



# It's not just about drinking tea

Dialogue between MSF, its patients and their communities

*“Discussion is impossible with someone who claims not to seek the truth, but already to possess it.”*

Romain Rolland, *Above the Battle*

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# Glossary

ANC	antenatal care
ALNAP	Active Learning Network for Accountability and Performance in Humanitarian Action
ART	antiretroviral treatment
ARV	antiretroviral
AZG	Artsen Zonder Grenzen (Doctors Without Borders)
CBO	community-based organisation
CM	community member
FSC	family support centre
ICRC	International Committee of the Red Cross
LNG	liquified natural gas
MoH	Ministry of Health
MSF	Médecins Sans Frontières/Doctors Without Borders
NGO	non-governmental organisation
OCA	Operational Centre Amsterdam
PLHA	people living with HIV/AIDS
PNG	Papua New Guinea
PNC	postnatal care
TB	tuberculosis

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## How to use this booklet

This booklet is intended to be used as a tool to inspire field teams to explore, develop and implement the explicit use of dialogue with our beneficiaries. It endorses aspects of programming such as outreach activities, and highlights how successful messaging can be integral to effective treatment outcomes for patients. In reading the booklet, try and draw comparisons to programmes with which you work, and analyse where the techniques discussed could be implemented, or expanded on, in your activities. Alternatively consider if any of the benefits of engaging in dialogue with our beneficiaries, for example in the areas of improving trust, access or medical outcomes, which emerged in this research could help to improve your programmes.

# Introduction



*Yida, South Sudan. Photo: Yann Libessart.*

## Up close and personal

Central to the work of Médecins Sans Frontières/Doctors Without Borders (MSF) are its patients – the people affected by distress and conflict whom MSF seeks to treat. MSF’s medical and operational staff, both international and national, choose to bring their humanitarian imperative and medical ethics as close to their patients as a medical humanitarian organisation should.

But while MSF ensures proximity to its patients and their communities, it is acutely conscious that crossing the geographic and cultural barriers to be with its patients in times of crisis demands more than medical skill and logistical know-how. Providing optimal medical care to its patients requires detailed understanding of their political and cultural context, their needs and habits, and the impact on them of the crises that MSF is there to address.

Such understanding does not come from one source. No single book, article or online resource is enough in itself to give MSF the knowledge and empathy it needs; this is something that can only be achieved through human interaction.

Many MSF staff know this from experience. To be close to your patients, accepted and safe amongst them, and trusted to provide care, you need to talk to them, explain your purpose, gain their trust, and provide the kind of medicine that will contribute to their ability to overcome the crisis.

Accepting this, we present an “inspirational” paper on MSF’s dialogue with its beneficiaries in the field where its medical services are provided.

## Strategic commitment

MSF Operational Centre Amsterdam (OCA) has recognised the benefits and potential of the discussions carried out in its projects. This is stated clearly in the current Strategic Plan (2011-2014): “We will invest in mutual dialogue with our patients in order to improve both our acceptance and our medical action.”

In stating this, MSF OCA has also committed to exploring ways of improving dialogue with its beneficiaries – which in practical terms is already an integral part of many programs and approaches such as outreach or health promotion in camps, negotiating our access with host communities, or explaining medical procedures to patients. By committing to understand what makes these interactions successful, MSF-OCA seeks to improve our skills in access and efficiency that an improved dialogue provides, and for the merits of acknowledging its beneficiaries for what they are – people, patients and communities enduring a crisis; people that MSF respects, identifies with and aims to serve.

## What is it?

For the purpose of this paper, we use the following definitions:

**Beneficiaries:** A term describing MSF’s patients and the communities in which they live.

**Dialogue:** A two-way, ongoing communication process or interaction between MSF staff, patients and the communities with whom MSF works, with the aim of increasing mutual understanding and improving decision-making processes and programming. Dialogue specifically aims to find value in the opinions of others and, rather than seeking to persuade or coerce others into a ‘right way’, constantly re-examines sets of ideas until common ground is found.<sup>1</sup>

## What do we know already?

A comprehensive literature review was conducted to summarise the knowledge and understanding on beneficiary dialogue in emergency response.<sup>2</sup>

Interaction in a humanitarian context is by no means a new idea; many factors and trends have played a part in bringing about increased interest in the topic over recent decades. Those include both donor and civil society-driven demand for more accountability and a people-centred approach.

The development sector has seen participatory theories and practices rise and normalise, starting with the post-colonial effort to recognise local capabilities, and leading to the emergence of participatory approaches in the 1970s with the ‘Rapid Rural Appraisal’ technique. This morphed a decade later into the more inclusive ‘Participatory Rural Appraisal’ method that attempted to answer the shifts in the sector linked to sustainability and local ownership.<sup>3</sup>

In the 1990s it metamorphosed into ‘Participatory Learning and Action’, which sought to create a two-way learning process. But this did not escape criticism. Despite addressing the exclusion of the vulnerable groups that the

development sector was trying to help, overuse of the word ‘participation’ threatened to turn it into just another buzzword to meet donor demands. Rather than meeting people’s needs, participation became only a nominal part of project activities.

In the humanitarian world, research carried out by ALNAP shows that, “Far more than a set of tools, (community participation) is first and foremost a state of mind, according to which members of the affected populations are at the heart of humanitarian action, as social actors, with insights on their situation, and with competencies, energy and ideas of their own.”

This trend for increased beneficiary participation can be followed in the aid literature, including *The Code of Conduct for the Red Cross and Red Crescent Movement and NGOs in Disaster Relief*, which states, “ways shall be found to involve programme beneficiaries in the management of relief aid”. The trend can also be seen in an increased will for aid organisations to hold themselves accountable to both donors and beneficiaries.

Community engagement has now become normalised in humanitarian aid, but the efficiency by which it is applied can vary.

Through the premise of meeting a humanitarian mandate, MSF and other humanitarian organisations must be mindful of their own power when engaging communities and negotiating within existing power structures. MSF should seek both to understand and to mitigate power imbalances so that it is able to provide the appropriate medical services to those in most need. The contexts in which MSF works are understood from many perspectives and involve people coming together

<sup>1</sup> Roberts, N. (2002)

<sup>2</sup> For full literature review and case studies see [www.msf.org.uk/study-review-dialogue](http://www.msf.org.uk/study-review-dialogue)

<sup>3</sup> Influenced particularly by the works of Robert Chambers and Amartya Sen.

with different knowledge, backgrounds and agendas.

It is against this backdrop of discourse on community empowerment and participation, and the implicit power that MSF occupies within the context in which it works, that we wish to examine the use of dialogue with MSF's patients and their communities.

## Our stories

To explore the positives of MSF's dialogue with patients and their communities, we visited three of MSF's missions and talked to people there – to staff, patients, carers and community members.

We used a qualitative design, describing three separate locations where MSF is thought to engage in better dialogue as defined above. Participants were selected purposively in order to supply as rich a text as possible using a flexible participatory technique. Additionally, we held focus groups with national and international staff.

The first project was in **Maban, South Sudan**, to where a massive population was displaced in 2013 following violence in Blue Nile state in neighbouring Sudan. MSF has received and aided tens of thousands of refugees in Maban and established and serviced camps

where they were resettled, including providing medical services, non-food items, water and sanitation and epidemic response.

The next project was in **Tari, Papua New Guinea (PNG)**, where MSF has been working since 2009, supporting the victims of violence with a surgical project and working closely with survivors of sexual and family violence, in its family support centre. In PNG, MSF's sexual violence guidelines are now being adopted countrywide.

The third project was in **Yangon, Myanmar**, where more than 18,000 HIV-positive patients were being treated at MSF clinics at the end of 2013. Knowing that Yangon is only one of five MSF projects in Myanmar, and that there are currently two more HIV/TB projects as well as two emergency projects in Rakhine, this case study was chosen to enrich our understanding of the impact of good dialogue in an urban and difficult context.

The findings of these visits are organised in three distinct themes: MSF values and their link to dialogue; saving lives – where medical practice and dialogue interact; and access, security and accountability.<sup>4</sup>

<sup>4</sup> For detailed findings see: [www.msf.org.uk/study-review-dialogue](http://www.msf.org.uk/study-review-dialogue)



Gogrial, South Sudan.  
Photo: Isabelle Corthier

## SUPPORTING THE MSF MISSION:

### Key themes showing the benefits of dialogue in MSF programmes: South Sudan, Myanmar and Papua New Guinea

#### 1 Back to MSF values: recognising proximity, trust and respect

When MSF's working values are recognised and seen positively by its beneficiaries, there are many opportunities for meaningful dialogue. Proximity allows MSF to remain visible and for its presence to be recognised in terms of solidarity beyond its healthcare activities. Proximity is understood by MSF as fulfilling part of the organisation's humanitarian mandate by showing solidarity with populations in need and as an essential part of understanding the shifting contexts within emergency settings. The review data from Maban show that proximity can have significance beyond MSF's operational agendas of population access and project security. Proximity itself, when acknowledged and appreciated by the local population, has value as a human characteristic, which in turn becomes key to enhancing the potential for dialogue – a language of humanity understood in spite of linguistic and cultural barriers.

As part of the narrative of what brought people to Maban, participants in the review made reference to the fact that MSF had found them, MSF was there with them and MSF had stayed with them against all odds. On reaching the relative safety of the camp, CM1 realised, *'only the diseases were too much and they cannot give us rest. But MSF stayed with us... Really those people are strongly with us. And they are doing good.'* *'When we sat here for one week, MSF arrived and made a hospital here.... We are also glad because they don't just leave us like that.'* (CM2)

*The proximity MSF displays through its modus operandi is valued as solidarity and, in this context, lays a strong foundation for dialogue and negotiation.*

Participants experienced MSF's working values through the organisation's visibility in the Maban, Batil and Gendrassa refugee camps and in MSF's approach towards patients. When participants were asked the opening question: 'Tell me how you come to be in Maban,' across the range of answers, ideas of MSF standing together with or being near to the population were evident, as were accounts of being supported by and welcomed at MSF's facilities. In this setting, the recognition of MSF's values of solidarity and proximity by the population may open up increased opportunities for positive dialogue.

CM12 related his experience of NGOs more generally, having heard of NGOs previously but never having come across them before he crossed into South Sudan: *'These organisations have played an important role in standing by our side... If not for these organisations, we might have scattered.'* In answer to a clarifying prompt asking what it was that made him describe MSF as good, CM6 answered: *'Because you are here, you are with us.'* Next to more tangible medical benefits, the simple presence of MSF in and around the camp was found to be meaningful to many.

*Trust and respect are best nurtured when different worldviews are recognised and when positive action is acknowledged by both MSF and community members.*

In Maban, participants referred to their experiences of MSF searching for sick people to illustrate the responsible role they perceived for it, and the trust that had been built from witnessing MSF staff come out into the camp.

*‘MSF finds the time to come and ask “is anyone sick in the community?” MSF is the one who can see you before your neighbour comes’ (CM2) and ‘If someone is sick, there are the ones who are reporting them and then they (MSF) will come and take him or her.’ (CM7) ‘MSF it is responsible for the patients and if there is someone who wants to die, they are responsible for that also.’ (CM6)*

In Tari, direct descriptions of effective dialogue appeared mainly in the form of medical explanations and reassurance. For example, on describing her feelings before receiving a caesarean section 18 months previously, CM4 said *‘how they talk and how they react – it’s helpful, so I wasn’t afraid. They came and they massaged my back and said “you’ll have your baby ok and your baby will be fine and you’ll still have another baby after a year or later.” That is how they comfort me and make me not scared.’*

In another illustration from Tari, the mother of a patient who had recently recovered from serious stab wounds explained her own experience of her daughter’s treatment:

*CM13 – ‘I saw my daughter was stabbed and, because the intestines were cut, the excrement was spread all inside. They put something into her mouth and into her stomach and they cleared all that rubbish so she was ok. That’s what I saw. Now, I knew that my daughter would die, should die al-*

*ready, but those white people after doing those kinds of things, stabilised her life.’*

Researcher – *And did they explain what they were doing – was it clear to you what was happening?*

CM13 – *They explained to me... maybe to make her breathe deep, they asked her to blow the bubble... I knew that she was on a safe journey.’*

This mother seemed to have a good understanding of what was happening, perhaps not accurately in medical terms, but in terms that reassured her. The explanation had been clear enough for her to be satisfied that the doctors were doing what they needed to in order to save her daughter’s life.

Amongst the international staff team in Tari, an awareness of the benefits of a reassuring, respectful attitude and the usefulness of simple medical explanations was evident, despite some medical practitioners feeling that they were less able to express themselves effectively in translation.

*Lae, Papua New Guinea. Photo: Fiona Morris*



## Reputation is everything

*In Tari, MSF's reputation as a practical resource is based on a pragmatic recognition of its ability to provide positive medical outcomes and 'return life' to people who have been seriously wounded. This reputation is supported by effective dialogue, which is best evidenced in the caring attitude of medics, the quality of simple medical explanations and the availability of assistance to all.*

In light of its reputation as a practical resource, MSF's presence in Tari is locally defined by its surgical facility within the Ministry of Health (MOH) hospital, according to all the participants interviewed. Beyond that, the surgery MSF performs is appreciated in particular for its treatment of victims of violence and recognised by many as restoring life to people in Hela province.

*'If MSF wasn't here, people would kill each other and chop each other. People would just come here to die. But MSF is here and they have been treated nice and now they are ok.'* (CM11) *'If she wasn't treated well with MSF I think she would have lost her life.'* (CM12) *'People are chopping each other and might die, but MSF is here to give them back their life... If MSF didn't come to Hela, I think all the Hela people will die. We would chop each other and just die. And now MSF is here, we are ok – they are bringing our lives back.'* (CM3)

There was a notable pragmatism underlying the recognition of MSF's presence besides the positive surgical outcomes that they described. For example when prompted for further explanations of how they knew MSF was providing a 'good' medical service, most peo-

ple referred to the efficiency of the service and described their decision to come to the hospital in Tari based upon a practical analysis of the speed with which they are seen and treated: *'I heard that MSF works very fast and sees the patients very fast'* (CM4). *'MSF, when the patients come in they don't leave them for a long time, they treat them straightaway, fast. That is why we say MSF is giving a hundred percent job here.'* (CM8)

Further to this, CM13, when describing her lack of surprise on learning that her daughter had been stabbed, explained that it was thanks to MSF that wider effects on the community were averted: *'Really it's common here. The people mostly kill each other. But if my daughter died, if she had died somehow, there should be a big fight going on'*.

Thus MSF's surgical role in the area is seen to do more than simply restore life and health. It is locally perceived to play a part in helping to mitigate further violence in the community by preventing the escalation of feuds. This feeling of trust and respect that comes across during a patient's experience of MSF's care, builds upon and adds to MSF's practical reputation. When experienced side-by-side, respectful, reassuring communication will support good medical outcomes and result in opportunities to enhance or nurture common ground. Finding common ground is a key element in optimising the value of that dialogue to make patients feel secure.

*Three elements combine to influence the 'patient experience' of MSF's long-term care: staff attitudes, continuity of care and equality of relationship between staff and patients. When all three of these are acknowledged and invested in positively, commitment to care and optimal engagement can be achieved.*



MSF's<sup>5</sup> reputation as an HIV treatment provider in Yangon is understood to be based upon the quality of its care. This is represented in particular by the delivery of a treatment package within each of its four clinics, free access to ARV treatment, and the maintenance of confidentiality, which is highly appreciated both in light of social stigma and in contrast to other experiences.

MSF's comprehensive approach is seen to be one of its greatest assets, particularly when contrasted with patients' experiences of other providers in the city: *'But there at the hospital it is not (complete). You have to go here and there – sometimes you'd go all the way but the CD4 machine would be broken and so you'd travel to National Lab instead... We have to pay out of our own pocket.'* (CM4) *'When you compare AZG to the hospital, when people have to change the drugs (first-line to second-line) at the hospital, they have to inform to the higher level and have this meeting, only then will the approval come down, stage by stage... but here (AZG) if the drug is not agreeable with the patient, then wait one week and we'll try it again. That's the difference.'* (CM1) This reliable

provision is partly understood in terms of MSF's capacity to respond where others cannot.

Linked to continuity and commitment is the attitude of staff towards patients. CM7 expressed the following concern about nurses, relating their behaviour to their ambition to move on from MSF and a related lack of genuine care: *'Some nurses, the way they treat them, they can be harsh... for these nurses they also come here to gain experience and when they have what they wanted they just leave to join other organisations.'* (CM7) Positive experiences of staff attitudes show how important an element of care this relational aspect can be: *'They have become close to these nurses – they are like a family.'* (CM1) This is reflected both in the atmosphere created in the clinics and the attitude of staff themselves: *'The attitude counts a lot... Sometimes the doctor may be busy because there are a lot of patients, or they may sort of shout a bit.'* (CM6) *'At AZG they have this waiting area and seats so patients are comfortable. So when people are comfortable they feel at ease so when it comes to communication, it's easier for them.'*

5 Referred to by all review participants in Yangon by its Dutch acronym 'AZG'.

***If they don't feel comfortable and they are shouted at, patients become quite temperamental.***' (CM5) Feeling comfortable and respected was clearly important.

In terms of dialogue, it is documented<sup>6</sup> that negative staff attitudes have significant potential to reinforce stigma. It is possible that people living with HIV/AIDS (PLHA) will interpret behaviour through the lens of discrimination due to their vulnerable situation, for example, ***'Because of the universal precautions, (staff) have to take certain steps to protect themselves and because of this, the patients can interpret it as discrimination. For instance the drinking cup. Although we know that we can't contract the disease by sharing the same drinking cup, they say, "use your own drinking cup".'*** CM6

Others described the difficulty they experienced in negotiating with staff in terms of the clear dependency of the patient's position: One participant, a volunteer for a local community-based organisation (CBO), described his role in terms of what he owes his organisation: ***'What they are doing for me is a lot. These drugs – AZG and other NGOs are all my benefactors.<sup>7</sup> I owe them my time as a volunteer – it's the least I can do.'*** (CM4) ***'Some patients they have something to say but they don't want to fight for themselves. But they need the drugs, they are in need, so they come. (Staff) speaking in a positive way can make all the difference.'*** (CM6)

Understanding these issues can be seen as an opportunity to enhance communication: MSF staff are well placed to be especially sensitive

to how their words and actions may be interpreted by a patient group that is already vulnerable to stigmatisation. It is this sensitivity that should be optimised in practice.

## **2** Saving lives: medical practice and dialogue

### Benefits of common ground

*When the agendas of MSF and its beneficiaries meet, a space opens up in which dialogue can take place. It is by understanding and respecting each other's agendas that dialogue can be most effective, because negotiations can be framed in terms that are acceptable to both parties (eg medic/patient, project coordinator/community leader).*

Acknowledgement of the practitioner-patient or provider-recipient tensions that are inherent between both agendas allows room to find common understanding and therefore facilitates or sets the terms for engagement. ***'When someone does something like the one of MSF, it is not a simple thing... If someone do something like this for you, it means that he likes you. He doesn't want you to go back to a bad situation but he'd like you to go and be better. And it's really a good thing.'*** (CM9)

This idea of part-dependence on an authority in health (such as a doctor), part-active participation (by individuals) was noted across interviews: ***'When I am sick I came here on a Wednesday. Then some medicines was given to me and I was instructed to come again for follow-up. When I finish this medicines, that is***

6 Madru, N. (2003) p. 48

7 The translator described use of this word as 'saviour with the addition of debt'.

*why I come back for follow-up today... I came here today because I feel there is no full improvements.’ (CM3) ‘Out there the child was not improving and he was suffering, so from there we come to MSF’ (CM4)*

*‘But human being of course has a time to die. Because everyone has his own time. On top of this also we need injections.’ (CM3)* This balance between an acceptance of circumstances or fate and a will to negotiate within those circumstances was also a common one. Patients are by no means passive recipients of aid – indeed there were many positive signs of engagement. But alongside the engagement come patient decisions that are perceived to be ideal by MSF practitioners. Observed from the practitioner perspective, this was identified as one of the hardest aspects of working in the context. People would come for help, but then suddenly decide to let fate take its course:

**M2 – ‘They will run away or they will not let you examine or they will not accept a transfer... that is some of the most frustrating situations. When you really know that ok by saying no to this then we just – it’s going to cause you to die or the baby to die or it will have serious, serious consequences. And you just have to write nicely on**

*the chart, you know, that this patient refused treatment. That takes a long time to get used to.’*

Thus shared agreement can look different from each perspective: on one side, the population seeking to regain the balance of social relations; and on the other, MSF trying to persuade beneficiaries to accept its interventions.

It should not be assumed that MSF’s view of itself as medical benefactor is shared with the population. The normative atmosphere of, for example, a refugee camp as one of mutual distrust between givers and receivers has long been discussed in academic circles.<sup>8</sup> But it is within this environment, alongside other NGOs and UNHCR, with their own mandates, methods and agendas, that MSF has the opportunity to prove itself worthy of the population’s trust. Trust, once gained, remains precarious but, just as dialogue plays its part in gaining it, trust broadens the chances for further dialogue to take place.

*An exchange of perspectives allows misunderstandings to be resolved and MSF’s reputation to be upheld, but more importantly sets the scene for a potential increase in successful health outcomes.*

The idea of polarised standpoints came across in this statement from a member of the sur-

8 See example cited in Voutira, E. and E. Harrel-Bond (1995) of Oxfam’s ABC on refugee registration which contains an annex entitled ‘cheating’: “Far from describing conditions directed towards engendering trust in individuals or environments, the handbook suggests and reinforces the commonly held belief that refugees are inherently untrustworthy.” P. 219



gical team during a focus group in Tari: *'In all honesty for me, when I first came here, I used to think to myself 'who chopped you and who chopped you.' And then after a while you stop caring. I mean it sounds terrible... but now-days I rarely ask people why or how... you know I think I'm more interested in providing the safest, best care we can for them.'*

Like the majority of that team, this staff member had completed more than one mission in Tari; however, he makes reference to the shock that many of the international staff said they experienced on first arrival. The levels of violence were reported to be hard to comprehend from an external perspective. However, within the same statement in which he says he stopped caring, he refers to wanting to provide the 'safest, best care' medically.

This paradox illustrates the difficulty experienced when two worldviews exist in close proximity, but it also shows that by focusing on an interest in providing the best care, quality treatment can be delivered without judgement. From his perspective, the type of dialogue that looks into how and why that patient is in his care is not useful for him to do his job, but perhaps the simple finding of a shared will for that patient to get better goes some way to close the gap in perspectives that exist between them. As a contrast, a member of the team working in the family support centre (FSC) described her experiences of conversing with patients to assess their emotional needs: *'And for me, that's about finding solutions with the people, finding common ground together, because that is when you can help people. Because if you can't find common ground together, you cannot find solutions, or they won't be solutions that they can use – they are useless.'* From her perspec-

tive, renegotiating what works for her patients through the consultation in terms of social determinants is the key.

*When two-way dialogue breaks down and rumour takes over, the consequences can be fatal, but, as evidenced, are not irresolvable. It is through the establishment and renegotiation of understandings that dialogue can be most effective, for example in resolving rumours after the hepatitis E outbreak in Maban.*

*'Jaundice is a very dangerous disease people are saying. I myself, I was sick with this disease also. But I got treatment in MSF.'* (CM2) During the hepatitis E outbreak in Maban and for some weeks afterwards, attendance in the maternity wards fell; this was believed to be linked to women avoiding coming to the hospital to deliver for fear that it was unlucky. The medical teams had to act quickly to rebuild trust and confidence in MSF's facilities. This was successfully achieved, in part by moving the main hospital to a new building, and in part by communicating carefully and effectively with key members of the community:

*M2 – 'You really have to be careful how you transmit your messages – when you introduce something new, when you cut out something... How you are transmitting the message. Because there's no need for mobile phone or internet in this camp, it just goes – like wildfire...'*

Awareness among the international medical staff, as well as the attendance at many community leader meetings by the project coordinator, allowed MSF to set up other opportunities to ensure that the correct messages filtered through and that feedback from patients could be gathered. Hourly health



Maban, South Sudan. Photo: Corinne Baker/MSF

talks also take place to the women waiting for antenatal and postnatal care on topics such as hepatitis, malaria, immunisations, hygiene and breastfeeding; because the talks are to a small number of people and in a safe, enclosed, female-only space, the women also provide feedback: *‘you changed this in the schedule and we don’t like it or we’ve heard about this implant you are offering – what’s that?’* (M1) MSF practitioners in the hospital in Maban had different levels of awareness of and involvement with the community and engagement was viewed differently between individual medics, but when engaged in purposefully and continuously, the results of positive dialogue were clear.

## Messaging can be lifesaving

*It is through messaging that MSF invests most in more prescriptive, or formal, dialogue activities in Maban.*

The importance of meeting medical needs can be seen as central to MSF’s *raison d’être* to save lives and alleviate suffering, but from a practitioner perspective it also carries great weight in establishing a relationship with the community. Successful outcomes are essential in building and maintaining MSF’s standing as a trusted service-provider. From the international staff focus group, it can be seen that this position is in fact fragile and at risk

of shifting if it were not for the effective use of dialogue between the outreach team, beneficiaries and hospital staff:

*M2 – ‘We went to this women’s meeting in a neighbouring camp and we were invited to talk about the new hospital that had just opened... And these were women elected by their Sheikh to represent the women of Gendrassa camp... they were quite a high ranking women. And they were all asking about this man who is employed to kill women in Batil. And then, sort of... where do we even begin?... Where are they, how to meet them? And sort of really emphasising that... there are only women working there and we want the best for you and... you know... But it just shows how important it is with these kinds of interactions – because I guess also in a way these women are kind of trend-setters. If they agree with something, it’s ok, and if they don’t approve, then... then it can be quite fatal for the others.’*

As MSF interacts with its beneficiaries through dialogue, the tool that a particular population uses to validate information does carry notable weight when considering the operational perspectives of community engagement. By seeking to understand how truths are sought and how messages (and reputations) travel, outreach activities can be designed to be specifically relevant for a local population.

An example gathered from the focus group with international practitioners supports this point, describing the struggle to persuade mothers to allow use of nasal gastric (NG) tubes for feeding their young babies. It also shows the team alluding to the importance of positive examples or actions of care.

M1 – *‘We showed them another baby who had done well – ok talk with the parents – and after a while they took it. And the baby survived.’*

M3 – *‘And then the mother became something like an ‘expert mother’ and she was asked to communicate to her village that NG tubes are not deadly for the child... “I accepted the NG tube and that’s why my child survived even though it was so little,” and apparently within this small community that really worked well. I mean that’s at least a thing to start with, no?’*

There is room to build on the successes of the outreach team’s activities in order to make the messaging system in the camp more of a two-way interaction with MSF. Providing information on health issues, health protection and water and sanitation advice is an essential part of MSF’s role in the area, but it is more often than not a one-directional communication channel from aid providers to aid recipients.

## Outreach validated

Through intensive daily work by the outreach team on water and sanitation messaging and awareness-raising of MSF’s work, lifesaving information can be spread and established within the camp setting.

The knowledge sharing or messaging of MSF’s work was referred to by most of the participants in Maban without prompt and was highly valued. The most common experience of MSF for participants outside the hospital compound was interaction with the outreach teams:

*‘They are telling us about housekeeping.’ (CM10) ‘They are telling us – giving us awareness. For example, keep the area clean and before eating, wash your hands with water and soap and after also like that. Also when you go to the latrine and also after coming from there, wash your hands with water and with soap also.’ (CM3)* These phrases, and many similar, describe the health messaging activities that the outreach teams perform every day around the camp. Every participant for whom this came up could name all the ways that MSF tells them to prevent disease and most referred to this activity as ‘protection’. Many of the interviewees prioritised (health) protection above anything else in their current situations: *‘Health is more important than anything else... This thing is taught to us by them. We did not bring it from elsewhere.’ (CM12)*

In Tari, there is potential to improve programming through outreach in order to optimise the value of dialogue, particularly in raising



Yida, South Sudan.  
Photo: Yann Libessart

awareness of the family support centre's work with victims of family and sexual violence to support the medical and emotional health of patients. There are opportunities to scale up outreach activities in order to promote awareness of who and what MSF is and, potentially, to improve security for patients and staff. Outreach activities should build on local expertise and experiences of security as a common issue.

*'It's better if MSF go and speak to them about how to stop violence. If you speak to them, they are human beings, they will listen and understand that those are the people who help us in the hospital and they will follow what you are saying.'*(CM8) *'It's good if you can talk on the road or relate messages with the patients coming to visit MSF – tell them to pass the message on.'* (CM11) *'There'll be enemies on the road – it's good that MSF only doesn't go alone. You should always go with some people.'*(CM5)

In Yangon in recent years, outreach and sensitisation with regard to HIV has taken on a different form: *'But nowadays because of the TV programmes, people have more awareness of this disease. So now the reaction is not as bad as it was in 2001. They are more prepared.'* (CM6) *'Now, lately, regarding this disease, there are programmes broadcast on TV. But still there are people who don't watch these programmes.'* (CM4) These TV programmes, as CM4 describes, may not be watched by a wide audience, but for those newly diagnosed with HIV, they may represent a lifeline for accessing information anonymously.

9 MSF clinics maintain confidentiality internally through a code system. Each patient is given a code at the start of their treatment, which stays with them throughout their years of care. They are called for appointments by this code rather than by their name, and their prescriptions and drugs are labelled with it. This is greatly appreciated by patients and adds to feelings of trust in the relationship that patients feel they have with MSF as a treatment provider.

### 3 Access, security and accountability

#### A catalyst for access

*Stigma is central to the experiences of people living with HIV/AIDS. In a low-prevalence context such as Myanmar, the experiences of discrimination and the shame associated with disclosure of a positive HIV status limit access to care by closing down the opportunities for open dialogue.*

The value of MSF's programme in Yangon, where HIV stigma has a negative influence on access to healthcare, is seen not only in its comprehensive treatment package, but also through the respect shown to patients through the programme's commitment to privacy and discretion. Participants in the review referred to MSF's good reputation for confidentiality within its clinics and related that as an important feature of respect and care. This is especially important for those patients who have moved to the city in order to maintain the anonymity that was not possible in their hometowns. *'After going back to my native town, some friends told me that my friend-doctor who referred me to Yangon told other friends I would last only one month... When I went back they thought I was a ghost!'* CM4 *'Other organisations when they call out, they just call out the name of the townships, they call out the name of the township and the age... they don't keep a code number like AZG.'* CM5<sup>9</sup>

The social backdrop to the disease seems to create a sense of risk that makes people fearful of reactions by the community to their

HIV-positive status, as well as individual fears of the disease itself. Once tested HIV-positive, many participants described a state of disbelief and non-acceptance, possibly as a consequence of stigma.

*‘My mother forced me to take the blood test and because I feared that I would have that disease I didn’t go back to find out.’* (CM8) *‘When I found out that I had this status I couldn’t accept it. That was in 2002. I got the treatment only in 2005... I couldn’t accept I was positive (until then)... At that time people don’t accept HIV, even I myself don’t accept it. People are very much afraid of that disease... as far as I know I didn’t do anything wrong that would make me contract this disease.’* (CM7) *‘I was going abroad and had to have a (routine) medical check-up for this disease. But I didn’t believe it.’* (CM6)

It is within this context of silence and denial, in addition to the fear of social isolation, that people struggle to know what to do in order to access care. *‘As for me, when I learned about this disease I didn’t want to talk to any people, I just stayed by myself and sometimes I would go to the pagoda. Sometimes when I saw a train coming I would think of jumping in front of it in a suicide way.’* (CM6)

So fear of the disease dictated by social stigma surrounding those who are HIV-positive thus seems to be a significant barrier to care. Participants reported a reluctance to ask questions openly, despite acknowledging that information was the first step in finding potential treatment: *‘Only when they contract this disease they come to know about this disease.’* (CM7) *‘When I got this disease, I didn’t know that these*

*organisations exist... (There was) no information.’* (CM6)

*MSF can identify and optimise opportunities for dialogue at different stages of the patient journey and in particular in the initial period after diagnosis, which was identified as the most fragile moment.*

In Yangon, the most fragile moment of limited access for the newly diagnosed patient is early on in their experience of living with HIV/AIDS. The period between diagnosis and treatment, whilst described as a time for searching for care and knowledge, is also an instant to increase dialogue between practitioner and patient, in order to optimise access to treatment and overcome that initial access barrier.

*‘They just don’t know what to do. They have this disease and they don’t know what to do and they don’t want to disclose their status... we don’t know where to go, what to do.’* (CM7) *‘It wasn’t easy to get help. Through a connection with a friend... I disclosed – that was easy because we were friendly with each other.’* (CM5) It is evident that the shame of disclosure impacts negatively on health. This was described most vividly by CM8 when narrating the experiences of a friend who never accessed treatment: *‘Only recently, less than 7 days ago, a friend who was very close to me died. Because she didn’t disclose, I couldn’t do anything for her. I had disclosed myself to her, but she didn’t say anything. Because she felt ashamed, she didn’t disclose and then she died.’*

However, constructive examples of learning about treatment options and HIV were often described in terms of luck or chance. CM6 de-

scribes a coincidental resolution to his friend's feelings of despair on discovering his HIV-positive status: *'He screwed up his paper (positive blood test results) small and hid it in a wall – he just went around riding the bus for 2 weeks. Only then someone told him there was this AZG so he retrieved the paper and he came to this centre.'*

One of the most common paths to accessing care was by word of mouth: *'This younger sister's husband's brother is taking treatment from AZG... so she told our mother. As for my mother, she is raw – she knew nothing about it.'* (CM9) *'I didn't know these organisations but through my friends. That friend's brother is taking treatment from AZG.'* (CM8) *'That friend's aunt has this disease... she is well-to-do. She says 'I sympathise with you, don't tell everybody. I'll give you the address.' That's how we came here.'* (CM3) On further prompting about how she knew it was safe to tell this friend's aunt, CM3 explained, *'I wanted to tell about my status and she opened up like that, so it was chance.'* CM4 described the seemingly impossible task of finding the information he needed and then, due to the difficulty of it, was inspired to set up an informal group with fellow sufferers which raises awareness about patient options: *'Because of that experience, we form a self help group. By chatting we find out among ourselves what to do, where to go.'* (CM4)

Dialogue can be used to overcome barriers to care by looking at catalysts for access, seen in Yangon as good quality pre-test counseling and a comprehensive treatment package.

Perception change towards the diagnosis of a positive HIV status was evident and seemed

to be related to the growing availability and uptake of pre-test counselling: *'There is still a reaction, but because of good pre-test counselling, people are well prepared. They can think ahead. If we have this disease what should we do? They can think ahead and prepare. They can think what things they can do.'* (CM6) *'By telling C1 (pre-test counselling), they know that they need to do a blood test. They got a clue. They come to know what to do.'* (CM7) Pre-test counselling equips patients with options and knowledge about HIV/AIDS so that the path to accessing care after a positive HIV diagnosis is clearer and less dependent on chance or individual risk.

In Yangon, the 'one-stop-service' approach is seen to be essential to participants, especially those from out of the city and those who are already financially disadvantaged, as it reduces travel time and additional testing costs. *'One good thing about Thasein clinic is that it has all the facilities. You can have blood tests, collect drugs and then you have counselling.'* CM8. *'You could have access to all at AZG – you can take blood tests, you can have x-ray, everything is perfect and complete.'* CM4. AZG's comprehensive approach is seen to be one of its greatest assets.

*Dialogue plays an essential part in supporting patient access to medical services.*

'Enemies on the road' was a common phrase used in PNG and people from outside Tari were especially nervous of entering town in order to reach assistance at the hospital. Talking to the community it became apparent that even those who did feel secure enough to make the journey often had their own explanation of why this was, for instance: *'We don't have enemies on the road be-*



*cause we've already compensated each other by giving them pigs.'* (CM7) However, it was clear that others felt that they would be more secure only once they had reached the relative safety of the hospital:

*'Enemies won't follow them into the hospital area, but if they meet them outside the hospital, they will kill them or attack them.'* (CM9) *'Inside the hospital I feel safe because of the securities around here. It makes us feel safer.'* (CM11) *'MSF provides securities for us and they keep the door locked and when someone comes to see us they check with securities and speak on the radio. That's why we feel safe inside.'* (CM4)

*Security within the hospital in Tari counts on local understanding and protection that in turn is dependent on MSF's reputation within the local community.*

Despite Huli people's views on resistance to outsiders and MSF's acknowledged position as outsiders, MSF is allowed to stay freely. There is no question in the narratives that it is the local population that permits this

rather than simply tolerating something they did not choose. *'It's because we know that they came here to do good work and they are here to help the Hela people. That's why we let them stay freely. When more people come back to the village from MSF, they give us good reports about MSF. People know about that so they won't disturb.'*<sup>10</sup> (CM8)

To expand on the difference MSF occupies as an outsider and why the perceptions of MSF are less negative, a logic can be found in all the narratives: that MSF will be safe so long as people know what they do. Not because there is evidence of the medical neutrality that MSF values, but because local people know that as individuals, they may come to rely on MSF at a future date. Leaving MSF to operate in safety is seen to be a pragmatic choice: *'(Once you are known) there won't be any enemies there because they know that if they have the wounds they will come to this hospital to see the white doctors. So they won't do anything to hurt MSF... They know that if they have accidents they will come straight to MSF.'* (CM6)

10 When transcribing, asked for clarification on the word 'disturb' the translator explained it was not a direct translation from a Huli word, but interpreted it: 'to attack or to stop MSF's work in some way'.

Another participant reflects this when he says, *'I don't think there is anyone against MSF. Because after all, when they get the bush knife marks and chop each other, where will they go? ... There's three things: The police are here to give law, the schools are here to educate. MSF is here to give us medicine and help us. MSF is one of three important things.'* (CM3) In his opinion, MSF is as central an institution in Tari as the police and schools. But it is important to remember that all three have been introduced into Huli society relatively recently and there are still many who do not attend school or respect the police or any law but traditional law. What stands out, however, is that MSF is not likened to foreign extraction companies. Or if they are compared, it is to emphasise MSF's value to the community, or acknowledge the separate agendas of the two:

*'All of us know and see that MSF, what they do is quite different... And all of us in my village we are very happy for that and people see that LNG or other companies are separate from MSF in what they do. You are here to help us, everybody knows that.'* (CM12) This last comment is a reference to the Liquefied Natural Gas (LNG) project that is active in the area.

The fact that many participants already see MSF as independent and impartial with no economic interest in the area is an important asset in perceptions of MSF's activities. When scaling up outreach and awareness to promote knowledge of MSF's work further afield, this can be emphasised, so that dialogue can occur within the accepted bounds of a medical, humanitarian agenda.

*Dawei, Myanmar. Photo: Ron Haviv/VII Photo*



***Dialogue** /di'ælɔ̃g/: a two-way, ongoing communication process to increase mutual understanding.*

Can MSF increase its engagement with local communities and improve the outcomes of its medical programmes by communicating better with the people it aims to help? Is drinking tea together enough for mutual understanding, or does a healthy dialogue require a more structured approach?

These were some of the questions we took to three MSF projects – in South Sudan, Myanmar and Papua New Guinea. There we talked to staff, patients, carers and members of their communities to find out what dialogue means to them.

Their message came across loud and clear: involving patients and communities in decision-making, and consciously looking for common ground, will help MSF build relationships based on mutual trust and respect, while improving its accountability and programming and gaining a better understanding of its patients' needs.

### **The conclusion?**

**Drinking tea together may be a good place to start, but establishing continuous dialogue is a two-way process and nothing short of essential.**