19

Phila Impilo! Live Life! Ways to healing for children in long-term hospital care

by LOUISE CHAWLA and JILL KRUGER

Making children partners in healthcare

To understand the longest reach of HIV infection in sub-Saharan Africa, it is necessary to consider the children who carry the disease and related illnesses like tuberculosis, or who have lost a parent or other family members to this epidemic. In addition to physical effects, children carry the emotional wounds of loss, fear, or social stigma, and they need emotional support as much as physical healing. An essential component of this support is to enable children to feel that they are agents who have some control over their lives, who can contribute to their own health and the well-being of others. Like all people, children need this sense of self worth and creative agency. South Africa is a country where the need to attend to HIV-affected children is especially acute. Almost one in five adults is HIV infected, more than a quarter of a million children below the age of 15 are living with HIV, and more than a million children in South Africa have been orphaned by AIDS. A related epidemic is tuberculosis, which was identified by the World Health Organisation Regional Committee for Africa as a leading cause of death among people who are HIV-positive and was declared an emergency in the African region.

These are mind-numbing numbers, and in the face of these statistics it is natural to try to attack the problem with

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a counter-barrage of numbers: how many children have been supplied with paediatric antiretroviral drugs or with treatment for tuberculosis, how many additional beds have been added to paediatric wards, how many programmes have been established to support the extended family networks and foster families that care for orphans. These are necessary steps to address the problem, but by themselves they can obscure the children behind the numbers who are very much alive. By themselves, these approaches also risk neglecting essential provisions of the United Nations Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child, to which South Africa as a nation is committed, and which acknowledge children's

Through the medium of her sock puppet, a girl has a conversation with artist-facilitator S'bu Sithebe.

Photo: Julie Manegold

rights to the free expression of their views on matters that affect them, including the right to be informed and involved in their own healthcare.

Phila Impilo! Live Life! Ways to Healing is a DVD and a book, which shows healthcare workers and parents how to engage the real children behind the numbers and enlist them as insightful partners in processes of healing. Who understands better than the children in hospitals and clinics how to make these places as comfortable, humane and health promoting as possible, in ways that touch the emotions and spirit as well as the body? The DVD brings together the voices of 23 children, six to 13 years old, in the paediatric ward at King George V Hospital in Durban, along with family members, healthcare providers, a child psychologist, and an artist, using a combination of English and isi-Zulu with English subtitles. Running time is 26 minutes. The 64-page book contains further insights by the children on holistic hospital care.

Dr. Sheila Bamber, Medical Officer for the ward, explains for both parents and healthcare providers how children's symptoms are sometimes similar and sometimes different than symptoms in adults, and the need for the quickest possible preventive care, especially in the case of children's TB, which can be cured. She also emphasises the emotional dimension of healing, such as the importance of greeting each child by name, with a gentle and respectful touch. Most inspiring is not the information that the DVD and book impart but the quality of care that they illustrate.

Methods for children's participation in improving the conditions of their care

In the King George V Hospital in Durban, *Phila Impilo*! introduced a set of participatory methods during a series of workshops over a period of two weeks. Although the programme's focus is children affected by TB and related illnesses such as HIV infection, the following methods could

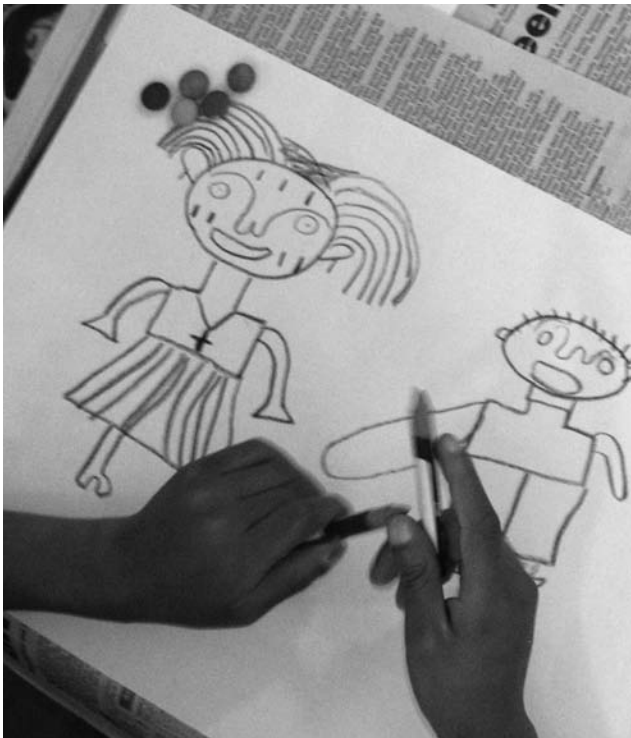**Drawing to the theme, 'The very best person in my life.**

Photo: Julie Manegold

that travelled from person to person. It was always possible to see from the light on children's faces exactly where the 'strength' had reached in the circle. Once or twice, if a child pressed the hand of another too hard, the group protested and the process restarted. These rituals gathered everyone together and affirmed the group's identity – especially important to do in a hospital setting because children had different treatments at different times and sometimes had to leave in the middle of activities, turning up again at a later stage in the day.

Thematic drawings

Art is an essential element of the *Phila Impilo!* programme. Some of the drawing topics included:
- 'The happiest day of my life' (an interesting range of responses, showing areas of personal affirmation important to children, including a strong emphasis on birthday parties);
- 'The very best person in my life' (a number of children drew loved persons who had passed on; some asked first if they could do so);
- 'Things I'm sad about in the hospital' (these comprised mostly drawings that facilitators thought would have been generated by the question about what frightened them in the hospital, such as injections); and
- 'Things I'm scared of in the hospital' (here animals made a surprising appearance, as well as insects such as flies and mosquitoes: yet for anyone who is ill and weak and has a fever, it is difficult to face and ward off intrusive animals and insects).

Many scenes in the DVD focus on the children's vibrant drawings and paintings: images of what is painful, such as injections and crying families, but also images of sources of strength and happiness, such as friends, play, and family visits.

be applied in paedriatric wards and clinics of all kinds:
- Daily rituals
- Thematic drawings
- A Tree of Life mural
- Collages
- Identity drawings
- Sock puppets
- *Umoya* letters (*umoya* is isi-Zulu for 'wind' and 'soul')
- Composite fabric painting.

Daily rituals

The start and end 'rituals' for each day were designed spontaneously during the first workshop, in response to songs and games which the children brought with them. The morning ritual, led by the facilitator Maria Makgamathe, brought all children and facilitators together in a circle. Paired couples stood side by side and greeted each other by hand, the first person with the right, the next with the left. Partners then wove around the circle, sharing this greeting with everyone while singing '*Sawubona* (isi-Zulu: I see you) to you' to the tune of 'Happy Birthday.' The end-of-the-day ritual, led by facilitator-artist S'bu Sithebe, consisted of 'passing strength' around the circle. Children and facilitators stood in a circle again, passing strength through a gentle squeeze of the hand

Tree of Life mural

The children made leaves and pieces of bark, which they assembled into a large tree that covered a wall in their ward.[1] Each piece of bark that formed the trunk carried the name of an illness identified by one of the groups of children along with the symptoms that they knew. The flourishing crown of green leaves carried the children's suggestions about what would make their treatment as comfortable and effective as possible. On the leaves the children wrote many sound and

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[1] The 'Tree of Life' method in *Phila Impilo!* was adapted from a similar method used by the Boston Institute of Arts, developed after September 11. Vivien Marcow-Speiser from Lesley University introduced the concept to Jill Kruger.

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feasible ideas, including play, nutritious meals, family visits, cards and letters, birthday celebrations, having an 'auntie' (nurse) to attend them at night so that someone would be there if they woke up frightened or in pain, and opportunities to go outside. As one child simply said, 'Walk them to the sun.' Possibly the most poignant message is, 'Have adults listen to us when we ask for help.'

Collages

On flexible cardboard (A3 size), children were asked to make collages 'to show the beauty that lies in my heart and in my soul.' Some children chose items for their collage simply because they found them beautiful (for example, a girl said that this was why she chose a piece of red lace). Many, however, cut out magazine images that reminded them of their homes: such as a car 'because we normally use a car, my father's, when we go to town,' or a bed because 'there is a bed like this at home.' A girl who cut out an image of a mother and child explained, 'This mother and child are looking out for each other. They resemble the relationship I have with my mother.'

Identity drawings

Like the collages, the purpose of this activity is to help children in situations of vulnerability confirm their sense of being, belonging and self-worth in the world. The children sat in a circle with their eyes closed, waiting for mystery gifts to be placed in their hands. The gift turned out to be a small mirror for each child. They pasted their mirrors on flexible A3 cardboard, and the facilitators then proposed that they write or draw their best personal characteristics around the mirror. Instead, the children spontaneously drew images of things of deep personal importance: people, houses, fish, flowers, trees. Their joy in reaching into a remembered outside world and recreating strong icons around their mirror was almost tangible as they worked.

Sock puppets

Since many children struggle to sew, they were given the simplest materials: patterned socks, buttons, and 'eyes' from a stationery shop. The materials were set on a table for the children to choose the sock, buttons, and eyes that they preferred, and facilitators then sewed on the buttons and covered them with the adhesive eyes. The children were asked if they would like to name their puppets. This naming activity was the first indication of how strongly the children felt about their puppets. Discussion and deliberation during the process of choosing names lasted an hour instead of the expected ten minutes.[2] The puppets enabled even the shyest children to speak confidently during one-on-one conversations, group discussions, and mini-plays that the children spontaneously created.

Umoya letters

Children who had lost a mother or other family member painted messages of love and then hung their messages in a row, to be carried to the world of the spirit by the breeze. In one of the most poignant scenes in the DVD, the children stand in a group, some with their arms around each other, quietly watching the wind deliver their messages to their loved one.

Composite fabric painting

After the workshops ended, facilitators returned to the hospital to capture the children's descriptions of their drawings and collages. At this time, some of the eldest children were asked to draw examples of the children's best and worst hospital experiences on a fabric banner that expressed the group's ideas.

Although it was not a 'method' by itself, each child's artwork was collated in an 'art book' with their collage on the front cover and their identity drawing on the back cover. In this way, loose pages were transformed into artefacts that children and their families could preserve and value.

The *Phila Impilo!* DVD was launched at a public showing in Durban in January 2008, where the children were given certificates of appreciation for their participation. Many parents were in tears at the launch, but the children were beaming. Two parents whose children had died came so that they could keep the DVD and certificate as mementos. Dr Neil McKerrow, Chief Specialist and Head of Paediatrics and Child Health at the KwaZulu-Natal Department of Health, plans to collaborate with Young Insights in Planning, the

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[2] The four youngest children named their puppets for favourite colours; five children chose animals, many chose celebrity names or typical children's names, and four chose characters from the *Takalani Sesame* television and radio programme, which explores tough issues that children face, including HIV infection. This programme is presented in South Africa's 11 official languages and models non-discriminatory behaviour among children. For more information, see Welch (2002).

A boy made this drawing of 'the happiest day of my life' – when his father visited him in the hospital.

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Photo: Julie Manegold

non-profit organisation that helped create the programme, in order to pilot the film and publication with medical and nursing professionals in hospitals, clinics and mobile clinics in two KwaZulu Health Districts, exploring how the programme's materials can be most effectively used to spread its example of respectful and creative partnership with children. Screenings will also educate lay people and selected NGOs about the issues that the children raise.

Reflections on the process

Studies by anthropologists have shown that children frequently have little personal space to call their own.[3] This is especially true in hospitals, where children are likely to be even more restricted than at home. *Phila Impilo!* shows how to transform institutional spaces in a large urban hospital into places that express the unique identities of the children who inhabit them, and how to introduce children's insights into processes of healing.

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[3] Jones (1993); Malone (2007); Ramphele (1993); Swart-Kruger (2001).

Under most conditions, it is a challenge to enable children to 'speak' in authentic voices, verbally or nonverbally. This challenge was intensified by the timeframe of the programme, which was limited to two weeks of workshops, with follow-up interviews. This is a short time in which to create trust and garner children's earnest perspectives, particularly when children have been schooled in cultural traditions that emphasise reserve in the presence of adults. Traditional Zulu cultural precepts that inform children's behaviour towards adults and older children, including older siblings, are encapsulated in the terms *ukuhlonipha* (to show respect) and *amahloni* (modesty).

All of the methods in the *Phila Impilo!* programme helped the children find and express their personal voice, but the use of the sock puppets deserves special mention. The puppets were initially intended as a simple element of fun and an alternative voice for children who might want to say things that they feared adults might find inappropriate. But from the first, facilitators commented on the way that children's whole beings 'lit up' when the puppets were introduced. A boy of eleven years who had been quiet and withdrawn, for example, became enthusiastic and took part with others once he was wearing his puppet. Children not only pranced about, creating scenarios in which their puppets spoke, but they treated their puppets almost like pets, patting and stroking them and putting them to bed under their pillows or into envelope beds in their art books. The sock puppets changed magically from moment to moment. They were toys yet alter egos, children's close friends, supporters and confidantes yet also their taskmasters. Sock puppets were treated as if they had feelings for their owners too.

The following words that a 13-year-old boy attributed to his puppet Unogwaja are representative:

I look after my friend. When he is sick I help him to take his pills. When I am sick as well he looks after me. I sleep during the day. When it is time for meals, I wake him up. I love my owner very much. When I have a headache he knows how to help me.

A 10-year-old boy shared similar feelings about his puppet Zikwe:

The puppet was my friend. It let me express what I felt but could not say. Like my dog, I could play with it. . . .

He then pretended to be the puppet, which said in response:

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GENERAL SECTION

"Some of the most potent 'medicines' available… are participatory methods that use the medium of the arts to lower the walls of isolation where children may be trapped by their pain and loss."

I love playing with my friend. He looks after me in the evening. He helps me with my blanket when I feel cold. I love him because I play with him during the day.

The puppets seemed to help the children develop their personal identities in a setting where they lacked core relationships that they might have in the outside world, like trusted friends and family members. This was especially important in a setting where a number of the children had very few visitors, and some had none at all or saw outsiders intermittently over many months of hospitalisation. A report on medical social work play therapy programmes also found that children favour puppets over other media for exploring illness and treatment, and that they use puppets to personify characters in the hospital setting and

to carry out treatment procedures (Helton and Smith, 2004). Other play therapists have noticed that children appear to feel released from anxiety and guilt when they can have puppets express what they want to say (Timberlake and Cutler, 2001).

The *Phila Impilo!* programme is a reminder of the humanity behind the tuberculosis and AIDS crises, and that this humanity is the channel for the most effective 'ways to healing.' It presents the resilient humanity of the children, family members, and healthcare providers. As Diane Melvin, a clinical child psychologist from Great Ormond Street Hospital in London, which partnered with the project, observes, 'Chronically ill children have interests, needs and rights.' Over and over again, the children in the film voice their conviction that, 'It is better for parents to tell children what diseases they have.' Hard as the revelation may be, it enables children to move beyond confusion and inarticulate fear to places of strength where they can be participants in creating healing environments for themselves and others. Some of the most potent 'medicines' available, the programme shows, are participatory methods that use the medium of the arts to lower the walls of isolation where children may be trapped by their pain and loss, building in their place communities of sharing and support.

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