

# "Embracing the shake" A South African story of hope

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# Breast cancer currently touches 1 in every 8 women

We see the devastating effect this have every day at our surgical and oncology units at Groote Schuur Hospital. Our public health services cannot keep up with the massive patient load and this has lead to the birth of Project Flamingo in 2010.



# Access to breast cancer (BC) care in South Africa: what does the literature tell us?



- Published studies on provider-related issues of BC care are limited
- Studies are frequently limited by a single-centre design. Multicentre studies are needed
- Milligan's descriptive analysis on diagnostic and surgical services (2022) importantly addresses some of the gaps and provides insightful information. It does, however, have some limitations, including that it reflects the perceptions and insights of those clinicians surveyed rather than hospital records, and it is a Master's thesis awaiting peer review

# Patient barriers to BC care: delays in Dx leading to late-stage presentation

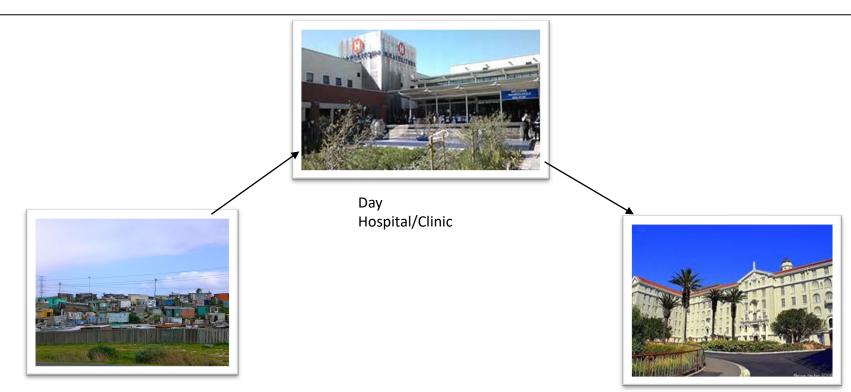
- In the USA, ≈64% of patients present with early-stage BC<sup>2</sup>
- In SA, state sector studies suggest that 54%<sup>3</sup> 75%<sup>4</sup> of BC patients present with late-stage disease (stage III-IV). Clinicians surveyed by Milligan estimated that 67% of patients presented with late-stage BC<sup>1</sup>
- A study among black women in Soweto<sup>5</sup> identified delays of > 3 months and a study in the Western Cape identified delays of 8.5 months between discovery of breast lumps and the development of other symptoms that led patients to seek care <sup>6,7</sup>
- Advanced disease at presentation is associated with worse outcomes, increased cost of therapy and limited treatment options, with many cases of advanced BC not being amenable to surgical intervention<sup>1</sup>



#### Abbreviations:

BC, breast cancer; Dx, diagnosis; SA, South Africa; USA, United States of America

# **Cape Town Metropolitan District**



Home

**Groote Schuur Hospital** 

# **Amathole District Eastern Cape**



Home

# Private Health Insurance





Home



Private Hospital

### **Delays in presentation**

The following are posited as explanations for the prevalence of late presentation of BC in SA:

Stunted health education<sup>7</sup> and other educational issues, Deficits in breast self-awareness.<sup>6</sup> Completed high school education and greater breast knowledge and awareness were associated with lower BC stage at presentation<sup>5</sup>

Preferential use of **traditional** medicine<sup>1</sup>

Fear of diagnosis<sup>5</sup>

**Failure to recognise that** symptoms were **serious** <sup>5,9</sup>

Transport problems<sup>5</sup>

Distance to a centre:

> 20 km: 62% with late stage Dx < 20 km: 50% with late stage Dx

(n= 5 338)<sup>11</sup>

Risk of late stage at Dx was 1.25-fold higher (95% CI: 1.09- 1.42)

per 30 km<sup>11</sup>

Rurality of patient – patients who present late are often from rural areas with few amenities<sup>10</sup>

Concerns about stigma; concerns about disfigurement<sup>1</sup>

Conflicting commitments, e.g. caring for children, sick family members<sup>5</sup>

"Interplay of biological, economic, geographical and psychosocial influences are important in delayed patient presentation" (Lince-Deroche et al, 2017)



Abbreviations:

BC, breast cancer; Dx, diagnosis; CI, confidence interval; SA. South Africa

# **Primary-care delays**

- In a cross-sectional study in the Western Cape, Moodley et al (2018) found the median time between a woman noticing breast change and receiving treatment was 110 days, with median patient, diagnostic and pre-treatment intervals of 23, 28 and 37 days respectively<sup>12</sup>
- Joffe et al (2018) found, inter alia, that patients experiencing > 2 referral health-system visits had more than twice the odds for advanced-stage presentation compared with those having 0 visits (self-referrals) and 1 visit (within the primary health system):<sup>5</sup>

"...multiple visits due to healthcare system failure to diagnose or inefficiency in scheduling appointments and retrieving laboratory results were major contributors to diagnostic delays and markedly impacted patient outcomes..."

"Sustained community and healthcare worker education may down-stage disease and improve cancer outcomes" (Joffee et al, 2018)



## SA's clinical guidelines for BC control and management

- SA's DOH BC control and management guidelines were published in 2017, but have yet to be implemented in the public sector<sup>1</sup>
- In particular, the guideline proposed specialist breast units staffed by an MDT 1
- The distribution and capability of facilities providing BC care are currently unknown (Milligan 2022, discussed later, is an attempt to rectify this)



- O'Neil et al applied ASCO's quality measures in 5 South African state hospitals to a sample of 1 736 women (ASCO is reasonably similar to South African guidelines)<sup>13</sup>
- They analysed the factors associated with care concordance and found:
  - Baseline care was reasonably concordant with the ASCO BC care quality measures for chemotherapy and endocrine therapy but poor for radiotherapy:
  - Radiotherapy equipment is in short supply in the SA state sector which is a barrier to use in breast conservation surgery
  - Patients living < 20 km from their hospital and primarily speaking English were significantly more likely to receive measure-concordant care

"More timely delivery of chemotherapy, radiotherapy, and endocrine therapy is needed in South Africa, particularly for women living > 20 km from the hospital or not speaking English" (O'Neil et al, 2019)



Abbreviations:

ASCO. American Society of Clinical Oncology: BC, breast cancer:

DOH. Department of Health: MDT. multi-

### Milligan's findings (2022)

- Mastectomy was available at all facilities
- Clinicians cited the foremost barriers to SOC were advanced disease at presentation, inadequate access to surgical expertise and lack of access to essential equipment
- The national average waiting time for surgery (28 days) is within the recommended timeframe from decision to treat, with two provinces outliers with waiting times of more than 60 days (Free State and We Cape)
- Milligan concluded that broad disparities exist in access to essential staging and diagnostic modalities between facilities in different prov
- There is limited capacity to provide key surgical interventions, partic SLNB and breast reconstruction.
- BC care in most settings within the public healthcare sector is not concordant with proposed national guidelines, with the exception of several established breast units in large urban centres.



"There is an urgent need to address the deficits in the distribution and capacity of BC surgical services in South Africa and to close the gap between policy and implementation" (Milligan, 2022)

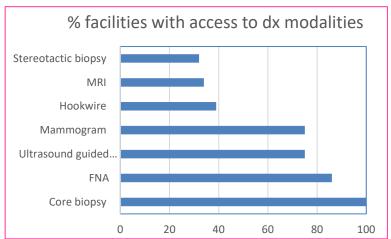
#### Abbreviations:

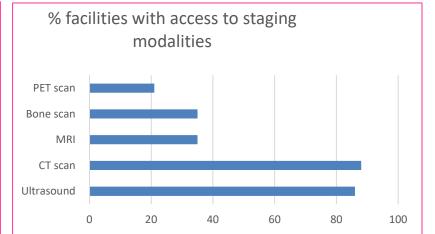
BC, breast cancer SLNB, sentinel lymph node biopsy; SOC, standard of care

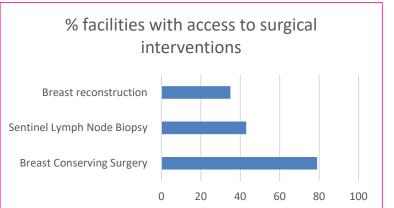
# Milligan's descriptive analysis (2022)

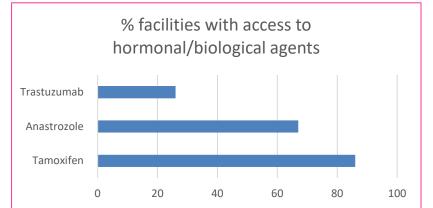
72 healthcare facilities surveyed 46 identified to provide BC services

Data from 43 facilities represented in the analysis



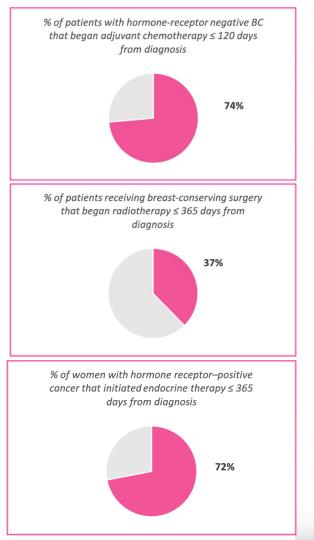


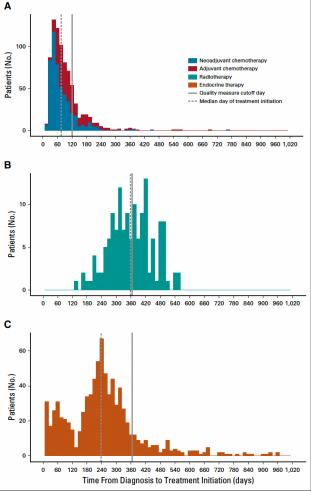




Abbreviations: BC, breast cancer CT, computed tomography; FNA, fine needle

aspirate; MRI, magnetic resonance imaging; PET, positron emission tomograph





# FIG 2. Days from diagnosis to first receipt of (A) neoadjuvant or adjuvant chemotherapy in the European Society for Medical Oncology—chemotherapy cohort, (B) radiotherapy in the ASCO-radiotherapy cohort, and (C) endocrine therapy in the ASCO—endocrine therapy cohort.

# O'Neil et al's findings (2019)



### **Abbreviations:** ASCO, American

Society of Clinical Oncology

### GROOTE SCHUUR HOSPITAL BREAST CLINIC STATS 2022

	CBC referral	New	Follow up	Core biopsies	Oncology Referral	MPH referral to oncology	New cancers diagnosed	Bedside Ultrasound in clinic	Ultrasound guided biopsy
January	59	240	75	63	52	4	56	17	6
February	33	236	108	102	50	11	61	33	12
March	70	239	129	82	40	4	44	64	11
April	31	232	122	91	47	7	54	36	12
May	54	173	167	76	50	1	51	25	10
June	26	193	94	44	13	2	15	27	6
July	28	201	121	74	50	3	53	14	6
August	39	237	146	42	43	8	51	23	7
September	42	247	140	155	53	7	60	48	12
October	58	265	172	99	53	7	60	48	18
November	61	311	137	161	58	6	64	88	17
December	32	151	76	65	27	2	29	27	10
Total	533	2725	1487	1054	536	62	598	450	127
				50% of core biopsies done are positive	20% of new patient referrals	15% of new patient referrals			

# Breast Telephone clinic

	Number of patients booked	Number of patients successfully contacted	Number of patients called again	Number of patients discharge	Number of patients recalled to breast clinic	BIRADS 4/5
January	238	220	11	72	29	15
February	215	208	17	54	23	11
March	296	262	15	83	32	15
April	374	326	10	110	52	35
May	285	205	28	93	34	28
June	302	241	20	84	36	16
July	242	213	8	85	30	15
August	252	224	9	86	32	18
September	289	252	14	87	42	24
October	276	247	14	82	30	25
November	273	210	46	81	32	14
December	253	212	18	117	31	15
Total	3295	2820	210	1034	403	231
Total	3233					
		85%	6%	31%	12%	7%
		91	%			



# The health care system

Only 3 breast centers nationally (9 provinces)

### AT GSH:

- 2 Diagnostic clinics per week
- 1 MDT clinic per week
- 1 Theater list per week
- 1 Mammography machine
- 2 Ultrasound machines
- Limitation on available drugs, tests etc



# Clinicians

The team at the GSH breast unit:

- 1 Full time breast surgery consultant
- 1 Part time breast surgery consultant
- ? 2 General surgery registrars
- ? 1 Fellow
- 1 Full time breast oncologist
- 3 Oncology registrars
- 1 Breast nurse
- 6 Rotating nurses
- 1 Breast radiologist
- 1 Breast pathologist
- 1 Genetic councellor
- No dedicated breast plastic surgeon
- 1 Admin support staff



### THE PROBLEM?

- Access to care
- Availability of resources

### PART OF THE SOLUTION?

Project Flamingo

# Nothing more and nothing less than a story of "embracing the shake"

Creating a functional system of support within our existing and challenged framework



### "Catch-up" Surgeries

Each surgery costs approximately R6000 in nursing and consumable fees with surgeons and anesthetists donating their time and skill gratis.





# Pamper packs

- On average 200 handed out per month
- A token of care for both patient and staff





# Other initiatives in the unit supported

- Radiology private sector collaboration, bed-side U/S in clinic
- Telephone clinic
- Online booking system
- Cancer advocacy
- Staff support
- Food drive
- Mentorship to other initiatives
- Student education
- NEXT...data and research





# Ongoing advocacy The "practical" solutions:

- Centralized vs decentralized care
- Private/public partnerships
- Proper mobilization and utilization of the nonprofit sector
- Adequate internal resource distribution
- Active clinician-based decision making
- Civil action
- Political action



# What if "systemic failure" is not the problem?

#### What if our INDIVIDUAL

- Loss of passion/purpose
- Extreme burnout OR "moral injury"
- Inability to consider a different reality
- Failure to consider our contribution to the collective

Is in fact, part of the problem?





# CANI IMAGINE A DIFFERENT REALITY?



- If it doesn't bother you, don't bother
- Imagine that I am you and you are me
- Have a dance with death
- Leave your ego at the door
- BE THE CHANGE.

Sometimes it is the small things we do that make a big difference.

Sometimes the solution is terribly simple.

We should never do nothing because a problem seems overwhelmingly big and our ability to contribute seems overwhelmingly small.





"Healing represents an expansion of consciousness and a movement in the direction of wholeness/ health. We can be healed by our illness but not cured of it OR we can be cured of our illness but not healed by it. Healing may or may not result in cure." (Christodoulou, 2005)

### **Our details**

### **NPC** details:

amaBele Project Flamingo Non Profit Company Reg. No: 2007/002115/08

### Bank details:

Project Flamingo

Nedbank Current Account no: 1088 254 950

Branch code: 101297

**PBO** number: 930 042 344

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