

'Learn from my story': A participatory media initiative for Ugandan women affected by obstetric fistula

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abstract

Silence Speaks is an international digital storytelling initiative offering a supportive environment for telling stories that too often remain unspoken and unseen and bringing these stories to relevant audiences. It facilitates workshops in which participants share and bear witness to tales of struggle and courage, resulting in short digital videos known as 'digital stories'. The workshops challenge media legacies of voyeurism and naturalised representation by ensuring that participants, not producers, have primary control over what is shared. The guiding vision is to listen deeply, facilitate reflection and transformation and encourage involvement in collective action to support justice and human rights. In 2006, the project travelled to Uganda to gather stories of rural women who have endured obstetric fistula. This *focus* describes the methodology used, which offered opportunities for counselling, health education and women's leadership development. It includes story excerpts and emphasises concrete local uses for these unique media pieces for health trainings and in policy advocacy settings.

keywords

digital storytelling, participatory video, Photovoice, obstetric fistula, narrative medicine

'When I first had fistula, I felt useless. Now I feel confident that I can be somebody in the community.' (ACQUIRE fistula digital storytelling workshop participant, Masaka, Uganda, August 2007)

What is digital storytelling?

Over the past 15 years, practitioners of digital storytelling around the world have refined their methods for facilitating the production of short,

first-person videos that document a wide range of culturally and historically embedded lived experiences (Lambert, 2002; Burgess, 2006). While the terms 'digital storytelling' and 'digital story' are used to refer to an array of widely divergent media practices and products, they originated in the early 1990s at the US-based Center for Digital Storytelling (CDS).

As developed by the centre, the digital storytelling workshop brings small groups of

people (typically eight to ten) together over the course of three to four days to share aspects of their own life experiences in a group 'story circle', record first-person voiceover narration, select and/or generate still photos and short video clips to use in illustrating the stories and assemble these materials into finished digital videos or 'digital stories' (CDS, 2008).

With its focus on first-person narrative, digital storytelling seeks to honour that the stories people share and listen to play a key role across multiple aspects of their lives (Thorne, 2000; Bruner, 2004). As anthropologist Eleanor Ochs (Ochs and Capps, 1996:20-21) writes,

'personal narrative simultaneously is born out of experience and gives shape to experience... we come to know ourselves as we use narrative to apprehend experiences and navigate relationships with others'.

Many digital storytelling practitioners also align with the commitment of participatory film and videomakers to challenging the power dynamics inherent in those media-making strategies which instead send trained 'professionals' into communities to extract and construct stories without adequately examining issues of ethics or decisions about ownership, in terms of how people and stories are represented (Barnouw, 1993; Servaes, 1996; White, 2003). In essence, the process of making media, with its potential to support reflection and skill building for participants, is just as important as the final media products that emerge.

Creating space for silenced stories

In 1999, I drew upon my lengthy experience in women's health and community development work and my interest in oral history and documentary film to co-found Silence Speaks, a not-for-profit international digital storytelling initiative offering a safe, supportive environment for telling stories that too often remain unspoken.¹

Our goal is to create spaces for bearing witness and nurturing individual and group transformation. The guiding vision is to listen deeply and encourage participant involvement in collective action to support justice. We emphasise work with youth and adults who have been denied the power to influence decision making that affects their lives, such as those who live in poverty, survivors of violence and trauma and those who face social stigma due to HIV and AIDS or other chronic health conditions. The stories they tell are shared in training, community organising and policy advocacy arenas to promote global health and human rights.

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The Silence Speaks approach is grounded in the belief that 'feminists must seek to transform "the inner world" of bodily experience, psychological colonisation and cultural silencing, as well as the outer world of material social conditions' (Thornham, 2000:8). In our years of doing this work, we have seen how digital storytelling can serve as a means through which individuals are able to reflect on the extent to which material circumstances (structures) and interior processes and motivations (agency) jointly shape their lives.

Silence Speaks encourages this reflective process by inviting the storyteller to step into a position of power and authority to articulate a story that 'talks back' to or resists dominant discourses about gender, health or trauma – even as it may inevitably also reflect them. Depending on geography and historic moment, these discourses tend to shift back and forth between narratives that are either problem-saturated and oppressive or relentlessly upbeat, thus eliding the complexities of women's and men's lives.

Silence Speaks processes also echo the teachings of Brazilian educator Paolo Freire (1970) who believed that the development of critical consciousness, a precursor to action for social change, must begin with close examination of one's own experience and its location within an unjust social and political context. Our role as Silence Speaks facilitators is to help workshop participants critically analyse their lives and situate them within broader historical frames.

The sensitive nature of fistula warrants the use of an alternative to traditional media production practices

Rather than appearing to document isolated incidents or reinforce negative stereotypes about categories of people, a set of stories created in a single workshop can weave together a collective social story of struggles for health and equality within a given context. The approach has proved especially relevant in Sub-Saharan Africa, where historic legacies of media exploitation and questions about visual and narrative representation continue to reverberate for journalists, filmmakers and those engaged in community development and gender equity work.²

Plea to 'learn from my story'

In August 2007, Silence Speaks had the opportunity to expand its work in Africa, through a collaboration with the ACQUIRE project, an international reproductive health and family planning initiative led by South African NGO EngenderHealth. Among the myriad health issues affecting African women, gender-based violence and the gendered dimensions of the HIV and AIDS pandemic have taken centre stage in the media spotlight.

The problem of obstetric fistula has received comparatively little public acknowledgement in print media or television news and has only recently been the topic of several widely released documentary films.³

Obstetric fistula is caused by obstructed labour – without timely medical attention and a caesarean section, the pressure of the baby's head against the mother's pelvis cuts off blood supply, causing tissue to die and a hole to form between the birth canal and the bladder and/or rectum. Chronic leaking of urine and/or faeces results, and this leads families and communities to ostracise and isolate women who suffer from the condition (Miller et al, 2005).

The problem was eradicated decades ago in countries with adequate health infrastructure, yet it persists in many parts of the developing world. EngenderHealth, through the ACQUIRE project, works with national governments and other local partners in countries in Africa and South Asia to address fistula. The ACQUIRE approach is holistic. The programme works with stakeholders at health facilities and community levels to prevent fistula from occurring in the first place, to increase access to clinical treatment and counselling for women living with fistula and to provide rehabilitation services that enable affected women to reintegrate into their communities.

Lessons from successful public health media campaigns have shown that visual media can play a vital role in educating communities, health practitioners and policymakers and support focused advocacy for action and change within the social and political environments in which wellness and illness exist (Wallack and Dorfman, 1996).

ACQUIRE staff working in New York and Uganda recognised the potential utility of developing media tools to highlight the plight of women suffering from fistula and document the realities of their lives. They were less interested in lengthy films, which cannot be effectively shown in trainings or at community events. They also understood that the sensitive nature of fistula warrants the use of an alternative to traditional media production practices, which can be inappropriately intrusive and leave people with a sense of having been exploited for the sake of capturing their lives on video.



KATIE TELU

Workshop participants get to know each other during an icebreaker activity.

In 2006 and 2007, ACQUIRE and its Ugandan partners engaged Silence Speaks to design a project that would capitalise on digital storytelling's ability to open people up to sharing intimate, relevant and accessible details about their lives, in digital video format. I recognised early on that we would need to adapt the workshop considerably, to suit the language, literacy and technology resource challenges in the rural district where the session would be held.

We would be a group entirely composed of women, which is unusual for a media production initiative (often women take leadership in communication and group process, while men run the equipment). But we understood that power dynamics embedded within differences of race, class, language and culture would subtly

influence relationships formed, stories told and representations developed. We acknowledged from the outset the importance of remaining mindful about how these dimensions of identity would play out in the establishment of meaningful connections among facilitators, interpreters, workshop supporters and participants.

The workshop process that my co-facilitator and I developed differed from standard digital storytelling curricula in several ways. First, we realised that we would not have access to computers and would therefore not be able to teach the participants hands-on computer skills, but we wanted nonetheless to include as many participatory components as possible. We decided to integrate photography and drawing into the project.

Secondly, we created a unique way to bring the women's orally shared stories to life, as audio recordings. Finally, we added various group processes and activities to mediate language and cultural differences and increase the therapeutic aspect of the workshop, as a way of acknowledging the lack of aftercare psychosocial support services for women who have been through fistula repair surgery. This helped us to realise our belief that collective storytelling and witnessing, if done with sensitivity and skill, can transform people's relationships to the past and reshape their sense of possibility for the future.

Recruitment and preparation

Identifying and confirming women to participate in the project was not a simple matter. ACQUIRE's local partners at Kitovu Mission Hospital, 120 kilometres outside of Uganda's capital Kampala, went painstakingly through patient records to draw up lists of women who had undergone fistula repair in the past few years and who might potentially be willing to reveal stories from their lives.

People create and discuss photographs as a means of catalysing personal and community change

Kitovu staff then conducted field visits to remote villages to talk to women in person, explain the rationale for the project, describe what would happen at the workshop and assess interest. The staff took care to assure prospective storytellers that all transportation, accommodation and meal costs would be fully covered. In the end, rather than the anticipated eight storytellers, we worked with a group of eleven women, eager and ready to share their lives with us.

In many digital storytelling processes, participants search through their own personal photographic archives for images with which to illustrate their recorded narratives. Because we

knew that our fistula participants were unlikely to possess such archives (due to the economic constraints they face as well as lack of access to cameras and processing facilities), we identified Photovoice (Wang and Burris, 1994; Wang et al, 1998) as an ideal method for assisting them in capturing images from their lives.

Not only would adapting Photovoice strategies into the digital storytelling process generate photos for use in the stories, it would offer basic training and skill building in a form of media production, allow the women to participate directly in the creation of visual content and give them something tangible to take away at the end of the workshop, in a setting where offering DVDs would be irrelevant (none of the women have electricity in their homes).

Photovoice is described by its originator Caroline Wang as 'a participatory action research method by which people create and discuss photographs as a means of catalysing personal and community change' (Wang et al, 1998:75). Unlike community photography projects which uncritically situate participants as 'artists' without questioning the extent to which they do or do not stand to benefit from their production of images (Ballerini, 1995), the goal of Photovoice is to use photographs to bring to the attention of key leaders and decision makers problems and issues affecting a community.

This view of media production fit perfectly with our vision for the fistula digital storytelling project. Instead of planning an exhibition of photos as an endpoint, however, we would incorporate the participants' photos into their digital stories, allowing them to 'show' details of their stories that might not emerge in the spoken voice-over narrations.

As a first step, ACQUIRE staff in Uganda brought the participants together for an orientation where they watched sample health-related digital stories by women from Swaziland, Lesotho and South Africa. They were supported in sharing



An interpreter, a participant and a workshop facilitator discuss story content.

summaries of their fistula stories and had the opportunity to hear and ask questions about the proposed workshop agenda. Most importantly, they were each given a disposable camera and shown the basics of camera use: looking through the viewfinder, framing the object to be photographed and finding and pressing the correct button.

ACQUIRE staff urged the participants to take pictures of their homes and villages to provide a sense of where the stories take place. Staff cautioned the women to obtain verbal permission from people whose photos they wished to take/include. The orientation was conducted with the assistance of interpreters, in the participants' languages (they spoke either Luganda, Runyankore or both).

Story development, recording and editing

Digital stories are often developed through a writing process. But because few of our fistula workshop participants know how to write and because we needed to work entirely through interpreters, we developed and carefully trained our team of interpreters on an alternative approach. We chose not to interview the women for two reasons.

First, we felt strongly that an interview process, whether audio or video, if done too soon during the workshop, would intimidate the women and make them overly conscious of the end product being created instead of affording them the chance to simply be witnessed, free of constraints and immediate expectations. Secondly, conducting interviews, whether audio or video,

and subsequently piecing together stories from what the interviewee has said, takes much more time and financial resources than what we had available to do well.

Instead, my co-facilitator and I adapted the tradition of narrative medicine (Charon, 2006), which invites the health practitioner to attend closely to the pain (physical or emotional) being shared by a patient and to co-construct a narrative about that patient's life story, thus giving rise to an affiliation between the two which is essential to the process of healing (Marshall-Clark, 2005). Although we are not health practitioners, the method seemed to offer useful guidance to our process, which demanded both presence and a sensitive way to collaborate on story development.

Working in the narrative medicine genre enabled us to co-construct meaningful stories with participants rather than about them

Like the orientation session, the entire workshop was conducted with the assistance of interpreters. After leading a series of introductory icebreaker activities to relax participants and give everyone a chance to begin getting to know each other, we facilitated a story sharing session, during which each woman took a turn standing in front of the group and telling her story. At the close of each story, we all applauded to acknowledge the courage of what had been put forward and make it clear that the participant had truly been heard.

My co-facilitator and I then worked with ACQUIRE staff and the interpreters to discuss the story content and make notes on what might be added or omitted to ensure that the finished pieces would be a manageable length (two to four minutes long or 300 to 400 words). Our choices about what to cut and what to recommend adding were based on a desire to honour the perspectives of each woman while also drawing out important themes and avoiding duplication of issues across the entire set of stories.

Next, the interpreters met with the participants in groups of two or three and reviewed with them the suggested edits. The interpreters took time and care to explain the edits and worked collaboratively with the women to add specific bits of dialogue, poignant details and useful public health information. Finally, we recorded each story directly onto a laptop.

Putting the pieces together

Once the story recordings were finalised, what remained were the tasks of generating additional visual material to illustrate the recordings and assemble draft videos to screen and celebrate at the end of the workshop. In addition to shooting photos and video clips of the women in a variety of environments, we built in an opportunity for them to produce drawings themselves.

The art making time gave participants something active to do while we were recording and offered them a chance to visually represent key moments in their stories. It also allowed for nonverbal communication that further transcended language and cultural differences and enabled the women to identify with one another's experiences and share those with interpreters and workshop facilitators.

While my co-facilitator and I scanned drawings and photos and assembled rough edits of the stories, the women went as a group to visit Kitovu Mission Hospital where they had been treated for fistula. There, they were given the chance to display their new confidence in breaking the silence that typically surrounds the topic by giving advice and support to a group of women who were at the hospital awaiting their own fistula surgeries.

When they returned to the workshop site, we completed the four-day process with a celebratory dinner and evening screening of the draft digital stories. The women were visibly moved to see and hear themselves on video, and those of us involved in making the workshop happen were in



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Two workshop participants review the photos they took to illustrate their stories.

turn deeply touched by the women's gesture of thanks, which was to perform several traditional songs of praise and gratitude.

Messy bits of the process were unavoidable. Our interpreters were inexperienced in that role and occasionally lapsed into speaking on behalf of the women rather than simply voicing exactly what was being said. This was a challenge to story development, which is most powerful when it can rely purely on vernacular speech. As nurses, the interpreters occupied a very different class position than that of the participants and tended to make assumptions about what the women needed to hear from us.

We could not always ensure that our comments and instructions were being accurately conveyed, but this is an unavoidable consequence of working

across languages. Some of the participants, for instance, did not understand that they would not have a chance to modify parts of their stories once recording was underway and we needed to make last-minute edits on the fly. For myself and my co-facilitator, sustaining consistent emotional attention as stories were being shared through interpreters while also dealing with practical issues like sound levels and background noise proved challenging as the days went on.

Although our process may seem cumbersome, it was in the end very effective on both a therapeutic and technical level. Working in the narrative medicine genre, which 'insists that the narrative of the body – damaged, violated or chronically in pain – be included in the dialogue about and within the self' (Marshall-Clark, 2005:269), enabled us to

co-construct meaningful stories with participants rather than about them.

Because we allowed for multiple iterations of each story and multiple opportunities for feedback, discussion and validation, the participants felt a high degree of ownership of and investment in the narratives. The incorporation of play and get-to-know each other activities, as well as the decision to involve only women on the teaching team, created strong bonds across class and culture.

As we had hoped, the entire process of creating photos, witnessing the re-telling of one another's stories and speaking out publicly did enable the women to reflect on their own lives, achieve a sense of validation about fistula experiences and express the desire to become advocates for change in their communities. On the final day of the workshop, ACQUIRE staff facilitated a debriefing session so that the participants could share their feelings about the process.

Digital storytelling offers great potential as a starting point for building leadership skills among women

The comments offered were overwhelmingly positive. Several of the women mentioned that the workshop had made them feel less isolated and alone with their fistula. One said, 'in the past, I thought that I was the only one suffering from this problem, that I was alone. Now I know that many people have the same problem'.

Another stated, 'in the village, I didn't know of others with this problem or how I got the problem. Now I have become united with others...' and a third simply said, 'I am not alone as I thought I was before'.

Participants also talked about having learnt more about the causes and implications of obstetric fistula. While the provision of basic health education was not an explicit objective of the workshop, our experience with the fistula project suggests that future efforts would do well

to integrate key information about health and well-being.

For instance, one participant said, 'I got to learn and have a new experience. In the villages, people are ignorant about fistula. Now we've learnt about the condition, we are not the same as we were before'. Another said, 'now I understand the causes of fistula, from these stories'.

Most of the participants voiced a strong desire to spread the word about prevention and treatment, suggesting that digital storytelling offers great potential as a starting point for building leadership skills among women and training them as peer health educators. One participant remarked, 'from today onwards, I will tell everyone what to do if they have this problem. ...I am going to spread the news about how to prevent fistula and what to do if you have the problem'.

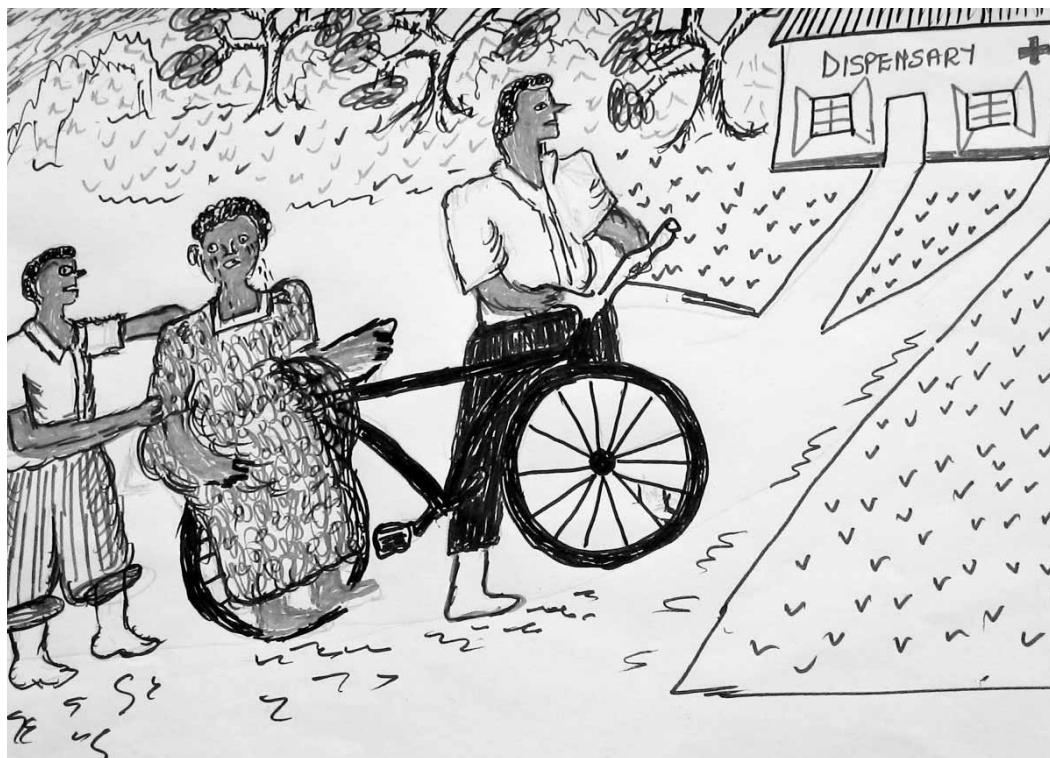
Another said, 'I will continue to spread the word that women must deliver in the hospital', and yet another remarked, 'this has been extremely informative. I can now go out and give health education about the condition'.

Finally, some of the women mentioned that the workshop had given them a sense of being people who matter, who are able and entitled to speak out. One said, 'it has been a great experience to stand in front of people and tell my story. I am not as shy as I was before'. Another stated, 'I feel well developed now... when I first had fistula, I felt useless. Now I feel confident, that I can be somebody in the community'.

A third shared that 'it has been a great experience learning how to be firm in front of other people. I can now communicate better with people in the community', and a fourth said, 'I have a sense of understanding that the world knows about us, that our problem will be known nationwide and that many people want to help us'.

Hopes for change

The collection of eleven digital stories created in our workshop recount hardships and celebrate



Drawing by Rose called 'Going to hospital', featured in her story.

achievements related to the participants' daily struggles with pregnancy, loss and relationships, as well as their search for safety, acceptance and dignity. In some instances, the stories confirm what is seen within the public health sector as common knowledge: that women with fistula are often rejected by their families and forced to live in isolation, or that reliance upon traditional birth attendants and healers continues to complicate efforts to promote hospital delivery.

Perhaps most poignant of all the images taken by the women were the repeated photos of beds and bedding, literal reminders of the years of contending with leaking urine – these shots suggest that not even at night, in the comfort of sleep, could they relax and forget about their condition.

The stories also challenge commonly held gender stereotypes and place individual experiences in context. Rather than situating themselves as passive victims, unaware of the importance of delivering at hospitals, many of the women revealed strong agency as they talked about how they actively sought healthcare but were deterred due to the realities of poverty. Sifa stated that,

'when I got pregnant, I went for my antenatal checkups. The health workers told me to go to a hospital when I was due, but my husband gave me money and told me to go back to the village to deliver. The day I started having labour pains, I told my older sister I wanted to go to the hospital. I had given her

my money for the expenses, but she had already spent it on other things. So we walked to the home of a traditional birth attendant instead’.

Mary added another dimension to the challenges of delivering in rural areas:

‘I got the problem of leaking urine from my first pregnancy, in 1985, when I was 20 years old. I had obstructed labour, so I could not deliver on my own. I failed to give birth after being in labour for four days. This was during the time of the war that brought Museveni into power. I looked for a place to give birth, but I couldn’t find one – there was too much gunfire.’

Her mention of the civil war situates the story in a historical moment and points to the ways in which structural violence intersects with the daily realities of women’s lives. Mary went on to display incredible persistence in seeking a cure for her fistula:

‘I saw three different doctors but nothing helped. I was given appointments for operations, but didn’t have any. I heard there were doctors in Tanzania helping women like me. When I went there, they had already left. At a local hospital, I had an operation but didn’t get well. I came back two more times, but I didn’t fully get well. Although I am not yet healed, I am better than I was at first.’

Mary is one of several participants who still suffer from the problem but who nonetheless were eager to share their struggles and find connection and solidarity with peers.

What was most striking about the women’s narratives was their refusal to unanimously reflect the belief that fistula patients are always abused or rejected by their male partners. Several of the participants did share this experience, but an equal number told another story. Irene, for instance,

stated that her husband was supportive from the start:

‘The doctor never told me what was wrong with me. My husband spent a lot of money on medicines, but nothing helped. One day a car stopped by the roadside near our home. They were people looking for women who were leaking. They told me there was treatment and gave me a day to go there. The villagers told my husband not to let me go, but he said he’d pay for my cure. I love my husband for being patient with my sickness.’

Like this man, Rose’s husband refused to bow to community pressures. She says,

‘people around me had lost hope, and my in-laws almost chased me away. Even my mother, when she saw how sick I was, she abandoned me. But my husband was loyal and stayed with me’.

These stories flatly contradict the idea that men are unsupportive and present an important – and alternative – positive media portrayal of African men.

The women’s stories are available for viewing on the web, where they are filling a media gap about how women themselves experience the problem of fistula and what they go through to obtain treatment.⁴ Yet their small scale, their attention to particular struggles and their public health relevance demand that they be seen locally.

To this end, the stories are being shared in Uganda through ACQUIRE’s ongoing training and technical assistance efforts to educate providers, counsellors, prevention educators and health policymakers charged with establishing gender equitable and accessible health systems in the country. I learnt recently that several stories were screened at a workshop focused on the development of a curriculum for fistula

prevention and management for nurses and midwives.

According to Dr Isaac Achwal, technical/medical consultant with ACQUIRE, senior health personnel present at the workshop were 'taken by surprise and became emotionally involved'. Achwal reported that one participant even said of the stories, 'these are too real and humbling. I never knew that these women go through these kinds of experiences'.

What does it mean to say that a person's experience is 'too real'? To me, the comment illustrates the vast gap that too often exists between health professionals and patients and suggests that the fistula workshop methodology offers women community media practitioners a way to address the indifference that so often accompanies collective suffering. Like oral history, this form of digital storytelling

'requires that the act of telling and the act of hearing always be followed by the shared act of interpretation that illuminates the historical or political sources of injustice and also reveals one's own responsibility in the face of it' (Marshall-Clark, 2005:269).

Our hope at Silence Speaks and ACQUIRE is that viewers will come away from watching the stories not only with greater compassion for women facing fistula, but also with a commitment to getting involved in whatever way they can – as a community member, health provider or policymaker – in making sure this completely preventable and completely gendered health condition is soon eradicated worldwide.

Notes

- 1 For more information about Silence Speaks visit www.silencespeaks.org.
- 2 For examples of Silence Speaks projects in Southern Africa, see www.genderjustice.org.za/projects/digital-stories.html or www.youtube.com/iompretoria.

- 3 A noteworthy example is 'A Walk to Beautiful', directed by Mary Olive Smith and produced by Engel Entertainment in 2006, which has won numerous awards and has screened in festivals and on public television around the world.
- 4 To view the stories, visit www.engenderhealth.org/our-work/maternal/digital-stories-uganda-fistula.php.

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