

DISABILITIES AND MEDICINE
A SURVEY OF THE AMMAN
SURGICAL RECONSTRUCTION
PROJECT 2012

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CONTENTS

PART 1- THE SURVEY	9
Introduction	9
Treatment duration and objectives	12
Pain assessment and management	18
An MSF canteen at the hotel?	
The meals issue and reactions to the catering project	24
Limitations of the survey	29
Treatment duration and objectives according to the medical personnel	30
Punishing or changing behaviours. What does MSF not allow?	34
PART 2- THE INTERVIEWS	39
Antoine Foucher and Jean-Hervé Bradol	39
Chiara Lepora and Jean-Hervé Bradol	44
BIBLIOGRAPHY	59

PART 1

THE SURVEY

INTRODUCTION

Our survey bears something of a resemblance to a study carried out by Vanja Kovacic in Homa Bay, Kenya, in which she investigated patients' disease coping mechanisms and their "dependence on medical institutions" (V Kovacic and J. Amondi, "Social navigation and HIV/AIDS", in "AIDS: a new pandemic leading to new medical and political practices" *Cahiers du Crash*, 2011, p. 81). In Amman, we also studied this "dependence" and its practical effects on long-term treatment, both from the patients' standpoint and from that of MSF's project teams. MSF-OCP was also keen for us to establish whether any questionable disciplinary measures were being taken against patients on the project, notably the withdrawal of medical care. Our study revealed that there was indeed a risk of withdrawal of medical care for those that did not respect MSF's rules: for the patients however it was not clear what sort of behaviour could lead to such a sanction.

We used a qualitative approach in our survey. Consequently, the people interviewed did not constitute the kind of statistically representative sample usually formed by the drawing of lots. However, we did seek to obtain enough diversity among our subjects to determine whether attitudes and points of view varied according to nationality and gender.

You may ask whether there is any point to a qualitative survey of a long-term MSF project in which the sample used is not statistically representative. The answer to this question can be found in one of the specific contributions of this approach, i.e. the focus placed on the different learning processes undergone by the patients: learning about their treatment, care and medicine (therapeutic modernity); learning about how MSF operates, the relationships of authority

within MSF as an institution, the negotiations possible with those in authority and with responsibility and the rules governing life in the hotel; learning also about their disabilities and the transformations to their lives caused by their functional impairment (learning processes shared between patients having suffered similar traumas and with similar injuries, each observing the outcomes and the benefits of treatment on others who have been there longer and received comparable medical care). This focus on learning processes can be found in a number of publications on chronic disease management, although these other publications have mainly studied the distribution of tasks between therapists and patients, the exercising by patients of diagnostic and therapeutic functions usually reserved for doctors, and the pedagogy surrounding patient support and the explanation of treatment objectives.

For the purposes of this survey, we interviewed patients about their care pathway before arriving in Amman, about their experience of medical care with MSF, their expectations, their relationship with the health care personnel and their perceptions of the hotel-rehabilitation centre system (rules of behaviour introduced by MSF) and how they had adapted to it. We also interviewed the care staff and practitioners about their relationship with the patients, their definition of treatment objectives, their prognoses and improvements to medical and surgical services.

We have also reported here on the tensions existing between the patients and those treating them. Our intention has not been not to criticise the MSF project or defend the patients against the institution, but rather to accept that “in any situation of interaction, however regulated, there is always the possibility of the unexpected or of non-compliance” (Nicolas Mariot, 2012). We also look at the way patients talk about their medical environment and living conditions, allowing for the fact that, for most of them, what they are experiencing is quite remarkable: they never imagined having access to this kind of medical service.

The tensions described correspond to the problems that were causing the most concern to the project's patients in September-October 2012. We have recorded and studied what they had to say about these problems and tensions and have concentrated much of this report on studying their words, as they reveal to us different ways of perceiving, fostering and strengthening patient autonomy.

Amman SRP (Surgical Reconstruction Project)

End of September 2012

(Source: Patient follow-up document from 26th September 2012)

Total patients: 282 incl. 49 women (17%)

Iraqis	136	48%
Syrians	108	38%
Yeminis	35	13%
Gazans	3	1%

Patients under 30 years of age: 154 (54.6%)

For new admissions, the project sets a monthly objective per nationality: out of the 50 new patients admitted each month, the objective is 25 Iraqis, 15 Syrians (30%) and 10 Yeminis (Amman, December 2012, ref: *Monthly No. of Patients and Care-takers January – October 2012*).

At the end of September 2012, out of a total of 282 patients, 79 had been receiving treatment for at least 4 months (28% of patients), including 46 patients who had been receiving treatment for at least 6 months (16% of patients).

In mid-December 2012, out of a total of 244 patients, 101 had been receiving treatment for at least 4 months (41% of patients), including 49 who had been receiving treatment for at least 6 months (20% of patients). (Source: Patient follow-up documents from 26th September and 13th December 2012).

At the end of September 2012, 265 patients and care-takers were accommodated by MSF in several hotels and six apartments. During the month of September, 150 patients and care-takers were being accommodated in the five-storey hotel in which we conducted this survey.

“Disability and medicine” survey: key figures

Number of interviews studied

Patients:

28 including 8 women

Iraqis 14 including 7 women

Syrians 10

Yeminis 4 including 1 woman

Their distribution by age was:

Under 30 years of age: 22, **30-44 years:**5, **45-59 years:** 1

Care personnel

Doctors, surgeons, physiotherapists: 13

Nurses (hospital) & care-takers - care assistants (hotel): 5

Administration, coordination: 3, as well as non-recorded interviews.

TREATMENT DURATION AND OBJECTIVES

Before being admitted to the Amman project, future patients are frequently told back in Iraq and Yemen that their treatment will last “from four to six months”. Once their treatment is underway and they realise that it will in fact last longer than this, they start to question the doctors, surgeons and nurses. Their questions reflect their hopes for the outcome of their treatment, their concerns about their family and professional circumstances, their desire to understand their medical treatment and, for some of them, their involvement in the events taking place back in their home countries. So, the patients ask for explanations about the duration and the outcome of their treatments. As for the health personnel, they all told us that they provide a medical response based on their knowledge and experience gained over several years of treating these kinds of injuries.

During the interviews we conducted for the study we observed a variety of expectations and attitudes on the part of the patients with regard to MSF’s project, ranging from trust to criticism. We have therefore included a large number of extracts from these interviews in this report in order to reflect the diversity of opinions and demands.

I TRUST YOU

071 Male patient, 50 years old, interviewed in September and December 2012

Both his legs were injured in an explosion. He had undergone several operations in his home country and arrived in Amman in a wheelchair. The first phase of his treatment lasted a year. He then went home for a year before coming back to Amman where he was treated for another two years and six months. He left the MSF project in 2012. He said his surgeon was “very patient”, always willing to repeat his explanations. “I remember once, in 2009, he said he was going to operate on me and started explaining how and why. It was a complicated operation. I told him he didn’t have to explain it all to me. I said “I trust you 100%”. He said no, first you have to understand and then, when your family calls you, you’ll be able to explain your operation to them”. As for the treatment objectives from the patient’s point of view, he wanted “to get rid of the wheelchair”, but was under no illusions that his legs “would be like they were before”. This expectation coincided with the surgeon’s own treatment objectives: “He

told me I'd be able to walk with crutches, and maybe later without crutches". The patient didn't complain about the duration of the treatment which he recognised was also due to repeated infections and difficulties controlling them.

087 Male patient, 29 years old, interviewed in September and December 2012 (see p. 21, 28)

He had been shot in both legs and had already been operated on five times in his home country: "None of my five operations were successful".

He had been receiving treatment in Amman since the beginning of September 2012.

"Before I came, they told me the treatment would take six months, but it's taking longer. I'm still here because I want proper treatment, but I really miss my family and my children.

The surgeon told me what kind of operation he was going to do. I didn't understand everything he said, but I'm confident. I trust MSF's doctors.

I'm very pleased with the way my legs have been cared for. I hope I'll be able to walk without crutches one day".

077 Patient, 22 years old, interviewed in December 2012 (see p. 22, 27, 36)

He had a double fracture in one leg. The surgeon explained the operation he was planning. "I said I trusted him, but I didn't understand a word he said. I find that the doctors here say one word and jump three lines [say little and fast], but I can understand that. They haven't got much time and they've got lots of patients. The surgeon hasn't got much time".

BE PATIENT

068 Female patient, 28 years old, interviewed in September and December 2012 (see p. 20)

She had been undergoing treatment since the end of 2010. She had suffered severe burns when planes opened fire on her house and set it ablaze. Before coming to Amman she had been operated on several times, "without good results". She was getting desperate.

"When I came to Amman, I thought I'd only be staying a week because I had lost hope. On the road to Amman, I had prepared the conversation with the doctor in my head. I thought he was going to say: "We can't do anything for

you”, and I would go home to my country a week later. But it wasn’t like that at all and I’ve been here a long time. But I don’t mind it taking a long time because we’re getting good results”. She asks her surgeon questions but he doesn’t say much. He just tells her: “Be patient”. She said that since she’d been here no-one had ever told her that there was a limit to the duration of her treatment: “They tell me it’s going to take time, but they never actually say how long”. The criticism concerns the lack of explanation provided by the surgeon, despite the many questions put to him by the patient. But this hadn’t undermined her confidence in him.

085-1 Patient, 21 years old, interviewed in December 2012

He had been standing near a petrol station when a car bomb exploded. He received severe burns all over his body. He had been on the MSF project for one year and nine months when we interviewed him.

“I hadn’t been operated on before coming to Amman. Here in Amman, I have been operated on twice to put in a device that stretches your skin [tissue expander]. The surgeon hasn’t told me how long the treatment will last. But as stretching the skin will take six months I don’t know why the surgeon doesn’t start reconstructing my ears. That way I won’t have to stay so long and I won’t wait six months. When I talked to the surgeon about it, he said, “Be patient”. He hasn’t told me how many times he’s going to operate on me. I’ve been here for a year and nine months and I don’t know how long I’ve got to go. I’d like it all to be over with because I have to go back to school. There’s an age limit for free schooling”.

WAIT AND ASK QUESTIONS

080 Male patient, 22 years old, interviewed in September and December 2012

He had been injured in the leg and tortured in his home country, then operated on several times. When we met him in December he had been on the MSF project for five months and had been operated on and treated for an infection. “Nobody has talked to me about how long the treatment will take and I keep asking them about it. This has been going on for five months. At my last consultation with the doctor, I asked him again. I think he’s like me. He doesn’t know anymore than I do, because he looks at my x-rays and tells me to come back in a month, and it’s been like that for five months. They don’t know and

nor do I, but I'm waiting. I see a different doctor at each visit and they all have a different opinion. One doctor told me I needed a new operation; the second one said that I didn't need the operation; a third one prescribed three weeks of physiotherapy. I started, but the physiotherapist told me to stop. So I'm at the hotel and I don't know what's going to happen to me.

Nobody knows what's going to happen to me in the future, not me and not the surgeon. Here's an example: at my last consultation a month ago I saw Dr. X. He looked at my X-rays and said there was a slight improvement. I asked him when he was going to take off the fixator on my leg. He told me he didn't know when because it wasn't clear (on the x-rays). He asked me to come back in two months. They're still thinking about what they're going to do for my leg! And I'm here, at the hotel, just waiting. I eat, I sleep and I drink... just water! At the end of the interview he added: "With no explanations from the doctors we feel like laboratory mice".

081 Male patient, 26 years old, interviewed in December 2012

He had been shot in the leg. He turned up at MSF's OPD in Amman and was admitted to the project three months ago.

"When I arrived on the project in Amman, I hoped that I would be walking normally again within two or three months. But the treatment is taking a long time without much result. In my country, I was operated on and had physiotherapy for a month and that did me a lot of good. But here I've been having physiotherapy for three months and there's been no improvement. On the contrary, I'm in more and more pain. What did me good here was when they operated on me to take the plates out of my leg.

Before he operated on me the surgeon told me what he was going to do, but he didn't tell me what the result would be or how long I would need treatment for".

084 Male patient, 33 years old, interviewed in December 2012

He was at the market when a car bomb exploded. He received shrapnel wounds to one of his legs. As he was running away, he was run over by a car. He had been operated on seven times in his home country before being admitted to the MSF project in Amman. His first stay was in 2010.

Before leaving for Jordan, he got a phone call from a staff member of the MSF project: "He asked me if I could stay in Amman for 4 to 6 months. But the doctors here tell you nothing. Once I asked a doctor for an idea of how long the treatment was going to take. He said maybe six months.

When I got here my leg was infected. It has been infected for four years. The infection comes and goes. The surgeon told me how important it was to treat the infection and that if we didn't treat it, the operation wouldn't work. He removed the plates and cleaned the bone. Then I went home to my country and 6 months later my leg was infected again. I called the MSF office and was brought back to Amman for the second time in 2012. I was put on antibiotics for two months and then went back to Iraq. The infection came back and I came back to Amman for the third time". He added: "The surgeon didn't tell me what results I could expect from the operation."

PERCEPTIONS OF TREATMENT DURATION AND OBJECTIVES

047 Male patient, 24 years old, bullet wounds to the leg, interviewed in September 2012

"I want to go home. I really miss my mother and my brothers and sisters."

054 Male patient, 22 years old, interviewed in September 2012

He had been shot in the arm. Before coming to Jordan he was afraid his arm would be amputated ("If I go to the doctor, he'll cut my arm off straight away"). He had been operated on in Amman and undergoing physiotherapy for five months.

"We're here for treatment and then we want to get home as quickly as possible and continue the fight. Once the treatment is finished I'll be out of here like a shot."

076 Female patient, 22 years old, interviewed in December 2012

She was at the market when a car bomb exploded. She was severely burnt and contacted MSF.

"I filled in the forms, but I didn't hold out much hope. But I did it anyway because I didn't know where else to turn. You won't believe it, but the night MSF called me I was in the depths of despair.

Before I came to Amman, I was told that the treatment would take four months [when we spoke to her in December 2012, she had already had a year and a half's treatment]. I knew that wasn't possible. I've left my son with my mother. I've been operated on several times and I'm satisfied because now I can use my arms and my hands – enough to take care of myself, change my clothes, get myself a glass of water... I know I'll never be like I was before, but I'd like to be independent enough to look after myself and my son.

Since I arrived here, I've never been back to my country [i.e. for a year and a half]. I'm finishing my treatment so I can be more independent when I go home."

051 A father accompanying his 10-year-old son, interviewed in September 2012

The treatment is taking longer than initially forecast ("It'll take six months, but we've been here for nine months"). However, the father-caretaker added: "That's not a problem. The important thing is that they treat my son." He has taken a year's unpaid leave to look after him.

063 A 19 year-old accompanying his young brother who had received shrapnel in the leg in a car bomb explosion, interviewed in September 2012

The treatment is taking longer than forecast: nine months so far, rather than the six months he had been told it would take. But this is not the most important thing as far as he is concerned. It is the quality of the medical care that counts most and in this respect the older brother considers that the care team has not failed - quite the contrary. He can see that the young boy is better since his operation and a two-month treatment for an infection, and so he has no desire to criticise. "My brother's health is the only thing that matters."

With regard to the explanations given by their surgeon or doctor about the duration of their treatment, the patients' reactions vary between two extremes. These opposing reactions can be seen in the following two quotations: "I think the doctor is like me. He doesn't know either", and, "I told him he didn't have to explain it all to me, I trust him". The person who said, "The doctor doesn't know either", is right if he meant that prognosis is not an exact science. It shows that he is aware of the uncertainty inherent in the treatment, its duration and its outcomes, including the possibility of therapeutic failure. It remains to be established whether the explanations given help patients to come to terms with their current and future disability, to continue learning to live with a chronic disability during their stay in Amman. We say "continue", because most of the patients arrive in Amman a year or often more after the trauma and have already experienced intense pain. They've been through a first phase of treatment after which the doctors in their home countries have often told them there was nothing more they could do for them.

The project's psycho-social team, led by a psychiatrist, sees patients when they

first arrive, before each surgical intervention, and upon request. Some patients follow a treatment prescribed by the psychiatrist and consult him regularly. In many cases, the psycho-social team is asked about the surgery and the post-operative care, and is also often asked to explain the diagnoses and the prognoses made by the surgeons and doctors.

PAIN ASSESSMENT AND MANAGEMENT

In our interviews with the medical personnel on the subject of pain management we obtained descriptions of what the practitioners consider to be good practice rather than accounts of the different attitudes and decisions they actually adopt in their medical work. We also discovered tensions between clinical pain assessment and the implementation of international norms recommending that patients be encouraged to assess their own pain levels. Yet according more confidence or relevance to the clinical observation of pain than to the assessment made by the patients themselves can lead to a paternalist attitude towards access to analgesics. This attitude arises when the care-provider questions the patients' credibility, considering that "they don't know how to measure their pain on a scale of 1 to 10", and that their own assessment is more accurate as it compares the numerical response with the physical signs and functional consequences of pain that they have been trained to decipher. One nurse told us: "You need to know what you're doing to detect pain". She added that by observing whether or not the patient was able to sleep, she could check the accuracy of the self-assessment: "There are sometimes patients who cry with pain and tell you that it's 5 out of 10, and yet they can't sleep at night. And then there are patients who say it's 10 out of 10 and when you go back half an hour later they're asleep" (Nurse 078, interviewed at the hospital). Another nurse stressed that she always explains how to use the scale: she translates it into qualitative terms such as "bearable pain" (1 to 3), pain that stops you from sleeping (4 to 6) and "unbearable pain" (7 to 10). The same nurse pointed out that there was uncertainty involved in any assessment, reminding us of the well-known fact that the feeling and expression of pain is different from one person to another. Therefore she draws on both the patient's self-assessment and her experience of the signs of pain, and checks the concordance between the self-assessment and the signs she would expect to find: "In my experience, I have seen patients who cry out with pain, but when you

look at their face you can tell that it's not that bad. Others don't cry out but their pain is intense enough to stop them from sleeping" (Nurse 079, interviewed at the hospital).

In other words, for these nurses, a realistic appraisal of pain levels has to be based on a combination of the patient's self-assessment and the clinicians' own appraisal. How this pain is then managed is determined by a protocol. One of the doctors stressed the importance of the self-assessment in treatment: using the intensity scale is a means of determining how the feeling of pain evolves, the "pain trajectory". "I consider it to be a very important follow-up marker". It can be used to produce a document (pain follow-up sheet) like the temperature sheet, i.e. to provide a solid basis for applying the protocol. It would be interesting to conduct a study into the implementation of this protocol, a participant observation carried out at the hospital.

Lastly, it is important to note that the practitioners working on this MSF project are dealing with types of pain that, as one of them acknowledged, he was completely unfamiliar with before coming to Amman: "I'm a surgeon. I follow the psychiatrist's recommendations. That's not my job. Take post-traumatic stress disorder, for example, I'd never heard of it before coming here. I know nothing about the subject."

According to the sociologist Isabelle Baszanger, in an article published in 1991 on deciphering chronic pain, "the first task of medical work is to find out whether the pain can be projected onto a body-map, to determine whether there's 'something or nothing'" (Isabelle Baszanger, 1991, p. 37). In his way, one orthopaedic surgeon recognised that, from his professional point of view, he is regularly faced with this "nothing". It's a "nothing" that he refers to other specialists, psychiatrists and psychologists: "We see quite a lot of patients who have been tortured and who complain of pain that's a bit hard to explain, doubtless due to a psychological trauma. They describe scenes of torture. Clinically and radiologically, we can't find anything. There's doubtless a physical element to it, but there is also psychological dimension. There are quite a lot of Syrians in this situation" (Surgeon 059, interviewed in September 2012).

PAIN MEASUREMENT

The most radical approach to pain measurement consists in comparing current pain with pain felt previously, especially during torture. Thus a patient told us that he had been arrested with a bullet wound to the leg. In prison he was sus-

pended by his arms for hours on end. In Amman, he was given physiotherapy. Before each session he took a pain-killer: "It calms the pain. It doesn't stop it, but I'm used to this level of pain". This patient refused to be operated on so that he could get home earlier. His shoulder was still painful when he left.

Another patient, severely burnt in car bomb explosion, told us that after an operation on his neck he was in pain for a week. Yet when asked about how he had assessed the intensity of the pain according to the numeric pain rating scale of 1 to 10, he said 3 to 4: "But it was more than that. I told myself that I could bear the pain with the painkillers they gave me, but they didn't help. It was ibuprofen and paracetamol. The pain went on for a week, but I put up with it because the pain after the accident was a hundred times worse".

At the hospital, the nursing staff note pain intensity according to the numeric pain rating scale used in self-assessment, but this method is controversial. Some patients obviously find it difficult to understand, whereas others admit that they don't give the real intensity of their pain, but the level they want to share with the medical team. This was the case of a patient who assessed his pain level to be 10 but told the nurse it was 7, thinking that he would be able to bear pain that could be considered "unbearable" (i.e. level 10). This patient was obviously acting more as a subject participating in an on-going negotiation with the medical team than as an assessor of his actual suffering. In truth, we are only confirming a well-known fact here: there's nothing exceptional about finding inconsistencies between the point of view of the person declaring his or her pain and the point of view of the person measuring it; the former is negotiating treatment and the latter is adhering to protocol by endeavouring to objectively identify the signs and give an objective foundation to medical decisions.

068 Female patient, 28 years old (see Treatment duration, p. 13)

"After the operations to my face and neck I was in a lot of pain; The doctor didn't explain why and the nurses who gave out the medicine asked me just one question: "How much pain are you feeling, give us a rating between 1 and 10?" I've been to schools, I know how they mark dictations, but the other patients in my room didn't know what to say, so they would ask me: "Do I say 3 out of 10 or 5 out of 10?" I spoke to the nurse about it. I said: "you should explain what you mean by rating because the other patients are asking me about it."

When the nurse left, everyone would ask the others what rating they had given.

For me, after my operation, I said that my pain level was 9 out of 10. I was given tramadol: two tablets a day. It calms the pain, but it doesn't make you sleep. It's not like the injection that calms the pain and sends you to sleep. With tramadol I feel like I've been anaesthetised and I don't like that feeling much because I'm not in my normal state. But I take tramadol anyway because otherwise the pain is unbearable.

When the tramadol is prescribed at the hotel, you have to go down to the nurses' office and they give you the tablet: they have to see you take it."

087 Female patient, 29 years old (see p. 13, 28)

"I was treated for an infection in my injured leg and then I was operated on. I was in a lot of pain after the operation and at first they gave me tramadol tablets, but I was still in pain and couldn't sleep, so they gave me tramadol injections for three days. Then they went back to giving me tramadol tablets. When they asked me to say how much pain I was in on a scale of 1 to 10, I said 7/8, but it was more.

Sometimes at the hospital I don't say anything about the pain. I tell myself it'll go away on its own."

ANALGESICS: SOME PATIENTS ASK FOR THEM, OTHERS REFUSE THEM

We have taken a close look at the relationship of negotiation between the patients and the medical team with regard to treatment. Many patients have been disabled for many years and have undergone surgery both in their home country and in Amman, and they also talk amongst themselves. It may be stating the obvious to say that these two learning experiences determine people's current attitudes, in particular with regard to the taking of analgesics. This is clearly illustrated in the interviews: patients request or refuse to take analgesics when prior experience of analgesics and rumour carry more weight than the opinion of the doctors.

047 Male patient, 18 years old, interviewed in September 2012

He had been shot in the leg and the bone tissue was infected when he arrived in Amman. He walks with crutches.

"After the operations, at the hospital, I asked for tramadol because it hurt so much, but sometimes they gave me other medicines that don't calm the pain. I ask for tramadol and sometimes they give me some, but it's rare. They often

give me other pain-killers. I took tramadol at the hospital in Yemen and in Egypt and I know it's good for calming the pain.

I asked if they would just give it me for the first five days after the operation because I don't want to become addicted to tramadol. They always give me other drugs.”

066 Male patient, 30 years old, interviewed in September 2012

He had been shot in the tibia. A plate had been placed along his tibia in his home county. When he was admitted to the MSF project, he said that the plate was causing him pain. Two months later the doctor said there was no need to remove it and replace it with another one, which is what the patient wanted. He said to the doctor, “I'd like you to take the plate off because it's hurting me. The doctor's answer was, “No, not yet. If you stay in Jordan for a few months we'll take it off, but not now”. I don't think it's right because it's the doctor who decides whether or not you're in pain. The doctor said there were people more in need of an operation than me. But I'm in pain and I can't live without pain-killers. At first the doctor prescribed a pain-killer for me for a few days, and ever since I've had to try and get hold of them myself [he shows us the drug: tramadol 50 mg]”. He added, “The plate is hurting me now, as we speak. I don't take tramadol every day, just when I'm in pain. I've already tried not taking it at night, but then I can't sleep”. Another patient in the room where we were holding the interview asked us: “If I take tramadol for a long time, will I become addicted to it?”

We observed that there was a rumour going around among the patients about the risk of addiction to tramadol: “Will I be able to do without it?” Some patients believe in this rumour to the extent that they refuse to take analgesics, especially if they consider their pain to be bearable.

**077 Male patient, 22 years old, interviewed in December 2012
(see p. 13, 27, 36)**

The taxi he was riding in was caught up in car bomb explosion. The taxi driver and a passenger were killed. This 22 year-old man was wounded in the leg: double fracture. Two years later, MSF admitted him to the Amman project. “I feel pain in my leg, especially when I walk or stand for any length of time. The doctor gave me tramadol, but now I've stopped taking it because I've heard the other patients say you can get addicted to tramadol. The nurse at the hotel, when he saw that I was in pain, told me to come and take some tramadol, but I said no.

I took tramadol for 10 days and then stopped. Now I don't go out of the hotel much so as not to set off the pain. I spend my time on my laptop."

**085-2 Male patient, 33 years old, interviewed in December 2012
after other occupants of the same room and in their presence**

He had received burns to the face, chest, stomach and arms in a car bomb explosion and had been operated on several times.

"Sometimes I'm in pain for a whole week after an operation. They give me tramadol and paracetamol, but I don't really like taking tramadol because I don't want to get addicted. I've heard that others are. I've also heard that it has side-effects on your stomach".

The medical personnel are aware of the potentially addictive nature of tramadol and take precautionary measures. Several doctors have clear memories of dealing with this pathology with a patient from Gaza – one surgeon talks about a group of patients from Gaza ("They want tramadol all the time. They are the only ones addicted"). One doctor: "The most serious case was that of a young man who had been taking 800 mg a day when the maximum dose is 400 mg a day. The difficulty for us was determining whether the real problem was pain or addiction. That's really, really difficult". This is why tramadol-taking is meticulously regulated at the hotel-rehabilitation centre: "The tramadol is kept by the care assistants. They give out the prescribed dose and watch while the patient takes one or two tablets. There's always a care assistant present". This regulatory procedure limits the taking of tramadol. But there is still the problem of determining when a request for analgesic is "justified" and when it could be qualified as an addiction. As a result, care providers appear to be divided about the expression of pain. Some of them show a paternalistic distrust: "There are cases where a patient at the hotel cries out in pain and asks for tramadol and morphine. We take him to the hospital and give him a Voltaren injection (diclofenac). The patient thinks it's tramadol and says he feels better." Many care-providers think that at the first signs of addiction, the patient should begin treatment with the psychiatrist and his "medico-social" team. There are other patients who ask for tramadol simply because they have seen that this drug reduces their pain. They compare it with the pain-killers they are currently being prescribed and state their preference.

AN MSF CANTEEN AT THE HOTEL? THE MEALS ISSUE AND REACTIONS TO THE CATERING PROJECT

During our visit in December, patients were told that a new meals system was to be introduced at the hotel-rehabilitation centre. This system would involve MSF providing patients with three meals a day in the reception room of the 5-storey hotel in which we were conducting the survey. Until then, MSF had only been providing breakfast.

For MSF, this new system was important from a medical point of view. “A *Monthly Prevalence of Health Risks among Patients and Care-takers*” survey carried out in October 2012 with 163 patients and 70 care-takers revealed an “addiction” to tobacco among 30.6% of the patients, and that 33.7% of patients and 51.4% of care-takers were overweight or obese (observation based on the calculation of the body mass index) and 17.7% of patients were underweight. The decision to take charge of all the meals was based on this data.

At the same time, it was announced that the distribution of three meals a day would result in a reduction in the daily allowance paid to patients and care-takers from 3.5 dinars (€3.2) to 1 or 2 dinars. MSF’s coordination pointed out that the patients would no longer need to buy their own food, which would make the reduction in the allowance manageable. This project caused heated reactions among the patients. We recorded both criticisms and approvals in our interviews in December.

Why take a special interest in the disagreements surrounding collective meals? Our aim was not to highlight the criticisms made of the MSF project or defend the patients’ cause. Generally-speaking, observing disagreements is a useful exercise because of the discussions and reflections they generate on the normative framework put in place by MSF. In other words, the observation of disagreements is fertile ground for the sociologist.

The discussions generated by the collective meals project and the consequent reduction in the patients’ daily allowance are revealing, as they help identify different ways of perceiving and promoting patient autonomy.

What, for instance, do the patients spend their daily allowance on? Most importantly, it allows patients who receive no support from their family and friends a certain amount of financial autonomy. Some of them use it pay for their subscription to Internet, above all for Skype and Facebook. It is also used to organise collective meals in and between rooms, with the patients pooling

money to buy food. This type of spending creates and maintains relations between patients, relations of dependence and solidarity: notably for the micro-collective organisation of meals and computer use.

In December, we therefore put the following question to all the patients we interviewed: “What do you think of the project for a new meals system?”

DO ALL THE PATIENTS EAT BADLY?

084 and 085

We talked to a small group of male patients who share the same room, all from the same region of the same country.

“We are not in favour of the new system. We’d rather make our own meals, then we know what we’re eating and we make it the way we like it. And it also means we can get together at meal times, and that’s a very pleasant and relaxing occasion for us.

We eat very healthily. Today we ate beans and tomorrow we’re having fish and then chicken with vegetables. We buy fruit, milk for people who have problems with their bones like me. The fruit is for people with burns. I know that one of the reasons for introducing these meals is because some patients don’t have a balanced diet. It’s true; I’ve seen that for myself. They eat chicken and rice every day, and shawarma. But there aren’t many of them and it’s their problem. Why make us all take prepared meals because there are patients who don’t eat sensibly? Tomorrow we’re going to do our own shopping for the week” [He shows us his fridge: meat, vegetables and a bottle of milk].

Someone else wanted to manage his own mealtimes according to his physical condition. “I’m not in favour of this new service either. I prefer preparing my own meals at whatever time suits me best. If I were only staying in Amman for a couple of months, I could live with it, but I’ve already been here for a year. I couldn’t eat meals chosen by someone else for a whole year. For example, two days ago my leg was hurting me and I didn’t sleep at night, so I slept the whole day. I made myself a meal in the evening. I wouldn’t be able to do that anymore. I don’t even go down for breakfast now.”

Everyone else in the room agreed: they don’t or no longer go down for breakfast.

070 We interviewed several women sharing the same room.

They were all of the same nationality.

“We don’t agree with the new project. We want to keep getting the allowance like before.

Why make me eat at a fixed time? For example, yesterday I didn’t get back from the hospital until around 4 o’clock: would there have been any food left for me? We don’t know how long the sittings will last. With my room-mates, we do our shopping together. We buy fruit for the girls, and fruit juice and milk.

MSF thinks the patients eat badly, but I buy milk, fruit and vegetables. I know that my daughter must eat vegetables and fruit, and drink fruit juice because of her burns.”

Someone else: “Preparing our meals gives us something to do. We go up to the floor where the kitchens are, we chat in the kitchens and then we eat our meal all together in our room and, for me, it’s a happy time. We laugh, we talk, and we can all sit on the floor without our veils.”

079 Female patient, 22 years old

“They want to distribute meals because they say the patients aren’t eating properly, but I think we can solve this problem another way. I know that the objective of all the patients is to get well and go home. It would be better if there was someone to advise the patients on how to eat correctly rather than leave people no choice about what they eat in the evening. I think there are reasons why some people are not eating properly: depression or homesickness, the need to see their family, the length of the treatment... all this makes them lose their appetite.

Of course there are patients who eat badly, but why punish all the patients by imposing meals on them rather than go and see the patients who eat badly and talk to them about it?” This woman shares food costs with the other patient in her room. “We take it in turns to do the cooking. We eat together and it’s fine like that. If it were possible, it would be a good idea to increase the allowance a bit and let us take care of ourselves”.

In September 2012, practically all of the patients stressed that the MSF allocation was not enough to enable them to eat properly for a whole week. It was only thanks to help from their families that they were able to buy the goods they felt they needed and were good for their health. Not everyone received help from their families, but they were often helped by their room-mates and compatriots. This dependence was precious.

IN FAVOUR OF AN MSF CANTEEN

08 Female patient, 28 years old

“I’m in favour of the new meals system because we are not well and after an operation it’s difficult for us to cook and go out and buy food.

And we have to stock our shopping (oil, onions, eggs, etc.) in our room, which is already on the small side.

I’m in favour as long as it’s not the same food as at the hospital, because the meals at the hospital are not good at all. Whenever I spend a few days at the hospital I lose three kilos.

Question: Do you go down for breakfast?

Never. I’ve never been down.

Question: And will you go down for the meals?

No, not if it’s like at breakfast where everyone eats in the same room. I thought it was going to be like at the hospital where they give you your meals in your room. If it’s like for breakfast, I’m against the idea.

There are women at the hotel who wear a niqab to go down for breakfast, but I could never do that. It wouldn’t be practical, especially with the devices on my neck.”

077 Male patient, 22 years old (see p. 13, 22, 36)

“I’m very much in favour of cutting the allowance and giving us our meals instead.

It’s too complicated to do the shopping, cook, go and up and down to the kitchen; with my leg it’s difficult for me to do all that. Patients and care-takers have been to see me because they know I was the first to put my name down on the list [a list of volunteers to try out the new meals system, but that was never used]. I told them: “You might be capable of cooking for yourselves, but I’m not; and I haven’t got anyone staying here with me”. They said to me: “How will you manage on 7 dinars a week?” I said: “I know it’s difficult, but I’ll cope”. For me, the most important thing is the treatment”. The patient explained that before having a room at the hotel he had been living in a flat: “I used to live with three young men. I contributed towards the meals, I put money in the kitty and they did the cooking. At the hotel, food is a problem for me. When I buy sandwiches it’s expensive and after a few days I’ve got nothing left.”

087 Male patient, 29 years old (see p. 13, 21)

“I’m for the new system. The meals will be more balanced and MSF spends a lot on medical care, but in some cases it doesn’t work properly because people aren’t eating properly. I think it’s good. You eat what you need, the meals are healthy and you have a balanced diet. It’s going to be more expensive for MSF, but it’s in our own best interest.”

These responses are a clear indication that food and meals cannot be dissociated from treatment objectives or from the way patients organise their lives at the hotel. All the patients we have just quoted confirm the importance they attach to the quality of the meals: they help the treatment. Some say that they take this objective into account when preparing their own meals, but that they also like cooking, deciding for themselves what they are going to eat and at what time, and who they share their meals with (as opposed to being with everyone else in the big restaurant downstairs). Others see the canteen as a good solution for ensuring the quality of meals and for sparing patients the effort of going shopping, doing the cooking and storing food products: i.e. the canteen would free them from troublesome activities. The patients who express this opinion take into account the limitations caused by their disability, by the after-effects of operations and by orthopaedic devices. Some specify that they don’t know how to cook.

Another form of opposition to the canteen was observed, based on a different argument altogether. The objection concerned the reduction of the daily allowance accompanying the new meals system. It was this reduction that posed a problem, not the distribution of the meals in itself (less contested if the meals were to be brought to the rooms where everyone is used to the company of the people with whom they would be eating). This criticism was frequently due to the need to have money to spend on things other than food, especially Internet access. There are about 50 laptop computers in rooms at the hotel-rehabilitation centre. The patients who own one and who we interviewed want MSF to provide free Internet access (this is a frequent request among the under 30s). MSF had envisaged doing so at one stage and the patients found out, which explains why they are now so insistent. For them, the Internet serves several purposes: it is a way of passing the time, a means of keeping in touch with their families and friends and also a means of keeping up-to-date – in the company of their compatriots – with events in their region and in their country. The cost of the 3G USB key and the subscription

is met by the patients. Those who do not get help from their families use their daily allowance to pay for this subscription. Some people organise a group payment of the subscription per room.

The catering project was shelved in 2013 and the daily allowance was increased.

LIMITATIONS OF THE SURVEY

We identified a number of subjects that were issues for the patients, notably the duration of treatments and the explanation of their objectives, as well as prohibited behaviour and rules of discipline on the MSF project. How did the practitioners and nurses react to these subjects when we interviewed them? What did they tell us?

We are aware that exchanges between care-providers and patients are ongoing throughout the treatment period, i.e. months or even years. We did not ask for access to these exchanges. Therefore, the dialogue we have been able to piece together from the accounts gathered during the survey clearly does not reproduce that which actually takes place during treatment sessions, during consultations, before and after operations, or in the home countries with the doctors who make the first selection of admissible patients and then later ensure the follow-up of those who go back to see them after a first phase of treatment in Amman. We are also aware that according to the stage and the progress of treatment, this dialogue changes. As patients with injuries or severe burns discover the effects of the treatments gradually, their discourse varied depending on whether they were interviewed just after their arrival, after an operation, after several operations or later on, once they had returned home.

It would be useful to monitor variations in attitude throughout the care pathway, but this would call for a different kind of survey from the one carried out during our brief visits to Amman. Our study is a snapshot of a specific moment in time.

There is a further limitation to our survey. We were not able to analyse the work of the medical personnel by monitoring their action over a period of several months, from the first contact and clinical examination through to post-

operative follow up, by observing different sequences of their work, the relationships between the doctors and the nursing staff, the surgeons and the doctors and the care-givers and the injured (which is what the sociologist Isabelle Baszanger did, for example, when studying the work of doctors in chronic pain treatment centres). This type of survey would have meant spending much longer at the hospital in order to note things down as they happened, record off-the-cuff exchanges, witness medical behaviour and thus develop an in-depth understanding of the concrete implementation of the MSF project in Amman. At the hospital, this was not feasible during our two-week visits and because of language difficulties. As a result, our approach to the medical personnel was different from that with the patients. The patients do not work. Part of their day is spent at the hospital undergoing treatment, but they spend much of their time at the hotel. This gave us the opportunity to spend time with the people we interviewed, to go back and see them, to attend group discussion, to observe how the rooms were organised and so understand what was happening and what was said – to some extent, at least. With regard to the medical personnel, we only had recorded interviews (lasting half an hour to an hour and in English), brief exchanges in the corridor, what we heard in a handful of meetings, notably the weekly meeting at which patient follow-up was discussed (in the presence of the medical team and coordination) and where the surgeons selected their patients from among the new admissions. Consequently, whereas for the patients we were able to base ourselves on what was virtually an ethnographical study associated with interviews held in Arabic, for the medical personnel we only had interviews and documents (reports, sitreps, statistical data and a few emails, mainly those sent to us in reply to questions sent to members of the coordination team or the desk).

TREATMENT DURATION AND OBJECTIVES ACCORDING TO THE MEDICAL PERSONNEL

The comments made by the surgeons during our interviews were of a purely professional nature. This was not the case with the patients who expressed points of view concerning their life history, social and cultural environment, family situation, individual experience of pain and disability, and their hopes and projects for their lives once the treatment is over. During their interviews, the patients talked spontaneously, whereas the surgeons responded as practitioners

responsible for orthopaedic, plastic or maxillofacial surgery. They spoke of their work, reconstructive surgery protocols, activity routines and surgical strategies. They told us how they perceived the effective implementation of their skills and how they worked to achieve this. It is therefore understandable that their responses were all fairly similar.

Here, for example, is how two orthopaedic surgeons explain their work and the duration of treatments.

059 Surgeon. This surgeon is on a short-term mission in Amman

“The surgical activity here is a bit different from anything I'd done on previous emergency missions where I worked on my own with a team of expatriates. In Libya, for example, we provided the primary treatment for patients arriving from the front line. Here, in Amman, the patients have already been treated elsewhere, with whatever means were to hand. When you're operating in Syria with bombs falling around you, you don't have time to do exactly what you want.

Here we're mainly dealing with problems of pseudarthrosis¹ and septic pseudarthrosis, in other words, patients who are going to need long-term treatment. The primary treatment has been provided elsewhere. Then they come here and we often have to remove devices and immobilise with an external fixator or a plaster cast, and then go back once we've got the results of the samples, which are often positive. After a long and variable period of antibiotics, another intervention is scheduled. So, people often come here for two or even three interventions. They stay for several months. This type of surgery on infected pseudarthrosis takes time. You can't hurry it, you have to let things cool down a bit and let the antibiotics do their work. These are people we're going to be seeing for a long time to come. And we're also making something of a rescue attempt, rescuing limbs. Sometimes things don't look good. We try to avoid being radical and suggesting amputation, but it can be a close call.”

057 Surgeon. This surgeon is part of the permanent medical team

“There are two orthopaedic surgeons on the project. We take care of all the patients arriving from Iraq, Yemen, Syria, Libya, Gaza and even Egypt. What we do here - reconstructive orthopaedic surgery - people can't get in their home countries. For example, the Iraqi patients that we operate on have

1. Complete and definitive union of a fracture beyond time normally required, forming a false joint: Pseudarthrosis is sometimes accompanied by an infection (septic).

already undergone several operations in Iraq and have serious complications. We're the last resort for these patients.

What we call complex surgery is often long surgery, involving interventions at different levels. The orthopaedic surgeon and the plastic surgeon may both need to be present at the same time. The interventions can last for 12 hours and this is only the first stage. Sometimes we have to operate a second, third or fourth time.

These are patients who have already been operated on several times and most of them have a chronic bone infection when they arrive... Treating this kind of pathology takes time. It involves cleaning the bone, treating with antibiotics over a long period, operating a second time, cleaning again, etc. until the bone is clean. This is a long process for the patient and a long process for us too. Fortunately, we get good results. We've compared them with those published in studies conducted all over the world.

The pathologies are complex, often with serious infections, because the source of the pathology wasn't clean – an explosion, a bullet wound, etc., and because of the bad weather in Iraq, the dust and hospitals that are not always very clean. So the patients arrive with serious infections that mean most of them have to stay a long time. The surgery itself doesn't take long, but we have to treat the infection, which is why most of our patients stay for more than three months on average. The infection has to be treated, otherwise there's no point in doing the surgery.

The surgery is complex. Sometimes we have to treat very difficult pathologies, for example 10 to 15 cm of bone loss, a shortened femur or one that is floating about all over the place, with a loss of 10 cm: this is very serious, even when there's no infection. Infection, bone loss, the patient who has already been operated on twenty or thirty times in Iraq... these are not easy cases. We don't keep all the patients for three months or six months; it depends on the pathology.

The patients arrive, they're seen in OPD, we get their lab work and x-rays done, everything they need. The anaesthetist sees them and gives the green light if they're ready for surgery. Then we see them and prepare them for surgery. Once the surgery is done, they stay at the hospital while the antibiotics take effect, for post-operative care, etc., then they go and rest at the hospital where we follow them up in OPD. Once they're well, if they don't need any acute care, we send them home, but that doesn't mean we've finished because we continue the follow-up, even in Iraq. We follow up patients who were operated on five years ago. I've got patients in Iraq that I've been following up

for six years. I have x-rays done every month, and lab tests. If they need another operation, we bring them back and operate on them again, and so on. That's for cases that are not too complex.

If the cases are very complex, we have to keep the patients here. These are often cases needing plastic surgery. For burns, the patients need to be seen every day: it makes no sense to send them back to Iraq and do the follow up over the phone. The plastic surgeon puts in tissue expanders and keeps the patient for six months or even a year. We have to keep them for a long time. After their operations, our patients usually go and rest at the hotel. Then they're given an appointment for a consultation. If they need a second operation we schedule it, otherwise we send them back to their home country, Iraq, Yemen... We don't send the Syrians back to Syria; we keep them here for their follow up."

"To be better": what does this mean for the orthopaedic surgeon? He has just told us: it means the functional deficits have been corrected according to the professional norms of reconstructive orthopaedic surgery ("our results are good compared with those presented by other studies conducted all over the world"), but it doesn't mean that the patient's treatment is over. Post-operative follow-up can go on for years. People may have returned to their country, but if their infection comes back or they need more surgical work, they have to return to Amman – as confirmed by several of the students we interviewed.

However, the surgeons' decisions concerning how long a patient should be kept on the MSF project in Amman are not always taken on purely medical grounds, as another practitioner explained to us.

041 Surgeon. This surgeon is part of the permanent medical team

"At the end of the treatment there are patients who want to stay on the MSF project. Some of them make up stories to persuade us to keep them for longer. I've finished by surgical work so these stories are none of my concern. But the patients say that the HCR has promised to register them and so they need another week or ten days. So, even if the treatment is over I say OK, you can stay and come back for an outpatients visit in a week's time. I give them a chance to change their lives by being registered with the HCR or obtaining a visa for the US. In cases like these we don't refuse, but lying, making things up, that's not acceptable."

It seems to us that this attitude can justifiably be described as paternalistic in the sense defined by the sociologist Nicolas Dodier who says: “a classic tool in the paternalistic clinical tradition is the “moral contract” between the doctor and the patient” (N. Dodier, “Les mutations politiques du monde médical. L’objectivité des spécialistes et l’autonomie des patients [Political mutations in the medical world: Objectivity of the specialists and autonomy of the patients]”, p. 130-131). In the relationship described by this surgeon in Amman, the moral contract requires the patient not to tell lies, not to make up stories. Subject to this provision, the doctor will agree to overlook strictly medical criteria in making a decision and allow more time to those supplicants who are respectful of the moral contract. Some patients quoted in this study expressed their adherence to a moral contract with their practitioners, sometimes at the cost of their autonomy. This is true of all those who told us that they had difficulty or were totally incapable of understanding the surgeons’ explanations of their treatment, but added: “I trust him”. In such cases, trust conflicts with informed consent, which the patients sacrifice because of their limited ability to judge the proposals made by their surgeons and out of respect for them. For their part, the surgeons maintain that they give the necessary explanations for the types of injuries, burns and infections that they have been dealing with on a regular basis for years.

PUNISHING OR CHANGING BEHAVIOUR: WHAT DOES MSF NOT ALLOW?

At the beginning of 2012, the psychiatrist responsible for the psycho-social team felt very strongly that not enough thought had been given to what type of patient behaviour should be deemed unacceptable. The limits between what was acceptable and what was unacceptable, as well as those of MSF’s own “jurisdiction”, were not clear. This psychiatrist especially condemned the “punishment” that consisted in threatening a patient with the withdrawal of medical care, with being excluded from the project. He added that “such threats have been routinely employed in disciplinary procedures”. He deplored the conduct of MSF workers who were more concerned with order and discipline than with the well-being of their patients.

At the time of our study, only patients who had been on the project for a long time reported knowing a patient whose medical care had been withdrawn. The

others said that they had heard talk of exclusions occurring in the past. But in fact 26 patients were excluded in 2012, including 24 Syrians (why the Syrians?). Only one of these cases was classified as a “security incident”. It concerned the theft of money and telephones. All the others were classified as “misconduct”, with the most frequent reason for exclusion (14 cases) being repeatedly and “unjustifiably” missing medical appointments (physiotherapy sessions and consultations). On the list of exclusions there were no cases of the kind of behaviour that had been much sanctioned before 2012, such as sexual relations and alcoholism. Nor were there any cases of violence against medical personnel or other patients, introducing weapons, conduct inciting political or religious disagreement - or in other words that creates conflict.

This last condition is mentioned in a document communicated to the patients and care-takers living in the hotels rented by MSF, but it is not included in the list of undertakings signed by patients before leaving Iraq and Yemen (MSF Amman Project Pre-departure Consent).

“Patients are free to discuss religious or political topics, or anything else, in a peaceful manner, but are requested not to engage in discussions that provoke racial or sectarian conflict between people, or to insult or verbally abuse any patient or staff member along racial or sectarian lines.” (*Requested Behaviour for Adult Patients Staying at the Hotel*, April 2012).

In September the following condition was communicated to new patients at the hotel who had not signed the list of undertakings before their departure as they had come straight from Syria: “Appointments for dressing changes, physiotherapy, psychology sessions and any other medical treatment must be kept. To cancel an appointment, please inform the relevant member of staff. Any patient who misses three consultations or other medical appointments will be excluded from the programme without further discussion.”

No patients brought the subject up with us, but there were indeed exclusions in 2012. It is therefore understandable that patients fear being excluded from the programme and tell us that they exercise self-discipline to avoid sanctions. However, they did ask us the following question: “What does MSF not allow?”, or sometimes more specific questions, such as “Does MSF prohibit the smoking of hookah in the hotel rooms?”, “Why does MSF not allow us to go outside for some fresh air after 1 o’clock in the morning?”, “Why aren’t visits from family or friends allowed in our rooms?”, or in the most extreme cases: “Are we in a prison?”

070 A mother accompanying a female patient

“I’ve heard other patients talk about people who made trouble. It happened before I arrived in Amman. I heard that MSF sent these patients away because they behaved badly. One man used to drink alcohol. He was drunk and caused problems. I also heard about men who had sexual relations with women.”

Another woman: “I heard another story. Someone accompanying a patient went into a woman’s room and they had sexual relations. I heard that the same thing happened at the hospital. The patients tell us these stories. That’s why we’re very careful, so as not to get sent home before the treatment is finished.”

077 Male patient, 22 years old (see p. 13, 22, 27)

“I knew a young man who lived in an MSF flat. He drank alcohol. They made that young man come and live at the hotel on the 4th floor. I saw him at the hospital the other day, but I avoided him. I didn’t say hello because I don’t want people to think I’m like him and send me home before the end of my treatment. I heard this story here at the hospital: if you miss treatment, if you don’t listen to what the doctors say, and other things, they send you home.”

084 Male patient, 33 years old

“I heard about patients who made trouble being sent home, but I don’t know any personally. I’ve only heard other patients talk about them. Their main topic of conversation is patients who have been sent home. It scares us and we don’t like to ask about our rights. We don’t want to get ourselves noticed, especially those of us who can’t get proper treatment in our home country. So usually we just keep quiet.”

079 Female patient, 22 years old

“I’ve been here in Amman for 2 years and I’ve seen patients sent home without finishing their treatment, and care-takers too. I know two people who were sent home because they were causing trouble: a woman and a man. The man doesn’t understand what he did wrong but the woman had a bad reputation. She behaved immorally. When you look at her, you wouldn’t think she was ill. It wasn’t a difficult case. I heard that she got sent home without finishing her treatment.”

Behavioural restrictions allow patients to be sent away from the hotel while continuing their medical care. This was the case for two former hotel occupants just before our first survey. We met them. One of them was sent away

because he went home for a few days in secret (or so he thought); the other because he had let his wife and child come to his room in the presence of another occupant of this room. Some patients may manage to get around some of the rules governing life at the hotel and we will not go into detail about secret goings-on that do not disrupt the general tranquillity of the establishment, but are in fact good for patient morale and autonomy.

Withdrawal of medical care is codified and a procedure has been put in place (in March 2012 and February 2013). It usually involves a “dismissal committee”. The make-up of this committee was discussed in February–March 2013 and it was decided to include the field coordinator, the medical director, the psychiatrist and the surgeon concerned. To the best of our knowledge, the participation of one or more representatives of the patients is not on the cards.

People are not necessarily aware of this procedure, however, hence the questions we were asked and that have mentioned above. In fact, the patients interviewed mainly referred to stories of exclusions and the rumours circulating about rules of conduct. Some of them mentioned, sometimes in public, acts of discipline that they had found offensive, as well as threats, sometimes of exclusion, and are unsure whether this is just certain individuals overstepping the mark or whether it reflects the position of MSF as an institution. Yet the system of sanctions discussed between MSF managers clearly specifies that “no staff member is authorised to threaten a patient with the withdrawal of their medical care as this decision for this rests entirely with the coordination”. We have entitled this section of the report “Punishing or changing behaviours” to reflect the discussions we had with the project’s medical staff. “I wouldn’t say that the idea is to punish, but rather to bring about a change in behaviour. And what can we do to make sure the patients change their behaviour? For example, there was a patient who smoked in his room. This was extremely dangerous for him and for everybody else. We couldn’t stop him with explanations. Nothing worked until we stopped his per diem for a day, and the second time for two days. This happened at the hospital where the patients don’t need their per diem to buy their own food. Usually once is enough and this patient stopped smoking in his room.

All the patients used to smoke in their beds, but we’ve put a stop to that [at the hospital]. I don’t see it as a punishment, but as a change of behaviour. We say to the patient, you can decide to smoke, but if you do, we will take away your per diem, like you would do with your child.

We don't stop people's per diem at the rehabilitation centre anymore, because the patients need this money to buy food. That's ancient history."

The same person told us that there is zero tolerance of behaviour classified as a "security incident", where there is no question of relying on people's goodwill. This includes introducing weapons and attacks on other patients, caretakers and medical personnel. "In such cases there is zero tolerance". The "Guidelines for the Dismissal of Patients and Caretakers" (Amman, 25 February 2013) also refer to behaviours that either transgress Jordan's legislation or undermine the "dignity and safety" of the beneficiaries of the MSF project, its personnel or any other persons. In 2012 only one dismissal was due to a security incident. Most were cases of patients not respecting rules considered necessary for the success of the surgical treatment and medical follow-up provided by MSF. Discipline is thus justified as a medical necessity, i.e. necessary to the reconstructive surgery. How can this attitude be reconciled with promoting patient autonomy?

The field survey presented in this report has aimed to provide a sociological analysis of the reception and long-term treatment of patients admitted to the MSF surgical reconstruction project in Amman. We hope that it will be of use in decision-making on the future of this project.

To explain certain aspects of the Amman project and incorporate current discussions and reflections on the present and the future of this project into this survey, we interviewed Chiara Lepora, programme manager, and Antoine Foucher, head of mission. These interviews were conducted by Jean-Hervé Bradol, Director of Studies at the CRASH, with whom the survey in Jordan was elaborated.

PART 2 THE INTERVIEWS

To explain certain aspects of the Amman project and incorporate current discussions and reflections on the present and the future of this project into this survey, we interviewed Chiara Lepora, programme manager, and Antoine Foucher, head of mission. These interviews were conducted by Jean-Hervé Bradol, Director of Studies at the CRASH, with whom the survey in Jordan was elaborated.

INTERVIEW WITH ANTOINE FOUCHER (3 JUNE 2013)

Jean-Hervé: MSF's treatment of patients is mainly concentrated in Amman. Is it always necessary to transfer them to Amman? Couldn't we consider treating some patients in their home country (Yemen, Iraq)?

Antoine: Today's programme is the fruit of seven years of technical lesson-learning and human and financial investment on the part of MSF. So, it would be costly and probably not particularly relevant to try and reproduce exactly the same thing elsewhere.

However, we don't have the resources here to cope with a public health problem on this scale, so we're looking into ways of extending our influence without increasing our costs. We are working on three ideas at the moment:

- Creating partnerships with hospitals that have the technical facilities our patients need and are willing to devote part of their activity to humanitarian action. In this type of scenario, MSF's added-value would be its detection, documentation and patient referral and follow-up capacity. We have already begun sounding out hospitals in Saudi Arabia and Lebanon.

- Delegating certain phases of patient treatment, such as physiotherapy, psychological care and post-operative follow-up, to partner NGOs, the MoH, etc. MSF would still coordinate the treatment cycle but could increase case management levels at no additional cost. We are currently finalising an ambitious partnership with the Red Crescent which will enable us to refer Iraqi patients in the final phase of their treatment.

- Training MSF project staff or others wishing to work in reconstructive surgery. We have already trained surgeons and anaesthetists from MSF Switzerland in Iraq and we are also working with the OCP's mission in Yemen.

The challenge for MSF now is to strengthen its political capacity so that we can develop and monitor our network of relations over the long term. The coordination will be recruiting a head of mission in 2013 to take charge of this specific dimension of the project.

Jean-Hervé: At the moment, we provide medical care to people who need an operation, for whom a surgical intervention is still an option, but not everyone with a disability needs a surgical intervention. Some may just need physiotherapy, mental health care, social assistance or adaptations to their housing. Are we planning on doing anything for this type of severely disabled but non-surgical patient?

Antoine: The Syrian crisis has forced us to adapt our relatively standard medical care provision to the specificities of a particularly difficult context. So we've developed "physio-only" physiotherapy care, for example, post-operative follow-up, OPD consultations, etc.

We've recently been trying to find ways of providing "global" care for our patients, incorporating legal protection, disability management, education for the children, long-term psychological care, etc.

There's still a lot of work to be done on what is after all a crucial aspect of our programme - re-establishing our patients in their social and vocational lives - but that often takes a back seat to surgical techniques.

Here again, we need the means to provide individual follow-up for our patients and to develop innovative partnerships with organisations offering complementary services. A better service for our patients, mutual benefits for the organisations - it's through the connectivity of skills and energies that we'll generate the most humanitarian added-value in the coming years.

Jean-Hervé: What is MSF doing for patients in particular need of protection, who are in danger in their home countries and can't go back after their treatment?

Antoine: Yes, it's a key aspect of the area explored in the previous question. In practice, we are in relation with the UNHCR and we do what we can to facilitate administrative procedures for obtaining legal protection. When asked, we produce medical certificates to help our patients take legal action and obtain compensation.

This raises the issue of the extent to which we're capable of organising and facilitating patients' lives beyond the strictly medical field.

In the past, this has usually been the responsibility of our mental health team, but there has always been considerable confusion about the exact scope of its mission and the resources that should be allocated to it. Frédérique Drogoul (OCP's mental health adviser) is currently guiding our reflection on this subject and we'll probably decide to separate the psychiatric/psychotherapy team from the psycho-social team in charge of social issues and the individual follow-up of patients' non-medical problems.

Jean-Hervé: You wanted to talk about the catering project.

Antoine: The aim of the "catering" project was to offer our patients a meals service that, in terms of quality and quantity, was adapted to their medical needs and compatible with their nutritional culture.

There was much reticence about this project, mainly due to fears that it would deprive patients of the social interactions generated by preparing meals together, sharing resources, etc. As a result, it was characterised as a purely technical arrangement intended to deprive patients of their subjectivity.

It's interesting to note that when the per diem allocated to patients was abruptly cut in half a few years ago, this caused no noticeable internal debate. And yet it was documented that with this amount of per diem patients were not getting the energy intake they needed for their treatment, and even care-takers couldn't afford a minimum standard of nutrition.

So, the social activity generated by jointly managing an unfair constraint was just the positive externality of a system that was insufficient in nutritional terms and over-ambitious in what it was trying to achieve socially and psychologically.

But the romanticising of this debate succeeded in undermining the project's

motivation and we decided to shelve the project and opt for an increase in the per diem accompanied by some health education to improve the patients' nutritional practices – also a somewhat ambitious project.

I think that with the perspective of extending the project (changing sites) we'll get another chance to look at this nutrition issue in a less charged atmosphere and we won't let ourselves side-step the social activity aspect this time.

Jean-Hervé: What do you think of the notion of *troublemaker*?

Antoine: I was very shocked the first time heard of it. It's the term the care teams tend to use for people who cause problems or who adopt so-called "deviant" behaviour. But calling people *troublemakers* not only reduces them to a single characteristic, it's also a way of avoiding having to consider the reasons for their behaviour. In other words, in a system like this, patients suffering from psychological or psychiatric problems are defined by the symptom of their distress and not as subjects of medical attention.

Jean-Hervé: I first heard talk of "troublemaking" in Amman a year ago. The team was worried about disciplinary problems. There was a legitimate concern about disruptions and tensions caused by certain patients. Are there still as many troublemakers a year later?

Antoine: No. The psy team is now better integrated into the patient's care pathway and is seen as legitimate by the rest of the team. In fact, simply questioning the label "troublemaker" has helped moved the reflection on this forward.

Now we need to start thinking about the care staff: they get no training in this field and there are no safety mechanisms in place. We expose them to people who pose real problems from a functional perspective, without giving them the means to understand the patients' psychical environment, without giving them any tools, without helping them to manage the stress caused by their professional activity.

It's a serious problem because our staff are seriously exposed. A physiotherapist on our programme works hard and when, twice a week, a patient flies off the handle, or others don't turn up for their appointments or refuse to do their exercises, we can't expect him to be spontaneously capable of finding the sense in all that, or of organising his work accordingly, as if by miracle.

Finding a solution for these reactions is matter of organisation and training, as

the patient's safety and dignity depend on the safety and dignity of the care staff. We're working on a training project on this subject for all our staff.

Jean-Hervé: What direction would you like to see the programme take now?

Antoine: In my opinion, the project should disseminate the technical capital it has accumulated through the partnerships mentioned in response to the first question. But if we dispense technical know-how and knowledge (publications, etc.), we should also organise ourselves to welcome technical know-how and knowledge from elsewhere. This is what we are working on via the partnership with Bordeaux Teaching Hospital, intended to catalyse the positive medical energies available in France and elsewhere. Many brilliant people are interested in contributing to the programme and we should develop a platform that can adapt to different forms of availability. The resource potential is considerable in this field and this is probably one of the most exciting aspects of the programme.

We also need to raise the programme's political profile, publish on the realities of treating people with war injuries and the individual and collective consequences once the acute phase of a conflict is over. We should also be more political in our medical reflection: What responses should we be considering to cope with the explosion in antibiotic resistance? We are in the front line in this domain; we should be communicating and engaging in the issue.

And we should move on from the kind of compassion-based communication to which we have too often given way on the programme (and I'm as guilty as anyone here) to a more strategic and militant kind of communication.

INTERVIEW WITH CHIARA LEPORA (3 JUNE 2013)

Jean-Hervé: MSF's treatment of patients is mainly concentrated in Amman. Is it always necessary to transfer them to Amman? Couldn't we consider treating some patients in their home country (Yemen, Iraq)? How could this be organised and for what type of case?

Chiara: It's important to view the project from a regional angle. The health care system is already regionalised. Patients are used to travelling from one country to another for treatment, especially for access to specialised care. From this point of view, the Amman project may be unusual for MSF, but there's nothing unusual about it in the Middle-East region. But we should still avoid referring patients to Amman if they can be treated at home, and keep the time they spend away as short as possible. This is why we are trying hard to develop more physiotherapy and infection management capacity in the home countries for very long-term treatments and treatments requiring less direct surgical follow-up.

This idea of decentralising part of the project is to avoid having too many patients in Amman for too long a period. We also need to develop care for people with disabilities in their home countries, to set up a system that helps us manage our patients with disabilities, including less severe disabilities.

Jean-Hervé: Do we just select people whose impairments are going to require surgery, or do we also admit people for whom we can't provide a surgical solution, but can help reduce their disability in other ways?

Chiara: We already have a lot of patients in Amman who are just receiving physiotherapy or psychotherapy.

Jean-Hervé: That's true for follow-up treatment, but weren't these patients at least expected to undergo surgery? Was there never any surgery planned for them?

Chiara: We do admit patients who we know won't be undergoing surgery. We admit them as non-surgical patients. This is new in fact. We started in August last year (2012).

Jean-Hervé: Are there many such patients?

Chiara: We've got a total of almost 300 patients in Amman; about 50 of them are non-surgical. It's a recent development on the project. At the moment, most of them are Syrians.

Jean-Hervé: The thirteen doctors deployed by MSF in Iraq only accept patients who need surgery.

Chiara: Yes. But if we manage to develop the physiotherapy network that we're working on in Iraq, access to physiotherapy will be possible without it necessarily being linked to specialised surgery.

Jean-Hervé: A large number of patients are suffering from a long-term disability. After Amman, they go back to their own country. How does the follow-up work then? What kind of care do they get after Amman? How are their needs for treatment addressed?

Chiara: We really want to ensure possibilities for long-term care in home countries. There's not much available at the moment. The patients stay in touch with the doctors from the MSF network. Some of them come back here after a year because their surgery has failed, or an infection has set in or there is some other problem.

Some patients stay in contact with their psychologists as most of them don't want to be referred to local psychotherapists. They prefer to continue their psychotherapy by Skype with whoever they were working with in Amman. A small proportion of patients stay in contact like this, but most of them just go home. We contact them after six months for a functional assessment, and then that's it.

Jean-Hervé: For these patients who go home and are assessed after six months, do we consider that they don't need any further treatment? Do they continue their physiotherapy themselves? Do we consider that it's not necessary?

Chiara: As far as we're concerned, the treatment is over. It's actually over by definition. The definition given when discharging cases considered to have been "successful" is "maximum benefit achieved" or, in other words, in medical terms, we can't do any more. Although, obviously this is debatable... But if we discharge a patient, it's because, in their particular case, we've done all

that we're capable of doing in Amman – which doesn't mean that they will never improve. Afterwards, the patients go on with their lives. For patients with a disability, their potential for improvement is not necessarily limited to a specific moment in time. But they will remain disabled for the rest of their life. They'll need life-long care. Their need will be more or less acute, part social and part medical. These are chronic patients.

Jean-Hervé: These are chronic patients, so logically they need chronic case-management. But when they return to Iraq for example, there is little chance of them getting this kind of chronic case-management – in fact, most of our patients won't get any.

Chiara: Exactly. This is why we are trying to develop care provision for people with disabilities in Iraq, Yemen, etc., in partnership with other organisations, such as the Iraqi Red Crescent. And at the same time, we would like the MSF network doctors to provide long-term follow-up. The doctor in Iraq would become the general practitioner of a chronic patient who he refers for specialised care at some point. This is not really how it works at the moment... Amman must remain a specialised project offering treatment over as short a period as possible, and the network project in Iraq must become increasingly separate from it.

At the moment, the network project is seen by many as the way into the Amman project, as if it were a satellite of Amman. Our goal is to separate these two projects and for them to have completely different objectives. The objective of the network project is to improve care provision in countries in crisis for complicated cases that need reconstructive treatment that doesn't exist or isn't accessible at home. This means that the network also takes into account the health context, the security context, etc., and even the social and economic context.

Jean-Hervé: And Amman becomes a technical service provider, but within the framework of a much broader treatment project, coordinated by doctors who are in the home countries.

Chiara: Yes, that's the idea. But at the moment it's more an idea than reality. We've been thinking about it for a long time, and that's what we're aiming to achieve - with quite some difficulty. It's not an easy concept to put in place.

We have to face the fact that the needs are far greater than we're capable of dealing with. And that means that a project like this has to accept that its rejection rate will always be much higher than its admission rate, and that there will be some very difficult decisions to take.

Jean-Hervé: You're referring to the selection of patients on the project.

Chiara: I don't think it's something that should be left up to the doctor. The coordinator of a project like this should be a person who monitors the context of a country as a whole, or of several countries, who decides that he or she is going to put four Medical Liaison Officers (MLO) here and two MLOs there, because he sees there as being more needs here than there. Again, the decisions these MLO make are not based purely on medical issues, but also on social and other issues.

Jean-Hervé: And quantitative issues too, in fact, as there will never be enough places... Will there be quotas?

Chiara: I don't think it's the doctors who should set the quotas. The coordinator should be the person to decide on priorities and adapt the number of MLOs and how they operate according to these priorities.

Jean-Hervé: Very true. It should be up to the project managers to make this kind of decision. But the result is that MLOs have to take a whole series of criteria into account. What's new is that the need for surgery is no longer mandatory, and medical criteria are less oriented towards technical surgery-related criteria. You're putting more emphasis on social and humanitarian criteria.

Chiara: I think we still need to keep two types of filter in place. With the first filter – operated by the network (and so by however many MLOs) –, the criteria are not strictly medical, but also political, humanitarian, or whatever else you'd like to call them.

But there is still a second decisional criterion applied in Amman. The surgeons, physiotherapists or other members of the specialists committee must still have the power to choose and say: "I can work on these patients, but frankly there's not much I can do for these others". So I think we need to keep this second filter in place.

Jean-Hervé: Do the MLOs still have to seek approval for their decisions to include a patient from the physiotherapist or surgeon in Amman?

Chiara: It depends. If the patients don't have to come to Amman, the MLOs are completely free to decide what to do. If they want to refer them to Amman, it's Amman that has the last word. So for these patients referred from one country to another, we keep the two filters. The filter used by the surgeon must be purely technical. I don't want the surgeon to start differentiating between Shiites and Sunnites, Yemenis and Iraqis, etc.

Jean-Hervé: Let's talk about these distinctions. How do you imagine that the project coordinator, the head of mission and yourself will organise your deployment with regard to the Shiites, Sunnites, Kurds, Syrians and Iraqis? What'll be the reasoning behind your deployment?

Chiara: The idea is more or less the same as it has always been. At the beginning, in order to reach a wide enough range of populations, there was an explicit policy of employing MLOs with different personal histories, different affiliations, etc.

Jean-Hervé: Is this what you see as the humanitarian dimension of the project: non-discrimination between the different communities?

Chiara: Not just. I'll take an example. Between a country at war and a country where there's unrest, I think there are more reasons for increasing the number of MLOs in the country at war. Not necessarily because the medical needs are greater. That's a foregone conclusion. But I think there are also more humanitarian reasons for being present in a context that is deteriorating and is difficult for the people. That's what I call the humanitarian dimension of the choices made. Does that sound logical?

Jean-Hervé: You give priority to wherever people are in the most difficult situation.

Chiara: ... the hardest situation, to which they are the least accustomed.

Jean-Hervé: In fact, it's a bit like what we call "impartiality".

Chiara: It's concentrating the most resources where the needs are greatest. We don't just define needs in medical terms, because it's impossible when the region has thousands of disabled people and we can only treat a handful of them. We have to add other impartiality filters.

Jean-Hervé: What other filters, for example?

Chiara: The medical context, for example. Where is there the most or least access? Is care provision good or bad? Is access determined to any extent by the type of illness or by ethnic type? We try to balance out all these needs. Ah, there's something I've forgotten to mention. The other objective of the network that we want to develop today, other than recruiting and choosing between contexts and patients and identifying patients who don't have access, is identifying and extending the medical network, identifying more and more medical facilities that could be part of this network and manage patients in a compassionate manner.

Jean-Hervé: Like for example, a group of physiotherapists in a town in Iraq, a group practice, etc....

Chiara: ...who tell us that they will take five patients free of charge. Or, for example, a plastic surgery hospital in Qatar that agrees to keep a bed free at all times for MSF patients.

Jean-Hervé: You will still have a limited number of places within the care system as a whole. You'll have to keep places for Iraqis, Syrians, etc. So you'll have to reason in terms of countries. You'll also have to reason in medical terms, in terms of the state of care provision in the region where the person lives. And you'll have to take community affiliation into account.

Chiara: These criteria don't carry the same weight everywhere. According to the context and the time, there are criteria that will become more important and others less so. The essential thing for the network is flexibility, the ability to adapt to different regions, different zones, different problems, etc. But at the end of the day, the choices to be made are going to be very hard indeed. And we need to accept that what we're offering to the region's patients is not as amazing as all that. Take the example of Iraqis. MSF is very proud of the fact that in 2012 it transferred around 350 Iraqis to Amman. That same year, the

Ministry of Health sent 2000 Iraqis abroad for specialised treatment. So our budget of €8 million that we're so proud of and also so worried about at MSF because it's such an enormous amount, it's nothing compared to the budget the Ministry of Health is devoting to sending patients abroad. It spends €40 million a year on that alone.

Jean-Hervé: We're still doing a seventh of their annual volume.

Chiara: And the conditions that we offer are not all that good. The patients sent abroad by the Ministry receive a much more generous allowance than our per diem and a whole series of other advantages that we don't offer. The people who come to us have either been unable to get treatment in the public system or are really poor and can't even reach the public system, or all the other systems have failed them. So these are cases that are either socially or medically very difficult. In fact, what we offer is not particularly attractive. What keeps us attractive is despair, which is not so bad.

Jean-Hervé: You gather up those who've been left by the wayside, in fact, either because they are too hard to deal with medically, or because they are too poor.

What transformations, improvements, redefinitions of the programme could be envisaged?

Chiara: For me, redefining and expanding the network is a really important objective.

There is also another aspect that the teams have spent a lot of time working on, and that's opening up the project to scientific study. To begin with, it produced the kind of scientific publications that have existed for a long time.

Now, there are also scientific collaborations with different types of specialised centres. And we're beginning to get students in medicine, surgery and physiotherapy, for example, who come and do part of their training with us. I've thought of another aspect; encouraging students to make as much use as possible of our data. Students could use our patient cohort (which is quite an exceptional cohort) for research purposes and to develop much more generalist notions than those we have today. The cohort in Amman represents one of the biggest patient cohorts of civilian wounded. It's important to appreciate this, as well as the fact that we also have six years' worth of data on these cases, data that we're not doing enough with. I think we have a responsibility to

make this data available. I find it a bit of a problem that MSF keeps hold of this data without using it. I don't know why we allow it to happen.

Jean-Hervé: Has anyone asked for this data?

Chiara: Not as far as I know.

Jean-Hervé: From a distance, it looks to me like, in these three surgical specialities (maxillo-facial, plastic and orthopaedic), we have the biggest series of old cases...

Chiara: ...old cases of civilian war-wounded...

Jean-Hervé: The armies have fresh cases most of the time, so the type of surgery is different.

Chiara: ...meaning we develop a whole series of specific surgical techniques that don't exist elsewhere.

Jean-Hervé: Yes. Are there any other private or public hospitals in Iraq with such a large case series?

Chiara: Yes, I can think of Wassy hospital in Baghdad, for example. They have case series of patients like ours, but they don't do any data-collection. They have records of admissions and discharges, but they don't keep any details or files.

Jean-Hervé: There are practically no files. Do they have bigger patient cohorts?

Chiara: Our cohort is relatively coherent at least - old, complicated cases. They have much more of a mix of cases - fresh, old, etc. So probably if we only take the cases that are the same as ours, they don't have as many. If we count all their cases, they have a lot more. But, again, it's a cohort that is much harder to use from a scientific point of view because there's more of a mix of cases, whereas ours is much more coherent.

Jean-Hervé: More coherent and better documented.

Chiara: Exactly. As I was saying, we have a responsibility..

Jean-Hervé: Original know-how is developed in this kind of situation that we should be passing on. According to the Hippocratic Oath, there's an obligation to do so.

Chiara: The third transformation, improvement and redefinition is really a redefinition of "programme results". How can we assess the quality of a programme on the basis of results that we don't actually agree upon? Today, we are evaluating the success or failure of our programme against criteria that are very surgery-oriented. It's the surgeon who decides that "maximum benefit" has been achieved. He decides this on a rather functional basis and pretty much relative to his own capacities, because not all surgeons will decide that "maximum benefit has been achieved" for the same patient.

I think that, as this is a programme on which no-one dies, we need to redefine much more specific treatment objectives, related more to the patients than to the medical facility.

Today we're trying to give some substance and content to the term "medical quality", but we don't know how to go about it and where to take it. It's a programme with chronic patients but who only stay in Amman for a limited period; people who had a life before and will have a life afterwards. These are not sick people in the sense that they are confined to bed and completely socially-impaired. No, these are people who spend a specific period of time in treatment during their lifetime.

Jean-Hervé: Just to make sure I've understood: when you talk about redefining the objectives, you mean, for example, for a young patient, the fact of going back to school?

Chiara: I think that the only outcome we should be looking for is patient satisfaction.

Is he going to go back to school? Will he be able to get married? Will he be able to hold a cup? It's not up to us to choose. By looking at things in terms of patient satisfaction, we can put patients back at the heart of their treatment; they can guide it where they want to go. That said, it's obviously very difficult to quantify these objectives.

Jean-Hervé: Yes and no. There are qualitative assessments with categories (satisfied, not completely satisfied, etc.). If you want to produce some statistics, there's always a way. To develop case definitions, you study frequency against the case definitions you've developed, even if they're subjective categories.

Chiara: Yes, except that here we're talking about chronic patients. So the time factor plays an important role. Do we ask them whether they're satisfied after their first intervention, whether they're satisfied when they return to their home country, whether they're satisfied a year later, and how many other factors will affect this evaluation?

Jean-Hervé: Yes, it's the same with all chronic diseases. You repeat the evaluations.

Chiara: Except that with other chronic diseases, there's mortality. Not with this one.

Jean-Hervé: I tried comparing the evaluation chart that the surgeons use against other norms. I compared it with insurance norms. I found that our chart was very functional in a physiological sense, but there was still a series of quite crucial questions on social aspects, on the ability to be active in society, to be relationally active in society, which go beyond simply asking a patient if he can put his hand behind his back. These criteria which are not strictly surgical also feature in the official chart.

Chiara: Yes, except that we're not using them at the moment to evaluate our work. The only statistics and baselines used in Amman are based on the "maximum benefit achievement" defined by the surgeons. This produces a very paradoxical situation. Today, if we look at the statistics for 2012, only 54% of patients gained "maximum benefit". So, all the others were failures, i.e. every other patient. But I don't think that's an accurate reflection of reality.

Jean-Hervé: From an orthopaedic point of view it corresponds to reality, an orthopaedic reality.

Chiara: The team in Amman conducted a study to try and demonstrate that we should stop taking cases that were over two years old; stop taking them because, according to the surgeons, there can only be limited improvements

in this kind of case. In the end, the study showed exactly the opposite of what the team was expecting to prove. The patients who are happiest to come here are the oldest cases, the most complicated, the most infected, etc. They probably don't improve very much in functional terms. If we look at their autonomy, they don't necessarily make much progress. But the way they see things, they were desperate before, and they are a bit desperate afterwards. That's enough to make them much more satisfied in comparison.

Jean-Hervé: What you're talking about is trying to invent a system for assessing the outcomes of care pathway that can be common to both the medical team and the patient. When you think about it, it's a bit like entering into a contract at the outset.

Chiara: I'd like to talk about the notion of "troublemaker". I'll start by telling you about what happened when I was on a field trip to Amman. The psychologists and psychiatrists asked me for a special meeting. They wanted to talk about the problem of suicidal intent. There had only been one or two suicide attempts, but intent was quite widespread. The project wasn't really capable of managing this type of problem properly; there wasn't enough medical attention or collaboration between the psychologists/psychiatrists and the others. They showed us some quite worrying data.

Jean-Hervé: Semiological data?

Chiara: Yes.

Jean-Hervé: So, in psychiatric or psychological terms, these people were suffering from depression.

Chiara: Exactly.

Jean-Hervé: Suicide is just the end result. There are quite a number of pathologies where patients become suicidal, but mainly in cases of depression.

Chiara: Exactly. So that's what they were talking to us about.

Jean-Hervé: They were talking about the frequency of relatively severe depression?

Chiara: That's right. They told us that they had prepared a questionnaire designed to detect this type of case and determine whether someone had suicidal tendencies. We told them that it was good, a very good tool, and they should use it at admission. They said no, that it was a triage tool. In fact, they wanted to give the questionnaire to the MLOs so that could do the screening and reject anyone with suicidal tendencies.

Jean-Hervé: That's awful! That's crazy! Were the expat clinical staff there too?

Chiara: Yes.

Jean-Hervé: And they didn't see any problem with excluding people with depression?

Chiara: Not really...

Jean-Hervé: For me, things came clear when I discovered that having an addiction was also a potential motive for exclusion. I mean when I realised that they saw an alcoholic not as a patient suffering from an addiction but as a "troublemaker". It's so radical! Perceiving people with a disease as "troublemakers" is usually what you see happening in society and what the doctors fight against. Well, normally... if I've understood what they taught me in medical school!

Chiara: Except that the Amman project is a little society and the patient/carer relationship is not a typical relationship because the patients are not exclusively patients, they are much more like people in a community. The fact that the first rule in the internal regulations is "no discussing politics and religion" shows that you consider your patient to be someone who is potentially dangerous and not as someone confined to their bed and attempting to cope with their health problems. So, you give him social rules, quite conservative rules, rules that in fact infringe all kinds of rights.

Jean-Hervé: Usually, this kind of rule ends up being over-applied and interpreted in the strictest way possible.

Chiara: If what you mean is "you must not cause violence", you should just say so. You don't then need to add, "Watch out, because if you start discussing politics or religion..." All these people come from extremely complex situa-

tions. You just need to say to them, “be careful, you’re with people who are different from you, so be careful”.

Jean-Hervé: People understand without being told.

Chiara: If you tell them that the rule is no discussing politics, they don’t understand. But “Don’t cause violence”, they understand better, at least I hope they do.

Jean-Hervé: The thing about the psychologists screening for people with depression to stop them accessing the surgery programme... I just can’t get over it!

Chiara: Then we get to the discourse on addictions. But the notion of “troublemaker” shouldn’t be caricaturised, reduced to a caricature that of course exists and that is the first that comes to mind. You have to appreciate that when you have 300 people spending 6 months under your responsibility in hotels-cum-rehabilitation centres, they form a society. There will be something of everything in this society. We, as doctors, practitioners, are not necessarily equipped to manage a community like this, as complex as this. So, with regard to our mishandling of discipline (and I really think we’ve overstepped the mark on a number of aspects), MSF the organisation, the association, should take its share of responsibility. For six years we’ve exposed the Amman staff to the complexity and difficulty of managing this community without supporting them and helping them to find solutions. Just an anecdote (but which is particularly revealing): when we told Paris about these unacceptable disciplinary measures, the reply was “the doctors, practitioner and expats who did that should be sanctioned”. They applied exactly the same logic.

Jean-Hervé: It’s also a disciplinary approach to social, cultural and political problems. People are accused of abuse of authority and so we sanction them. “Sanction the sanctioners”, that was the reaction.

Chiara: Yes, except we mustn’t ignore this complexity. We need to look for and find solutions. I think the first solution would be to reduce the time spent receiving care, the duration of treatment in Amman.

Jean-Hervé: It’s inevitable that there’s a certain amount of “policing” to be

done in an institution like this, which is a permanent community of several hundred people.

Chiara: Again, I think we should learn from the way other chronic diseases are managed, by, for example, making the patients assume much more responsibility. I'm not talking about individual patients, but the patients as a community, by creating groups and a system of mentoring like in the management of AIDS, where a mentor who already knows the ropes provides support to a new arrival and tells him what to do and what not to do. So, we should make the community much more responsible for managing itself. The patient who comes back at 11 o'clock at night, who wakes everyone up because he feels like a chat or playing loud music shouldn't become MSF's problem. People need to learn to manage themselves.

So we need to differentiate between levels of problems. Individual problems which have medical causes and consequences must be treated in a medical manner. Problems that have a social consequence, such as a social attitude that poses a problem to others for example, should be treated by the patient group in the first instance.

But we also need to define what conduct to adopt with regard to the criminal problems that exist, that are going to exist and which are very difficult to handle. Again, we're not in our home country, but then nor are the patients. Going through legal channels is not an option. Excluding someone from the care system because he's a criminal is not necessarily the best choice either.

Jean-Hervé: If there's criminal activity within the care system, then you have a valid motive.

Chiara: From an institutional standpoint, we can't keep the person. But in medical terms, theoretically, a person can't have their medical care withdrawn for criminal reasons.

Jean-Hervé: Except when the criminal activity concerned is directed against the care system itself. For example, if somebody steals from a doctor's surgery, the doctor is completely justified in refusing to take him back as a patient.

Chiara: Yes, but how far are you willing to take this kind of reasoning? Would you withdraw care from someone involved in criminal activities within the institution but who could be put at risk of dying?

Jean-Hervé: At risk if dying, no. You don't exclude anyone whose life is at risk. But usually people are only at risk of dying for relatively short periods. Afterwards, in cases of chronic care, if people are a menace to other patients, or to members of staff or equipment, you are completely justified in telling them that we can't treat them, that we think they're in need of care but their behaviour means we're not able to provide them with it. To say to them, "we can't take your treatment any further. My advice to you is to seek medical care elsewhere and think carefully before behaving in the same way with your new medical team. Here, you can't just steal my wallet during a consultation. I can't treat you in these conditions. Even the best medical ethics couldn't persuade me to treat you in a situation like this". Of course, there are always the borderline cases. I'm not saying it would be easy. But at a purely theoretical level, it's not that complicated. It's very difficult to put into practice, but in conceptual terms, it's not very difficult.

Chiara: It is when it comes to defining the limits. If you take extreme cases, of course it's not difficult. There are conditions in which it's impossible to treat someone. So we don't even try because it's not possible. But once you get into the "grey areas", such as the patient who doesn't follow your advice, for example, who tries to push in, who is troublesome to the point of preventing you from doing your job properly... I think that this grey zone is where the problems lie, and our teams have trouble knowing how react.

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