

## Only 1 in 3 childhood cancers diagnosed, treated

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Hilowhe Mocow knows every farm animal and cartoon character adorning the corridors and wards of the Tygerberg Children's Hospital. Over the last two years he also got to know the doctors, nurses, and even the cleaners doing their rounds in the children's cancer ward in the Cape Town academic hospital.

Nurse Nelia is teasing him about the woman from the newspaper liking him so much that she wants to take his picture, and although the corners of his mouth curl up into a shy smile, his eyes seem tired and worried.

Today his four-year-old daughter Najima is completing her second round of chemotherapy and tomorrow they will be going back home to Malmesbury, a small town in the Swartland region about 70km north of Cape Town.

Since she was diagnosed with kidney cancer shortly after her third birthday in December 2010, they have probably made this trip a hundred of times for Najima's three days of treatment, every week. "It has been very difficult," admits Hilowhe, who has been guarding over his daughter night and day from a bedside chair while the chemotherapy battles the cancer inside her little body.

He worries not only for Najima, but also for his wife back home in Malmesbury who has to bring up their five other children on the money he makes from working in a friend's shop on the days when he is home.

Hilowhe is cautiously optimistic. After completing her first round of chemo, Najima fell sick again and in January of this year they heard that the cancer has spread to her liver.

"I was very scared and confused. I was very sad because this is a dangerous thing," says Hilowhe explaining his disbelief when doctors told him that his little girl had cancer. "I've never seen it before. Nobody in my family has had cancer."

Hilowhe remembers it as if it was yesterday. Najima has been ill for days and wasn't getting any better. "She wasn't eating and her stomach was swollen. So we went to the clinic where they took her blood. The doctor there didn't know what was wrong with her so they sent us to Groote Schuur

[Hospital in Cape Town] and after a few days they said she had cancer,” recalls Hilowhe. Najima was admitted to hospital and immediately underwent surgery to remove the tumour from her kidney. The treatment was then followed up by the weekly chemotherapy sessions.

However, Najima is in a way one of the lucky ones. It is estimated that in South Africa around 2 500 children develop cancer every year, but less than a third (700 children) are actually diagnosed and treated.

“We suspect some cases are treated, but just not reported [to the Paediatric Cancer Registry], but many go untreated because they are just never diagnosed,” says Professor Christina Stefan, head of Paediatric Oncology at Tygerberg Hospital. She explains that the average rate of childhood cancer in other countries is between 140 and 150 cases per million, and therefore, South Africa, with its 16 million children below the age of 15, should see around 2 500 cases in this population per year.

The main cause for the under diagnosis is a lack of awareness. With the large majority of cancer cases occurring in adults, especially the elderly, many people don’t realise that children can be affected too, and even fewer know the symptoms of childhood cancer.

This ignorance not only occurs in the wider public, but also among health care workers, often resulting in months of misdiagnosis before the actual cancer is identified and treated.

Stefan and her colleagues from Stellenbosch University conducted a study to determine the causes behind the spate of childhood cancer cases only presenting for treatment at an advance stage of the disease, making it more difficult to treat. “We always assumed it was due to the parents or the caregiver, their lack of education or their social situation. But to our surprise our study found that the delay in diagnosis was due to us – the health care professionals,” says Stefan. “At every level – the clinic, referral hospital, general practitioners and even specialists – patients were being misdiagnosed, and it took a long time to identify and start treating the cancer.”

In an effort to create awareness of childhood cancer among health care workers, Tygerberg Children’s Hospital is hosting a workshop later this month where members from every health care facility in the Western Cape will be trained in identifying the symptoms of childhood cancer.

According to Stefan, the tragedy of childhood cancer in South Africa is not a lack of medicine, working machinery or long waiting lists as is often reported in the media in reference to adult cancer. Despite there only being 20 paediatric oncologists in the country serving a population of 16 million children, Stefan is unequivocal that the health care facilities and support groups for childhood cancer are ready and able to deal with anything. “When a child needs the treatment, it is done immediately, no delay. All the drugs are available and it is free of charge for children below the age of six years,”

says Stefan.

The tragedy is that the children who need the treatment, simply don't access it.

Most common cancers among children

The most common childhood cancer in South Africa is leukaemia (cancer of the blood), followed by brain tumours, lymphoma (cancer of the lymph nodes) and neuroblastoma (cancer of the kidney) – the type of cancer Najima had.

The cause of childhood cancer is mostly unknown, however, in South Africa with its high prevalence of HIV – which is often transferred to children at birth – more and more children are presenting with Kaposi's Sarcoma, a type of cancer associated with HIV infection.

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