

Terminally ill children suffer from neglect, say health experts

Many of these children die without any palliative support and suffer unnecessary discomfort and pain, unless an overburdened NGO steps in

Chris Bateman

South African children with terminal diseases and debilitating conditions are poorly catered for, too often enduring insufficient, impersonal and inappropriate state care, forcing NGOs to step in with super-specialist and home care, and also provide distressed families with support.

So frustrated are the thinly stretched palliative care NGOs that they are considering mounting a constitutional court challenge to force improved state funding for child health care through the South African Children's Palliative Care Network, (PatchSA), a collective of paediatricians, oncologists, health care activists, academics and children's right groups.

Two of the country's top paediatricians and government advisers on child health, Professor Neil McKerrow, head of paediatrics and child health for KwaZulu-Natal, and Professor Haroon Saloojee, head of the division of community paediatrics at the University of the Witwatersrand, agree that there are

several long-standing stumbling blocks.

Chief among these is the lack of ring-fenced funding, child health torch bearers willing to take on population-level responsibility, specialist posts for coordinating and managing chronic conditions and palliative care, and appropriate care closer to affected children.

Paediatrician Dr Michelle Meiring, founder of the palliative care NGO Paedspal, says although a national strategy and policy framework for palliative care was approved in April 2017, "we've been knocking on closed doors for 20 years".

"Children die, usually without any form of palliative support and so suffer unnecessary pain and discomfort. Parents are left to grieve and get on with their lives, also unsupported. Nobody really complains. There's a lot of emotive lip-service, but no real implementation," she said.

Her view is backed by McKerrow who says NGOs are "picking up the slack, which is not their job. At provincial level provinces have to translate the national policy and create programs, integrating them into existing services. But they need



Overextended: Palliative care NGOs want to go to the constitutional court to get funding for child health care. Photo: Tim Graham/Getty Images

training and support and the only resources to do that at present are the NGOs."

Saloojee adds: "Despite all our efforts, our ability to realise adequate palliative care for all remains suboptimal and distant.

"Palliative care has long been a Cinderella service. Despite advocates like Michelle and many others having long articulated the need, the palliative care services offered within the public health system, for both adults and children, have languished as an extra and not received the attention and recognition they deserve. In most settings including hospitals, palliative

care is mostly offered by individuals who have an extraordinary interest rather than as a routine part of holistic care," he says.

Meiring says she and her colleagues approached the Human Rights Commission following two years of inaction after the national strategy and a policy framework on palliative care were put in place.

"There was simply no funding for human resources — not a single paediatric palliative care post was funded — we had some integration training initiatives and opioid supply assessment, but no implementation," she says, adding that in spite of the

constrained financial environment, generalist palliative care can be delivered cost-efficiently by anyone with a basic modicum of appropriate training. All experts who spoke to the *Mail & Guardian* concurred.

Series of mishaps

Meiring said that shortly before Covid-19 struck in 2020, several stakeholders met to discuss palliative care implementation, raising hopes when the then children's commissioner, Angie Motshekga, was urged to organise a presidential portfolio meeting.

"But then Covid happened. I followed up with the Human Rights Commission just 18 months ago, together with the Non-Communicable-Diseases Alliance, but three of the Human Rights commissioners died and Angie fell ill. The HRC was also overloaded with Covid human rights cases," Meiring added.

McKerrow said that in line with the global move away from the now dramatically lessened child mortality and morbidity towards supporting children to thrive, the United Nations Children's Fund had prepared a workshop to redesign and overhaul health services for South African children under the age of five, including a "roadmap" with timelines.

"But Covid attacked, and the conversation was not picked up again. We recognise the need to redesign our

health services for a broader focus. To move away from survival, not drop it. Neonatal mortality is still unacceptably high, but if we don't start looking at children thriving, the gap between low- to middle-income countries and high-income countries will just get greater, and we'll fall further behind," he said. "Former national deputy director of health Dr Yogan Pillay gave us the go-ahead, but then he resigned."

McKerrow said it was key to manage child disabilities and chronic diseases as close to their home as possible, citing surveys conducted in Limpopo, the Eastern Cape and KwaZulu-Natal showing that up to 30% of children under the age of five lived more than half an hour by car from their nearest healthcare facility.

"There are very few super specialists outside Gauteng, the Western Cape and KZN, with just a smattering in the other six provinces and virtually none in Mpumalanga, the Northern Cape and the North West. Comprehensive holistic care for children with chronic conditions is all

centralised and inaccessible — and it's doctor-centric," he said.

It was crucial to create streamlined flows from rural clinics and community hospitals through to district, regional and tertiary hospitals, he added.

The chief responsibility for any super-specialist such as paediatric oncologists, or any specialist with a palliative care interest, was to create pathways from a child's home to their hospital, taking responsibility for their entire catchment area, McKerrow said. "You don't deliver care to each child, but you create a system with capacity and skills to deliver care on your behalf, removing referral blockages for the more urgent cases.

"It's not a matter of NGOs taking on the responsibilities of government. The NGO must complement things. Government has a huge obligation to provide care for our children."

Saloojee said there seemed to be an increasing recognition by clinicians and health managers of the need for palliative care, especially for children,

with more champions emerging. But this was happening on an ad hoc basis rather than as a coordinated streamlined plan.

"The question for me is, 'what will it take?' I'm somewhat pessimistic. In the current austerity atmosphere, it will be a difficult task. The bottleneck is not the availability of drugs or additional care, certainly not in hospital settings. It's finding willing individuals willing to champion this cause. I think creating greater awareness among paediatricians and healthcare staff that they could be champions has more chance of success than creating more funded posts," he said.

Dr Natalya Dinat, a veteran health activist, palliative care specialist and the founder of the Wits Palliative Care Centre, which caters to 6000 patients annually at the Chris Hani Baragwanath Hospital, disagrees that a legal arm wrestle with the government is a winning, albeit desperate strategy.

She favours compulsory palliative care training for all categories of health workers, but especially pae-

diatricians, oncologists and general practitioners.

"Skills such as communication around difficult areas, basic pain and symptom management are required by all health workers," Dinat asserts.

Compassion failure

More funding for NGOs to provide health services is neither sustainable nor desirable, she says. "When government outsources healthcare services there's blurred accountability, which, at its most horrific, can end with a Life Esidimeni-type situation. Parallel services cannot fix a broken system. It cannot and does not work. You end up with the poor looking after the destitute and government washes their hands of the whole issue."

Meiring stressed that most child welfare services are outsourced to NGOs.

Dinat said a donor funded project started in 1998 demonstrated feasibility and good quality end of life care and that savings were possible in adult palliative care. Gauteng gov-

ernment approval in 2006 came after she and a top health economist demonstrated that for every rand spent on the Palliative Care Centre, it saved the hospital complex R2.00. Part of the reason the centre's work has not spread nationally is South Africa's health service has "all but collapsed", she says.

"We need massive public investment in nationally-owned healthcare. Our services have been chronically underfunded, especially when private-public partnerships introduce profit factors, commoditising healthcare. Also, health institutions have been hollowed out with state capture — just look at the PPE [personal protective equipment] scandals."

She backed the call for ring-fenced child palliative care funding, emphasising that "good, comprehensive care of dying children is as essential as any other service".

"It's not a nice-to-have optional extra. Society can be judged by the way they treat their children and their dying. We need to do more," Dinat said.

Family details 4-year-old's agonising battle with neuroblastoma

The *Mail & Guardian* spoke to one family who lost their four-year-old daughter to aggressive and agonisingly painful neuroblastoma cancer three years ago.

A middle-class white family without medical aid, their experience and "rescue" by an NGO, highlights the hundreds of painful and undignified child deaths at home or in understaffed and overburdened state hospitals where palliative care has yet to come of age as a vital and critically needed speciality.

The Philbins, who live in Pinelands, Cape Town, are only now starting to come to terms with the death of Gracie Rae, who was initially treated at the Red Cross War Memorial Children's Hospital in Rondebosch before being moved home for specialist care by the NGO, Paedspal. She died a relatively peaceful death there, just 14 months after being diagnosed.

Paediatrician Dr Michelle Meiring, the founder and director of Paedspal, who arranged voluntary nursing care and an opioid drip at home for Gracie, visiting the family twice daily, says neuroblastoma is a horrible cancer.

"It arises in primitive nerve tissue anywhere from the coccyx to the base of the skull and is initially indolent and easily missed, with vague symptoms. Gracie would have died an agonising death had we not intervened. We tried chemo in the beginning. It holds the cancer for a bit, but it tends to break through," she said.

"With Gracie it broke through in the brain and metastasized to the abdomen — she was riddled. When they survive this long, they get resistant to the pain-relieving medication and doses have to go up and up. We were using bucket-loads of medication in the end. Luckily I lived close by so I could operate like the old-fashioned GP and do regular home visits."

Initially admitted to Red Cross Hospital on a drip for days at a time, Gracie was desperate to return home, says her mother, accounts administrator Katie: "It was so difficult with both of us working. It was actually chaotic."

Gracie's father, Ian, a restaurant manager, said his daughter was one of 20 children in a ward, meaning the level of care was diffused. Katie described one potentially upsetting incident when a hospital porter with a metal body removal container inadvertently entered the ward looking for a child who had died in a neighbouring ward. "Gracie asked me what that thing was but I fudged it — that would never happen with home care."

Ian illustrated a claim by Meiring that euthanasia would be far less contentious, and in less demand, if proper palliative care existed, saying that, in hindsight, they would have "seriously considered" ending Gracie's life earlier, had she not benefitted from expert pain control.

"Unless you've gone on a close journey with a family, you don't realise the gaps in service provision. Many surgeons and oncologists think that palliative care is easy, just a bit of morphine and some counselling, but it's so much more," says Meiring.

Ian says Gracie's initial diagnosis took time. "We were going away for the weekend, and she had a runny nose and was a bit ill. The GP told us it was a viral infection and gave us Panado. She then cycled between a really high fever and sleep and the doctor kept on sending us away. Eventually we'd had enough and asked for a referral to Red Cross Hospital where they did a lumbar puncture which was inconclusive. But then, true as God, the first doctor who really examined her felt a mass in her abdomen and we went for further testing."

Katie said they were given three



Peaceful death: Gracie Rae and her family were 'rescued' by an NGO when she was diagnosed with cancer

options upon diagnosis. "She had a couple of weeks if we did nothing. The second option was a small bit of chemo to see if we could extend her life for a year. The third was to go all out, go to the USA and try experimental stuff, but she could still die from complications of the chemo mix. Initially I wanted to do nothing ... it was, like, just leave my baby. Ian thought we should try the life extension option. But I gave up my job when she was diagnosed so we could give her the best life we could. We had a whole team of doctors."

The Philbins decided honesty was the best policy regarding Gracie and her sister, five-year-old Ella, in all decisions. Meiring and Di Burger, a

Paedspal family counsellor, helped prepare Gracie's nursery school classmates, teachers and parents for her death. Paedspal also provided pro-bono psychotherapy and art therapy for Ella for a year after her sister died. Her trauma was still evident when the *M&G* interviewed her parents and Meiring three years later; she avoided all eye-contact and conversation with Meiring.

"I think I still remind her too much of those final days when I was there all the time," says Meiring. Cape Town residents rallied to Gracie's side after her terminal diagnosis, funding a trip to Disneyland and serenading her at the airport, sending her fluffy toys

and superhero suits (her favourite besides animals), providing meals for the family, and rides in a fire-engine and helicopter.

Ian, his eyes glistening, says: "It was a very humbling experience. People you've never met before, giving us stuff. They never excluded Ella — Gracie was dying but she was the one living with it."

Gracie's parents and Meiring described her as "extremely courageous, an old soul, wise beyond her years and always asking after others".

"She lived her last weeks intensely, and said things like 'don't worry mum, I'll still live on in your heart'." — **Chris Bateman**