## PALLIATIVE CARE FOR NON-CANCER ILLNESSES

JOHN WERU- 17/08/17

### INTRODUCTION

- Cancer is responsible for a low percentage of deaths globally- 16.7%, WHO, 2016.
- Palliative Care services still tailor made for cancer patients, WHO, 2005.
- Non-cancer death perceived as dying of the "wrong diagnosis", Murray et al,2005.
- 2/3 of people dying are > 75 years.
- Shift for access on basis of need rather than diagnosis.

### WHY CANCER OVERREPRESENTATION?

- Societal acknowledgement of CA as a terminal illness.
- More definable palliative phase in CA than non-malignant illness.
- Maximizing quality of life in non-cancer illnesses often requires expertise in that specific disease, with aggressive disease-focused interventions.
- Budget constraints preclude aggressive disease-focused management of illness.

### FACTS IN NON-CANCER ILLNESSES

### 5 main issues

- Multiple symptoms
- Limited self care ability
- Subjective, downward trajectory
- Emotional distress
- Poor nutritional status

### **TRAJECTORY**



Time

End-of-life

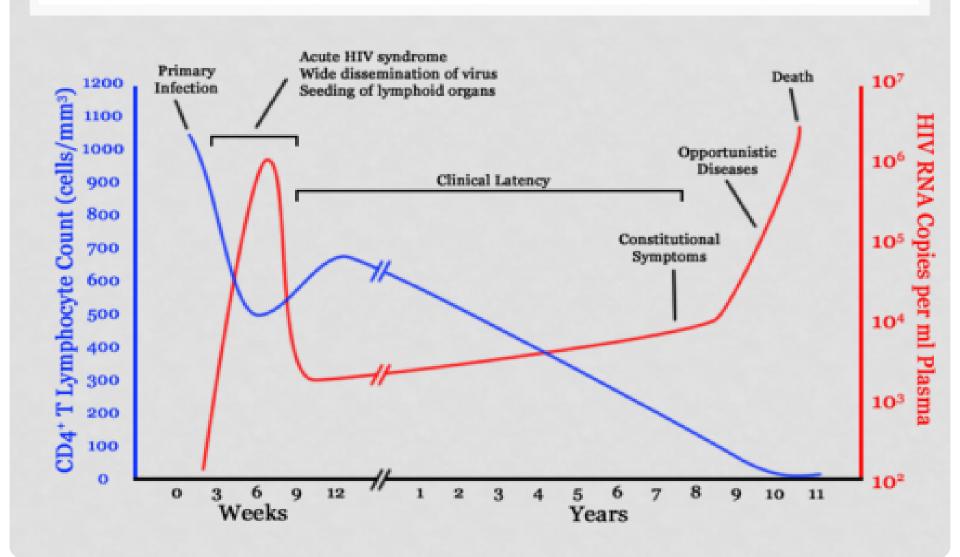
### WHAT IS GOOD PALLIATIVE CARE

- Maintaining Dignity
- Respect
- Good communication
- Clear information
- Best possible symptom control
- Psychosocial support
- Continuity of care
- Advance Care Planning

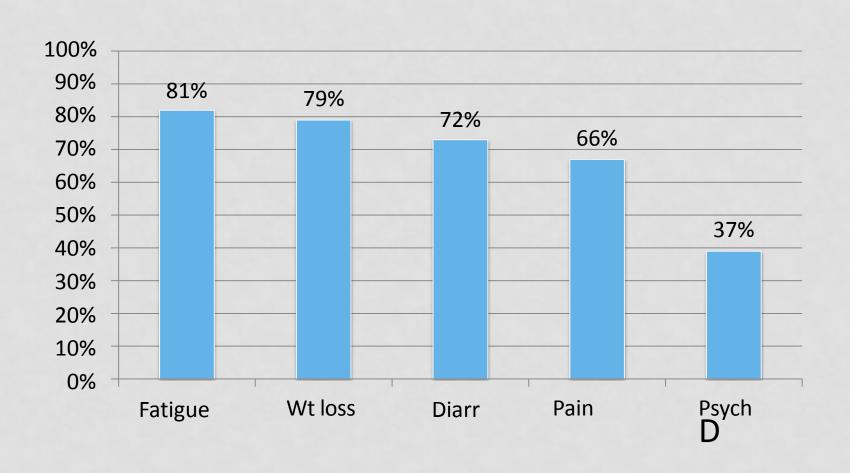
### HIV/AIDS

- Advent of antiretroviral therapy (ART) has transformed HIV from a terminal to a chronic condition.
- More extensive symptom affects quality of life- roles of palliative care in ameliorating distressing symptoms.
- Multiple, shifting challenges and symptoms that the patients and families face as they face this life-limiting disease.

### HIV DISEASE TRAJECTORY



### SYMPTOM BURDEN



### CASE 1

- Patient BS was diagnosed with HIV in 2000, on  $3^{rd}$  line ARVs with a CD4+ count of 50 cells/ $\mu$ L, and his last viral load was1800/ml. Seen complaining of burning, shooting pain lower limbs which was of insidious onset and started at the toes but has spread proximally. What type of pain is BS experiencing:
- Nociceptive pain
- Neuropathic pain
- Chronic pain
- Hyperalgesic syndrome

### **MECHANISM**

• Chronic immune activation with increased production of pro-inflammatory cytokines .

ARVs lead to mitochondrial toxicities.

Malnutrition and cor-morbids lead to nerve injuries.

### **MANAGEMENT**

- The goal is usually to manage pain and stop the progression of the symptoms and patient distress.
- Patient education is key.
- Pharmacologic treatment is multimodal, involving several types of medications.
- Anticonvulsant such as gabapentin or pregabalin, titrate to effect.
- Antidepressant such as a SSRIs eg duloxetine can be added.
- Refractory symptomatology, adding a long-acting opioid has been shown to have pain relieve effect.

### **OPPORTUNISTIC INFECTIONS**

- Work up; BS is also found to have cryptococcal meningitis, tracheal candidiasis and intestinal cryptosporidiosos resulting in chronic diarrhoea.
- BS is semicomatose, jaundiced, dehydrated with multiple skin & mouth lesions.
- Stage of disease?
- Best approach: Quality symptom management, attention to the patient's quality of life, timely, quality patient and family communication with individualized social support is also a key consideration.

### **WEIGHT LOSS**

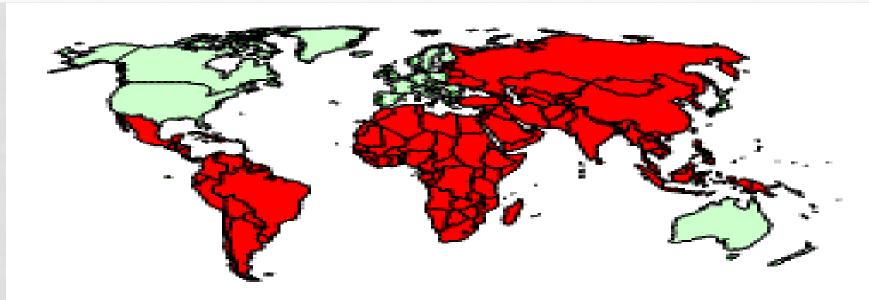
- BS has lost 12kg in the last 1 month (56-44kg).
- Wasting syndrome.
- Timely effective treatment of HIV with antiretroviral medications is key to treatment of wasting syndrome.
- A diet rich in calories and protein is recommended so as to stop or minimise loss of muscle mass.
- Exercises such as weight lifting.
- Patient and family education as to the cause and prognosis in HWS is a significant factor in overall quality of life.

### **STROKE**

### Challenges:

- Symptoms control- weakness, paralysis, post stroke pain
- Speech loss, loss of balance, memory loss, visual & emotional difficulties
- o Communication and goals of care
- Feeding options
- Home care and assisted living

# FACT



- stroke as the 2<sup>nd</sup> cause of deaths
- stroke as the 3<sup>rd</sup> cause of deaths

Stroke Education Ltd (NZ) 2006

### **FIGURES**

- Stroke is the 2nd major cause of death worldwide and the leading cause of long-term disability in adults. (Donnan GA 2008)
- According to the WHO, 15 million people worldwide have a stroke ever year, 5 million of whom die and 5 million are permanently disabled.
- In the US alone, there are about 5.5 million stroke survivors and every 45 seconds someone has a stroke. Every 3 minutes someone in the USA dies from a stroke, and about half of stroke survivors are left disabled.

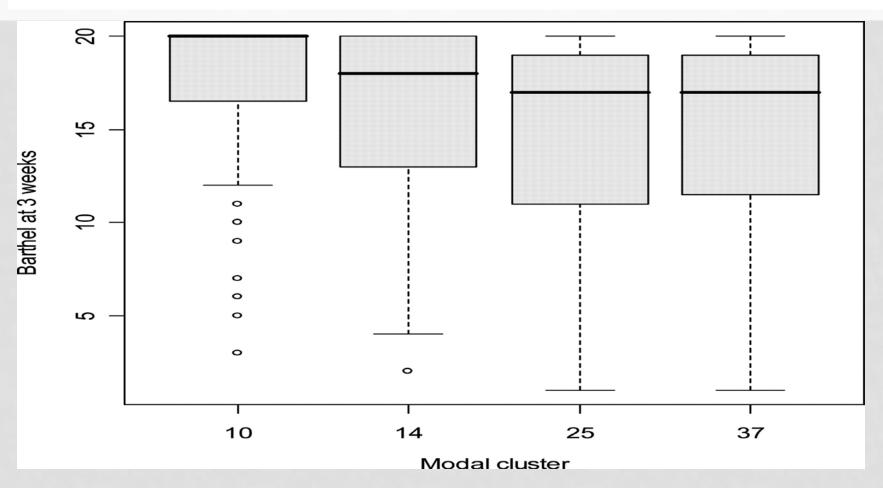
### **OUT OF 10!**

- About 2 out of 10 people who have a stroke die within the first month.
- 3 out of 10 die within the first year.
- 5 out of 10 die within the first 5 years.
- The more time that passes after a stroke, the less is the risk of dying from it.

### **COMMON SYMPTOMS IN STROKE**

- Fatigue
- Pain
- Lack of energy
- Weight loss
- Pressure sores
- Difficulty swallowing
- Poor appetite
- Early Satiety
- Restlessness
- Psychological-anxiety, depression

# PSYCHOLOGICAL DISORDERS AFTER STROKE ARE AN IMPORTANT INFLUENCE ON FUNCTIONAL OUTCOMES-ROBERT ET AL 2010



### **CASE**

- 81yrs, female, widow, wheelchair-bound, multiple admissions, previous CVA-2014.
- Semiconscious, Central Post Stroke Pain (CPSP) Lsided weakness, agitated, aspiration pneumonia fever.
- Empirical Antibiotics started.
- Poor feeding
- CT head: intracerebral haemorrhage.
- Daughter- do all; Son- DNR
- Challenges?

### **CHALLENGES**

- A case for referral to Palliative care?
- Chronic disease management
- Feeding
- Continuity of care
- Symptom management CPSP
- Family conflict
- ACP

### CHRONIC STAGING OF STROKE

• Karnofsky Performance Status <50% or Palliative Performance Scale <40%.

or

- Inability to maintain hydration and caloric intake with 1 of the following:
  - a. Weight loss >10% in the past 6 mo or >7.5% in the past 3 mo
  - b. Serum albumin < 2.5 g/dL
  - c. Current history of pulmonary aspiration not responsive to speech language
  - d. Dysphagia severe enough to prevent patient from continuing foods/fluids

### **STRATEGY**

- Knowledge and use of effective communication techniques
- Knowledge, skills, and competency in running an effective patient and family meeting
- Integrate scientific evidence and the best available evidence about patient values and preferences when making a recommendation about the best course of continued care
- A structured approach to setting patient goals in patients with stroke care may be reasonable to improve the quality of health care
- Commence ACP discussions early

### **CENTRAL POST-STROKE PAIN**

- Chronic pain in those body areas that have lost part of their sensory innervation occurs in 1% to 12% of stroke patients.
- Due to partial deafferentation of the spinothalamic tract or its cortical projections.
- Only amitriptyline and lamotrigine have been shown to relieve pain, but the studies were small (n=15 and 30, respectively). Johnsson et al, 2005 & Hanssen et al, 2012.
- Levetiracetam, pregabalin and carbamazepine have not been found to have meaningful pain relief in CPSP

### **CPSP**

- In a randomized clinical trial of gabapentin for neuropathic pain syndromes, only 9 people in the study population (3%) had CPSP.
- Although venlafaxine has been found to be effective for a variety of neuropathic pain syndromes, its benefit in CPSP is unknown is not proved.

### **SUMMARY**

- Difficulties in identifying dying in non-cancer patients.
- Uncertainty and prognostic paralysis exist.
- Multiple symptomatology a significant challenge.
- PC an integral component of quality care for non-cancer illnesses.
- There is need for recognition of the importance of PC for non-cancer illnesses. PC fraternity, policy makers and society at large has a duty.
- Individualised assessment & approach key in provision of Quality PC

#### Palliative care can help you and your family...

Evaluate treatment options

Establish treatment goals Manage pain and symptoms like nausea, fatigue and sleep problems

Understand what to expect throughout your illness

CARE

Receive social or spiritual support

Navigate the health system

Resolve healthrelated financial or legal concerns

Cope with worry, stress or depression



### NHPCO.ORG/BEINGMORTAL

"WE'VE BEEN WRONG ABOUT
WHAT OUR JOB IS IN MEDICINE.
WE THINK OUR JOB IS TO ENSURE
HEALTH AND SURVIVAL. BUT
REALLY IT IS LARGER THAN THAT.
IT IS TO ENABLE WELL-BEING."

Atul Gawande Being Mortal: Illness, Medicine and What Matters in the End