



ULTIMATE SURVIVOR: Dorah Mokoena (12) was given almost no chance of survival after sustaining burns at six months old. With no hands, she touches the piano keys at her school up the road from Children of Fire where she lives in Melville.

PICTURES: LEBOHANG MASHILOANE

'The largest insult to the human body'



FULL OF BEANS: Sicelo Maduna (8) has had several operations, and tomorrow his nose will undergo surgery once again.

On the one side of his face, an eye twinkles with the mischief of childhood. On the other side, a forgotten marble-like sphere, hazed over by the passage of time, stands dead still.

And just below them, forming the inverted triangle of the human face, is Sicelo Maduna's new nose. Not long ago, it was surrounded by the dark stitches of surgery. A few days later, playing in his khaki shirt and navy shorts, he said it made him "happy" when he looked into the mirror and saw the latest addition to his face.

Tomorrow, as his small body is anaesthetised once more, the surgeon prepares to perform another operation on his new nose. By tomorrow afternoon, it will be one step closer to looking what's considered "normal" in our society.

A few weeks ago, the shape of the nose was stencilled onto a flap of skin partially cut away from his forehead. The skin was then turned and taken down over the gaping hole where his original nose once was.

That one, the one the little boy (now 8) was born with, was completely ravaged in a shack fire which also burnt off his one arm, his hair, and the front part of his skull. The entire surface of his face was devastated on that day, leaving him with barely any lips, eyes or a nose.

He was a newborn then, a one-month-old baby boy whose history would be melted into his skin.

Since then, his face has been an ever-changing landscape – innumerable skin grafts, an operation to insert artificial material in the part of his skull eaten up by the fire, another operation to release the contracture of his lip and later the contracture of his eyelids, a balloon insertion into his forehead to create the tissue for his new nose, and then the nose operation itself.

And, if a miracle decides to happen, he will also have a corneal transplant in his eye, but right now it seems unlikely – there is not enough eye lid left to cover the eye.

Sicelo is one of an estimated 15 000 South African children who survive serious burn injuries every year. Such statistics, however, are hard to come by, and the number could be even higher as the statistics were collected over the years by the Red Cross Children's Hospital who relied on their register of patients to make an estimate for the country. That figure does not include the many fatalities or anyone over the age of 12.

And, according to Bronwen Jones, founder of the non-government organisation Children of Fire which has taken Sicelo into its permanent care, "it is estimated that one third of these burns are caused deliberately".

She says that burn injuries are mainly a result of highly complicated socio-economic problems.

"Many South Africans are living with post-traumatic stress, and an awful lot of

Children who are burn survivors face a dual existence: they are just normal little children but society struggles with their outward appearance, writes Tanya Farber

people are very unhappy and react to their situations in different ways," she says. "They might harm other people."

"There are unwanted children, jealous partners, and impatient 'step' parents. All these situations can lead to burn injuries. There is also burning as punishment, but people don't understand how serious a burn actually is. Then again, there is burning as learning. I have had survivors coming in with burnt hands because someone wanted to teach them how dangerous a hot plate on a stove was, for example."

"People are genuinely psychologically depressed. In a squatter camp, an altercation between two people can result in the throwing of a stove or a container of hot water. Adults know to jump out of the way, children don't. Or sometimes, inexperienced parents will sometimes leave their child on the bed next to a tub of hot water."

injuries, few professionals want to venture down that path.

"It's the topic that nobody wants to work with," says Professor Psaras, "because it's exactly like working in an intensive care unit – it requires major round-the-clock dedication, and it can also be a thankless task because many die. But it is very satisfying when a child comes in with 80% burns and then survives."

One such miracle child is Dorah Mokoena (12). At the tender age of six months, she was left unattended in a cot in a wooden shack. It is believed that a burning blanket landed on her face, and as she lifted her little hands to pull it off, they too were eaten up by the fire.

After a few hospitals refused to treat her, Dorah was finally put into a ward where she would be given painkillers until she died from her injuries.

But, with her soul trapped inside her

"Sicelo is a very friendly little boy. What has happened to him has made him so resilient"

All these issues get entangled in the realities of poverty – lack of electricity, open flames for cooking and light, children in the care of other children while parents work or search for employment, arson, prima stoves, highly flammable closely-packed shack dwellings, a lack of awareness, no equipment to stamp out a fire that's just started.

The list is endless, and the results are recorded on the melted skin and disfigured bodies of those who survive what the Burn Foundation Australia calls "the largest insult to the human body".

Wits professor of plastic and reconstructive surgery George Psaras has performed several operations on Sicelo, the most recent of which was his nose operation on behalf of the Smile Foundation.

He says "A burn is the worst kind of injury in terms of trauma because it is both painful and deforming – aesthetically and functionally it is devastating. It can also happen to any part of the body. The more severe burns cause major harm to motor skills and development. Limbs are often lost, eye sight can be lost – there is no end to the damage a fire can cause to the human body."

But, despite the high statistics and the devastating effects of severe burn

The NGO has also helped about 4 000 residents at the Joe Slovo camp, while other projects it runs include fire fighting training and disaster recovery.

"It's not that we just refer the children to the surgeons, the surgeons now also refer kids to us."

For Sicelo and Dorah, their home at Children of Fire is a place where they feel integrated into a community that won't judge them for looking "different".

They are also often in the company of Feleng Mahamotse – a 4-year-old boy who was badly burnt on one month, 6-year-old Anele Nyongwana and Sizwe Hlopho whose exact age is not known but x-rays have put him at around 6.

"We chose a birthday for him in January," says Jones, "on the same day as my son."

During the day, the children are surrounded by other survivors. There are twelve children at the school that Jones has established just up the road from the Children of Fire house and office.

For them, a classmate being absent because of surgery is nothing out of the ordinary. Skull implants, prosthetic ears, surgery to toes, necks, arms, knees ... are "events" taking place all year round.

This environment is a place where nobody will stare at you because of the damage caused to your face and body.

"The children who survive burns have a problem integrating into society, and finding appropriate schools. Also, our society is not geared towards helping the disabled. As a society, we need to pay more attention, and we need to offer the best corrective surgery," says Psaras. But, prevention of fire or any other agent of burns, is the main priority.

"The media must generate awareness about this massive problem," says Psaras. "There needs to be far more education on burn prevention and safety interventions. It is really about awareness and education."

But, he adds, it is part of a far more complex set of problems related to the situations many South Africans live in.

"When you have no electricity, you have to light a candle. But then people leave candles next to a cot with a baby in. That's very common. As soon as people are using primus stoves and other such things, the more chance there is of people getting burnt. So, the provision of electricity in itself would greatly reduce the problem."

Unfortunately, those unaffected by burns can scarcely imagine the havoc it causes the human body.

And, in every burn situation, there are so many variables which will determine how severe it is. A damaged eyelid, for example, can lead to loss of sight because the eye is no longer protected. A loss of the lips, too, causes problems way beyond aesthetics – drooling, eating problems, and rapid tooth decay through exposure to dry air.

At the same time, the formation of teeth in children is affected because the



Feleng Mahamotse (4)



Sizwe Hlopho (6)



Anele Nyongwana (6)

mouth acts as a sling which helps the teeth to develop in rows along the jaw.

Facial scars, complete loss of certain features, contractures (scar tissue that pulls and deforms the face or body), loss of limbs, loss of movement caused by contractures that occur at the joints ...

All these are possible outcomes for any survivor of burns, and sadly, it is often children who are most affected. They are more likely to get burnt because they're unaware of danger, and their bodies – which are still developing – are less likely to deal with the trauma that a burn inflicts.

But there are those whose drive to survive takes them beyond the dire physical harm caused to their bodies.

Speaking about little Sicelo whose face he has seen change over the years, Professor Psaras describes him as a "very friendly little boy. All that has happened to him has made him so resilient. If he was in this room, he'd pick up my phone, my glasses and my pen and he'd start playing with them and asking me a million questions. You can't contain him, he is full of beans."

Classifications

Superficial: sunburn without blisters; usually heals by itself

Partial thickness: blisters, already invaded dermis, but not right through; may or may not heal itself depending on depth

Full thickness: subcutaneous tissue, difficult to treat, remove dead tissue and replace with other skin, always needs intervention

Types of injuries:

There are many sub-categories of thermal injuries but the main ones are:

Hot water
Flames: inhalation-injury component (for example shack, aeroplane crash, etc)

Pulmonary (lungs): cuts chances of survival significantly

Electrical: also burns muscle and bones

Chemical: chemicals/acids cause chemical reaction – thermal reaction – burn

Contact details

Children of Fire and its associated Johannesburg School for Blind, Low Vision and Multiple Disability Children are non-profit organisations that rely on donations and the work of volunteers. To find out more, call 011-726-6529, 011-482-4258, visit www.firechildren.org or e-mail firechildren@icon.co.za

■ Chris Hani Baragwanath Hospital has a specialised burns unit which treats adults and children. For more information, call 011-933-9174.

■ The Smile Foundation is a non-profit organisation which provides surgical intervention to transform the lives of children with facial burns, cleft palates, and other facial or cranial anomalies. To find out more, call 011-783-4177 or visit www.smilefoundationsa.org