

A Guide for Low-Resource Settings



In collaboration with
the Breast Course for Nurses and RAD-AID International

Preface

According to the World Health Organization, breast cancer continues to be a leading cause of cancer death for women worldwide and the world's most prevalent cancer (<https://www.who.int/news-room/fact-sheets/detail/breast-cancer>). Early detection and treatment have been proven effective in improving health outcomes and saving lives in high-resource countries and need to be applied in low-resource settings. Establishing reliable care pathways is essential for the management of patients with breast cancer.

This resource serves as a guide for healthcare workers in providing breast care navigation so that individuals are referred for further diagnostic services and treatment when appropriate. Although much of the information is relevant to any patient navigator, the content is specifically targeted toward healthcare workers in low-resource settings.

The development of this patient navigation resource grew from the collaboration between the Breast Course for Nurses (BCN), a South African non-profit organization that trains healthcare workers in breast health, and RAD-AID International, a non-profit organization that provides radiology services and education in low-resource countries to improve global health.

We trust that the following 3-part module will provide the reader with applicable and practical content and resources to assist patient navigators in helping patients along their breast cancer journey in the healthcare setting. The information may be adapted to suit the needs of specific healthcare systems in any local area.

Breast Course for Nurses
www.breastcourse4nurses.co.za



RAD-AID International
www.rad-aid.org



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Acknowledgment / Contributors

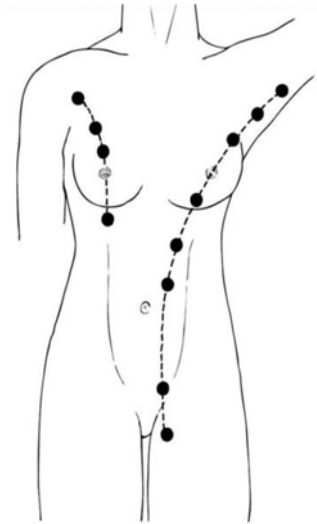
PART 1

Principles of Breast Cancer Management: Following the Continuum of Care

BREAST ANATOMY

What is a breast?

- ✦ Specially modified glands in the skin and are present in all infants at birth
- ✦ Usually one breast is present on either side (left and right) of the chest
- ✦ Sometimes one or more accessory (extra) breasts may be present along the “breast line” from the arm-pit down to the groin, this is normal



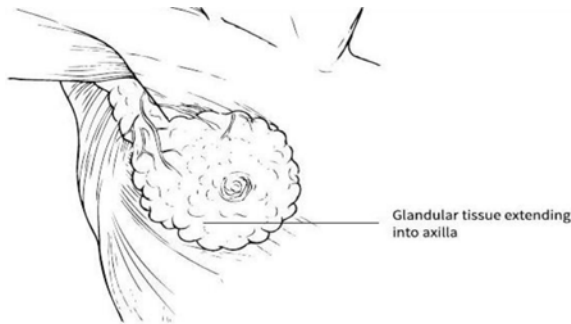
The normal breast at birth:

- ✦ Development is the same in new-born boys and girls
- ✦ All infants are born with nipples and small amounts of breast tissue
- ✦ The nipple and areola are well developed
- ✦ Breast bud under nipples
- ✦ Breasts may be slightly enlarged in a new-born
- ✦ They may enlarge further for a few weeks and even produce small amounts of milk

- ✦ This disappears after a few months as sex hormones no longer produced
- ✦ Special tissue under the nipple will later grow to form breasts in females

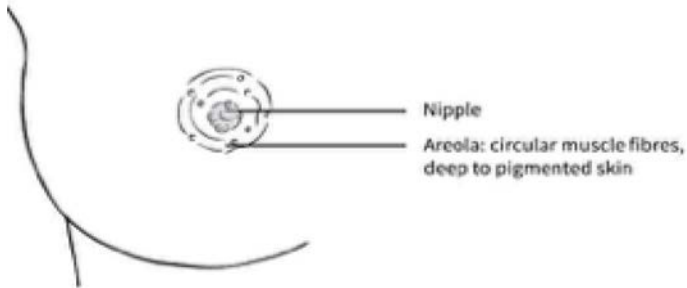
What is the structure of the normal mature breast?

- ✦ Consists of:
 - ✓ *The nipple and areola*
 - ✓ *About 10 or more lobes*
 - ✓ *Supportive and fatty tissue*
- ✦ Shaped like a pear and the tail of breast tissue extends under the arm
- ✦ Some women have breast tissue that can be felt in the armpit and this may be more noticeable during pregnancy



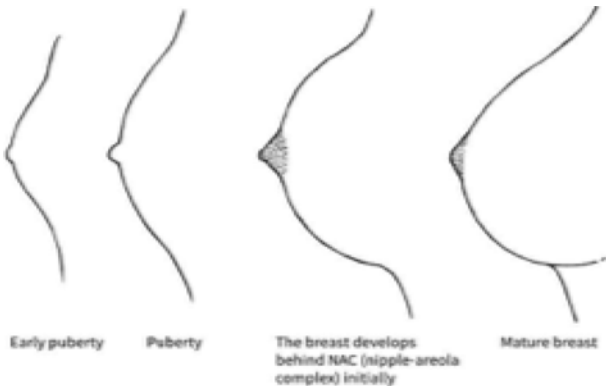
What is the structure of a normal nipple and areola?

- ✦ The nipple-areola complex (NAC) is made up of the nipple, which usually sticks out, and the surrounding areola
- ✦ The areola is darker coloured or pigmented
- ✦ Under the skin of the areola is a circle of muscle which contracts when the nipple or areola is touched
- ✦ The areola has sweat glands which can be seen as slightly raised pale dots.
- ✦ The NAC is fragile and in order to avoid trauma and infection, should not be routinely squeezed.



Changes with Age: Development :

- ✦ Breast bud development can start as early as age 8 or later at age 15
- ✦ It is normal for growth to take place between these variable ages
- ✦ Breast growth starts in the tissue under the nipple and areola, this can feel firm like a mass
- ✦ This will continue to develop up to 25 years
- ✦ Sometimes one breast will grow larger before the other one grows
- ✦ This is called asymmetry and is generally normal



Changes with Age: Menstrual Cycle:

- ✦ It is normal for the breasts to change throughout the month when a woman has her period or monthly bleeding
- ✦ The breasts can become fuller and feel swollen and tender before her period starts
- ✦ Common to have premenstrual tenderness
- ✦ If a patient is known to have lumpy breasts (due to confirmed fibrocystic tissue, fibroadenomata or cysts etc.), these lumps may also feel larger
- ✦ It is easier and more comfortable for the woman to have her breasts examined after the period is finished and before Day 14 of the cycle

Changes in pregnancy:

- ✦ Breasts may change or double in size
- ✦ Any non-cancerous growth or normal lumps e.g. fibroadenoma, can also double in size
- ✦ The nipple and areola become darker in colour / increased pigmentation
- ✦ Cancer may occur in pregnancy, but this is rare

Changes during lactation:

- ✦ Just before a baby is born, the breasts make colostrum (sometimes called the “first milk”)
- ✦ The first milk is thicker and a little stickier than the milk that will come a few days later
- ✦ Colostrum is very healthy for newborn babies
- ✦ Milk production increases for a few days after birth
- ✦ When a baby stops breastfeeding, it may take a few days for the milk production to stop

Changes with Age: Menopause:

- ✦ As a woman ages and her period stops, this is called Menopause

Involutorial phase:

- ✦ Between 35 and 55 years (extended if the patient is on hormone replacement therapy)
- ✦ The lobules, part of the breast tissue that makes milk, start to shrink
- ✦ This shrinkage is known as atrophy
- ✦ As the lobules atrophy, the tissue is replaced by fibrocystic changes (tiny round pockets that hold water-like fluid)

Post-menopausal breasts:

- ✦ Continue increasing in size
- ✦ The lobules are replaced with fatty tissue
- ✦ As the woman gains more fat, the breasts can become larger
- ✦ The fatty tissue feels softer than the lobule tissue
- ✦ Shape starts changing and it is normal for the breasts to droop more

The definition of a normal breast depends on the age and stage of the development of the breast

BENIGN BREAST CONDITIONS

What does benign mean?

= *The condition (e.g. a breast lump) is not malignant, i.e. not cancerous*

- ✦ A benign lump may increase in size but does not spread into the surrounding tissue to elsewhere in the body
- ✦ Many normal changes occur in a woman's breast as she becomes older
- ✦ Most are included in the concept of ANDI = Aberrations of Normal Development and Involution
- ✦ ANDI includes all benign changes that take place in the breast with age

The breast changes with age and hormonal status

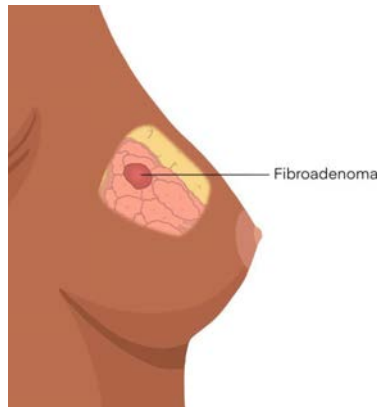
Age

- ✦ Development: 15-25 years
- ✦ Cyclical activity: 25-45 years
- ✦ Involution: 35-55 years

Hormonal status

- ✦ Pregnancy
- ✦ Breast feeding

1. Fibroadenoma:



General

- ✦ Common between 15-35 years
- ✦ Proliferative lump
- ✦ One fibroadenoma or many fibroadenomas (fibroadenomata)
- ✦ Not associated with malignancy if first appears in the appropriate age group however, family history of breast cancer must be taken into consideration
- ✦ May have cyclical changes in size on a monthly basis and will increase markedly during pregnancy (goes back to original or even smaller size after pregnancy)

Diagnosis

(All women with a new mass in the breast should be re-examined within 2 months)

- ✦ Triple test:
 - ✓ *Clinical diagnosis finding(s): round and moveable, rubbery*
 - ✓ *Cytology finding(s): distinctive pattern (but it is generally best to confirm diagnosis using core biopsy)*
 - ✓ *Ultrasound finding(s): smooth mass*
 - ✓ *Mammogram finding(s) if over the age of 40: round and white*

Management

- ✦ The most important thing is to make sure the woman has a fibroadenoma and NOT a breast cancer
- ✦ Any woman with a new lump in the breast <25 years must have a clinical follow up at 4 months. If any increase in size of the lump is noted, further investigation is required
- ✦ Any woman with a new lump in the breast >25 years must have cytology + ultrasound
- ✦ Any woman with a new lump in the breast > 35 years must have histological diagnosis and referral to a breast clinic
- ✦ Any woman with a new lump in the breast >5cm or painful or pregnancy is planned = remove surgically

2. Cyst/ Fibrocystic Changes:

General

- ✦ Lumps in the breast filled with fluid
- ✦ Fluid may be yellow, green or very dark
- ✦ Micro (<1cm) or macro cysts (>1cm and generally palpable)
- ✦ Associated with shrinkage of the lobes of breast (involution)
- ✦ Common in 40's
- ✦ May cause anxiety due to lump (patient could potentially think it is a cancer)
- ✦ May be tender
- ✦ If untreated: usually disappear after menopause
- ✦ If on hormone replacement therapy (HRT): may continue to get cysts
- ✦ Must not be assumed on examination alone that breast cyst is benign as patient may have a cystic cancer



Ultrasound image of a cyst

Diagnosis

- ✦ a:

- ✓ *Clinical diagnosis: generally smooth firm mass*
- ✓ *Mammogram: well defined lesion*
- ✓ *Ultrasound: fluid filled*

Management

- ✦ Aspirate if:
 - ✓ *Palpable*
 - ✓ *Suspicious looking on ultrasound or mammogram*
 - ✓ *Hard and tender (may provide relief if drained)*
- ✦ Provide reassurance

Cyst Aspiration

- ✦ a 23G needle can be used with a 10ml syringe
- ✦ if the fluid is blood stained: send for cytology
- ✦ if the fluid is not blood stained it generally does not need to be sent off unless there are other indications of possible malignancy

3. Mastalgia (Painful Breasts)

General

- ✦ Painful / tender breasts
- ✦ Over 70% women get mastalgia in their lifetime
- ✦ Common in adolescence and women in 40's
- ✦ Most commonly occurs in the upper outer quadrant (UOQ) of the breast
- ✦ Cyclical vs non-cyclical

Diagnosis

- ✦ Determine if cyclical or non-cyclical
 - ✓ *Cyclical*
- ✦ 20 - 40 years
- ✦ Monthly changes with menses



Aspiration of a cyst

- ✦ Hormonal changes
 - ✓ *Non-Cyclical*
- ✦ > 40 years
- ✦ Consistent
- ✦ Musculoskeletal pain

Management

- ✦ Determine if cyclical or non-cyclical
- ✦ Take a history and perform clinical breast exam (CBE)
- ✦ >40: consider mammogram and ultrasound
- ✦ New well-fitting bra

- ✦ Topical nonsteroidal anti-inflammatory drugs (NSAIDS)
- ✦ Reassurance / time spent with patient

4. Duct Ectasia and Periductal Mastitis

General

- ✦ The terminal ducts become wider as they approach the nipple
- ✦ Inflammatory changes can develop around the terminal ducts causing scarring and inversion of the nipple



Ultrasound image showing duct ectasia

Periductal mastitis

General

- ✦ Inflammatory condition of the nipple and retroareolar area often due to ductal ectasia
- ✦ Commonly causes small abscesses, scarring, purulent drainage from nipple
- ✦ May result in an inverted nipple

Diagnosis

- ✦ Often difficult to diagnose
- ✦ Cancer may present with similar symptoms

- ✦ Duct ectasia may result in periductal mastitis

Management

- ✦ >40 years:
 - ✓ *Mammogram and ultrasound*
 - ✓ *Send fluid for cytology*
 - ✓ *Manage complications*
 - ✓ *Complications include:*

- ✦ Discharge
- ✦ Lump under areola
- ✦ Nipple inversion
- ✦ Abscess formation

Women with these symptoms should be sent to a breast clinic for special investigations

5. Nipple inversion

General

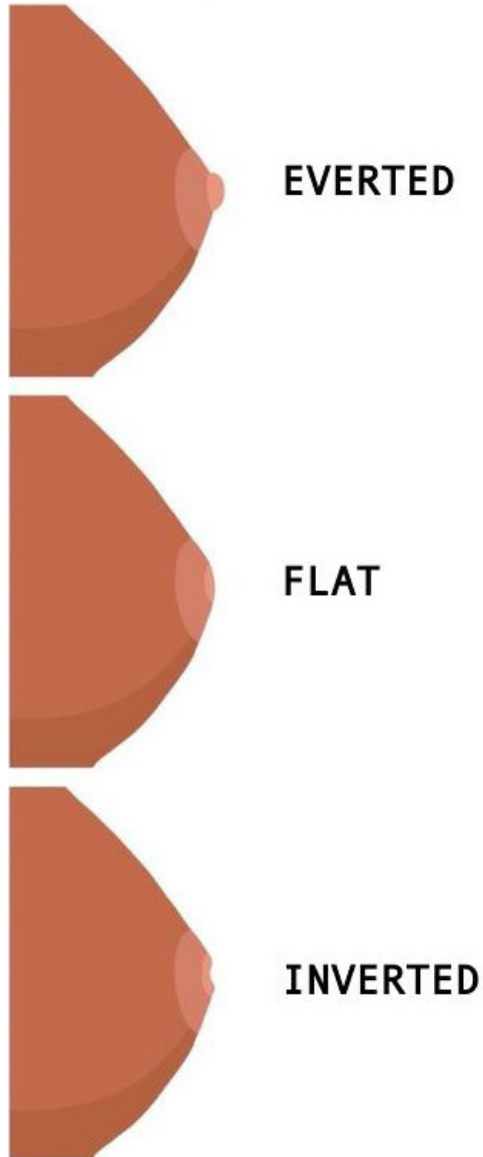
- ✦ Very common
- ✦ If new: cause for concern
- ✦ If longstanding: often a developmental abnormality
- ✦ Always ask the patient how long the nipple has been inverted

Diagnosis

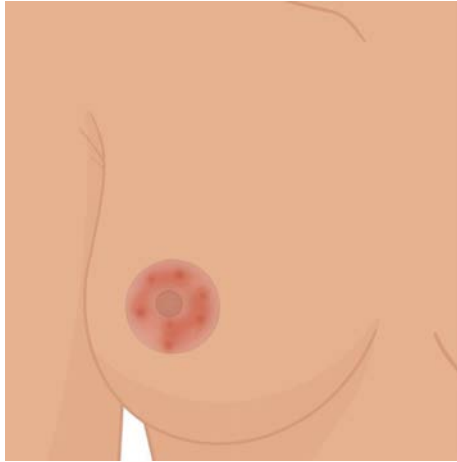
- ✦ Ask the patient if the nipple inversion is new or longstanding
- ✦ All new cases of nipple inversion should be referred for special investigations

Management

- ✦ >Reassurance
- ✦ Surgery can be done but results are not predictable
- ✦ May evert during breastfeeding



6. Eczema



General

- ✦ Breasts are covered with skin
- ✦ Any skin condition may therefore develop on the breast(s) e.g. skin cancer, eczema etc.
- ✦ Very itchy

Diagnosis

- ✦ Common if patient has eczema elsewhere
- ✦ Must distinguish from Paget's Disease

Management

- ✦ Steroid cream
- ✦ These patients must be followed up to make sure that the eczema improves
- ✦ If not improving with the use of steroid cream - a skin biopsy must be done

Paget's Disease usually begins in the nipple and is unilateral. Eczema is usually seen on both breasts.

7. Nipple Changes

General

- ✦ Relatively common
- ✦ May be problematic during breastfeeding

*Cracked nipples

- ✦ Very common in breastfeeding mothers
- ✦ May cause pain with breastfeeding and can result in mastitis or an abscess
- ✦ A little breast milk should be left on the nipple at the end of each feed
- ✦ The nipple must be kept dry between feeds
- ✦ If it becomes a problem, antibiotic cream can be applied

*Nipple polyps

- ✦ An abnormal but non-cancerous growth from the wall of a duct
- ✦ Relatively common
- ✦ Remove with local anaesthetic if problematic (may bleed during breastfeeding)
- ✦ Leave alone if no problems

*Keratin pearls

- ✦ A small yellow bead which appears on the nipple
- ✦ Very common and requires no treatment

8. Nipple Discharge

- ✦ Four types of fluid are commonly discharged from the nipple
- a. Milky fluid
 - ✦ This is normal around the time of breastfeeding
 - ✦ It may continue for a long time after breastfeeding has finished and is commonly from both breasts
 - ✦ If it is completely unrelated to pregnancy, a serum prolactin level should be done

- b. Greenish or brownish fluid
 - ✦ This is generally thin and is from more than one duct
 - ✦ It is abnormal if it leaks out of the nipple spontaneously and the woman has to wear a breast pad
- c. Bloody fluid
 - ✦ There is always a pathological cause for bloody discharge from the breast
 - ✦ Often, the cause is not cancerous but all women with a bloody discharge need a mammogram and, if possible, an ultrasound scan
 - ✦ The fluid should be sent off for cytology
 - ✦ A bloody nipple discharge is always abnormal
- d. Watery colourless fluid
 - ✦ This should be treated the same as bloody fluid

9. Infections of the Breast

- ✦ Infections of the breast may be
 - ✓ *Associated with lactation*
 - ✓ *Not associated with lactation but due to breast changes*
 - ✓ *Associated with systemic disease*
 - ✓ *Benign conditions mimicking infections*

*Lactation infections

- ✦ Staphylococcus aureus is generally the cause of breastfeeding abscesses
- ✦ Often seen in abscesses caused by ductal ectasia but many other bacteria can be involved
- ✦ Candida may also be seen in breastfeeding mothers
- ✦ General infection is known as mastitis - treat with broad-spectrum antibiotics and analgesia
- ✦ If an abscess has formed – treat with incision and drainage and then antibiotics
- ✦ Mothers should continue to breastfeed until the infection has completely resolved

***Non-breast feeding infections**

- ✦ Immune system causes
 - ✓ *Tuberculosis (TB)*
- ✦ Relatively common in TB endemic areas
- ✦ Occurs in HIV-positive or negative patients
- ✦ Diagnosis must be made
- ✦ Should be treated for TB systemically
 - ✓ *Smokers:*
- ✦ Seen near the areola area
- ✦ May cause a fistula
- ✦ Women are generally in their 30's
 - ✓ *Cancer:*
- ✦ Occasionally a cancer may cause a blockage which then leads to an infection
- ✦ Inflammatory breast cancer may mimic
 - ✓ *Diabetes is associated with an increased risk of infection*
 - ✓ *HIV is associated with an increased risk of infection*
 - ✓ *Cellulitis*
 - ✓ *Abscess*

Causes

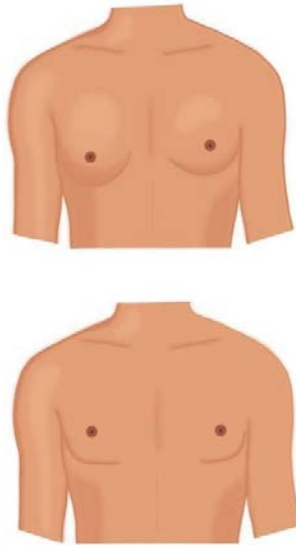
- ✦ An associated condition or abnormality in the breast
- ✦ An abnormality in the immune system
- ✦ A particular pathogen (Streptococcus or Staphylococcus) and occasionally TB

Management

- ✦ Always look for the cause of the infection
- ✦ Diagnosis (histology) + antibiotics
- ✦ Surgery: incision and drainage

Anyone with an unexplained infection/redness of the breast >1 week should be referred to breast clinic

10. Gynaecomastia



General

- ✦ Common in younger men (15-30 years) and older men (60-75 years)
- ✦ Involves the tissue behind the NAC
- ✦ There is usually no specific cause
- ✦ It may be caused by certain drugs

Management

- ✦ Men <35 years
 - ✓ *Clinical follow up*
 - ✓ *Investigation is not needed if the diagnosis is typical of gynaecomastia*
- ✦ Older men:
 - ✓ *Ensure it is not a malignancy*
 - ✓ *Surgery is an option*

Gynaecomastia does not increase the risk of malignancy

DIAGNOSIS AND MANAGEMENT OF COMMON BREAST SYMPTOMS: APPROACH TO DIAGNOSIS AND MANAGEMENT OF COMMON BREAST SYMPTOMS:

< 20 years old:

- ✦ Mastalgia and normal clinical examination = reassure and discharge
- ✦ Palpable lump (consistent with typical fibroadenoma
- ✦ a - < 3cm, mobile, well-circumscribed) = reassure and discharge
- ✦ Large fibroadenoma (> 5cm) = surgical excision
- ✦ Palpable lump that is not typical of a fibroadenoma = breast ultrasound

20 – 25 years old:

- ✦ Mastalgia with a normal clinical examination = reassure and discharge
- ✦ Patient feels a lump with a normal clinical examination = reassure and discharge
- ✦ Benign thickening / bilateral nodularity = reassure and discharge
- ✦ Palpable lump (consistent with a typical fibroadenoma) = ultrasound
- ✦ Suspicious asymmetrical thickening = ultrasound then core biopsy
- ✦ Suspicious palpable lump = core biopsy and ultrasound

25-39 years old:

- ✦ Mastalgia with a normal clinical examination = reassure and discharge
- ✦ Patient feels a lump with a normal clinical examination = reassure and discharge / ultrasound only if patient is not reassured by the normal clinical assessment or strong family history
- ✦ Benign thickening / bilateral nodularity = reassure and discharge
- ✦ Suspicious asymmetrical thickening = ultrasound then core biopsy
- ✦ Palpable lump = core biopsy and ultrasound

>40 years old:

- ✦ Mastalgia with normal clinical examination = routine mammogram and discharge if normal
- ✦ Patient feels a lump with a normal clinical examination = routine mammogram and discharge if normal
- ✦ Benign thickening / bilateral nodularity = routine mammogram and discharge is normal
- ✦ Routine check-up = offer once off mammogram and discharge if normal
- ✦ Check up for family history = lifetime risk of breast cancer >17% biannual mammogram, >30% annual mammogram
- ✦ Asymmetrical thickening / small / vague lump = URGENT mammogram then ultrasound guided biopsy
- ✦ Palpable, obvious lump = fine needle aspiration (FNA), core biopsy and URGENT mammogram

CANCER

Definition of cancer

= a disease caused by cells that can multiply uncontrollably and then break off and spread both locally and beyond the breast to other areas of the body (metastasize).

- ✦ there are many types of cancer
- ✦ cancer can originate from many organs in the body

Types of cancer

- ✦ breast cancer describes many different diseases and that is what makes the understanding and the treatment both difficult and interesting
- ✦ some cancers are slow growing and tend to cause problems locally with ulceration in the breast and don't really spread beyond the breast
- ✦ other cancers are fast growing and although they are still small, cells break off and travel to either the lymph nodes or to a distant organ.
 - ✓ *The stage before breast cancer = carcinoma in situ*
- ✦ The commonest form is ductal carcinoma in situ or DCIS
- ✦ This means that the malignant cells are still in the ducts and have not yet moved into the surrounding breast tissue
- ✦ It is therefore not an invasive cancer yet
- ✦ Ductal carcinoma in situ will progress to invasive cancer over time as the malignant cells break through the wall of the duct and then spread into the surrounding fatty tissue
- ✦ therefore the invasive cancer will form in the area of the DCIS
- ✦ Lobular carcinoma in situ (LCIS) is very complicated and far less common.
- ✦ if LCIS is found anywhere in either breast, it means the woman is more likely to develop a breast cancer at some stage in her life although it may not actually be in the same place where the LCIS has formed

2 common types of breast cancer:

- ✦ Ductal carcinoma (originates in the ducts)

- ✦ Lobular carcinoma (originates in the lobules)

Less common types of breast cancer:

- ✦ Inflammatory
- ✦ Tubular
- ✦ Papillary
- ✦ Colloid
- ✦ Mucinous
- ✦ Paget's disease
- ✦ Malignant phyllodes tumour
- ✦ Medullary carcinoma

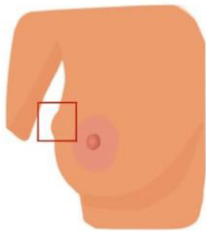
Signs and symptoms of breast cancer

- ✦ A lump that is not clearly defined.
- ✦ Thickening of the breast
- ✦ Skin dimpling
- ✦ Redness of the skin
- ✦ Peau d'orange skin changes (due to skin oedema)
- ✦ Nipple changes: either bloody discharge, inversion of the nipple or Paget's disease

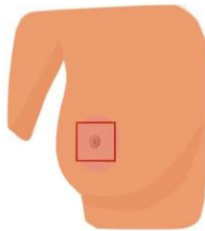
What to look for when examining the breast:

- ✦ Asymmetry
- ✦ Skin changes
- ✦ Peau d'orange
- ✦ Redness
- ✦ Change in the nipple
- ✦ Inversion
- ✦ Change in the skin over the nipple
- ✦ Obvious nipple discharge

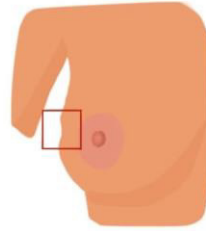
Symptoms to look for:



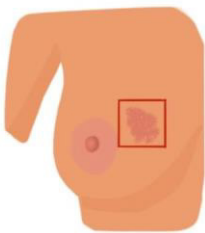
Lump



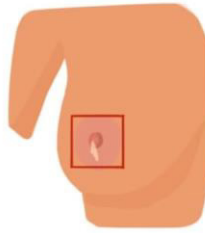
Pulled in nipple



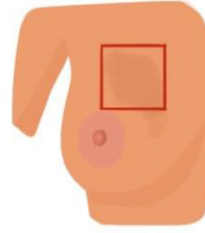
Dimpling



Redness/rash



Dripping

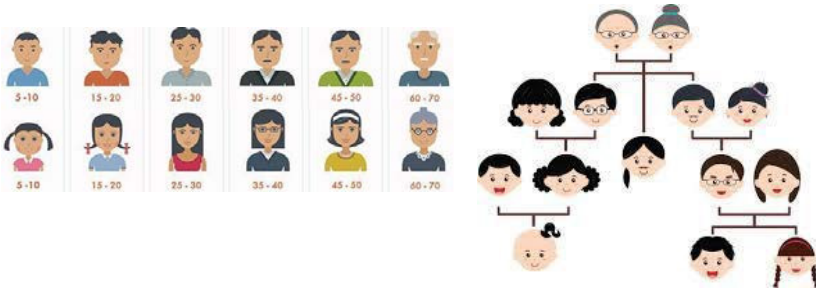


Skin changes

Risk factors

- ✦ In 90% of cases, the cause for a woman developing breast cancer is unknown.
- ✦ There are, however, a number of known risk factors:
 - ✓ *gender: women are more likely to develop breast cancer than men*
 - ✓ *age: the older a woman is, the more likely she is to get breast cancer*
 - ✓ *family history: 5% of women have a gene abnormality (Breast Cancer-*BRCA* type 1 or 2 mutation). They have a 50 - 85% risk of developing a breast cancer*
 - ✓ *previous radiotherapy to the chest wall: patients who have had radiation for a lymphoma have an increased chance of breast cancer*
 - ✓ *personal history of breast cancer - if a woman has had one breast cancer, she is at a higher risk than normal of developing another breast cancer*

- ✓ *living in a first world country*
- ✓ *having a personal history of having had atypical ductal hyperplasia or a new fibroadenoma over the age of 40*



Breast Self-Examination (BSE)

- ✦ breast self-examination should be done on a monthly basis
- ✦ teach the patient to look for change in their breasts and axillae
- ✦ pre-menopausal women: it is easier to examine breasts after the period is finished and before day 14 of the cycle (before they start enlarging again)
- ✦ post-menopausal women (or if your cycle is irregular): self-examination can be done any time of the month but it should be consistent.
- ✦ If you have breast implants, you should still perform breast self-examination

Clinical Breast Examination

How should the patient be prepared for a breast examination?

- ✦ The patient should undress down to her waist and put on a gown with the opening in the front
- ✦ The examination must be done somewhere private and well lit
- ✦ Always explain what you are going to do

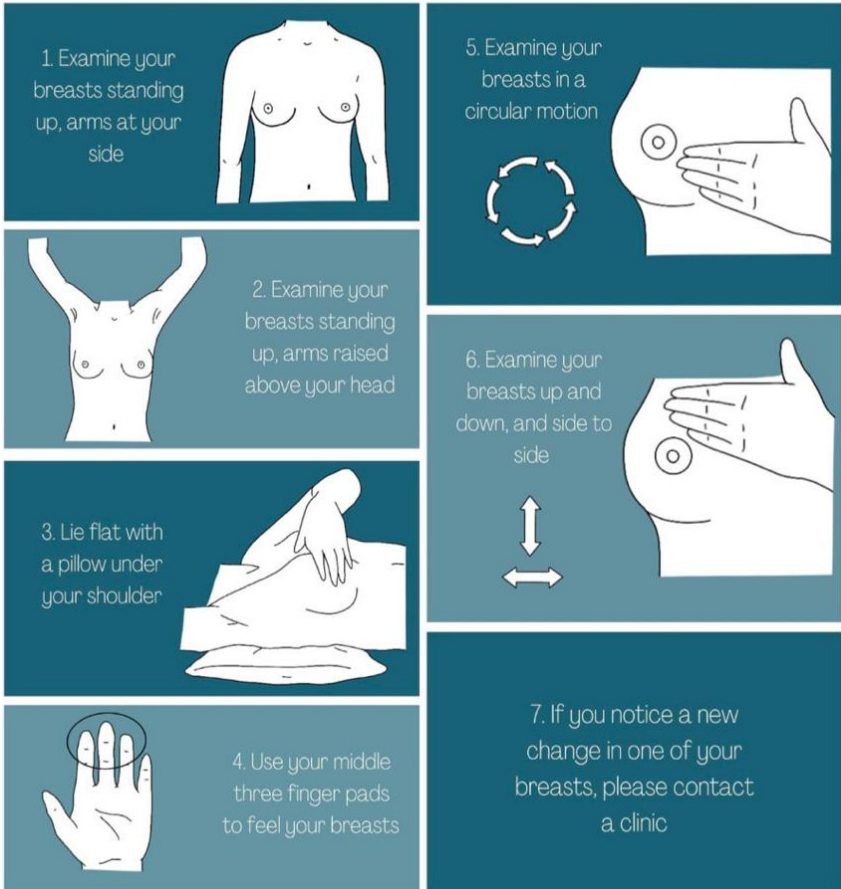
(Most women will be comfortable sitting undressed down to the waist.

However, some teenagers may be uncomfortable and women who have large

tumours may be very reluctant to show you their breasts particularly if the tumour is fungating or smells offensive)

- ✦ It is very important to be able to have a good look at both breasts

Breast self-examination



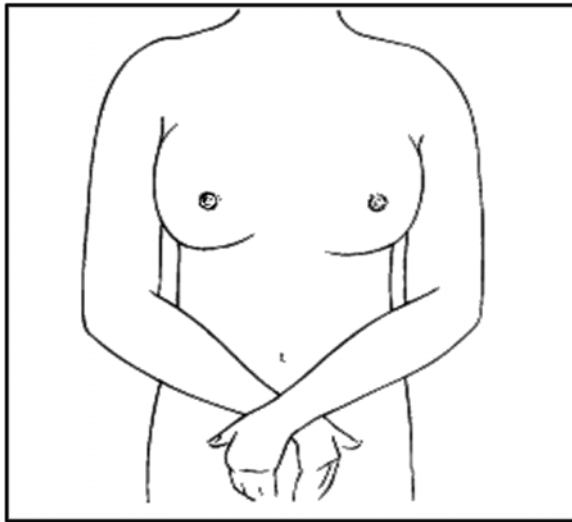
Example of Breast Self-Examination

Step-by-step examination of the breasts

- ✦ The examination consists of both looking (inspection) and feeling (palpating)
- ✦ Wherever possible, the examination should be done in a standardised step-by-step manner

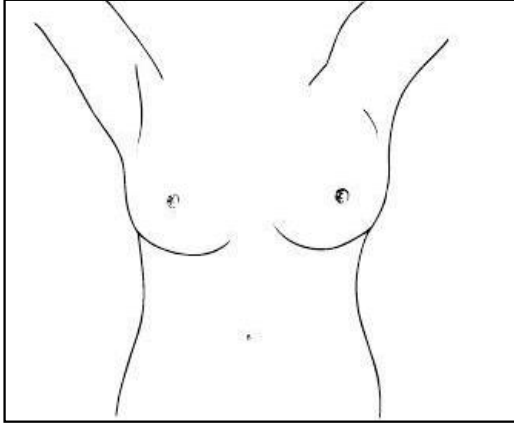
Step 1:

- ✦ Sit the patient down on the examining couch and look at her breasts with her arms relaxed
- ✦ Look for breast asymmetry, nipple inversion, skin changes and redness



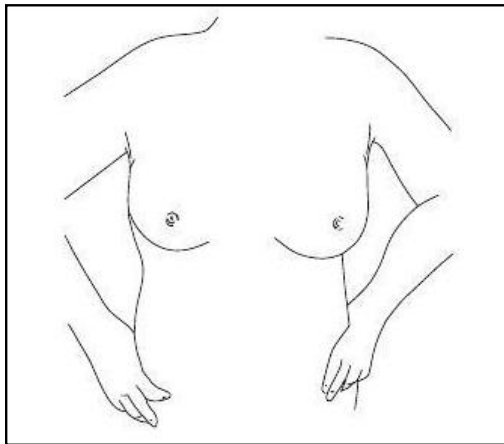
Step 2:

- ✦ Ask the patient to raise her arms above the head.
- ✦ Look for any skin puckering.
- ✦ Ask the patient to point out where the problem is.
- ✦ Look specifically in that area to see if there is any change in the skin while she is moving her arm.
- ✦ This will help identify if a lump is attached to the skin.



Step 3:

- ✦ Ask the patient to put her hands on her hips and squeeze.
- ✦ Look and see if the area over the lump changes.
- ✦ This will show whether a lump is attached to the underlying muscle.



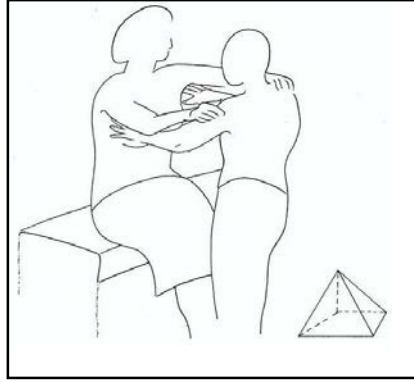
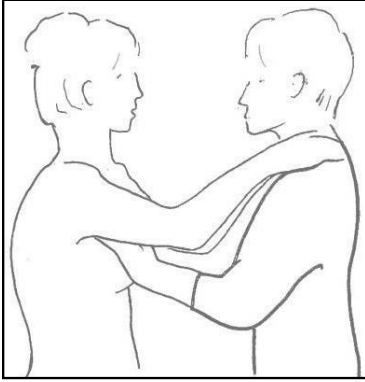
Step 4:

- ✦ Feel in the area above the clavicle (collar bone) for any lumps in the neck.



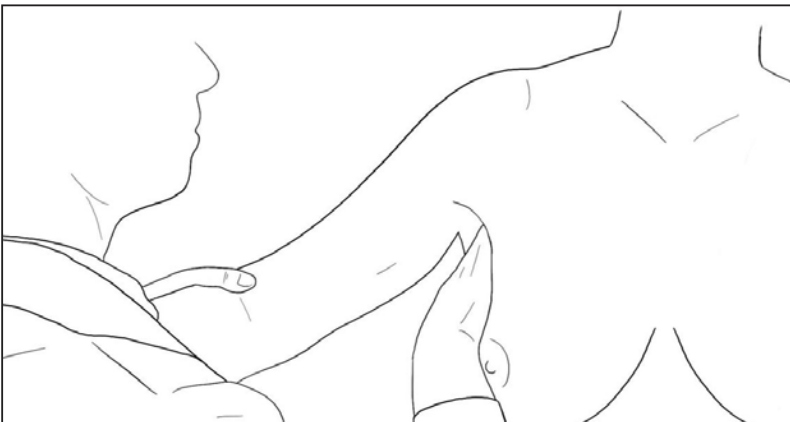
Step 5:

- ✦ To examine the armpits properly the patient must be relaxed.
- ✦ If the patient is very ticklish it helps to press more firmly.
- ✦ The best way to get the patient to relax her muscles is by asking her to extend her arms and rest them on your shoulders while you examine the armpits.
- ✦ Feel in the two armpits (axillae) at the same time for any lumps. This allows you to compare the two armpits.
- ✦ The armpits are shaped like pyramids. You should feel along the inside wall and towards the front (anterior) for lymph nodes. Remember to feel at the top of the armpit also.
- ✦ If you think you feel a lump, examine that armpit very carefully.
- ✦ If you think you can feel a lump in one armpit it is best to examine that side alone.
- ✦ Palpating the armpits is an essential part of breast examination.



The following is an alternative way to examine the patients axilla:

- ✦ with the patient sitting upright on the examination table, support the arm on the examined side and ask the patient to fully relax the arm.
- ✦ the skin of the axillary region will be completely relaxed in this way
- ✦ this makes it easier to note any enlarged lymph nodes
- ✦ the arm should be held at an angle of about 45 degrees
- ✦ palpate the axilla with your free hand
- ✦ use the tips of your 2nd, 3rd and fourth fingers



Step 6:

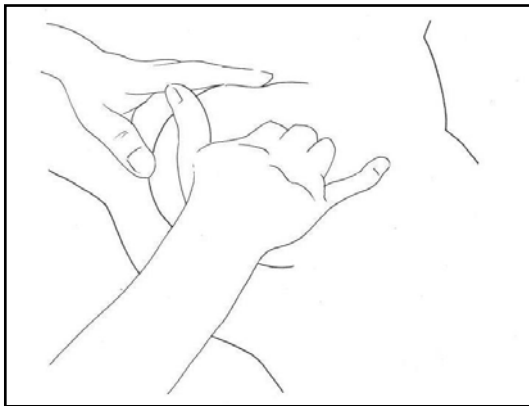
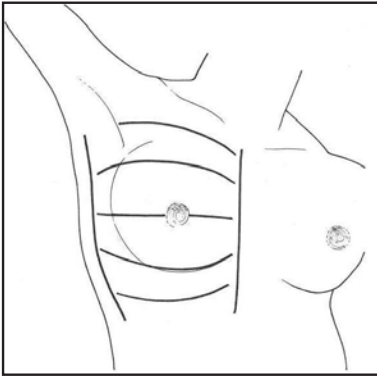
- ✦ Finally lie the patient down flat on her back and palpate (feel) her breasts with her arms above her head.
- ✦ This will flatten the breasts and make examination easier.
- ✦ It is easier to think of the breasts being divided into four strips and then palpate each breast from the centre of the chest outwards.
- ✦ The breast extends from the clavicle (collarbone) above to the 6th rib below.
- ✦ The whole area of the breast must be examined.
- ✦ Always use the pulps of your fingers (the most sensitive part of your hand) with the rest of your hand gently resting against the breast.
- ✦ Do not use cold hands.



Step 7:

- ✦ Never forget to examine behind the nipple-areola complex (NAC) for any abnormalities such as skin changes, lumps or an inverted nipple.

- ✦ It is best to leave the nipple examination to the end once you have won the woman's trust.



When is the best time to examine a woman's breasts?

- ✦ Examining the breasts can be very difficult particularly in young women.
- ✦ They can vary enormously depending on individual changes, the age of the patient and the stage of the menstrual cycle.
- ✦ The ideal time to examine a young woman is between day 6 and 14 of her menstrual cycle. (Day 1 being the first day of the period.)

BREAST CANCER SCREENING FOR ASYMPTOMATIC WOMEN (PRIMARY, SECONDARY, TERTIARY PREVENTION)

General:

- ✦ All people are at risk of developing cancer
- ✦ Cancer is however more common in women, in those with a family history of breast cancer and the older one gets. These are all risk factors.
- ✦ Cancer can never be fully prevented however there are measures that can be taken to reduce the risk of developing cancer.
- ✦ In order to understand the prevention of a condition, one needs to understand the following terms:

✓ *Primary Prevention*

= to prevent injury or disease before it occurs

- ✦ Example: Not exposing oneself to a causative agent, e.g. asbestos, and thereby preventing the condition, Asbestosis

✓ *Secondary Prevention*

= the detection of a disease in its early phase

- ✦ Example: Going for screening for various conditions, e.g. mammogram or cervical cytology screening

✓ *Tertiary Prevention*

= to prevent or reduce complications of a disease.

- ✦ Example: Controlling a person's Diabetes and therefore preventing complications of the condition

What is breast screening?

= Screening (surveillance) is looking for a disease before it is clinically obvious to either the patient or an examining doctor.

- ✦ It is looking for a hidden disease in people who appear to be well.
- ✦ Many diseases are screened for, such as cervical and breast cancer.
- ✦ Breast cancer screening includes clinical examination and a mammogram.

What is population screening?

= Population screening means screening all women over a certain age in the general population.

- ✦ The aim is to detect early breast cancers in women who have no breast complaints.
- ✦ Ideally a breast examination and mammogram should be done.
- ✦ Most developing countries, such as South Africa, do not have a population breast cancer-screening programme in the public sector.
- ✦ Most developed countries have population screening for breast cancer.
- ✦ Population screening for breast cancer is a low priority in the public sector in South Africa and is controversial in developed countries.

When should population screening for breast cancer be done?

- ✦ The frequency of mammogram screening and the age at which it starts depends on the country.
- ✦ Mammogram screening programmes start at 40 years of age in the United States of America (USA) and are done every year.
- ✦ In Europe, it often starts at 50 years of age and mammograms are done every 1 to 3 years.

What is individual screening?

- ✦ In countries without a public breast screening programme, such as South Africa, some individuals who can afford it may go for regular monitoring.
- ✦ This is known as individual screening or surveillance.
- ✦ The frequency and age when individual screening should start is the same as that for population screening.

(If a woman has a family history of breast cancer, she should be offered screening starting at the age of 40 or 10 years before the age of the youngest family member when she is presented with breast cancer, whichever comes first. She should be screened every year.)

SPECIAL INVESTIGATIONS OF THE BREAST (I.E. DIAGNOSTIC SCREENING)

- ✦ The triple test is a combination of 3 different ways of investigating the breast:
 - ✓ *Clinical assessment (history and examination)*
 - ✓ *Imaging*
 - ✓ *Cytology*
- ✦ All three investigations should agree for the diagnosis to be accepted.
- ✦ An accurate diagnosis can usually be obtained with the triple test but the diagnosis should be confirmed with a histological diagnosis

What is a mammogram?

= a radiological investigation (mammography) in which the breast is compressed and then x-rayed.

- ✦ The underlying breast tissue is seen and abnormalities may be detected.
- ✦ A mass is an abnormal area, which may have the appearance of being cancerous (malignant) or non-cancerous (benign).
- ✦ A mammogram may be normal or may show:
 - ✓ *Microcalcifications: these are specks of calcium, which are due to abnormal cells. These abnormal cells may be benign or malignant.*
 - ✓ *A mass: this implies there is a breast lump, which may look benign or malignant on a mammogram. Breast cancer appears white on a mammogram.*
 - ✓ *Architectural distortion which means that the breast tissue does not have the normal appearance. The change is generally an area of straight lines and may be associated with a lump or area of calcifications. It is most commonly due to either cancer or previous surgery.*

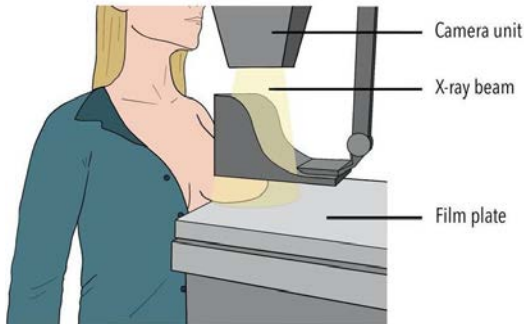
What is an ultrasound scan?

= a way of imaging tissue using sound waves.

- ✦ Different types of breast tissue absorb and reflect the sound waves in different ways and produce a computerised picture.

Mammography

Each breast is compressed horizontally and then obliquely.
An X-ray is taken of each position.



- ✦ Cancers usually look different from non-cancerous masses.
- ✦ An ultrasound scan is good at telling the difference between a solid and a cystic mass.

Younger women tend to have firm breasts. As mammograms are less reliable in these women they should rather have an ultrasound scan.

Some women over 50 with dense breasts may also be advised to have an ultrasound scan.



What is an MRI scan?

= a magnetic resonance imaging scan is a special scan using large magnets that produces pictures of the breast.

- ✦ It is not widely used and should only be requested by specialist breast units.

What is cytology?

= the examination of cells obtained from an aspirate.

- ✦ The cells are studied under a microscope to see if they look cancerous or not.
- ✦ Cytology is one of three parts of the triple test.
- ✦ What results can cytology give?
 - ✓ *Inadequate: that means that too few cells have been removed to confidently make a diagnosis.*
 - ✓ *Benign: normal looking breast cells or a diagnosis of fibrocystic change, fibroadenoma or fat necrosis.*
 - ✓ *Atypical: some cells look abnormal. A core biopsy must always be done if the FNA result is atypical.*
 - ✓ *Suspicious: the lump is probably a cancer but the diagnosis cannot be made for certain.*
 - ✓ *Malignant: the lump is definitely malignant.*

What is histology?

= a sample of solid tissue is examined under a microscope.

- ✦ This is a very helpful way of making a generally accurate diagnosis.

What is an excision / excisional biopsy?

= a procedure of removing a piece of tissue or the whole lump by surgery in an operating theatre.

- ✦ If the lump can be felt, it can be taken out without any imaging before the operation.
- ✦ If the lump is only seen on mammogram or ultrasound scan, the patient should have a needle placed into the lump during imaging before the operation.
- ✦ This makes the lump easier to find at surgery.
- ✦ Excision biopsy can be done under local or general anaesthetic.

PRINCIPLES OF GRADE AND STAGE

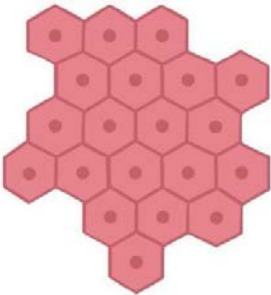
★ Grade

- ✓ *The grade of the cancer describes how active ('busy' or aggressive) a cancer is and how 'cohesive' (sticky) the cells are.*
- ✓ *The higher the grade, the faster the cells are multiplying and the less cohesive the cells are*
- ✓ *The faster the cancer grows the more likely it is to metastasize if treatment is not given*
- ✓ *Breast cancer is graded from 1 to 3 with grade 1 being the least aggressive and 3 the most aggressive.*
- ✓ *The lower the grade the better the prognosis.*

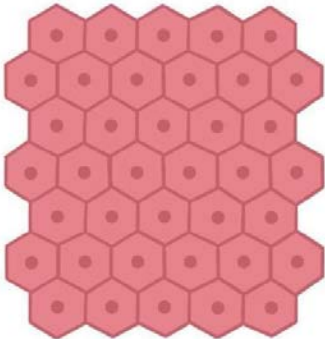
★ Stage

- ✓ *Describes the following:*
 - * The size of the cancer
 - * Whether it has spread to the lymph nodes
 - * Whether it has spread to other parts of the body
- ✓ *Therefore staging is based on the size of the primary tumour in the breast (T), the spread to the nodes (N) and whether it has spread (metastasized) via the bloodstream (M).*
- ✓ *There are 4 stages of breast cancer with stage 1 describing early cancer (small tumour with no spread to nodes or other organs) and stage 4 describing advanced cancer that has spread around the body.*
- ✓ *The earlier the stage, the better the prognosis.*

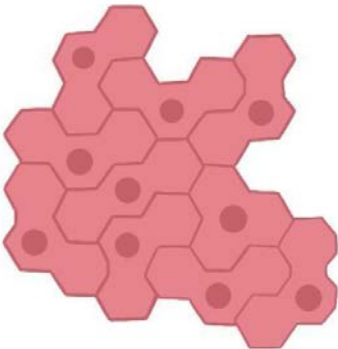
Grade 1

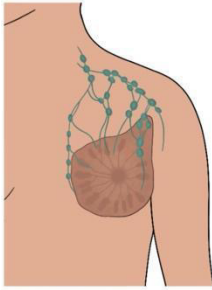


Grade 2

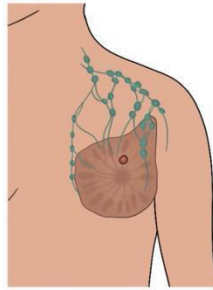


Grade 3

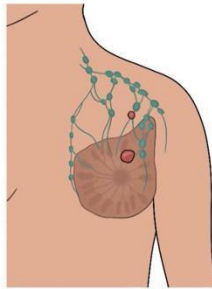




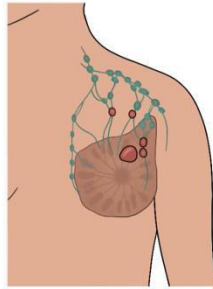
Stage 0



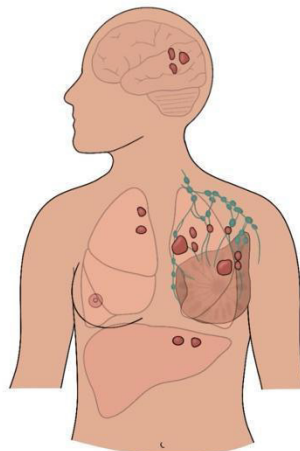
Stage I



Stage II



Stage III



Stage IV

UNDERSTANDING A RADIOLOGY REPORT

Below are 2 examples of radiology reports. The first example is a report of a mammogram. The second example is a report of a mammogram including an ultrasound.

Radiology reports will differ depending on the radiology practice however, certain terms should be included regardless of where the imaging is done. For example, if a mammogram is performed, the report should include the Breast Imaging Reporting and Data System (BIRADS) scoring system.

Various terms and important fields relevant to each report are explained below the example reports:

Example 1:

PATIENT	:	
PATIENT ID	:	
ADDRESS	:	
TELEPHONE	:	
REQUEST DATE	:	
VISIT NUMBER	:	
REFERRING DR	:	

BILATERAL MAMMOGRAM

CLINICAL: 75 year old patient with previous surgery for DCIS. Routine follow up.

FINDINGS:

Breast density category B.

No mass or sinister microcalcifications are present. No interval change compared with the mammograms of 2014 and 2012. There is no axillary lymphadenopathy, architectural distortion or skin thickening.

COMMENT

There are no features of malignancy. Routine screening is advised.

BI-RADS® CLASSIFICATION: Mammogram Right 1 Left 1

DR _____

The report should always include the following *personal details*:

- ✦ Patient name
- ✦ Patient date of birth or ID number
- ✦ Patient contact details
- ✦ The date that the imaging was done
- ✦ The referring doctors name

Breast density = refers to the amount of fibroglandular tissue in breast relative to fat. Categorised as:

A: mostly fatty

B: scattered density

C: consistent density

D: extremely dense

Interval change = this includes any changes compared to a previous similar study.

Axillary lymphadenopathy = changes in the size and consistency of lymph nodes in the axilla.

Architectural distortion = this is where there is change / distortion to the breast tissue but with no definite mass visible. It can have a malignant or benign cause.

BIRADS classification = Breast Imaging Reporting and Database System. This score indicates how concerned the radiologist is regarding the mammogram. It is measured from 0 – 6.

0 – need additional imaging or prior examinations

1 – negative

2 – benign

3 – probably benign

4 – suspicious

5 – highly suggestive of malignancy

6 – known biopsy, proven breast cancer

The report should always be *signed off* by the radiologist that performed and reported the investigation.

Example 2:

PATIENT :
PATIENT ID :
ADDRESS :

REQUEST DATE :
VISIT NUMBER :
REFERRING DR :

Clinical :

- 31 Year old female with a palpable lump in the right breast. Strong family history of breast cancer.

LIMITED MAMMOGRAM & BREAST ULTRASOUND - N63

Findings

Right Breast:-

Breast composition: BI-RADS category (c) – heterogeneously dense breast parenchyma, which may obscure masses.
Normal breast contours. Skin, subcutaneous tissue and nipple areolar complexes normal.
Increased retroareolar parenchymal density. No discrete masses, spiculated lesions or pathological clustered microcalcifications.

Ultrasound:-

Bilateral heterogeneously dense fibroglandular parenchyma.
There is a poorly circumscribed, irregular hypoechoic lesion in the retroareolar position of the right breast, correlating with a clinically palpable lump. The lesion measures 1,1 x 1,0cm. There are areas of posterior acoustic shadowing. No other breast masses or cysts.
No axillary lymphadenopathy.

COMMENT

Suspicious appearing lesion in the right breast. Ultrasound guided core biopsy of the lesion is advised.

BI-RADS Classification Mammography Right 4/Left 1
BI-RADS Classification Ultrasound Right 4/Left 1

DR.

Category C breast density – this is most likely as the patient is 31 years old as per her history.

Microcalcifications = specks of calcium due to abnormal cells. These abnormal cells may be malignant or benign.

Hypoechoic lesion = this refers to a solid lesion unlike for example a cyst, which is filled with fluid.

Acoustic shadowing = this occurs when the sound wave encounters a very dense structure and therefore nearly all of the sound is reflected resulting in a shadow.

BIRADS classification Right 4 / Left 1 (mammogram and ultrasound) = This indicates that the radiologist has classified the right breast as a 4: suspicious and the left breast as a 1: negative after performing a mammogram and ultrasound on the patient.

UNDERSTANDING PATHOLOGY REPORTS

A pathology report related to a breast cancer will provide specific information about the breast cancer as there are many variations. The following template is from the College of American Pathologists or CAP. This provides a standard template as to how specimens are analysed and reported.

The report should include:

- ✦ Size and location of tumour
- ✦ Surgical margins
- ✦ Type of tumour
- ✦ Grade of tumour
- ✦ Lymph node status
- ✦ Hormone receptors
- ✦ Her2 status and Ki-67%

The example below is the template used for breast cancer excisions or a mastectomy. Alongside the template are definitions and descriptions of what is being referred to on the report:

Clinical:

Previous Results:

Macroscopic:

Container is labelled:
 Contents of container:
 Procedure:
 Specimen laterality:
 Size of specimen:
 Weight of specimen:
 Tumour site:
 Tumor size:
 Ipsilateral skin satellite nodules:
 Peau d' orange:
 Additional findingsL:
 Lymph node sampling:
 Key to blocks:

Microscopic:

Invasive carcinoma:

- Histologic type:
- Tumor focality:
- Size:
- Nottingham histologic grade: I, II or III (/9)
 - * Glandular differentiation: /3
 - * Nuclear pleomorphism: /3
 - * Mitotic rate per 10 HPF: /3
- Microscopic description of tumour: Optional

Extent of invasive carcinoma:

- Lymphovascular invasion:
- Perineural invasion:
- Paget's disease of the nipple:
- Ulceration of skin:

Ductal carcinoma in situ:

- Nuclear grade:
- Extensive intraductal component (EIC):
- Architectural pattern(s):
- Necrosis:
- Microcalcifications:
- Size (extent) of DCIS: When only DCIS or microinvasion is present
 - * Number of blocks with DCIS:
 - * Number of blocks examined:
- Lobular neoplasia:

Margins:

Macroscopic = what the specimen looks like when seen with the naked eye.

Contents of the Container – always complete a laboratory form stating where the tissue is from and what operation was performed.

Peau d'orange = red, thickened and pitted skin that resembles an orange peel. A sign of breast cancer.

Microscopic = what the tumour looks like under the microscope.

Size = this will be the maximum size of the tumour.

Nottingham histological grade = a grading system to score (from 1 -3) the tumour that takes 3 factors into consideration.

Ulceration of the skin = breakdown of the skin indicating locally advanced breast cancer.

Ductal carcinoma in situ = DCIS or pre-cancer. Malignant cells are still in the ducts. This may surround an already invasive tumour.

Margins = this will be positive if there is ink on invasive carcinoma.

NAVIGATING THE PATIENT WITH BREAST CANCER

- Margins cannot be assessed.

Invasive carcinoma

- margins uninvolved
 - * Distance from closest margin:
 - * Specify margin:

_ Margin (s) positive

- * Specify margin (s):

Lymph nodes:

- Total number of lymph nodes examined:
- Number of lymph nodes with metastases:
- Size of largest metastatic deposit:
- Extranodal extension:
- Method of evaluation of sentinel lymph nodes:

Treatment effect

- No response (pNR):

No change or some alteration to individual malignant cells, but no reduction in over all cellularity.

- Partial response (pNR)

A minor loss in cells (up to 30% reduction in cellularity), but overall cellularity still high OR between and estimated 30 - 90% reduction in tumour cellularity.

- Near complete response (near pCR):

A marked disappearance of cells such that only small clusters or widely dispersed individual cells remain, > 90% reduction in tumour cellularity.

- Complete response (pCR):

No invasive carcinoma identifiable, ductal carcinoma in situ present/absent; only vascular fibroelastosis, often containing macrophages remain.

Lymph nodes:

- Nodal metastasis absent, evidence of therapeutic effect absent.
- Nodal metastasis absent, evidence of therapeutic effect present.
- Nodal metastasis present, evidence of therapeutic effect absent.
- Nodal metastasis present, evidence of therapeutic effect present.

Immunohistochemistry:

- ER: I= /3; P= /5 (T= /8) (>2/8 = positive)
- PR: I= /3; P= /5 (T= /8) (>2/8 = positive)
- HER2/Neu: 0 (negative), 1+ (negative), 2+ (equivocal), 3+ (positive)
 - * FISH requested:
- Ki-67:

Additional findings:

COMMENT:

- Histologic type:
- Size:
- Histologic grade:
- Immunohistochemistry: ER: ?8; PR: /8; HER2: ; Ki-67:
- Lymph nodes:

PATHOLOGIST:

Specimen Orientation = this should be done by use of sutures or clips placed on the specimen surface and documented on the laboratory form.

Sentinel Lymph Nodes = are identified by the surgeon by uptake of radiotracer or dye or both. They are considered sentinel lymph nodes if less than six nodes are removed.

Axillary Lymph Nodes = are removed by bloc resection of axillary tissue. The nodes are divided into levels i – iii.

Lymph Node Metastases = divided into 3 categories – isolated tumour cells (clusters of cells <0.2mm), micrometastases (<2mm) and macrometastases (>2mm).

Treatment Effect = the response of the invasive carcinoma to therapy is a strong prognostic factor for disease-free and overall survival. The tumour bed will be evaluated.

Immunohistochemistry = a special staining process to assess the hormone receptors of the tumour.

Ki67 = a proliferative marker. The more positive cells there are, the more quickly they are dividing and forming new cells. A higher percentage suggests a faster-growing, more aggressive cancer.

Pathologist = the pathologist assessing the specimen must sign off on the report.

MANAGEMENT OF BREAST CANCER, INCLUDING SIDE EFFECTS OF DISEASE PROCESSES AND TREATMENTS

Surgery

Types of surgery

- ✦ Surgery to the breast
 - ✓ *Wide Local Excision*
 - ✓ *Lumpectomy*
 - ✓ *Quadrantectomy*
 - ✓ *Tumorectomy*
 - ✓ *Breast Conservation Therapy*
 - ✓ *Lump Out*
 - ✓ *Mastectomy*
- ✦ Surgery to the axilla

Breast surgery may be:

- ✦ Diagnostic (e.g. excision biopsy) – with or without radiological guidance
- ✦ Therapeutic
- ✦ Done to achieve symmetry

Aim of surgery

- ✦ Adequately remove cancer
- ✦ Maintain breast shape
- ✦ Minimise asymmetry

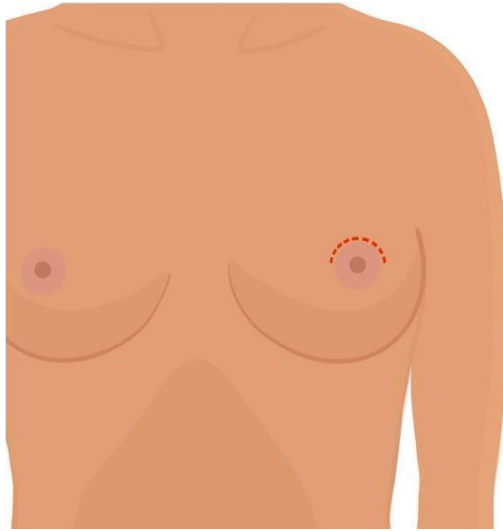
In the correct patients: Mastectomy = Wide Local Excision + Radiotherapy

Wide Local Excision (WLE)

= excision of the tumour and surrounding breast tissue

- ✦ must be combined with radiotherapy (for +/- 6 weeks)
- ✦ a wide local excision is NOT a good idea if:

- ✓ *Multicentric disease (pre cancer/cancer in more than one area of the breast)*
- ✓ *More disease than seen on the mammogram/sonar (difficult to follow up the patient)*
- ✓ *Radiotherapy, e.g. if the patient had previous radiotherapy or lives in country with no radiotherapy machine*



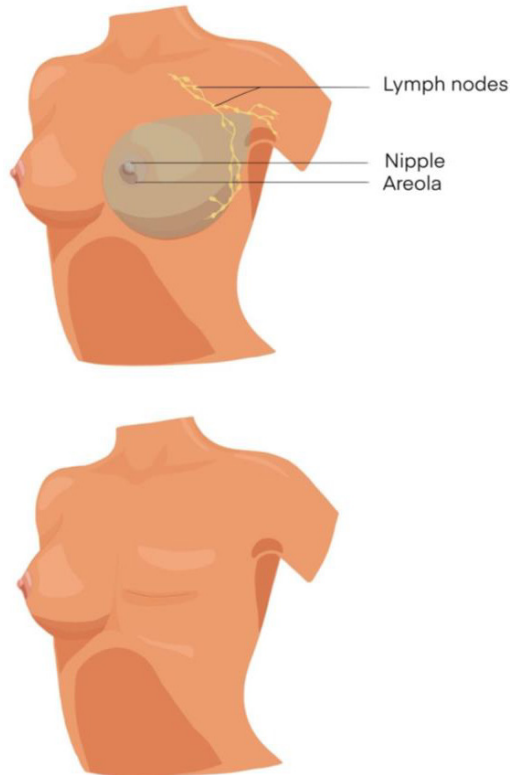
✓ *Mastectomy*

= removal of all breast tissue

- ✦ flat chest +/- reconstruction later
- ✦ immediate reconstruction (keep the overlying skin)
- ✦ a mastectomy should be considered if:
 - ✓ *Tumour is not seen on mammogram/sonar*
 - ✓ *Small breasts: may be cosmetically better to do a reconstruction*
 - ✓ *Family history*
 - ✓ *(Age)*
 - ✓ *(Type of cancer)*

✦ operation types

- = Simple mastectomy
- = Modified radical mastectomy
- = Skin sparing mastectomy
- = Nipple sparing mastectomy



Reconstruction

✦ Timing

- ✓ *Immediate*
- ✓ *Staged*
- ✓ *Delayed*

✦ Types of reconstruction

- ✓ *Prosthetic*
- ✓ *Autologous: using muscle or fat*
- ✓ *Surgery to the Axilla*

= Information about the status of nodal involvement is vital in the planning of adjuvant systemic therapy

- ✦ it will predict the chance of getting another problem from the breast cancer
- ✦ if a patient has palpable axillary nodes, they need an axillary dissection (removal of the lymph nodes)

Sentinel Lymph Node Biopsy (SLNB)

= to trace the first node that drains the breast and remove that node

= Check for evidence of cancer at the time of surgery using cytology and frozen section and if positive: go on to do a completion axillary dissection

✦ For patient with:

- ✓ *No palpable axillary lymph nodes*
- ✓ *No nodes on radiological imaging*

Axillary Dissection (AD)

= removal of the lymph nodes

✦ For patients with:

- ✓ *Palpable axillary nodes*
- ✓ *Node positive breast cancer*

Surgical Complications

✦ Immediate:

- ✓ *bleed*
- ✓ *anaesthetic problems*

✦ Later / Long Term:

- ✓ *seroma formation*

- ✓ *infection*
- ✓ *poor wound healing*

Complications Related to Axillary Surgery

- ✓ *Complications can also be dependent on whether a reconstruction is performed or not*
- ✓ *The longer the operation the more side effects*
- ✦ Numbness in upper arm
- ✦ Swelling of arm
- ✦ Decreased shoulder movement
- ✦ Long term or late effect: Lymphoedema
 - ✓ *This is the abnormal collection of fluid under the skin due to a problem with the lymphatic system (removal of lymph nodes during surgery or due to the cancer)*
 - ✓ *Lymphoedema can be managed but not cured*
 - ✓ *Patients should be encouraged to start with gentle exercises soon after surgery to reduce the risk of developing lymphoedema*

Chemotherapy

= use of drugs to treat cancer

- ✦ Interferes with all stages of cancer development:
 - ✓ *Rapid, uncontrolled reproduction of new cells*
 - ✓ *Loss of normal function of cells*
 - ✓ *Invasion to surrounding tissue*
 - ✓ *Spread around the body*
- ✦ Doesn't differentiate between healthy cells and cancer cells so there are many side effects

Reasons for giving chemotherapy

- ✦ Adjuvant therapy:

= given to reduce the chance of metastases or recurrence (i.e. curative)

✦ Preoperative (neoadjuvant) chemotherapy:

= given to reduce the size of cancer to allow for surgical removal

✦ Palliative chemotherapy:

= given to prolong life or improve quality of life (i.e. non-curative)

Adjuvant Chemotherapy

✦ Biology of the primary cancer should be treated rather than the stage

✦ Dependent on the general health and age of patient and the wishes of the patient

✦ Given after adequate surgery if any of the following cancer features are noted:

✓ *Grade 3 ductal carcinoma*

✓ *ER -ve or HER 2+ve*

✓ *1-3 nodes involved with cancer*

✓ *Bigger ductal cancers (>3 cm)*

Neoadjuvant Chemotherapy (NACT)

✦ Inflammatory carcinoma

✦ Inoperable cancer

✦ Mastectomy

✓ *Size*

✓ *Position: very medial or lateral cancers can be difficult to get clear excision margins*

✦ May be given to downstage a cancer as the cosmetic outcome depends on the ratio of size of cancer:size of breast, for example NACT may downstage a cancer which will result in a better cosmetic outcome when a WLE is performed.

✦ Other reasons

Chemotherapy Regimens

✦ Adjuvant / Pre-Surgical Regimens

✓ *drugs given are generally considered to be most effective*

- ✓ *intention is to cure*
- ✓ *Regional variation as to what are considered to be best drugs*
- ✓ Anthracycline + Taxane based regimen for breast cancer
- ✦ Palliative Regimens
 - ✓ *multiple and varied: no correct regimen for everybody*
 - ✓ *intention is to prolong life with minimum side effects*
 - ✓ *many lines may/can be given*
 - ✓ *generally less side effects*

Regimen should be tailored to the biology of the cancer and the individual needs of the patient

Which regimen is used?

- ✦ Choice of drugs is dependent on:
 - ✓ *cost/reliable availability of the drugs*
 - ✓ *generally, most effective cancer drugs are used first*
- ✦ The frequency of doses depends on:
 - ✓ *regimen*
 - ✓ *effect of drug (pharmacokinetics)*
 - ✓ *individual's tolerance*

Monitoring of Chemotherapy Patients

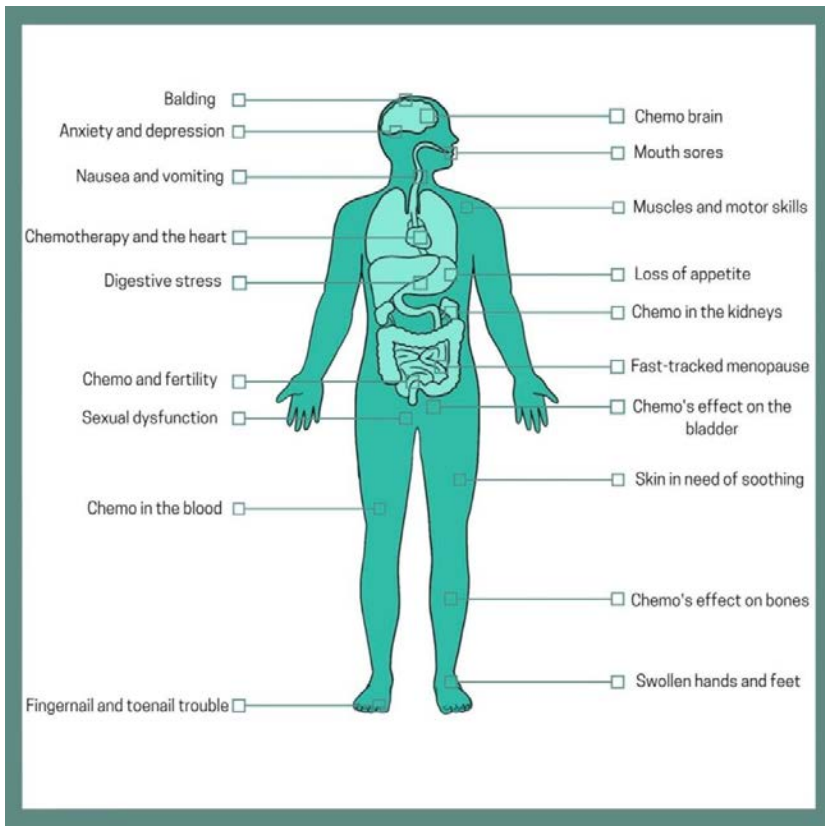
- ✦ Before
 - ✓ *Correct drugs for correct patient*
 - ✓ *History of patient and side effects*
 - ✓ *BP*
 - ✓ *FBC (+/- U and Es, LFTs)*
- ✦ During
 - ✓ *Check site of administration every 5-10 minutes to ensure no extravasation*
 - ✓ *Regular checks to ensure no allergic reaction to drugs*
 - ✓ *Make sure patient is comfortable and safe*
- ✦ After

- ✓ Patient should have emergency number to call and know when they should use it
- ✓ Patient should have brochure with drug information and side effects (this should be in their own language)

Stop infusion if the drip stops running or if the patient complains of pain!

Side Effects of Chemotherapy

= chemotherapy side effects depend on the regimen used and the individual response of the patient



1. Hair loss

✦ Anthracycline (“red devils”), Taxanes and Cyclophosphamide

- ✦ Occurs 7-10 days after 1st dose
 - ✦ Complete or partial on the head and elsewhere on the body
 - ✦ Usually grows back after chemotherapy but is often not as thick and may be grey/curly
2. Nails
- ✦ Ridged and discoloured
 - ✦ Use moisturisers and keep nails short
 - ✦ Avoid chemicals such as washing up liquid or household cleaners
 - ✦ Wear gloves where possible
3. Mucositis
- = inflammation of the mucous membranes
- ✦ Common with Cyclophosphamide, Methotrexate and Fluorouracil
 - ✦ Usually affects the gums and intestinal lining
 - ✦ Managed with good oral care
4. Constipation
- ✦ May be due to chemotherapy drugs, analgesics or anti-emetic drugs
 - ✦ Encourage patients to add seeds or dried fruit to diet
5. Diarrhoea
- ✦ Usually due to Methotrexate and Fluorouracil
 - ✦ Can occur at any stage in treatment cycle
 - ✦ Treat as emergency: drugs to control it must be given immediately
6. Neutropenic Sepsis
- ✦ neutropenia: low white cell count in blood
 - ✦ sepsis: infection in the bloodstream
 - ✦ Damage to rapidly dividing cells, not only cancer cells
 - ✦ Chemotherapy stops white cell production so minor infections can become a major problems
 - ✦ Symptoms include:
 - ✓ *Feeling unwell*
 - ✓ *Temperature $>38^{\circ}\text{C}$*
 - ✓ *Low WCC on FBC*

- ✦ Most common 10 days after 1st cycle
- ✦ More likely to occur in older people
- ✦ Emergency treatment required: intravenous broad spectrum antibiotics and Neupogen to stimulate production of cells

Neutropenia is a medical emergency!

7. Nausea and Vomiting

- ✦ Anthracycline and Carboplatin cause nausea and vomiting
- ✦ Can occur at any time, even in anticipation of receiving the next dose
- ✦ May also be due to the drug having a direct effect on the stomach and small intestine or stimulation of the vomiting centre in the brain
- ✦ The best management is to prevent it! (i.e. most chemotherapy protocols include Antiemetics before and after chemo e.g. Kytril, Valoid, Maxalon, Valium)
- ✦ Antiemetics can be given orally, rectally or via IV
- ✦ non-drug treatment includes small frequent meals or regular dry foods, prevention of dehydration and IV fluid if dehydration suspected

8. Extravasation of Chemotherapy Drug

= when chemotherapy drug leaks from the cannula or is given by mistake into soft tissue rather than into the vein

- ✦ Before chemotherapy, check the cannula or needle into port has easy flow of blood back through the line
- ✦ Extravasation may occur at any time during the infusion
- ✦ Signs and symptoms:
 - ✓ *pain*
 - ✓ *tingling or burning at site of administration*
- ✦ Over time there may be swelling, redness, blisters or necrosis
- ✦ Suspect extravasation if there is interruption in blood flow, absence of blood return or resistance to fluid bolus

Management of Extravasation

- ✦ Stop drug immediately

- ✦ Attempt to withdraw any fluid in line or cannula using 10ml syringe whilst withdrawing the needle
 - ✦ Elevate the limb
 - ✦ Apply ice pack to area
 - ✦ Seek medical help
9. Anaphylactic Shock
- = severe allergic reaction
- ✦ Signs and symptoms:
 - ✓ *Hives*
 - ✓ *Swelling of tongue/lips (resulting in difficulty in breathing)*
 - ✦ Treat by immediately stopping the infusion, call attending doctor, give antihistamine via IV and steroids if necessary
10. Infertility
- ✦ This is unpredictable
 - ✦ Premature ovarian failure (POF) is common in women over 35 years of age after chemotherapy
 - ✦ Contraception must be used as younger women may still be able to fall pregnant during and after chemotherapy
 - ✦ A luteinising hormone releasing hormone (LHRH) analogue given at the time of chemo may decrease the incidence of POF - e.g. Goserilin
 - ✦ Pre-chemotherapy fertility options include egg harvesting and ovarian preservation e.g. IV and steroids if necessary

Endocrine therapy

- ✦ Choice of drug depends on menopausal status
- ✦ Post-menopausal = not naturally had a period for 2 years
- ✦ Endocrine therapy starts after chemotherapy and radiotherapy
- ✦ Generally advised to have it for 5 - 10 years
- ✦ It decreases risk of recurrence by 50% and risk of 2nd breast cancer by 50%
- ✦ Endocrine therapy is used for any estrogen positive breast cancer (ER +ve)

Types of Endocrine Therapy

Mechanism of Action:

1. block estrogen receptors
 - ✦ e.g. Tamoxifen
 - ✦ Known as Selective Endocrine Receptors Modulators (SERMS)
 - ✦ Stimulate growth in other cells (bone and endometrial)
 - ✦ Usually for pre-menopausal women
 - ✦ Side Effects
 - ✓ *Increased risk of deep vein thrombosis (DVT)*
 - ✓ *Stroke*
 - ✓ *Hot flushes*
 - ✓ *Vaginal discharge*
 - ✓ *Weight gain*
 - ✓ *Thickening of lining of uterus (may lead to an increased incidence of endometrial cancer therefore annual ultrasound of the uterus is advised)*
 - ✓ *Decreased libido*
 - ✓ *Many side effects similar to those of menopause*
 - ✓ *Pregnancy is contra-indicated*
2. Stop estrogen production
 - ✦ Premenopausal women: oophorectomy, Goserelin
 - ✦ Post-menopausal: Aromatase Inhibitor (AI)
 - ✦ E.g. Aromatase Inhibitor
 - ✓ *only effective if the ovaries have stopped working*
 - ✦ Side Effects
 - ✓ *Muscle and joint aching*
 - ✓ *Osteopenia*
 - ✓ *Osteoporosis*
 - ✓ *Fractures*

- ✓ *Hot flushes*
- ✓ *Dry vagina*
- ✓ *Weight gain*
- ✓ *Decreased libido*

Management of Side Effects:

- ✦ Patients should be managed by an oncological team
- ✦ Supplementary calcium and bisphosphonate is given to prevent osteoporosis
- ✦ Non-steroidal anti-inflammatory drugs (e.g. ibuprofen or diclofenac) are given for joint or muscle aching
- ✦ Vaginal estrogen products (ring, suppository, cream) can be used for vaginal dryness and atrophy
- ✦ Vaginal estrogen is absorbed by local tissues and not into the bloodstream

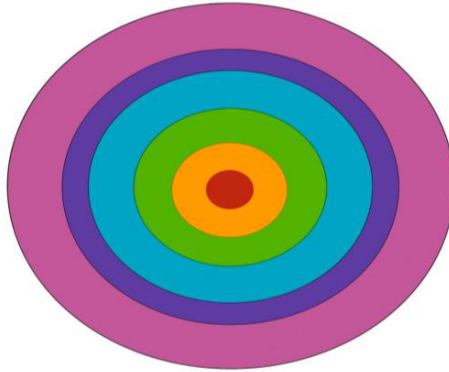
Targeted Therapy

= when a drug is used which acts selectively on a metabolic pathway in a cell

- ✦ Fewer side effects
- ✦ Breast cancer target therapy drug currently used = Trastuzumab (Herceptin)
- ✦ The drug is very expensive
- ✦ Side Effects
 - ✓ *Cardiac dysfunction*
 - ✓ *Diarrhoea*
 - ✓ *Redness at injection site*
 - ✓ *Muscle pain*
 - ✓ *Nausea and vomiting*
 - ✓ *Weight loss*

Targeted therapy

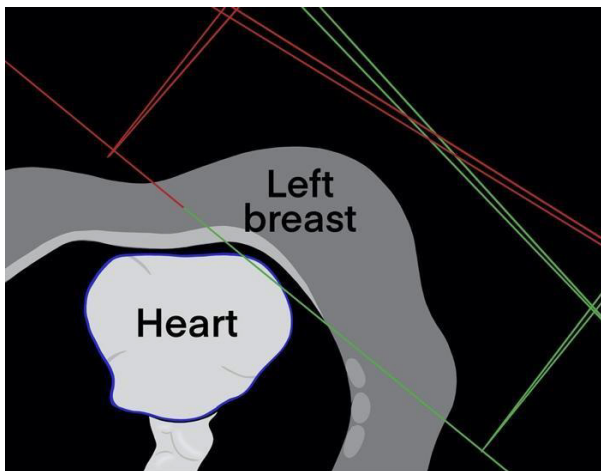
Targets cancer cells directly,
avoiding normal cells



Radiotherapy

= ionising radiation to treat cancer

- ✦ Local treatment
- ✦ Alters deoxyribonucleic acid (DNA) in cells causing cell death
- ✦ The beams are delivered using a linear accelerator



Radiotherapy is given:

- ✦ For metastatic deposits
- ✦ Commonly to manage bony secondaries
- ✦ As adjuvant therapy (after surgery)
- ✦ As primary therapy to decrease the size of the tumour if it is inoperable
- ✦ To dry out fungating tumour

Adjuvant Radiotherapy

- ✦ After a wide local excision
- ✦ As part of planned management
- ✦ After a mastectomy if:
 - ✓ *Tumour > 5cm*
 - ✓ *> 1-3 lymph nodes are involved*
 - ✓ *Surgical margin contains cancer*
 - ✓ *Initially presented with inflammatory cancer*

Adjuvant radiotherapy reduces the risk of the cancer recurring on the chest wall and axilla

Adjuvant RT contra-indications:

- ✦ Previous radiotherapy
- ✦ Pregnant women
- ✦ Women with weak heart/lungs
- ✦ Known frozen shoulder

Administration of Radiotherapy

- ✦ Use of external beam linear accelerator
- ✦ Area is mapped using a computed tomography (CT) scan
- ✦ The original tumour site is noted
- ✦ Fields are planned so that maximal dose is given to the original site
- ✦ Booster dose may be given
- ✦ Usually the whole breast is included
- ✦ Axilla and supraclavicular area may be included if there is lymph node involvement

- ✦ Generally given 4-6 weeks post surgery/chemotherapy but this does vary

Side Effects of Radiotherapy

- ✦ Local redness
- ✦ Local burning sensation
- ✦ Radiation to surrounding organs may result in decreased cardiac or lung function
- ✦ If the axilla is irradiated – lymphoedema risk increases
- ✦ Breast may become puckered/distorted
- ✦ Prosthetic reconstruction may become hard
- ✦ Autologous reconstruction may lose volume
- ✦ Loss of shoulder movement and function
- ✦ Tiredness: the effect is cumulative
- ✦ No hair loss (unless the brain is irradiated)
- ✦ No nausea
- ✦ Late side effects may include rib fracture and pneumonitis

Dosage

1. Standard dose:
 - ✦ 50Gy given in 30 doses over 6 weeks
 - ✦ Booster may be given to tumour bed
 - ✓ *50Gy in 25 fractions over 5 weeks the (boost) 10Gy in 5 fractions to lumpectomy cavity, total dose 60Gy*
2. Hypo fractionation:
 - ✦ Smaller dose
 - ✦ 40 - 42Gy given in 16 cycles
 - ✓ *Canadian Protocol: 4 weeks – 266cGy daily dose in 16 fractions, total dose 4256cGy*
Boost if necessary to the lumpectomy cavity x4 fractions

Management of Side Effects of Radiotherapy

- ✦ Avoid soaps and perfumes

- ✦ Cornflour (maizena) can be dusted on to the skin to keep it dry and reduce friction
- ✦ Pat skin dry or air dry if the skin does get wet
- ✦ Refer to lymphoedema therapist if lymphoedema is suspected
- ✦ Skin care: Aquaphor healing ointment, Eucerin cream, Calendula cream (over-the-counter) or Biafine topical emulsion (prescription required)
- ✦ Grade 2 skin dermatitis - moist desquamation; grade 3 skin dermatitis – silvadene cream 1% or Medi-honey

FOLLOW-UP PATIENT CARE AND SURVIVORSHIP (HOW, WHY AND WHAT)

Cancer survivor = any person with cancer, starting from the moment of diagnosis. A breast cancer patient in long-term remission should be monitored for local or distant recurrence as well as a new primary breast cancer, other cancers or may even require long-term management of metastatic disease.

Survivorship Programmes:

This includes surveillance for recurrence (local or distant), screening for secondary primary cancers, assessment and management of long-term effects of breast cancer and its treatment, health promotion and care coordination should be managed by a multidisciplinary team (MDT) together with a locally trained nurse, clinic doctor or general practitioner.

The American Cancer Society (2015) / American Society for Clinical Oncology breast cancer survivorship guidelines state the following:

Treatment Type	Long-Term Effect	Late Effect
General	Body image issues Sexual dysfunction Limited RoM shoulder Fatigue Skin sensitivity Numbness / weakness arm Breast asymmetry	Lymphoedema
Surgery	Seroma	Neuropathy
Radiation to breast / chest wall / regional lymph nodes	Pneumonia Breast atrophy	Skin discolouration / pain / telangiectasia Shortness of breath Cardiovascular disease Second primary cancer

Chemotherapy	Cognitive impairment Ovarian failure Infertility Weight gain Obesity Neuropathy Oral health issues Hair loss	Osteoporosis / osteopenia Increased risk of cardiovascular disease Increased risk of leukaemia
Hormonal therapy – Tamoxifen	Hot flushes Changes in menstruation Mood changes Increased triglycerides	Increased risk of stroke Increased risk of endometrial cancer Increased risk of blood clots
Hormonal therapy – Aromatase Inhibitors	Vaginal dryness Decreased libido Musculoskeletal symptoms / pain Cholesterol elevation	Osteopenia (premenopausal women) Osteoporosis Increased risk of fractures
Targeted therapy	Increased risk of cardiac dysfunction	

Each long-term or late effect will require its own management.

Below are a few examples:

- ✦ Chemotherapy: causes a risk of cardiac dysfunction therefore the patient should consult with a cardiologist.
- ✦ Tamoxifen: causes endometrial thickening therefore increasing the risk of endometrial cancer. The patient should have annual uterine scans to assess for changes.
- ✦ Aromatase inhibitors: causes musculoskeletal symptoms therefore the patient should have an annual bone density scan and be managed appropriately.
- ✦ Contralateral breast cancer: patients should continue to see their surgeon or oncologist for follow up to have clinical breast assessment and imaging to assess for a contralateral breast cancer.

Patients should be educated on how to assess for signs and symptoms of recurrence. A recurrence may occur within months or years of the initial breast cancer. Teach the patient to do self-examination and what to look out for.

✦ Local recurrence:

- ✓ *New lump*
- ✓ *Changes in the scar (including thickening)*
- ✓ *Skin changes around the scar (inflammation or redness)*
- ✓ *Nipple discharge (if a lumpectomy was performed)*
- ✓ *Nodules on the chest wall*

Patients should also know how to assess the contralateral breast and how to look out for regional or distant metastases:

✦ Contralateral breast:

- ✓ *New lump*
- ✓ *Skin dimpling*
- ✓ *Redness of the skin*
- ✓ *Peau d'orange skin changes*
- ✓ *Nipples changes including discharge*

✦ Regional recurrence:

- ✓ *Lump or swelling in the lymph nodes (axilla, supraclavicular and neck)*

✦ Distant recurrence:

- ✓ *Pain*
- ✓ *Breathing difficulties (shortness of breath, coughing)*
- ✓ *Continuous weight loss*
- ✓ *Loss of appetite*
- ✓ *Constant severe headaches*

Breast self-examination post breast cancer treatment:

Follow-up care is crucial after breast cancer treatment such as radiation therapy. BSE will help you identify changes that occur between clinical breast examination and mammogram. BSE is not considered a replacement for your mammogram. Sometimes BSE will allow you to find recurrences and other breast changes early, which is an excellent opportunity to assume an active role in your own healthcare (Pierce, 2009).

(See BSE section for proper techniques demonstrated).

Important follow-up steps are:

- ✦ Patient should continue to perform BSE
- ✦ Patient should have their clinical breast examination
- ✦ Mammogram and or breast magnetic resonance imaging (MRI) for women who are considered high risk
- ✦ As per guidelines: recommend mammogram six months after cancer treatment on the treated breast, then yearly as per radiologist recommendation
- ✦ Recommend follow-up care with clinician every three to six months for the first two years and then yearly thereafter
- ✦ If the patient needs breast reconstruction this should be performed within six months after radiation therapy

When to Perform BSE:

- ✦ BSE should be performed once every month
- ✦ If the patient is still having a regular menstrual cycles (premenopausal), they should perform BSE on the 7th to 10th day after the onset of their cycle, at this time the breasts are less tender or swollen
- ✦ If the patient is no longer having a menstrual cycle (post menopausal) or their cycle is irregular, they should choose a day such as their birthday or the first day of each month to perform BSE
- ✦ If the patient has breast implants they should continue to perform BSE on a monthly basis
- ✦ If the patient has had a mastectomy or breast reconstruction they should continue to perform BSE on the chest wall, axillary region, inframammary and supraclavicular region

How to perform BSE:

- ✦ The average examination, depending on the size of the breast and density should take about 5-10 minutes per breast
- ✦ The examination can be performed in a number of ways:

Standing up - a visual examination in front of the mirror and repeat the entire examination on the **other breast**

Lying down - repeat the previous steps entirely (Pierce, 2009)

IMPACT OF BREAST CANCER ON THE PATIENT AND FAMILY LIVING WITH THE DISEASE

When addressing the impact of breast cancer on the patient and their family, one needs to look at the patient in a comprehensive manner.

Comprehensive care, also known as holistic care, is defined as a system of total patient care that considers the physical, emotional, social, economic and spiritual needs of the person, his or her response to illness, and the effect of the illness on the ability to meet self-care needs. – Mosby's Medical Dictionary, 9th Edition, 2009, Elsevier.

Physical Impact

The physical impact of going through the journey of breast cancer may include many aspects. Change in appearance of the patient's body due to treatment received may be the biggest physical impact.

When providing care for the patient, physical activity can reduce the number of side effects from the treatment received and can also improve quality of life. It is important to take the history of your patient and create a care plan which can be adapted as needed. Managing a patient's side effects from treatment may not always involve medication and may therefore not always need intervention from a doctor. Something as small as taking a patient for a walk after surgery may alleviate physical discomfort and aid in the patient's healing process rather than being stuck in bed.

Physical care from a nurse's perspective should be to ensure early mobilisation of the patient. Wound care post-operatively also falls under physical care. This may be done by the nurse or doctor. Each hospital/unit/doctor will have their own protocols for this and should be followed.

If the patient is experiencing emotional distress from the change in body appearance due to treatment, the nurse may be able to provide support;

however, intervention from a counsellor, social worker or psychologist may be required.

Sexuality implications form part of the physical impact. Sexuality is the intimate relationship between 2 people, it means connecting with a person physically, mentally and emotionally. The loss of a breast (or breasts) or altering of the body may result in sexuality issues. A social worker could be encouraged to be involved with the patient's journey to assist with sexuality issues throughout the disease journey.

Emotional Impact

= these are the emotional problems that are experienced by the patient and their family.

As a person steps into a healthcare facility to be treated, they become a patient. In the build-up to diagnosis and once diagnosed, most patients journey along an emotional roller coaster. Feelings of fear, anger, anxiety, frustration and depression amongst others can be overwhelming. Patients react differently and some need more support than others.

✦ Examples of emotional or psychosocial problems include:

- ✓ *Loss of independence*
- ✓ *If a parent, they may feel loss of control of life and ability to care for family*
- ✓ *Wounds (specifically fungating tumours) may cause insecurity*
- ✓ *If a partner is present, the patient may feel unloved or rejected by the partner*
- ✓ *Depending on the disease process, the patient may be scared of dying*

It is best to speak with the patient and see what type of support would be preferred. Certain patients may benefit from a support group, others may prefer a one-on-one session with a trained professional. Emotional support begins at the patient's first appointment with the doctor and continues all the way through treatment and into the phase of life following their treatment.

Although most patients receive emotional support from their family and

friends, this should also be given by the health care providers treating them. Doctors treating patients are not always available to give enough emotional support generally due to time constraints therefore patients should be offered support from trained health care professionals in this field. This may include a psychologist, psychiatrist, social worker or counsellor.

Nurses will often spend the most time with a patient therefore, whether in the chemotherapy unit or post-operatively in the ward, emotional support can be given. Patients very often develop a relationship with the nurses taking care of them. The patient builds trust with the nurse and may benefit from emotional support given by the nurse.

Emotional support goes beyond the diagnosis and treatment of breast cancer. Feelings of loneliness or being unsure, even confusion, are common once treatment is complete. It is therefore important to encourage patients to build relationships with fellow breast cancer patients or to get involved with or attend support groups. This will allow the patient to be a part of a community once their treatment is complete and will decrease the feeling of loneliness.

Social Impact

Social support is usually received from a patient's friends. However, many patients, when asked who will support them through their treatment process, will say that they do not have anyone to support them and often would prefer to not have to "bother" anyone to help them.

It is important to always encourage patients to have at least one friend to help them when needed through their treatment and cancer journey. This person should be someone that is available at all times if the patient needs help with anything from transport to and from therapy, assisting with meal preparations, transporting children to school and activities or merely being there if the patient needs a friend.

A nurse can also provide social support in a certain capacity. Advocate

for the patient and their needs and rights as they go through their cancer management.

Economic Impact

Health care can be very expensive. Whether a patient has health insurance and is treated in a private institution or no health insurance and is treated at a public institution, there are still costs involved.

Patients may avoid consulting a medical professional or avoid going for treatment if the cost is too high. Being diagnosed or treated does not only involve the cost of local or systemic treatment but also the time off of work to be at the treatment facility, the transport to get to and from the treatment facility and the various other costs that may arise.

It is not the health care provider's job to provide any form of economic support to the patient. Health care providers can however refer patients to the many support groups that may be able to assist where needed. Individual institutions may also have certain support structures available, for example, a transport fund.

A pamphlet should be given to all newly diagnosed patients with a list of support groups, where they are based and their contact details. Patients may be embarrassed to ask for help therefore giving them contact details of those that can help will make the patient feel more in control and independent.

Spiritual Impact

Patients and health care providers all have different spiritual backgrounds. This needs to be taken into consideration and respected when treating patients. Health care providers should not push their own spiritual beliefs onto a patient as the patient may have their own beliefs and it can make them feel very uncomfortable.

It is advisable to have a space available for a patient along with their family if they need some time alone. This may be to process news they have just heard,

a time of silence or a time of prayer.

Patients also receive spiritual support from their places of worship (for example temples, churches, synagogues or mosques). Having a list of the local spiritual workers and their contact details is helpful if a patient wishes to interact with one.

- ✦ It is helpful to have resources available to give to the patient if needed as the diagnosis of breast cancer and its treatment entails a lot of information as it is
- ✦ There is no use in giving the patient endless pamphlets regarding everything from maintaining a healthy lifestyle to where to buy a wig. It is too much for a patient. Instead, encourage your patient to speak with you and then you can refer the patient depending on the specific need. This will prevent the patient from having too much information that may in any case be unnecessary.
- ✦ It is, however, vitally important for information to be given verbally and in writing. With all the information that a breast cancer patient receives, it is impossible to remember it all. The overload of information may even result in patients feeling so overwhelmed that they do not want to go ahead with treatment
- ✦ Encourage your patient to keep all their medical documents in one dedicated file. Any information given verbally should also be given in writing to the patient to add to their medical file.
- ✦ Encourage patients to keep copies of all test results and reports in their medical file. This makes it easier if the patient is referred to other healthcare professionals who will need access to the documents.

SELF-ADVOCACY

There are many organisations involved with breast cancer. It is vital to know the organisations that are in your local area and which are relevant to your patients. We will look at this again in Part 2 of the training module under the heading of “Community resources and supportive services for patients”.

Organisations concentrate on different issues, namely:

- ✦ education
- ✦ support
- ✦ advocacy

Education:

- ✦ This may be aimed at educating patients, family, health care providers, or the public.
- ✦ Education programmes should have a clear message with only a few points to ensure that the message is understood.
- ✦ When educating people, as far as possible, it should be done in their own language. Written material should also be shared.
- ✦ Make sure that the information being shared is relevant to the local area.
- ✦ Breast cancer survivors should be used in education campaigns to share their stories and experiences.

Support:

- ✦ Once a person is diagnosed with breast cancer, it is important that support is made available.
- ✦ Support is available in many different ways. Examples to follow:
 - ✓ *Health care workers (nurses, social workers, psychologists, psychiatrists or counsellors).*
 - ✓ *Non-Profit Organisations (NPOs) run by breast cancer survivors or trained volunteers.*

- ✓ *A buddy system (making use of local breast cancer survivors who will be able to share their story and support someone going through their treatment process).*
- ✦ Informal support is often also available in the way of religious organisations, friendship groups or school groups.

Advocacy:

= campaigning for a cause / identifying a problem and fighting to get it solved.

- ✦ Advocacy challenges are dependent on the area in which the patient lives and receives treatment.
- ✦ Examples include: advocating for medications for treatment to be available in the local area.

It is very helpful and useful to have a list of local NPOs in your area that you can refer patients to should they require it. The list should include the aim of the organisation and also their contact details.

PALLIATIVE CARE

- ✦ Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with a life threatening illness through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems
- ✦ It aims to improve quality of life and not to cure the disease
- ✦ It starts when a patient is given the diagnosis of a life-threatening disease
- ✦ Many of the principles and practices of palliative care are the same as those of good care for patients who have curable or chronic conditions

Purpose of Palliative Care

- ✦ Improve quality of life and relieve unpleasant symptoms
- ✦ Provide pain relief and other distressing symptoms
- ✦ Regard dying as a normal process
- ✦ Integrate psychological and spiritual aspects of patient care
- ✦ Help patients live as actively as possible
- ✦ Help to provide a support system to the patient and family
- ✦ Use a team approach to address needs of patient and family

Terminal care

= also known as end-of-life care addresses the needs of the patient and family when the patient is dying

- ✦ It is the last phase of palliative care and is usually given in the last weeks or days of life
- ✦ It aims to provide symptom management, comfort and dignity during the dying process

Palliative care is not:

- ✦ No care
- ✦ Substandard curative care

- ✦ Denial
- ✦ Active avoidance
- ✦ Referral
- ✦ Assisted suicide

There are various tools that can be used to identify patients for palliative care. Supportive and Palliative Care Indicator Tool (SPICT) is a commonly used tool and was designed using a practical evidence-informed guide to identify patients at risk of dying and who require palliative care alongside curative treatments.

As per the SPICT tool, look for 2 or more general indicators of deteriorating health:

- ✦ A poor or deteriorating performance status (in bed or chair for >50% a day)
- ✦ Dependent on others for most care needs due to physical and / or mental health problems
- ✦ 2 or more unplanned hospital admissions in the past 6 months
- ✦ Significant weight loss (5-10%) over the past 3-6 months, and / or a low body mass index
- ✦ Persistent, troublesome symptoms despite optimal treatment of underlying condition(s)
- ✦ Patient asks for supportive and palliative care, or treatment withdrawal
- ✦ Specifically for cancer:
 - ✓ *Functional ability deteriorating due to progressive metastatic cancer*
 - ✓ *Too frail for oncology treatment or treatment is for symptom control*

Common Problems that need to be Addressed

- ✦ Management of pain
- ✦ Preventing discomfort
- ✦ Care of open sores
- ✦ Preventing bedsores

- ✦ Preventing constipation
- ✦ Breathlessness
- ✦ Nausea and vomiting
- ✦ Emotional distress
- ✦ Incontinence

In Order to Provide Palliative Care, the Individual needs:

- ✦ Compassion
- ✦ Trust
- ✦ Communication
- ✦ Honesty
- ✦ Patience
- ✦ Time
- ✦ Knowledge and skill
- ✦ Sense of humour

Principles of Pain Management

- ✦ Correct assessment of pain
 - ✓ *Always check that the patient is taking their medication correctly and then obtain more details about the pain.*
 - ✓ *The PQRSSTT method is helpful:*
 - P** – *what provokes the pain?*
 - Q** – *quality of pain, e.g. burning, sharp, stabbing, dull ache, tingling?*
 - R** – *does the pain radiate anywhere else in the body?*
 - S** – *site: where is the pain?*
 - S** – *severity: how bad is the pain on a scale of 0 (no pain) – 10 (severe pain)?*
 - T** – *timing: when is the pain particularly bad?*
 - T** – *treatment: what is the patient taking and does it help?*
- ✦ Choice of the best medication
- ✦ Correct dose and timing of the medication

- ✦ Correct frequency
- ✦ Managing side effects of the medication
- ✦ Emotional support to the patient and family

Analgesia

- ✦ Should be given orally when possible
- ✦ It must be given regularly and according to a strict schedule
- ✦ It is important to prevent or reduce pain rather than only to treat it when it is already present
- ✦ The commonly used analgesics include the following:
 - ✓ *Mild pain: paracetamol 1g 4-6hrly*
 - ✓ *Moderate pain: Diclofenac (Voltaren) 25-50mg or Ibuprofen (Brufen) 200-400mg 8hrly*
 - ✓ *Amitriptyline (Trepiline): 10-25mg*
- ✦ Relieves neuropathic (nerve) pain
- ✦ It is best taken at night before going to sleep
 - ✓ *Severe pain: Morphine (or Tramadol)*
- ✦ Excellent for severe pain
- ✦ Give oral morphine whenever possible
- ✦ Always shake the bottle before use
- ✦ Give the sufficient dose to relieve pain
- ✦ Give it every 4 hours
- ✦ Remember to manage the side-effects of morphine proactively

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Pierce, D.(2009). Breast health education: Postradiation. *Journal of Radiology Nursing*, 28 ,3. doi:10.1016/j.jradnu.2008.12.006

PART 2

Role of the Breast Health Navigator

WHAT IS A PATIENT NAVIGATOR AND THE HISTORY BEHIND IT

A patient navigator is an individual, usually a healthcare professional, that focuses on patient needs as the patient goes through a medical journey. A patient navigator walks alongside a patient and guides them along their journey assisting with barriers, challenges and processes along the way. This aids the patient in receiving timely and required care throughout their cancer journey.

Cancer navigators are trained to identify barriers to care. By resolving the barriers, the cancer navigator ensures that the patient receives and adheres to the treatment prescribed. This in turn generally improves the patient's cancer outcome.

Cancer navigators that are trained cancer nurses will coordinate care and treatment amongst a team of health care providers from a multidisciplinary team. These cancer nurse navigators guide patients along their cancer treatment journey and also advocate for them and their close family. This assists in the patient having a less challenging, and therefore a more seamless, cancer management journey.

The first patient navigation program was thought of and initiated in 1990 in Harlem, New York by Dr Harold Freeman. It focused on the window of opportunity to save people's lives from cancer by eliminating barriers to timely care between the point of a suspicious finding and the resolution of the finding by further diagnosis and treatment*

The scope of patient navigation has changed greatly over time and in most situations in the present way of navigation, scope has been expanded include the whole continuum of care:

- ✦ Prevention
- ✦ Detection

- ✦ Diagnosis
- ✦ Treatment
- ✦ Survivorship
- ✦ Palliative care*

Dr Harold Freeman and Rian Rodriguez identified the following *9 principles* in their article on the history and principles of patient navigation:

1. *Patient navigation is a patient-centric healthcare service delivery model.*
 - ✦ This means that the patient is placed in the centre of their journey
 - ✦ The journey begins from diagnosis and continues all the way through into survivorship or end of life care
 - ✦ The patient remains at the centre throughout their journey and should receive holistic care in a sometimes complicated healthcare system
2. *Patient navigation serves to virtually integrate a fragmented healthcare system for the individual patient.*
 - ✦ This describes how patient navigation is used as a guide for patients going through a complex system of care and allowing for as smooth and timeous a journey as possible
3. *The core function of patient navigation is the elimination of barriers to timely care across all segments of the healthcare continuum.*
 - ✦ This is managed by having a one-on-one relationship between the patient and the navigator
4. *Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers.*
 - ✦ The navigator should have a defined role and place within the multidisciplinary team
5. *Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum.*

6. *The determination of who should navigate should be determined by the level of skills required at a given phase of navigation.*
 - ✦ This describes that there are different types of navigators. Individuals can range from a member of the community to trained individual to a nurse
 - ✦ The type of navigator required will depend on what is required by the patient
7. *In a given system of care there is the need to define the point at which navigation begins and the point at which navigation ends.*
 - ✦ An assigned navigator will be present for a designated period of time through the patient's journey
 - ✦ This may begin at a consultation or only once the patient commences treatment. It may end at the end of treatment or continue into survivorship or end of life care
8. *There is a need to navigate patients across disconnected systems of care, such as primary care sites and tertiary care sites.*
 - ✦ Patient navigation is especially important in situations where healthcare systems are fragmented. Fragmented healthcare systems are seen more frequently in low to middle income countries.
9. *Patient Navigation systems require coordination.*
 - ✦ A patient navigator may work with only 1 patient or many patients
 - ✦ The navigator needs to have a co-ordinated plan and needs to understand and work within a navigation system
 - ✦ There should be a leader in the navigation system to co-ordinate the navigators working within the system*

*Freeman H, Rodriguez RL. *History and principles of patient navigation. Cancer.* 2011;117:3539-3542.

If one looks at the term “poor” it essentially means that a person has no choice in decision making. In a report by the American Cancer Society’s 1989 *Report to the Nation: Cancer in the Poor**, 5 of the most critical issues related to cancer among the poor were identified:

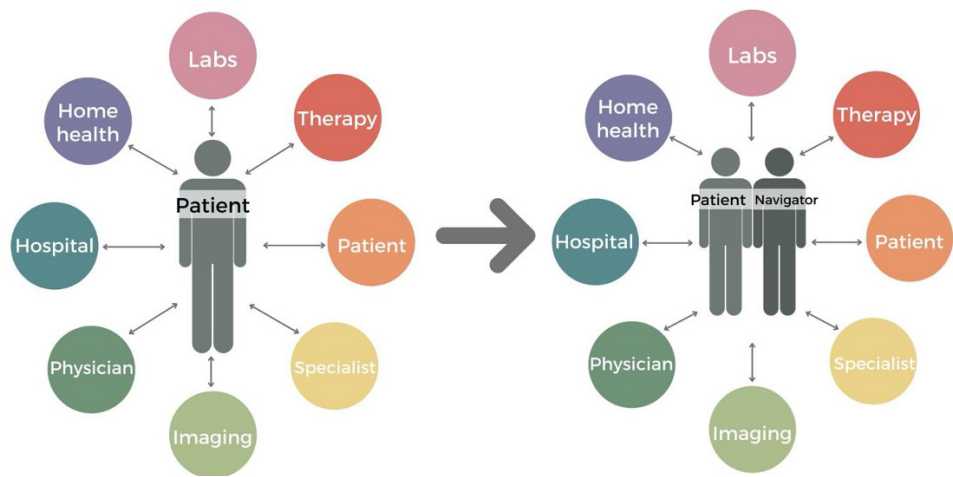
1. Poor people endure greater pain and suffering from cancer compared with other Americans
2. Poor people and their families must make personal sacrifices to obtain and pay for care
3. Poor people face obstacles in obtaining and using health insurance and often do not seek care if unable to pay for it
4. Cancer education programs are culturally insensitive and irrelevant to many poor people
5. Fatalistic ideas about cancer are prevalent among the poor and prevent them from seeking care.

**American Cancer Society (ACS). A summary of the American Cancer Society Report to the Nation: cancer in the poor. CA Cancer J Clin. 1989;39(5):263-265.*

Although the above report is an old report, one can see how this is still relevant to modern day healthcare in many low to middle income countries.

It is commonly said that the patient should remain at the centre of his / her care. This is known as patient-centered care. This means that the patient actively participates in their care plan in close cooperation with the healthcare professionals. Patients should understand their care plan, be a part of it and be involved with the decisions re their management. Being at the centre of their care also allows for access to support structures additional to not only their primary health care provider.

A patient navigator should be at the centre with the patient. They are part of the patient’s care plan. They assist the patient with understanding of their condition, coordination of their care plan, addressing barriers to care, interpretation and access to supportive services.



SCOPE OF PRACTICE



The National Cancer Institute describes a patient navigator as the following:

“A person who helps guide a patient through the healthcare system. This includes help going through the screening, diagnosis, treatment, and follow-up of a medical condition, such as cancer.

A patient navigator helps patients communicate with their healthcare providers so they get the information they need to make decisions about their health care.

Patient navigators may also help patients set up appointments for doctor visits and medical tests and get financial, legal, and social support.

They may also work with insurance companies, employers, case managers, lawyers, and others who may have an effect on a patient’s healthcare needs.

Also called patient advocate.”



In order to complete these tasks, a patient navigator is required to work within a scope of practice to ensure that all the patient requirements are met in a competent and legal way. Scope of practice varies from navigator to navigator as not all navigators hold the same qualifications.

The American Nurses Association describes scope of practice as the “services that a qualified health professional is deemed competent to perform, and permitted to undertake – in keeping with the terms of their professional license.”

Patient navigators need to understand their role within the patient's journey.

A patient navigator, unless a trained medical professional, cannot:

- ✦ Diagnose
- ✦ Perform physical assessments
- ✦ Provide hands on care
- ✦ Treat disease
- ✦ Counsel patients

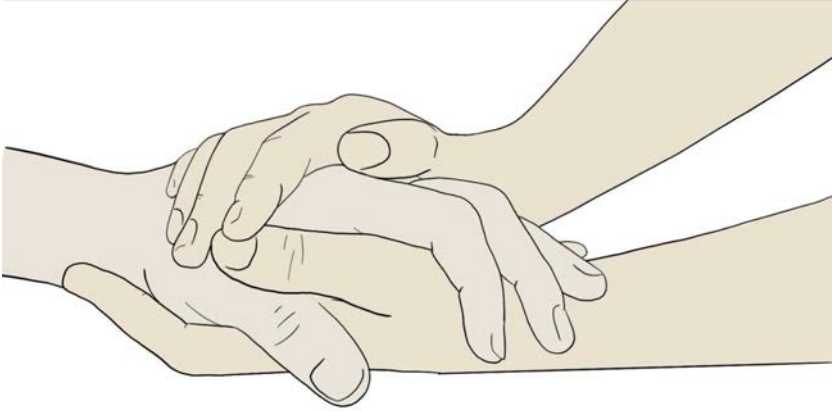
Navigators need to work according to core competencies and their professional qualification as there is no documented scope of practice specifically for patient navigators. It is important that boundaries are set at the beginning of the navigation process and that the navigator remains within these said boundaries. This will assist with distinguishing between a professional and a social or personal relationship.

Patients may ask for help or assistance with tasks that may not be part of the navigator's professional role. It is not always easy to say no, especially when one is dealing with a patient who may be very vulnerable. This is why it is very important to have boundaries from the beginning of the relationship with the patient and for the patient to be made aware of these at the start of the journey. This ensures that the relationship between patient and navigator remains professional throughout the patient's journey.

A patient navigator is not the same as being a person's friend. Conflicts of interest could easily happen in this situation. This does not mean that the navigator is not friendly with the patients but they need to maintain a professional working relationship through their journey. Navigators are assistants or guides for patients.

Patient navigator

assisting you along every step of your journey



The scope of practice of various health care professionals may have overlapping functions however, there are certain functions that only trained and qualified health care providers can complete.

Medical doctor or physician

= can diagnose, treat and manage the symptoms of a disease. They oversee the general health of the patient.

Nurses

= in general, are there to administer prescribed treatment, monitor side-effects and provide care. Nurses also assess physical and psychological response to illness and therapy.

Social workers

= provide counselling, treat and manage mental health issues and also assist with the co-ordination of general services.

Community health workers

= usually promote screening and prevention.

Patient advocates

= assist with advocacy issues and provide education or awareness drives for the community.

Case managers, clinic co-ordinators or medical record keepers

= these people work in administration and co-ordinate and facilitate patient care from a records point of view.



These, and many more make up the healthcare team

Types of information provided by various navigators will vary depending on training or education and the professional level of the navigator. All navigators should have general knowledge on health issues but for example, an oncology navigator should have knowledge on cancer from diagnosis through treatment and into survivorship or palliative care.

Referring back to the description of a patient navigator by the National Cancer Institute - a patient navigator guides a patient through the health care system. The navigator should therefore have an understanding of the healthcare system and processes and should be able to provide the assistance required by the patient as they go through their medical journey.

Nurse Navigator

- = a professional registered nurse with oncology based knowledge
- = navigates through all phases of the cancer continuum

Patient Navigator

- = has a basic understanding of cancer, healthcare systems and access to care
- = assist patients with access to information, support and resources

Social Work Navigator

- = social worker with oncology specific knowledge
- = assists with overcoming barriers to care generally specific to the healthcare system and patients psychological assessment

Other Navigator Types

- = financial
- = volunteers

In their guidelines, the South African National Department of Health Clinical Guidelines for Breast Cancer Control and Management provides the concept of a patient navigator, which is not a formal qualification or post, but a delegation of the nurse / counsellor who will take the responsibility of being a contact between the patient and the healthcare system.

They state that a patient navigator aims to address the following barriers to care:

- ✦ Psychological
- ✦ Medical systems
- ✦ Socio-economic
- ✦ Communication/Informational.

As per the policy, patient navigators should be placed at:

- ✦ The District/Regional Hospital
- ✦ Hospital where oncology care is provided

- ✦ Community (usually not-for-profit organisation (NPO) driven)

The aim is that this leads to earlier presentation, better compliance and improved treatment outcomes.

In summary, the scope of practice of the patient navigator is determined by the qualification of the said navigator.

Activity 2.1

- ✦ What is your professional designation if you have one?
- ✦ Do you know your scope of practice and how it would apply to you in a navigation role?

Make sure that you understand your role and scope of practice before you guide a patient through their journey in the healthcare system.

CORE COMPETENCIES

Navigators may have many roles. Depending on the needs of the patient and family and the type of navigation programme that the specific individual has completed, the navigator should have knowledge in health promotion, experience within a healthcare setting, effective communication, teamwork and leadership skills.

Core competencies for all healthcare professionals have been described by the Institute of Medicine (IOM, 2003) as the following:

1. patient-centered care
2. teamwork and collaboration
3. evidence-based practice
4. quality improvement
5. informatics

The Health Professions Education: A Bridge to Quality describes these 5 core competencies as follows:

1. *Provide patient-centered care Competency:*

- ✦ identify, respect, and care about patients' differences, values, preferences, and expressed needs
- ✦ relieve pain and suffering
- ✦ coordinate continuous care
- ✦ listen to, clearly inform, communicate with, and educate patients
- ✦ share decision making and management
- ✦ continuously advocate disease prevention, wellness, and promotion of healthy lifestyles, including a focus on population health

2. *Work in interdisciplinary teams Competency:*

- ✦ cooperate, collaborate, communicate, and integrate care in teams to ensure that care is continuous and reliable

3. *Employ evidence-based practice Competency:*

- ✦ integrate best research with clinical expertise and patient values for optimum care
- ✦ participate in learning and research activities to the extent feasible

4. *Apply quality improvement Competency:*

- ✦ identify errors and hazards in care
- ✦ understand and implement basic safety design principles, such as standardization and simplification
- ✦ continually understand and measure quality of care in terms of structure, process, and outcomes in relation to patient and community needs
- ✦ design and test interventions to change processes and systems of care, with the objective of improving quality

5. *Utilize informatics Competency:*

- ✦ communicate, manage knowledge, mitigate error, and support decision making using information technology.

Although the above core competencies are for healthcare professionals, one can see how they overlap with the work of a navigator, who more often than not, is already a healthcare professional to begin with.

Patient navigators should provide one-on-one assistance to patients as they go along their medical journey. Navigation should be provided through the following processes:

- ✦ Prevention and Risk Reduction
- ✦ Screening
- ✦ Diagnosis
- ✦ Treatment
- ✦ Survivorship
- ✦ Palliative Care

Activity 2.2

The terms below are all related to a patient's medical journey. Place each of the terms in their applicable column: (the answer is provided at the end of this chapter)

PREVENTION / RISK REDUCTION	SCREENING	DIAGNOSIS	TREATMENT	SURVIVORSHIP	PALLIATIVE CARE

- ✦ Diet
- ✦ Genetic testing
- ✦ Decreasing alcohol intake
- ✦ Biopsy
- ✦ Staging investigations
- ✦ Hospice care
- ✦ Surveillance for recurrence
- ✦ Sun Exposure
- ✦ Pathology report
- ✦ Exercise
- ✦ Radiotherapy
- ✦ Smoking cessation
- ✦ Gender specific screening
- ✦ Bereavement care
- ✦ Age specific screening
- ✦ Surgery
- ✦ Surveillance for new primary
- ✦ Immunization
- ✦ Systemic therapy

A patient navigator works with not only the patient but also other health care professionals to establish and maintain respect, trust, care, dignity and participation of that patient in their care.

Patients require empathy, compassion and they deserve their treating health care professionals to have an understanding of their cultural and socioeconomic backgrounds. Navigators need to be able to have good communication skills and the ability to establish effective and trusting working relationships with the patients.

Navigators will come into contact with many health care professionals as they journey with the patients. The navigator should build professional relationships with the healthcare team by understanding the role of each member and ensuring that each member knows who the navigator is and what their role is for the patient.

Navigators will also communicate and work with allied resources for the patients they are assisting therefore it is also vital to develop professional relationships with these members of the team. Having open and good communication with allied resources makes getting assistance for patients in a time of need much easier.

ATTRIBUTES/CHARACTERISTICS OF THE BREAST HEALTH NAVIGATOR

The below skills and abilities pertain to most types of patient navigators although these have been specifically written for a breast health navigator.

The breast health navigator should have the following skills and abilities:

- ☐ Previous experience in the breast cancer field (e.g. breast nurse)
- ☐ Detailed knowledge about breast cancer – from prevention to diagnosis through to treatment and survivorship or palliation
- ☐ The navigator should have witnessed a tissue biopsy and where possible, attend a breast cancer operation
- ☐ The navigator should have an understanding of, and have witnessed, a mammogram and ultrasound
- ☐ The navigator should have visited an oncology unit where chemotherapy and radiotherapy are administered
- ☐ Good communication skills (verbal, non-verbal and written)
- ☐ Organised and good planning skills
- ☐ Ability to communicate effectively with healthcare providers, patients, family and anyone involved with the patients care
- ☐ Appropriate documentation skills (e.g. written or computer data)
- ☐ Effective participation within a team
- ☐ Counselling and teaching skills
- ☐ Ability to interact with people from a variety of cultural and social backgrounds
- ☐ An understanding or involvement with breast cancer programmes, NPO's or advocacy programmes
- ☐ Remain up to date with patient navigation information

The South African National Department of Health Clinical Guidelines For Breast Cancer Control And Management states that patient navigators should have the following strengths:

- ✦ Strong interpersonal and communication skills
 - ✓ *navigation is centered around communication therefore having strong interpersonal and communication skills is vitally important*
- ✦ Culturally sensitive
 - ✓ *in South Africa and many other low to middle income countries, there are always many different cultures to take into account. The culture of the patient should not influence the care provided by the navigator*
- ✦ Computer literate
 - ✓ *being computer literate assists in many ways, from communication with the patient, monitoring of the patient over time and capturing data, all of this can be done with the assistance of technology*
- ✦ Patient-advocacy focus
 - ✓ *patient navigators not only guide patients along their journey but also advocate for them with regards to access to care, management, fair and timeous treatment*
- ✦ Understands hospital processes, structure and function
 - ✓ *in order to navigate a patient through a system, the navigator needs to have an understanding of the system, the facilities of care and the treatments the patient will be receiving*

While not all treatment facilities will have all of the below, navigators may have to interact with some or most of the below professionals:

- ✦ Medical oncologists
- ✦ Radiation oncologists
- ✦ Surgeons
- ✦ Radiologists
- ✦ Pathologists
- ✦ Geneticists

- ✦ Pharmacists
- ✦ Clinical trial staff
- ✦ Physical therapists
- ✦ Nurses
- ✦ Chaplains / other religious leaders
- ✦ Occupational therapists
- ✦ Lymphoedema therapists
- ✦ Dieticians
- ✦ Social workers
- ✦ Financial workers

JOB DESCRIPTION

Think back to the core competencies module as you work through this next section.

The requirements or job description of a patient navigator will differ depending on the patient's home location and place of treatment. The job description is also dependent on the skill set of the navigator and therefore their scope of practice.

Ideally, once a patient is diagnosed, he or she should meet with the navigator. Meeting at this early stage allows the relationship between the patient and navigator to start as early as possible. It allows the navigator to be involved from the beginning of the patient's journey.

Not all patients will want to discuss their management or personal feelings or concerns at this stage as they may be feeling overwhelmed from their new diagnosis or potential diagnosis if investigations are still underway. The journey ahead may feel like a huge challenge and the patient may be intimidated by the navigator for reasons such as the navigator being a complete stranger and the lack of understanding at that point as to why they would need to have a navigator. It is however important to make the connection and meet if possible. This will aid in building trust with the patient and whoever else may be with the patient such as a family member or caretaker.

By meeting and assessing the patient's distress level and immediate barriers, a care plan can be developed in the early stages of the patient's journey allowing the patient to be able to focus on important matters such as making informed decisions and be active within their care and management options. The navigator should do a distress screening on the initial visit and subsequently at any times of greater risk for distress such as:

- ✦ Pre or post-operative visits

- ✦ Consultations with oncologist
- ✦ Initiation of any type of treatment (e.g. chemotherapy, radiotherapy, endocrine therapy)
- ✦ Transition into survivorship or palliation.

Examples of questions to ask may be, but are not limited to, the following:



Responsibilities of the navigator may include, but are not limited to, the following:

Navigator responsibilities		Identify barriers to care (poor health literacy, language barriers etc.) and provide resources or referral as appropriate. Understand that barriers may occur outside of the diagnostic and treatment facilities (e.g. transport, financial, social)	Ensure the ongoing assessment and support of the patients' physical, mental, emotional, spiritual, educational, sexuality and family needs
Ensure holistic care is provided to the patient incl. their overall health and wellbeing	Ongoing communication with the patients' medical team		Reduce anxiety and fear by providing counselling and education
Assist patients with insurance claims and documentation	Assist with transitional care between providers, departments and facilities if applicable		Practice principles of infection prevention and all standard precautions for the patient and navigator safety
Ongoing communication and response to patient enquiries throughout the journey	Assist with coordinating transportation services as needed		Explain diagnosis, test results and treatment plans to patient and family members
Ensure patients understand their legal rights	Confirm and remind patients of future appointments		Facilitate, coordinate and attend, as needed, appointments with treating medical professionals

The South African National Department of Health Clinical Guidelines For Breast Cancer Control And Management states the following are the roles and responsibilities of a breast nurse / breast patient navigator:

A. District / Regional Hospital (within the specialist breast clinic):

- Patient education
- Tracking biopsy results
- Facilitating referral to the breast MDT
- Networking with other NN/PN
- Psychosocial support

B. Hospital where oncology care is provided:

- Provide patient and caregiver education
- Ongoing psychosocial support
- Assist the patient with treatment decision making
- Assist or make referrals to allied healthcare workers, not in the immediate MDT, such as social worker, dietician
- Assist or facilitate transportation arrangements when it is a barrier to care
- Track interventions and outcomes
- Contact patients where appointments are missed

C. Community:

- this is usually NPO (not-for-profit organisation) driven

IDENTIFYING AND ADDRESSING BARRIERS TO CARE

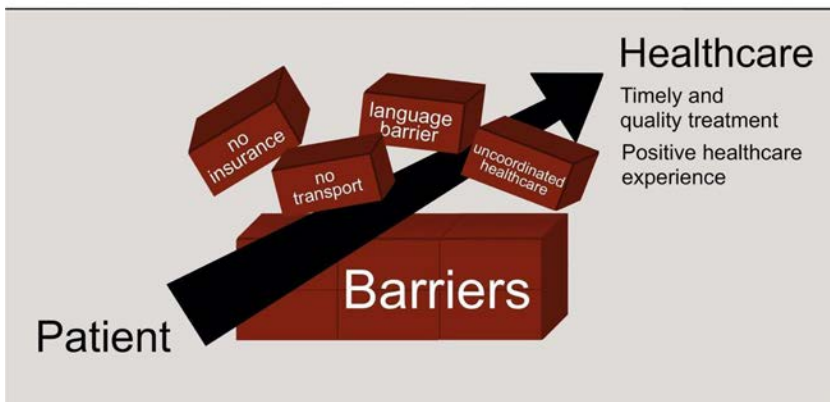
A ‘barrier to care’ is described as a situation that makes treatment difficult. Another word for barrier is an obstacle.

Patients face many barriers to care through their journey in the healthcare system. In certain countries, healthcare systems are more fragmented than in others. Patient navigators are vitally important especially in places with fragmented health care systems seen mostly in low to middle income countries as a part of the navigators role is to identify and address barriers that the patient will encounter along their journey.

Patients that are underserved or uninsured often face the most barriers to care and experience the most delays in receiving a diagnosis and going on to receive treatment. Patient navigators should work with the patient and alongside the healthcare team and where possible, assist in providing solutions to the barriers.

In most cases, the fewer barriers that a patient has to face, the more compliant they will be with treatment and, although not in all cases, generally the better the outcome will be from their disease.

The role of a Patient Navigator



In order to assist a patient with their barriers to care, a navigator should be able to provide or connect patients with the appropriate resources and support. Navigators should know how to ask the relevant questions to get an appropriate response from the patient. For example, a navigator could ask a patient, “what is the main reason you would not be able to attend a medical follow up appointment?” The answer should guide the navigator as to what referral or assistance is required. Navigators should also streamline appointments or paperwork when necessary to prevent delays in the system for patient care.

A patient navigator must be able to address, develop and implement plans or interventions to assist a patient with barriers to care.

Barriers to care can be divided into 2 sections:

- ✦ system barriers (those that exist at the healthcare system level)
- ✦ personal / social barriers (those that exist at the individual patient level).

Below are examples of barriers to care that patients may face, along with possible solutions:

Barrier Type	Specific Barrier	Solution
System Barriers	<ul style="list-style-type: none"> - <i>Poor coordination of care / scheduling care</i> - <i>No access to patient navigator</i> - <i>No / inadequate medical insurance</i> - <i>Immigration status</i> - <i>Lack of trained health care providers</i> 	<ul style="list-style-type: none"> - <i>Try to coordinate appointments for the patient</i> - <i>Ensure that the patient keeps their records from appointments and takes them to all future appointments</i>
Socio-economic / Financial Barriers	<ul style="list-style-type: none"> - <i>No medical insurance</i> - <i>Inadequate insurance</i> - <i>Treatment costs</i> 	<ul style="list-style-type: none"> - <i>Direct patient to NPO's that may provide financial assistance</i>

Logistical Barriers	<ul style="list-style-type: none"> - <i>Minimal access to transportation</i> - <i>No reliable transportation</i> - <i>Transportation costs</i> - <i>Living a far distance from treatment facilities</i> - <i>No access to child care</i> - <i>Long wait times (e.g. overloaded clinics)</i> - <i>Delayed appointments</i> - <i>Inconvenient appointment times</i> - <i>Medical and work schedule conflicts</i> 	<ul style="list-style-type: none"> - <i>Assist patient in sourcing resources that may provide transportation</i> - <i>Direct patient to treatment facility provided transportation services</i> - <i>Assist with arranging child care by asking community neighbours, friends or family</i>
Education	<ul style="list-style-type: none"> - <i>Low level of health literacy</i> - <i>Minimal ability to complete medical forms</i> 	<ul style="list-style-type: none"> - <i>Explain processes as they happen to ensure the patient understands</i> - <i>Assist with completing paperwork required</i>
Cultural / Language / Communication Barriers	<ul style="list-style-type: none"> - <i>Cultural beliefs re treatment</i> - <i>Difficulty speaking or reading the primary language used by the healthcare team</i> - <i>Fear of the healthcare system</i> - <i>Lack of knowledge of the diseases</i> - <i>Poor communication</i> - <i>Stigma surrounding the disease</i> - <i>Lack of interpreters</i> 	<ul style="list-style-type: none"> - <i>Assist with guiding the patient to local NPO's that may assist with stigma / cultural issues</i> - <i>Have a list of interpreters or local community members or survivors that can assist with interpretation</i>
Emotional / Psychosocial Barriers	<ul style="list-style-type: none"> - <i>Fear (of diagnosis, treatment, side effects, economic problems)</i> - <i>Stress, anxiety and depression</i> - <i>Mental health issues</i> 	<ul style="list-style-type: none"> - <i>Direct patients to supports groups or have a buddy system making use of survivors from the local community</i> - <i>Explore the option of a social worker</i>

Cultural beliefs, including myths and stigma, play a large role in barriers to care for many patients. This will be discussed in more detail in the “Cultural Awareness and Competency” section.

De-Educating or “unlearning” followed by Re-Educating:

The concept of de-educating a person to allow for re-education may result in the patient approaching their condition in a more positive way. Myths and stigma surrounding breast cancer can cause a patient with a new breast cancer diagnosis to have many thoughts and concerns that many be of no relevance to their condition.

A patient navigator should speak to a patient upon diagnosis and should ask the patient what fears and thoughts or understanding they have about their diagnosis and condition.

The navigator can provide a safe space for patients to talk about this as patients may be nervous, anxious, concerned or even embarrassed to discuss what they are thinking.

The navigator may have the answers to some of their points and navigators should research and keep up to date with common myths and stigma surrounding breast cancer. Patient navigators may however not have all the answers and will need to discuss certain questions with the treating doctor. In this case, the navigator can note the points from the patient and explain that he or she will get the answer and get back to them as soon as possible. It is important to remember that as a navigator, one does not have to have all the answers all the time!

Once these myths and stigmas have been addressed, whether directly by the patient navigator or indirectly via the doctor, the patient may feel better educated and it may assist in the patient having a more positive association with their diagnosis or condition.

A well-known Breast Clinic in Cape Town, South Africa, (with permission obtained to share the following information), held open conversations between their medical students and patients in the breast clinic re their barriers to care. 47 patients spoke about their specific barriers. The average

age of the patients was 55 years old (a range from 19 – 82 years).

The table below indicates the barriers to care for these specific patients:

Problem	Number of Patients	Percent
Transport	20	41%
Communication / Knowledge	14	29%
Financial concerns	8	17%
Psychological / Support / Psychosocial	8	17%
Staff in Clinic / Hospital Issues	8	17%
Waiting Times	7	14%
Primary Health Care System Issues	4	8%
Family Concerns	4	8%
Physical Effects	2	4%
Stigma	2	4%
Accommodation Near Hospital	2	4%

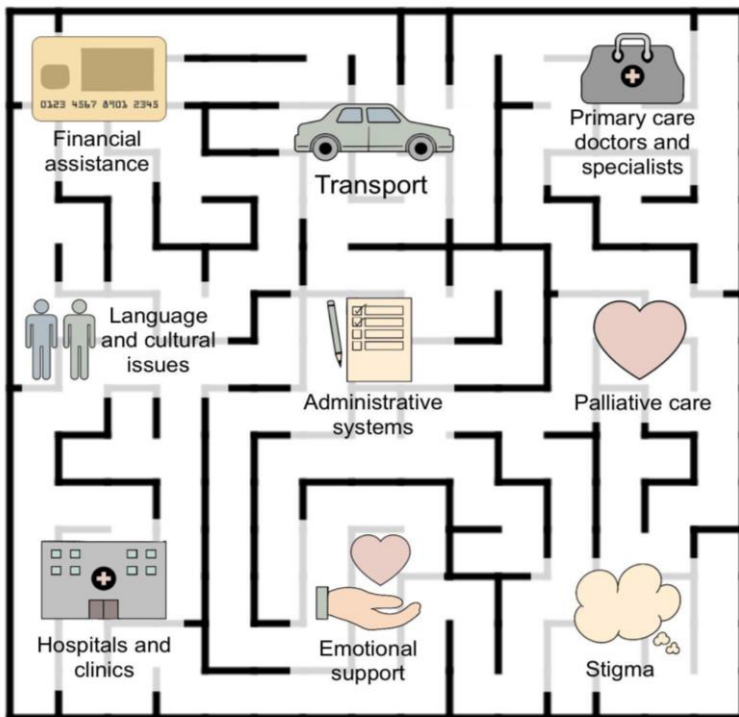
As one can see, the top 3 barriers to care for these patients were transport issues, communication / knowledge and financial concern. These are very common barriers to care seen especially in low to middle income countries.

The patients in this specific breast clinic currently do not have a patient navigator to assist them with these barriers although many additional practices have been put into place to assist. For example, there is a transport fund for patients with transport issues, there is availability of a patient counsellor, and local NPO’s work with the clinic to provide services such as care packs and prosthesis post mastectomy. One can see how a patient navigator would be able to minimise many of the barriers as listed above as they would act as a point of contact for many of these patients.

One must remember that everyone can make a difference when it comes

to assisting patients with their needs - big or small. It is essentially about knowing what is locally available and who to contact for specific services. A patient navigator would ideally know, and have contact with many of the resources available and would streamline the process on how to refer a patient to the applicable person or place should it not be directly available within the treatment facility.

The image below depicts a maze and this gives an idea of how a patient going through the healthcare system may feel. Not only is the healthcare system a maze to navigate, it also has many challenges along the way. The role of the navigator should be to give the patient directions through the maze of the healthcare system and to assist with the challenges faced along the way.



Activity 2.3

Think about the following and then complete the activity below:

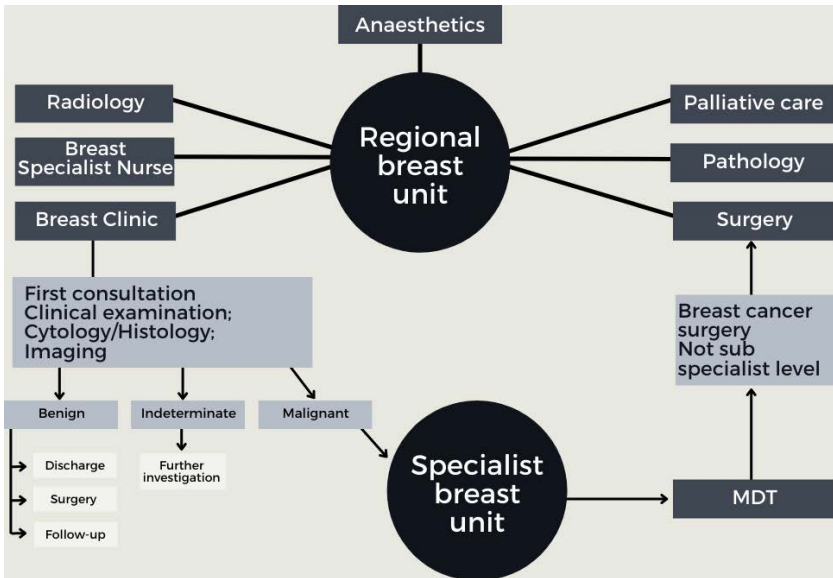
- ✦ What are the barriers to care that you see in your local clinics and hospitals?
- ✦ How do you address these problems?
- ✦ Do you have systems in place to assist patients with these barriers?
 1. Spend some time thinking about, and investigating this. Draw up a table similar to the one in this section to list the barriers to care that patients face in your local area. Once you have your list, focus on one of the barriers. List and describe the possible solutions or how you could assist to overcome this barrier.
 2. What specific cultural barriers are seen in your local area? Please describe these barriers and provide possible solutions.

REFERRAL PATHWAYS AND TIMELINES

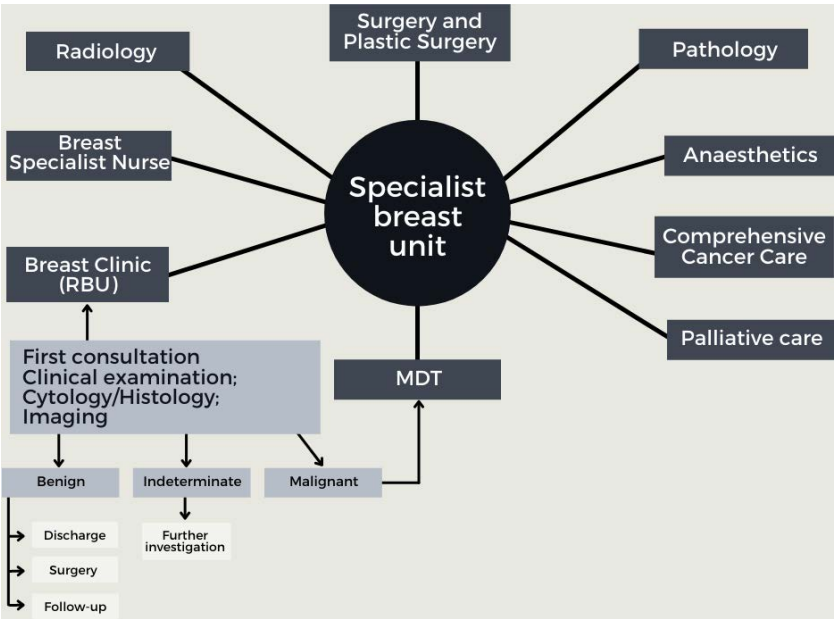
Referral Pathways

Below are examples of referral pathways in a regional breast unit and a specialised breast unit as adapted from the South African National Department of Health Clinical Guidelines For Breast Cancer Control And Management.

Service requirements for a Regional Breast Unit (RBU):



Service requirements for a Specialist Breast Unit (SBU):

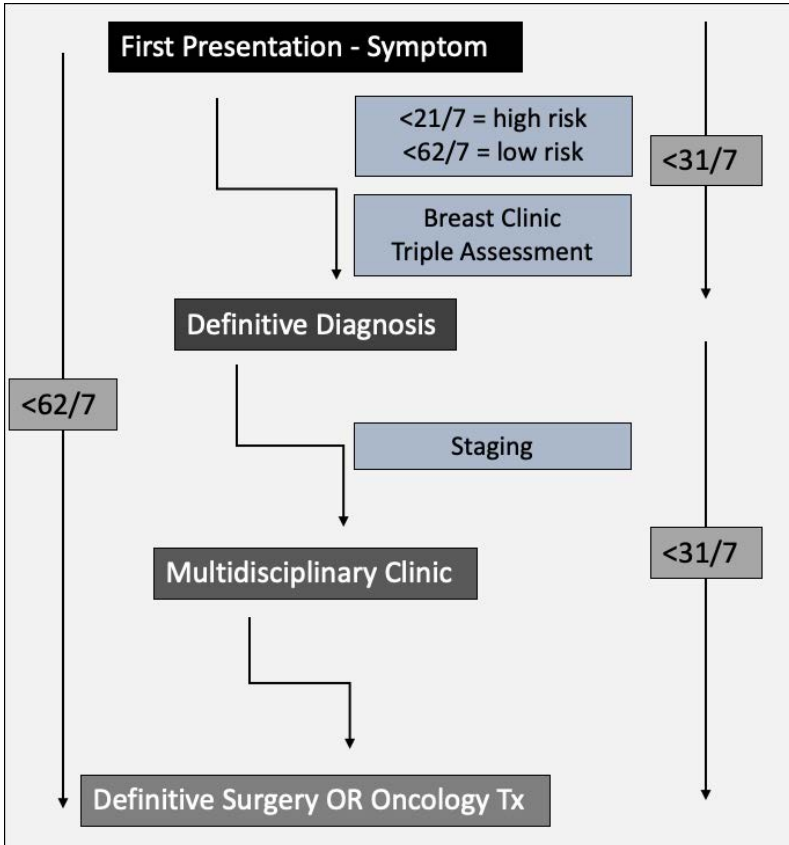


Timelines

There is often a delay from when a patient first notices a change in their breast to when they actually seek management or treatment. There may be many possible reasons for this. There should however be a standard timeline in place from once a patient presents at a clinic with a breast symptom until the point of definitive surgery or oncology management.

This timeline will differ from country to country and is dependent on the policy or standard of the given country.

Below is an adapted version of the timeline of patient care upon presentation of breast symptoms taken from the South African National Department of Health Clinical Guidelines For Breast Cancer Control And Management:



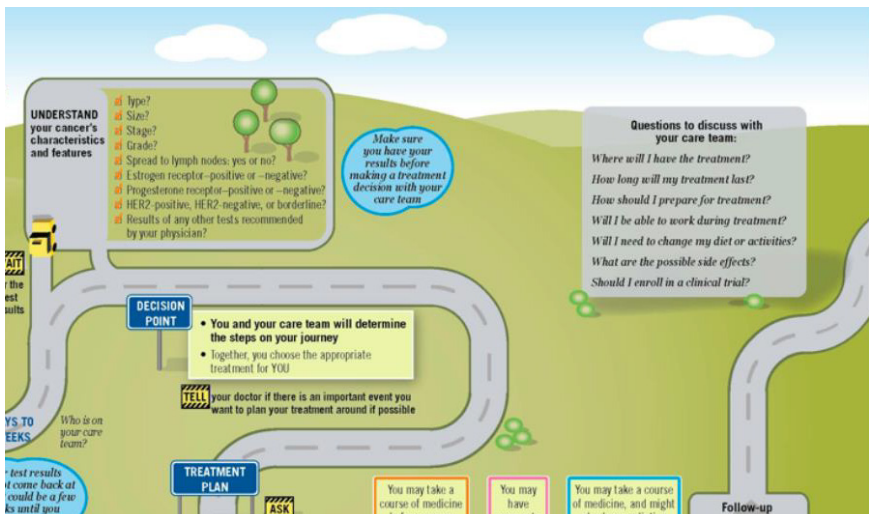
This diagram indicates that it should take no longer than a period of 62 days from presentation with a breast symptom to the patient receiving definitive surgery or oncology management. As in many countries, timelines are set up as a guide and provide a standard of care.

Realistically, these timelines are not always accurate and while some patients may go through the system in a shorter time, many or even most, will take longer to get through the system than the standard provided timeline.

Delays between presentation and definitive surgery or oncology management may include the following:

- ✦ multiple biopsies to get a diagnosis
- ✦ lack of transport to and from facilities to have investigations
- ✦ lack of funding to get to and from healthcare facilities
- ✦ poor health literacy
- ✦ lack of diagnostic equipment or trained professionals to use such equipment
- ✦ multiple discussions at multidisciplinary team (MDT) meetings due to not having all the required results available or MDT's not meeting on a regular basis
- ✦ overloaded systems (for example: appointments for staging investigations or availability of surgery lists)

Below is the “Steps on the Journey” diagram for early stage breast cancer broadly used in the USA:



<https://www.breastcancercourse.org/treatment-timeline/>

A common cause of delay in a patient receiving a diagnosis, being discussed at an MDT and ultimately receiving management, is not due to the patient but very often, a system issue. Examples includes:

- ✦ a delayed appointment at a breast clinic due to a continuous backlog of patients to be seen (including follow up of oncology patients)
- ✦ a delay in processing of specimens (e.g. FNAB or core biopsy) resulting in a delay in receiving the result
- ✦ overloaded treatment facilities that can only accommodate a specific number of patients (e.g. radiotherapy machine in an oncology facility)

Below are examples of patients from a public facility within South Africa.

Personal information has been changed to protect the patient's privacy. Once you have gone through these patient timelines, please complete the questions below.

Patient 1:

Mary is 68-year-old female.

She noticed a breast symptom in January 2020.

She went to her local clinic and had a fine needle aspiration biopsy (FNAB) on the 6th February 2020.

Mary then had an appointment at the Specialist Breast Clinic on the 10th November 2020.

At this appointment, she had a mammogram and a core biopsy.

Mary was given an appointment for a CT scan on the 23rd December 2020.

Mary did not pitch for this appointment, and it was later found out that she had returned home to her family in another province of the country.

It is unsure if Mary went home to seek traditional management for her breast disease or if she did not understand that she required urgent management.

Mary re-presented at the Specialist Breast Clinic on the 18th May 2021.

She was booked to have a new mammogram and also a CT scan on the 11th June 2021.

This unfortunately couldn't happen due to system errors, and she therefore had the CT scan on the 11th June and the mammogram on the 30th June.

She was discussed at the multidisciplinary team meeting (MDT) on the 30th July 2021.

When she initially presented, she had T2N0Mx breast cancer.

By the time she re-presented, she had progressed to have T2N1M0 breast cancer.

Mary was contacted and given an appointment on the 5th August 2021 to discuss her treatment plan.

Mary commenced with an Aromatase Inhibitor (AI) on the 12th August 2021.

Patient 2:

Rachel is a 57-year-old female.

In March 2021 she noticed a breast symptom.

She went to her local clinic and had a FNAB on 16th March 2021.

She was given an appointment for the Specialist Breast Clinic on 15th May 2021.

At this appointment, she had a mammogram.

Due to logistical reasons, she had a core biopsy 2 days later on the 17th May 2021 at the Specialist Breast Clinic.

She had a CT scan on 25th June 2021 and was then presented at the MDT on 2nd July 2021.

Rachel has T1N0M0 breast cancer.

She commenced with chemotherapy on the 8th July, the same day as her appointment for discussing her treatment plan.

Patient 3:

Lottie is a 62-year-old female.

In June 2020, Lottie fell and hurt her breast.

She noticed a change in her breast but presumed it was from the trauma of the fall.

She delayed getting it assessed due to the Covid-19 pandemic and lockdown.

Lottie had a FNAB on 18th May 2021.

Her appointment for the Specialist Breast Clinic was on the 7th June 2021 at which she also had a mammogram.

Lottie had a CT scan on 2nd July.

Needing further information, Lottie then had a core biopsy done on the 15th July.

She was discussed at the MDT on 30th July 2021.

Lottie has T2N1 breast cancer.

Lottie commenced with chemotherapy on 5th August 2021, the same day as her appointment for discussing her treatment plan.

Patient 4:

Felicia is a 48-year-old female.

In January 2021, she noticed a breast change and went to her local clinic.

She had a FNAB on 27th January 2021 and was given a date for the Specialist Breast Clinic on the 14th April 2021.

At this appointment, Felicia had a mammogram and a core biopsy.

Felicia was booked for a CT scan on the 10th May 2021 but she missed this appointment due to transport issues.

It was rebooked for the 10th June 2021.

She was discussed at the MDT on 11th June 2021.

Felicia has T4N1M1 breast cancer.

She had an appointment on 17th June to discuss her treatment plan.

Felicia commenced with chemotherapy on the 1st July 2021.

Patient 5:

Sindiwe is a 61-year-old female.

In August 2020, she noticed a breast change.

On the 3rd November 2020, she had a FNAB.

She was given an appointment at the Specialist Breast Clinic on the 25th November 2020.

She had a mammogram and core biopsy done at that appointment.

She was given an appointment for a CT scan on 17th December 2020 but she did not pitch for the appointment.

Sindiwe was not seen again at the Breast Clinic until she re-presented on the 11th May 2021. Sindiwe explained that she had returned to her home in another province.

She had decided that her breast cancer was not very serious and that it could wait as she wanted to be home over the Christmas period.

Only when she started developing other symptoms did she realise that she needed to return for treatment.

On the 11th May, Sindiwe had a mammogram and was booked for a CT scan on the 4th June 2021.

On the 11th June 2021, she was discussed at the MDT.

On the 17th June 2021, Sindiwe had an appointment to discuss her treatment plan.

She commenced with chemotherapy that same day.

Activity 2.4

Based on the service requirements for a RBU and SBU in South Africa and the example from the USA, spend some time researching your own countries service requirements.

1. *Do you have any service requirements already set up?*
2. *Where would you, as a patient navigator, fit into the service requirements?*

Activity 2.5

As per the previous activity, find out if your specific treatment facility or the local clinics or hospitals have a timeline that is used as a guideline for patients in the system.

Making use of the local timelines used in your facilities or the ones above (should you not have access to any standard local timelines), please answer the following:

1. *Are these timelines realistic?*
2. *What causes breakdown of the timeline in your specific area?*
3. *Where do we, as healthcare professionals, fall short in adhering to these timelines?*

Activity 2.6

As per the patient example provided in this section, please make use of patient examples from your local breast clinic or hospital that have gone through the diagnosis process and are currently undergoing treatment.

1. *Draw up the timeline for 4 patients draining from different areas.*
2. *Once you have drawn up the timeline, assess each of them to see where the delays are and why there are delays.*
3. *Are the delays due to the patient or the system?*
4. *Are any of the delays seen in all 4 of your patient examples?*
5. *Are there any specific delays that could easily be rectified?*

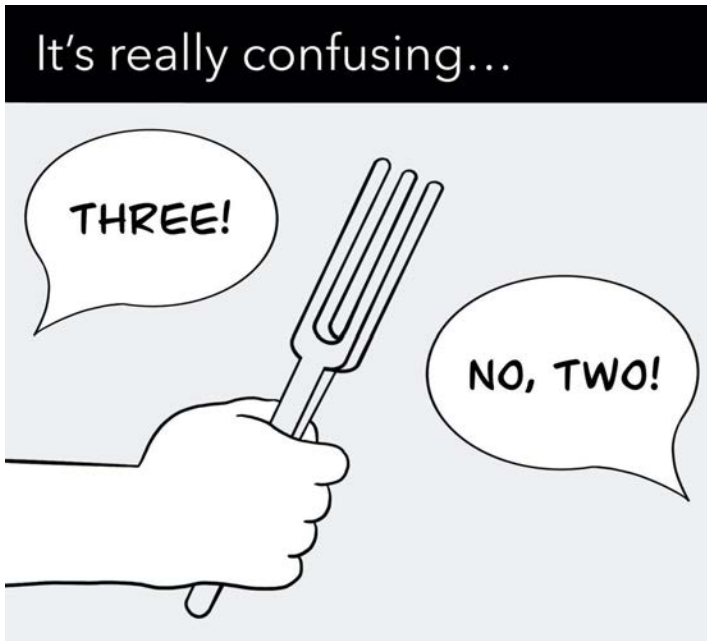
COMMUNICATION AND ADVOCACY

Merriam Webster defines communication as, “a process by which information is exchanged between individuals through a common system of symbols, signs, or behaviour”

There are 4 types of communication:

1. Verbal
2. Non-verbal
3. Written
4. Visual

Communication is a key aspect of navigating a patient through the healthcare system. There should be constant and clear communication channels between the health care providers, the patient and the navigator.



Communication should not be confusing.

When a patient navigator is introduced to a patient and their family, the navigator should start an assessment process.

Is the patient:

- ✦ ready to talk?
- ✦ ready to discuss the role of the navigator?
- ✦ ready to hear about support services?

This initial conversation and meeting sets the standard for the journey going forward. Remember that as a patient navigator, you are there to listen and provide support and not to instruct and set rules.

Actively listening to the patient and family allows the person to know that you are fully involved with them in that moment of time and that you are not distracted with other thoughts. When one actively listens, you take note of not only the verbal communication but also non-verbal such as facial expressions, tone and posture.

Navigators should remember the following quote by the author Stephen Covey, “Most people do not listen with the intent to understand; they listen with the intent to reply.” We are all quick to want to have our say. Remember to take a step back and first always listen to the patient.

The role of the navigator is not only to facilitate appointments or address barriers to care, they also need to be very aware of the patients’ needs. They need to listen. Listening provides support. It is a valuable tool to understand the patient. The most important part of communicating is not talking, but listening.

Whether listening to the patient, the patient’s family, caretaker or the healthcare provider, what happens when we listen?

- ✦ we convey and create trust and loyalty

- ✦ there is transparency with the relationship between the navigator and the patient, patients family, caretaker or healthcare provider
- ✦ the navigator will have the best interest of the patient, patients family, caretaker and the healthcare provider at heart
- ✦ one gains respect of one another
- ✦ the patient feels in charge and remains so in the management decision making process
- ✦ one feels cared for

Remember:

LISTENING
is not waiting to
 **SPEAK**

Importantly, the navigator should be able to communicate with the patient in the patient's home or primary language. The navigator also needs to assess and understand the patient's level of health literacy as it is of no use using medical terms or abbreviations if the patient does not understand these. This could go on to cause further fear or anxiety for the patient. The navigator needs to be the "interpreter" of difficult medical terms.

Activity 2.7

- ✦ What about communication is important to you?

Healthcare providers and in turn, navigators, may have to have difficult conversations with patients and their families or caretakers. These conversations may be to do with the cancer diagnosis, possible treatment options or prognosis.

The well-known SPIKES protocol provides a step-by-step framework for difficult discussions:

S – Setting

P – Perception

I – Invitation

K – Knowledge

E – Empathy

S – Summary / Strategy

Step 1: S – Setting up the Interview

- ✦ arrange for some privacy
- ✦ involve significant others
- ✦ sit down
- ✦ make connection with the patient
- ✦ manage time constraints and interruptions

Step 2: P – Perception

- ✦ use open ended questions to get a picture of how the patient perceives the medical situation

Step 3: I – Obtaining the Patient's Invitation

- ✦ patients do not always wish to know all details, therefore only offer answers to questions they may have

Step 4: K – Giving Knowledge and Information to the Patient

- ✦ start at the level of comprehension and vocabulary of the patient
- ✦ use nontechnical words
- ✦ avoid excessive bluntness
- ✦ give information in small chunks and regularly check the patients understanding

Step 5: E – Addressing the Patient’s Emotions with **Empathetic** Responses

- ✦ observe for emotion
- ✦ identify the emotion
- ✦ identify the reason for the emotion
- ✦ connect with the patient re the emotion

Step 6: S – Summary and Strategy

- ✦ provide a clear plan going forward to decrease anxiety or uncertainty

* <https://theoncologist.onlinelibrary.wiley.com/doi/epdf/10.1634/theoncologist.5-4-302>

Always keep the conversation open ended. Make the patient, their family or caregiver aware that you are listening and that you are focussed on them. Ask your patient questions and allow them to answer as a measure of their level of understanding.

Activity 2.8

A 40 year old mother of 2 young children is diagnosed with stage 3 breast cancer. She is told that she will need surgery, chemotherapy, radiotherapy and endocrine therapy. She has not yet been given details of her treatment but has been told that should she go ahead with the management, she should have a good prognosis. With minimal information provided at this stage by her healthcare provider, she is booked to see you, the patient navigator.

- ✦ Using the SPIKES protocol and communication techniques, briefly describe how you would have a discussion with this patient.

CULTURAL AWARENESS AND COMPETENCY

It is very difficult to change a person's beliefs if they have grown up learning and following specific cultural ways that have been a part of their belief system for many centuries.

Myths and Stigma

Myths and stigma are commonly heard terms when it comes to breast cancer. A myth can be defined as an incorrect belief, misinformation or a misconception or, the opposite of a fact.

Common myths surrounding breast cancer include the following:

- ✦ I can only get breast cancer if I have a family history of it
- ✦ deodorant causes breast cancer
- ✦ wearing a bra causes breast cancer
- ✦ eating a lot of sugar causes breast cancer
- ✦ having an annual mammogram will definitely pick up breast cancer in its early stage
- ✦ all breast cancer is treated in the same way
- ✦ breast cancer is contagious
- ✦ breast cancer always presents as a lump
- ✦ only older people get breast cancer
- ✦ only women can get breast cancer
- ✦ mammograms cause breast cancer

Stigma is generally the disapproval of, or discrimination against, a person based on perceivable social characteristics that serve to distinguish them from other members of a society (Wikipedia). Unfortunately, there is stigma related to breast cancer especially surrounding mastectomy and the loss of the female appearance.

Below are some figures from an African perspective with regards to breast cancer:

Kingham, Sierra Leone:

11% of people are unable to afford the transport costs to hospital

Nigeria:

38% of women are divorced within 3 years of having a mastectomy

Congo:

96% of women under the age of 50, present with locally advanced breast cancer at the time of diagnosis

Tanzania:

91% of women present with locally advanced breast cancer at the time of diagnosis

One can see from the above that although we know that poor health literacy and access to healthcare is a large cause of people presenting with locally advanced disease, myths and stigma surrounding breast cancer also play a role.

Many women will not want to consult with a healthcare provider when they notice a breast change as they may:

- ✦ culturally believe they brought the problem on themselves
- ✦ believe it is a spell as a result of witchcraft or other occult practices
- ✦ want to consult with a traditional healer as their primary caregiver
- ✦ be scared to be diagnosed with breast cancer as their culture may believe it is a bad omen, meaning the person will be shunned from their community
- ✦ be scared of having a mastectomy or surgery as this will result in their partner leaving them as they may feel that they are no longer female after the surgery or cancer management

Breast cancer and its management is challenging for anyone that is diagnosed. If one adds myths or stigma to this, it can become a very daunting and fearful experience.

Complementary and Alternative Medicine (CAM)

In simple terms, complementary medicine can be described as non-prescription medicine which is usually available from health shops, pharmacies and many other general shops. Unlike prescription or over-the-counter medication, complementary medicine is usually easily available for any customers. It is important for patients to check with their treating doctors if they can make use of complementary medicine especially when undergoing cancer management.

Patients are often reluctant to share their use of CAM with their treating doctors as they fear the response of the conventional doctor. It is important to educate your patients to share this information as it may have a direct effect on conventional medicine. For example, CAM may cause drug interactions with chemotherapy and certain CAM may cause bleeding in a patient undergoing surgery.

The term alternative medicine is used for medical products or practices that are not the standard of care. Alternative medicine is therefore used in place of conventional or standard medicine.

Complementary = used together with conventional medicine (e.g herbal powders or supplements)

Alternative = used in place of conventional medicine (e.g acupuncture)

Complementary and Alternative Medicine (CAM) is a mostly unregulated industry with no statutory professional regulation. Regulation is there to protect patients.

Unregulated industry means that anyone can call themselves a professional and can practice a form or treatment on a patient, even without training or experience as there is no standard of practice.

Internet access has become more readily and easily available and even in the poorest communities, smartphones are accessible and people therefore have access to information. Unfortunately, access to information does not mean that the information is accurate. As there is no moderation or editing of information freely found on the internet, sources can easily supply false or inaccurate information and are very often aimed at selling a product more than providing accurate information.

110 breast cancer patients (half from the private sector and half from the public sector) were asked questions regarding their use of CAM. This was done between hospitals located in Cape Town and Johannesburg, South Africa. Data showed that 20% of private patients and 8% of public patients made use of CAM pre-diagnosis. Post diagnosis with breast cancer, this figure changed to 45% use in private and 68% use in the public sector.

Supplement additions were as follows:

Private:	Public:
Vitamin C/D	Herbs
Omega 3	Green Tea
Cinnamon	Cannabis Oil
Turmeric	Black seeds (anti-cancer)
Probiotics	
Sutherlandia Powder	

Other modifications that were noted included use of homeopathy, massage, regular exercise, acupuncture, prayer, yoga and meditation.

If a patient chooses to use CAM, it remains their responsibility to inform their medical practitioner about what they are using and to ensure that they understand what they are taking and why. Many patients will make use of CAM simultaneously with their conventional treatment.



Is what we see really what we get?

Traditional Healers

In Koinan, Sierra Leone:

- ✦ 37% of women with a breast mass consult a traditional healer

A traditional healer does not have any formal medical training but is deemed competent to provide healthcare within a local community. Traditional healers make use of plant, mineral or animal substances.

The WHO defines traditional medicine as the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of

health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness.

Services of traditional healers go far beyond the uses of herbs for physical illnesses. Traditional healers serve many roles which include:

- ✦ Being custodians of the traditional African religion and customs
- ✦ Educators about culture
- ✦ Counsellors
- ✦ Social workers
- ✦ Psychologists*

*Understanding traditional African healing – MG Mokgobi

In many LMIC, traditional healers are the first point of contact for people presenting with a breast complaint. While it is easy to say that traditional healers do not have any role in the management of patients with breast problems, we need to step back and realise that for many people, traditional healers are the “doctors” of their community.

As healthcare professionals, instead of ignoring traditional healers and their role, and becoming frustrated when patients present late to a healthcare facility as they have first consulted with a traditional healer, perhaps we should be looking at how we can integrate traditional healers into the system. Working with, and educating traditional healers may be the best way to get patients to present at a healthcare facility with their breast complaint at an earlier stage.

Activity 2.9

Cultural awareness and competency is a very broad topic. It is also not only country or town specific but community specific.

Looking at your specific community:

1. Name 4 myths surrounding breast cancer.
2. What stigma is seen in your community related to breast cancer?

3. Please list and describe any complementary or alternative medicine used in your community.
4. Do you have traditional healers or a similar type of healer in your community? What is their role in the community?

UNDERSTANDING HEALTH LITERACY

Health literacy is defined as the ability to obtain, read, understand, and use healthcare information in order to make appropriate health decisions and follow instructions for treatment.

Having a good health literacy will allow patients to make their own decisions re their health care as they will have good communication skills with their medical team and will be able to advocate for their choices and decisions.

Navigators should be able to provide information to their patients in a simple or easy-to-understand language, in an organised manner, and should allow for questions where repetition of the information will occur. This will allow the navigator to ensure that the patient understands what has been explained. This is part of effective communication.

Compare the following 2 situations:

Patient A	Patient B
French speaking	English speaking
85 years old	40 years old
Multiple comorbidities	No comorbidities
Lives alone in small rural town 60 kms from hospital	Lives with family in the city near the hospital
Diagnosed with stage 3 breast cancer	Diagnosed with stage 1 breast cancer
Told she needs multiple investigations	No further investigations required currently
Told she needs to prepare herself for treatment	Told she will be having surgery in 2 weeks' time
Given a pamphlet in English about surgery, chemotherapy, radiotherapy and endocrine therapy	Introduced to a nurse in the doctor's office that explains the way forward leading up to the surgery date
Told to be in the hospital in the North wing in 4 days' time	Given written documentation re where and when to report for surgery
Leaves the appointment anxious and feeling lost	Leaves the appointment with a plan and understanding of the way forward

Which patient do you think would benefit most from meeting with a patient navigator?

Patient A would definitely benefit more from meeting with a patient navigator. One can see that Patient B has been given sufficient information and she leaves her appointment knowing what her next step is in her management. Patient A on the other hand may have the following questions or concerns:

- ✦ I don't understand much of what the doctor said as he spoke very fast and in English which is not my primary language
- ✦ What is stage 3 breast cancer?
- ✦ How will I get to appointments from my town as I do not have my own transport?
- ✦ What are the investigations that were mentioned?
- ✦ I am already sick with high blood pressure and diabetes, how can I also have cancer?
- ✦ Will I die?
- ✦ What does treatment mean?
- ✦ English is my third language, I don't understand the pamphlet that I was given
- ✦ No one told me that I would need surgery, chemotherapy, radiotherapy and endocrine therapy, they just mentioned treatment. What do these words mean?
- ✦ The doctor said I must be in the North wing of the hospital in 4 days, where is that and why must I go there?
- ✦ Who will help me?
- ✦ I am feeling lost and anxious, maybe I should just not go back the hospital

And the list goes on. One can easily see that while Patient B may still benefit from a navigator, patient A definitely needs the navigator specifically to:

- ✦ answer questions
- ✦ explain the terms used by doctor

- ✦ assist with barriers to care
- ✦ assess and monitor distress levels
- ✦ guide the patient through the healthcare system

Typically, patients with low health literacy:

- ✦ Are older
- ✦ Have limited education
- ✦ Have a lower income
- ✦ Have chronic conditions
- ✦ Do not have English (or the treating countries primary language) as their home or primary language

Patients with low health literacy will require the navigator to assist with the following:

- ✦ Completion of medical documents
- ✦ Clarification of instructions from treating health care providers
- ✦ Use of appropriate resources to explain relevant terms (e.g. pictures or verified websites)

You may come across many of the terms below as you work with healthcare providers and patients along their journey. Please familiarise yourself with these terms and abbreviations used in breast cancer and its management:

Term / Abbreviation	Definition
2D	Two-dimensional
3D	Three-dimensional
AI	Aromatase inhibitor
ANC	Axillary nodal clearance
ANDI	Aberrations of normal development and involution
AH	Atypical hyperplasia
BCS	Breast conservation surgery
BD	Bis die (twice per day)

Term / Abbreviation	Definition
BIRADS	Breast Imaging Reporting Data System
BOADICEA	Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm
BRCA	BRCA genes repair DNA that is damaged so normally act as a tumour suppressor. Mutations can occur in BRCA 1 or 2 genes resulting in an increased risk of developing cancers, especially breast cancer
BSA	Body surface area
CBE	Clinical breast examination
CT scan	Computerised axial tomography scan
CV	Cardiovascular
CXR	Chest x-ray
DCIS	Ductal carcinoma in situ
DNA	Deoxyribonucleic acid
DIEP	Deep inferior epigastric perforator (flap)
DVT	Deep vein thrombosis
ER	Estrogen receptor
FBC	Full blood count
FNA or FNAB	Fine needle aspiration (biopsy)
GI	Gastrointestinal
Gy	Gray (unit of radiation dosage)
HBOC	Hereditary breast ovarian cancer (syndromes)
HER2	Human epidermal growth factor receptor (2)
HIV	Human immunodeficiency virus
HRT	Hormone replacement therapy
HT	Hypertension
IBIS	International Breast Cancer Intervention Study
IM	Intramuscular
IORT	Intraoperative radiotherapy

Term / Abbreviation	Definition
IUD	Intrauterine device
IV	Intravenous
Ki-67	A proliferative index based on amount of Ki-67 protein detected. An indicator of how the cancer is likely to behave.
LABC	Locally advanced breast cancer
LCIS	Lobular carcinoma in situ
LD	Latissimus dorsi
LHRH	Luteinising hormone-releasing hormone
LR	Local recurrence
MAOI	Monoamine oxidase inhibitor
MBC	Metastatic breast cancer
MDT	Multidisciplinary team
MRI	Magnetic resonance imaging
NAC	Nipple areolar complex
NGO	Non-governmental organisation
NSAID	Nonsteroidal anti-inflammatory drug
NV	Nausea and vomiting
OCP	Oral contraceptive pill
PABC	Pregnancy associated breast cancer
PASH	Pseudoangiomatous stromal hyperplasia
PC	Palliative care
PET scan	Positron emission tomography scan
PO	Per os (by mouth)
POF	Premature ovarian failure
PNS	Peripheral nervous system
PPI	Proton pump inhibitor
PR	Progesterone receptor
RNA	Ribonucleic acid
RoM	Range of movement

Term / Abbreviation	Definition
RT	Radiotherapy
SERM	Selective endocrine receptor modulator
SERD	Selective endocrine receptor degrader
SC	Subcutaneous
SLNB	Sentinel lymph node biopsy
SSRI	Selective serotonin reuptake inhibitor
TB	Tuberculosis
TDS	Ter die sumendus (three times per day)
TENS	Transcutaneous electrical nerve stimulation
TRAM	Transverse rectus abdominis myocutaneous (flap)
TDLU	Terminal duct lobular unit
US	Ultrasound
WBC count	White blood cell count
VNPI	Van Nuys Prognostic Index
VUS	Variant of unknown significance
WLE	Wide local excision

Term	Definition
Adjuvant therapy	Therapy given after surgery to lower the risk of tumour recurrence
Axilla	The armpit
Benign	Non-cancerous
Biopsy	Removal of a piece of an organ or tissue for analysis to determine if it is cancerous
Excision	Removal by use of cutting
Genetic	Inherited
Metastasis	Spread of cancer cells to other parts of the body

Term	Definition
Neutropenia	Often due to chemotherapy, this is the reduction in the number of neutrophils (type of white blood cell) in the blood
Oncologist	Medical specialist who treats cancer
Pathologist	Medical specialist who identifies diseases by studying cells and tissue under a microscope
Prognosis	The most likely outcome of a disease, dependent on the stage of the disease and the patients response to treatment
Prosthesis	An artificial substitute for a missing body part, internal or external e.g. breast implant or bra insert
Psychiatrist	A medical doctor, specialising in psychiatry, trained to diagnose and treat mental disorders with medication and therapy
Psychologist	A person who studies behaviour and mental processes and who is educated to perform psychological research, testing and therapy
Radiologist	A medical specialist who interprets images such as x-ray, mammograms, ultrasounds and scans
Remission	Free of disease at the time of screening or re-testing
Tumour	Abnormal growth or swelling in any part of the body – benign or malignant

As a navigator, you may hear or come across new terms or abbreviations on a regular basis. It is helpful to carry a notebook with you at all times so that you can make notes for future reference.

Activity 2.10

Please complete the following 30 multiple choice questions. This activity is used to self-score your own health literacy by quizzing you on the content of Part 1 of this training module.

(The answers are at the end of this module)

Score:

- ✦ 23/23 – excellent
- ✦ >17/23 – good
- ✦ 11 - 16/23 – you need to revise part 1
- ✦ <11/23 – please study part 1 again

Please circle 1 answer for each of the following questions.

1. *What are the aberrations of normal development and involution (ANDI)?*

- a. Early signs of breast cancer
- b. Common variations of normal which may result in the formation of lumps
- c. Common problems seen during childhood
- d. They are not common and of no clinical importance

2. *Inverted nipples are:*

- a. Common
- b. Part of the normal breast changes during pregnancy
- c. Only important if they are present at puberty
- d. Only important if they develop in men

3. *What breast changes are common in women between 35 and 55 years of age?*

- a. Cyst formation
- b. Fibroadenomas
- c. Pigmentation changes in the nipple-areola complex
- d. Both nipples become inverted

4. *Clinical assessment of a woman's breast consists of:*

- a. Taking a good history

- b. Taking a history and asking important questions
 - c. Taking a history, asking important questions and performing a clinical examination
 - d. Taking a history, asking important questions, performing a clinical examination and requesting special investigations
5. *What is the most important factor if there is a family history of breast cancer?*
- a. Whether the relative died of breast cancer
 - b. The age of death from breast cancer
 - c. The age of presentation of breast cancer
 - d. The type of treatment given for breast cancer
6. *It is best to examine a woman's breasts:*
- a. During her period
 - b. Immediately after her period
 - c. Just before her period
 - d. Between days 6 and 14 of her menstrual cycle
7. *What is the triple test to investigate breast cancer?*
- a. Clinically examine the breast, axilla and abdomen
 - b. Clinical assessment, imaging and cytology
 - c. Mammogram, ultrasound scan and biopsy
 - d. Chest x-ray, mammogram and needle aspiration
8. *Women with a strong family history of breast cancer should have regular mammograms starting:*
- a. From puberty
 - b. 25 years of age
 - c. At the age of 40 years or 10 years before the earliest age when a

family member presented with breast cancer, whichever came first

- d. At the age of 50 years or when they reach menopause, whichever comes first

9. *What is a core biopsy (Tru-cut) needle?*

- a. A special device to obtain a small sample of tissue
- b. A needle for performing fine needle aspiration
- c. A cutting needle used in open excision
- d. A special needle to mark the lump in a stereotactic biopsy

10. *Are fibroadenomas associated with an increased risk of cancer?*

- a. Fibroadenomas are easy to diagnose and are not associated with breast cancer
- b. There is a slightly increased risk of cancer if a fibroadenoma develops in older women
- c. There is a high risk of a fibroadenoma becoming malignant in younger woman
- d. Most fibroadenomas will become malignant over time

11. *Paget's disease:*

- a. Is a benign condition due to involution of the breast in older women
- b. Looks like eczema of the nipple and is a sign of breast cancer
- c. Is a rare form of breast lump caused by leprosy
- d. Presents as a keratin pearl on the nipple and needs no treatment

12. *When should a nipple discharge be investigated?*

- a. If it is bloody
- b. If there is a small amount of green discharge from one nipple
- c. If it is milky and from both breasts during late pregnancy
- d. If a little thick discharge can be squeezed out of a nipple

13. *The grade of a breast cancer indicates:*

- a. The risk of it spreading
- b. The size of the tumour
- c. The type of tumour
- d. Whether the cancer has spread to the lymph nodes or not

14. *What does a breast cancer look like on a mammogram?*

- a. A black area
- b. Many small grey patches
- c. Usually a large red area with both black and white patches
- d. A white area

15. *What is the main aim of breast cancer treatment?*

- a. To prevent the cancer spreading to the other breast
- b. To save the breast at all costs
- c. To prolong life and cure the cancer if possible
- d. To remove the breast as this will always cure the cancer

16. *Important complications of removing the axillary lymph nodes include:*

- a. Weakness of the arm
- b. Swelling of the arm
- c. Swelling of the chest
- d. Weakness of the hand

17. *What is a sentinel lymph node biopsy?*

- a. The lymph nodes closest to the breast are removed
- b. The lymph nodes furthest from the breast are removed
- c. The lymph nodes in the neck are removed
- d. All the lymph nodes in the axilla are removed

18. *Hormone therapy should be given if:*

- a. The cancer cells are ER +ve
- b. The cancer cells are ER –ve
- c. The cancer cells are HER2 +ve
- d. The hormonal status of the cells is unknown

19. *Mucositis due to chemotherapy presents with:*

- a. Bloody stools
- b. Red urine
- c. A swelling in the armpit
- d. A sore mouth

20. *What management is correct in chemotherapy patients who develop severe diarrhoea?*

- a. They can be treated at home with oral rehydration fluid
- b. They should be sent to hospital urgently
- c. They can be treated at a clinic with diluted “coke”
- d. Wait for 12 hours to assess whether the diarrhoea will improve

21. *An important feature of neutropenic sepsis is:*

- a. A low white cell count
- b. A high white cell count
- c. A raised platelet count
- d. A raised haemoglobin concentration

22. *Lymphoedema is best prevented by:*

- a. Diagnosing cancer early so that less surgery is needed
- b. Using adjuvant radiotherapy rather than chemotherapy
- c. Keeping the arm bandaged after surgery

- d. Removing all the axillary lymph nodes

23. *What is the main aim of palliative care?*

- a. To improve the quality of life and relieve symptoms
- b. To save money by keeping the patient out of hospital
- c. To remove the responsibility from the family by hospitalising the patient
- d. To transfer care from doctors to nurses

COMMUNITY RESOURCES AND SUPPORTIVE SERVICES FOR PATIENTS

Navigators play a role not only in the patient's journey but also in the community. Navigators may be involved with outreach programmes, prevention and screening. Outreach programmes are run with the aim of promoting the value of early detection and prevention, how and where to access cancer care or resources and to make the community aware of what services are available in their local area.

It is vitally important to remember that when giving out resources for patients, they should always be community appropriate. For example, there is no use in teaching a patient from a very poor community with no running water how to perform breast self-examination (BSE) in the shower. If they do not have the facility to shower, they may think that they cannot do a breast self-examination and therefore not check their breasts for any changes.

Navigators should therefore have knowledge on the community in which they are working and the people that they are interacting with. Navigators also need to have basic knowledge surrounding cancer signs and symptoms, screening guidelines, facilities and available resources.

The navigator needs to:

- ✦ analyse each person's situation individually
- ✦ educate each person according to their facilities, health literacy and surroundings
- ✦ provide the correct and relevant community resources and referral to appropriate supportive services

Medical Screening = the systematic application of a test or inquiry to identify individuals at sufficient risk of a specific disorder to benefit from further investigation or direct preventative action. (these individuals not having sought medical attention on account of symptoms of that disorder) – Oxford

Textbook of Medicine, 5th Edition

In simple terms, medical screening is to look for disease before you have symptoms. Screening can detect diseases in their early state, making them generally easier to treat.

Population Screening

When providing or performing population screening, the following must be considered:

- ✦ the population being screened should be high risk for developing the disease (for example: breast cancer screening for women between the ages of 50-70 years old)
- ✦ the disease must have a better prognosis if it is picked up at an earlier stage (for example: stage 1 breast cancer has a better prognosis than stage 3 breast cancer)
- ✦ the investigation used as the screening tool should be safe and effective at detecting the disease being screened for (for example: breast cancer is more easily detected on mammograms done in postmenopausal woman than premenopausal women)
- ✦ the screening tool should be cost effective

Health WorkForce in Africa

The WHO recommendation for healthcare providers (physicians, nurses, midwives) is 230:100 000 population (WHO Health Report 2006). In Rwanda, this figure is 84:100 000 (Farmer et al BMJ 2013).

The WHO recommends 50 physicians : 100 000 people. In South Africa, this figure is 60:100 000 yet in Mozambique, it is only 2:100 000 (Collins et al SCIENCE 2010).

From the above, one can see that the reality for most LMIC is that there are not sufficient healthcare providers for the population. This has a direct impact on a person with a potential disease or condition.

The importance of patient navigators, community resources and supportive services is evident. Not only do patients rely on these types of services but healthcare providers also need the assistance when managing and treating a patient with a condition such as cancer as there are in general, not enough healthcare providers to supply all the necessary services.



Within Southern Africa and many other LMIC, awareness is simply not enough. A different model is necessary to improve the general well-being of the majority of people. Stigma and myths need to be addressed before one can create awareness around breast cancer. Education of primary health care nurses needs to be a priority. A primary health care nurse is, in most cases, the first person to see a patient with a breast complaint. If the nurse is not educated in breast health, mainly how to perform a correct clinical breast examination, the patient will not be appropriately referred and certainly not in a timely manner.

Sadly, the most important prognostic factor for a patient with breast cancer is where the person lives as this, in general, determines their access to healthcare facilities. Access to affordable care is often not easily available for people living in rural areas. There is a lack of appropriate and affordable referral systems. Transport is an issue. There are large discrepancies between private and public healthcare.

There is also a lack of data about the current situation and without data, in many cases, solutions cannot be motivated for or provided.

In South Africa, there are many breast cancer related NGOs and support groups. A few examples are listed below:

1. Reach for Recovery (RFR)

✦ www.reach4recovery.org.za

A national organisation that provides support to breast cancer patients. Support is provided in the form of hospital visitations where literature is distributed. Beyond hospital visits, RFR provides services of prosthetic fitting and prosthesis, where suitable. Raising awareness surrounding breast cancer forms a core tenant of RFR.

2. Breast Course for Nurses

✦ www.breastcourse4nurses.co.za

An education based non-profit organisation aimed at upskilling health care workers in breast health and conditions.

3. Project Flamingo

✦ www.projectflamingo.co.za

Project Flamingo provides catch-up surgery lists to decrease the waiting time for breast cancer surgeries in the public health sector.

4. Cancer Alliance

✦ www.canceralliance.co.za

A collective group of cancer control non-profit organisations and cancer advocates brought together to provide a platform of collaboration for cancer civil society to speak with one voice to affect change for all South Africans affected by cancer.

The Cancer Alliance has links to many of the cancer NGOs in South Africa.

Community Resources in the USA:

1. Breast Cancer Research Foundation: www.bcrfcure.org

2. Susan G. Komen: <http://www5.Komen.org>
3. National Breast Cancer Foundation: www.nationalbreastcancer.org
4. American Cancer Society: www.cancer.org
5. National Coalition of Oncology Nurse Navigators: www.nconn.org
6. National Comprehensive Cancer Network: www.nccn.org

Activity 2.11

Based on the above examples and the information provided in Part 1 under the heading of “self-advocacy,” please create a list of relevant non-profit organisations and community services working in your local area and place each under the following categories:

- ✦ Support
- ✦ Education
- ✦ Advocacy

Remember to include up-to-date contact details / website address (if available) and a brief description of each for you to use as a reference going forward.

PATIENT AND COMMUNITY NEEDS ASSESSMENT

Meg is a 40 year old female from a small rural town with poor cell phone signal. She lives with her husband and 2 children (aged 10 and 8). Her husband works Monday to Friday on a farm nearby. Meg does not work but looks after the house and the children. Meg's parents-in-law live close by in the same town. They are fit and well and like to help Meg with the children during the week. Meg's husband uses the car they own to travel to and from work during the week. Meg has a sister, aged 42, who has an intellectual disability. She lives with an aunt in town but Meg assists with her care as it is full time work for the aunt.

Meg felt a lump in her breast 3 months ago. When she first felt it, she went to the local clinic but was told it was a normal lump and that she should come back if it gets worse. 2 months later, it had doubled in size so she went back to the clinic. The clinic did a biopsy and 3 weeks later, she was informed that the result showed breast cancer. She was then given an appointment to go to a specialist breast unit at a hospital which is a 2 hour drive from her home. The appointment date was a month away. There were no earlier appointments available.

Meg arranged to go to the appointment at the hospital. Her husband had to take a day off of work to take her there and wait for her. Her children had to stay with the grandparents for the day. They left at 04h30am and arrived home that evening at 19h00.

Meg underwent a few investigations at the hospital but she was given 2 other appointments on different days for further tests that need to be done. She has been told that most likely she will need to have chemotherapy, then surgery, followed by radiotherapy and there is something else she was told but she cannot remember. Unfortunately, her husband was not allowed into the consultation with the doctor due to Covid-19 protocol.

Meg is unsure what lies ahead of her as she does not know anyone that has had breast cancer. She has heard however from people in the community that if you have breast cancer, you will die. Meg is usually very organised and sensible, however, since finding out that she has breast cancer, she is feeling anxious, sad and mentally all over the place. She is forgetful and has already misplaced her follow up appointment dates and times.

Activity 2.12

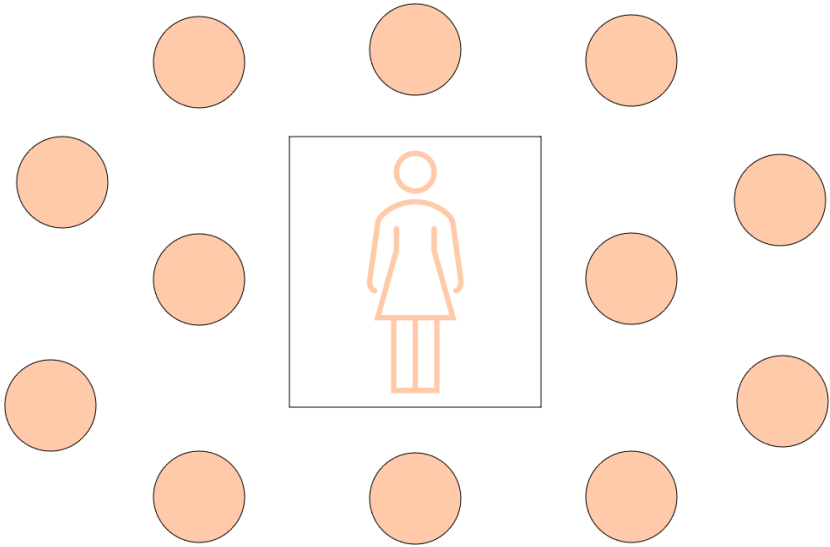
Let's look at how you, as a patient navigator, would assist a newly diagnosed breast cancer patient, in this case, Meg.

1. Taking all you have learnt thus far into account, draw up a detailed analysis and plan of how you, as a patient navigator, could assist Meg with her current situation.
 - ✦ Remember to take your specific scope of practice into consideration and make use of what you have available in your local area.
 - ✦ Think about barriers to care and where you would fit into her journey going forward.
2. Cost analysis for Meg:

Not only is cancer management expensive, so is the diagnostic process. In the image below, in each of the circles, fill in the monetary cost estimation for Meg's story. This can include, for example, transport costs to and from appointments and the day off work for her husband. Each bubble should represent 1 specific cost.

- ✦ What other cost implications does Meg have?

Try to complete as many as possible. The idea is to see how much Meg's cancer diagnosis will cost her family.



ACTIVITY ANSWERS

Activity 2.2

<i>Prevention / Risk Reduction</i>	<i>Screening</i>	<i>Diagnosis</i>	<i>Treatment</i>	<i>Survivorship</i>	<i>Palliative Care</i>
<i>Diet</i>	<i>Genetic testing</i>	<i>Biopsy</i>	<i>Radiotherapy</i>	<i>Surveillance for recurrence</i>	<i>Hospice care</i>
<i>Decreasing alcohol intake</i>	<i>Gender specific screening</i>	<i>Staging investigations</i>	<i>Surgery</i>	<i>Surveillance for new primary</i>	<i>Bereavement care</i>
<i>Sun exposure</i>	<i>Age specific screening</i>	<i>Pathology report</i>	<i>Systemic therapy</i>		
<i>Exercise</i>					
<i>Smoking cessation</i>					
<i>Immunization</i>					

Activity 2.10

1. b

2. a

3. a

4. c

5. c

6. d

7. b

8. c

9. a

10. b

11. b

12. a
13. a

14. d

15. c

16. b

17. a

18. a

19. d

20. b

21. a

22. a

23. a

PART 3

General Principles of Breast Health Navigation

DEFINE MISSION, GOALS, AND OBJECTIVES

Patients remain patients, regardless of the setting where they are receiving care and irrespective of their culture, race, background, health literacy level, or available funding.

Patient navigators are needed in both rural and urban facilities, both privately funded and government facilities, and in both high-income countries and low to middle-income countries.

The roles and responsibilities of the navigator will, in principle, remain the same regardless of the setting; however, the finer details and duties of the patient navigator will differ depending on what is available within the given setting.

Mission:

Provide personalized assistance to patients and their families, identify, and overcome barriers to care, and increase access to medical and psychosocial resources across the continuum of care.

The focus and *mission* of the navigator is to reduce barriers to care and provide support to the patients and their families or caregivers.

Within the multidisciplinary team setting, the navigator works as an advocate, care provider, educator, counsellor, and facilitator to ensure that every patient receives comprehensive, timely, and quality healthcare services.

Goals of navigation can be described in 5 categories:

1. Coordination of care - this involves ensuring timely access to support services, appointments, tests, and procedures (in summary, the navigator identifies and addresses barriers to timely and appropriate breast cancer care during screening, diagnosis, treatment, and palliative care)
2. Education of patients - navigators provide patient-centered education to patients, families, and caregivers on the cancer

diagnosis; treatment; side effects and their management; and clinical trials to ensure that they are informed and involved in the shared decision-making process (in summary, the patient navigator organizes and prioritizes healthcare and educational resources to help guide individuals and families through the cancer care continuum from diagnosis through survivorship)

3. Providing psychosocial support - facilitating the development of coping skills, and referral to psychosocial resources
4. Identifying barriers and resources - helping to improve access to needed patient resources
5. Advocating for patients - identifying and overcoming barriers to care by providing individualized assistance/resources while ensuring as the patient's advocate that their goals, preferences, and voice are heard*

*Navigating the Cancer Continuum: Patient Navigation in Cancer Care 2.0
Guiding patients to quality outcomes

Objectives:

- ✦ Assess barriers to care and engage individuals and families in creating potential solutions for transportation, financial, food instability, and social challenges
- ✦ Identify the unique needs of the individual and facilitate appropriate support
- ✦ Reduce time from the person first noticing an abnormality to initial treatment
- ✦ Track and monitor patients to ensure timely and appropriate care
- ✦ Increase individuals' and family experience and satisfaction with care through shared decision-making in pathways to care
- ✦ Provide education on breast cancer prevention, screening, diagnosis, and treatment

- ✦ Identify appropriate resources (practical, social, physical, emotional, spiritual) taking into consideration reading level, health literacy, culture, language, and amount of information desired
- ✦ Provide referrals and connect patients to appropriate behavioural health resources, including support groups, substance abuse treatments, and social services as needed
- ✦ Document and communicate navigation activities and patient outcomes
- ✦ Provide resources for the community on health issues, prevention, screening, treatment, and research

BENEFITS OF A BREAST HEALTH NAVIGATION PROGRAM

The benefits of a breast health navigation program are to improve patient, as well as system outcomes.

Benefits of breast health navigation include the following:

- ✦ Facilitates timely access to care
- ✦ Helps overcome barriers to care
- ✦ Positively impacts health outcomes through education, support, and earlier detection of breast cancer
- ✦ Supports coordination of care through the entire cancer continuum
- ✦ Facilitates communication between individuals, family/caregivers, community resources, and the healthcare team
- ✦ Helps lower distress levels for individuals and families
- ✦ Provides health promotion education, resources, and support groups to individuals, families, communities
- ✦ Helps individuals identify financial, social, and other support resources
- ✦ Provides educational and community resources on breast cancer prevention, screening, and treatment
- ✦ Coordinates care with the multidisciplinary team from the time of diagnosis throughout treatment

Improved patient outcomes include access to health care and required resources and it refers to decreased duplication of services, less fragmented care and improved communication between the treatment facilities (including the MDT) and the patient.

Benefits of being a navigator

The National Consortium of Breast Centers states that certification benefits the professional who earns the certification, the individual's employer, clients, patients, and the family of those for whom care and services are provided.

The benefits include the following:

1. Individual:

- ✓ *greater confidence in providing care/services*
- ✓ *heightened ability to discern complications*
- ✓ *more effective education of patients*
- ✓ *enhanced collaboration with peers, colleagues, and team members*
- ✓ *personal satisfaction*
- ✓ *career advancement*
- ✓ *increased earning potential*
- ✓ *the acknowledgment of achievement by peers and employers*
- ✓ *recognition of efforts to improve knowledge and skills*
- ✓ *validation of qualifications, knowledge, and skills*

2. Employer:

- ✓ *knowledge that the professional work environment includes advanced professional employees*
- ✓ *greater retention of employees due to professional and personal satisfaction*
- ✓ *reduced exposure to risk*
- ✓ *enhanced care for patients and clients to distinguish them from competitors*
- ✓ *a way for employers to sort through resumes at a primary level*

3. Patients and families:

- ✓ *assurance that the provider of care is qualified and competent at more than a basic level*
- ✓ *improved quality, safety, and accuracy of care by advanced skilled professionals*
- ✓ *expanded knowledge to be shared about choices and treatment options*
- ✓ *more empowerment in decision making*
- ✓ *knowledge that the professional has the shown the desire to improve their quality of patient care and service delivery**

*National Consortium of Breast Centers (NCBC). Breast Patient Navigator Certification (BPNC). Why should I get certified? www2.bpnc.org/why-should-i-get-certified. Accessed June 28, 2018.

Activity 3.1

This is an activity you can start now and continue with as you work with patients.

- ✦ Please keep a diary or record how you feel your patients benefit from working with you.
- ✦ List the positive points but remember to also look at where you could potentially do more for your patients.
- ✦ Look at how you can improve the effectiveness of your navigator skills.

COMMUNITY ENGAGEMENT AND OUTREACH TO STRENGTHEN PATIENT RESOURCES

You have studied the “community resources and supportive services for patients” section in Part 2. In your specific area, there will most likely be many of one type of service but, in turn, a lack of other important services.

Remember the following, with a particular reference to breast changes and breast cancer:

Awareness in communities aims to ensure that community members are informed about:

- ✦ general healthy lifestyle choices
- ✦ risk factors
- ✦ what is normal and does normal change with age
- ✦ screening process
- ✦ signs and symptoms of a disease
- ✦ how to perform self-examination
- ✦ addressing myths and stigma
- ✦ available resources

All material that is provided to the community is to be:

- ✦ neutral in terms of gender and race
- ✦ user-friendly and easy to understand
- ✦ straightforward with no double meaning
- ✦ in the primary language of the community (and additional languages if possible)
- ✦ evidence-based
- ✦ visually easy to understand (for examples, making use of pictures)
- ✦ easily accessible for all in the community

Below is an example of a resource that was developed by the Breast Course for Nurses, a Cape Town based non-profit organisation (NPO). Afrikaans- and Xhosa-speaking Registered Nurses assisted with translations. English, Afrikaans, and Xhosa are 3 of the 11 official languages of South Africa.

This resource was developed to be used within a breast clinic, in the community, and for teaching sessions.

Breast Cancer / Bors Kanker / Umhlaza Webele

It important to know your breast's normal shape, skin colour and nipple appearance so that you can notice if it looks abnormal /

Dit is belangrik dat jy jou normale vorm van jou borste, velkleur en tepel se voorkoms ken sodat jy kan sien of dit abnormaal is /

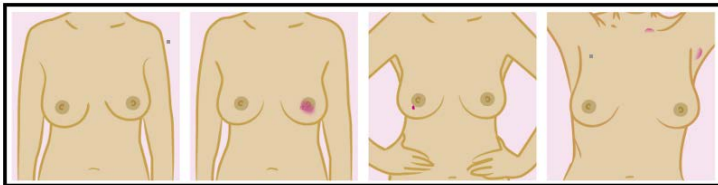
Kubalulekile ukwazi ubume bebele obububo, ibala lofele, nengono ukuba zijongeka njani, kwenzel'into yokuba ukwazi ukuqaphela xa libonakala ngendlela engavamanga okanye engaqhelekanga.

**Signs and Symptoms of Breast Cancer /
Tekens en Symptome van Bors Kanker /
Impawu Zomhlaza Webele**

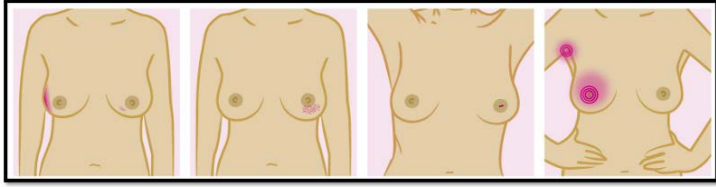
LOOK FOR CHANGE!!! / KYK VIR VERANDERINGE!!! / QAPHELA UKUTSHINTSHA!!!



With thanks
to the:



English	A change in size or shape	Redness or a rash on the skin and/or around the nipple	Discharge (liquid) from one or both of your nipples	A swelling in your armpit or around your collarbone
Afrikaans	Verandering in grootte en vorm	Rooiheid of 'n uitslag op die vel of rondom die tepel	Afskeiding (vloeistof) van een of al twee tepels	Swelling onder die arm of rondom jou sleutelbeen
Xhosa	Utshintsho kubume okanye umlinganiselo	Ububomvu okanye irashalala kufele olungqonge ingono	Incindi ephuma kwingono zakho zombini	Ukudumba ekhwapheni okanye kwithambo lentamo



English	A lump or thickening that feels different from the rest of the breast tissue	A change in skin texture such as puckering or dimpling (like an orange skin)	If your nipple becomes inverted (pulled in) or changes its position or shape	Constant pain in your breast or your armpit
Afrikaans	A knop of verdrukking wat verskuilend voel as die res van die bors weefsel	'n Verandering in vel tekstuur soos verdimpeling (soos 'n lemoenskil)	As jou tepel ingetrek is of as dit verander van posisie of vorm	Konstante pyn in jou bors of onder arms
Xhosa	Iqhuma okanye ukuqina okuvakala ngokwahlukileyo kwisihlunu sebele	Ukutshintsha kofele noburhabaxa obufana nokudala izinxonxo nje ngexolo le orenji	Ukuba ingono zakho ziba nezinxonxo okanye utshintsho kwindlela yobume bazo	Ihlala ihleli intlungu ebeleni lakho okanye ekhwapheeni

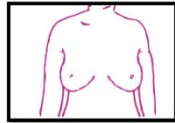
Breast Self-Examination / Bors Selfonderzoek / Iimviwo Amabele



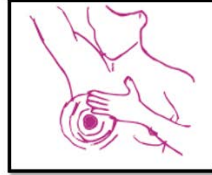
English	Afrikaans	Xhosa
<i>Self-examination</i> = you examine your own breasts	<i>Selfonderzoek</i> = jy ondersoek jou eie borste	<i>Ukuzihlola ibele</i> = uhlola ibele lakho ngokwakho
<i>Clinical breast examination</i> = done by a trained health care professional	<i>Kliniese borsonderzoek</i> = gedoen deur 'n opgeleide gesondheidswerker	<i>Uviwo lwebele lwekliniki</i> = lwenziwa ngugqirha okanye umongikazi oqeqeshiweyo wezempilo
Perform a self-examination once a month	Doen 'n selfonderzoek een keer per maand	Yenza uhlololo kube kanye ngenyanga
Any change should be investigated	Enige verandering moet ondersoek word	Naluphina utshintsho kufuneka luphandwe

NAVIGATING THE PATIENT WITH BREAST CANCER

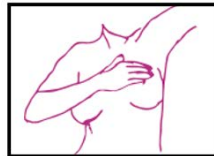
English	Afrikaans	Xhosa
<i>If you menstruate, it is best to do the examination a few days after your period ends and before day 14 of your cycle</i>	<i>As jy menstrueer, is dit die beste om die eksamen te doen 'n paar dae na die einde van jou tydperk en voor dag 14 van jou siklus</i>	<i>Ukuba usexesheni, kukulungile ukwenza uviwo emva kweentsuku ezimbalwa emva kokuba ixesha lakho liphelile kwaye ngaphambi komhla 14 wesijikelezo sakho</i>
<i>If you do not menstruate, it is best to do the examination on the first day of the month</i>	<i>As u nie menstrueer nie, is dit die beste om die eksamen op die eerste dag van die maand te doen</i>	<i>Ukuba ungumtu ongahlambiyo, kulungile ukwenza uviwo ngosuku lokuqala enyangeni</i>
<i>You know your breasts best! Therefore, when performing a self-examination, you will notice if there is a change</i>	<i>Jy ken jou borste die beste! Dus, wanneer jy 'n selfonderzoek doen, sal jy agterkom dat daar 'n verandering is</i>	<i>Ungoyena uwazi ngcono amabele akho! Ngoko ke, xa wenza uvavanyo, uya kubona ukuba kukho utshintsho</i>



English	Afrikaans	Xhosa
Examine your breasts in front of a mirror with your arms at your sides and then raised over your head.	Onderzoek jou borste voor 'n spieël met jou arms aan jou sye en dan oor jou kop.	Hlola amabele akho phambi kwesipili, ingalo zakho zisemacaleni, uze uphinde xa ingalo ziphezulu.
Look for CHANGE!! Size, shape, contour, dimpling, redness, nipple inversion. Don't forget to examine both breasts as well as both armpits.	Soek vir VERANDERING!! Grootte, vorm, kontoer, dimpling, rooiheid, tepel inversie. Moenie vergeet om beide borste sowel as oksels te ondersoek nie.	Jonga UTSHINTSHO!! Ubungakanani, ubume, ubunxoxo, ukuba bomvu ingono ezitshone ngaphakathi. Ungalibali ukuhlola amabele omabini nasemakhwapheni.
Lie down on your back with a pillow under your right shoulder.	Lig op jou rug met 'n kussing onder jou regter skouer.	Lala ngomqolo unomqamelelo phantsi kwegxalaba lasekunene.



English	Touch your right breast using your left 3 middle finger pads to feel for any lumps in your breast. Work in circular motions.	Make sure to examine the whole breast. Remember, the breast tissue extends all the way into the armpit. Use firm, smooth pressure starting from the nipple and working outwards towards the edge of the breast.
Afrikaans	Raak jou regte bors met jou linker 3 middelvingersblokkies om te voel vir enige knoppe in jou bors. Werk in sirkelbewegings.	Maak seker dat juy die hele bors ondersoek. Onthou, die borsweefsel strek al in die oksel. Gebruik ferm, gladde druk vanaf die tepel en werk uit na die rand van die bors.
Xhosa	Bamba ibele lakho lase kunene usebenzisa iminwe ephakathi emi-3 ukuva iqhuma ebeleni lakho. Sebenza ngokuhamba okujikelezayo ngesandla.	Qiniseka ukuvavanya ibele lonke. Khumbula ukuba ibele linwenwela ekhwapheni cinezela ibele ngokuqinisekileyo thambileyo uqale engonweni usebenzele ngaphandle ukuya kwisiphelo sebele.



English	Feel up and down the breast. Feel for changes from top to bottom and side to side. Use 3 levels of pressure: <i>Light</i> to feel tissue closest to skin <i>Medium</i> to feel a little deeper <i>Firm</i> to feel the tissue closest to the chest and ribs	Move the pillow to the left shoulder and repeat steps 4 – 6 using your right hand on your left breast.
Afrikaans	Voel die bors op en af. Voel vir veranderinge van bon a onder en van kant tot kant. Gebruik 3 vlakke van druk: <i>Lig</i> om die weefsel naaste aan die vel te voel <i>Medium</i> om 'n bietjie dieper te voel <i>Vas</i> om die weefsel naaste aan doe bors en ribbes te voel	Skuif die kussing na die linkerskouer en herhaal stappe 4 – 6 met jou regtehand op jou linkerbors.
Xhosa	Live ibele phezulu nangaphantsi macala onke. Sebenzisa ukucinezela amanqanaba abe-3: - okuthambileyo ukuva isihlunu esisondele kufele - okuphakathi ukuva nzulu	Yisa umqamelo kwicala lasekhohlo uze uphinde isitephu sesine ukuya kwesesithandathu, usebenzise isandla sakho kwibele lasekhohlo.

The above resource:

- ✦ provides the information in 3 languages
- ✦ is in an easy-to-understand format
- ✦ makes use of images as well as writing
- ✦ is colourful and catches the attention of the reader
- ✦ provides basic, yet important information, about breast cancer signs and symptoms and how to perform a breast self-examination, therefore, making it applicable to the community

Activity 3.2

Depending on what services are lacking in your area and local community, design your own community project.

Although they aren't mutually exclusive, there are 3 main themes that your community project is to fall under:

- ✦ Advocacy
- ✦ Education
- ✦ Support

Be creative with this project but also remember to make sure that your community project is something new and relevant to those in your community and not just a repetition of what is already available.

Remember to consider the following:

- ✦ Relevance to the community
- ✦ Funding available
- ✦ Use of volunteers
- ✦ Sustainability of the project

PSYCHOSOCIAL AND PHYSICAL NEEDS ACROSS THE DISEASE TRAJECTORY (DISTRESS SCREENING)

Much of the information provided in this section is taken from the book, “Management of breast cancer in a general hospital” by Dr. Jenny Edge and Dr. Ines Buccimazza. The chapter about Psychosocial Distress is written by Linda Greeff, a cancer social worker from Cape Town, South Africa.

Evaluating and managing the psychosocial impact of cancer should be part of routine clinical practice. It is an integral part of a patient-centric, comprehensive, and coordinated treatment programme aimed at meeting the needs of patients and their families. The standard of care internationally is that all oncology units should have access to psychosocial care.

All cancer care should ensure the provision of appropriate psychosocial health services by:

- ✦ Facilitating effective communication between patients and care providers
- ✦ Identifying each patient’s psychosocial needs
- ✦ Designing and implementing a plan that links the patient with needed psychosocial services, coordinates biomedical and psychosocial care, and engages and supports patients in managing their illness and health
- ✦ Ensuring systematic follow up: re-adjusting the plan as necessary

From the above information, one can see how the duties of the patient navigator overlap with those of psychosocial health workers.

Although ideally, each treatment facility should have a local social worker, psychologist, psychiatrist, or other psychosocial health providers or the ability to refer a patient to one of these health workers, this is not always the case, and a patient navigator may need to assess the patient and assist with these requirements, or look into how to refer a patient.

Psychosocial problems created or exacerbated by cancer can cause additional suffering. If a patient has unaddressed psychosocial problems, they may

not adhere to prescribed treatments or even attend their medical therapy appointments.

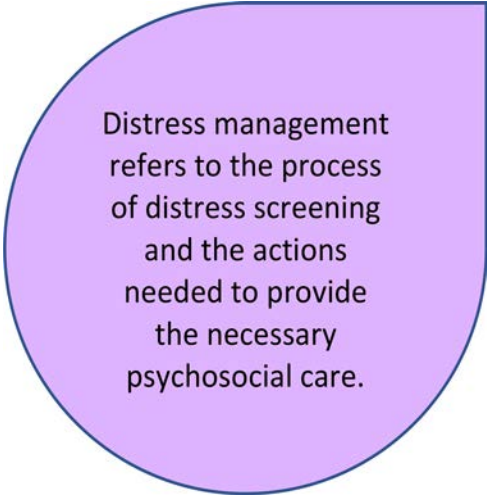
The diagnosis of cancer can result in the following triggers of psychosocial distress. They are essentially, barriers to the patient's cancer care:

- ✦ Depression, anxiety, or other emotional responses to the cancer experience
- ✦ Resurfacing of previously controlled physical and or emotional conditions
- ✦ Lack of information or skills needed to manage the illness
- ✦ Lack of transportation or other resources
- ✦ Disruptions in work, school, or family life
- ✦ Impact of poverty and financial challenges

Offering effective delivery of services is dependent on the following:

- ✦ Identification of psychosocial health needs
- ✦ Linkage of patients and family to necessary support services
- ✦ Easy availability of support for patients and families to facilitate the management of the illness and emotions throughout the cancer care trajectory
- ✦ Coordination of psychosocial and biomedical health care
- ✦ Follow up of care to ensure or monitor the effectiveness of services

The above should be facilitated by effective patient-doctor communication and multidisciplinary team communication. Where there are language barriers or poor health literacy, lack of referral systems, or fragmented care, it is easy to see how a patient may have fears of treatments, lack of knowledge, emotional distress, fragmented care, and ultimately, a poor outcome from their cancer management. The patient navigator needs to be able to screen for this not only at the beginning of treatment but at periods throughout the patient's management. Reassessing problems, talking with the patients, referring the patients, and reassessing care plans will aid in the patient's effective care and management.



Distress management refers to the process of distress screening and the actions needed to provide the necessary psychosocial care.

What does the term “distress” mean?

As per Holland and Alici (2010), distress is “the multifactorial unpleasant experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its symptoms, and its treatment”. It continues that it, “extends along a continuum ranging from common normal feelings of vulnerability, sadness, and fear, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential spiritual crisis”

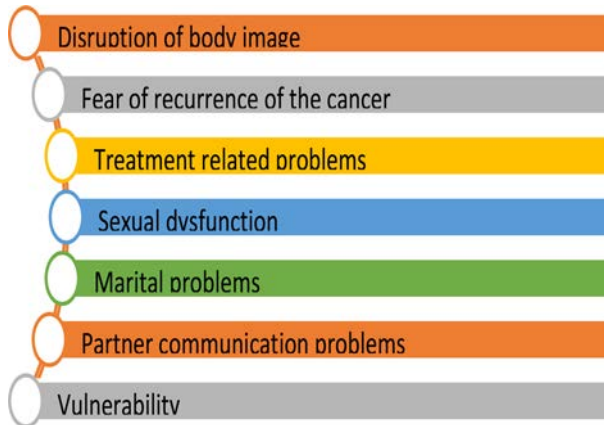
How to screen for distress:

It is important to identify, monitor and treat distress from the start of cancer treatment. This will contribute to the quality of life of the patient and reduce the burden of suffering throughout the cancer journey. Not only the physical health of the patient is assessed at the beginning of treatment, but also their social, emotional, psychological, and spiritual situation.

Patients may need to be referred for professional help, which can generally only be decided once they have been screened. The purpose of the screening is to identify the level of distress and to refer the patient to the correct

psychosocial support services and resources as soon as possible, to ensure effective management of the patient and family from the start of the cancer treatment all through the trajectory of care.

Common psychosocial issues experienced by women diagnosed with breast cancer include the following:



The NCCN distress thermometer can be used as this is a tool used to identify the level and nature of the distress. It also aids in planning the referral of the patient and family for appropriate intervention. The patient is screened for distress at the first consultation. Although this is not always possible, the navigator is able to do this as a part of their initial assessment of the patient when they first meet. A patient with a score of 5 or more on the NCCN distress thermometer should be referred to the appropriate support services.

The NCCN distress tool is available in the navigators tool section of the module.

This distress management score is made up of a visual rating scale. Once referred, an oncology or general social worker or a cancer specialised navigator will conduct a full psychological assessment and develop a care

plan to assist the patient and family. The distress tool can be used along the trajectory of care to ensure that the patient and family are provided with quality holistic care from diagnosis to the terminal care phase.

Making use of distress screening:

- ✦ Allows open communication between the patient and healthcare team
- ✦ Prevents stigma surrounding asking for help from an early stage
- ✦ Ensures timely referral or support

How to manage emotional impacts:

Remember that cancer impacts all aspects of the whole family's life – physical, emotional, spiritual, social and financial. All patients and their families will have a unique experience. Therefore each situation is to be dealt with individually.



- ✦ Support groups / local NGOs
 - ✓ *These may provide help, and inspire and support patients and their families.*
- ✦ Peer support groups
 - ✓ *Help to normalise the cancer experience*
- ✦ Patients

- ✓ *Connect a newly diagnosed patient with someone that has been through a similar treatment regime*
- ✓ *This helps them start their treatment with more certainty, builds hope, and assists in developing coping strategies to empower them*

If one partners a patient with someone that has been through the experience, the ideal goal is to link them with someone of a similar age, culture, and diagnosis. This will allow the patient to have the most benefit from the interaction.

For most patients, navigating the healthcare system is a major factor, especially in LMIC. Think about the following:

- ✦ Medical insurance availability and obtaining authorisation for treatment
- ✦ Fragmented health care systems that are often inadequate
- ✦ Limited resources and support
- ✦ Financial burdens (not only treatment but also, for example, rehabilitation, complementary therapy, and spiritual care)

Activity 3.3

- ✦ What psychosocial needs do your patients have?
- ✦ Do you have social workers or trained individuals to assist the patients?

When do patients usually experience the most distress?



Becoming aware of an abnormality of the breast



Diagnosis



During the cancer workup phase awaiting results (e.g. CT scan, blood tests)



From treatment to treatment (e.g. completing chemotherapy and starting radiotherapy)



Going home after surgery



Completing therapy



Commencing with the survivorship phase



Monitoring for recurrence



Terminal care

TOOLS USED IN NAVIGATION

Once a patient navigator has been connected with a patient and has obtained their permission, the navigator needs to perform an intake assessment. A goal of each facility is to have a consistent process for assessing and evaluating patients. Standard tools are recommended for use.

Below is an example of a tool that could be used. You can also adapt the below tool to suit the requirements of your facility or patient but remember to be consistent with the tool that is used.

Dates are always required. You may need to complete an intake form in an adapted format at various times of the patient’s journey as their information may change. Having dated information will allow for a better idea of a timeline of the patient’s journey.

Patient Navigation Intake Form

LMIC

Patient Details

Name:

Date of Birth:

ID / Passport number:

Contact number(s):

Email address:

Residential address:

Name of spouse / significant other / household member:

Contact details of spouse /significant other / household member:

Gender:

- ☐ Male
- ☐ Female
- ☐ Other:

Race:

Home / preferred language:

Marital status:

- ☐ Married
- ☐ Never married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated / not living with partner / spouse
- ☐ Partnered

Household description:

✦ Number of people living in the household including the patient: _____

Highest level of education:

Referral

Date of referral:

Referred by:

Consent

Consent obtained for: (Patient to initial items she consents to, or crosses out items she does not consent to)

- ☐ Treatment information
- ☐ Obtaining medical records
- ☐ Communication with health care providers
- ☐ Information to be used for research purposes
- ☐ Telephonic / email communication

Signature of patient:

Medical Team

Name of primary doctor:

Speciality:

Contact details of primary doctor:

Other members of medical team:

Treatment Facility

Name of treatment facility:

Treatment facility registration number:

Contact details of treatment facility:

Financial Details

Financial status:

☐ Private / self-funding

☐ Medical insurance

✓ Name of insurance: _____

✓ Insurance number: _____

Employment status:

☐ Full-time

☐ Part-time

☐ Unemployed

☐ Self-employed

☐ Retired

☐ Student

☐ Other: _____

Household income (per month):

Clinical Information

Diagnosis:

Co-morbidities:

Summary of following reports (attach reports if available):

- ☐ Biopsy:_____
- ☐ Surgery:_____
- ☐ Imaging:
 - ☐ CT scan_____
 - ☐ PET scan_____
 - ☐ Mammogram_____
 - ☐ Ultrasound_____
 - ☐ MRI_____
 - ☐ Bone scan_____
 - ☐ MUGA_____
- ☐ Bloods:_____
- ☐ Additional results:_____

Previous cancer history:

Surgical history:

Medical history:

Family history:

- ☐ Breast cancer: _____
- ☐ Ovarian cancer: _____
- ☐ Prostate cancer: _____
- ☐ Other: _____

Smoker:

- ☐ Yes: How many per day? _____
- ☐ No
- ☐ Please specify what you smoke? (e.g. cigarettes, marijuana etc.):

Alcohol intake:

- ☐ Yes: How many units per week? _____
- ☐ No

Describe patient's daily activity level (mark only ONE):

- ☐ Fully active and able to carry on all usual activities without restriction
- ☐ Restricted in physically strenuous activity, but can walk and able to carry on light housework
- ☐ Can walk and take care of myself, but unable to carry out work activities
- ☐ Requires help taking care of myself and spends more than half of the day in bed or a chair
- ☐ Cannot take care of myself at all and spends most of the day in bed

Current medication:

Current supplements:

Allergies:

REVIEW OF SYSTEMS (any symptoms or current problems):

Constitutional:

- ☐ poor appetite
- ☐ fatigue
- ☐ weight gain
- ☐ weight loss
- ☐ poor sleep
- ☐ fever
- ☐ headache

Eyes:

- ☐ blurred vision
- ☐ double vision
- ☐ tearing/watery eyes
- ☐ sensitivity to light

Ears, nose, mouth & throat:

- ☐ difficulty hearing
- ☐ ringing in ears
- ☐ sinus problems
- ☐ nose bleeds
- ☐ dry mouth
- ☐ taste changes
- ☐ hoarseness
- ☐ pain with swallowing

- ☐ difficulty with swallowing

Cardiovascular:

- ☐ chest pain
- ☐ irregular heart beat
- ☐ high blood pressure
- ☐ swelling of feet or ankles
- ☐ heart murmur
- ☐ pacemaker

Respiratory:

- ☐ shortness of breath
- ☐ cough
- ☐ coughing up blood
- ☐ asthma or wheezing

Gastrointestinal:

- ☐ abdominal pain
- ☐ diarrhoea
- ☐ constipation
- ☐ heartburn or indigestion
- ☐ nausea
- ☐ vomiting
- ☐ blood in stools

Genitourinary:

- ☐ frequent urination
- ☐ painful urination
- ☐ blood in urine
- ☐ leakage/ incontinence

- ☐ vaginal dryness

Neurologic:

- ☐ headaches
- ☐ dizziness
- ☐ memory loss
- ☐ problems walking/ falls
- ☐ numbness/ tingling

Psychiatric:

- ☐ depression
- ☐ anxiety

Hematologic/ lymphatic:

- ☐ enlarged lymph nodes
- ☐ arm swelling

Skin:

- ☐ itching
- ☐ easy bruising
- ☐ rash

Endocrine:

- ☐ hot flashes
- ☐ change in tolerance to hot or cold weather
- ☐ excessive thirst
- ☐ night sweats
- ☐ chills

Allergic/ Immunologic:

- ☐ allergies
- ☐ runny nose
- ☐ itchy eyes

Musculoskeletal:

- ☐ bone pain
- ☐ joint pain
- ☐ muscle weakness

Current treatment and plan:

Surgery

Chemotherapy

Radiotherapy

Endocrine therapy

Targeted therapy

Complementary therapy

Other

Navigator Meeting

Date:

Duration of meeting:

Method of communication:

- ☐ In person
- ☐ Telephonic
- ☐ Letter
- ☐ Email
- ☐ Online chat
- ☐ Other: _____

Identification of barriers

Financial and Insurance:

- ☐ difficulty meeting co-pays
- ☐ requires financial planning
- ☐ low financial literacy
- ☐ non-medical financial needs
- ☐ uninsured
- ☐ underinsured
- ☐ other: _____

Transport:

- ☐ own transport
- ☐ public transport
- ☐ requires transport funding
- ☐ other: _____

Logistical:

- ☐ clothing
- ☐ dependent care

- ☐ food
- ☐ housing problems
- ☐ transportation
- ☐ utilities
- ☐ other: _____

Care coordination:

- ☐ appointment making
- ☐ home health care
- ☐ incorrect referrals or orders
- ☐ needs referral
- ☐ next stage of care
- ☐ physical comorbidity
- ☐ treatment or medical supplies
- ☐ other: _____

Cultural, spiritual and distress:

- ☐ beliefs conflict with treatment
- ☐ difficulty coping with diagnosis
- ☐ difficulty coping with treatment
- ☐ difficulty coping with survivorship
- ☐ end of life concerns
- ☐ lack of support
- ☐ negative perceptions of medical team/care
- ☐ mental health comorbidity
- ☐ spiritual crisis
- ☐ stigma/discrimination
- ☐ treatment related depression or anxiety

☐ other: _____

Employment:

- ☐ ability to work through treatment
- ☐ family members employment affected
- ☐ needs job accommodations
- ☐ stigma/discrimination at the workplace
- ☐ unemployed
- ☐ dependent care provider (is the patient providing care to a dependent child/parent/adult?)
- ☐ other: _____

Communication:

- ☐ primary language other than English
- ☐ cultural barriers to communication
- ☐ poor health literacy
- ☐ language barrier
- ☐ other: _____

Navigator Details

Name:

Contact details:

Date of consultation:

Next meeting date:

Notes:

Navigator Name:


Navigator Signature:

Patient Name:

Patient Signature:

Distress Management Tool

The NCCN distress thermometer (discussed in the psychosocial and physical needs across the disease trajectory chapter) and problem list for patients:



National
Comprehensive
Cancer
Network®

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10

9

8

7

6

5

4

3

2

1

0

No distress

PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.
Be sure to check YES or NO for each.

YES

NO

Practical Problems

☐ Child care

☐ Food

☐ Housing

☐ Insurance/finances

☐ Transportation

☐ Work/school

☐ Treatment decisions

Family Problems

☐ Dealing with children

☐ Dealing with partner

☐ Ability to have children

☐ Family health issues

Emotional Problems

☐ Depression

☐ Fears

☐ Nervousness

☐ Sadness

☐ Worry

☐ Loss of interest in usual activities

☐ Spiritual/religious concerns

YES

NO

Physical Problems

☐ Appearance

☐ Bathing/dressing

☐ Breathing

☐ Changes in urination

☐ Constipation

☐ Diarrhea

☐ Eating

☐ Fatigue

☐ Feeling swollen

☐ Fevers

☐ Getting around

☐ Indigestion

☐ Memory/concentration

☐ Mouth sores

☐ Nausea

☐ Nose dry/congested

☐ Pain

☐ Sexual

☐ Skin dry/itchy

☐ Sleep

☐ Substance use

☐ Tingling in hands/feet

Other Problems: _____

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Activity 3.4

- ✦ you have an example of an intake form above. Spend some time doing research, and then develop your own follow-up form to be used when patients see you for follow-up sessions.

PATIENT EDUCATION THROUGHOUT THE CONTINUUM OF CARE

This is a self-learning section you will need to complete.

Why is ongoing patient education necessary to ensure an optimal continuum of care? Think about the following points:

- ✦ Patient needs and educational need change throughout their journey
- ✦ How does one cope with the publicity surrounding breast cancer (for example “Pinktober”)
- ✦ How does one, as a patient, cope with friends contacting you to offer support and advice
- ✦ Patients need to recognise that cancer is many different diseases and that the cancer another person has may not be the same as the individual’s
- ✦ Reliable information needs to be available for patients to access with regards to the treatment that they may not yet have had (for example, surgery and then radiotherapy)
- ✦ Helping patients to come to terms with where they fit in the cancer survivors spectrum (i.e. a feeling of guilt as another person has “worse cancer” or had chemotherapy/mastectomy/cancer at a younger age/ children etc.)
- ✦ Ongoing follow up and why that is necessary.

Activity 3.5

1. Please create a patient education care plan for each phase of care (e.g. diagnostic, treatment, remission, end of life – as applicable) for Patient A and B below.

Your care plan components include:

- ✦ Assessment (e.g. patient readiness for learning, health literacy, communication barriers, other barriers to learning)
- ✦ Objectives (e.g. short- and long-term goals, the patient identified goals)

- ✦ Method of teaching (e.g. written materials, oral instruction, demonstration)
- ✦ Learning evaluation (e.g. teach-back, goal completion)

Patient A

A 34-year-old mother of 3 lives with her extended family in a village 2 hours from the nearest breast care centre. She is unfamiliar with the healthcare system and has limited literacy skills. The patient felt a 5cm lump in her left breast. She presents to your facility for evaluation and undergoes a breast ultrasound, followed by an ultrasound-guided core needle biopsy for the breast mass. Subsequent pathology shows a grade 3, triple negative invasive ductal carcinoma (i.e. not sensitive to hormones) with a Ki-67 of 60%

The patient is treated with neoadjuvant (primary) chemotherapy; followed by a mastectomy. She has an axillary clearance(3/15 nodes positive); then receives 6 weeks daily of radiotherapy.

Two years after the completion of treatment, the patient presents with progressive headaches and shortness of breath over the past 3 months. She is diagnosed with brain and lung metastases. The patient is provided with hospice care and dies two months later.

Patient B

An obese 55-year-old woman lives alone and has a screening mammogram as part of a breast cancer awareness event at the breast care centre across the street from the bank where she works. She is found to have right breast calcifications spanning 13mm, and the patient is scheduled for a diagnostic mammogram and a stereotactic core needle biopsy the following week. The pathology reveals high-grade DCIS that is hormone receptor-positive (ER+/PR+).

The patient is treated with a lumpectomy and has a negative sentinel lymph node biopsy (0/2 nodes positive), followed by 6 weeks of radiotherapy and 5

years of an aromatase inhibitor. After two years on an aromatase inhibitor, the patient complains of joint pain and is switched to Tamoxifen for the remaining 3 years of treatment.

The surveillance plan for the patient includes annual clinical breast exams and mammograms every 6 months for 2-3 years, followed by annual mammograms. The patient has no evidence of disease 10 years after treatment.

2. Try to complete this activity with fellow patient navigators. Make use of role-play scenarios and have fun!
 - ✦ develop a patient scenario around coping with friends/family offering support and advice
 - ✦ have one participant be the patient (Mary), and the other participants are the Navigator(s)

Patient Case: Mary is a 35-year-old woman newly diagnosed with a right breast Biopsy/Imaging 2.0 cm invasive ductal carcinoma, ER+ HER2-tumour with suspected involved lymph nodes. Mary is a single mother of two children ages 8 and 10. She owns a house cleaning business and volunteers at her children's school. Her mother relies on Mary for transportation and helping with grocery shopping and medical appointments. She is sent for genetic testing which shows she is BRCA -ve

Treatment plan: Lumpectomy with sentinel node biopsy advised to have chemotherapy followed by radiation therapy and endocrine therapy.

Initial Meeting: On your first meeting with Mary she states, "I told my mother and best friend about the cancer. They cried and were so scared. They've offered to help in any way they can, but I hate to take help. My other friends from the children's school are all calling, and I'm just overwhelmed. I've always been the one to help others. My sister said I shouldn't do chemo and should change my diet to vegan and take some natural herbs. After the surgery, I won't be able to work for a while, and I don't know how I'll manage

with chemo. I don't know what to do.”

Group Exercise

- ✦ Identify/list potential barriers to care
- ✦ Identify/list local cancer centres and community resources
- ✦ How can you help Mary make a support plan?
- ✦ Role-play the scenario of meeting with Mary to discuss and walk through the above exercise
- ✦ Explain to the family what their risk of breast cancer is

Help patients identify their support needs and make a list of what family/friends can do to help, provide the patient with options when an offer of help is made. For example, Mary may identify she has the following needs:

- ✦ Transport and grocery shopping for her mom
- ✦ Taking the 10-year-old to soccer practice
- ✦ Home cooked dinners delivered on Mondays, Wednesdays and Fridays
- ✦ Donation of pre-paid gas / fuel cards

IMPORTANCE OF MULTIDISCIPLINARY COMMUNICATION AND TEAMWORK

Importance of multidisciplinary communication and teamwork:

- ✦ In community and healthcare settings, good communication with all members of the care team is essential and poor communication can negatively impact patient health outcomes
- ✦ There are many common barriers to communication as well as effective solutions to those barriers
- ✦ Active listening, communicating with empathy, open-ended questions, affirmations, and shared decision-making are strategies that can improve your communication with individuals, families, and other healthcare providers
- ✦ Patient navigators may have difficult conversations with patients, families, and other healthcare providers and should use strategies to do so respectfully and clearly
- ✦ Cultural competency refers to being sensitive to people coming from a variety of backgrounds and cultures, acknowledging their ethnic and spiritual beliefs, supporting the delivery of quality care, and helping to make sure they get the care that best suits their preferences and needs
- ✦ Patients and other healthcare professionals may have needs that may be similar or different from one's own, being aware of one's own biases is important so they can be minimized

Activity 3.6

Before you continue, what is your understanding of the following terms?

1. Personalised medicine
2. Patient-centered care
3. Multidisciplinary team

Evidence based medicine:

= the practice of medicine in which the physician finds, assesses, and implements methods of diagnosis and treatment on the basis of the best available current research, their clinical expertise, and the needs and preferences of the patient

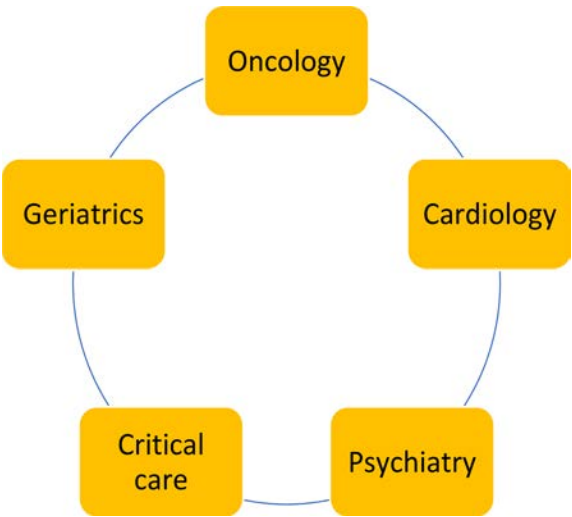
**Mosby’s medical dictionary*

Multidisciplinary Team (MDT):

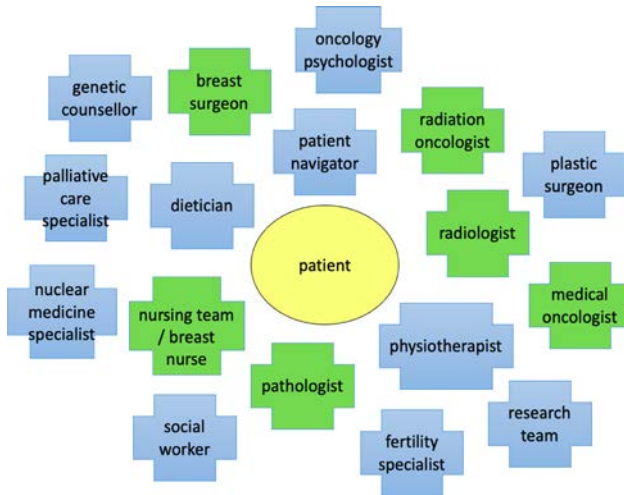
= a group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients. Multidisciplinary teams may specialize in certain conditions, such as cancer.

**NHS Data Model and Dictionary*

MDT meetings are used by many specialties:



MDTs will look different and be made up of different members depending on the location of the MDT and the specialty required. In principle, a breast MDT can include the following members and the members may be present or join virtually:



As indicated in the above diagram, there can be many members of an MDT. The green blocks indicate the core team of disciplines for a breast MDT. This means that these members are vital in making up the breast MDT.

Discussing patients at an MDT ensures that the treatment plan for each patient is individualised. There is no “one size fits all” approach. Patients managed by an MDT generally have a better outcome as they are treated by not only 1 specialist but by a whole panel. Every aspect of management is taken into consideration.

Individualised care plans for patients reduce mortality and improve quality of life. MDTs follow guidelines that ensure a standard of care is maintained.

Multidisciplinary teams usually have regular meetings where all new breast cancer cases are discussed and a plan is decided upon.

Patients that do not have breast cancer but have a complicated breast condition may also be discussed at these meetings.

Patients should be discussed at their initial breast cancer diagnosis and a comprehensive plan is determined. The patient is then rediscussed after each treatment component and also if they develop a local or distant recurrence.

Decisions on how to manage the patient are dependent on tumour biology (the make-up of the cancer), the stage (early stage, locally advanced or metastatic), and patient factors or preferences (age, risk factors, family history, comorbidities, social circumstances, treatment goals). It is very important to be aware of the patient's choice and make sure that their preferences and treatment goals are included in the plan. This is patient-centered care.

Not all hospitals or treatment facilities have MDTs. The group make-up may also differ from facility to facility. If not all specialists or services are available at a facility, it is important to establish and make use of outsourced links and referrals where necessary.

Ideally, the group will have regular face-to-face meetings where cases are discussed. Technology has allowed meetings to also happen virtually. For example, some patients can be managed by a regional breast unit. The regional breast unit will virtually meet with the MDT from the specialist breast unit and discuss their cases. If management from the specialist unit is not required, the patients can be treated at the regional unit knowing they have had the benefit of being discussed by the specialist team.

Ultimately, a patient being discussed at an MDT will generally have fewer risks with regard to treatment and will have greater benefits and outcomes.

Patient navigators are a part of the MDT. The navigators build relationships with the medical team and especially those who are working with the patients

that are being assisted by the navigator. If the MDT members understand the roles and responsibilities of the navigator, they will more likely support the idea of a patient navigator and will use them within the team.

The navigator is not expected to present their patients at the MDT but are expected to be in attendance to listen to the information provided by the medical team and to add any important points that they may have picked up when in conversation with their patients.

Records of patients to be presented at the MDT are to be made available prior to the meeting and ideally be prepared by the individual that will present the patient case. A general summary of the patient is to be prepared to share in the meeting along with having the following documentation available:

- ✦ Medical history
- ✦ Pathology reports
- ✦ Imaging scans and reports
- ✦ Diagnostic examination results
- ✦ Blood results
- ✦ Previous treatment if applicable

Patients are not present at the majority of MDT's and therefore one may consider an MDT as not "shared decision making" as the patient is not involved at that time. It is however important to remember that although the patient is not present, the personal choice of the patient will still be taken into consideration and the final decision regarding management remains the patient's decision.

Patient-Centered Care:

= providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

**NAM*

Benefits	Pitfalls
Cost reduction	Cost of running MDT
Pooled data and resources	Logistical challenges
Adherence to treatment guidelines	Increased complexities
Access to trials	Turf wars
Better communication between professionals and the patient	May lead to delay in treatment if all information is not available
Training opportunities	Medicolegal considerations
Broad-based care and follow up	

**multidisciplinary care for brca, pitfalls, and barriers: Farrowfield et al*

Activity 3.7

Do you have additions to the table above?

What, in your opinion, are the benefits versus pitfalls of MDT’s in your local area? Add your thoughts to the table below:

Benefits	Pitfalls

Personalized Medicine

= an emerging practice of medicine that uses an individual's genetic profile to guide decisions made regarding the prevention, diagnosis, and treatment of disease. Knowledge of a patient's genetic profile can help doctors select the proper medication or therapy and administer it using the proper dose or regimen.

**National Human Genome Research Institute*

Genomic testing:

Genes control the behaviour and activities of all cells, including cancer cells. A genomic test looks at groups of genes and how active they are. In simple terms, it looks at the personality of the cancer. This influences how a cancer is likely to grow and respond to treatment.

(Important: a genetic test is different and looks for mutations (unusual changes) in genes that are inherited, or passed from one generation to the next and looks at the susceptibility of the individual to different diseases)

Examples of genomic testing for breast cancer include:

- ✦ Onco Dx
- ✦ Mammaprint
- ✦ Mammastrat

These look at various genes in the cancer and predict how the cancer will behave and what treatment it will respond to. Most genomic testing is currently still very expensive and not easily available and therefore not an option in many LMICs.

DATA COLLECTION

As with any interventional programme, data collection and analysis is vital. Without data, one cannot provide statistics and without this, one cannot advocate for changes or needs. Patient navigators in LMIC, while not a new idea entirely, is still a mostly unknown position.



In order for patient navigators to become the norm within LMIC, navigation programmes and their outcomes will need to be assessed and evaluated. Objectives will need to be met and positive changes will need to be seen within communities. The programme will need to be tailored to suit the specific community in which it is offered as the access to care and needs of patients will differ depending on what is available within the local area.

What information will need to be recorded and assessed?

- ✦ Objectives of the programme
- ✦ How the patients and medical team perceive the programme
- ✦ Decrease in barriers to care
- ✦ Increase in patient satisfaction regarding management

Monitoring outcomes of the programme and the benefit of the navigation programme will provide insight as to the needs of the local community which can then be addressed.

The navigator programme will initially need to be monitored, assessed, and adapted on a more frequent basis if it is new to the local area. Once established, annual reviews are to be done to ensure that the programme remains realistic, has improved outcomes for patients, and remains a required part of the patient's journey.

Patient navigators will need to be involved in the collection of data, analysis of the data collected, and reporting of the outcomes.

Patient navigators need to constantly remember that whatever information they obtain from or about a patient is confidential and must remain so. Documentation and data capturing must be legally compliant.

As with any evaluation process, the patient's needs are identified and analysed. A plan is decided upon and then implemented. Monitoring and assessments need to be done on a regular basis and then further improvements can be decided upon and put into place.

Data collected will need to be analysed and assessed on a regular basis so that updates and improvements can be made to the navigation process and programme. Once data is collected, the following is to be considered:

- ✦ were patients very dissatisfied with any part of the service and how can this be improved
- ✦ identify the part of service requiring the improvement
- ✦ identify who is responsible for actioning the improvements
- ✦ are further details required from the patients in order to action improvements
- ✦ prioritise the improvements list
- ✦ create an action plan to manage the improvements

A date is set to implement the improvement and a follow-up date is set to reassess the progress of the improvement.

Below is an example of a navigator programme patient survey. A similar one can be created for a navigator programme medical team survey.

Navigator Programme Patient Survey

Please rate the below on a scale of 1 to 5.

1: very dissatisfied

2: dissatisfied

3: neutral

4: satisfied

5: very satisfied

1. *What is your overall rating of the navigator programme?*

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

2. *What is your overall rating of your navigator?*

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

3. *How satisfied were you with the information you received?*

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

4. *How satisfied were you with the timeliness in which your navigator returned your calls ?*

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

☐ N/A

5. *How informed do you feel your navigator was about your case?*

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

6. *How satisfied were you with the helpfulness of the information you were provided?*

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

7. *If applicable, how satisfied were you with the support services you received?*

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ N/A

8. *How satisfied were you with the responses/answers your navigator gave to your questions?*

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

9. *How satisfied were you with the time spent working together with your navigator?*

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

10. *How satisfied were you with how the resources provided to you matched your condition and situation?*

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

11. *If you were to recommend this navigation service to others would you describe your experience as:*

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5

Do you have any overall comments about the patient navigation programme?

Do you have any suggestions for how the navigation programme can be improved?

Thank you for participating in this survey. Should you require feedback about your answers and comments, please provide your name and contact details below:

Name: _____

Contact details: _____

RESOURCES: BOOKS, WEBSITES, COURSES

Available and applicable resources will be dependent on where you live, where the patient lives and is being managed or treated, and what facilities you have in that area. In order to navigate a patient through a system, you will need to know about your available resources and how to use them.

Below are resources that have been referred to in this Patient Navigation Module (Part 1 – 3) along with other useful resources which may be helpful for you, as a patient navigator, to use when setting up your own system and resources.

Websites:

www.breastcancer.org

www.cancer.gov

www.canceradvocacy.org

www.laosa.co.za

www.macmillan.org.uk

www.ncbi.nlm.nih.gov

www.nccn.org

www.nioh.ac.za

www.nhs.uk

www.radiopaedia.org

www.cancerresearchuk.org

www.pepcourse.co.za

www.canceralliance.co.za

www.komen.org (this website has a comprehensive one page printable document of facts and resources)

www.nationalbreastcancer.org

www.cancercare.org

Books:

✦ Breast Care – J Edge and D Woods

- ✦ Handbook for the management of breast cancer in a general hospital – J Edge and I Buccimazza
- ✦ Finding Hope that Heals, by Wendy S. Harpham, MD at the National Cancer Foundation INC (free ebook)

Smartphone Applications:

- ✦ ABC's of Breast Health (free breast health app)

Additional Reading:

- ✦ The South African National Department of Health Clinical Guidelines for Breast Cancer Control and Management: https://www.knowledgehub.org.za/system/files/elibdownloads/2021-03/Clinical%20guidelines%20Breast%20Cancer_0.pdf
- ✦ Oncology Patient Navigator Training: The Fundamentals George Washington University (GW) Cancer Institute © 2015

Courses:

- ✦ Breast Course for Nurses: for all healthcare providers - www.breastcourse4nurses.co.za
- ✦ Breast Care Course: for registered / professional nurses – contact: breastcarecourse@gmail.com for further information
- ✦ Bettercare Breast Care: for all healthcare providers - <https://bettercare.co.za/learning-programmes/breast-care/>

Activity 3.8

Make a list of resources that you will be able to use for yourself and the patients that you will assist. These resources can include but are not limited to:

- ✦ printable materials
- ✦ books
- ✦ websites
- ✦ pamphlets
- ✦ videos or links to videos

Acknowledgment

Thank you to all the contributors from the Breast Course for Nurses and RAD-AID International, that made this important public health resource guide available worldwide. In the ever-changing global health system, we trust that this breast care navigation resource provides a base of knowledge and information to assist all patient navigators in their critical roles in breast cancer care as they guide patients through their cancer journey.

“Education is the most powerful weapon which we can use to change the world” – Nelson Mandela.

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- Content and images from the books listed below were used in this module with permission from the authors.
 - ✦ Breast Care (Bettercare) by Dr Jenny Edge and Prof David Woods
 - ✦ Handbook for the Management of Breast Cancer in a General Hospital by Dr Jenny Edge and Dr Ines Buccimazza
- Book layout & design:
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