

Richer punters win in SA's cancer treatment lottery



Colorectal cancer (Stage IV) survivor and public health sector worker, Dr Lindy Dickson.

Picture: Chris Bateman

Cancer patients with deeper pockets live longer in South Africa, survivors, social workers and staffers from among 35 non-governmental support organisations told a unique 'Voice of Cancer' Forum in Cape Town last month.

The screening and treatment access gulf between the public and private sector was dramatically illustrated in story after story told by survivors who had journeyed the vastly differing routes – with outcomes speaking for themselves. Increasingly life-threatening and even fatal waiting times, medical aid funds drying up and a lack of compassion or empathy by public sector staff overwhelmed by patient numbers were themes among cancer survivors whose courageous stories gave a human face to cold but alarming statistics.

Simple and basic interventions – like one or two dedicated nurses screening patients at every public clinic and day hospital, de-stigmatisation/information campaigns and priority referral for urgent public sector cases – would significantly reduce what deeply flawed, outdated registries indicate as one-in-five person prevalence. The survivor forum was facilitated by the local Campaigning for Cancer NGO and backed by the American Cancer Society and LIVESTRONG (cycle champion Lance Armstrong's organisation). It was aimed at making cancer a national health priority through a united survivor-informed 'call to action'.

Colorectal cancer (stage IV) survivor, Dr Lindy Dickson, three years out of medical

school with a Master's degree in trauma and emergency care and close to completing her PhD in nursing, is in her third year of remission. The chief reasons for her survival are simple: she's ideally placed within the medical community (with robust medical aid insurance) and was 'blitzed' through the private system. Dickson went from suspected ruptured appendix to actual diagnosis and radical surgery and waking up in an ICU in a mere nine hours. Less fortunate patients who ran the now well-publicised gamut of public sector woes told the Forum of two- to four-month waits to achieve lesser outcomes. Dickson cited a paramedic colleague, also diagnosed with colorectal cancer, whose medical aid lapsed (unbeknown to the patient, her husband had stopped paying premiums for two months), who was forced to transfer out of the private sector to the state sector.

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Despairing patient dies

'Once she saw what the system was going to offer her in terms of waiting times and delays, she just gave up [and later died]. By way of a wake-up call to her colleagues, she said that while undergoing chemotherapy, she sat 'in an entire circle of doctors undergoing the same therapy'.

Ismail-Ian Fyfe, an accountant and Catholic deacon who lost his mother and fiancée to cancer before being diagnosed with stage II(a) prostate cancer, said it took him two-and-a-half months to get into the oncology unit at Groote Schuur Hospital and five months before being treated. Illustrating a widespread and potentially deadly problem of late presentation of symptoms, he said his private GP found blood in his urine during a routine bond insurance medical, referring him to a urologist who assumed it was an old kidney injury from playing rugby. However, when the bond insurers insisted on a full diagnosis, a colonoscopy was performed and the swollen prostate discovered and found to be malignant (end of June 2004). By this stage his medical aid reserves were exhausted so he was referred

to the Woodstock Clinic, where doctors read the reports but redid the entire work-up with a referral to Groote Schuur Hospital's Oncology Unit (in mid-October 2004). Only in November did his actual treatment begin, his oncologist reportedly commenting that he was 'very lucky' the malignancy had only progressed to a stage IIB, enabling a cure.

'While undergoing treatment I had to Google it all. Nobody mentioned what the treatment side-effects would be, there were no brochures, information, nothing at the hospital,' he said.

Screening at tertiary and district level 'impractical'

Dr Dickson, who has an 'inside out' view of the public sector, having worked in state hospitals in Gauteng and KwaZulu-Natal before moving to the medical department at Victoria Hospital in Cape Town, challenged any state sector doctor or nurse to fit any kind of cancer screening into their daily routine of 'stab-wounds, vehicle accidents and dehydrated babies'.

'You cannot practise preventive health care in our setting because you're too busy triaging. What's needed are dedicated areas in a clinical setting where you will screen people and give them information. For example, Pap smears (given the strong link between HIV and cancer of the cervix) should be running every day in these clinics. We're only picking this up in really advanced stages,' she added, pointing to research showing that 43% of cancers were preventable. Employing one or two nursing sisters at every rural, peri-urban and urban clinic country-wide to screen for prostate



Ismail-Ian Fyfe, an accountant and Catholic deacon, diagnosed with stage II(a) prostate cancer.

Picture: Chris Bateman

antibodies and conduct these and breast examinations, do Pap smears and check skin lesions would 'work wonders in reducing this massive burden of disease'.



Steven Small, 63, a former company director, diagnosed with colorectal and liver cancer three years ago.

Picture: Chris Bateman

'Once you have stage IV it's a huge resource nightmare to keep a person on this planet,' she said. Like many other cancer survivors she sees posters on TB, HIV, breastfeeding and safe sex 'everywhere, but very few teaching people how to be on the look-out for cancer'. This now career-restrained mother put her mild weight loss, tiredness and abdominal discomfort down to overwork, adding: 'I was too young, had no family history of cancer, had never smoked and rarely drank and had undergone all the routine Pap smears and breast exams – it was pretty left field'.

Misdiagnosis adds to patient's woes

Steven Small (63), a former financial advisor and company director, was diagnosed with colorectal cancer in September 2008 and it spread to his liver six months later. A locally qualified GP and family member who was a director of a pharmaceutical company in New York reassured him that South Africa had among the best cancer doctors in the world. Yet what Small witnessed 'with great sadness' was that the majority of patients were unable to access their expertise. 'It's the money that counts. I told my prof at the UCT research hospital (an adjunct of Groote Schuur) that my op was costing me R400 000 to take a section of colon out and six weeks at Kingsbury Hospital (private); he said it would have cost me about R48 000 at Groote Schuur'. Small said he was misdiagnosed four times by various GPs over one year, 'continually' being told that blood-specked diarrhoea and lower

abdominal pain were 'just a stomach bug'. Like several other cancer survivors being advised by his doctor to 'go home and prepare your will' felt like a death sentence. 'When I was told this for the third time by an oncologist I said I'd been in the insurance game for 30 years and thus knew how to prepare a will and that I have a positive mental attitude and believe in miracles,' he added defiantly. Echoing other survivors, he said being laid off on disability pension was 'devastating – they gave me no choice'.

'My wife found me at home with a bottle of whisky that night and by early 2009 I'd become an alcoholic.' A spiritual and psychological healing journey facilitated by a drug counselling friend helped him back to sobriety (and he believes healing).

Capetonians have it best – public sector doctor

Dickson said having worked in state hospitals in KwaZulu-Natal, Gauteng and the Western Cape left her with the impression that the waiting times for public sector patients were far worse in the former two provinces. 'At Groote Schuur (as a clinician) you can get hold of people whereas in the other provinces you feel like you're working in isolation – you can't access the help you need – there's just too much patient load. There you cannot afford to be on the phone trying to get through to an oncologist to massage the clinic bookings system,' she said.



Mariana Lourens, an oncology social worker from the Eastern Cape.

Picture: Chris Bateman

Linda Greeff, a director and co-founder of People Living with Cancer, herself a 24-year survivor of ovarian cancer and now an oncology social worker, described cancer patients in the public sector as 'desperate'.

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'When you hear of a patient driving down from Nelspruit to Pretoria Academic Hospital for palliative radiation only to hear that the machine is broken and that they are out of the proper pain meds, it's heartbreaking,' she told the Forum.

She said patients in the private sector had better access to information, social workers and support groups, whereas in the public sector one social worker served an entire oncology department servicing 'how many thousand people'. A state social worker was 'too busy dealing with applications for disability problems and so on, they simply don't have the time'.

The majority of new cancer cases are diagnosed in Gauteng but this is believed to be related to the larger number of cancer diagnostic facilities there (25). KwaZulu-Natal follows with 18.6% of cases and the Western Cape with 18%.

Thin but surprising data

Country-wide 74 431 people were diagnosed with all types of cancer (except skin) in 2009, with cervix and breast the most common sites at 13.6% and 12.4% respectively. The male/female split (all sites) in 1999 (the latest of two years for which data translated) was a surprising 49.1 - 50.9% respectively.

Mariana Lourens, an oncology social worker from the Eastern Cape, made a heartfelt plea for more cancer information to be made available in traditional languages and 'in line with socio-cultural context'. She conducted qualitative research on Xhosa-speaking patients' understanding of cancer, its treatment and its influence on their compliance and said there was a strong emotional connotation to the Xhosa term for radiation.

'They call it *Ukutshisa* – to burn the devil with fire/flames, and believe the patient is burnt with an iron, leaving permanent scars or put onto a machine that cooks, destroying vital organs and kills you,' she said. A cancer-buddy programme that used cancer survivors to help overcome stigma and superstition was urgently needed. Community doctors also needed to implement structured cancer awareness projects and help with practical issues like finances, time off work and transport, she said.

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