

recultivating community

an interview
with

Howard Kasiya



howard Kasiya works in partnership with local communities in central north Malawi attempting to address issues of HIV/AIDS. The following interview took place in August 1996 at Ekwendeni Hospital which now acts as Howard's base for community work. This is the same rural hospital in which Howard previously worked as a medical doctor for ten years.

towards shared confidentiality

We have been trying to move away from a centralised hospital approach to counselling and caring towards building more community-orientated responses. One of the ways we have tried to do this is through developing 'shared confidentiality'. Within the medical model of counselling, the counsellor talks with the client and says 'okay, when you have problems, please come to me.' This was resulting in nurses and physicians doing the counselling. It wasn't being practiced by community members, and therefore it was the patient-doctor relationship that was being built upon above all else. In that sort of counselling, other people, even

the spouse or relatives, could not be brought into the circle. The relationship between the counsellor and the client was being prioritised.

This was causing problems. The client was not free to talk with other people and it was creating problems with the relatives. The relatives of the patient would want to know what the problem was. At the same time, the number of HIV/AIDS patients was increasing, and those who were trained in the hospital as counsellors were not able to manage and cope with the increasing numbers. They were straining themselves to try to cope with the influx of HIV/AIDS patients. We also found that this form of counselling and confidentiality was increasing and supporting the stigma that was surrounding HIV/AIDS in the communities.

Those who were wanting to share their stories in the beginning were being told not to by their doctors. The doctors were saying: 'This is between you and me. What we have discussed is private.' The men especially were taking this advice and were not sharing their status with their spouses.

We have started introducing the idea of 'shared confidentiality' and the situation is beginning to change. The patient is giving their consent to let others know their status. It is the patient who is talking to the relatives, to whoever is wishing to know. Because of this, we are breaking through the barriers between the client, the spouse, the relatives, and the community. We are also dealing with the stigma. This is resulting in

people in the community coming together and starting to help those who are sick.

After the client has spoken with the counsellor, he or she then communicates with the people closest to them - those who would want to know of their status, and those who are likely to help them. This small group, usually it is only two or three people, will then come and see the counsellor and they will discuss the issues together. Instead of just considering the HIV/AIDS status, they also talk about the impact of the infection on the individual, on the family, and on the community. They discuss the immediate impact and also the future impact. In our case, we are including in the discussions the children who are in the household who may be orphaned later on.

Now that we are bringing these people together and discussing everything, we are finding that we are making progress in planning with the community and the family for the future of the children. Previously we as workers within the hospital were registering orphans. Now the community is registering the orphans. They are coming up with their own methods on how they are going to help them. We have found this very helpful. The children have been identified and the needs assessment is being carried out while the parents are still alive.

Once we have talked to people in the community about HIV/AIDS, confidentiality takes on different meanings. If a person in the village starts showing the signs and symptoms of AIDS, the community will

already suspect he or she is HIV and AIDS infected. The community already knows. Shared confidentiality is reducing the stigma and encouraging the community to take responsibility. Often people aren't tested until they are very ill, so mobilising the community is very important. In the past, when people were told they were infected they would often react by telling the doctor: 'Now I am going to commit suicide, I am going to drown myself, I am going to hang ...' But we have very few of these statements and expressions now that the stigma in the community and the sense of isolation is decreasing.

Those workers who have already studied other models of counselling, models of counselling based on one-to-one work and medical ways of working, are sometimes finding it difficult to make the switch towards more communal ways of working. There are a number of reasons for this. I think they are already dealing with an atmosphere of stigma, either their own or within the hospital, and therefore the idea of shared confidentiality is a threat to them. On the other, hand there is the time problem. They don't have enough time to do the follow up and to invite the participation of the community. They don't have the time to introduce their clients into the family, into the community. They don't have the time to let the community play their part.

a grassroots structure

In this area we have trained five CARE counsellors, one in the

hospital and four volunteers who are already working in the community. We have divided our region into different catchment areas, each with about four to eight villages - which means that there are less than 1,000 people in each area. From each of these catchment areas has been created a committee which is in charge of local AIDS programs. They use their own volunteers to care for those with HIV/AIDS and for the orphans. The volunteers from one area cannot cross and go to another area. It is the duty of each catchment area, each community, to motivate their own people. If they don't then they will not receive any support. They have to take the initiative. It is the only way we can do it, and we have found that it is working very well.

recultivating self-help

Recently, new notions of development and changes to the political system have caused us some problems. In the past, people would volunteer to build roads, to mould bricks, to build schools and clinics. All sorts of things would be done on a self-help basis. But during the campaign for the recent general elections we were constantly told that there ought to be no free things or free work. We were told that if we work we ought always to get something, some money for it in return. We were told that if we worked at self-help development, that this was cheap labour, a sort of slavery. As a result, it is now possible to meet people who will say, 'So, you want me to be a

volunteer, or to help. How much am I going to receive to do that?' With that sort of message coming in it is becoming difficult to get people to mould bricks and build something unless there is something attached. This way of thinking has affected volunteer work in all sectors, in relation to all social problems.

So now we have to start again and recultivate the nation, recultivate ideas of self-help. When we were starting the program in 1989 we had a lot of people who were voluntarily coming to work. After that the voluntary spirit dropped down, but we didn't give up, and now with the CARE counselling we are picking up again. It's helping us a lot. We are being honest with people. We say to whoever is going to participate in the program that they shouldn't expect any personal monetary benefits. That's the first thing. But, more importantly, CARE counselling is inviting people to see the problems within their communities as one people - together - rather than as individuals. They are coming together as a community and are identifying problems as their own, rather than being told, 'this is the problem, please do this.' It is reviving community ways of working.

Many other programs pay allowances to their volunteers. In our program we don't. Our volunteers cover a distance of 35km coming and 35km going, just to attend a monthly planning committee. They are not given an allowance or any food, nothing. They come because of their commitment, because they have seen the problem. They come, attend the

meeting, plan, and go back home. We cannot afford to give allowances. In some ways we wish we were giving them allowances but, in other ways, working without allowances is the best from our point of view. If you start giving allowances it has a lot of effects, especially in a country like Malawi where most people have no wage or income.

Allowances change things. For example, now if you don't give civil servants an allowance they won't attend a workshop. Before they go to a workshop they will ask, 'How much are we going to receive as an allowance?' This means that departments are now forced to send different people to each different workshop even if it does not concern them as otherwise people complain of favouritism. Secondly, where allowances are involved, people go for the money and not for the materials. Therefore they get the money, they get little of the information, they come back, they sit down and nothing happens. These are the complications of allowances. They are not helping.

There are times when we have been advised to put in our budget proposals an item for allowances, and we have said to them we would rather run the program without money than have money with allowances. And so they find it very strange, but we are being very honest with people and with donors. As far as our program is concerned, we would rather have the program and use the efforts of the people than have the motivation of money. It won't do us any good.

Building on the spirit of the

community is how we are surviving - more than surviving. The spirit of wanting to assist each other is coming back. I am so grateful for this. If ever that spirit was dying I believe CARE counselling would be able to reactivate it and bring it back.

from hand-outs to hands joined

Moving away from needing more and more money has relieved us. When we were starting the program in 1989 we were giving out items which in the end we discovered was creating its own problems. We couldn't manage with the influx of people who were requiring such items. And in any case we were causing trouble by differentiating. For example, consider the case of an orphan who had no food, who had no clothing, who had nothing. This situation had not come about because he/she is an orphan, but because the entire community was lacking such things. Most of the children of that community are lacking education, are lacking health facilities, are lacking food. Therefore, when you start giving things just to the orphans, the other children - who are also lacking such things, start developing attitudes either towards the program or towards their guardians and parents. At the worst extreme they would even wish their parents died so they could benefit from these other facilities which were being given to the orphans.

What is happening now is that, within the catchment areas that we have established, communities are

coming up with 'income-generating activities' whose products would be of good use and would be sold or traded within their own area. They come with those ideas to us and we sit down and discuss them. We include the accountant in these discussions who has the business and management skills, and in the end we agree on what direction to take. We have set up this structure for the development of 'income-generating activities', but the communities are entirely taking the responsibility. What we are doing as a program co-ordinating body is: firstly, to find financial assistance for them, financial support, and material support; secondly, to help them with the technical management of the income-generating activity idea; and, thirdly, to find marketing for them. Otherwise the entire activity is being done by the community.

For example, the community here came up with the idea of wanting to build a training centre where youths and orphans could be trained locally in different skills, like knitting, sewing, cooking, carpentry, homecrafts, shoe repairs, and all those sorts of things. It is interesting that they have already come up and started to mould bricks. We have started the building. The people are identifying their own problems and are coming up with solutions. Momentum is building.

community generated projects

The consultations have helped us to discover that the community wants to do these things together. So much so that it would be

difficult for an individual to start an 'income generating activity' on his or her own. With the structures we have come up with we would say to him or her, 'Please go back to your community committee and discuss it with them'.

We have welcomed this because it is also helping us as workers. If we supported individual income generating activities there would be a lot of families that would come in with ideas and in the end it would be difficult for us to manage. This way we can support the community and share their ideas with others. It is cheaper too. Community participation is cheaper. Not cheaper in terms of cost per head, but it's cheaper in terms of time spent and the management cost. But most importantly it is building the people together. It is giving the people hope.

building on cultural traditions of care

I think that our work has cultural unity as its fundamental basis. Within the training program we ask the following questions:

- What sayings do we have in our languages that capture the importance of working together?
- What cultural activities do we have that strengthen community participation?
- What role can the culture play in reducing the impact of AIDS?
- What cultural themes are we using already in counselling practices?
- What are culturally acceptable and practised ways of conveying a

behaviour-change message?

Our culture is rich in proverbs that teach the generations the importance of working together. There is a tradition of community caring. That's why previously orphan care has not been a problem. Extended families worked together to assist the orphans. These new ways of working are building upon old traditions, traditions of working together.

We build on these traditions when we go into the community. We do not jump straight into talking about HIV/AIDS. First of all, we explore the collective ways of caring that they have already. We bring to them some examples of different problems and ask how they would deal with them. For example, we would ask, 'If the house is set on fire as a community, what would you do?' And they all say, 'We would all run and try to extinguish that fire'. And then we'd explore why and they would come up with different answers. It becomes clear that everyone is seeing the problem as something they deal with all together. No-one is demanding that you go and extinguish the fire, but, because you have seen the problem, united, without being told, you just stand up and go and help.

We also use the example of drowning. We say, 'When you see that a child is drowning and two or three people are there, what would you do?' Usually the first answer is, 'All of us are going to go and try and rescue that one'. So then we ask, 'What if one of you does not know how to swim?' And they say, 'Okay, this other one is going to go into the village and notify

the people whilst these other two are starting already to search for that child, to try to save the child who is drowning'. From there we start to explore: 'What motivates you?' And they say: 'It is our tradition to help each other, to assist each other.' One of the other things that they will say is, 'If you don't, the next time a problem could come to you and people will not help you.' We explore these examples and then we bring in the proverbs which they know, traditional proverbs that build on unity.

Those traditional practices of working together make people do things as if from instinct, as part of them. So they don't find it strange. I think that the spirit of assisting each other has been planted in us. We try to build upon this when we go into the villages and communities. Little by little we then come to the problem of HIV and the AIDS crisis and we explore its impact. And we introduce Mr/Mrs AIDS and Mr/Mrs CARE.

Mr/Mrs AIDS & Mr/Mrs CARE are becoming very popular! They are becoming well known. Mr/Mrs CARE is a friend to the communities. They are helping us to examine how much the communities know about HIV and AIDS and what they think they can do about the problem. We used to have trained volunteers play the parts of Mr/Mrs AIDS and Mr/Mrs CARE, but lately we are preferring to ask members of the community to play the roles themselves. We are starting to enjoy it. I think that they enjoy the progress from the traditional stories, to the issues of HIV/AIDS and its impact,

and then to the introduction of Mr/Mrs AIDS and Mr/Mrs CARE. That progress, or procession, is stimulating. It's fun too - to be asking each other, to look at a person as Mr/Mrs AIDS and somebody as Mr/Mrs CARE. It's a concept which is very new but at the same time funny. So they ask a lot of questions.

seeing the fruits – outside the institutions

I am trying to get these ideas promoted because I am enjoying the work. As an individual I am enjoying it, but also I am seeing the fruits. I am enjoying working with the community. I am becoming part of them. Since last year I have been a full-time worker with the AIDS program. I am not wanting to go back to the hospital, to the clinical side! I can practice my clinical work when I visit patients in the home-based care program. I have the medicine with me when I go to assess the health of the patients in the home-based care program. For the ten years before this work I was a doctor working in the hospital, so I can see the differences.

There are times in the hospital, maybe because of your own stigma or because of the pressures of working there, that the moment that you see a patient has AIDS, your professional spirit of wanting to assist them completely goes down, and instead you want them discharged immediately. It's common. It's very easy to be overwhelmed when working in a hospital with HIV/AIDS and without the community spirit. When

you are in the hospital each face tells you a negative story. When you are working in the community, even with the same patients you have met in the hospital, their faces tell you the positive side of the story and it is invigorating.

You can't enjoy seeing the patients in the hospital. If I see the same patient in the hospital and then in the community - in the community, I just love to stay and spend time with the patient. That's one of the things which we are experiencing. We want to share these things with other people.

I have visited two or three hospitals in the UK. It was difficult for me to accept it, to accept the atmosphere and what was happening. The patient had to be alone so often - and sometimes there was communication through machines. To me that was very difficult. One wouldn't manage to do that in our setting - traditionally it would be difficult to accept. There is even difficulty here putting any limits on when a person can come and see a patient in the wards. It becomes difficult, the people just want to stay with the relatives all the time! In the UK I found that even if you wanted to pray with the patient, the patient had to give their consent - you had to sign somewhere before you can sit with the patient. That is also different here. This is a Christian hospital, but a Muslim can come here and talk about his religion. The medical people would not say, 'The patient hasn't given you the permission to do that'. They'd just come and share.

staying away from outside intervention and with community

Right now we are discouraging the establishment of a TB unit far away from the main wards of this hospital. It would be like a prison. If ever there was someone visiting you it would be either your relative or a doctor, that's all. They want this because TB is infectious and also because it is often associated with HIV/AIDS. But it would isolate the people completely. We are saying, okay, people with TB are infectious for their first two weeks of treatment, but after that they are not as long as they continue taking the drugs. So we could perhaps isolate them for those three weeks, but they don't have to be there for the rest of their treatment. They have to share their social feelings with other people. Sometimes the isolation wards can be like a prison.

In relation to the care of orphans, again institutions should be the last option. The extended family, or orphan support groups and maybe fostering and adoption, ought to be the priorities. If you can't do that, if there are barriers to all these other ways, then you can take that child to an institution, but otherwise no. We have people from outside that have gone around and collected a lot of money. They have, of course, seen the statistics in Malawi on HIV/AIDS patients and the orphans. Then they come here and the first thing they want to do is start an orphanage. That is destroying the efforts of bringing and building the community participation.

We resist these ideas because they do not help. Institutions destroy the future of the child. Those sort of ideas which, in principle, as concepts, may sound very good, on a long-term basis have very destructive effects. Of course there are a few orphanages now being built in Malawi, because the people had already collected a lot of money which they had to spend on an orphanage or they'd lose it.

At the same time, there is a lot of money being spent on infrastructure development and the management of that development. This is being spent whilst our people, our children, are starving - they don't have even a meal or two meals a day. This money could have been spent to feed them, or to help those patients in this area. The nearest free medical services with modern facilities is about 60km away. The patients around here have to either depend on other people to give them money to pay for the local medical services or wait and die at home without any help. And yet they spend money on institutions or infrastructure! It is destroying the efforts of the people. It is destroying the perception and hopes of many, and it is also destroying the future of the children. In areas like Malawi, where economically it is difficult to survive and there are a lot of areas which need support, I think the use of money should be prioritised and used to meet the efforts of the communities, to support whatever they are doing - like their income-generating activities.

If the communities were asked, perhaps they'd ask to be bought a sewing machine. The community

would know that if they could use a sewing machine they could make clothes for their children and they wouldn't need the money to go and buy those things. If the communities were asked maybe they would say, 'Okay, why don't you buy us maize wheel'. Then they would put in a maize wheel and they would benefit from that. The women wouldn't have to walk a long distance for the food, they would be using it there and the money they would make would be useful for other activities. Maybe it is only us at the grassroot level in the community who are seeing these things and having these thoughts. Those who are working in the offices, maybe they don't see what is there. Maybe all that they can see are their own offices. They think that the best option for the community is to set up an atmosphere like they have in their own offices - like an institution. If they went into the community and saw exactly what is happening they would appreciate the efforts of the people, and maybe they would want to do something that builds upon those efforts.

futures

I am really becoming very interested in how to apply these ideas in different areas, not only in HIV and AIDS - for example, the social problems of the youth. I want to try to use these new ways of working to try to motivate the youth. To explore how they can see their behaviours, how they can see the problems and how they can assist each other, and, later on, how they see their own future. How

can we use these ideas in community work around the social problems of alcoholism, drug abuse, sexual abuse, all those things? I am certainly convinced that we can do something, that we can use these ways of working in different areas. I think that it is going to work.

It is already beginning to work here. People sometimes have said, with wonder: 'You say counselling is working in the community?' And I say, 'Come and discuss it with the people'. Sometimes the reason why it doesn't work is because of imaginary thoughts. People imagine problems that they are going to face even before they try. They imagine that clients will not want us to share the confidentiality. They imagine that people will not want to assist other people. These sort of imaginary thoughts get in the way. If they imagined differently they would see other possibilities. We have tried to abandon the negative imagination and think instead that, whatever happens, we are simply going to do it. Now we are having the patients come in to us, they are coming to the volunteers for help rather than the volunteers having to go to them. They have seen how other people have been helped. They have seen that the CARE counselling is really creating and giving the people hope. There is a lot of hope that the people are finding.