VISION
COPING WITH CANCER
VISION, MARCH 2017

Fixing the Patent Laws - one step at a time

On International Women's Day, 8 March 2017, the UN Human Rights Council convened a panel discussion on access to medicines in the context of the right to health. The Panel Discussion was convened as a result of a resolution proposed by Brazil, China, Egypt, Haiti, India, Indonesia, Paraguay, Peru, Senegal, South Africa, Thailand and adopted by the Council in July last year. The resolution calls special attention to concerns around intellectual property, implementation of TRIPS flexibilities and impediments to access to medicines. Of course this was heavily protested by developed countries. Still the resolution and the convening of the Panel is a big deal given that developed countries and MNC pharma are resisting any discussion on this subject (access to medicines and human rights) in any international forum where the issue of IP or trade is also linked to it.

The final resolution adopted is here: https://documents-dds-ny.un.org/doc/UNDOC/LTD/G16/140/37/PDF/G1614037.pdf?OpenElement

Fix The Patent Laws has sent a short but sharp one page letter to the human rights council from the Tobeka Daki Campaign reminding them of the significance of the day, the gravity of the topic being discussed and the need for urgent action on access to affordable breast cancer treatment for all women who need it while highlighting the hideous actions of Roche to undermine and prevent access to affordable biosimilars while refusing to drop prices in spite of their exorbitant profits and despite research showing that a sustainable, profitable price for trastuzumab would be USD 240.

Gauteng gets additional R3bn, but ...

The bad news, according to Jack Bloom, DA Gauteng Shadow Health MEC, is that the money for maintenance in Gauteng hospitals and clinics has been slashed by more than half, from R750 million last year to R356 million.

The overall health infrastructure budget is down from R2 billion to R1.6 billion and it is projected to fall even further to R866 million in 2018/19 and R914 million in 2019/20. This is grossly inadequate to deal with growing maintenance backlogs in our hospitals and clinics, as well as build new health facilities for a growing population.

Mr Bloom says that there is doubt whether enough money has been set aside to fix all the identified problems at Charlotte Maxeke Johannesburg Academic Hospital and other hospitals. He said "The smelly and moldy emergency room at the Jeppe street clinic in inner city Johannesburg that I visited last week may not be fixed soon either. Maintenance and repair has again not received the priority that it deserves in the provincial budget."

CanSurvive buddy training

A very successful training course was held during February when more than 40 survivor and caregivers attended.

The speakers were Dr Devan Moodley, Linda Greeff, Carin Marcus and Bernice Lass. It was full of interesting information aimed at helping our buddies to understand what is required of them when supporting patients and caregivers. It is hoped to run a half day course for caregivers only in the near future.

PSA and male cancer support group

Monthly support groups are held at the Boardroom at MediClinic, Constantiaberg, Plumstead

28 March 17:45 – 19:00

For more information contact:

Helpline: 076 775 6099

Email: info@can-sir.org.za. Web: www.can-sir.org.za

Our grateful thanks to Medi-Clinic for providing a home for our activities and refreshments for our members. It is much appreciated by us all.

Caring for your skin during radiation therapy...

by Dr Yastira Ramdas

More than half the population diagnosed with cancer will receive radiation therapy at some point as part of their treatment. One of the most common side effects of radiation therapy is a skin condition called radiation dermatitis.

Although it might seem like a minor matter compared to the complexity of cancer treatment, skin care is important for patients undergoing radiation therapy because the procedure can lead to excessive skin dryness and damage that can lead to infection.

What is a skin reaction?

A skin reaction is the change that your skin, in the treated area, may go through as a result of your radiation treatments. Some patients have a mild skin reaction, while others have a significant skin reaction. Everyone is different and skin reactions will vary from person to person.

Skin reactions can show up in the first 7-10 days, and may get worse over the course of the treatment.

Radiation-induced dermatitis can be classified as acute or chronic:

- ❒ Acute radiation dermatitis occurs within 90 days of exposure to radiation. The patient may have skin changes ranging from:
  - ❖ Faint erythema (reddening) and desquamation (peeling skin) to skin necrosis (death of skin cells) and ulceration, depending on the severity of the reaction

Onset of chronic radiation dermatitis may occur from 15 days to 10 years or more after the beginning of radiation therapy. It is an extension of the acute process and involves further inflammatory changes in the skin.

- ❒ Chronic radiation-induced changes in the skin are characterised by:
  - ❖ Disappearance of follicular structures (pores)
  - ❖ Increase in collagen and damage to elastic fibres in the dermis
  - ❖ Fragile surface skin (epidermis)
  - ❖ Telangiectasia (prominent blood vessels)

Cause and risk factors

Unfortunately, radiation injures or kills healthy cells as well as the cancer cells in the treated area. Repeated radiation exposure causes an imbalance in the tissue damage and repair, so that exposed skin is damaged faster than it can repair itself.

Treatment related factors that increase the risk and severity of reactions include:

- ❒ High daily and cumulative radiation doses.
- ❒ Large treatment field
- ❒ Treatment to areas with skin folds
- ❒ When radiation is given together with certain chemotherapies
- ❒ Poor nutrition
- ❒ Pre-existing skin disease
- ❒ Application of skin creams to exposed area immediately before treatment

Durban born Dr Yastira Ramdas is a Radiation Oncologist working at Netcare's Waterfall City, Pinehaven and Krugersdorp hospitals.
She was previously a specialist consultant at Charlotte Maxeke Johannesburg Academic Hospital running the Breast Cancer Unit and lectured to fifth and sixth year medical students.

Steps to keep your skin protected

1. Keep your skin clean

- ❒ Bathe or shower daily using warm water and a mild unscented soap, such as Neutrogena®, Dove®, baby soap, Basis®, or Cetaphil®. Rinse your skin well and pat it dry with a soft towel
- ❒ When washing, be gentle with your skin in the area being treated. Don't use a washcloth, scrubbing cloth, loofah or brush
- ❒ The tattoo marks you received before your treatment are permanent and won't wash off. You may get other markings during treatment such as an outline of your treatment area with a purple felt-tipped marker
- ❒ Don't use alcohol or alcohol pads on your skin in the area being treated

2. Avoid irritating your skin in the treatment area

- ❒ Wear loose-fitting, cotton clothing over the treated area
- ❒ Use only the moisturisers, creams, or lotions that are recommended by your doctor or nurse
- ❒ Don't use makeup, perfumes, powders, or aftershave in the area being treated
- ❒ You can use deodorant on intact skin in the area not being treated. Stop using it if your skin becomes irritated
- ❒ Don't shave the treated skin. If you must shave, use an electric razor and stop if the skin becomes irritated
- ❒ Don't put any tape on the treated skin
- ❒ Don't let your treated skin come into contact with extreme hot or cold temperatures. This includes hot tubs, water bottles, heating pads, and ice packs
- ❒ Don't apply any patches to the treated area, including pain patches
- ❒ If your skin is itchy, don't scratch it. Ask your doctor for recommendations on how to relieve the itching
- ❒ Do not swim in a chlorinated pool
- ❒ Avoid tanning or burning your skin during and after you are finished with treatment. If you're going to be in the sun, use a PABA-free sunblock with an SPF of 30 or higher. Also, wear loose-fitting clothing that covers you as much as possible
- ❒ The heat from a hot tub, sauna or steam room may irritate or worsen your skin reaction. So avoid these places whilst on treatment

During the weekly visits to the oncologist, whilst on treatment your skin is always assessed. There are assessment tool that can be used to identify grades or degrees of skin reactions. Skin should be assessed before the initiation of treatment and regularly thereafter.

Understanding your "pain relief journey...your lifestyle adaptation"

by Christa du Toit

Last month we discussed the definition of pain. Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective. "Pain is what the patient says hurts" The cancer is not always the cause of a pain symptom and causal factors could have a major influence. This could include the treatment, concurrent disorders, worsened by insomnia, exhaustion and many more.

Our study focused on the development of a lifestyle adaptation programme for patients together with their families, diagnosed with chronic pain. We need to adapt your lifestyle accordingly. Lifestyle may be defined as an individual's energy towards living and constitutes the driving force towards a desirable direction. Your multi-disciplinary team should understand the entire illness process in order to ensure the holistic care; they will explore your needs and experiences

Often the multi-disciplinary team cannot take your pain - your "problem" - away, but they will support you to manage the specific symptoms. Once you take cognisance, understand that this problem is not going to go away, I need to learn how to cope with this, manage this, the first step has been taken.

Braunwald stated that fear and stress have a negative influence on mental health and can cause brain cells to shrink and even die. Patients and their families need to understand the condition, ask the right questions and get the right answers, and therefore communication is essential with both the patient and family. Little thought is given to lifestyle adaptations due to the fact that many patients have an unrealistic gloomy perception of their prognosis. The basic elements of the patients, family or your caregiver are notably affected with your diagnosis. At a time when nourishment and rest are crucial, you have to cope with new/different dietary requirements, disrupted sleep, anxiety, depression, pain and many more stressors. No aspect of your life is immune to this crisis. Work schedules, leisure time and social life have been interrupted and altered. Primary relationships are in a transitional phase. Personal goals and dreams, beliefs and values are undergoing change as a result .These aspects become the new ingredients of the lives of those who are affected

Understanding your diagnosis, your treatment plan and the complexity of your multidisciplinary healthcare team is crucial. Once this has been clarified we can start adapting. Kritzinger *et al* stated adaptation may be proclaimed as the ability to modify, convert or alter something. Rapid change adversely affects the majority of people, who commonly experience that such change is too much to handle and to cope with. In an effort to preserve relationships, people tend to make one compromise after another for prolonged periods on end, which result in serious problems seeing that relational synergy is ignored.

Although mild or moderate anxiety is needed to accomplish developmental tasks and motivate goal directed behavior, anxiety in overdrive results in altered cognitive function. Consequently people become reactive and essentially give up. Anxiety is often the consequence of poor communication or not understanding and this could result in confusion or sometimes restless behavior. Using one's available support systems significantly influences the adaptive ability of the individual to cope with stress. Sometimes by just "talking the problem out" with someone who is empathetic hampers the escalation of the stress response

The lifestyle adaptation programme, often used in support groups, implements "The Pain wheel-Understanding your pain in totality". With the end result that the communication between the specialist of your pain - you yourself, your doctor, your family and any caregivers will improve. We need to walk this path together, adapt together. Concordance in perceived needs of family members and caregivers leads to greater need satisfaction, and it is advocated that the patient and family (rather than just the patient) be focused on due to the relationship between social support and patient recovery.

Christa du Toit works for Janssen Pharmaceuticals as Medical Scientific Liaison: Pain.

Discovery Health Exhibition and Shavathon

CanSurvive were happy to be present at the Discovery Head Office in Sandton to meet survivors and interested onlookers when a Shavathon and exhibition was held earlier in March

Healing hate

Three decades at cancer's bedside has taught me about fear. I have seen denial postpone critical diagnosis. I have watched mistrust and anger yield poor choice. I have fought against terror that spreads malignancy by delaying treatment. I have shared fury and devastation as horrid growths rip apart bodies, destroy families and end life.

After so many thousands of patients, so many wasted lives, you would think I would have given up. Fear, anger and loss should have burned me out. Have I not accepted that man's fate is to suffer and die? Cancer wins. We lose.

The opposite is my truth. I have seen the glory that is man. I see great victories, miracles, every day. The courage of patients, friends and families. The sweat, work and brilliance of visionaries, scientists and great physicians. I see stunning breakthroughs and new horizons today and coming so quickly, in tomorrows near. The losses of a career have taught about courage and the infinite ability of man to conquer. The destruction of disease has taught that the enemy of hope is fear.

Once again and always, we face another disease. That societal sickness is the growth of hate. As with cancer, it is fed by fear. As with cancer, it is spread by ignorance. As with cancer, mistrust, and anger result it pathologically horrible decisions destroying dreams, opportunity and lives. Hate is a disgusting, oozing, bleeding, aberrant tissue that kills.

Hate feeds off ignorance. Like a depleted immune system, it grows when fear and confusion open lethal opportunity by suppressing reason, communication and trust. In those vital moments, when those who would choose love and community are too confused or scarred to speak, hate spreads its lethal metastasis. Hate wins. We lose.

However, I have seen the glory that is man, and I know of his courage to fight disease. A cancer found early is weak, flimsy and, deprived of cause and nourishment, no more than a few dead cells under the surgeon's knife. Such is hate. Dreams, reason and courage, vanquish irrational fear; the spread of hate can be stopped and the horror it threatens, will fade.

When faced with cancerous growth, a healer has a calling and an opportunity to act. If the doctor and patient can overcome fear, and, with trust, work together, there is hope for cure. Faced with cancerous hate, we are called and must act. Sprouting from ignorant anger in a putrid soil of fear, hate grows until it threatens every child, every mother, every father, and every soul. Only if we can overcome hate, is there is hope for life.

James C. Salwitz, MD

Dr. Salwitz is a Clinical Professor at Robert Wood Johnson Medical School.

He lectures frequently in the community on topics related to Hospice and Palliative Care and has received numerous honours and awards, including the Physicians Leadership Award in Palliative Care.

His blog, Sunrise Rounds, can be found at http://sunriserounds.com

Palliating the doctor

Being an oncologist can be an awfully hard job. You give body, mind and soul, you love your patients. Then, sometimes, the cancer takes over and those who have become your teachers and friends, die. It can be hard to find balance. You have failed. For some doctors the practice of oncology wipes them out. There is a secret to being able to join the fray, every day, month and year; know that, whatever happens, there is always something you can do.

When I was first in practice, I took care of a young woman, a girl of 19, who had advanced colon cancer. Surgery, repeat surgery, chemo after chemo, radiation, every treatment we tried, failed. She became weak. Her abdomen swelled. She became jaundiced. I remember gold tears on deep yellow tanned skin. Her pain and fear increased. I became frantic, anxious, even angry. How could this pure child die? I called every "expert." There seemed nothing I could do.

Then, late one evening, making rounds, I heard her crying down the hall. I realised that while I was searching the medical world for a cure, I was failing to take care of her real need. I could sooth her fear and control her pain. A small amount of pain medicine and a slight sedative. A hand held. That evening she finally rested, quietly talking with her parents. She laughed. I realised, there was something I could do. There would always be something I could do.

For oncologists who believe that their only role is to battle disease, to fight against death, to attack with treatment after treatment, there will always be failure. Again and again, they experience deep loss. They become shells with a burned out soul.

For oncologists that understand their role is to relieve suffering, whether by treating disease, relieving symptoms or just the compassion of a smile and a touch, there is balance. They will never fail their patients, never desert them, always have something to offer.

What is critical about this discovery, this approach to care, is that it is good not only for the patient and family, it is healing for the doctor. It allows her to attack the disease, when that is the right thing to do, but always be ready to give comfort and soothe symptoms. To stand by each patient, no matter what happens. There is balance in the knowledge that even if the disease explodes and life is coming to an end, the doctor has a role and purpose. Closure not only for the patient, but for the physician.

Being an oncologist will always be an awfully hard job. You love your patients, and some die. However, for me there is the comfort of knowing that whatever happens, I will be there. My small place in the cycle of life.

WINGS OF HOPE

Group members gather together for a friendly chat after listening to one of the excellent speakers who spend their Saturday morning helping and educating cancer survivors and patients. The Group meets on a Saturday morning at the Netcare Auditorium at 76 MaudeStreet, Sandton.
Meetings will be held on 11a March, 22 April, 3 June and 15 July.

Can Uganda drive more cancer patients to hospital?

Friday morning at the Uganda Cancer Institute is free screening time. Being the biggest cancer facility in the country, coupled with ever-increasing cases, one would expect to see some quite big numbers. But that is rarely the case.

But just a few metres away on the opposite treatment side, a sizeable number patients could be seen. Many hurdled in groups, some still wrapped up in their warm clothing, blankets and sheets, often with protruding tumours on the face and others with bold heads probably from tough cancer treatment. A few walked around. Some had been here for days and others weeks, they said, hoping in vain to see a doctor.

Workers at the Institute say the contrast between the screening side and treatment side does not surprise them. Dr Noleb Mugisha, one of the few oncologists at the 50-year-old Institute located at Mulago Hill, says there is a scramble at the treatment clinic because people are in pain.

"They only report after their tumours start paining and that's why we lose them. Any doctor prides in treating to cure but by the time they come here their cancers are irreversible and there's nothing much we can do," he says bare hiding his frustration. There are many of his colleagues who share his view.

It's one problem that experts at the World Health Organisation (WHO) have recognised and want to reverse. So, it released a new set of guidelines to early diagnosis and treatment of cancer aimed at ensuring increased survival.

The country-level intervention guidelines are summarised in three steps; improving public awareness of different cancer symptoms and encourage people to seek care when these arise, investing in strengthening and equipping health services and training health workers so they can conduct accurate and timely diagnostics, and lastly ensuring people living with cancer can access safe and effective treatment, including pain relief, without incurring prohibitive personal or financial hardship.

Evidence shows treatment for cancer patients who have been diagnosed early are two to four times less expensive compared to treating those diagnosed with the disease at more advanced stages. And, this does not only reflect in terms of what one pays for medical service but also the fact that one can continue to work and support their families if they access effective treatment in time.

To health minister, Jane Ruth Aceng, reducing the cancer diseases burden in Uganda should not be viewed as the duty of the government only. Instead, each person can take responsibility as more than a third of all cases are preventable with simple lifestyle measures.

http://www.bizcommunity.com/Article/196/335/158384.html

The health benefits of wheat bran

By: Megan Lee

A wheat kernel is made up of three parts; the bran, endosperm and the germ. Wheat Bran is the hard outside layer of the kernel which is usually separated from the other parts of the kernel by milling. It is an indigestible plant component and is therefore where almost all of the fibre within the grain comes from, typically containing approximately 45% of dietary fibre, of which more than 90% is insoluble fibre. It is one of the most researched dietary fibres and is most strongly associated as being effective in maintaining bowel regularity.

There is a vast body of scientific evidence demonstrating the positive impact dietary fibre and specifically wheat bran has on health. There are more than 70 studies stretched over a period of 80 years looking at its health benefits. These benefits include:

Colon and breast cancer

There are 3 main protective mechanisms of wheat bran against colon cancers. Firstly, it dilutes potential carcinogens (cancer-causing agents) because it creates a bulky stool which reduces access of carcinogens to the cells lining the colon. Secondly, it accelerates the transit time of matter passing through the colon so there is less exposure of faecal matter to the cells of the colon. Studies have also found that wheat bran is the best diluter and has the shortest transit time compared to pectin, guar gum, cellulose and oat bran. Thirdly, is the effect when wheat bran is broken down by bacteria (fermented) in the colon to Short Chain Fatty Acids (SCFA) such as butyric acid which may inhibit the growth of tumours. Lastly, studies have also found that phytic acid as well as other plant compounds such as beta-sitosterol may be protective against colon cancer development.

In 2011 a systematic review and meta-analysis of 25 studies was conducted which included a total of 1.9 million participants. They confirmed that a high intake of dietary fibre, particularly from cereal and whole grains (more so than fruit, vegetables and legumes), has a significant protective effect against colon cancer. There's a 10% reduction in risk of colorectal cancer for each 10 g per day intake of total dietary fibre and cereal fibre.

Fibre has also been linked to a potentially protective effect in breast cancer. In a large study analysing adult women, they found that total fibre, particularly fibre from cereals and possibly fruit, is protective against breast cancer in premenopausal women. Possible mechanisms for this may be the role fibre plays in weight management and the potential for fibre to bind to oestrogen.

Emotional benefits

A study that was conducted at the University of Cardiff on 139 participants looked at how high fibre cereals could influence fatigue over two weeks. They found that people with higher fibre intakes experienced less emotional stress, fewer cognitive difficulties and less fatigue.

High fibre intake also helps with heart disease, weight loss, constipation and diverticular disease, and irritable bowel syndrome

FUTURELIFE® SMART FIBRE™ 2IN1

It contains HOWARU® Premium Probiotics, a blend of clinically studied probiotics that has been scientifically formulated to contain 2 of the most studied probiotic strains for gut and immune health, Lactobacillus Acidophilus NCFM® and Bifidobacterium Lactis HN019™. Each 1g sachet contains 1.2 billion CFU (colony forming units) HOWARU® Premium Probiotics at time of manufacture.

For more information on FUTURELIFE® Smart Fibre™ 2in1 as well as all the other products in the FUTURELIFE® range, please visit www.futurelife.co.za.

CancerCare Support Group

27 March 18:00 – 19:30

"Coping with family when going through cancer treatment "

The venue is the
4 floor Rondebosch Medical Centre, Klipfontein road

Phone 0219443700 for more info

Cancersupport @Centurion

Join us at our monthly meeting for refreshments, a chat with other patients and survivors and enjoy an interesting and informative talk.

Next meeting: 15 March at 18:00
at Unitas Hospital boardroom
Please phone Marianne AmbrosePhone 0219443700 for more info or Matjatji Machubeng at 012 677 8271 office hours, if you have any questions

The group is open to any survivor, patient or caregiver.
No charge is made.
The Group is hosted by Netcare.

NETCARE
You're in safe hands

The things patients say … about support groups

"A majority of the members are cancer survivors (including myself) and we mutually support one another as we cope with having cancer. I enjoy the camaraderie. I have known and been with some of these men and their wives for 16 years. It is like having an extended family."
- Richard Nesbitt, patient

Canadian Virtual Hospice

Canadian Virtual Hospice has entered its 14th year of providing information and personalised support to Canadians and people from every country around the globe. They have grown from a regional pilot project to the most comprehensive online knowledge management centre on palliative care, end-of-life care, loss and grief in the world (Fassbender, 2015). When they launched they had a part-time Executive Director, a physician and two job sharing, part-time clinical nurse specialists. Their team now includes physicians with specialisation in adult, paediatrics, long-term care and rural palliative care, nurses, psychosocial specialists including a children's grief specialist, spiritual care advisors, ethicists, a pharmacist, a community moderator, translator, communications specialist, editors, administration and IT.

They are grateful to the Winnipeg Regional Health Authority for their operating funding, to Canadian Partnership Against Cancer for project funding and to their countless partners who work with them to grow services for patients, families and health providers.

What visitors to the site are clicking on: How long can someone live without food or water?

1. Does morphine make death come sooner?
2. What can be expected with end-stage liver disease?
3. When Death is near
4. What can be expected as brain cancer progresses?
5. What happens if someone has a morphine overdose?
6. What can be expected with end-stage multiple sclerosis?
7. What is palliative care?
8. What happens when someone has cancer?
9. What can be expected with liver metastasis?
10. My friend's mother is dying, what can I say to her family?
11. Tips for talking with someone who is dying
12. How can I support my husband who's been diagnosed with cancer and is waiting for test results?

The Canadian Virtual Hospice has launched a series of 16 how-to videos to support family and professional caregivers with accessible instructions and visual demonstrations for common caregiving tasks. The videos walk viewers through step-by-step demonstrations on topics such as safely giving a bed bath and helping with bed and wheelchair transfers and giving medications. The videos are available on the Canadian Virtual Hospice website

Contact: http://virtualhospice.ca or info@virtualhospice.ca

CanSurvive
CANCER SUPPORT

Let's talk about cancer!

Join us at a CanSurvive Cancer Support group meetings for refreshments, a chat with other patients and survivors and listen to an interesting and informative talk.

Upcoming meetings:

PARKTOWN Hazeldene Hall (opposite Netcare Parklane Hospital) - 11 March 09:00

SOWETO, Jabulani - 18 March

KRUGERSDORP Netcare Hospital Group - 1 April 09:00

CHARLOTTE MAXEKE Radiation clinic - 5 April

HEAD and NECK Group, Rehab Matters, Rivonia - 6 April 18:00

Enquiries:

Mobile 062 275 6193 or email cansurvive@icon.co.za

www.cansurvive.co.za :
www.facebook/cansurviveSA

The Groups are open to any survivor, patient or caregiver.
No charge is made.

COMMUNICATION BETWEEN DOCTORS AND PATIENTS -

Words matter

Because of the uncertainties of the medical universe, sometimes we sanitise our own concerns when we are advising patients and their families. We may see an individual in the office with unexplained weight loss and a change in her bowel pattern. While we may fear that a malignancy is lurking, we would be wise to keep our own counsel on this impression pending further study. This patient, for example, may be suffering from a curable thyroid disorder.

Words matter. We all have heard how patients and families can dwell on one or two words uttered by a physician, who may have spoken at some length on a patient's condition. In these cases, the families may have inferred more serious news than the physician intended. Doctors need to be mindful of this phenomenon when we are communicating. Which of these messages would you prefer to receive on your voice mail?

"Please make an appointment to review your biopsy results."

"Your biopsy results are benign. Please make an appointment so we can discuss them further."

On other occasions, physicians may opt to leave out certain words or suspicions. Why unload anxiety on folks before the truth is known? Additionally, not every patient wants the whole truth administered in a single dose. These scenarios demonstrate the advantage that a physician has when he has an established rapport and relationship with his patient.

Conversely, I don't feel we are helping patients and their loved ones when we overly sanitise the medical situation in order to postpone an unpleasant physician task or to create hope that may not be realistic. There's a balance to be attempted, and I still struggle to achieve it.

Michael Kirsch, M.D.

http://mdwhistleblower.blogspot.co.za

Uncertain expertise

"An expert is a person who has made all the mistakes that can be made in a very narrow field." - Niels Bohr

Five experienced, well-published, and widely respected head and neck cancer surgeons are sharing the dais at the national medical meeting to explore the topic "Can We Be Better?" The panel represents a spectrum of experts from around North America and they have served as programme leaders, department chairs, and deans. Those of us in the audience know that these people collectively have seen everything. They are smart, compassionate, and gifted. We would trust any one of them to care for a family member.

"So," intones the moderator as he displays a PET/CT scan with a massive cancer of the throat, "You did well on that last case. Let me make this even more difficult."

Each case is complex. The panelists work through discussions of patients who have undergone extensive surgical procedures and have received radiation therapy and chemotherapy, only to have the cancer return.

"Oh, boy. That's a recurrence after treatment? Wow. I wouldn't have much to offer that one," says one of the experts.

"How about some chemotherapy?" asks the moderator.

"I have had a few patients do surprisingly well when they were placed on long term anti-cancer antibodies," says one of the others.

"The data are not very supportive of that approach," says the moderator. "The research says it extends life by only a few weeks and the drugs cost about $10,000 per month."

"About one-quarter of lifetime medical expenses occur in the final year of life," notes another.

"I would have the patient and family work with the palliative care team. There was a Boston study demonstrating that people receiving no treatment actually lived longer than people receiving chemotherapy near the end of life," says another.

And so it goes. Back-and-forth with no textbook answers. The panelists gamely quote research and recall patients who have done well and have done poorly. They suggest palliative care, hospice referrals, and comfort measures. They discuss costs. They review the principles of shared decision making. They acknowledge that, at some point, further active treatment is always futile.

"And what if he was in his eighties instead of being in his fifties?"

Dr Bruce Campbell is a Head and Neck Cancer Surgeon. He has been a leader of the MCW Multidisciplinary Head and Neck Cancer Programme of the Froedtert Cancer Centre. He evaluates patients with tumours of the oral cavity, throat, sinuses, voice box, thyroid, and neck. Read his blog at http://www.froedtert.com/HealthResources/ReadingRoom/HealthBlogs/Reflections.htm

asks the moderator. "Would you change your mind based on his age?"

The panelists glance at each other and smile. "It depends," they say.

Those of us in the audience understand that the requisite skills to care for these difficult patients does not come easily, even to these world-class experts. Their abilities and judgement have accumulated slowly in layers over the course of long and thoughtful careers.

I look around the room and nod to one of my East Coast colleagues who does what I do. Other surgeons shake their heads and whisper to each other. I suspect they are all remembering patients and situations that were equally vexing.

Then one of the surgeons on the panel says this: "My worst nightmare is having all of my head and neck cancer patients come back from the grave to visit me."

It is a shock to hear him say this, but I know what he means. When things go well, our patients can live long and functional lives. When thing go badly, though, the final weeks and months can be horrible for both patient and family. As surgeons, we grieve as well, although we realise our suffering pales when compared to what the family experiences. The memories of those patients remain. Even when we have established solid relationships and have compassionately helped patients transition through the stages that approach the end of life, we still feel as though we have failed them.

I glance over my shoulder to check the reactions from the back of the auditorium. The rows are filled with young men and women - the medical students and residents - who are at the meeting to present their research and discuss their posters. They are just beginning their journeys as physicians, filled with anticipation while they decide on their potential careers paths.

I wonder: What must they be thinking, watching these senior surgeons appear to struggle with patient care decisions? If these chairs, deans, and surgeon-leaders nearing the ends of their clinical careers are still anxious and uncertain about caring for these patients, why would these young physicians ever want to select this field of practice?

It wasn't all that long ago when I was sitting in those seats and wondering the same thing. A few patient encounters, welcoming families, and serendipitous moments directed my footsteps. I still experience anxiety at times, although those anxious moments sometimes let me know I am still alive.

Building a career and a life around the difficult moments has rewards. Some of our students and residents will, in fact, be drawn to the flame. I try to share the rewards with them and encourage them to be reflective. My task is to help provide them the tools to find meaning and peace that will carry them deep into careers that will never, ever offer certainty.

CONTRIBUTIONS FOR PUBLICATION

VISION is an e-newsletter for cancer patients and caregivers and we would like to be able to provide information on suitable support meetings anywhere in South Africa so please, let us have your details for 2017.

Your comments, articles, and letters submitted for publication in VISION are always welcomed and can be sent to the Editor at: cansurvive@icon.co.za.

CALENDAR

March 2017

11 CanSurvive Cancer Support Parktown Group, Hazeldene Hall, Parktown 9:00

11 Wings of Hope, Netcare Auditorium, Sandton. 10.00

15 CanSurvive Charlotte Maxeke Group, Radiation Floor P4

18 CanSurvive Jabulani Group at HapyD, 1432 Buthelezi St.

23 Cape Gate Oncology Group, Oncology Centre 10:00. Cancer and depression.

25 Bosom Buddies Support Group, Hazeldene Hall, Parktown at 09:30 for 10:00

27 Cancercare Support Group, Rondebosch Medical Centre, Coping with family when going through cancer treatment.

28 Can-Sir Malecare Support Group, Mediclinic Constantiaberg, Plumstead, Cape Town, 17:45 – 19:00

April 2017

1 CanSurvive Cancer Support West Rand Group, Netcare Krugersdorp Hospital, 09:00

5 Reach for Recovery Group meeting 13:45 Lifeline offices,2 The Avenue, Cnr Henrietta Street, Norwood

5 Cancercare OuteniquaSupport Group, GVI Boardroom,3 Gloucester Ave. George 10:00 - 12:00

5 CanSurvive Charlotte Maxeke Group, Radiation Floor P4.

6 CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00

8 CanSurvive Cancer Support Parktown Group, Hazeldene Hall, Parktown 9:00

15 CanSurvive Jabulani Group at HapyD, 1432 Buthelezi St.

15 CancerSupport@Centurion support Group at Netcare Unitas Hospital, Centurion at 16:00

18 Can-Sir Malecare Support Group, Mediclinic Constantiaberg, Plumstead, Cape Town, 17:45 – 19:00

19 CanSurvive Charlotte Maxeke Group, Radiation Floor P4

20 Cape Gate Oncology Group, Oncology Centre 10:00. Living with pancreatic cancer.

22 Wings of Hope, Netcare Auditorium, Sandton. 10.00

24 Cancercare Support Group, Rondebosch Medical Centre, Nutritional focus after treatment maintaining your health.

May 2017

3 CanSurvive Charlotte Maxeke Group, Radiation Floor P4.

3 Cancercare OuteniquaSupport Group, GVI Boardroom,3 Gloucester Ave. George 10:00 - 12:00

4 CanSurvive Head and Neck Support Group, at Rehab Matters, 1 De la Rey Rd. Rivonia at 18h00

6 CanSurvive Cancer Support West Rand Group, Netcare Krugersdorp Hospital, 09:00

13 CanSurvive Cancer Support Parktown Group, Hazeldene Hall, Parktown 9:00

13 Bosom Buddies Support Group, Hazeldene Hall, Parktown at 09:30 for 10:00

16 Can-Sir Malecare Support Group, Mediclinic Constantiaberg, Plumstead, Cape Town, 17:45 – 19:00

CONTACT DETAILS

CanSurvive Cancer Support
Parktown and West Rand Group :
CanSurvive Head and Neck Support Group, Rivonia,
Contact: 062 275 6193 or cansurvive@icon.co.za
Charlotte Maxeke Group: Contact Duke Mkhize 0828522432
Jabulani Group: Contact Sister Bongiwe Nkosi: 0835760622 or Raynolda Makhutle: 0837534324

CancerCareSupport Group, 4th Floor, Rondebosch Medical Centre. Contact: linda.greeff@cancercare.co..za or phone 0219443700 for more info

CancerCare Cape Gate Support group: 10h00-12h00 in the Boardroom, Cape Gate Oncology Centre.|
Contact: Caron Caron Majewski, 021 9443800

GVI Oncology Somerset West Group for advanced and metastatic cancers. Contact person: Nicolene Andrews 0218512255

Can-Sir, 021 761 6070, Ismail-Ian Fife, info@can-sir.org.za Helpline: 076 775 6099.

Cancersupport@centurion: Marianne Ambrose 012 677 8271(office) or Henriette Brown 072 8065728

More Balls than Most: febe@pinkdrive.co.za, www.pinkdrive.co.za, 011 998 8022

Prostate & Male Cancer Support Action Group, MediClinicConstantiaberg. Contact Can-Sir: 079 315 8627 or Linda Greeff: linda.greeff@cancercare.co.za, phone 0219443700

Wings of Hope Breast Cancer Support Group 011 432 8891, info@wingsofhope.co.za

PinkDrive: www.pinkdrive.co.za, Johannesburg: febe@pinkdrive.co.za, 011 998 8022; Cape Town: Adeliah Jacobs 021 697 5650;
Durban: Liz Book 074 837 7836, Janice Benecke 082 557 3079

Bosom Buddies: 011 482 9492 or 0860 283 343, Netcare Rehab Hospital, Milpark. www.bosombuddies.org.za.

CHOC: Childhood Cancer Foundation SA; Head Office: 086 111 3500; headoffice@choc.org.za; www.choc.org.za

CANSA National Office: Toll-free 0800 226622

CANSA/Netcare Support Group 10:00 Clinton Oncology Centre, 62 Clinton Rd. New Redruth. Alberton. Second Friday each month.

CANSA Pretoria: Contact Miemie du Plessis 012 361 4132 or 082 468 1521; Sr Ros Lorentz 012 329 3036 or 082 578 0578

Reach for Recovery (R4R) : Johannesburg Group, 011 869 1499 or 072 7633901. Meetings: Lifeline offices, 2 The Avenue, Cnr Henrietta Street, Norwood

Reach for Recovery (R4R) : West Rand Group. Contact Sandra on 083 897 0221.

Reach for Recovery (R4R) Pretoria Group: 082 212 9933

Reach for recovery, Cape Peninsula, 021 689 5347 or 0833061941 CANSA offices at 37A Main Road, MOWBRAY starting at 10:00

Reach for Recovery: Durban, Jenny Caldwell, 072 248 0008.t

Reach for Recovery: Harare, Zimbabwe contact 707659.

Breast Best Friend Zimbabwe, e-mail bbfzim@gmailcom

Cancer Centre - Harare: 60 Livingstone Avenue, Harare Tel: 707673 / 705522 / 707444 Fax: 732676 E-mail: cancer@mweb.co.zw www.cancerhre.co.zw

News in brief

Diagnostic mammograms find more cancers, and more false-positives

Thanks to high-tech imaging, mammograms ordered when breast cancer is suspected are catching more tumours - but the percentage of false alarms is up.

A recent study found the breast cancer detection rate rose to nearly 35 per 1,000 diagnostic mammograms from 2007 to 2013. That's up from 25 per 1,000 noted in a 2005 report from the US Breast Cancer Surveillance Consortium.

These so-called 'diagnostic' mammograms are performed because of certain symptoms or other suspicious findings. They are not the same as routine screening mammograms, said the study's lead author, Brian Sprague.

This higher detection rate probably reflects the switch from film to digital technology, which permits identification of smaller lesions, said Sprague. But it's concerning, he said, that the rate at which women called back for a biopsy rose to over 12 percent from 8 percent in the earlier report.

"When they do recommend a biopsy, the probability of it being cancer now is lower than it used to be," Sprague said. In other words, the anxiety, inconvenience and discomfort of biopsy may prove to be unnecessary, he said. He mentions that the investigators evaluated results of more than 400,000 mammograms, reviewing data from more than 400 radiologists and 92 radiology facilities. The total is roughly representative of the United States.

Brian Sprague is associate professor of surgery at the University of Vermont College of Medicine.

The report was published online in the journal Radiology.

Scientists discover the properties behind cancer curing molecule

Scientists at the Universities of York and Huddersfield have improved understanding of a molecule that destroys cancerous tumours without harming healthy cell tissue.

The discovery opens up the potential for highly effective new cancer treatments that are free of serious side effects. The research team has developed and patented a cancer treatment regime that exploits the unique properties of the molecule – a protein named Cluster of Differentiation 40 (CD40).

Professor Jenny Southgate, from the University of York, said: "Most cancer therapies are toxic to all cells and finding a therapy that can kill cancer cells selectively whilst sparing a patient's normal cells is the 'Holy Grail' for cancer researchers.

"By using the urothelial research platform developed by our team, we were able to discover how one promising drug target, called CD40, is able to distinguish between normal and cancer cells, resulting in cancer cell death."

Tumour cells proliferate by continuously dividing. This places them under considerable stress, but they have developed protective properties that enable them to cope. CD40 removes this protection so that the tumour cells die, but because normal cells are not placed under "oxidative stress" they are unharmed by the protein.

Instead of working purely with tumour cells, researchers made comparisons with the effects of CD40 on normal cells as well as engineered cells that allowed them to mimic the process of cancer development.

Dr Nikolaos Georgopoulos, from the University of Huddersfield, said: "Cancer therapies, such as chemotherapy and radiotherapy, are 'hit with a hammer' approaches. Hit as hard as you can and kill the tumours as well as you can. But there is usually some collateral damage. There are side effects. We knew this CD40 molecule seemed to be very good at killing tumour cells. So we decided to observe what it does at the molecular level. If we understand what it does and what's so special about it, we can design our own way to kill tumours. We have now identified exactly why this molecule can kill tumour cells and why it leaves normal cells unaffected."

Reducing adverse effects of rectal cancer treatment

A new study from Karolinska Institutet in Sweden shows that short-course preoperative radiotherapy combined with delayed surgery reduces the adverse side-effects of rectal cancer surgery without compromising its efficacy. The results are presented in the journal The Lancet Oncology.

Preoperative radiotherapy was gradually introduced into Sweden in the early 1990s, with a consequent improvement in prognosis for people with rectal cancer and reduction in the risk of local recurrence.

"Back then we showed that preoperative radiotherapy reduces the risk of local recurrence by over 50 per cent for patients with rectal cancer," says principal investigator Anna Martling, senior consultant surgeon and professor at Karolinska Institutet's Department of

CanSurvive
CANCER SUPPORT

Head and Neck Support Group

The CanSurvive Head and Neck Support Group is for anyone who has had trauma to the head or neck – not only cancer related – although that applies to the vast majority. The Group is for patients who are just starting this journey, as well as those who are many years down the treatment and recovery road.

The objective is to provide information, share experiences, and help with coping mechanisms. It is run FOR the patients BY the patients. There is always a medical member of the Morningside Head and Neck Oncology Team present. Partners are encouraged to attend the meetings as well.

The informal and supportive meetings are usually held on the first Thursday of each month at Rehab Matters, 1 De la Rey Rd. Rivonia from 18h00 to 20h00. The next meeting will be on Thursday 6 April. There is also a Facebook group: South African Head and Neck Support Group

For more information, contact Kim Lucas, on 082 880 1218 or e-mail: lct@global.co.za.

Molecular Medicine and Surgery. "Thanks to our results, radiotherapy is recommended to many rectal cancer patients."

However, radiotherapy can cause adverse reactions and the optimal radiotherapeutic method and the interval between it and the ensuing surgery have been mooted. The study now presented in The Lancet Oncology is based on the claim that the adverse effects of rectal cancer treatment can be reduced by administering more but lower doses of radiation for a longer time, or by increasing the interval between radiotherapy and surgery. These hypotheses have now been tested in a study in which rectal cancer patients were randomly assigned to three different treatment arms:

- Standard therapy, i.e. short-course (5x5 Gy) radiotherapy with direct surgery within a week.
- Delayed surgery with short-course (5x5 Gy) radiotherapy followed by surgery after 4-8 weeks.
- Delayed surgery with long-course (25x2 Gy) radiotherapy followed by surgery after 4-8 weeks.

The results of the study show that patients with delayed surgery develop fewer complications with equally good oncological outcomes. It also showed that there is no difference between long-course and short-course radiotherapy other than that the former considerably lengthens the time for treatment.

"The results of the study will give rise to improved therapeutic strategies, fewer complications with a sustained low incidence of local recurrence, and better survival rates for rectal cancer patients," says Professor Martling. "The results can now be immediately put to clinical use to the considerable benefit of the patients."

http://www.medicalnewstoday.com/releases/315822.php

Gene therapy shows promise for aggressive lymphoma

Thirty-six percent of over 100 very ill lymphoma patients appeared disease-free six months after a single treatment, according to results released by the treatment's maker, Kite Pharma of California.

These patients had not responded to usual treatments and had no other options, Kite said in a news release. Overall, more than four out of five patients with the blood cancer saw their cancer reduced by more than half for at least part of the study, according to the company.

"This seems extraordinary ... extremely encouraging," one cancer specialist, Dr. Roy Herbst. But Herbst, chief of medical oncology at Yale Cancer Centre, said longer follow-up is needed to see if the benefit continues. Side effects, which had been a concern, seemed manageable in this study, he said.

The therapy - called CAR-T cell therapy - enables the patient's own blood cells to kill the cancer cells. A patient's blood is filtered so immune cells called T-cells can be altered to contain a cancer-fighting gene. The cells are returned to the patient intravenously, and the cancer-targeting cells then multiply in the patient's body.

http://tinyurl.com/jj4sg8h

Chemo overused in younger colon cancer patients?

Young and middle-aged patients with colon cancer are up to eight times more likely to receive postoperative systemic chemotherapy than patients aged 65 years and older, a recent study has found. The postoperative chemotherapy does not improve survival, which begs the question – is it being overused in younger colon cancer patients? The findings were published online in JAMA Surgery.

The cohort of young and middle-age patients were also 2.5 times more likely to receive multiagent chemotherapy than older patients across all tumour stages, notes the research team. Multiagent chemotherapy is not currently recommended for most patients with early-stage colon cancer, they note.

"While younger patients who underwent surgery tended to have better survival than older patients, the addition of postoperative systemic chemotherapy did not result in matched survival improvement," the researchers note. "Our findings suggest overtreatment of young and middle-aged adults with colon cancer," they conclude.

The study's findings have significant clinical and economic implications, because patients with cancer are vulnerable to the adverse effects of chemotherapy toxicity. Quality of life can be reduced, and physical, functional, social, and emotional well-being can be affected, the researchers say.

In addition, the cost of chemotherapy for colon cancer is high, and overuse can create economic burdens. "Appropriate use of chemotherapy in colon cancer treatment should be investigated and evaluated in further research," they conclude.

http://tinyurl.com/gmkoa3g

Why patients misunderstand their cancer diagnoses

Cancer patients and their doctors often collude to avoid the difficult conversation about whether their disease is terminal, a recent University of Wisconsin Carbone Cancer Centre study finds.

Dr. Toby Campbell, associate professor of medicine and chief of palliative care at UW Health, and his colleagues analysed 64 recorded routine clinical encounters with lung cancer patients at four academic medical centres across the country to understand the roots of a well-documented phenomenon: Cancer patients often don't understand that their cancer is not curable.

They found that medical visits with oncologists following scans

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tended to follow a similar script: First, they talked about symptoms; next the oncologist talked about the images from diagnostic scans. This was quickly followed by talk of the next course of treatment.

"We noticed an absence of talk about what the scan results meant – for both good and bad news," says Campbell, a thoracic oncologist and the study's senior author. "Scans to assess how chemotherapy is working present the opportunity to talk about the impact of treatment on the cancer. These results show if treatment is going to help them live longer or not."

In only four of the 64 sessions was there a frank discussion about prognosis; three of those were in response to questions from the patient or a caregiver.

"Oncologists routinely face confronting their patients with unwelcome news and the social norms which guide our human interactions lead them to disclose the news in a ways which allows patients to maintain their optimism," Campbell says. "We also noticed that patients rarely ask their oncologists to be clearer about the news or to talk about the impact on their life. So it's fair to say the two collude to avoid talking about prognosis.

"However, an inaccurate understanding of their disease also means that they can't participate in shared decision-making about their options or about end of life care."

Fortunately, Campbell and colleagues have a simple conversational fix: After revealing the scan results, the oncologist should ask, "Would you like to talk about what this means?"

"This gives control back to the patient who can then can give the oncologist permission to relay bad news, if necessary," Campbell says. "It also creates space to empathise with the patients."

http://tinyurl.com/huvjlyo

New clinical trial treating cancer with cheap malaria drug

Experts from St George's University of London, and St George's Hospital have joined forces to investigate whether a common and cheap malaria drug can be used also against cancer.

The trial is to investigate whether the drug can help cancer patients by reducing the multiplication of tumour cells and decreasing the risk of cancer spreading or recurring after surgery. If it does, the drug could be used to provide a cheaper adjunct to current expensive chemotherapy.

Professor Devinder Kumar, a colorectal cancer surgeon based at St George's Hospital, said: "We are proud to have set up this pioneering study at St George's University and St George's University Hospitals NHS Foundation Trust.

"We hope that this study will help to answer some really important research questions to see if a simple intervention with an established, off-patent and affordable antimalarial drug such as artesunate taken for two weeks before surgery can reduce the risk of cancer recurrence in patients with Stage II/III bowel cancer.

"The overall aim of our research is to improve patient survival and quality of life. Research into repurposing drugs in this way for new disease indications is vital and an excellent use of resources for the NHS."

Artesunate is derived from the plant Artemisia annua, also known as sweet wormwood. The Chinese scientist Tu Youyou, whose research in the 1960s led to the development of artesunate from a plant used in Chinese traditional medicine, was awarded the Nobel Prize for Medicine in 2015.

http://tinyurl.com/zrjdomk

Drug may protect ovaries and fertility from chemotherapy damage

A drug already used to slow tumour growth may also prevent infertility caused by standard chemotherapies, according to a study published online in the Proceedings of the National Academy of Sciences.

Led by researchers from NYU Langone Medical Center, the study found that the drug everolimus protects ovaries from cyclophosphamide, a chemotherapy used often against breast cancer, but known to deplete the supply of egg cells needed to achieve pregnancy.

Female mice treated with everolimus, along with chemotherapy, were found to have more than twice as many offspring afterward as mice treated with the chemotherapy alone. Such strong results with an available drug, say the study authors, may speed the process of applying for permission to test it in premenopausal cancer patients.

"Our results argue that everolimus may represent a fertility-sparing drug treatment to complement the freezing of eggs and embryos, which are valued methods, but time-consuming, costly, less effective with age, and not protective of long-term ovarian function," says first study author and NYU Langone reproductive endocrinologist Kara Goldman, MD.

"Patients face devastating choices as they try to balance cancer treatment against their ability to have children in the future, including young girls," says Goldman, also an assistant professor in the Fertility Center at NYU Langone. "We need more options."

http://www.medicalnewstoday.com/releases/316233.php

Thank you to Netcare !

CanSurvive Cancer Support Groups wish to thank Netcare for their assistance and encouragement.

We value the support and generosity of Netcare and their staff and their commitment to helping us to improve support for cancer patients and their families by providing a comfortable and accessible venue and refreshments for our meetings.

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