

Art-based reflections from 12 years of adolescent health and development-related research in South Africa

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Summary

This paper presents empirical and methodological findings from an art-based, participatory process with a group ($n = 16$) of adolescent and young advisors in the Western Cape Province of South Africa. In a weekend workshop, participants reflected on their participation in 12 years of health and development-related research through theatre, song, visual methodologies and semi-structured interviews. Empirical findings suggest that participants interpreted the group research encounter as a site of empowerment, social support and as a socio-political endeavour. Through song, theatre and a mural illustration, they demonstrated that they value 'unity' in research, with the aim of ameliorating the conditions of adolescents and young people in other parts of South Africa and the continent. Methodological findings document how participants deployed art-based approaches from South Africa's powerful history of activism, including the struggle against apartheid, the fight for anti-retroviral therapy and more recent social movements towards decolonization.

Key words: adolescence, participation, art-based research, South Africa, empowerment

INTRODUCTION

Adolescents and young people in South Africa are among the first generation to be born with democratic freedoms, following the first democratic election in 1994. Those born into AIDS-affected households are also among the first to grow up with access to life-

saving anti-retroviral therapy (ART) as part of the world's largest public HIV programme (Burton *et al.*, 2015). Despite this irrefutable progress in health and human rights, South African AYP bear the ongoing legacies of colonialism, apartheid and HIV/AIDS. These include the effects of South Africa's late roll-out of ART, which

resulted in an estimated 330 000 preventable deaths, and 35 000 babies to be born with HIV between 2000 and 2005 (Chigwedere *et al.*, 2008). Babies exposed to HIV *in utero* experience persistent health challenges as adolescents (Hudelson and Cluver, 2015; Goga *et al.*, 2019), and children who lost caregivers to AIDS-related illness shoulder additional caregiving responsibilities (Cluver and Orkin, 2009). As the first generation born into democracy, young Black South Africans are subject to narratives of being ‘born free’, which espouse principles of equity and opportunities for everyone to flourish (Walker, 2005). Unfortunately, there is a marked gap between these social and economic promises, and the lived realities of young South Africans within contexts of pervasive poverty, unemployment and HIV/AIDS.

Previous decades have seen increased interest in participatory and art-based approaches in health and development-related adolescent research, which have been documented as having transformative potential to catalyse social change (Mitchell and Sommer, 2016). Participatory approaches were developed by Freire (1970) with the aim of lessening oppression, improving the lives of impoverished peasants (Breunig, 2009). They have since been applied to research with youth: a group that is often marginalized and excluded from research, policy and decision-making (Swartz and Nyamnjoh, 2018). Participatory and art-based approaches can elicit youth evidence about their health, while acting as modes of representation, knowledge co-creation and mobilization to respond to pressing social and health challenges (Mitchell and Sommer, 2016).

Youth participation came to be considered a precondition for successful HIV programming in the early 2000s (UNICEF, 2002; Ross *et al.*, 2006; Campbell *et al.*, 2009), and is now considered a ‘marker of quality’ in youth-related policy, intervention and research (Cahill and Dadvand, 2018). Despite its popularity, there is a great deal of variation between research methods described as ‘participatory’ (Swartz and Nyamnjoh, 2018). Although there are various frameworks for youth participation [e.g. (Hart, 1992; Treseder, 1997; Wong *et al.*, 2010)], it has been suggested that participatory research must pay more attention to socio-cultural contexts, the role of process and place, and the dynamic nature of participation (Cahill and Dadvand, 2018). Youth experiences of participation in health-related research in South Africa remain underexplored.

In response to these evidence gaps, we conducted participatory, arts-based activities with a long-standing group of AYP affected by HIV ($n = 16$, aged 15–27 years at the time of the research described in this manuscript) in the Western Cape Province, South Africa. This group had

engaged in a series of advisory and research activities over the prior 12 years, including policy engagement, research design and arts and games-based activities, described elsewhere (Cluver *et al.*, 2021). They also informed the design of a number of large, mixed-methods longitudinal cohorts: a national survey of adolescents (Meinck *et al.*, 2015), a cohort of adolescents living with and without HIV (Toska *et al.*, 2017), a cohort of adolescent mothers and their children (Toska, 2020), randomized controlled trials of parenting support programmes (Cluver *et al.*, 2018), and research to identify development accelerators for adolescents in Africa (Cluver *et al.*, 2019).

Our objectives were to understand their experiences of participating in research over the span of the group’s existence, including benefits, challenges and what constitutes a meaningful research encounter for them. We aimed to address key knowledge gaps on the process and dynamic nature of participation, with a focus on the socio-cultural contexts of HIV-affected AYP in South Africa.

Background: participatory and art-based methods in South African research and activism

Theatre, songs and visual methodologies have rich histories in research and activism globally and in South Africa.

The use of theatre in transformative research, education and activism has its roots in ‘Theatre of the Oppressed’, developed by Boal (Boal, 1974) to promote individual, social and political transformation through the development of critical consciousness. It has since been engaged globally as a tool for political and social transformation (Boal, 1974; Logie, 2021). Theatre has also been deployed as a tool of resistance in South Africa, and was a common feature of protests against racist apartheid legislation (Larllham, 1985). It was later used as a form of ‘entertainment education’ to disseminate HIV prevention information (Larllham, 1991), and to engage HIV/AIDS attitudes, health practices and reduce stigma (Durden, 2011). Theatre-based participatory research methods have been used as a transformative approach within Southern Africa to amplify marginalized voices and vernacular knowledges, critique the social world, expose new insights and imagine new possibilities (Logie *et al.*, 2019).

The use of song can also create ‘political alternatives’ to the present (Redmond, 2013), and express difficult-to-articulate views (Mbhele and Walker, 2017). South African struggle songs have been described as ‘*weapons in a cultural arsenal that draws on years of resistance...*’ (Mbhele and Walker, 2017). They offer a joint language to activists and researchers, and, due to their call-and-response structure are part of a democratic process in social movements that can create connections between

groups of people (Mbhele and Walker, 2017). Struggle songs have a legacy of deployment by youth, including famously by Black schoolchildren during the Soweto uprisings of 1976, which vastly changed the socio-political environment of apartheid South Africa (Ndlovu, 2017). Later, historic songs were re-written and deployed to advocate for HIV medicines (Walker, 2018). Song is also used in other health promotion and research initiatives. For example, a recent malaria prevention intervention in Limpopo engaged participatory risk analysis and song development (Anderson *et al.* 2018).

Visual methodologies have also been engaged to take action against pressing social issues. The Publications Act of 1972 criminalized the production and distribution of ‘undesirable’ works, quashing ‘visual rights’ and aiming to invisibilize Black South Africans and violences of the apartheid state. In response, resistance art emerged from the Black Consciousness movement, often in the form of murals, banners, posters and graffiti with confrontational political messages that foregrounded the realities of life under apartheid (Williamson, 1979). Later, the ‘Hope and Healing Campaign’ challenged HIV/AIDS-related stigma using participatory visual methods (Francis and Hemson, 2006). Self-created body maps of women living of HIV have been engaged as a participatory research methodology with an ‘activist emphasis on body politics’ (MacGregor, 2009) to forefront and visibilize women’s embodied experiences. Around the world, participatory visual methodologies are used with youth affected by adversity to understand their experiences and perspectives. Such methods can capitalize on youth strengths such as attention to detail, visual communication and local knowledge of contexts and environments (D’Amico *et al.*, 2016). They can support young people to express themselves freely, avoiding feelings of giving a ‘wrong’ answer (Veale, 2005; Leitch, 2008; D’Amico *et al.*, 2016). Participatory visual methodologies, when combined with other methodologies that add context and narration, can effectively support youth to convey lived experiences (Leitch, 2008). They have been engaged in health-related research with young people in Southern Africa to identify and respond to maternal health challenges (Musoke *et al.*, 2016), inform adolescent-friendly health facilities (Hodes *et al.*, 2018) and understand relationships between life histories and health practices of adolescents living with HIV (Gittings *et al.*, 2022).

The AYP who participated in these activities have been exposed to the aforementioned histories of South African art-based activism. They were born immediately following the anti-apartheid struggle (1950–1990s),

grew up against the backdrop for the fight for ART (1990–2000s) and came of age alongside the #rhodesmustfall and #feesmustfall movements for decolonized, accessible tertiary education (2015–2016).

METHODS

Design and history

During a weekend workshop in January 2020, the Western Cape Teen Advisory Group (TAG) engaged mediums of participatory theatre, song, the development of a graffiti wall image, and participated in semi-structured interviews to reflect on their experiences as adolescent advisors in research. Ethical approval for this study was provided by Research Ethics Committees at the Universities of Cape Town (CSSR 2013/4, 2017/01, 2019/01; HREC 226/2017) and Oxford (SSD/CUREC2/12-21; R48876/RE001, RE002; RE003; R53899/RE001).

Initial TAG members were an advisory group recruited from a quantitative observational cohort of children and adolescents affected by HIV (10–17 years old at baseline in 2007). Regular (semi-annual or annual) activities engaged with the original cohort, and also siblings and neighbours, following consent procedures. Over time, a stable cohort of 15–24 members was established with whom this participatory set of activities was developed. While some members disengaged/aged out, others had children or brought siblings or family members.

The workshop was pre-dated by a year-long reflexive process to facilitate the closure of the research relationship with this group, who are now mostly young-adults. In a series of iterative group discussions, TAG members and researchers critically reflected on 10 years of research and reimagined the research relationship based on shared ideals. The previous decade of engagements was unpacked in close dialogue to reconcile the existing relationship with new intentions to shift paradigmatically towards a participatory and emancipatory approach. Notions of power, and the meanings and values that underpin participatory research were explored together.

This required a critical lens to how power had been constituted in the research relationship, unpacking distinctions between research and social service provision and fostering bi-directional engagements premised on learning and sharing. The aim of this critical co-reflection was to facilitate a power shift that would reorient the relationship to promote co-generation, co-ownership and co-accountability throughout the research cycle.

As part of this process, young advisors and researchers co-designed a 12-month plan, comprised of a series of activities for longitudinal reflection and dialogue with the

larger group of adolescent advisors. Through a democratic process, they decided that they would like to reflect upon, and jointly close out the research encounter by activities including: (i) developing a participatory mural to be displayed in a public space; (ii) the development of a participatory play; and (iii) a ‘youth-on-youth’ engagement festival to showcase the mural, perform the play and display memories and research outputs in a walk-through gallery. This paper reflects on the weekend workshop, in which the participatory play and mural were developed at the conclusion of this 12-month process. The process of this weekend workshop is described below.

Participatory play development

Six ‘stations’ with sticky notes, a polaroid camera, paper and markers were set up with prompts about research experiences. Participants visited each station, reflecting individually on their experiences and writing them onto sticky notes. On the second day, small participant groups at each station themed responses by grouping sticky notes thematically.

This was followed by a workshop on the components of telling a story, with focus on structure, consideration on what they wished to convey to the audience in feeling, thinking, audio and visually. Participants then self-organized into sub-groups based on identified themes and determined how they wished to express each theme. They then presented these back to the group for discussion, and jointly created a play storyline.

A theatre and dance practitioner worked with the group to develop transitions and to ‘weave’ the story together. She also provided guidance on movement and verbal projection.

The play was rehearsed multiple times, and video recorded. It was to be performed for an audience at a final ‘youth engagement festival’, which was cancelled due to COVID-19.

Songs

Participants included songs in the play, interspersing physical performance with singing. This was not a pre-determined part of the workshop, and songs were selected and (re)written by participants themselves. These songs are presented and analysed separately to give attention to their richness and meaning.

Participatory mural development

The mural was co-developed with adolescents, researchers and a team of visual artists who acted as observers over the weekend to visually represent their reflections on the research encounter. The artists developed an

initial concept based on their observations, which they shared with the group during two rounds of discussion and feedback. The mural was designed to be featured on a large public wall as part of the youth festival. Given the cancellation, the artist team digitized the visual, which has been verified and shared with the group in a notebook and over social media.

Semi-structured interviews

Semi-structured interviews were conducted with all 16 workshop participants by three facilitators during and directly following the workshop to explore their workshop and TAG experiences. Interviews lasted 20–40 min in length, were recorded with consent and transcribed verbatim. isiXhosa language interviews, songs and parts of the play were translated into English and transcribed.

Analysis

We (members of the author team) transcribed the play and songs verbatim, based on a video of the final rehearsal performance, and wrote a scene-by-scene summary. We wrote a descriptive text to accompany the mural image (Figure 1). We thematically analysed the play, mural, song and interviews, using Braun and Clarke’s (Braun and Clarke, 2006) thematic analysis approach. We took an inductive approach (Patton, 1990), and the themes that emerged most strongly from the data were the focus of analysis and writing.

After data familiarization by reviewing transcripts and re-watching video recordings of the play, three co-authors generated an initial list of codes for data from each method. The data were double-coded for reliability, after which we sought, reviewed, defined and named themes. We integrated findings through triangulation using a convergence-coding matrix (O’Cathain *et al.*, 2010) assessing agreement, silence and dissonance between findings from different methods. Findings were verified by one co-author in a member-checking exercise with six members telephonically and social media. A digitized version of the mural was validated with TAG members in a closed Facebook group [ethical approvals provided by the University of Cape Town (HREC 226/2017, version 7.0) and the University of Oxford (IDREC R48876/RE003)].

Positionality, intersubjective identities and reflexivity

The positionalities and inter-subjectivities of the TAG members and researchers inevitably shape the process and outcomes of research. The TAG members attending the weekend workshop were Black [Racial categories



Fig. 1: Digitized version of participatory mural.

(Black, Coloured, Indian and White) are used to refer to the Statistics South Africa categories of African, Coloured, Indian and White. We use the term 'Black' to refer to Black African people, given that others may identify as African (although we also acknowledge that Coloured or Indian people may also identify as Black). We use these socially constructed terms to acknowledge the legacy of South Africa's socio-political history and the heterogeneous groups whose lives have been differently impacted by the colonial and apartheid regimes.] isiXhosa-speaking South Africans living in urban informal settlements in the Cape Town area. Researchers included two young Black isiXhosa-speaking females, who lived in similar contexts to participants, one Black isiZulu male, one Coloured male, one Coloured female and three white foreign females.

The research team was older than TAG members, and, despite varying socio-economic backgrounds, had higher education and household income. Within the research team, there were linguistic, racial, nationality, class and gender differences which shaped power dynamics. We carefully and consistently considered these inequities, and aimed to minimize their potentially harmful effects by engaging local researchers with identities similar to TAG and through pre-workshop activities on power and participation to acknowledge and engage power inequities.

Participatory and art-based methods were intentionally designed with the aim to purposefully mediate against power inequities, complicate conventional ways of knowing and engage in the production of knowledge in a way that shifts power. Despite these efforts, power will inevitably shape the research process and outcomes, and our attempts do not remove the possibility of harm.

FINDINGS

There were three themes, spanning methods, that adolescents suggested were central to their experiences and important to their meaningful participation in the research. The most prominent was 'unity', with participants displaying a strong sense of group identity, premised on solidarity, working together and supporting one another. Individual and collective empowerment through the research process was another strong, cross-cutting theme. Finally, participants conceptualized their involvement in research as action for social change.

Participatory visual 'mural'

Image summary (left to right)

The left side shows water being poured into hands. This water is a metaphor, born from a group experience of a

water outage during a weekend camp. They conserved the little water they had, sharing it using a jug. The jug of water represents how the group has worked together to overcome challenges.

The water is passed from one person to another (including participants and researchers), a show of teamwork. It is used to water a Baobab tree, which are notorious for growing strong and flourishing in difficult conditions. The difficult conditions that the tree grows within represent both their individual and collective struggles. The tree symbolizes their group, and what it has co-created (grown) together.

The 'fruits' are the benefits of their collective engagement in the research process. These include direct personal benefits such as social support, friendship and skills to navigate adverse circumstances, as well as changes to policy and programming brought about by the research products. Participants and researchers pick and share the fruits that the tree has borne, symbolizing how what has been created together is shared for the benefit of all group members.

At the far right is a 'research truck', into which fruit is being placed for transport to other parts of Africa. In addition to sharing the benefits of their involvement in research with their immediate group, the 'fruits'—research findings and their impacts—are being shared for the benefit of other AYP on the continent. When asked by a researcher if the 'research truck' felt extractive, a participant replied '*it isn't taking something away because it is already within us*' (Female, Age 19).

The background represents a merging of landscapes. The cityscape represents Cape Town urban imagery where participants live. The country landscape symbolises the places outside of the city where TAG weekend camps have taken place, which are known for their fruit farms.

This visual data contain three overarching themes: empowerment through overcoming individual and group challenges; 'unity' in group research, demonstrated through the image of participants jointly working together and collectively reaping the benefits of their work; and, knowledge creation for social change.

Theatre

In the play, themes of empowerment (through overcoming individual and collective adversities) as well as unity, and social change through research were also present. Participants presented and reflected upon their intersecting adversities of poverty, grief and loss, crime and social isolation.

The play was comprised of three main scenes in which participants enacted and reflected on different aspects of their experience as adolescent advisors.

The first scene opens with a 'support group' with a facilitator and three participants. After a round of introductions, the group is introduced as TAGs, where young people connect, discuss issues and advise one another. The facilitator explains that sometimes activities are fun, and others relate to sad topics. She introduces this session as focused on grief and loss, encouraging participants to share freely.

A young man introduces himself and shares that he was diagnosed with HIV after finding out that his baby was HIV-positive. He feels isolated, depressed and unable to speak openly about his HIV status, and does not know anyone else who is living with HIV. The facilitator thanks him, advises him to have faith and not lose hope, and asks after his baby and his baby's mother.

The next participant describes being in a car accident in which his brother was killed, describing losing strength and 'fighting to move on'. The facilitator thanks him and advises that God will give him strength. She says it is important to accept his circumstance so as not to get depressed, and that talking is important for healing: '*because once you cough it outside, you take it out from you.*' She encourages him to continue to '*walk the journey*' and attend sessions.

The final participant discloses that her father passed away and that they are struggling at home. She does not have anyone to talk to, does not know what to do and is keeping '*everything inside*'. Sobbing, she says this is the reason why she joined the group. The facilitator pats her on the back, encourages her not to be sad and to continue to attend, saying that sharing is important but not easy.

The facilitator closes the group by expressing her gratitude that everyone attended. She says that some people are '*killed by their thoughts and things they keep on the inside*', encouraging them to continue to open up, and hugs each member. The group transitions to the next scene, singing 'Senzeni na' followed by 'Jikelele' (described in the 'songs' section below).

In the second scene, a participant accidentally leaves her phone on a chair, which another finds and secretly pockets. The group looks for the missing phone, and discovers the 'thief' after calling it. He becomes sheepish and apologises, saying that he is desperate for money. In reply, the young woman whose phone he took asks him '*do you understand unity? You see, we said we work together, do you understand this concept? . . . we are supposed to be sisters, brothers and friends*' He replies saying '*I know, I am sorry guys, it was not by choice.*'

The scene ends and is transitioned with the group singing ‘Nkosi sikelela iAfrica’ (God Bless Africa).

The next scene includes spoken word, song and dance. It starts with a poem that unpacks and interprets the rationale for this act of stealing, outlining challenges of poverty, a difficult childhood, isolation, substance abuse and emotional challenges. Participants hum and sway in the background, the back row with raised, clenched, fists—a sign of power and resistance.

*‘Yes I am a thief
Not by choice but out of desperation
I am broken inside because of my pain
The way I grew up and now I am left alone with
no good friends besides me
So what do I do?
Do I continue stealing?
And take substances to destroy myself
Who is there to help me?’*

As she wonders aloud ‘*who is there to help me?*’, two other participants come forward to speak in response. They reflect on the support that their group has provided, and the life skills they have learnt through the process:

*‘... We made friends and family and were also
taught how to face our struggles and challenges’*

...
*Everything we have learnt at TAG
We take ... into our in our daily lives
TAG has taught us a lot
We made friends and family
And these are the only people we can rely on’*

Songs

Three songs, ‘Senzeni Na’, ‘Jikelele’ and Nkosi Sikelela iAfrica, were sung in the play, reflecting themes of unity, empowerment and overcoming individual and collective struggles. Through these songs, participants communicated how they situate their personal and collective struggles as part of a broader movement for social change through research.

Senzeni Na

The first song ‘Senzeni na’ means what we have done. We used that song after the first act because that was the sad moment when we shared sad stories, such as being HIV/positive, people looking down at you because you lost your father or people not motivating you because you lost a brother. (Male, 19)

An isiXhosa/isiZulu language struggle song, Senzeni Na rhetorically asks ‘What have we done?’ (to deserve this?). In the play, participants sang the first line of the song as a call and repeat after sharing experiences of grief and loss, including family death and being diagnosed with HIV. Through this song, they reflect on the health and social injustices that they have faced, and relate them to historic struggles.

Jikelele

The second song ‘Jikelele’ which teaches us about unity, and TAG teaches us about unity, which is carrying over from the song ‘senzeni na’ because we engaged ourselves at TAG and they are teaching us to be united. (Male, 19)

Jikelele (English translation: globally/everywhere) is an upbeat song, and was sung before the beginning of the second scene. Participants re-wrote this song, substantially altering it from its original lyrics to communicate their experiences in research:

Jikelele/iTag siyayithanda ifundisa ulutsha ngeunity
jikelele

(translation: Globally/We love Tag, it teaches youth
unity globally/everywhere)

This song is followed by a poem that elaborates on the song (while the song is hummed in the background):

*In TAG we are one
In TAG we are a family
In TAG we communicate
In TAG we put our differences aside
In TAG we are similar
...
In TAG we are loving
...
In TAG we are united
In TAG we feel safe when we are together
In TAG we go through many things.*

In this celebratory song and poem, participants express the importance of the group aspect of the research process, referring to their group as united, loving and a family. They understand their involvement in research as part of a global initiative, and desire to support AYP in other parts of Africa and around the world through their research. Themes of unity and research as part of a global initiative for social action and change are present.

Nkosi sikelela iAfrica

'God bless Africa Lift high your beliefs. Hear our prayers so we can be one. Even during the toughest times God give us strength to conquer and fight the evil'. (English translation)

The final song in the play is 'Nkosi sikelela iAfrica' (God Bless Africa), sung after the theft scene. It is hummed in the background during the performance of a reflective poem on the social and structural factors that led to the theft. Contemporary struggles facing South African youth that emerged in the play and interviews included poverty, crime, substance abuse and social isolation, and this song is deployed in the context of these issues. The poet asks aloud '*what do I do? . . . who is there to help me?*', and this song is used as a response to this reckoning.

The play ended with the group singing: 'Sibe moya munye'/(English: United in one spirit)

DISCUSSION

Empowerment, unity and social change as principles of meaningful participation

We present findings from three art-based approaches—a visual output, play and songs—employed by a group of AYP to reflect upon their experiences in participatory research. Participants drew upon these experiences, and their personal and collective challenges to suggest a vision for the engagement of AYP in research. Themes that emerged strongly and consistently across these three methods included principles of working together (unity), addressing individual and collective adversities (empowerment) and knowledge creation for social action and change. These principles align closely with Freire's (Freire, 1970) emancipatory theory, and core tenets of participatory approaches which include empowering, dialogue-based processes that enable both teachers and students ('researchers' and 'the researched') to choose and transform how they see the world; research is carried out 'with and by' local people, as opposed to on them; and 'knowledge for action' with explicit aims of transforming the social and structural conditions of reality (Scott and Shore, 1979; Cornwall and Jewkes, 1995; Nouri and Sajjadi, 2014).

These provide important insight into aspects of health and development-related research that are important to South African AYP.

Empowerment, defined as overcoming individual and collective adversity (Amendola, 2011), was a theme evident across all data sources. In the mural, the metaphor of tending to a tree that is renowned for growing in adverse conditions was used, whereas in the play and

songs, participants presented adversities of grief, loss and social and structural challenges which they were empowered to navigate through the research encounter. Participants demonstrated how they leveraged the research encounter to empower themselves and each other by: learning from, and teaching one another; supporting each other through difficult times while holding each other accountable; and situating their challenges within broader social and structural environments in which they took action through their participation in research. This finding dovetails with the aims of participatory approaches, in which the location of power is central (Cornwall and Jewkes, 1995), and participants are engaged as knowledge holders and critical inquirers of the social and political issues and inequities that affect them (Nouri and Sajjadi, 2014; Macaulay, 2017).

Unity was a strong theme across data sources. It was apparent in the mural's image of participants and researchers working together and sharing in the benefits of research. In the play, participants held each other to the principle of unity, referring to their group as a family, a community and being 'one'. They wrote a song that says: '*We love TAG because it teaches youth about unity*', and selected another song with the lyric '*United in spirit*'. Unity was also a strong theme in the interviews, describing TAG as 'family', 'humanity', 'unity' and 'togetherness'. Participants demonstrated their conceptualization of unity to include aspects of dialogue and critical enquiry, which are central to participatory approaches (Freire, 1970; Abrahams, 2005; Nevin et al., 2008). They depicted unity as including emotional support, shared experience, friendship, shared goals and repeated coming together over an extended period of time. This principle of unity reflects values of humanity and relationality that are central within Southern African cosmologies (Ramose, 2002; Menkiti, 2004). The principle of unity also connects research to a broader political and social process. Their relationships with one another and researchers were central to the research encounter and were consistently linked to their conceptualization of themes of empowerment and research for social change.

A third way that findings aligned with participatory approaches was that participants conceptualized their involvement in research within a frame of 'knowledge for action' (Scott and Shore, 1979) with explicit social and political aims. This was evident across data sources, where they expressed their desire for their research findings to benefit other AYP. This was especially clear with the song 'Jikelele' in which participants sang about their desire for their research to have global reach. The 'research truck' in the mural reflected the process-focused,

empowering aims of participatory research through co-ownership of the process and its associated outputs (Freire, 1970; Cornwall and Jewkes, 1995; D'Amico et al., 2016). A key aspect of linking individual experiences with social action is the process of developing a critical consciousness, that is, becoming aware of the contexts in which one is situated in order to 'take action against the oppressive elements of reality' (Freire, 1970). This was demonstrated in the play first when they reflected together about experiencing grief and loss, singing the rhetorical question 'Senzeni Na?'/What have we done? and second when they considered the social and structural conditions that led a participant to steal. Through this process, participants located agency to mobilize for personal and social change. Specifically, through song and theatre, they: considered the possibilities of resisting oppression and locating choice and agency; engaged their group as a source of strength, healing and education; and engaged the research process as a vehicle for addressing social and structural adversities.

Drawing upon history to reflect upon and re-imagine research

'through song, we are able to theorise while struggling and fighting.' (Walker, 2018)

Participants drew upon their historic political consciousness to reflect upon, and situate their involvement in over a decade of health and development-related research using theatre and songs.

Use of historic songs

Senzeni Na, the first song sung by participants was originally an anti-apartheid song (English translation):

*What have we done?
Our sin is that we are Black
Our sin is the truth
They are killing us
Let Africa return*

Following apartheid, this song was deployed during the fight for a national ART programme. It was re-written by the Treatment Action Campaign (TAC) to call for life-saving medicines (English translation):

*We want AZT, We want Biozole, We want
Nevirapine from you Thabo Mbeki
What have we done?
What is our sin? Is it AIDS?*

Since then, Senzeni Na has been used as a song to protest other injustices, such as Gender-Based Violence and in the struggle for accessible, decolonized education in the #rhodesmustfall and #feesmustfall movements.

The second song, Jikelele ('Globally'/'Everywhere') also has a rich activist history. Originally a religious song, Jikelele was re-written by TAC and deployed in the fight for ART. Famously, the TAC and Annie Lennox re-wrote it to advocate for global access to the prevention of mother to child transmission, singing about how ART prevents babies from contracting HIV globally/everywhere (Walker, 2016).

The third song, Nkosi Sikelela iAfrica has been used in protest action as a cry for change, unity and strength to fight oppression (Ndlovu, 2017). Composed in 1897, it was adopted by the African National Congress in the 1920s to represent the Pan-Africanist liberation movement (Ndlovu, 2013). During apartheid, it was the national anthem of the oppressed Black majority, calling for 'compassion, human solidarity and human dignity to be restored to the African continent and its people' (Ndlovu, 2013). It carries the Pan-Africanist origins of the anti-apartheid liberation movement, referring to 'Africa', rather than only 'South Africa' (Ndlovu, 2013). It has been rewritten in response to political and social shifts. It was adopted as the South African national anthem at the advent of democracy in 1994, but modified to include parts of the former Afrikaans national anthem, as well as English lyrics (Zwane, 2019). In recent years, this modification has become a contentious issue. During the #rhodesmustfall and #feesmustfall movements, the song was sung without the English and Afrikaans, with the suggestion that the oppressive histories nullify claims to democracy (Zwane, 2019). Notably, participants sung the version without English and Afrikaans, demonstrating a historical consciousness of this song, and an alignment with its recent applications in the movement for decolonization.

The use of songs within protest in South Africa has 'become ubiquitous' as a way to 'unify, strengthen and engender resolve in the face of state oppression' (Walker, 2018). Song was engaged in the anti-apartheid struggle as a 'medium of communication to conscientize, educate, inform, politicise and liberate the people... provid(ing) a tremendous source of sustenance for the marching crowd' (Ndlovu, 2017). 'Senzeni na' and 'Nkosi Sikelela iAfrica' were sung during the 1976 Soweto uprisings. Following the advent of democracy, the TAC made regular use of song, deploying 'culture as intervention' (Mbhele and Walker, 2017) by re-writing historic songs to advocate for life-saving HIV medicines.

Protest songs—including ‘Senzeni Na’ and ‘Jikelele’—were sung by activists and HIV-positive choirs (‘The Generics’), to advocate for the implementation of a national ARV programme (Walker, 2018). The deployment of struggle songs within contemporary social movements of #rhodesmustfall and #feesmustfall demonstrate ongoing resistance to the evolution of the brutalities of apartheid and colonialism (Mbhele and Walker, 2017).

Songs absorb new meanings, while linking and cultivating an ongoing identity of struggle (Mbhele and Walker, 2017). In (re)deploying struggle songs, the Western Cape TAG demonstrated that they understand their participation in research as a form of resistance to contemporary social and structural forms of oppression. They situate the contemporary issues on which their research is focused within ongoing histories of oppression rooted in apartheid, colonialism and the AIDS-epidemic. Through re-writing and singing these songs, they demonstrated agency and suggested that the research encounter is, and should be, a space of solidarity and resistance. The assertion that struggle songs can contribute to ‘*political alternatives in the present*’ (Redmond, 2013), and allow people to articulate views that they otherwise have not had opportunities to express (Mbhele and Walker, 2017) is relevant here. Through this participant-generated method, data emerged in relation to the socio-political aims of research and solidarity in the research encounter that was not present elsewhere in 12 years of research. This process of engaging song allowed for new meanings for the research encounter to be created, articulated and shared.

Theatre for action

South African theatre has a number of characteristics that participants demonstrated. These include: addressing pressing societal issues; actors serve as role-makers, rather than working from pre-existent scripts; the use of song, dance and music and a de-emphasis of ‘technical’ theatre; recording cultural history; and enacting educational components (Larham, 1991). Participants engaged theatre as form of activist art. They deployed this method to: (i) explore their research experiences; (ii) reflect upon, and critique oppressive socio-structural realities faced by AYP; and, (iii) re-imagine the research encounter as a space of solidarity and resistance. For example, in final scene of the play, participants stood with raised clenched fists while reflecting on their socio-structural realities and engagement in research. The raised fist was a symbol of anti-apartheid struggle, popularized within the Black Consciousness movement 1960–1980s (Ndlovu, 2017). It has been used during

contemporary struggles against racial and colonial oppression in South Africa and internationally in the Black Lives Matter movement and the #rhodesmustfall/#feesmustfall movements for decolonized tertiary education.

Therapeutic technologies through theatre

In the opening scene, participants enacted their initial experiences in research through a scene closely reflecting an HIV support group. It exemplified notions of ‘Therapeutic Citizenship’ (Nguyen, 2005) documented in HIV programmes across the continent, premized on the ideas that sharing secrets is healing, that people are empowered through working on themselves, and that reconfiguring silence and stigma is necessary for healing and acceptance.

However, this research was not an HIV support programme, nor was it structured as a support group. Why then did they carefully curate and perform this part of the play?

At the time of recruitment into the original advisory group (2008), some participants were accessing health and social programming, making it possible that they understood their recruitment and involvement in research to be part of such programming. This suggestion triangulates with feedback that the research team received in an informal evaluation in 2018. Since this evaluation, consistent efforts were made to engage the cohort on new framings and understandings of their participation. This required unpacking existing relational dynamics between the cohort and researchers and a shift towards equitable sharing of knowledge to strengthen relationships.

At the time of the play, this group had engaged in a year-long process of reflecting upon the research, including delineating between research and programming. Although not factually accurate, this opening scene offered an indirect way to signal that the group initially came together because of shared experiences, including shared adversities of caring responsibilities, grief and death, and in some cases, living with HIV. Adult HIV prevalence is 20.6% in South Africa, and HIV affects most households and families (Human Sciences Research Council, 2018). It is likely that the play presented an opportunity for openness about something experienced by many AYP, but rarely discussed.

As multiple iterations of the play were performed, the characters became increasingly proximate to the actors themselves. For example, in the first cut of the play, a participant used a pseudonym. As it was re-performed, he exchanged the pseudonym for his real name. Another provided increasingly intimate details of an experience of family death throughout the

performances. Theatre may have offered an outlet to express intimate personal experiences, and show aspects of themselves that they were otherwise unable to share.

Although they depicted their initial involvement in research as something it was not—a support group—this scene also demonstrates how participants re-signified the research encounter as therapeutic. Importantly, this support was group-based and included shared experiences of adversity.

Critical reflections and limitations

The painting of the mural and play performance was cancelled days before they were planned due to COVID-19. While the mural has been digitized and shared with participants, the play has yet to be shared, raising questions on critical dissemination practices (Ritterbusch, 2016), as findings will likely be shared first in an academic article.

Data were collected over the period of a weekend workshop, but premised on a year of iterative engagements in which participants and researchers learnt and reflected together on power and participation in adolescent-focused research. These ‘setting the ground’ engagements inevitably shaped the way participants engaged in the weekend workshop and undergird the data in ways that is difficult to account for.

This process also required significant time, resources and a fundamental conceptual shift. Participatory art-based methods require that researchers be flexible about study focus, have sustained interest, manage logistics and be reflective about power in research relationships (Musoke *et al.*, 2016). The significant investments required bring up questions of sustainability (Ritterbusch, 2016), especially within the current research funding climate.

CONCLUSION: LIVING HISTORIES, FUTURE DIRECTIONS

Theatre, song and visual mediums are central to South Africa’s rich history of political and health activism. Participants drew upon these layered histories of resistance to make meaning of, and resignify the research encounter, by engaging art-based struggle tools of song and theatre. They re-wrote struggle songs, engaged imagery of resistance (raised fists) and curated, re-interpreted and performed TAC-inspired HIV support services. In doing so, they situated their involvement in health- and development-related research within an ongoing social and political struggle.

In addition to HIV and health challenges, they also identified social and structural adversities as important

contemporary challenges for AYP including poverty, crime, substance abuse and inadequate social support. They explored these issues, and creatively identified individual and collective tools of resistance. This demonstrates the suitability of art-based and participatory approaches to generate rich, context-relevant empirical findings about adversities faced by AYP in multi-level health and development research, policy and programming. Findings also elucidate how such approaches can generate rich methodological findings for application to research, policy and programming with AYP.

Findings dovetail with a literature on the benefits of engaging adolescents through participatory and arts-based research methods that are age-appropriate and contextually grounded. They suggest that principles of empowerment, unity and knowledge creation are important to South African AYP in research. Finally, findings demonstrate the capacity of young people to understand research, co-generate arts-based methods and to critically reflect on, resignify and (re)imagine health-related research.

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