentation and diagnosis (mean =days)	p value
Diagnostic delay		
2 biopsies	15	(p= 0.0772286)
>2 biopsies	25	
Treatment delay		
Surgery	66	(p= 0.026159)
Non-surgical	41	
Delay: Place of surgery		
Tertiary Hospital	67	(p= 0.411541)
Secondary Hospital	51	

Table 2: Provider delay factors

Table 3: Comparison of the Cape Town study with other similar studies

Study	Country	n	Patient delay	Provider delay	Total delay
UK Cancer Waiting Times Report, 2015-16⁵	UK	313,786	-	-	<31 days 98.8%
Bleicher et al (2015)⁶	USA: SEER NCBD	94 544 115 790	-	-	<30 days 77.7% 69.5%
Hansen et al 25 (2011)¹⁸	Denmark	2212	-	-	Median 65 days
Beanie et al (2009)¹⁹	Australia	30	Median 84 days	-	-
Kaire Innos et al (2013)¹⁵	Estonia	703	Median 16 days	-	-
Qiang Huo et al (2015)¹⁷	China	1431	-	>30 days 60.4%	-
Amornsak et al (2014)⁷	Thailand	180	Median 12 days	Median 21 days	-
Ibrahim et al (2012)⁸	Nigeria	201	Mean 365 days*	-	-
Pace et al (2015)⁹	Rwanda	144	Median 150days*	Median 150days*	Median 450days*
Otieno et al (2010)¹⁰	Kenya	389	-	Mean 87.9 days	-
Mousaa et al (2010)¹²	Egypt	163	Median 96 days*	-	-
Chintamani et al (2011)¹³	India	100	Median 67.5days (rural) 53.7days (urban)	-	-
Unger- Saldana et al (2015)¹⁴	Mexico	886	-	-	Median 210 days*
Maghous et al (2016)²⁰	Morocco	137	Median 180 days*	-	-
Dalwai et al (2015)¹⁶	South Africa	45	-	Mean 70.1 days	-
This study	South Africa	33	Median 56 days	Median 84 days	Median 157days

*original data in months

DISCUSSION

Early detection and management of breast cancer is the main goal of any dedicated breast cancer unit. It has been shown to be associated with a better prognosis and outcome. Breast cancer delays can be both due to patient and provider delays. The median overall delay for patients diagnosed with breast cancer at Mitchells Plain District Hospital does not compare well with institutions in developed nations but it is similar to studies done in developing nations. The largest contributor to this delay was provider delay. The main contributors to provider delay were related to diagnosis (almost exclusively related to tissue diagnosis) and treatment (mainly patients who received surgery as their first definitive therapy). Since our study retrospectively reviewed hospital folders, we were unable to fully assess the causes of patient delays. Some of the reasons given for delayed presentation was lack of information about breast cancer, fear of diagnosis, use of alternate medicine and lack of financial resources to visit (pay for transport to) health facilities. In our study, older women presented earlier than their younger counterparts which could be as a result of greater awareness about the necessity of breast cancer screening and regular breast examination in women above 50 years of age. There is, however, no standardised screening program in the country and the women in our study only presented to hospital because they had breast symptoms. Family history of breast cancer seemed to heighten the sensitivity of the women to the condition and positively enhanced their health seeking behaviour. Women with employment presented later than unemployed ones which is possibly a projection of work related time constraints.

Provider delays were mainly related to diagnosis and surgery. Most diagnostic delays were related to obtaining proper tissue diagnosis. Usually, the first 2 attempts at getting biopsies were done without image guidance and if unsuccessful, image guided tissue sampling was performed. Most inadequate biopsies were due to technical difficulty and clinician inexperience. These delays could be reduced by having a dedicated clinician trained in image guided tissue sampling to perform all biopsies. Surgical delays were mainly due to lack of adequate theatre time as opposed to lack of experienced clinicians. In some cases, failure of patients to keep

surgical appointments contributed to treatment delay. Secondary level (district) hospitals were noted to have quicker theatre accessibility and thus shorter surgery waiting times.

CONCLUSION:

One of the main problems with access to breast cancer care in South Africa is lack of a standardised policy in the management of patients. Currently, we do not have a system that ensures that cancer patients get timely referrals and treatment. Lack of financial and human resources make it a challenge to implement a nationwide screening program.

Patient delay can be reduced by raising patient awareness about breast cancer. Provider delay can be reduced by timely referral of suspected cancer cases, improved diagnosis services and rapid access to definitive cancer therapy. Diagnosis delay can be reduced by having a dedicated clinician trained in specialised techniques such as image guided biopsies. Creation of national breast cancer care guidelines would help streamline healthcare services and help create acceptable standards of care.

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CHAPTER 4: APPENDICES

APPENDIX A: DATA COLLECTION FORM

DATA COLLECTION FORM: DELAYS AT MITCHELL’S PLAIN DISTRICT HOSPITAL BREAST CLINIC *(Information to be obtained from patient folders)*

Patient Folder Number:

Date of First Visit: (DD/MM/YY)			
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Patient Gender: Tick appropriate (√)

Female	
Male	

Who referred this patient to GSH/MPH Breast clinic?

Self	
General Practitioner/Private Facility	
Day Hospital / clinic	
District Hospital	
Other	

Date of Referral: (DD/MM/YY)			
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DEMOGRAPHICS

Patient age range	
<30 years	
30-39 years	
40-49 years	
50-59 years	
60-69years	
> 70 years	

Distance from home to MPDH

Distance in kilometres (km)	
< 1km	
1-5kms	
5-10kms	
10-20kms	
>20 kms	

Job profile

Employed	
Unemployed	
Unknown	
Other (specify)	

Marital status

Single	
Married	
Unknown	
Other (specify)	

PATIENT RELATED FACTORS

What was this patient's presenting complaint?

Breast Lump	
Breast Pain	
Breast Nipple Discharge	
Nipple retraction	
Breast skin changes	
Lump in axilla	
Symptomatic metastasis (specify)	

What was the duration of symptoms?

0-2 weeks	
2-4 weeks	
4-8 weeks	
8-12 weeks	
> 12 weeks	
Not sure	

Family history of relevant malignancy? (First degree relatives only)

Breast	
Ovary	
Other	

DIAGNOSTIC PROCEDURES

What Imaging was done for this patient?

Modality	Positive Result	Negative Result
Mammography		
Ultrasound		
None (give reason)		
Repeat Imaging (if any): Modality Used:		

*Positive Result: Findings in keeping with breast carcinoma

* Negative Result: No features of breast carcinoma

Date of Imaging:			
Date of Repeat Imaging: (If any)			

Reason for repeat imaging:	
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What Biopsy Procedure did this patient undergo?

Fine Needle Aspirate	
Core Biopsy	
None (give reason)	
Repeat Biopsy (if any): Method used:	

Date of Biopsy:			
Date Results Obtained:			
Date of Repeat Biopsy: (if any)			

Date Results of Repeat Biopsy:			
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Reason for repeat biopsy:	
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What was the Biopsy result?

Carcinoma in situ	
Ductal carcinoma	
Lobular carcinoma	
Other	

Clinical stage of disease on presentation

T	
N	
M	

Stage	I	II	III	IV
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DEFINITIVE THERAPY

Date First seen at the Combined Breast Clinic: (DD/MM/YY)			
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What was the first mode of definitive therapy received?

Chemotherapy	
Surgery	
Palliation	
Patient declined treatment offered	

Date definitive therapy given (DD/MM/YY)			
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What Surgical Procedure was done for this patient?

Lumpectomy and Sentinel lymph node biopsy	
Lumpectomy and Axillary node clearance	
Mastectomy and Sentinel lymph node biopsy	
Mastectomy Axillary Node clearance	
Mastectomy and reconstruction	
None (Briefly explain why)	
Unknown	

Date of Surgery (for patients who had neoadjuvant therapy):			
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Location of surgery

Mitchells Plain District Hospital	
Groote Schuur Hospital	
Victoria Hospital	
New Somerset Hospital	
Private Health Care provider	
Other	

AREAS OF DELAY

If date of definitive management longer than 1 month from date of first clinic visit
give reason why

In-hospital Diagnosis delays: Imaging related	
In-hospital Diagnostic delays: Biopsy related	
Patient declined to have diagnostic procedure (biopsy/imaging) as initially planned	
Patient did not follow up at the breast clinic as planned	
Patient declined to have surgical procedure/neoadjuvant chemotherapy as initially planned	
Patient opted for traditional healer/second opinion prior to planned therapy	
No available theatre time	
Patient failed to turn up on set surgical date	
Administration /clerical issues (e.g. given wrong date)	
Long duration of time between referral by primary health care provider and review at the breast clinic	
No delay in the care of this patient	

OUTCOME

What was the patient's outcome? (6 months after first clinic visit)

Patient discharged from clinic after completing therapy	
Patient still on follow-up at the Breast Clinic	
Patient lost to follow-up/absconded hospital care	
Patient Died	