



Solidarity and friendship

An interview with Claver Haragirimana

by David Denborough



Claver Haragirimana is the co-founder of OPROMAMER, an association to promote solidarity among people with mental illness in Rwanda. OPROMAMER is working to transform understandings about mental health and to reduce the significant burden of stigma faced by mental health patients and ex-patients in Rwanda. Founded by former patients of a psychiatric hospital with which it is now affiliated, OPROMAMER has grown from a single person's vision to become a nationwide organisation with twenty independent groups and 1000 members. In addition to advocacy work, Claver's organisation runs a savings club that has supported the development of small economic projects and enabled members to access loans to pay for school fees or healthcare. This interview of Claver Haragirimana was conducted by David Denborough.

Key words: *Rwanda; mental health; stigma; solidarity; mutual aid; OPROMAMER; Power to Our Journeys*

It took us a little while to find the office. Jean Paul Ndayisaba had carefully driven us out of Kigali (the capital of Rwanda) and we'd shortly passed the National Neuropsychiatric Hospital of Ndera. When we hesitantly turned onto a red dirt road, Claver Haragirimana appeared with a friendly wave and directed us the final distance. This greeting was obviously a common ritual ... 'It's often hard for people to find our office', Claver later explained.

I was very happy to be visiting this office of OPROMAMER – an organisation whose name is an acronym from the French: Organisation pour la Promotion et la solidarité des Malades et Handicapés

Mentaux au Rwanda. I was looking forward to learning more about this organisation of former psychiatric patients who are supporting each other, acting in solidarity, engaging in economic projects, and seeking to diminish the overwhelming stigma and discrimination that exists in Rwanda about mental illness/health.

Claver Haragirimana, their co-founder, welcomed Paul and I into their small office. From this moment on, I started to get some sense of what a profound achievement it was for this office and this organisation to exist. And I started hearing from Claver about its history.



DD: Can you please tell me about how this very important organisation began?

CH: I'm the co-founder of this association for the promotion of solidarity of people with mental illness here in Rwanda. We are connected with the nearby Ndera psychiatric hospital, the national referral hospital here in Rwanda, because in the past we were patients there. We founded our organisation eight years ago because of the stigmatisation of ex-psychiatric patients. We are stigmatised in the society, discriminated against, the women raped. We are poor because of the stigma about mental

illness. If we are successful in applying for and getting a job, then as soon as people learn that we were psychiatric patients then we are rejected. So, I decided to gather together with others in the same situation. Now we gather ourselves and think what we can do to resolve our problems in sustainable ways. With my colleague, co-founder Veneranda Ufitwenaryo, we sat together, discussed the issues, and concluded to create an association to advocate for ourselves.

We now work at national level, we are known as a non-government organisation. Of course,

we are struggling, because we had nothing at first, no finances, no facilities. We had only the idea and our experiences and determination. We still face many problems, but here we are. And you are sitting in our office.

DD: It's an honour for me to be here.

CH: The hospital helped us to start. Brother Charles Nkubili, who is the Director of Ndera Hospital, has been a very important advocate for us. He gave us advice and technical assistance and we started our first local group. We were around 30 persons who take treatments at the hospital but live in society. Most of our first group were whose husbands had abandoned them due to their illness – and the stigma about their illness.

As we started to meet together we realised that the economic situation for our people is so severe. So we started with a savings club. We met every Tuesday and each week each person would save 100 Rwandan Francs (10 US cents). After three months of saving at this rate it's then possible to seek a small loan to start a small economic project. This was our first technique – to find how we can develop our economy. These projects are now growing. In the past years we are now cultivating some land – that the hospital has made available to us – and we are raising chickens,

DD: As an association?

CH: Yes. And we continue to meet every Tuesday here in this office. In these meetings we share our experiences and advocate with and for each other. For example, if there is a problem for one member, if they are facing discrimination, then the whole group will wake up and go to advocate for that member.

DD: That's fantastic.

CH: Yes. And now this group is just one of twenty groups that we have founded. Some are far from here, in different districts.

DD: Wow. How did this become possible?

CH: We are now country-wide. After creating this first group, we went back to the national

referral hospital and asked them to tell us how many patients there are from each district. In this way, we found which districts have many patients, we went there, and collaborate with the local authorities in order to form local groups. Each of the twenty are independent and carry out their own economic projects. Some keep bees, some cultivate land, and so on.

To be together, to be part of a group, is a big thing in our society. When some people come and find we are together, and that they can be together with us, it means a lot. Especially if we have been cast out by many others.

We do four principal things. Firstly, we think together and we do together. If a woman and child is suffering discrimination, we think together and then go with her to advocate and facilitate for change. Secondly, we fight for our economy, to develop our economy in the group. Thirdly, we do what we call psycho education, we can ask our group members if there are particular topics they want to learn more about and then arrange for a director from their hospital to share knowledge. And fourthly, our groups are a message to the wider society. Overtime, our goal is to transform understandings about mental health and reduce the stigma that is still so strong here.

DD: Yes. Every achievement you have just described is all the more significant because of the obstacles you're facing.

CH: As to my own experience, in 2006, when I was in high school I was traumatised by genocide consequences and spent time in the nearby psychiatric hospital. I was there for three months. When I returned to my home, my family refused to pay my school fees. I stayed and no matter how much I asked them to help, they refused. So I created my own job of cutting people's hair here and when I earned enough money I returned myself to school. When I finished my education and applied for my first waged job, I got it! But after three days, the manager found out I had been in the hospital and rejected me. This happened eight times for me until I decided to not apply for a job any more. To protect myself from more

disappointment. Sometimes I had ideas to end my life, thinking what can I do? I was intelligent at school. I have abilities to give, but the society fails to integrate me. That was when I went to the hospital to suggest forming an association or organisation of mental patients. At first some people said, 'You are crazy. You cannot do something like this.' They discouraged me. But Brother Charles Nkubili heard us.

Early on in our work the police would come here, worried about what we were doing, gathering together. But I continue, I continue. And now our organisation is known, but the problem is still to find partners. Some people still fear to collaborate with us because we are 'crazy'.

DD: Is this still true?

CH: Yes. Here in Rwanda, culturally, when it's known that you are a mental patient or you have a mental health disorder, then we are ignored and rejected by the society. Even families reject you. If you have a husband, the husband will abandon you. When you have a wife, she will abandon you. And if you are not married, then it will be very hard to become married. When I had an idea to be married, I asked my family to help in the process and they refused: 'It's not possible. You have a mental illness.'

DD: Usually marriage involves family arrangements ...?

CH: Yes. So that is a problem when you are an ex-patient in Rwanda. The society rejects you, even the family, the parents, the colleagues. There is a culture of stigmatisation. It's not easy.

DD: Your collective work is an amazing achievement. How did you meet the co-founder of this organisation?

CH: When I went to the hospital and kept suggesting the creation of this association, they gave me the phone number of one other former patient. I called him.

DD: You found one other person and together took action. You started to take action to work against this rejection.

CH: Yes, first there was one person, me. Then there were two. Now we have a thousand members. And yet we are always struggling. We have nothing to start, and I cannot ask the other members to help me because they are in a bad situation of economy. They are a vulnerable person, I cannot ask them to contribute. They are always asking to be helped. And for me to get the transport to visit the groups in the other districts, it's a big thing for me. I try to sacrifice myself because I am a founder and because I'm inspired. But it's not easy. We have no financial means, but we have many projects, we have many dreams and we are looking for friendship.

As we've been talking, various people have been entering the office and taking their seats on the wooden benches next to the walls. At this point in the interview, it suddenly dawns upon me that Claver has asked the local group members to come to meet with me. We turn to greet them ...

CH: Yes, here we are ... together. They wish to share with you some of their daily life ...

DD: Please thank them for coming. It is a great pleasure for me to meet with you all ...

CH: I think your driver can interpret ... can do that?

DD: Paul, would that be okay? Can you translate for me, if I say something first?

P: Yes.

DD: My name is David Denborough, and I am from Australia. Before I hear from you, I just want to say that I think your association is so important. I think it is a profound achievement and I am going to go back to Australia and tell my friends who have also spent time in psychiatric hospitals about what you are doing here. It is a great pleasure and honour for me to visit your association and to meet with you all.

And so, each group member through translation, then begins to share something about their daily lives including past and present hardships. One young man is currently homeless and desperate to find a sponsor to assist him to return to school. He speaks with a passionate desperation. He has not given up. An older woman is concerned when it rains that her dwelling will collapse.

People also speak of their happiness to be in this life and to be in this association. What it means to meet every Tuesday and to save 250 Rwandan Francs each week together. We then took a moment to celebrate that one member has just received a loan for her children's school fees (US\$20). Others spoke of how the savings group has enabled them to pay their medical insurance.

Then, part way around the group, someone explains to me that the next person is not a patient. She is the niece of a group member. If a group member cannot attend a meeting, perhaps there is a crisis, then a family member stands in for them. They can then relay what happened at the meeting to their loved one. As this young woman starts to speak gently about her aunt, I am so moved. Later, I realise that out of a group of perhaps 16, there were two family members present. The other family member is a mother who speaks about her daughter. She wants to explain to me that her daughter is meant to take her psychiatric medications three times a day, each time with food, but she doesn't have enough food to have three meals a day. And if you take the medications without food the side-effects are extreme.

As this mother speaks it begins to rain. At first the drops are light, but then the sound on the tin roof becomes all encompassing. We look around at each other and smile. Paul has to dash to the car to make sure the windows are closed. I make some room on my bench, so that the next person to speak can sit next to me and Claver who takes over the translation.

As the smell and sound of the rain envelops us, the sharing of stories continues.

One group member says:

This group helps us to continue to survive. When we meet in this group and everyone knows the problem of each other, it helps us breathe. And it helps us with our children too. When my children know that their mother has a problem of mental illness it becomes a big problem for them but because I come to this group, this group helps me to help my children.

The last person to come and sit next to me is the leader of this local group. He takes my hand. He asks me, 'Will you be our friend? And will you introduce us to others?'

I gather my breath, and stand up. I turn to the group and try to convey that I would very much like to accept this offer of friendship. And that I will introduce them to my friends who have also spent time in psychiatric

hospitals. And that I know they too will want to be friends and to make further introductions.

I also ask the group if they would be willing to share their work at the International Narrative Therapy and Community Work Conference that is to take place in Kigali in August 2020. There are smiles and nods.

It has been a profound meeting and it seems appropriate (as we were in Rwanda) to end with song. So I try to sing the song which represents the Power to Our Journeys Group - a group of people in Australia who have spent time in psychiatric hospitals.

POWER TO OUR JOURNEYS

A song by Sue and David

A journey of 1,000 miles begins with one step
We're coming together now,
we're talking about respect
It shouldn't be too much to ask
to listen and to learn
To fill the libraries with strategies that work

Chorus: There is power to our journey
There is hope in this room
Voices to be heard
And stories to be told

What could this be
that we've planted here today?
What could this be
that we are watering so carefully?
Could they be friendships,
something so sacred, yet so simple?
Could they be friend 'ships' to sail?

As we tell our stories,
we remember friends on similar journeys
We take their hands, and join them in rage
And join them in sorrow,
and join them in hopefulness

Well, we're trying to get it together
But, together we have it all
Well, we're trying to get it together
But, together we have it all

There is power to our journey.

I am so moved by the encounter that I don't do a good job with the singing. But I am in gracious company. The group leader says, 'Can you send us the lyrics to that song? When you are here next, we will sing it together.'

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The leadership team of OPROMAMER consists of:

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