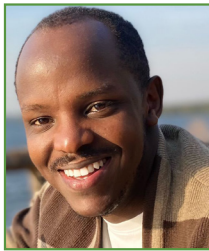




# Collective responses to mental health stigma: Sharing lived wisdom

by Joseph Kalisa



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## Abstract

This paper draws on the rich history of collective narrative practice. It describes a series of conversations with people in Rwanda who had been subject to stigma associated with mental health issues. Although stigma was an experience shared by group members, we were careful to avoid generalisation, and to attend to both individual and collective experiences. Working in ways that honoured local culture and tradition, we arrived at a shared metaphor of mental health stigma being like *imungu*, the cowpea weevil. This enabled us to draw on participants' extensive knowledge of managing the destructive effects of *imungu* on crops and harvests when eliciting local responses to mental health stigma. Rich stories emerged about the diverse ways in which people resisted stigma, and how these were connected to sustaining relationships and cultural resources. Participants drew connections between poverty and mental illness and emphasised the role of solidarity and collective economic development in responding to the effects of stigma. These local knowledges, which sometimes diverged from 'mainstream' psychological prescriptions, are shared here in the hope that they might contribute to other communities facing similar hardships.

**Key words:** *stigma; mental health; collective narrative practice; Rwanda; OPROMAMER; economic development*

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Collective responses are required when collective communities, such as ours in Rwanda, face significant hardships. I was hungry for examples of such responses to inform my work and was relieved to find that the field of narrative practice holds many. I learnt that the work of the CARE counsellors (CARE Counsellors & Sleip, 1998) was fundamental to developing collective narrative practices. I read about community responses to sexual abuse in Bulawayo, Zimbabwe (Kaseke, 2010), and the work of Caleb Wakhungu and the Mt Elgon Self-Help Community Project (Wakhungu, 2013), whose innovative ways of using narrative ideas to galvanise social movement and economic development resonated with challenges experienced by the community I was working with.

The community therapy approach of Brazilian psychiatrist and anthropologist Adalberto Barreto also broadened my understandings of mental health difficulties in communities and illuminated ways to approach them. The procedures and protocols of mental health systems can work to diminish and devalue individual and collective local knowledges. Barreto wrote that such 'exclusion and diminishment of people's local knowledge is a key contributor to psychic misery, and when people's local knowledge is devalued, this leads to an interiorisation of misery: misery becomes an internal experience' (in Barreto & Grandesso, 2010, p. 34).

The following conversations show me looking for ways to honour and earth the local knowledges and survival wisdoms people have developed through responding to mental health stigma. I invited a group of mental health peers from OPROMAMER (see Denborough, 2019) to be interviewed over several sessions. They were facing difficulties with their mental wellbeing as well as struggles with stigma, poverty and many other social problems. I was curious to learn what local knowledges and wisdoms they had developed to respond to mental health stigma. My hope was that through documenting large and small practices of living through hard times, a double storied narrative could be developed and shared with other individuals and communities with similar experiences, inviting reciprocity and connection.

## *Structuring safety*

Before the colonial period, wellness in Rwanda was fundamentally based in families and communities (Denborough, 2020). The introduction of structural approaches to health care became itself a source of

suffering. However, the erosion of community ways of responding to hardships was met with resistance, and people continue to cherish 'communitas': ways of operating in social formations that bring togetherness while preserving individual distinctiveness (Denborough, 2001). This communitas is what OPROMAMER members and other peers in mental health have been creating to build solidarity.

It has become a tradition that whenever OPROMAMER members meet, they engage in singing and dancing before speaking about hard things affecting their lives. Before our conversations, I joined them in dancing and singing of songs of resistance and hope. This ritual helped us to feel comfortable together and made me not a stranger to the group. It also laid a foundation for decentred practice (White, 1997): I arrived as a community member, not as a visiting expert there to ask questions and prescribe solutions to the group. The singing and dancing helped to establish safety for a group conversation about the injustices members had endured due to stigma and the ways they were responding. Our welcoming warm up was similar to those described by Barreto, who uses rituals of welcome often involving 'a song and a clapping and joining of hands' to 'build a collective ethos' (in Barreto & Grandesso, 2010, pp. 35–36).

### ***Red and yellow card metaphor***

When working as a practitioner with communities that have been significantly affected by mental health hardships, it is important to understand the power and privileges I walk into the room with. As someone representing a mental health system that devalues people's lived experience and knowledge, it is especially important to avoid transferring any such dismissal of local wisdom. I wanted to find ways for people I was meeting with to stop me or give me warning when they felt I was being disrespectful. This was crucial to us having a meaningful engagement.

Narrative therapy builds on existing metaphors and cultural or traditional rituals to find ways to support those going through difficulties. For example, the Tree of Life and Team of Life metaphors have been profoundly significant in enabling meaningful conversations in communities (Denborough, 2014b; Ncube & Denborough, 2014). A 'red card' and 'yellow card' metaphor, originating from football, was used by Sabine Vermeire in a training I attended. In football, when a player commits a fault, they are given a yellow card as a warning and a red card as a send-off. I liked using the red and yellow cards as they provided a way

for trainees to feel comfortable alerting the trainers to potential issues without needing to use verbal communication.

I introduced the yellow and red card idea to the OPROMAMER members as a way for them to direct me about themes they did and did not wish to speak about. This supported my decentred practice and enabled those attending to stop me if a question was not comfortable or if I asked a 'stupid question'.

## Naming and defining the problem

Once we had structured safety in these ways, I initiated a discussion about naming the problem people were facing. Narrative therapy accords significance to the names given to problems by individuals and communities, rather than the therapist naming or labelling the problem for them. In Kinyarwanda, giving a name to something helps to characterise and differentiate it. In fact, the absence of a name for a problem makes it difficult to identify: it is through finding a name for something that we know what we're dealing with. Michael White (2007) advised that it is the job of a therapist to support people in negotiating richly described experience-near definitions of the problems and predicaments they face. When problems are named and externalised, especially in the context I come from, this allows people to speak about problems with greater ease and less stress. It also presents opportunities for dialogue about the issues without bringing conflicts, paving a way for cooperation in speaking about problems (White & Epston, 1990).

I invited people to develop individually distinctive names and descriptions for a problem that might conventionally take a single name: 'stigma' (*akato*): 'What name would you give to this problem that is affecting your lives?' I wrote down people's suggestions: sorrow, loneliness, sadness, deep wound, cloud, fog, running water, *imungu* (cowpea weevil – a pest), a dark, shapeless and faceless creature.

When working with a group of people experiencing a 'similar' problem, it is important that we don't assume that the problem has homogenous effects in people's lives. Although we had gathered some similar names for the problem, I was careful not to generalise any of the names. However, some felt that it was important to retain the language of *akato* to describe what they were up against. This provided an opening to acknowledge particular experiences of the problem, even while speaking collectively.

Joe: As you were naming and speaking of the problem, I was curious about whether you think the problem exists differently in each of our lives. Do you think *Akato* is the same or different?

Yvonne: There are so many different forms of *Akato* and ways it attacks us. For some of us, there is that *Akato* that attacks from inside and that which attacks from outside. There's the *Akato* that always makes you feel unworthy, despairing and hopeless. This makes you question yourself so much, and you don't get to know how best to remove it as it mixes up with your own identity. That which attacks externally is also painful, for example when people see you differently – as a sick person. It is less painful and easier to win over when the external *Akato* is not helped by the internalised one.

Jado: For me, I would say that *Akato* looks like injustice because injustice deprives you of your rights, respect, dignity and the honour that everyone deserves.

Paul: I would like to complement what Jado said. *Akato* will always give birth to disrespect and loss of dignity and rights. Sometimes you hear someone saying that because you have mental illness, you don't have the right to go to school, you don't have the right to marry, or you don't even have the right to live. In short, all the rights that others have, you're deprived of. *Akato* deprives it from you, and it makes all around you see you as a negative person.

Members described their different encounters with *Akato*. We all acknowledged each member's particular experience and knowledge. After further conversation, the group members came to feel that *Imungu* (cowpea weevil) might best describe how stigma had affected them and their loved ones.

Clarisse: I think *Imungu* would say it all: just like how a weevil infests crops in the field, that's how stigma infested our lives. Slowly it eats you inside out.

I placed some paper in the middle of the group and we listed all the things members knew about the cowpea weevil. Group members described how the weevil's

effects on crops were not uniform and depended on various factors. For example, weevil infestations would be more severe in the eastern part of Rwanda than in the northern part of the country because the humidity and the temperatures of the east favour their growth. It would also depend on how crops were stored after harvesting, and the type of the crop grown. All this knowledge about the weevil was significant in understanding the problem. Members were invited to draw on their knowledge of imungu's effects on crops to identify similarities with ways mental health stigma had affected each one of them.

## Collective responses to mental health stigma

I wanted to invite members of the group to share knowledge and skills that were useful in responding to imungu in the fields, and then link these skills with ways members were keeping their heads up despite being attacked from all corners by stigma. Through honouring these collective skills and knowledges, we breathed life into their legacy in each person's life.

Building up on the metaphor of Imungu and the local knowledge community members had in responding to the pest whenever it attacked their field opened possibilities and allowed people to speak about sensitive and painful experiences in ways that didn't retraumatise group members.

Together we explored cultural and traditional ways that farmers respond to imungu attacking their crops:

- dipping seeds or spraying ash on crops
- spreading seeds on hot ground and exposing them to sunshine
- spraying specific pesticides that kill imungu
- using sand to prevent imungu from infesting crops
- keeping the harvest in clean containers and regularly monitoring the fields.

Joe: When we were speaking about the ways we can prevent or respond to imungu when it attacks our fields, I wondered whether there were connections between these skills and the ways you responded to the Imungu that has been affecting your lives and our communities?

Slowly, we collectively mapped the ways members were preventing, fighting or responding to the diverse effects of Imungu. I engaged members in tracing the history of each skill and understanding and exploring traditional and cultural connections with these knowledges (*isooko*<sup>1</sup>). I also asked about the people and things that had brought this knowledge into the person's life.

As we were engaging with these rich skills and knowledges about collective responses to mental health stigma and Imungu, we held awareness that problems can be persistent (Denborough, 2014a) and that people are always finding ways to respond to Imungu whenever it attacks. We sought to harness these skills in ways that honour innovative and traditional ways of surviving.

### Joining in solidarity

As members described the ways they were responding to Imungu, joining with others in groups emerged as a very profound way of building a team of support and solidarity. In Claver Haragirimana's interview with David Denborough (2019), he described how OPROMAMER builds friendships among people with lived experience of mental health difficulties. In collective cultures such as ours, there is a very long history of people being close to each other and joining others in social groups. When community members, families or groups join together, new ways of responding to community problems arise. Across Rwandan history, there have been so many ways in which people have come together through community practices such as *umuganda*<sup>2</sup> (Uwimbabazi, 2012), which built community solidarity and collective responses to community challenges. Problems are dealt collectively rather than individualistically. During my conversations with OPROMAMER members, I was curious to understand the history of the groups people were involved with and what had led people to joining them.

Joe: It seems joining OPROMAMER groups was something intentional from each of us here. I am wondering if you can share more with me about how groups have been helpful when responding to Imungu/Akato?

Clarisse: The group has been so helpful. Usually, when struggling and experiencing hardships and you meet with those who have similar experience, it builds morale so much and you feel understood. It makes you feel that you're not alone in this, and that there are others who experience the same challenge.

You feel comfortable, and whatever you speak you know that they won't laugh at you. Being in groups takes away the guilt of living with a mental health condition. I think there are so many ways that we benefit from joining others with similar experience. It builds our confidence and I feel I have brothers and sisters who are ready to join the journey with me.

Joe: Do you think this makes Imungu happy, sad or a bit of both?

Clarisse: Very sad. I think when we join and we're able to confront those who are stigmatising us and reach out to our local leaders for services and things we deserve, we're so much better off than if we did it individually. People just say, 'It's the mad person's word' and discriminate against you. But with the groups, we join with one voice.

OPROMAMER has garnered vast numbers of new members who have joined together in solidarity and are creating social movement against mental health stigma, challenging the discourses and reclaiming their lives.

### ***Socioeconomic empowerment***

The story of OPROMAMER is full of desire for financial independence as a form of reclaiming lives. Members are fundamentally concerned with being productive and contributing to their families and society.

Joe: I know you have all joined the savings and credit groups. Do such income-generating activities help in lessening the effects of Imungu in your lives or do they make them stronger?

Clarisse: Of course, it helps lessening so much [laughter]. It makes Imungu super weak. When we don't have money to pay for our basic needs, the community gets justification and associates it with our mental health conditions. You know the common narrative that when you have money, you buy respect? When we're able to pay for our needs and provide for our families, we're included in community and family decisions. I think poverty is also a mental illness because it makes you think bad things about yourself. When we're able to pay for our medical insurance, school fees for our children, food for our families and so on, it's a kick to Imungu.

Speaking about the relationship between mental health and economic empowerment allows us to acknowledge the complexity of experiencing mental health difficulties in societies that are equally struggling with economic hardships. When Clarisse said that poverty should be categorised as a mental illness, this was a significant act of placing the problems affecting people's lives into the social contexts that contributed to them. Practitioners might take note of this analysis as a way to avoid internalising and individualising the problems people are experiencing.

When members of OPROMAMER come together, they don't only build solidarity and form a common voice for their rights, they also support each other through small loans and savings programs. The history of this socioeconomic approach to resisting and fighting stigma can be traced through group members' histories with poverty, and through legacies that members carry from their loved ones both living and deceased. For example, when I asked Jado when he had come to know that economic empowerment was a strong response to mental health stigma, it opened a history of his relationship with his father.

Jado: Sometimes what pushes me to work hard and get economically self-reliant is that whenever I remember my father's legacy in our village, and how people always mention that the way I behave, or my use of drugs does not portray my father's legacy, they say, 'Your father was a real man, and he would be ashamed of you if he saw you poor'.

Joe: And when you think about your father, what is your guess about what he would say? Would he say the same thing, or he would say something different if he saw what you're going through and the ways you're responding to what is happening in your life?

Re-remembering conversations open a two-way understanding of a person's relationship with an important figure in their lives (White, 2007). Inviting Jado's father into the group conversation built reconnections with Jado's father's hopes and dreams for Jado.

Jado: I think he would see how much I am trying to struggle and I think he would say that there will always be 'haters' because I know he also had haters who used to speak ill

against him. And what he used to do was to prove them wrong. Every time they mentioned that he was a drunkard, he could say that he could pay for his children's school fees and yet the neighbours who bullied him could not afford to do so. If he saw how I am fighting with this drug, he would say to me, 'keep going and strive to have your own financial independence'.

Joe: Do you think it would make a difference if you had this knowledge with you every time you're facing Akato?

Group members described how Akato/Imungu feeds on the experience of poverty and creates negative identity conclusions for individuals experiencing economic hardships. It is one of its biggest tricks. The discourses around success and failure in our communities have contributed and worsened the situation for people experiencing mental health hardships. When members are economically empowered, they gain back the humanity and respect that Imungu erodes. Income-generating activities are another way to bring together members with lived experience of mental health and to build collective solidarity and group values and goals.

## *Staying focused on dreams and values*

Some of the members felt that it was important to fight mental health stigma through staying focused on what they want to achieve in life and the things that they value. Staying focused helped in proving wrong those who thought we were of no value.

Yvonne: They expect you to do wrong even when you do something good, and they feel it's the illness that is making you act the way you are. So, we always try to prove them wrong through doing what is contrary to what they are expecting from us. For example, when I was getting stigmatised at school, I used to make sure that I followed the school guidelines well and performed well in class. Of course, this was an additional weight that others didn't experience, but that's why we're calling it injustice. Akato/Imungu drives you from the place you are to some other smelly and

dirty place, and that's why you need extra collective support to uplift yourself from the deep pit. When you decline being put into that smelly place by Akato, then you're starting a journey of conquering and de-infesting yourself.

Joe: Yvonne, I was wondering, how you did realise that staying focused was important for you? Is there a story that you can tell me in relation to staying focused and how you came to learn about it?

Thinking about what we give value to during hardships can guide us in seeking meaning in the things that are happening in our lives. Over the next few minutes, we explored the history of this skill in Yvonne's life and who played a part in making it visible.

Joe: When hearing how Yvonne has been responding to mental health stigma through staying focused and being guided by her values and dreams, does this resonate with anyone here? Are there stories of our lives that we're reminded of by this?

By inviting outsider-witness responses, I sought to weave together connections and resonances among members and to build a team of support for Yvonne. Through these invitations, stories about staying focused on values and dreams were richly described and made visible to group members. This built and nurtured a team of support among the members. They said that staying focused on what was meaningful to them was profoundly helpful in keeping stigma at bay.

## *Keeping Silence*

Some members stated that at times they would just keep silence, and this helped them in fighting against stigma. In Rwandan culture, a lot of people don't like speaking or sharing their feelings. Conventional mental health approaches see this as wrong: mental health campaigns speak about 'breaking the silence'. I was curious about how some members of OPROMAMER were using silence as a skill to fight against stigma.

Jado: Whenever faced with stigma at home, I take time alone and just keep silent. I don't respond right away until I feel I am okay to speak out or not. This is just how I am; I like speaking less.

This brought a double story to Keeping Silence and exploring meanings of Keeping Silence in relation to breaking the silence. As with stigma itself, group members had different experiences of and attributed different meanings to Keeping Silence. For example, Yvonne described how Keeping Silence was not the 'typical silence', but rather a silence that helped her improve her communication and relationship with her siblings. Keeping Silence when faced with stigma provided her with space to reflect on whether and how she would respond, rather than responding when filled with anger. A reactive response would feed Imungu. When we ask ourselves who a response benefits, we're able to honour and acknowledge the different ways that people experiencing hardships are responding.

Jado's knowledge about keeping silent demonstrated that there are many ways of responding to mental health stigma that are not in the mainstream. I was reminded of the importance of double listening and inviting those we meet to give meaning to what they are experiencing. In doing so, I avoid being complicit with the powers and politics that reward silence in the face of injustice and honour the person's right to determine their own actions and initiatives in relation to social and mental health hardships.

## Speaking to Self

Through struggling with and surviving mental health difficulties and stigma, members had developed other responses that diverged from conventional methods.

Joe: I wanted to go a little back to what Yvonne and Jado mentioned about Keeping Silence. It sounded to me that there was an additional ritual that you did: that you could speak to yourself during this period. I am wondering if you could speak more about this. Would that be, okay?

Yvonne: I think what we miss is love and warmth from society. When people refer to you as 'crazy' and a nuisance, it is hard to survive. We all love and wish to be loved, so when the people around us fail to say good things to us, we do it for ourselves. Sometimes I can take time alone and say to myself, 'Yvonne, you're beautiful' [as Yvonne is laughing, the whole group is smiling back].

Paul, who had been silent for some time during the conversation jumped in with a story.

Paul: Can I tell you a story? I am not sure if it's true or not. There was this man who got a very big post at his home and wrote these words: 'BYOSE BIZASHIRA'[loosely, 'everything will end']. Whether he had money or was poor, whether he was sad or happy, whenever the man was speaking to himself, especially during difficult times, he would say, "'byose bizashira": no situation is permanent'. I have found this useful. Some of my family members used to mistreat me but now respect me because of the ways I am striving and surviving. Recently I read a story of a man who had been voted in as president of a country, yet he was a herdsman. This strengthens me.

Joe: This is very profound, Paul and Yvonne. I am wondering if any other member would like to make a reflection on what Yvonne and Paul have said about Speaking to Self as a skill of survival.

The invitation to inject personal resonance (White, 2007) into what was being spoken about allowed rich discussion of this skill. Some members had found that Speaking to Self and proclaiming what they want in life had been significant in responding to hardships, and that Speaking to Self implied taking out time alone to tell themselves things that society had failed to tell them. People also shared rich metaphors they used when Speaking to Self, such as 'the sun will rise again'. These brought resilience and contributed to standing up to difficult conditions brought about by stigma. Speaking to Self became a strong pillar for their survival: when they were pushed to the ground by Imungu, Speaking to Self held them tight.

Joe: I'm wondering, do you think some of these ways can be found in our culture or traditions? Is there a history of Speaking to Self in Rwandan culture?

This enquiry invited group members to link their skills to culture and traditions and offered an opportunity to revisit our culture and how some people are recreating cultural ways in the face of hardship.

Jado: Speaking to Self is like our traditional community night gatherings. They are the same because each one of us would be given *icyivugo*<sup>3</sup> that spoke of who we

preferred to be and the wishes, dreams and hopes we had for ourselves and the community. These traditional sayings are a form of Speaking to Self. When you have a *ibyivugo* [plural], it guides you through the journey of life.

The *ibyivugo* Jado described are traditional verses about *intore*<sup>4</sup> (Dahlmanns, 2015), which are recited when people are speaking about themselves. A child might grow up with a family's *icyivugo* that represents their identity and community uniqueness.

## Songs of courage

Songs have been significant throughout history in helping those experiencing hardships. They carry hope. In conversations and situations where people are not comfortable speaking about their experiences, singing songs can become a means to communicate and share individual and group experiences. Denborough (2001) has written that song and melody accompany us through life. Songs were true companions for some of OPRMAMER members who were going through hardships. Many members loved listening to songs and miming to those that spoke to them. Those who knew how to sing could compose songs for themselves as well as joining in solidarity with others' songs of hope.

Yvonne: I can create song lyrics depending on the situation I am in. Sometimes if I can't keep silent, I compose a song for that specific situation. For example, if I am being disrespected, I can sing a song for disrespect, and I often use singing to resist stigma and continue the lifeline I set myself to.

I asked about the history of this skill of singing for Yvonne: when she realised that songs were helpful in resisting to stigma, and what steps she had taken to harness the skill.

Joe: Yvonne, it sounds to me that whenever you sing, Imungu is unhappy, is that right?

A rich description was then developed about songs. As each member reflected on songs of survival and sustenance, we all joined in miming the song. Before the end of the meetings, we joined in singing and dancing.

## Pausing off

In Rwandan tradition, collective and group conversations are not brought to a close; they pause. Conversations continue even when people go different ways – their hearts stay connected. In Kinyarwanda they say *Gucumbikirishiriza aho* or *Guhumuza ibiganiro* whenever group gatherings come to an end. The latter is often used in reference to milking cows. It is a taboo in Rwanda to say, 'I have finished milking'. Instead, one would say 'I have paused milking', implying that the cow's milk never gets finished but rather the cow pauses for another time. Similarly, conversations in groups don't finish. Hearts stay connected and when we get back to meetings, we reflect on how the previous conversations made us feel when we were not together, and about thoughts we had outside the group as a result of the conversations we had together.

In this spirit, I will pause off here with an invitation to consider how reading this paper has made you feel, whether there are expressions that caught your attention, what thoughts came up as a result of reading these accounts. Are there themes that struck a chord or that reminded you of collective ways of responding to mental health stigma that you like to share back with us?

## Notes

- <sup>1</sup> We used *isooko* to refer to a fountain of skills and wisdom that has been passed on from generation to generation.
- <sup>2</sup> *Umuganda* is traditional practice where members of the community come together to do community service such as cleaning streets, building water sources, toilets, etc.
- <sup>3</sup> *Icyivugo/Ibyivugo* refers to a person's poem/song used for self-glorification or self-praise and stories evidencing self-commitment.
- <sup>4</sup> *Intore* referred to a warrior, but has recently been used to refer to cultural tropes and people of virtue.



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