



## “My story”—HIV positive adolescents tell their story through film



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### ARTICLE INFO

Available online 5 April 2014

#### Keywords:

Digital story  
Narrative therapy  
HIV  
Adolescents  
Coping

### ABSTRACT

The global commitment to universal access for people in need of antiretroviral therapy has transformed the lives of adolescents with HIV. In contrast, there has been limited commitment at policy or service level to the need for effective therapeutic interventions which can help them to cope with their life experiences. It is imperative that the scale up of antiretroviral therapy programmes is accompanied by evidence-based therapeutic approaches if we are to assist adolescents to make informed treatment and secondary prevention decisions and to enjoy happy, fulfilled lives. This pilot study sought to evaluate the digital storytelling process as a therapeutic intervention for 12 HIV positive adolescents and young people within Africaid's Zvandiri programme in Harare, Zimbabwe. Drawing on narrative therapy, each storyteller created a digital film in which they narrated their life experiences and dominant themes in their lives. Storytellers found the process therapeutic as it helped them to move away from the negative themes which dominated their lives to a newer, richer perspective of their lives in which they had overcome challenges. Their films have provided caregivers and programmers with new insights into the challenges they faced and appropriate interventions for other adolescents living with HIV.

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### 1. Introduction

The global commitment to scaling up access to antiretroviral therapy has dramatically improved the survival of children and adolescents with HIV. Of the 34 million people living with HIV, 2.2 million are young people aged 10–19 years (WHO, 2012). In Zimbabwe there are an estimated 173,031 HIV positive children under 15 years with an estimated 7801 new paediatric infections in 2011. 100,805 of these children are estimated to be in need of antiretroviral therapy whilst only 46,000 were receiving treatment at the end of 2012 (DSS, 2012). Children with HIV are now surviving into adulthood and having children of their own. (See Table 1.)

Despite survival improvements, the childhoods of children and adolescents living with HIV (ALHIV) are typically dominated by numerous complex physical, psychological and social stressors which impact on their well-being and affect their ability to enjoy happy, healthy, fulfilled lives. Yet in contrast to policy and programming for antiretroviral therapy, there has been relatively little commitment to the need for effective therapeutic interventions that can help them to cope with their life experiences.

The lives of children and adolescents with HIV are typically characterised by frequent illness and hospitalisation (Ferrand et al., 2007), grief and bereavement for parents and siblings (Parsons, 2012) and the need to come to terms with their own HIV status, a process that is commonly delayed and this can result in psychological challenges (Butler et al., 2009). The negative effect of these experiences is further compounded by stigma and discrimination which children and adolescents perceive and/or experience, whether at home, school, community or society at large. This is exacerbated by growth delay and skin disfigurement, which are common in children and adolescents with HIV (Ferrand et al., 2007). They may have cognitive impairment that manifests as poor executive functioning and reduced mental speed (Ferrand et al., 2007). This intellectual impairment is exacerbated by poor school attendance. Adolescents with HIV face overwhelming challenges related to emerging sexuality and concerns about relationships, future child bearing and marriage.

These experiences result in poor confidence and low self-esteem. It is increasingly recognised that adolescents are at risk of poor mental health due to their life experiences. A study in Harare, Zimbabwe amongst 229 adolescents with HIV demonstrated that psychological well-being was poor (median score on Shona Symptom Questionnaire [SSQ] 9/14) with 63% at risk of depression. Self-reported adherence to antiretrovirals was sub-optimal. Median SSQ score was higher amongst those with poor adherence to antiretroviral therapy (Mavhu et al., 2013).

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**Table 1**  
Study participants/characteristics.

Pseudonym	Age	Sex	Orphan status	Primary caregiver	Age at diagnosis	Age at disclosure	Years between diagnosis and disclosure	Duration on ARVs	Subject of story
1 Lindiwe	20	F	Total	Maternal aunt	14	15	1	4	Life
2 Susan	21	F	Total	Sister	13	13	0	8	Life
3 Amanda	20	F	Total	Grandmother	16	16	0	2	Life
4 Precious	22	F	Total	Paternal aunt	15	15	0	7	Life
5 Keith	20	M	Total	Grandmother	16	16	0	3	Life
6 Brian	22	M	Total	Grandmother	16	16	0	4	Life
7 Frank	22	M	Total	Uncle	17	17	0	4	Adherence
8 Tendai	20	F	Total	Maternal aunt	16	16	0	4	Stigma
9 Mazvita	21	F	Total	Aunt	16	17	1	3	Disclosure
10 Rudo	22	F	Total	Maternal aunt	14	14	0	6	Relationships
11 Alan	21	M	Total	Grandmother	16	16	0	4	Support groups
12 Nigel	18	M	Paternal	Mother	14	14	0	3	Getting tested

Shaded area = Workshop 1, Non-shaded area = Workshop 2.

The effectiveness of antiretroviral therapy depends on high levels of adherence, yet adherence is challenging particularly for adolescents. Poor adherence to antiretroviral drugs results in inadequate viral suppression and subsequent treatment failure. Various studies have now confirmed high levels of virological failure in the adolescent population resulting in the need for 'second line' antiretroviral drug combinations (Charles et al., 2008; Nachega et al., 2009; Ryscavage, Anderson, Sutton, Reddy, & Taiwo, 2011).

These diverse, complex challenges threaten to override any therapeutic benefit of antiretroviral therapy if not adequately addressed. Conventional approaches to helping young people with these challenges have focused on a variety of psychosocial support interventions such as counselling, memory work and support groups (USAID, 2012; WHO, 2009). However, these vary greatly in their quality and content and often little is known as to their effectiveness. In the recently launched WHO guidelines (WHO, 2013a) most recommendations relating to adherence support for adolescents were made on the basis of expert opinion (WHO, 2013b). This is in part because, until recently, it was assumed that perinatally infected children died within the first two years of life. As a result scale up of antiretroviral therapy to children in low and middle income countries has lagged behind that in adults. Even in adults few adherence interventions have been rigorously evaluated. Development and rigorous evaluation of more innovative adherence interventions for adolescents are consequently lacking and the same applies to psychosocial support interventions. It is imperative that culturally appropriate adolescent and family-centred interventions are developed which engage adolescents in a therapeutic process, acknowledge their life experiences and help them to cope with their experiences so that they can move forward in their lives.

### 1.1. Africaid

Africaid is a non-governmental organisation in Harare, Zimbabwe ([www.africaid-zvandiri.org](http://www.africaid-zvandiri.org)). Through its Zvandiri 'As I am' programme, Africaid provides treatment, care, support and prevention services for children and adolescents with HIV which complement their clinic-based care. These community interventions are primarily led by HIV positive adolescents and ensure a holistic approach which seeks to improve both psychosocial well-being and health outcomes.

Africaid has worked with HIV positive adolescents on a variety of therapeutic approaches including the use of storytelling, for example "Our Story" book (Africaid, 2006). In 2010, Africaid piloted a digital storytelling project with 12 HIV positive adolescents from Zvandiri. The primary goal was to evaluate the digital storytelling process as a therapeutic approach to helping young people come to terms with the events in their lives and to develop coping strategies. The secondary goal was to explore the potential for this approach as an adolescent-led advocacy and training tool.

### 1.2. Narrative therapy

This project is based on the assumption that people experience problems when the stories of their lives, as they or others have invented them, do not sufficiently represent their lived experiences. It recognises that the stories that people continually tell each other and themselves are the most powerful influence on the way in which they understand the world, live their lives and define their identities. These stories are commonly distorted by unrecognised and unexamined social norms. Narrative therapy assists an individual to re-story their life in ways that promote healthy development rather than keeping the person dominated by negative perceptions of themselves and their lives. It encourages the storyteller to regain a sense of authorship and re-authorship of their own experiences in the telling and retelling of their own story (White & Epstein, 1990), to see their experiences for what they are, rather than, as other people would have them believe them.

Narrative therapy is based in 'social constructionism' or the idea that the way people experience themselves and their situation is "constructed" through culturally mediated social interactions (Shapiro & Ross, 2002). People tell dominant stories where certain aspects and themes have come to represent their experiences and these become a powerful factor in reinforcing and embedding the person's perception of her dilemmas and conflicts, and of her view of herself. This methodology is also drawn on in Memory Work, a psychosocial intervention which aims to build resilience in children through helping them to understand their family history and to reconstruct their lives (Denis, 2012).

Storytelling is by no means new. In all African cultures, a strong oral tradition has enabled the stories of its people to be passed down through generations. In Zimbabwe, the oral tradition of 'ngano' involves

the telling of folktales. Although one person narrates the story, listeners (mostly children) play an integral part in shaping the ngano because they are involved in the narrative process. The traditional form of the ngano goes from negative to positive, providing a 'fairy tale' ending. The real life ngano are more realistic and some maintain their negative stance throughout. Overall however, the purpose of ngano was to instil a sense of hope in children and give them strength to endure, in the belief that things will always turn out alright in the end (even if this not always the case). The folktales have evolved over time to incorporate ideas that are relevant to urban children and are still commonly used today (for example tales now include mention of cars or incorporate English phrases which they understand) (Makaudze, 2013; Mutasa, Nyota, & Mapara, 2008).

Although storytelling is deeply rooted in traditional culture, children today are rarely afforded the opportunity to tell their own stories—stories which are full of challenging, overwhelming experiences with which they are required to cope and grow. Where life is dominated by challenges, there is a high risk that children and adolescents with HIV become defined by these difficulties.

### 1.3. Digital storytelling

Digital storytelling builds on the narrative therapy approach by enabling the individual to reflect on their life and experiences, with the narration of their story through digital media (Lambert, 2013). The storyteller produces a short video-clip, illustrated with photographs, drawings, words and music. Through participating in this process, the individual is helped to re-tell their own story in a way that promotes healthy development.

There is a large global digital storytelling movement. However, as far as we are aware, there have been no digital storytelling initiatives carried out specifically with adolescents living with HIV within the southern African region to date and there is little evidence of its application amongst this group, either as a therapeutic intervention or advocacy tool. Yet if this methodology provides an effective, acceptable and sustainable intervention for young people with HIV, it will provide a valuable tool for enhancing more traditional counselling services and in complementing clinical care for this group.

## 2. Methods

### 2.1. Overall design

Twelve adolescents attending Africaid support groups were purposively selected to attend a ten day digital storytelling workshop during which they would create their own digital stories. Six created stories about their lives and six created stories related to specific themes. Storytellers opted to show their films to their caregivers. Two focus group discussions were held with storytellers on completion of their films and one focus group discussion was held with caregivers. Detailed field notes including verbatim quotes were written during the focus group discussions.

### 2.2. Study setting

The study was set within Africaid's Zvandiri programme in Harare, Zimbabwe. At the time of this pilot project Africaid had 540 support group members aged 5–24 years and ran 20 support groups across Harare. All support group members are aware of their HIV status and are engaged in treatment and care through local clinics. The majority of the attendees are from low income residential suburbs/townships initially established for the urban poor during colonial times and are characterised by densely packed housing.

### 2.3. Sampling

Twelve HIV positive young people (aged 18–22) enrolled in Africaid's Zvandiri programme in Harare were purposively selected to join the project. Selection was made on the basis of previous interest in storytelling processes and media techniques. They were required to have knowledge of their HIV status, to be able to read and write and free to attend for the duration of the workshop. It was made clear that they were free to withdraw from the process at any time. Workshop attendance did not interfere with clinic appointments or school attendance.

### 2.4. Technical review group

A technical review group was convened prior to the project, including two young people living with HIV, one HIV advisor, one child health advisor, one paediatric/adolescent HIV nurse counsellor and a media educator. Its role was to finalise the project design, oversee implementation and evaluation and ensure the appropriateness of activities.

### 2.5. The digital storytelling workshop

Two ten day digital storytelling workshops were held with a group of six participants (storytellers) per workshop. These were facilitated by a media expert (LF) and a specialist paediatric/adolescent HIV nurse counsellor (NW). Both facilitators were well known to all storytellers. The workshop was held at Africaid's support centre as this was considered to be a safe, familiar environment for the young people.

The ten-day digital story workshop was adapted from Lambert's seven steps of digital storytelling (Lambert, 2013) and Payne's description of the narrative therapy process (Payne, 2006) which seeks to facilitate changed, more realistic perspectives, and open up possibilities for the person seeking assistance to position him or herself more helpfully in relation to the issues retold. Although each storyteller was engaged in the production of their own digital story, the workshop was a facilitated group process.

The workshop was designed to be fun, highly participatory and allowed storytellers to work on their own material at their own pace and in their own way. Sessions were structured in one hour sessions with fun energisers between these sessions.

The workshop began with the facilitator introducing storytellers to the concept of digital storytelling. They were then invited to write a 'narrative' or story that tells them and others about their life, by drawing on first hand, experiential knowledge. In the first workshop, storytellers were invited to tell the story of their life. In the second workshop, storytellers first identified film topics based on key issues affecting adoles-

Digital Storytelling Process	
1.	Introduction to DST
2.	Writing first draft of narratives
3.	Clarifying and Extending
4.	Recording audio narrative
5.	Collating visual narrative
6.	Story board development
7.	Compilation of narratives in to a digital story
8.	Screening of digital story (dependent on storyteller's wishes)

cents with HIV. They then chose which topic they wanted to focus on. The narrative, when read, was limited to 3–4 min in order to focus the narrative on the story they wanted to tell and to control the film

production time. They could write their narrative in English, Shona or Ndebele, two major indigenous languages.

On the completion of the first draft of their story, the facilitator asked clarifying and extending questions, encouraging each storyteller to reflect on the effect of these experiences and to describe how they had responded to these events. This one-on-one process enabled storytellers to re-story their experiences with a far richer narrative than initially developed. The facilitator guided the storyteller through a more participatory, in-depth process than is often possible in more traditional one-on-one counselling. Storytellers then read their narratives to each other and provided emotional support for one another when sharing painful memories. They celebrated each other's successes and encouraged one another to share these in their films. In this way, the workshop was both an individual and group therapeutic process.

Once storytellers were satisfied that the narrative provided a true reflection of their story, they recorded their audio narrative in a studio. They then chose visual images to bring their story to life. Storytellers were trained to take photographs and encouraged to use whichever image they believed would best convey their message, including old and new photographs, documents or their own paintings and drawings. They were then trained to develop a story board in which they arranged their visual and audio narratives. Following iMovie training, they were assisted to produce their own film by assembling the audio and visual narratives.

On the completion of their films, storytellers were asked if they would like to share their film with other people in their lives. This involvement of outside witnesses is considered an important step in narrative therapy and the therapeutic process (Payne, 2006). All participants chose to show their digital stories to their caregiver. This was done in a group setting with all storytellers and caregivers together. Africaid counsellors were involved in order to assess the impact of the storytelling process and provide individual counselling as required.

Discussions were then held with the storytellers and caregivers together to support them following the production of their story and to assist them with any issues arising. This included an exploration of both the storytellers' and caregivers' reactions to the films and a discussion around how storytellers wanted to use their stories.

## 2.6. Data analysis

In order to explore the therapeutic role of the digital storytelling process, qualitative data was analysed from various stages in the process: 1) the digital stories (transcripts), 2) field notes from 2 focus group discussions with the storytellers (field notes) and 3) 1 focus group discussion with caregivers (field notes).

The audio narrative and visual narrative from the twelve films were transcribed. Translation was not required as all storytellers opted to use English in their films. Names or other personal identifiers were removed from transcripts before they were coded. Two researchers coded each transcript. Discrepancies were resolved by discussion. Codes were grouped into categories and emerging themes were then identified following the general principles of thematic analysis (Attride-Stirling, 2001). Common themes amongst the different data sources were identified and illustrated with quotes. Although transcripts for earlier versions of the film were available we only included the transcripts of the finished film here.

## 2.7. Ethical considerations

Written informed consent was obtained from all storytellers. Written parental/guardian consent was also obtained to ensure that adolescents' participation would not incur difficulties at home.

It was agreed that the storytelling process would be ceased for individual participants experiencing distress. Storytellers also had daily opportunities to provide support to one another.

Storytellers were informed that the films were their own property and would not be shared with anyone without the permission of the film maker, particularly to prevent involuntary disclosure of the storyteller's HIV status. Film makers were able to withdraw their material from the process if they wished. Storytellers were informed that the audience for the films was the storyteller themselves but if they wanted to share their film with someone else, including a wider audience for advocacy purposes, that was their choice and would be discussed on the completion of their films.

## 3. Results

### 3.1. The therapeutic role of digital storytelling

In keeping with the ngano format, all storytellers narrated a journey of physical and emotional changes, focusing initially on childhoods dominated by difficult experiences before then describing how their lives had changed over time.

All storytellers chose to begin their stories by describing lives dominated by memories of sick parents, stigma, a lack of understanding of what was happening to them and their own ill health. These experiences were common to all films. The description of these events was conveyed through their voice narrative, often in short, poetic phrases but also greatly enhanced through their choice of visual images to convey their experiences and emotions. Images included photographs from when they were young, when they were sick or facing difficulties such as being unable to go to school. They used words and drawings to convey their experiences, such as the drawing of a 'broken heart' or the words "stigma" and "discrimination".

Storytellers all described a childhood characterised by a lack of control over events in their lives and an overwhelming feeling of being controlled by external factors. "This pandemic took charge of my life" (Keith); "Sickness began to rule" (Frank).

Several storytellers described feeling hopeless when they learnt about their diagnosis which was often disclosed after a prolonged period of illness. This was both frightening and disempowering; "The walls of hope, love, life and everything good crumbles" (Susan). Mistrust and secrecy were common with one girl describing "I felt my father was hiding something so decided to my own research" (Mazvita). Storytellers' voices were typically characterised by sadness.

Many storytellers described not knowing the cause of their parents' death or the reason for their own ill health. Even when not explicitly stated, they had clearly recognised that they should not discuss certain issues which caused a considerable amount of distress as they wanted to know more. "Questions kept on ringing in my head?" (Keith). "It feels terrible when someone blinds you so that you see nothing? I needed clear answers why my mother died" (Mazvita).

Lindiwe's film depicted her anger at her father for hiding his HIV positive status from her. She discovered after his death that he secretly took antiretroviral drugs whilst his children knew nothing.

"My mother died because of my wicked father" (Lindiwe, 18 years)

When narrating their experience of disclosure, they described feeling "Shocked by my status". They depicted anger and betrayal towards family members in relation to the way they were infected or as a result of not being told their HIV status earlier. These emotions were often linked to a sense of blame. "I was very angry. He never told me what was happening" (Amanda); "I am the only child [in my family] affected...

*it is something that pains me a lot. I felt the great pain inside my heart” (Lindiwe).*

Storytellers described stigma and discrimination in their daily lives. One girl used a video image of her disappearing from the screen, symbolising her feeling of being insignificant—*“Imagine how it feels to be treated as if you are not human” (Tendai)*. She described a childhood where she frequently encountered *“people with lack of heart for other people”*.

They commonly described and illustrated their stories to show the challenge associated with being physically different from their peers—for example being stunted or having skin disfigurement. As they became older, their concerns started to focus on delayed puberty; *“I had stunted growth...even menstruation was delayed” (Rudo)*.

Feelings of isolation and loneliness were commonly described; *“My peers did not want to associate with me...share books together” (Tendai)*;

*In her film, Amanda disclosed for the first time how she had tried to kill herself after discovering her status.*

*After years of feeling isolated and fearful for her own death, she stopped her Antiretroviral drugs. Through Zvandiri she met other adolescents with HIV and spoke of how this transformed her hopelessness. “I know one day my dreams may come true” (Amanda, 20 years)*

*“At that time I did not talk to anyone” (Lindiwe).*

The feelings narrated were not all negative. Many adolescents described the pain of losing loved ones, something they had not been encouraged or able to talk about in other settings. They described multiple losses including the death of their parents and siblings and a childhood growing up without these people in their lives. They used their films to reflect on the memories of these people, speaking with fondness and love for their loved ones. *“My father lit up my world. So when that man was taken away from me I couldn’t take it” (Susan)*. Many incorporated old photos that they had been unable to display previously.

Fear and uncertainty for the future was commonly described; *“Sometimes I would wonder when it would all end” (Susan)*. Their experiences of family deaths and recurrent messages that *“HIV kills”* left them worried and fearful for their future. Lack of information and answers, compounded by stigma and discrimination, resulted in poor confidence, lack of self-esteem or hope for the future.

Adherence was described as a major challenge. Although they had access to medication they had many fears around *“How am I going to swallow these tablets for the rest of my life?” (Amanda)*.

Having described the earlier part of their lives, they went on to narrate how their lives then changed. Different themes emerged around factors which had helped to *“make our lives longer, strengthen our bodies and put smiles on our faces” (Frank)*.

The most significant influence in the storytellers’ lives was the emotional support they received. They described the way specific individuals, clinics or organisations had been pivotal in providing support which had helped them to feel loved and cared for, in contrast to stigma and discrimination. *“My family gave me support, love and care. My sister occupied the role of counsellor, giving me information about HIV. My father’s love for me was unconditional; he gave me confidence and lit up my world” (Susan)*.

This was commonly linked to a sense of acceptance. When describing her arrival at the Africaid programme, one girl narrated *“I found*

*what I call a family, friend, supporter and inspiration. What makes me cry tears of joy is that I found a family with heart that never selects but takes me as I am despite my HIV status” (Tendai)*.

Others described this acceptance in the context of dating, relationships and disclosure to partners; *“He accepted me and I am happy about it. He told me I love you for who you are” (Rudo)*.

This is in sharp contrast to the earlier narrative in their films in which they described being isolated and stigmatised. *“I felt more at home, happy and accepted” (Alan)*.

The importance of peer support was highlighted in all films. Introduction to peers living with HIV was described as transforming and was the pivot around which the mood of the stories changed from negative to positive. Peer support activities enabled them to share with others with similar experiences and they no longer felt isolated. One storyteller explained *“I do not have intentions to lose the true friendship that I have” (Precious)*.

In contrast to the beginning of their films, storytellers explained how they now have a sense of control and freedom in their lives and how these have helped them to cope better; *“I can now take control of my life, I have kissed away the fear and frustration” (Susan)*. *“You will never be able to pull me down, I can now walk alone for as many years” (Frank)*. One storyteller focused his story around being a dancer, *“In dance, I keep on two stepping and I will never stop” (Keith)*.

One of the recurrent themes was the participation and active engagement as service providers. All storytellers had played an active role as peer counsellors and they described how this had given them a purpose and helped to build their confidence. *“My dream is to become a nurse so that I can look after other HIV positive people” (Amanda)*.

There is growing recognition of the importance of child participation for its own sake (U.N. General Assembly, 1989) and for its therapeutic benefits (Save the Children, 2010). The stories epitomised why this is critical. Storytellers described how important their sense of ownership of the Zvandiri programme was to them. *“Zvandiri is led by children and adolescents with HIV...who participate at every level...the youth get to experience what it is like to be at the forefront of a huge project. It is we who facilitate” (Alan)*.

They described the role of skills acquisition in their lives as being important. *“I have developed skills in coping with my situation. I can now look after myself, take steps to protect myself” (Alan)*; *“I can now see the opportunities given to me” (Nigel)*.

One of the most notable themes to emerge was the sense of increased confidence in the storytellers. *“Through support, I feel confident and able to make informed choices. I am now confident, independent and most of all ever smiling” (Tendai)*. This was evident in the written narrative of the film, the tone of their voice in the audio narrative and in their use of images to convey their messages. One storyteller chose to use her own recorded songs as the soundtrack for her film.

Having described the role of emotional support, acceptance, peer support and participation in their life stories, key themes emerged in the films regarding the impact of this support.

Participants commonly described a feeling of renewed ambition and optimism in their lives; *“My dream is to have a good job” (Brian)*; *“I hope to get married and have our own HIV negative children” (Rudo)*. To illustrate her ambition, one girl chose to include a visual image of her dressed as a nurse in her HIV clinic.

Similarly, this was reflected in the storytellers’ description of their desire to live. In contrast to the earlier feelings of hopelessness, suicidal ideation and having no purpose, they then went on to describe a new desire to live; *“I now have the desire to live...hope for a brighter future” (Alan)*. *“I will achieve my goals because I have a positive mind” (Lindiwe)*. *“My life has been a rollercoaster, (but is now) going from strength to good health” (Susan)*. This was mirrored in the sense of acceptance running through each film; *“Whatever you do, do it with heart and acceptance, being HIV positive is not the end of my life” (Tendai)*; *“The door opened, the light came in to my life” (Lindiwe)*. These perspectives are in sharp contrast to the wider social stories about growing up with HIV, such

as the prevailing myth that children with HIV will not survive through childhood.

### 3.2. Participation and ownership

When reflecting on the digital storytelling process, storytellers were proud of their role in pioneering a unique approach. All storytellers felt that this was a process which they owned and led. *“It is exciting to be the first to try this. It truly is a project for teenagers, led by teenagers” (Precious)*. They also explained that being central to the process was very helpful in giving young people a voice and the platform to share their own experiences; *“I could really speak freely (through my own film), about things I have never shared with anyone before” (Keith)*. They stated that they would like to now train their peers to make their own digital stories; *“This should be made available to everyone in Zwandiri. We know how to do it now so we can teach them” (Susan)*.

### 3.3. Skills acquisition through digital media

All storytellers gained new skills in photography, film making and storytelling. They explained that this gave them new confidence and belief in themselves. Many described how they had struggled to achieve in school but were proud they had been able to produce their own film; *“Who would have thought that me of all people would be able to create something like this?” (Brian)*. Participation in this process helped them to view themselves as capable young people with capacity to acquire new skills, in contrast to their previous self-perception. Storytellers wanted to pursue further training in media production.

Caregivers described their surprise that the adolescents had been able to create the films. All caregivers were excited by the process of digital storytelling and wanted to know when they would have the same opportunity; *“It is not just the children who have gone through difficult times. We have had so much pain in lives. We’ve lost our children. Now we’re looking after grandchildren. We should make our own films” (Grandmother)*.

### 3.4. Improved understanding and communication with caregivers

All storytellers chose to show their films to their caregivers and were proud to do so. They explained that it was the first time that they had shared their experiences with caregivers in such an open and direct way. In particular, the impact of family deaths had rarely been discussed with their caregivers. *“I never knew before today that my granddaughter felt this way. We had never talked about her mother’s death” (Grandmother)*.

Similarly, many storytellers had never had the opportunity to describe the anger, resentment and fear in their lives yet they were able to share this through their film. They explained that their future is rarely discussed at family level due to uncertainties about their prognosis. This results in limited opportunities for sharing their hopes, ambitions and desire for their future; *“I had no idea that this is what he wanted to do with his life or that it was possible. We often try to protect our children as we don’t know how long they will be with us. But I have heard differently today” (Aunt)*. Storytellers were able to share these aspirations in their film narratives. The girl who chose to include photos of herself dressed as a nurse explained *“I wanted to show myself as a nurse, to feel it and believe it will come true one day” (Amanda)*. Indeed, a year after completing her film, she went on to nursing school. Whilst this cannot be solely attributed to taking part in this storytelling process, she reported that it had helped her to believe in herself and to pursue her dream.

This method of communication was extremely helpful for caregivers who all shared their surprise at hearing the different knowledge, experiences, emotions and aspirations of the adolescents in their care. One caregiver explained she *“did not know that my child knew so much about HIV. She knows much more than me. We now need to know all this*

*information too” (Aunt)*. Caregivers described how this new insight would help them to talk about the issues affecting their adolescents.

Eight storytellers chose to use their films as an opportunity to acknowledge the support of specific caregivers whom had been significant in their lives. Caregivers were visibly moved and emotional by hearing the storytellers’ gratitude for their support.

### 3.5. The role of digital stories in training and advocacy

Storytellers and caregivers explored how the films would be used. All agreed that the films are an important personal document and should be kept safe and shared with specific family members who knew the HIV status of the storytellers.

They discussed potential risks and benefits of sharing their films to a wider audience. It was emphasised that the storytelling process was initiated as a therapeutic intervention for individual storytellers and that any additional use of their films was their own choice and that each decision would be respected. Four caregivers felt that the films should be shared widely and one grandmother told her grandson, *“You should be proud of your film and what you have achieved. This will help people understand more” (Aunt)*.

Six storytellers voluntarily decided their films would be an important advocacy and training tool and that they should be used in controlled settings, where their films could be viewed but not taken away by individuals. Two suggested that their films be used freely as training and advocacy tools as although they were describing their own individual experiences, these were experiences commonly shared by their peers. *“I think it is important that people see my film. How else will they know how we [HIV positive young people] feel when they stigmatise us. It will help other children not to be stigmatised” (Tendai)*. However, four storytellers described concerns that they would be stigmatised if the film was to be seen by a wider audience. In particular, they were concerned that this would jeopardise their chance of relationships.

## 4. Discussion

All films provided rich data in support of the literature documenting the challenges which HIV positive children and adolescents face (Bandason et al., 2013; Ferrand et al., 2007; Mavhu et al., 2013; Parsons, 2012). However, results from this small study suggest that the digital storytelling process has the potential to be an important therapeutic intervention for adolescents with HIV. All storytellers were able to reflect on their life experiences in what they described as a different, interesting and often fun way. They were able to explore the impact of these experiences on them, and through a process of externalisation and discovery, to re-tell their story. In this way, they were able to move away from a perception that their life story was dominated by negative experiences but to instead discover the many ways in which they had overcome these challenges and to celebrate their own resilience. They developed a newer, richer perspective of their lives in which they had overcome difficulties and gained new coping strategies, strength and purpose for their future.

This process provided them with an opportunity to consider re-telling their story within a framework which encourages focus on positive transformation, rather than on the difficulties in their lives. Through their films, they were able to debunk prevailing myths from their childhoods such as the commonly held belief that a child with HIV will not survive, go to school or grow up to have relationships and families of their own. It is argued therefore that the therapeutic value of this approach lies primarily in providing storytellers with a mechanism for acknowledging the way they have overcome the challenges in their lives and to appreciate their successes and achievements.

As in cognitive behavioural therapy, their self-awareness improved, they developed a better self-understanding and improved self-control. They were able to identify their own dysfunctional thoughts and

beliefs from their earlier years which were mainly in relation to how other people perceived or behaved towards them. Through the process, they were able to move to a more functional cycle in which their thoughts were more positive and they were able to acknowledge their successes on their journey. They were helped to confront the difficulties in their lives and were able to describe happy, peaceful and often joyful emotions.

Storytellers commonly explained that they were able to display emotions which they had previously been unable to share with family, friends or health workers. Visual images which had not previously been shared were included within their films. For example one storyteller described how she had not included the photo of her disfigured skin as it was too painful but on the last day, she arrived with the photo, explaining that it must be included as it was an important part of her story and journey.

Painful memories and experiences were not forgotten. Instead storytellers were allowed to embrace these as a critical part of their story and were helped to re-look at these experiences as having had an effect on them rather than defining who they are. They were able to remember significant people in their lives whom they had lost and to document them as a critical part of their life story.

Storytellers described the importance of having a permanent document of their journey which they could keep forever. Alan speaks confidently in his film about his 'desire to live'. A year later, his social circumstances changed and he stopped his antiretroviral drugs. He explained he had lost the desire to live. When shown his own digital story, he was reminded of a time when he was confident and determined. He chose to recommence antiretroviral drugs.

As in Memory Work (Denis, 2012), storytellers also found therapeutic benefit in the sourcing of physical documents which were important to them and reminded them of their identity, family history and their journey. Six storytellers chose to ask relatives for old photographs of their parents or siblings who had passed away. Many were able to obtain photographs of themselves as a younger child which brought back memories of sickness, stigma and discrimination. Whilst this was an emotional process for them, they also described how it was important to them to include these images in their film so that they did not get forgotten.

An unexpected outcome of this project was that caregivers also found the process helpful both in terms of improved understanding of their children but also as a therapeutic intervention of their own. Grandmothers stated that it was usually too painful to think of the death of their children (parents of the storytellers). However, hearing about them and seeing their photos in the films helped them to share memories of their children. Mothers explained that it had been difficult to come to terms with their own HIV status but that they had been encouraged by their own children's films to accept their HIV status. They were also able to appreciate the positive influence they had played in the storytellers' lives. This potential role for caregivers is significant when it is increasingly recognised that programmes need to involve caregivers more in interventions for ALHIV (WHO, 2013b).

Since this study, six storytellers have opted to share their films for the training of health workers across Zimbabwe. The films have been highly effective at strengthening service providers' awareness of the needs and experiences of children and adolescents with HIV. They have also used their films to advocate for services for ALHIV. Storytellers did however opt not to share their films over the internet.

#### 4.1. Study limitations

This methodology is time consuming as it targets young people who commonly have no experience in IT or photography. An individualised approach is often needed to allow for storytellers' varying competencies. However, it has been demonstrated to be a feasible approach as young people with no prior experience with a camera or computer

were able to create powerful, emotive films. Two storytellers have since completed graphic design courses and are now journalism interns. Both plan to now run digital storytelling workshops for their HIV positive peers.

Computers require power supply and this was often erratic in the study setting. However, this was overcome through the donation of a generator. Conversely, this project demonstrates that the use of technology in resource-limited settings is not only acceptable but that it is also feasible.

The requirement for computers and cameras may be seen as costly. However, if this approach can improve the psychological well-being of young people with HIV it will impact on adherence to antiretroviral therapy and reduce the risk of treatment failure. Although a cost effectiveness study was beyond the scope of this project, it seems fair to suggest that the cost of a camera and computer, benefiting numerous adolescents, is significantly less than just one adolescent requiring second or third line antiretroviral treatment.

There is important ongoing therapeutic value that such films can have, through revisiting them when motivation is lagging or the circumstances of a young person changes to become less favourable again. However, this requires the continuity of support groups, as well as ongoing access to DVD players, in order to realise this benefit once the films have been completed and the intervention is ostensibly completed.

Despite these limitations, and in the context of such little evidence around therapeutic interventions for adolescents with HIV, this paper makes a valuable contribution to the literature on evaluating therapeutic interventions for this group.

## 5. Conclusion

Whilst the global community celebrates increasing access to antiretroviral therapy, adolescents with HIV face considerable challenges with adherence. Perinatally HIV-infected children are growing up, but this is reliant on optimal adherence which in turn is affected by the challenges in their lives. If we are to prevent a global disaster in which young people run out of treatment options following poor adherence, global and national policies and programmes must urgently focus on their psychosocial needs.

From this small study, it is recommended that service providers integrate innovative, dynamic counselling approaches which appeal to the interests and capacities of adolescents. Whilst there is continued need for more formal counselling approaches already used, there is an urgent need for new approaches which actively engage young people in reflecting on their lives and which help them to develop a view of their life which enables them to grow and develop. This digital storytelling process confirms to young people that their story really does matter. It validates their experiences and shows them that others place value in their experiences and the way they have overcome difficulties.

## Acknowledgements

The authors wish to thank the adolescents, young people and caregivers who participated in this pilot project. We thank Maruva Trust (FRICAID 2010–2012) and the Government of Zimbabwe's Child Protection Fund (PCA-2012-0003) for funding this work. We are also extremely grateful to The Solution Centre, Zimbabwe who donated Apple computers and software for the project.

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