

Art Therapy's contribution to alleviating the HIV burden in South Africa.

By Dr Hayley Berman and Nataly Woollett

South Africa carries one of the world's most prevalent burdens of disease, HIV. Living surrounded by so much illness and death and against an historical backdrop of violence and poverty, many young people have had multiple exposures to trauma and bereavement with little opportunity to grieve and recover. One of the many tragedies in South Africa is a deficit of parental figures to provide containment, safety and a space for processing complex trauma and complicated grief. At present there are insufficient therapeutic resources to meet the depth and breadth of need. Many of the existing psychosocial practitioners, while facilitating courageous and extraordinary projects, have inadequate training and are often traumatized themselves.

Two art psychotherapists, one having worked within a community art therapy centre, the other in the public health system, outline the psychosocial context in which many young South Africans are raised. They describe an experiential art therapy group with HIV counsellors with the primary objective of becoming 'surrogate parents', enabling their capacity to work more effectively and creatively with groups, increasing their propensity for empathy, being able to receive emotional support, as well as encouraging group cohesion with increased productivity.

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Introduction

Mental health and HIV

Mental health needs of children and adolescents globally do not get the attention and resources required, but are severely underserved in low and middle-income countries (LMICs) such as South Africa (Cortina et al, 2012; Patel et al, 2007). Mental disorders account for a large proportion of

disease burden and mortality in young people in all societies, but especially so for youth in LMICs as a result of scarce resources and strong associations with social determinants of health, such as poor attachment, poverty, food insecurity, violence, poor access to education and healthcare etc. (Patel et al, 2007). The HIV pandemic has increasingly brought attention to the unmet mental health needs of children and adolescents. In 2012 it was estimated that there were approximately 369 000 adolescents under the age of 14 years and 720 000 15 to 24 year olds living with HIV in South Africa (Shisana et al, 2014).

Orphanhood

Around 15 million children in sub-Saharan Africa have lost one or both parents to the AIDS epidemic, including 2.5 million in South Africa (UNICEF, 2013). In South Africa, the overall level of orphanhood in 2012 among those 0–18 years of age and younger was 16.9% (maternal, 4.4%; paternal, 9.3%; double, 3.2%) (Shisana, 2014). Many adverse outcomes of being orphaned have been reported, including loss of effective guidance and supervision, inconsistent care, psychological distress and poor mental health, loss of educational opportunities, impoverishment, increased sexual vulnerability, and high rates of risk taking (Lowenthal, 2014). Studies from African countries have found that compared with non-orphans, children and young people who have lost at least one parent to AIDS have more unmet basic living needs, and more psychological problems including negative mood and pessimism (Remien et al., 2007). They are often exploited by new caregivers and have to survive with limited resources (Remien et al., 2007). In addition, being orphaned as a result of HIV/AIDS has more severe consequences than being orphaned as a result of non-AIDS related death (Cluver et al., 2011). Cluver and colleagues (2011) report that children and adolescents orphaned by AIDS were 117% more likely to be suffering from post-traumatic stress disorder than children and adolescents whose parents were alive, and also 67% more likely than children and adolescents orphaned by other causes, including homicide, suicide and cancer.

Bereavement and grief

One of the key risks for poor mental health, especially among orphans, is bereavement (Cluver et al, 2012; Willis et al, 2014). Research indicates that most bereaved children and adolescents will show resilience in adjusting to loss, however, certain factors may influence their ability to grieve. How children comprehend and understand the reality and complexity of death depends on many factors including; the child's level of cognitive development, the nature of his/her relationship with the person who died, the specific manner of the death, resilience, quality of subsequent care and social support (Webb, 2003; Wood et al, 2006). After a major death, a child's immediate social

environment either facilitates or inhibits his/her ability to engage in adaptive grief processes and achieve key developmental tasks (Li et al, 2008).

Cross-cultural research on natural grieving processes suggests that most humans need to recognise their grief and be able to express it directly in order to resolve their loss (Li et al, 2008). This can become formidable in contexts such as South Africa where there is a culture of silence around death and grieving when it comes to children and adolescents (Wood et al, 2006). In many instances, children and adolescents are not told that their parent has died, or are informed of events with euphemisms such as the parent has 'gone away'. It is also quite typical for adults to whisper in the child's ear while they are sleeping regarding death of a family member and these events are discouraged to be discussed again thereafter (Daniel et al, 2007). Oftentimes, although intended to be protective, children and adolescents are excluded from cultural rituals, such as funerals, that would aid in their grieving and legitimise their role in participating in community practices (Daniel et al, 2007). AIDS-related bereavement is likely to be especially complicated and difficult to accommodate, largely as a result of HIV related stigma and its latent denial (Wood et al, 2006). The denial inherent in this silence and its formulation over time and through development leads to poor understanding of perinatally infected (i.e. those infected vertically at birth) children and adolescent's own HIV disease and reinforces stigma around HIV with costs to mental health functioning (Daniel et al, 2007; Woollett et al, 2016). Profound and multiple losses, often unrecognised and unmourned, can lead to complications in the ability to grieve. Doka (1989) defined the concept of 'disenfranchised grief' as the grief people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported (Crenshaw, 2005

Resilience

There is little doubt that HIV leads to experiences of anxiety and depression in children and adolescents, and a 'pathologising' focus may serve as a significant contributing factor, in highlighting the hardship experienced by children and adolescents. However, in contrast, Masten (2001) coined the term 'ordinary magic' to refer to resilience as something nurtured by everyday resources, common to individuals, families, communities and cultures. These conventional roots of resilience suggest that resilience is not rare and that active steps can be taken to develop and sustain resilience among young people who are placed at risk by ordinary and extraordinary hardship. There is evidence to suggest that resilience is present in the lives of many children and adolescents living in circumstances of extreme adversity and HIV (Woollett et al, 2016). Recent traumatology research attributes fostering resilience to multiple sources; including individual, family, community, culture - it is contextual, cultural, epigenetic and relational (Southwick et al, 2014).

The power and potential of image-making in relation to an other

There are considerable challenges to implementing mental health interventions at a public healthcare level in South Africa, that need to be thoroughly addressed for optimum impact. These include lack of skilled mental health professionals available to intervene and the need to utilise and upskill lay counsellors to meet the demand ethically with targeted training and consistent expert supervision (Ventevogel, 2014; Mendenhall et al, 2014). Addressing mental health care in children and adolescents, has the potential to improve HIV treatment and prevention; however, with poor resources of specialised mental health providers to facilitate care, the emotional needs of patients are largely untreated. Psychologists and psychiatrists are in short supply with 0.28 psychiatrists and 0.32 psychologists per 100,000 population working in the public health sector (Lund et al, 2010).

It seems prudent that not only are more creative arts therapists needed to provide appropriate support for children and adolescents in the public health sector in South Africa, but also that task-sharing, whereby non-mental health specialists provide mental health services under supervision of specialists, may be the most feasible way to deliver inexpensive, effective mental health services in primary care (Mendenhall et al, 2014). Increased skills in the use of non-verbal methods of working in conjunction with experiential and theoretical psychodynamic input are required and are easily transferable. The counsellors we worked with were open to this way of engaging patients and did not require prior qualifications other than HIV counselling and testing training.

Non-verbal means of working with children and adolescents have been proven to be effective for the treatment of bereavement and post-traumatic stress disorder (PTSD) (Webb, 2003; Goodman et al, 2009). Research indicates the meaningful contribution of neuroscience to understanding the importance of the use of images and 'action-oriented' interventions in working with those who experience trauma, the precursor to PTSD (van der Kolk, 2007).

Trauma, the emotional response to a terrible event underscored by fear, helplessness or horror, demonstrates long-term effects. In particular, it interferes with declarative memory, or conscious recall of the event, whilst implicit memory, emotional responses, sensorimotor sensations related to the experience remain intact (van der Kolk, 2007). The images and experiences are stored in incoherent, disorganised and fragmented ways, often indescribable in words. Non-verbal methods offer a simplified mode of communication when direct verbal access to trauma-related experiences are not possible or advisable. These methods facilitate recall of memories, enabling them to be processed and for the artist to have control over this process (Buk, 2009). The creative product

serves as a container for the affect, aiding in emotional regulation. Creating art uses both sensory and emotional stimuli, thus making the artistic process a beneficial vehicle to access and integrate memories (Lusebrink, 2004). The act of creating offers the opportunity to externalise and make meaning associated with painful experience.

There also needs to be overt recognition of the power dynamic latent between adult counsellors and child/adolescent participants and managed ethically. Contextually, obedience to and respect for adults are values that are strongly emphasised so that young people seldom speak up or voice their opinions to adults (Clacherty & Donald, 2007). Practices that utilise non-verbal methods, such as image-making, are particularly ethical as they offer children and adolescents active participation in the therapeutic process, authenticating their voice through their engagement, offering more developmentally appropriate means of accessing information, diminishing stress in the child/adolescent-adult interaction and providing a more comfortable method of engagement than language (Clacherty & Donald, 2007; Willis et al, 2014). The therapeutic relationship, the creative process and the work in a group promotes integrated relationships, integration in the brain and ultimately a path towards emotional and physical health (Siegel, 2017).

Community Art Counsellors – Lefika La Phodiso’s model

Lefika La Phodiso (meaning ‘rock of holding or healing’ and referred from now as Lefika) is Africa’s first psychoanalytically informed community art counselling centre. Established in 1994, it’s core mission is to respond to the deficit of mental health resources in South Africa.

Applied psychoanalytic thinking informs the model of practice. The notion of ‘cryptonymy’, has been useful in looking for ways to help unlock the inaccessible ‘mental graves’ that disrupt symbolisation and integration. These ‘mental graves’ refer to the locked up or put away parts of ourselves – seemingly dead and unavailable for use (Abraham & Torok, 1975). This is particularly relevant when exploring the multiple levels of trauma, and trans-generational secrets and myths that permeate South African society. It is also relevant to the specific denialism on a governmental level in relation to HIV/AIDS and the stigma associated with disclosure, resulting in the embedded secretive encasement of the disease.

Case study

In 2008 an HIV/AIDS public health organisation approached Lefika to run a two-day training course with their HIV lay counsellors in order to enable them to work more effectively with groups. The objective was to expand their current reach of clients through group work, and support them in the work they were currently doing. These counsellors face the day-to-day challenges of coping with the

physical and emotional needs of affected and infected individuals, families and communities in public health clinics. Their duties include pre- and post- test counselling, prevention of mother-to-child transmission counselling, HIV disclosure and adherence counselling for groups of adolescents. Many were outreach workers linked to the hospital setting but visiting patients in their homes in more rural communities, thus largely unsupported and unavailable for supervision. They were regarded as 'volunteer' counsellors, many without qualifications, some illiterate, and paid a stipend (below a living wage) for doing this important work. All the participants consented to the process being documented and pseudonyms have been used.

There were 18 counsellors, (all women), ranging from ages twenty to sixty, with high expectations. The group expectations were very concrete including: a certificate, wanting to play and have fun, and acquisition of new skills. Reflexive space was felt by most to be boring, exhausting (many fell asleep) and not productive. The catered food felt insufficient and not 'good enough' revealing enormous emotional hunger and dissatisfaction. Their feelings of being taken from, without getting anything back (failed cases, dead clients) was projected onto me as facilitator. It was as if asking them to explore their feelings or thoughts was experienced as theft. Both the group and I were fragile and defensive.

In response to the group state of mind, they were invited to tear up wads of old newspaper, as an outlet to physically and verbally express their frustration and rage. This process in itself was a vehicle for a release and simultaneously offered an opportunity to transform the chaos and mess into something more productive. There was some discussion about creating something from the fragments as a group, or engaging with the debris on an individual level. Predictably, the group chose individual engagement; they were not able to be a group yet. Some participants created figures, many created bunches of flowers – usually referring to a funeral ritual. Some of the mess was left on the floor which came to represent those patients who could not be helped, those that refused to take their medication and died.

One group member created a fist of power, and painted it red. Someone in the group noticed the 'red fist' and said it was (not looked like) a placenta. She said it was the afterbirth, 'bloody and ugly'. Other group members laughed, not able to respond empathically. The person who created it felt attacked and misunderstood. It was interesting the attack was directed at the 'placenta', the most primordial container. There seemed to be a constant to-ing and fro-ing, between life and death forces. I commented on the striking sense of an absence of empathy, patience or respect for one another. I interpreted that they were probably so overwhelmed, exhausted and full of other's stories

and tragedies as well as their own, that there did not seem to be any more space to have empathy for their colleagues.

The following day, after having some space, distance and having recognised the very fragile space they inhabited, I came back with some anxiety and a greater sense of empathy for their enacted struggle. I reflected my experience of them as functioning within a protective and defensive realm. I spoke about the usefulness of the group as a microcosm, providing a mirror of their external worlds. They were invited to create an image of the moment or experience that led them to choosing to do this work as HIV counsellors. They were given a significant amount of time and space to create an image and then to share their images in pairs, allowing them to develop trust and really listen to one another and have space and time for personal reflections. When they returned to the large group, many chose to share their stories within the container of a collective witness. This process elicited profound emotion and sadness.

Most shared very personal and tragic histories. The encrypted secrets so tightly held inside finally had room to breathe, be witnessed and heard. There was room to cry, to be sad and connect with the multiple disappointments and losses. Many disclosed their HIV status and spoke of the shame of illiteracy and not having had access to information about HIV and AIDS. This gap in their own experience propelled them into this work – to repair the damage. This process felt like a huge breakthrough, as if the unbearable pain that they were so carefully defending against the previous day was given room to 'be'. The complex paradox of having held these secrets in the context of their work which primarily involves encouraging their clients to disclose their HIV status and go onto treatment, exacerbated the potential impact of 'unlocking' their 'mental graves'. We reflected about the significant movement from sleepiness, boredom, disruption, anger, sadness to joy in such a short space of time, and the capacity and resilience of the group to survive some of the unbearable feelings. There was evidence of a capacity to mourn and grieve, which seemed unavailable for thought or experience earlier in the group process.



Extended group work with HIV counsellors

Almost a year later, Lefika received some funding to work within the HIV/AIDS sector and approached the head of psychosocial services (co-author Nataly Woollett) to continue with this group. She was enthusiastic, as the clinics were facing many changes and the counsellors were under attack from clinic management. The adherence groups for adolescents that the counsellors were facilitating had poor attendance and the adherence statistics had dropped dramatically, the counsellors were blamed for this problem. Counsellors were made to feel responsible and therefore felt like failures. In responding to this pressure, counsellors had abandoned the structure of support/counselling groups, and shifted the adherence groups to more outcome-based, didactic, HIV education groups.

The group met for an intensive 4 days of training with monthly full day workshops to integrate and present their applied practice. Some went on to complete the full Community Art Counselling training at Lefika over 18 months.

The working group

Over time, with different interventions, and surviving the projections, attacks and pain, the group formed sufficient trust enabling the use of the group dynamics as an object to learn and grow from. The image-making process became an important vehicle to communicate complexities. Lizzy risked sharing her diagnosis of a brain tumour with the group and traced her hand proudly, 'with this hand I can do anything!' The quality of the images and reflections indicated an increased capacity for

curiosity as well as an increased capacity to hold loss and reflect on the 'other'. In acknowledging this shift, it became possible to be transparent about the group process and evolution since the previous year. Memories shared included feelings of mistrust and anxiety. Lettie remembered, 'I was very angry, I felt I couldn't exist'. Several group members expected to be told how to run a group, not how to be in a group. Experiential learning was unfamiliar and felt to be a waste of time. Their responses mirrored the developmental phase of the group at the stage of dependence.

The group's dependence can vary from expectations that the conductor provide practical solutions, to views of the conductor as an omnipotent and omniscient figure, who is the source of strength and gratification (Nitsun 1989, pg252).

The group was able to acknowledge their initial defensive acting out behaviour. We were able to reflect on the experience of a working group capable of entering sustained moments of integration as opposed to the early phases of a group that exuded 'un-integration' and fragmentation (Winnicott, 1965). Using objects and/or art materials assisted to gradually detach from the dependence of the mother, as a transitional bridge learning to be independent yet relational. Particularly within the context of the HIV epidemic, the image provides evidence of existence and offers valuable opportunities for active witnessing of one another's experiences. The image can function as memory that may preclude repression or foreclosure. Making developmental links to the process enabled each group member to begin to apply their experience to working with their clients in the clinics.

The group was invited to engage with clay to explore early childhood connections of a significant relationship that had felt held and connected. Many group members allowed the clay to determine what emerged, and trusted the material to elicit form rather than predetermining it. Phumi spoke profoundly of the messiness of the clay and the resistance with which she engaged with it. She compared the clay to HIV+ children at the clinic who are malnourished, dirty, have sores and whom she did not want to touch. As time went on, she came to know the clay and what it could do, and made the analogy of getting to know these children and coming to respect their individual qualities and being able to play with them and be available to them. She spoke of the transformation of the children once they were on antiretrovirals (ARVs) as being able to play and relate. She said, 'I felt a bond with the clay eventually as I do with the children'. Interestingly, the following week, the clay had cracked which she associated with the fragility of the children (and by extension, those parts of herself). One group member said, 'it is when we know what we know and can't bear to think we know it.' This is not only a manifestation of the 'unthought known', but also the things that are known yet never articulated, so prevalent in South African society. The stigma of HIV and AIDS and

the added myths of needing to protect children from the truth make for a very uncomfortable psychic position to be in.

Death in the room

Group members spoke of multiple losses of patients, colleagues and family members and expressed how little emotional support they had to manage it all. Sibongile spoke of an HIV+ four year old who was raped and not on treatment. She sobbed about her own experience of rape. Zandi created a black 'doek' [head cloth] usually worn to signify that someone has died. She reflected on making it beautiful, and embellishing it with buttons and beads respecting those who have died, while acknowledging that through death something beautiful that holds memory can be internalised.

We reflected on the group process, the silence, the sadness and the capacity to sit in the depths of emotion without having to escape the pain of it. Through experience we were able to weave in the learning of applied thinking within their workplace. The weaving of ritual, memorial, making images and playing – the activities of doing enabled by 'things' in the environment – allowed something to be worked through. Perhaps the combination of doing and thinking, promotes a 'deeper' and potentially more sustainable outcome. They could see the possibility of moving away from their didactic approach of providing solutions, to being able to sit in the unknown space and survive it. We could explore the current situation of being able to trust what had emerged without limitation, and consider the quality of silence and the holding capacity of the group.

Applied thinking and practice

In preparation to end the group, stories filled the space describing moments of engagement with clients using their new art counselling skills and increased capacity for empathy. Phumi shared something about her shift in approach and attributed it to her time at Lefika. 'A child was diagnosed HIV+, usually the nurse tells the child and starts medication without consulting or counselling the child, nor mother. I intervened, and spoke discretely with the mother empowering her to tell her child with my support and we used drawing to help the child express her feelings about it'.

Counsellors seemed to be able to provide a more compassionate and considered approach to the needs of the client and the situation. They used the term 'containment' to describe an added capacity of patience, and 'holding' to describe an increased capacity for empathy. Ntuli reflected a situation of a mother who came into the clinic and found out her child was HIV+. The client sat and cried with the counsellor. When she had finished crying she said, 'thank you, I could not do this at home' and left the room. This example alluded to the capacity to provide a safe space, tissues and a glass of water and instead of feeling helpless and useless she felt 'good-enough'.

There was an increased consciousness and theoretical understanding of what trauma, bereavement and the 'unthought known' bring that elicit a compensatory or reparative mode of being. They could understand how their fear of conflict or discomfort propels them to engage their defence mechanisms and carefully structure and determine the outcomes. We were able to reflect about ways of facilitating a group, allowing space for the unknown, and for a more open approach to a group's natural evolution.

Consolidation of their journey

The group exhibited their work and provided witness to one another's journey. Ntuli said; 'The group gives you the courage to learn to be safe. When I missed a session I felt like a baby missing a feed, I was very thirsty. The group provides nourishment.' They had acquired a new space to think and be thought about.

Zandi, carried on working on her 'doek' and added a key that she sewed onto it, 'it is a symbol of opening any door in my life.' She gathered found objects and seeds from within the studio and outside, symbolic of planting seeds for the future. The images embodied the contradictions and struggles, hope and hopelessness, resilience and foreclosure.

Some overall reflections seemed to capture the precariousness of life and the importance of Winnicott's notion of 'going on being' (Winnicott 1956) and the reliability of an environment. The participants expressed surprise and gratitude for the fact that they could leave their art work in the studio between training days and would return to find them still there. The therapeutic space could hold and take care of their internal worlds, and the images provided visual evidence of the shifting narratives in their lives. 'I talked about things that were difficult to talk about and the world didn't end'. The reflections indicated that something of the importance to 'speak one's mind' had been internalised, sharing in a group as a possibility of something that could always be available to them revealing the importance of survival and resilience.

Conclusion

Cultural silence does not help children, adolescents or adults deal with loss and bereavement; it increases isolation and undermines a sense of security (Daniel et al, 2007). Breaching cultural silence may be seen as a protective factor enhancing resilience (ibid). As evidenced above, creating, sharing, documenting and remembering significant people in their lives whom they had lost, was a critical element of their life story. This facilitates a parallel process with the child and adolescent patients they treat in the public health system. The authors strongly advocate that with the

provision of sensitive and appropriate training for carers, gains can be felt on a greater scale with less reactivity and destruction, and more mindful reflection and containment.

This chapter particularly highlights the struggle inherent in the attempt to provide sustainable pockets of care in response to the HIV/AIDS epidemic. The epidemic itself on many levels precludes making sense of, and straddles living with death and investing in life continuously. While the authors have been aware of their search for hope and resilience to keep believing and engaging in the work, they have also become aware of the constant negotiation from illusion to unbearable disillusionment and despair. There seems to be a continual vacillation of understanding and not understanding, of myth and 'reality', of denial and enactment, moments of hope and often immense hopelessness. Therefore, Donald Winnicott's belief that illusion is absolutely necessary for healthy development holds true in such a context. 'You can only accept being disillusioned, if you have been illusioned' (Green quoting Winnicott, 1999, pg30).

The orphans, guardians and counsellors in this case material reveal the continuums of hope and despair and the capacity and failure to hold and be held. As practitioners, we need to embrace the complexity, beauty and transformational potential of this work. The invitation is to attune to and make overt, the multiple layers of engagement. There are profound internal connections, inter-connections between individuals, between the images made and the reflections, within a group and the broader psychosocial sphere inhabited by complexity of the HIV/AIDS epidemic. The richness of these layers of relational spaces facilitate opportunities for physiological changes in the brain, in the quality of empathic connections and thus the expansive potential of preventative and palliative social cohesion and well being.

"Thanks for the caring for our children and their caregivers and thanks for the caring of ourselves" (lay counsellor after training).

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