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Photo : Valérie Dupont

CONCEPTUAL FRAMEWORK

Transversal project AH-SCD *

Doctors of the World

*** Access to healthcare &
sociocultural determinants**

WE CARE FOR THOSE WHO THE
WORLD IS GRADUALLY
FORGETTING

1/58

NOUS SOIG NONS
CEUX QUE LE MONDE
OUBLIE PEU À PEU

Médecins du Monde -février 2008- dsc@medecinsdumonde.net



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CONCEPTUAL FRAMEWORK

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This project reference document is part of the project entitled "Access to care and socio-cultural background" launched by Médecins du Monde.

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Introduction

This reference programme is for aid workers who provide assistance, whether abroad or in France, to populations of various cultural origins. It aims to improve the relevance of dialogue and exchange between aid workers and beneficiaries, by improving consideration of population values, norms and needs.

Aim of this reference programme

This reference programme proposes to make medical staff more aware of the impact of socio-cultural background on access to care. The various topics addressed will cover the different ways to treat health, disease and care, both from the population and medical staff points of view. This will provide professionals with a multi-disciplinary introduction to enable them to take a critical look at the interactions involved in humanitarian action.

This reference programme will address the issue of “Access to Care and Socio-cultural Background.”

More particularly, it will, first, define and identify socio-cultural determinants in relation to access to care, and show how an appropriate knowledge of these socio-cultural determinants will positively impact on access to care.

Secondly, this programme will try to enable proper identification of both individual and collective behaviour of populations and medical staff. It will also propose answers to the questions which are most often raised by professionals working in the field in relation to the representation of the disease (from social and individual perspectives and also as a collective cultural event with norms and constraints), to the different aspects of care (medical staff/patient exchanges), to the cultural aspects of treatment (care pathways), of the social aspects of traditional medical systems and of the interactions between the various medical systems (pluralism of care).

Third, this reference programme will provide a methodological approach specifically for internal procedures and tools for medical staff to use on a daily basis, to help them to identify both social and cultural aspects of care. In addition to a broader reflection to improve care and interactions, it will also provide professionals with a global overview of the situation as compared to their own practice and take socio-cultural issues into account in the definition, implementation, follow-up and evaluation of projects.

This programme aims at improving the exchange process as part of humanitarian aid, not from a practical or utilitarian standpoint but from an ethical point of view, for projects dedicated to the populations and especially focusing on their cultural specificities. It will then generate reflection on the importance of socio-cultural background for access to care right across Médecins du Monde.



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I- Influence and impact of socio-cultural background

-Current situation: socio-cultural background is a common concern

Over the last few years, problems relating to access to healthcare have essentially been seen in relation to the effects of the Bamako initiative (renunciation of free access to care), which leads to exclusion from care for the poorest groups. While many initiatives have been taken to improve financial accessibility and health centre attendance, considerations of restrictions on access to care because of the population's socio-cultural background are not common. The work performed by Médecins du Monde in Latin America and the Caribbean Islands represents the beginnings of a response to this issue. As a matter of fact, the Médecins du Monde teams in Mexico, Bolivia and Nicaragua organised training sessions on "intercultural issues" and issued appropriate learning support materials in co-operation with health ministries and local associations. This reference programme, initiated by Médecins du Monde teams, is therefore in line with the projects already implemented by those same teams and local associations which were either directly or indirectly involved. Thanks to these initiatives Médecins du Monde will promote the importance of socio-cultural background among professionals to improve consideration of its impact.

The focus on culture in health projects is not recent, but it still remains a challenge: as far as medical humanitarian work is concerned, cultural aspects of care often appear to be inappropriate to project coordinators or in emergency situations; fastidious surveys and intricate anthropological analysis take too long, etc. However, cultural aspects of health are often an issue raised by medical staff and, more generally, humanitarian workers in the field, as shown by the increasing participation of anthropologists as moderators in health worker training. As a matter of fact, misunderstanding of various health practices, the relative efficiency of medicine for some diseases, the ethical aspect of "culture" during the interactions between medical staff and the population, weigh heavily on health programmes.

In 2002, and in response to growing demand, the WHO (World Health Organization) issued a strategic report addressing traditional medical practices, with a view to improving understanding of these medical practices, facilitating their integration into existing health systems and maintaining and preserving these practices (while highlighting the complexity of this issue and taking a cautious approach to attempts to integrate traditional healers into primary care programmes.¹)

The respect of human rights and hence of the diversity of cultures is an increasingly important issue raised by the United Nations and various governments (for instance, Hugo Chavez has committed to major programmes towards a better integration of Latin America and Caribbean Islands and the preservation of their respective cultural identities) and, more generally, any organisation involved in development. The issue of socio-cultural background is certainly one of the important aspects of any new development assistance policy. In this report, Médecins du Monde proposes a global overview of the different ways towards a fruitful communication between beneficiaries and humanitarian aid personnel.

¹ Foster, G.M., 1983 « Introduction à l'ethnomédecine », in *Médecine traditionnelle et Couverture des Care de Santé*, Geneva, WHO: 17-24.



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-Definition of socio-cultural background

What is the concept of socio-cultural background? Why should we consider it? To what extent can the study of socio-cultural background benefit the dialogue between medical staff and beneficiaries?

We can already answer this last question. The efficiency of strategies implemented by aid programmes conflicts with the various perceptions of health and behaviours of the target populations. In other words, the programmes are not always properly interpreted and even if they are, they cannot always be implemented for many reasons. That is why we shall consider the impact of socio-cultural background on access to care.

First, **socio-cultural background can be defined as the norms, values, knowledge and practices of populations in connection with health issues, which govern the different ways to practice, communicate on and consider health, disease and healthcare issues...**

1- Cultural aspects of health

-Disease and body issues: common knowledge as compared to biomedical knowledge and practices

“Diseases can be transmitted just by looking” “Drinking water is clean water, which has not been drawn anywhere”, “A healthy child is a fat child”

There are many ways to consider health, disease, the body and pain issues all over the world. Let's consider cultural aspects of health by taking food as an example – this generates and governs many beliefs and representations of health, which differ from scientific knowledge. There is no need to go as far as the Papua or the Yanomami populations to realise the cultural aspects of eating. In Europe, during the pasteurian period, people believed in the properties of ingesting fresh blood to fight against anaemia or weakness. This belief had nothing to do with the nutritional qualities of blood but was more of **a rationale based on analogy**. Hence, red meat and wine fortify workers and chicken breast is good for convalescents. Until recently, big eaters generated admiration and in popular opinion, being healthy meant having enough to eat. Still in many countries around the world, having diarrhoea does not mean you are ill, but represents a natural mechanism for “purging” the body of toxins left by food (“It cleans the belly, it takes out dirtiness”).

Nowadays in Europe, representations of food no longer rely on “red meat and fresh blood = strength but fish = memory” “eat your soup, you will grow up”, “carrots will give you rosy cheeks” etc. Alternative medicines, which are based on the same sort of beliefs, rely on the believed attributes of food, which are based on analogy. In other words, food's nutritional qualities are turned into moral, even magical, qualities. Vitamins, trace elements, antioxidants, as shown on TV or in magazines are part of our vocabulary and become theoretical or magical, concepts as the nutritional qualities highlighted in the adverts promise us youth, longevity, defence against colds and flu, good skin... This relies on traditional knowledge. To enhance its credibility, this knowledge is often linked to scientific ideas and



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scientific language is used and twisted and reinterpreted. Because of this scientific language, we believe in these qualities, even if we don't have any real idea of how or why.

In Western and Southern countries, people often think that our ancestors' food was healthier (despite the fact that the quality of food has been constantly improved by the introduction of pasteurization and the cold chain, for example), and that tradition is supposed to be safer and better. This relies on a reference to the land or the earth, which represents the world and its natural properties. This also relies on respect for the values of older people; we cannot completely disregard what our elders say, even if we know that it is not completely true. **Thus, innovation, such as the implementation of technologies or biomedical principles, may be considered as an aggression.** Hence, some messages delivered as part of child health promotion (malnutrition, AME) conflict with popular food beliefs. There are specific beliefs relating to early childhood: in Africa, a pregnant woman must not eat red meat to avoid haemorrhaging during labour, and she must not eat bananas, to prevent her from giving birth to a weak baby; the ingestion of some acidic fruits may make a child irritable... The populations will not stick to a health programme if various magical and sacred prevention practices cannot be followed because they are considered as conflicting with modern health standards. For example, the Tohenthal practice (which consists of making a new-born baby drink water which has been blessed with verses from the Koran) conflicts with AME principles.

That is why any transfer of technology has to account for any cultural aspects. **The introduction of biomedical science should not be based on a distinction between "knowledge" and "ignorance"** but on the integration of new data into existing belief systems. There is a concoction of those two types of belief; **in other words the health programmes are neither rejected nor adopted as such, but are partially integrated**, by working together to redefine the meaning. It is then important to take into account medical practices which may challenge and conflict with existing cultural aspects, in order to avoid the following situations: women who think that they are immunized against malaria,² who refuse vaccination because they fear it will make them sterile, or who want to build latrines to prevent measles.

Question: What happens to popular beliefs about health and disease when they are faced with our health programmes which rely on biomedical standards? The all-encompassing medical science may reconsider its own practice to prevent target groups from resisting, which would limit the impact of the innovation.

- Complexity of care pathways?

"I am very disappointed when I examine women who attend the doctor's consultation for the first time and discover bone metastasis. I ask the families why has she waited for such a long time? Why did not you come to the hospital before? They answer that they first thought it was a bad spell, so they went to the traditional healer. He said that she would get better soon. After they did not have any money left, so they had to wait and sell an ox before they could afford the trip to come to the hospital."

A senior doctor working in a haematology department in Mali.

² Jaffré Y, 1989, *Le forgeron, la pintade et la vaccination*, Bobo-Dioulasso: OCCGE



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In West Africa, cancer is still considered as somewhat devilish, which leads patients to seek inefficient treatments, leading to some severe, and sometimes irreversible, complications. The devilish aspect comes from a traditional interpretation: the cancerous tumour is considered as a spell cast by a poisoned arrow. The round shape of the tumour is the sign that the spell has taken hold.³ To get rid of it, you must seek the healer's advice. This interpretation of the disease is more widespread in the bush areas where populations have limited access to medical information. The occurrence of a tumour and deteriorating health are rarely attributed to cancer. Pain, first considered as a temporary sign, will get the patient to seek medical advice. **To treat themselves, patients will look for local support,** recourse to care occurs as a consequence of advice sought from neighbours, family or friends. If symptoms are considered as devilish from the beginning, they will consult traditional medicine, traditional doctors or healers. After many unsuccessful attempts however, time goes on and when they attend hospital and find the right department, it is often too late. Hence, in addition to inappropriate referral, the complexity of various treatment options, which do not provide the proper response to a serious disease, may be fatal.

Case study from a Malian doctor

"My patients come to me once they have entirely run out of their own resources because they have been involved elsewhere. They have lost time, firstly to get the right diagnosis and they do not have any more resources and, secondly, when they have the diagnosis in getting the treatment. I believe there are two reasons. First, is the perception of the disease: people will first look for local assistance i.e. they will speak with one another one and will be told "I had the same disease and was treated by the healer over there." Hence they do so, and the healer goes on and on without any success. This is one way to act, but there are others, such as being told, for example, "this disease, this is witchcraft, you have first to be treated as follows" and people lose time. The second reason is that they start by consulting the local doctor who was recommended by someone saying "I have had the same disease and he managed to treat me." They go and see the doctor, who takes time to issue an appropriate diagnosis, because the disease does not come into his area of expertise. We are often confronted with existing prescriptions whose purpose is not always clear to us, or people have attended so many consultations without any success, that they finally meet someone who tells them "go and see this doctor"; no doubt it is time consuming and in that case, both CSCOM⁴ and medical staff may be held responsible, and it's a problem of incompetence. Old Mr X, for example, suffered from a myeloma: what happened then? He did not even attend the healer, his neck was injured; he went and saw the doctor and was prescribed analgesics that's all. When pain came back, he went and saw another doctor and was prescribed analgesics again. Pain, again, but it was too specialised for the doctor and he did not refer the case to the appropriate specialist. At last, as Mr X was about to go back to his village after 3 consultations, he met a young doctor who referred him to me. Upon consideration of X's whole history, no doubt there have been problems with communication and interpretation, even on the part of the doctors!"

The study of different care pathways can also be of interest in helping to understand prevention issues. Implementing prevention programmes, which rely on the first symptoms of a disease, may not be easy. In many countries, for economical and practical reasons, the first reaction of people facing primary signs of a disease is observation. The patient takes time to watch how the disease progresses, as use of health services represents a financial burden and is time consuming. In fact, if the disease is considered as mild, people do not go to the doctor. Moreover, people will not attend any hospital when they consider themselves to be healthy, (even if attendance is free, the time spent waiting for the doctor is time not spent earning money).

The result of in-depth discussions with mothers from various cultural areas show that the way they perceive the well being of their children is radically different from current child growth and development monitoring practice. Mothers' understanding of child health is not at

³ This relies again on analogy. For further details, see Chapter II.

⁴ CSCOM: Community health centre



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all in line with technical information provided by health educators. Hence, in many areas, the absence of disease combined with fatness (a fat child is supposed to be strong), proves that the child is healthy and is growing and developing normally. Mothers consider that the ability to walk and weaning are the most important steps for proper growth and development. The importance of the above mentioned steps and associated behaviour (proscribed foods, magic or religious taboos) prove that mothers want their children to be autonomous as soon as possible. The abovementioned two steps (walking and eating like grown ups and perhaps also speaking) are sufficient proof of adequate development.

Research carried out in West Africa⁵ showed that, although families regard severe malnutrition (*marasmus and kwashiorkor*) as an important issue, chronic, moderate or mild child malnutrition is considered normal. When forms of severe malnutrition are noticed by parents, these are rarely considered as a disease linked to nutrition. The local perception of the disease aetiology differs radically from the biomedical approach. Causes may be natural, supernatural or linked to social issues. Malnutrition problems are never linked to child feeding. Such perceptions affect the treatment pathways as, in some cases, malnutrition will be deemed as a supernatural spell and will be referred to a *marabout*. Hence, messages delivered to the target populations, including traditional healers, will have to be adapted.

There are several fundamental points to consider in relation to treatment pathways: pain is a starting point, the cultural interpretation of the problem, family discussions and various local treatment options.

- Linguistic issues

(The role of language – semantic and cognitive factors)

The language used during exchanges between medical staff and patients is an important issue as both new words and concepts will be used: how many languages can translate “asepsis”? The command of local languages is certainly an important issue during contact between medical staff and patients, hence in the process of access to care. To communicate with medical staff, the patient will use words and refer to notions he or she currently uses. If health workers do not come from the same country or ethnic group, their own cultural backgrounds will not provide them with all the necessary tools to be able to understand the patient. Hence, exchanges between medical staff and patients are bound to what both participants are able to understand through a fog of words, semiotics and semantics.

For a patient, what is the meaning of: “*You have a homonymous lateral hemianopsia*”? And for a doctor, what does the following mean: “*It is painful outside, but not inside*”? **In relation to oral communication, the modern health system is complex – both parties, (health worker/patient) do not use the “same language”, even if they speak the same words.** The patient will express both pain and symptom, he may have an idea what is causing it, but may be unwilling or unable to express it; he may ask for treatment, while being unwilling to reveal anything else...

⁵ Suremain C.E, 2000



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Information delivered by health workers will always be interpreted by the patient and what the latter understands will depend on the way the message is conveyed by the health worker.

2 - Social issues in managing health

“If we do not suffer from the disease you are interested in, we might die! 6”

The difficulties met during the implementation of a programme may include, among others, the following factors: patients who complain that insufficient attention is paid to what they say, who remain unresponsive and refuse to adhere to a programme, doctors who implement programmes which will be misappropriated. In fact, from one programme to another, the same mistakes are often made. The process may be different, but the problem remains the same. It is therefore important to identify difficulties and learn lessons from failures. Social aspects of health may be helpful for improving this understanding.

- Misunderstandings in medical staff/patient relationships

« Les conventions sociales règlent l'usage du regard » Le Breton, 1995

In Northern and Southern countries, populations often complain about the quality of health care, and more particularly, about the difficulties which health professionals have with communication. In fact, it has been noted that medical staff may not be concerned enough with patients' anxieties and are more concerned with their own responsibilities and making sure that they do not make any mistakes in diagnosis. The particular illness plays a crucial role in the complex relationship between medical staff and patients. The disease has an impact on both the duration and quality of interaction. In fact, the involvement of the medical staff is not the same for acute diseases as for serious, chronic diseases for which a long treatment period may lead to a stronger relationship between both parties. In West Africa⁷, previous surveys conducted in public health centres treating acute conditions have unfortunately highlighted major problems, not only in the way patients are welcomed, but also in the delivery of treatment and care. In general, in spite of the improvements brought to the organisation of health systems and medical staff training, important and recurring barriers have been pointed out. These have a negative impact on health systems: the large social gap between medical staff and patient, poor quality of reception, withholding patient medical information, carelessness as to the quality of care provided. Except for a minority of privileged cases, patient-health worker exchanges are short and sometimes violent: it has been noted that the patient is not considered as such. The quality of those exchanges will then greatly impact on the patients' behaviour, and she or he may delay in their recourse to health services and this explains the preference for the traditional system, which is considered to be more human.

⁶ B. Dujardin, 2003

⁷ Y. Jaffré and J.P. Olivers de Sardan, 2003



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Service user complaints reflect an expectation for better attention, comprehension and information, which will enable patients to be involved in decisions about their health. These communication difficulties often exclude patients from the modern health system.

During a consultation in a department of internal medicine, a patient came for abdominal pain. She had been scanned but did not bring the scans with her, because no one had told her to. The doctor wanted to know if the results of the scan had been explained to her and what her previous doctors had said. She then tried to remember their words but, as they did not make sense to her, she could not pass on the right information to the doctor:

- “ - They told me that I have bile segments
- What do you mean by bile segments???
 - Oh, I don't know, you are the doctor; they told me my appendix is inflamed
 - ??? OK. When did they tell you that?
 - In January I think
 - OK. You will have to be scanned and then come back (...)

This first exchange often impacts on the interactions which follow, i.e. subsequent attendance at the health centre. The patient is often disappointed by the negative outcome of this first consultation. A new failure leads them to reconsider the effectiveness of the doctor and may even lead to disenchantment with the medical system. The patient, who was expecting so much from modern science, does not get tangible results and does not know why. He or she will get progressively discouraged by the lack of appropriate information, and will look for other practices, other medicines: *“The doctor did not treat the disease”* Africa. The health worker – patient relationship, and the interactions with families are, therefore, core issues in the process of care, as they will impact on the patient's confidence in, and perception of, the efficiency of the medical staff, the programme and the health systems. This will have an impact on the use of services, both for treatment and prevention: *“We do not have enough time to speak with patients and this impacts on their trust. It often happens that having sought medical advice at the hospital, they will refer to the healer because they did not catch what the doctor said or the welcome was inadequate. For instance, sickle-cell anaemia is a chronic disease: the patient should realise that it is a genetic disease, that a traditional healer can not be of any help, and that only measures to prevent crisis episodes will provide them with sufficient relief; but if the patient does not understand and he goes on suffering, in spite of one or two appointments with the doctor, he will believe in something else and at last will go for broke and refer to the healer.”* A doctor

Many aspects of the health worker-patient relationship must be considered, i.e. the place where care is provided, the medical staff involved, the way the disease is described and how the subsequent treatment is explained. If insufficient time is taken to provide information about a chronic disease, the patient will seek other kinds of treatment, which they consider to be more efficient as they are supposed to ensure total recovery.

- Group strategies: family and social issues around healthcare

Any disease will be allocated a specific mark or status within the group by the patient and this is based on cultural issues. While some diseases with little social consequence may be



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faced individually, other diseases, including STIs or fertility problems, may challenge social links and status. Some diseases may be cared for with appropriate treatment; others are more stigmatising and may challenge the identity of the patient, who is caught between the illness and society.

AIDS, for example, is associated with this problem; it is a “shameful” disease. Except for infection by blood transfusion, AIDS is taken to reflect sexual promiscuity or drug use. In certain countries, prevention actions conflict with these beliefs: buying or accepting a condom means sexual “promiscuity”.

Hence, **the availability of care within an adequate health facility does not necessarily mean using it: the implementation of such actions may come up against individuals’ personal issues.** Power struggles and conflicts may be caused within the individual’s family or social group by the sudden change in his/her habits –the opposition of community elders to some innovations, fear of being marginalised for taking the proposed action: *“If my mother notices a condom in my handbag, she will then automatically think that I sleep with everybody, I can’t accept the ones which I’ve been offered, it is too risky. My parents will hit me and my friends will laugh at me and gossip...”*

Other surveys have shown that the implementation of some programmes, such as child survival projects, are focused on the mother’s own background and do not account for social aspects of health behaviour. Hence, the major roles of the father and other family members are rarely mentioned. However, the family plays a key role in how health is managed, insofar as the child socially belongs to his or her family.

For example, an anthropological survey carried out in cooperation with epidemiologists specialised in the role of under-nutrition on developmental delays in Brazzaville.⁸ The aim of this survey was to consider how social inequalities impacted on children’s health. This survey was prepared to test a hypothesis that was already accepted: the link between children’s health and the economic situation of the parents. As many surveys conducted in Europe, the United States and third world countries have shown that the poorest populations have the poorest health, it is questionable if further proof was really necessary. However, this survey showed conflicting results. It found that children suffering from serious malnutrition belonged, in fact, to families whose socio-economic situation appeared to be adequate, throwing into question the supposed proven link between nutritional deficiency and living conditions. The explanation was sought in the breakdown of family support, which prevented the mother from securing appropriate care for her child. As for the epidemiological survey, some questions raised in the questionnaire, which had been formulated on the basis of case studies, enabled social indicators to be identified (deprivation of links between mother and family head, specific marital status of mother etc.). The data processing of this survey enabled identification of a group of children suffering from serious malnutrition for which usual risk factors, such as a physiological causes (eg. birth weight) or causes linked to overall household socio-economic status, were less significant than data on family or marital status of mother.

If social factors, therefore, impact on severe growth deficiencies should not we adapt programmes to different target groups, according to sociological criteria?

In other words, **health programmes rely on biomedical principles whereas according to the targeted population, these programmes are supposed to have both medical and**

⁸ Gruénais M.E, 1985



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social dimensions: eating patterns are governed more by social norms (age or sexual differences, prohibited foods and dietary habits) than by strict nutritional concerns. Similarly, hygiene may relate to issues of aesthetics or glamour.

There is a real link between partial adherence to actions and constraints that may be internal or external to the family or social group. Medical practices rely on social data and are inserted into a system of power relationships. So programmes must consider social factors as a core issue. Development plans will have to be consistent with (and based on) local systems.

-Material, social, economical and political environment

"Poor health is a core issue of poverty" Amartya Sen

For some diseases, "environmental" aspects are deemed as important as biological ones, which may no doubt hinder the medical process. Malnutrition and diarrhoeal diseases are examples of this type of condition. Poverty and hygiene issues make living conditions difficult. The environment encourages development of diseases and negatively impacts on the adherence to advice delivered by medical staff. Hence, health education panels delivered to women⁹ may promote information on food, and especially the importance of nutritionally adequate food, but if they cannot afford such food they will not change their diets and will eat whatever is available. Inadequate nutritional intakes, in effect, can be caused by a poor standard of living.

J. Brunet Jailly explains that people living in extreme poverty in southern countries are subject to the decisions of their institutional representatives (spouse, head of family, of village etc.) and that individual consent is inconceivable¹⁰. A wife never attends medical services without her husband, husband without his wife, parents without one of their children, children without their father or mother. Diagnosis, consideration of proposed treatment and subsequent decisions will not be taken by one individual but by part of the family. Duration of treatment depends on the advice of the family (which provides the funds) and doctor. *"All my young diabetics will die of keto-acidosis before adulthood because insulin is much too expensive and parents can not afford it, or they think it represents too much money. If the father does not buy it, where can a nine-old child find insulin? The families involved often have five or six children the cost of insulin for one person is the same as the cost of feeding the family for one week. They quickly make their choice – or, rather, they do not have any choice, the others will live and the treatment of the sick child is left to god."* A doctor.

As for individuals without social welfare, the issue of treatment for chronic diseases leads patients to seek the most affordable treatments. Hence, expensive drugs for life, as proposed by the doctor for the treatment of diabetes, and which will control but not heal, will compete with the healer who says that he can quickly treat the disease once and for all. Another relevant issue is the stopping of treatment. Serious conditions like AIDS raise the issue of compliance with long-term treatment, which may consist of many drugs per day. It often appears that patients who see a noticeable improvement after the first treatment will stop the treatment. They will seek treatment on a sporadic basis, for one problem after

⁹ Bouchon M., 2006

¹⁰ J. Brunet-Jailly, 2003



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another. Patients suffering from chronic diseases behave as if they were acute diseases. They want to recover as quickly as if they were treated with analgesics. They are not able to manage the treatment on a long-term basis, except if they have appropriate financial resources: *“When they stop, they are asked: why did you stop? I didn’t decide to stop, but the box was empty, they reply. They could not buy other drugs.”* A doctor.

“When we look at prescriptions, we can see that the medical staff wrote the appropriate quantities but, given the price, the patient did not buy enough drugs and he just bought less expensive ones ...” A nurse.

An article on tuberculosis in Haiti written by A. Castro and P. Farmer addresses the paradox concerning the treatment of this disease, whereby, despite the existence of effective drugs, the prevalence of the disease continues to increase. In reality, the proliferation of drug-resistant strains is due to various factors both at an international level (globalisation and the price of drugs) and local issues (poverty, the state of local health systems, or lack thereof, and difficulties with access to healthcare, increasing social inequalities). As a result they question biomedical assumptions whereby the increase in tuberculosis is due to cultural beliefs, which are considered as too restrictive. They highlighted the economic aspects, which are considered as a “pathogenic force”. According to them, a proper survey on the role of drugs must take social factors into account as well as considering the necessary financial investments to improve healthcare, diagnosis and access to medicines.

Recommendations based on principles which comply with biomedical health norms in programmes require situations which do not always reflect the reality of the social and material circumstances of the target groups, usually the poorest members of society. **The constant gap between programme aims and their applicability in practice (nutritional advice for the poorest populations, mosquito nets in a room where 15 people live, advice on hygiene rules where there is no water available etc.) results in the poorest groups having to make the most effort.**

As a result, we should bear in mind the very close interactions between socio-cultural and economic/political aspects. Hence, the price of healthcare, family income, transport costs and power structures within medical services can be determinants of health service utilisation.

- Change agents:// the appointment of “coordinating agents”, i.e. individuals who act as intermediaries between target populations and development programmes

In order to make up for deficiencies and improve the acceptability of projects, one of the core points of these programmes is the participation of “coordinating agents” or “bridges”. In line with the emerging ideas about *empowerment* and participation of local communities, these individuals are considered as an alternative solution for the social integration of projects. These people constitute a “bridge” between communities and programmes, acting at the junction between biomedical and local systems. They are really in a privileged position, since they represent an “entry point” to the medical world, while being familiar with local cultural beliefs and practices. However, most of the time, they act on a voluntary basis, which makes their role of intermediary harder because of difficult living conditions (can we

¹¹ Olivier de Sardan, 1995.



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expect voluntary involvement from the poorest?) and language and communication difficulties. The results of surveys exploring the impact of these coordinating agents and their involvement in programmes are unclear: poor material and information support (given the poor training provided) allocated to these “coordination agents”, leaves room for, or even encourages, a misappropriation of activities. Moreover, they are hampered by the same social constraints which have a negative impact on the population: *in one programme, one of the best trainee agents was a woman, who was obliged to stop participating because her husband said she was away from home too often. Other agents have been obliged to stop because they got involved in political and religious conflicts between catholic and protestant communities which led to the isolation of these communities. Finally, some agents left to look for seasonal work.* Results of a survey in Ecuador.

The project co-ordinators have to deal with the integration of “coordination agents” within the target populations. **Many issues relating to power and to the misappropriation of projects generate conflicts within the organisation and turn these agents into service providers.** Any project will generate challenges and specific conflicts, which are unevenly spread among the agents according to their respective positions (power struggles).

The numerous challenges in implementing projects include the following:

First, the appointment of an agent: thanks to his connections in the district or the village with local authorities, an individual may become an intermediary between programme and populations and, as a result, will have increased power within his area. For instance, he may use his new position to apply for local political elections and he will have to return favours to those people who helped him to achieve this status. This is a social issue.

A **second** issue may be material, which will increase the power of a social group (for example, acquisition of a building for an association). There are similar issues linked to various prerogatives and privileges, such as vehicles.

The agent will strengthen his position thanks to his ability to distribute something (eg. *Per-diem* payments, better access), which reflects his new social status. If he can not distribute enough, he will then look elsewhere for what is not directly provided by the project: these are unofficial practices and misappropriations which will enable him to make money. The implementation of *per-diem* payments may cause uncertainty in the continuity of activities. If *per-diems* are stopped because of missing funds, people may refuse to go on working. Thus, project coordinators are of the opinion that maintaining *per-diems* is essential to ensure proper continuation of the activities. If these payments are not maintained, the project will not succeed. The correlation between *per-diems* and success of the project is an additional constraint.

Projects rarely pay sufficient attention to the impact of social background and political aspects on how programmes function. **Once the strategy has been defined and implemented by all the actors involved, projects often differ from what was initially planned.**

Social impacts of projects are complex and the way they are perceived, transformed and even diverted from their objectives by target populations makes their implementation very tricky. However, both local volunteers and “coordination agents” may be of real help as intermediaries between programmes and populations, provided that they take traditional knowledge into account. Most of the time, however, this is unfortunately not the case, as this new position is considered by them as a promotion: *“In my district people are old fashioned, they do as old people do, they have not changed with progress and they have not understood that they must do so, (...)”*



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have been selected and trained, so I am able to explain that to them now..." A coordination agent trained in health education.

We should always bear in mind that any new programme will be set up in a local arena where there are different strategic groups. "Coordination agents" will be active in a local system where they may have some influence and they have sufficient command of the rules of "development" to make the most of them. Hence, during the implementation and the follow-up of a programme it is important to take into account rivalries, quarrels and conflicts between people that may negatively impact on a project.

- Problems linked to the proliferation of aid

This relates to the lack of coordination between professionals and the lack of continuity in programmes: this poor co-ordination between development and humanitarian professionals, as well as between the ministries involved, may even lead to ignorance of one another's planned or implemented measures. This may negatively impact on local populations' perception of aid, as the competition between various actors will no doubt negatively affect their credibility and legitimacy.

The segmentation of activities resulting from the increasing implementation of "vertical" programmes (AIDS, tuberculosis, vaccinations, etc.) prevents any synergies from being realised and increases health services dysfunction. The variety of aid provided in some geographical areas and lack of coordination between the actors may lead to confusion among populations who may not be able to properly identify the different actors: "Yesterday I attended an information panel on micronutrients but I could not have my child vaccinated."

When implementing a programme, it is important to check that it will not conflict with existing ones. For this reason, an assessment of projects already in place is essential.

The preceding paragraphs have described the impact of constraints on access to care. A good command of the socio-cultural background will be helpful in reaching target populations since, if we can properly explain and identify these issues, we can then improve the effectiveness of the proposed activities. In other words, better knowledge of the populations' beliefs governing practice, their everyday perceptions of health and their subsequent use of health services is fundamental.

For this reason, the following chapter will discuss how to identify key individual and collective behaviour patterns in relation to how the populations manage their health.



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II- Proposed identification methods for professionals: identifying problems and difficulties with interpretation

One of the core specificities of health as an issue is its very broad nature. To fully understand health behaviour requires a holistic approach that includes the individual, religion, interactions between individuals and their environment, belonging to a minority group, the health system, essential requirements for medical activities etc. **A good understanding of health-related behaviour can only be achieved through a comprehensive approach.** That is why this report will provide guidelines and explain how patients' healthcare pathways relate to their own beliefs. This report will address the various conception processes relating to disease, then we shall examine the different approaches to disease, and the different ways to access care and treatment pathways and the collective management of health. Finally, the report will provide advice on professionals' own perceptions in the field, which will help them to have a critical overview, which should be useful for their activities.

1- Individual behaviour relating to disease and care

This chapter should enable professionals to understand how population beliefs on disease are construed, how their causes are explained, why people do not attend health services, how patients treat themselves and select the appropriate treatment.

- What are the populations' beliefs in relation to disease? Traditional beliefs about symptoms

"Disease strengthens"

Beliefs about disease: how does it work?

Traditional beliefs about health issues correspond to all the beliefs gathered on disease, health and care issues... A patient will have experienced various conditions and symptoms, such as diarrhoea, vomiting, she or he may be aware of the importance of food issues... These symptoms are expressed in various ways within the body. The patient, relying on **traditional beliefs, will compensate for the lack of knowledge of biomedical science by an accurate description of the symptoms.** In any culture "the language of disease", or of symptoms, will describe pain, anomalies, signs, problems, by reference to a specific part of the body (ie. the organ supposed to be affected by the disease): *to have a headache, painful heart or disease of the stiff neck* for meningitis, *dead leg* for poliomyelitis etc. **Traditional beliefs generally rely on visible problems noticed on a sick body.**¹²

¹² May we however specify that according to Pagnol and César, "*breaking somebody's heart*" may not be literally interpreted ... Whereas *se faire du mauvais sang ou de la bile* (i.e. to worry oneself sick) comes from an old medical theory (theory of humours, cf Hippocrates), according to populations there is no link between distress and bladder ... Y. Jaffré, 1996



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In the course of their consultations, doctors come up against popular beliefs every day, which have an unknown impact on patients' motivation or reservations. On one hand, the traditional knowledge does not generally reflect the medical approach. For populations, each symptom noticed generally corresponds to a specific disease. On the other hand, where biomedical science will identify, as the case may be, gastro-intestinal or gynaecological disease, populations may consider these as a single disease. By interpretation, these visible symptoms, which seem to have the same origin because of their form or consistency, will be grouped together. Populations will then refer to "*the disease which causes balls*" which may include either a hernia, a tumour or haemorrhoids. These mismatching interpretations will lead to treatment pathways based, for some diseases, on traditional beliefs instead of biomedical science, where the link between treatment/disease is not always clear to patients (as for chronic diseases). However, in other cases, the trouble noticed may correspond to a symptom duly identified by biomedical science, such as for measles, where traditional beliefs match biomedical diagnosis. This disease is often properly identified and named. Then the correspondence between traditional and biomedical names will facilitate discussion between medical staff and patient, since both are talking about the same disease.

Traditional beliefs will also define the difference between what is disease and what constitutes a normal state of health. For example some cultural beliefs may not consider a symptom which medical science considers to be caused by disease as a symptom: for instance, tapeworms are considered by some ethnic groups as enabling digestion.

Traditional beliefs rely on experience and therefore focus on what is felt and seen. According to the principle of analogy, beliefs are built on sensations or similarities. Traditional beliefs group together things which seem similar: without any scientific words, explanation of the body's disorders will match commonly used words and hence will gain credibility based on what is close to them and common. There is often a mix-up between cause and symptom. For instance, a cough after a cold would cause tuberculosis.

The causes of disease

In many areas of the world, traditional beliefs about the causes of disease rely on the two-cause principle (natural/material causes and supernatural/spiritual causes) and incorporate the principle of various specific or simultaneous causes. Populations will consider social causes as essential and determining since a disease is often deemed as a disorder, due to a non-observance of applicable standards or social norms. Of course, differences exist between urban and rural populations, whether these populations are able to read and write or not, sedentary or not etc. Hence, it has been noted in urban areas that various interpretations of a disease will co-exist and people of different communities may even pick up beliefs and practices from each other.

Concepts are not exclusive: various beliefs may be referred to and applied for a same disease. There is a mix between the various disease representations, which are interlinked, in a way that is specific to each community.



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Improving understanding of behaviour

As mentioned above, a population's interpretation of diseases generally generates a “coded” denomination that will help to overcome one's fear of the unknown. By ascribing a name to a disease a first diagnosis will be issued, one or various troubles may be linked to a familiar disease according to the organ involved or visible signs, such as, for example, indigestion. But people may also give a name to **the disease according to its supposed severity**: in Wolof, malaria is known as *sibiru*, from *sibir* which means *come back tomorrow*. The translation of traditional names of diseases may be relevant to help understand behaviour. These traditional appreciations of duration of disease will impact on health service attendance, more particularly because of the differences of interpretations between traditional and biomedical approaches. For instance, if the populations accept the seriousness of a disease because of its persistence it is difficult, as in the case of hepatitis, for example, to accept long term care without any drugs. Interpretation will lead to the identification of a disease. According to the different possible interpretations, a patient or family will seek advice of the appropriate “doctor”. These elements, which should be considered in conjunction with economic factors, will lead to a separation between diseases that are treated locally and those which are treated by “white medicine”.

In summary, traditional beliefs may try to explain the occurrence of diseases on the basis of observations of the body and of suffering, but they can also be based on the way diseases are transmitted, their duration or the efficiency of treatments. This leads us to consider the various treatment pathways taken by populations.

It is essential that medical staff gain a good knowledge of the traditional name and translation of diseases to identify beliefs and subsequent practices. Names ascribed to a disease by populations are always linked to body, pain, treatment, duration aspects etc. The issues of appreciation of severity, duration and the evolution of a disease are most relevant to proper understanding of health-related behaviour.

- Treatment pathways: a rational approach?

The treatment pathway generally corresponds to a specific process, i.e. to a series of choices between drugs, consultation of doctors, doctrines and beliefs, **whereby the successive choices and evolution of requests depend on the perception of the disease, degree of anxiety and the perception of how effective treatment is (Benoist, 1996)**, as well as the **means available**.

The treatment pathway relying on the experience of the disease always incorporates both individual and social dimensions. Generally, the first reason why patients seek care is for pain relief. Patients will estimate and choose on a practical basis the possible options according to their ability to stop pain. Modern medicine will be sought in the areas it is supposed to be most effective, i.e. for acute diseases as can be noted from the high levels of consumption of modern analgesics. As for linguistic issues, this concern may be confirmed by many words ascribing diseases by linking the location in the body and pain designation (bellyache, headache etc.)

Taking the following treatment pathway, relating to fever management, as a case study, we can look at how it relates to pain, perceptions, degree of anxiety and available support (economic and social):



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1. The individual perceives the first signs of fever (or s/he may notice s/he has a *hot body*: designation). Fever, like diarrhoea is considered as an “everyday” disease, which is not seen as very serious as it occurs frequently, recurs and quickly disappears thanks to paracetamol and a natural recovery. Hence, it will be managed at home, as this is the cheapest and least restrictive way to recover. This first step varies according to social status: women and children will more often be treated at home than men. In this first section we can identify three items linked to the management of the disease: a cultural aspect (perception of the disease), an economic aspect and a social aspect (self-medication more frequent for women and children).
2. When s/he gets worse, the patient’s perception of the disease will lead to recourse to other people and s/he will look for the most efficient solution: the patient has noticed s/he feels worse and will describe the problem to relatives. In choosing a healthcare option, neighbourhood, relatives, family all have some influence.
3. Upon description of the fever, an assumption will be issued then a disease will be named and deemed to be natural or supernatural. By adherence to all the proposed perceptions and interpretation of the condition, the patient will choose the most appropriate recourse. In southern countries, if fever appears with convulsions, “crisis”, the patient will seek the healer’s advice, since the crisis is separated from the preceding fever and is instead associated with the occult. The patient will then be taken to the healer even if they know that the free clinic may treat other fevers and, in some cases, can be less expensive.

A 4th section could be added, which would be constituted by: perceived ineffectiveness of the therapist because the problems persist and recourse to another therapist and/or medicine/structure. The recourse to any kind of care is not exclusive. People may skip from modern to traditional structures if there is no result, they will even go back and forth between both types of medicine. Disease beliefs are versatile; they can be questioned by individuals after three days of inefficient treatment. **The recourse to care is determined by trial and error** as well as by “word of mouth”, or the importance of the patient’s relatives who will recommend a good therapist. Hence, the quality of communication and establishing trust can impact on the efficiency of prescriptions and treatment.

It is important to understand that populations’ choice of treatment options (whether modern or traditional) depends, in part, on each option’s ability to achieve results.

To conclude, **health behaviour is pragmatic and rational**: populations use what they can, according to what they can really afford. In other words, the conjunction of modern care systems, traditional practices and magic protections may be considered as a fruitful synergy, it is an “asset”.

To have an adequate overview of the different pathways taken for a disease, one may consider the populations’ representation of the disease (which does not always match the



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one provided by biomedical science), its name (used by relatives), other criteria such as the evolution of the condition (when the problem began and how it has progressed) and the perception of the treatments' effectiveness. Hence, to understand why a patient delays attending a free clinic and to provide adequate preventive care in case of a disease, the abovementioned issues must be taken into account, so that health workers and the population can communicate well from the outset.

- Medicines as social and cultural indices

Addressing the issues of access to care we need to talk about medicines, as they cover all the aspects of the health system, ranging from the privacy of the consultation where they make patients feel better and confirm the diagnosis, through to their sale which presents major socio-economic issues. In most southern countries, any market will propose various leaves, potions and chemical products (with a "price per tablet") that offer treatment.

The reputation of a remedy, its name, its presentation and its supposed therapeutic properties, whether true or not (it does not matter once the belief is shared), may help us to understand patients' conduct towards drugs. Hence, **dexamethasone** or **falbitone**, which are *cortico-steroids*, are bought by women who do not feel fleshy enough (in Mali these drugs are called *dafurukubanin* or *bobarabanin*, which mean "fat cheeks" and "fat bottom" respectively). Furthermore, stimulating effects of **ephedrine** make it an accessible "drug" and anxiolytics increase the effects of certain drugs, **aureomycine** becomes a lubricant, enabling women to simulate desire, antidepressants are considered as stimulants and antibiotics have been the subject of an advertising campaign to explain that "they are not to be used systematically." **The use of medicines and their misappropriation will show, far better than surveys would do, the health, aesthetic or psychological concerns of the populations. The use of drugs also reveals the ways in which health information has been appropriated, sometimes with serious consequences.** Without any medical advice and appropriate knowledge of a medicine's composition and its specificities, customers will rely on the noticeable effects alone to assess the drug. In other words, **the reference is the effect produced or expected instead of the active chemical molecule.** A medicine becomes an attractive substance, promoted by advertising, the representation of which is used as the product itself.

In addition, some drugs become "indices" such as drugs used for HIV/AIDS: treatments are marked by their reputation because there is only selective access to them and some are considered as a "social index". If they have better recourse to a "market" or "drugstore on the ground", many purchasers will evoke money issues as on the market, drugs may be purchased per unit. Moreover, pharmacies have complex procedures and require adequate prescriptions, which may be difficult. The hubbub of the market will ensure confidentiality and the privacy of purchasers, who are too ashamed to go to the hospital to explain their disease. To conclude, these objects are related to knowledge and influence and are part of an overall health system and various networks.

The above advantages do not prevent there also being negative perceptions of medicines (due to the fact that populations have poor information about them, the strength of their effects and side effects), which are also echoed by politics. Reservations about medicines may be expressed as non-compliance reflecting scepticism about biomedical science and prescriptions. Refusing medicines leads to recourse to other medical practices, especially in countries where traditional knowledge is particularly widespread and where that traditional



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practice, unlike biomedical science, is a spiritual expression which confers harmony and stability.

The perception of drugs by populations raises specific queries for health professionals. As well as making inventories of traditional concoctions, it may be advisable to understand how medicines are used and related beliefs. Professionals should not only try to gain knowledge on traditional remedies but also to understand the sense which populations attribute to a simple injection. The role of medicines in day-to-day life is essential to improve understanding of health issues. The different uses of medicines may enable better knowledge of more general cultural issues, such as links with knowledge, order or authority.

- Health worker-patient relationships: different perspectives and communication difficulties

In medical staff/patient relationships, the health worker's appreciation of the disease usually differs from that of the patient. There is often a discrepancy between beliefs and practices of medical staff, which are based on a biomedical approach to health, and traditional beliefs and practices. This discrepancy covers more than biological issues: the identification and categorisation process of diseases does not always match the traditional existing categorisation. Hence, whereas biomedical science will "*control risk factors*" the population will rather "*be placed under the protection of*" factors. Medical staff will refer to biomedical information that is not necessarily known by the population. Hence various linguistic and information issues may arise. Access to medical practice does not necessarily mean an adequate understanding of information delivered by medical staff. **The messages of the biomedical system are often reinterpreted and misappropriated.** Any care delivered has its own sense and medical activities are always reinterpreted. The doctor will analyse any symptom reported by the patient and translate it into biomedical language, which rely on biological science. The patient has his own idea of the disease and has construed his own explanation; this may refer to individual but also collective beliefs.

How can we explain these important discrepancies in communication between medical staff and patient? If we try to identify the main causes of the lack of communication between professionals and populations, we can refer to medical training.

Medical training, as it is currently delivered to students, tends to reflect Pasteurian principles. Education provided to students is, above all, steeped in the same logic: a cause, a disease, and a treatment. One of the specificities of medical training is that the medical profession is very hierarchical, people focus on technical aspects and both neutrality and distance vis-à-vis patient and pain, prove that you are a good professional. The abovementioned training underestimates cultural and social issues, and patients' expectations are often supposed to hinder the medical cause of the problem. In fact, in difficult situations (palliative care, civil war etc) medical staff are paradoxically supposed to support people in distress while at the same time stop themselves from really listening or participating or getting closer to the pain to be able to fight it.

The hospital medical curriculum prescribes the right behaviour towards patients to be adopted by students and thus controls reactions towards body and disease. In any healthcare facility medical staff are supposed to adhere to the following principles delivered by the university: objectification of the body, no emotional involvement, protective distance



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and self-control. A real professional is not supposed to show what he or she feels: *“When she died, nobody said anything, we went on working as if nothing happened”* A nurse.

“At the hospital, during your training, you get used to showing nothing, even if you are disgusted or you feel depressed, it’s like a code.” A student.

In medical studies the patient disappears behind the disease. The institution will help in some dramatic situations: the patient is not this woman suffering from AIDS with young children but a reference number allocated to her bed or her file. In that way, the patient may lose his own identity ie. social or emotional specificities, as an anonymous body prevents medical staff from being affected too deeply. This method enables the health professional to take some distance to hide behind knowledge thus standing “on the side lines.” The patient is the “other one.” As for care, by taking distance by adopting a technical approach, medical staff stand aside from disease and pain as shown by the patient. It is, however, difficult to avoid any involvement in the patients’ situation – especially if you see him every day. One of the biggest difficulties in the relationship between medical staff and patients relates to managing to find the right distance, ie. being neither too close nor too distant. It is difficult to find the “right” place. Health workers are subject to a proper distance from patient’s pain. For C. Mercadier¹³ medical workers are subject to a “mirror effect”. This is difficult to bear, especially if there are similarities between the health worker and the patient, such as such as occupation, age, where they come from etc. For Y.Jaffré¹⁴, the “personal history” of a health worker may impact on his or her relationship with the patient.

Conventional medicine must maintain good relationships with patients as high-tech care can have a disastrous effect: it turns the patient into an anonymous being and the doctor becomes a technician whose acts result from instrument-based data. Healthcare is not only “technical” and medical staff are not “technicians”. Patient must be involved in the debate and subsequent decisions about therapy, or, at the very least, they must give their consent. Quality of care also covers interpersonal relations between patients and medical staff. The welcome, empathy, respect for the individual, time devoted, information provided and professional integrity play an important part in the quality of care, as perceived by patients. **It is precisely because they have physical contacts with patients (examination, palpation, etc.) and “contact” can be ritual practice, that healers are appreciated, and sometimes preferred, by populations.**

For an individual who feels sick, treatment is not enough, and interactions with medical staff are crucial to build a relationship based on trust. In order to improve communication, medical staff must avoid the pernicious effects of lack of consideration of a patient’s culture and improve their own command of rules, codes and norms related to care issues. The doctor must dedicate sufficient time for consultations at the request of an anxious patient.

¹³ Mercadier C., 2002

¹⁴ Jaffré Y., 2003



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2- Collective management of health

-“Other medical practices”: The role of traditional medical practices and links with conventional medicine

“Patients will ask ‘white’ medicine to get rid of the symptoms and ask traditional healers to identify the real causes of the disease and to find ways to fight against it.” Olivier de Sardan, 1995

In spite of the important part played by modern health systems, they are not exclusive. In relation to health, each individual may seek other types of care. In many countries, including Europe, patients will turn more and more often to different care systems, which are not linked to each other. In spite of the predominant authority of biomedical science prevailing in modern western countries, an increasing part of the population refers to other types of healthcare.

These traditional practices will precede, replace, come along with or follow other therapies. They are called bone-setters, fire removers, shamans, witch-doctors or traditional therapists.

Recourse to traditional medical practices has often been wrongly attributed to the deficiencies of the health system. Yet populations really believe they may be both efficient and complementary. As diseases are related to culture, symbolism and norms, treatment may not only care for the physical aspects of the disease. How can modern medical practices succeed in appeasing angry spirits or refocusing vital energies? Finally, communication and relationship difficulties, the complexity of medical jargon, and lack of certain diagnosis in some situations due to the lack of analytical methods or x-ray facilities, mean that modern practices may not compete with traditional ones which provide a comprehensive approach to the patient and his anxiety.

Hence, in spite of the predominance of biomedical practices, some issues may favour medical pluralism, which “*far from disappearing with the occurrence of modern science, draw from it a more important role to play*” (Benoist, 1996). Medical staff distancing themselves from pain and human anxiety, combined with the increasingly technical aspects of their work, encourage increased recourse to traditional and religious practices to care for so-called diseases of the spirit (Jacquemot, 1996). There are diseases pertaining to white people and there are the *others*... **People have favoured connections between traditional therapists and patients:** the same language for the identification of symptoms, same interpretation of the causes of the disease or even of the qualities of medications. The patient does not feel left out of the care process, as he has the same references as the healer, and these references are part of their common knowledge. The way a diagnosis is delivered and patients’ expectations for treatment rely on a common knowledge, which facilitates their acceptance and assessment of effectiveness.

In order to issue diagnosis and subsequent treatment, populations and healers will “pick up” information from various practices. Nowadays, the language used by traditional practice and populations show various connections between traditional beliefs and biomedical science. Take, for example, the following argument: *Chloroquine cures malaria, the disease has been treated with Chloroquine, therefore this disease was malaria*. Many healers use words from biomedical science and ascribe them to traditional beliefs and practice. They may use words such as “bacteria”, “virus”, “microbes” to describe a condition. There are many factors, such as



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health education campaigns, the distance to the hospital, health service attendance by relatives (or self attendance).

As has been shown for treatment pathways, patients have a practical approach to the management of their health. They do not want to definitely and absolutely stick to a type of medicine but pick up the different methods made available to them (ie. homeopathy, allopathic, plants, pills, acupuncture techniques and surgery etc.). **One single goal may be achieved: relief and recovery.** For a single disease there will be several corresponding care proposals from which the patient will make his choice, unless he accepts all of them. Recourse to different treatment options, whether modern or traditional, at the same time is a common practice.

Moreover, in Brazil, the existence of various cultures will lead up to recourse to different kinds of medical practices. **Any reference to traditional medical practices should be considered from a historical, local and global point of view.** Hence, recourse to traditional medical practices, self prescription or religion shows the various relations between the inhabitants of *favelas* and their environment which may be socio-economic, traditional or based on the accessibility of services. **Relations between medical staff and patients and insufficient health structures will encourage the recourse to traditional medical practices and religion.**

However, the merger between traditional and biomedical practices may not work as populations may systematically refuse biomedical practices, such as vaccination.¹⁵ For instance, in Brazil, the Amazonian group called Madja-Kulina reconsider vaccination on the basis of its own beliefs. Their medicinal plants may either heal common pains (occasional injuries, bellyaches or headaches) or “mixed plants” are used to heal more serious diseases. According to them, medicines are supposed to heal common pains (headaches without any connection to occult issues) whereas vaccination is supposed to treat more serious diseases. In addition to initiation and learning, the power of shamans depends on the *dori* – a substance that is shot under the skin. Shamans’ power leads to the abstract world of spirituality, which is alien to biotechnological science. However, vaccines are considered to interfere with this power. The wisdom attributed to some plants such as *dori* may be attributed to injectable substances, which also get into the body and produce changes. The universal vaccine would then be shot into the body of any inhabitant, which would deprive the shaman of one of his specificities, i.e. being the only one holding the power thanks to their knowledge of plants. Hence vaccines compete with the shaman's specificity of injecting and healing disease. The Madija-Kulina shamans claim that they are deprived of their practice because of these biomedical activities. The power of vaccines makes them lose the *dori*. Hence, vaccination is considered as a violation of traditional medicine which is usurped by new techniques. Wisdom ascribed to the vaccine enables all the immunised inhabitants to avoid the disease without any intervention by the shaman. At the same time, like the *dori* or mixed plants shot by the shaman, the vaccine’s wisdom may also bring disease. Hence, Madija-Kulina fear both vaccines and shamans. During the notification of a vaccination campaign, several inhabitants will run away from the village or prefer to go about their daily business rather than taking any risks.

Over the last few years, the integration of traditional medical practices into modern structures has been recommended by the WHO. The above consideration of “therapeutic knowledge attached to therapists” will require bringing two completely separate worlds

¹⁵ Laplante J., Bruneau J., 2003, « Aperçu d’une anthropologie du vaccin: regards sur l’éthique d’une pratique humanitaire », *Historia, Ciências, Saúde_Manguinhos* vol.10



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together. But this cooperation appears to raise many issues. For instance, it often appears impossible, once taken out of a network where they are used according to specific codes, to use plants for “scientific” purposes. The same plant will have different qualities depending on when it was picked, where it grows and always according to the way it has been mixed with other substances etc. Moreover, some practices are dangerous and it may be difficult to control them. A healer is not supposed to be asked to recognise only the non-risky part of his practice and in such a case, he may hide the other part of his activities. Finally, a marabout or shaman is more than a healer and the absorption of their practice within a programme would mean the absorption of their social and political status, (prestige and power).

Professionals must not draw quick distinctions between tradition and modernity in a world where allopathic drugs are sold all over the world. They must recognise the various forms of treatment pathways, the issue of complementary care, and the expectations and frustrations which are generated by attending hospitals. All the above issues will lead to medical pluralism. However, they must carefully consider attempts to incorporate traditional practices, because this not without risk. They may be able to identify social, economical and political issues linked to the various traditional medical practices and their respective representatives.

- Classification of target populations

A target group or population may be selected prior to any action. However, there are pending issues: Is the selection of targets always relevant? Is it really possible to identify target groups? And, above all, what are the consequences of this selection?

“The selection of a group necessarily leads to the exclusion and the stigmatisation” B. Taverne.

Some targets (AIDS target groups, sex workers, drug users, mothers of children suffering from malnutrition...) may be marginalised because they have been targeted. Their selection as a target group makes them feel as blamed, as they may be suspected of transmitting the disease. Targeting is an “accusation” about their present or past conduct and consequently their morality and way of life may be questioned. In many areas of the world, tuberculosis means poverty and poor living conditions. **Targeting may lead not only to stigmatisation but also to exclusion. The selection process is therefore a delicate issue and this type of side-effect must be avoided.** In countries, for example, where prevention was essentially focused on the heterosexual transmission of HIV, AIDS was considered as being due to women, whereas AIDS used to be considered as a “gay disease” in North America. The public health recognition of the fact that women are biologically and socially more vulnerable to the AIDS infection is combined with a popular tendency to demonise sex workers and other “sexually immoral” women who are also considered to be dangerous and contagious. Hence, this may have pernicious effects: if resources are essentially allocated to women and AIDS, as required, the current belief that AIDS comes from women will be confirmed, diverting attention from the roles and responsibilities of men. Nowadays in Nepal for instance, AIDS carries racial, caste and gender connotations. In Africa, women do not want people to discover that they have condoms at home; this would mean that they are prostitutes.



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The identification of the target group is a delicate issue. Being seen to be specifically targeted can lead to the differentiation of individuals within their own group.

- Community participation and the position of coordination agents: ambiguities, strategies, resistance and power issues

Power issues in relation to health and disease

Several programmes mention that the involvement of populations in health issues would increase efficiency: the involvement of populations appears to be necessary to gain their support. However, while the population's involvement is essential, it is often a difficult issue with underestimated complexity.

A project may be considered as a sphere where political, economic and status issues may arise, which will automatically lead to conflict situations. If these issues are not properly identified, they may arise and backfire against the project. **We must bear in mind that any actor (population, target, village head...but also professional) will implement strategies and conduct to preserve his or her own interests. The involvement in a project means to be linked to all resources associated with the project.**

These include economic resources (the most apparent: money, work, per diems), cultural (newly acquired know-how, training etc.), social (coordination agent networks, personal relations, contact lists, integration in administrations etc.).

The project may not only considered as the simple implementation of a health programme, it is also brings into question the existing hierarchical positions and roles, categories and groups of social agents. The project may generate various conflicts due to the distribution / ownership of resources and the new distribution of power is a core issue. The actors of a development project have a strategic role and may regulate the actions in which they are involved or issues they are faced with.

The issue of motivation appears to be essential to understand populations' behaviour. The consideration of sense given by populations to a specific action will help to understand and explain people's conduct. Hence, during the implementation of a project, it may be necessary to consider the sense given to it by both individuals and the community. Why would populations be willing to get involved in such actions? How will this interest be considered by the population? To which extent can target populations (ie. the most vulnerable) be involved in a project?

- Identification of actors

Previous programme experience, politico-administrative aspects, existing relationships between the team and the village, and selected local agents who have specific connections with project coordinators will have a sizeable impact on the ability to identify urgent needs and suitable representatives among the population. When gathering information, **we may notice the influence of one group on another, which means that beliefs and**



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considerations of the minority are left aside, and this minority is not therefore in a position to convey their own interests and opinions as if they were general interest.

This is especially the case for women, who are involved in private and domestic matters. We may then ignore essential information, because participation and needs assessments will have focused on a convenient vision and have ironed out differences. This issue may seriously impact on the success or failure of a programme, and should not be underestimated. In fact, case studies¹⁶ highlight that target groups are heterogeneous and also that their overall **view of activities may radically differ from those of other actors.** The involvement of minorities should be encouraged. Then, in some cases, a proper selection of participants may account for the ability to express oneself, as it may be unadvisable to bring together people who have different hierarchical positions within the community.

When conducting a needs assessment in a village it may be important to know who attended and who did not and why, and thus identify practical (time, distance) or social (duties and coalitions) issues which may impact on the ability to attend. The absence of certain actors and the subsequent distortion of the information collected must be considered. As there are many issues affecting the flow of information, it is advisable to avoid organising the needs assessment in a manner which is too formal. Programmes must ensure that the weakest groups (in terms of social status or ability to convey information) can effectively provide information and express themselves.

- Community health and humanitarian aid: an ideal relationship?

A community-based approach implies that the population will manage its own health, estimate its needs and find relevant solutions. Community health provides a new way to organise health issues, which result from transformations undergone by developing country health systems and claims that communities are able to manage their own health and bring solutions which respond to their needs. Hence, individuals and families become responsible for their health and well-being, as part of the concept of *empowerment*, which actually disguises governments' abandonment of its important role in determining the populations' living conditions, especially the poorest. **This community-based health approach relies on an ambivalent view of "community", ie. on a traditional management of collective goods which is not always the case as** conflicts, inequality and pressures on minorities are everyday issues within villages or districts.

A community-based health system, even if artificially created, may serve as a springboard towards actions, provided that professionals account for the influence of strategic groups, various pressures, and conflicts in relation to the access to care by the poorest. It is important to properly understand the how the community is organised, issues raised by hierarchy (board management) and the populations' perceptions of health services. A community health centre that does not have the population's approval will negatively impact on any project in which it is be involved. On the contrary, a community health centre duly

¹⁶ Olivier de Sardan J.P



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approved by populations will serve as an efficient interface for the implementation of a project.

3- Beware of the risks of cultural approach and to the temptation for ethnocentrism

Exchange between a doctor (M) and an anthropologist (A):

M: "When we were students, we decided to create a maternity unit in Senegal, but nobody attended the maternity unit for a simple reason, we had appointed a Wolof to manage the unit and it was a Toucouleur community. I said to myself then, we are ignorant doctors, if we had sought advice from an anthropologist, we would have not made the mistake"

A: "You said 'for a simple reason.' There is never a simple reason for the failure of a project. I am rather convinced that it is not due to the fact that the manager was Wolof, or that, at least, it might not be the only reason. It's true, anthropologists often say 'Be careful with ethnic conflicts' but for that case, I am not sure."

Do health projects, which are not approved by populations because they do not want to give up their "gris-gris" (charms), really exist?

In this section, we shall draw your attention to the issue of cultural stereotyped beliefs and ideas of relief and development professionals towards populations. It does not mean that cultural aspects of populations' reactions towards programmes should be neglected but that it is easy to consider the cultural issues as the only cause of programmes' failure. This will be underlined by the following example from an anthropological study¹⁷ commissioned by an institution to check why a maternal mortality programme in Ecuador did not find support among the local population. The abovementioned institution had raised the issue that women from poor backgrounds, by reference to traditional practice and standards, were reluctant to attend antenatal consultations, to give birth in maternity units and to use appropriate contraceptive methods (ie. traditional midwives care for pregnant women and they are willing to have many children etc.) and subsequent rejection of modern knowledge and practices (medical practice, contraceptives...). As a matter of fact, the study revealed that the above issues were based on the specialist's beliefs about the target population rather than on reality. Hence, first, the adherence to a certain kind of tradition, which is the case for rural populations in Andes, does not automatically entail purely traditional behaviour and beliefs. Secondly, biomedical practices, as set forth by western countries, are not rejected by rural populations but are implemented, as show by parents' efforts to send their children to school and the purchase of goods, which are usually accessible in towns. This survey also revealed that **a tendency to provide an interpretation based on cultural issues prevents us from questioning ourselves about how the programmes have been implemented and, above all, the way care is provided.** For indigenous women, by raising the issues of traditional practices, we avoid talking about the health worker – patient relationship, as well as the type of programme...

In the field, we must not forget that professionals are individuals with their own standards and references, their own conducts, habits, and practices which sometimes radically differ from the populations. Moreover, the same issues may arise within medical teams where expatriates' culture may conflict with local colleagues.

¹⁷ Fassin D., 2000



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While trying to understand the various interactions between programmes and populations, surveys should also focus on the beliefs and reasoning of professionals.

*"A critical approach is essential to differentiate between scientific knowledge from common sense and ideology: constantly challenging oneself and others on both results and also implicit assumptions involved in reaching these results are important to ensure scientific findings."*¹⁸

In addition to an approach focused on cultural issues which prevents a critical look at oneself, "humanitarian" issues are to be considered very cautiously. Relief workers have often been blamed for tending to standardise different cultures, by means of health issues, and promoting "morality", legitimised through emergency response.¹⁹ Whereas relief actors have now agreed to question their own practice, we must never forget that **relief and development programmes must not be diverted by ideology**. Targeted populations are too often considered as "victims", whereas both social and cultural aspects are neglected: "This man who has suffered from a tsunami or a dictatorship is no longer considered as Balinese or Burmese or pertaining to a social or ethnic group or to a political party, he is a victim. (...) Although they are considered as such by foreigners, the populations do not really consider themselves as victims."²⁰ **Relief work must not rely on a monologue that neglects culture because of the urgency of an emergency.**

¹⁸ Fassin et Jaffré, 1990

¹⁹ R. Brauman

²⁰ B.Hours, 2007



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III- Methodology issues... from otherness to (re)cognition

While this reference programme does not aim to implement an overall methodology applicable in the field by all actors or to transform those actors into anthropological trainees, it does aim to encourage open-mindedness and raise awareness of other people's culture. These guidelines will provide professionals with appropriate methodology for taking a broader look at situations and questioning their own beliefs so that, based on better comprehension of other beliefs about disease and healthcare, they can have improved relationships with patients, which are based on a real dialogue instead of a monologue.

1- Assessing socio-cultural determinants of health-related behaviour: improve your understanding to be able to take action

It is essential that professionals have a good knowledge of social beliefs and norms in the relevant subject area and that they are able to talk to the population about proposed programmes. This may enable professionals to take into account information delivered by patients and the population's needs, as well as helping these professionals to gain better knowledge of health services and locations, population beliefs and practices. This can thus improve the quality of decisions and prevent pernicious effects (anticipate any risk of disruption to social organisation or to work or time management...). The professionals must consider the importance of target populations' perceptions of the various programme themes.

Two specific goals:

- Consideration of norms, values, practices and beliefs and transmission of knowledge and practice: identification of key cultural issues
- Consideration of target populations' resources: way of life, social organisation, issues of power and available resources ...

Carrying out an assessment: methodology issues

First, conduct a literature review of existing surveys on the target population and create a bibliography of available documents. It is advisable to raise some queries which may help to clarify the context (Organisation of family eg. patriarchal/matriarchal organisation of society). What is the position of children? What are the taboos issues, which may be raised by the actions (eg. foods which are not permitted?) What is the hierarchy of the group? Even if the above records may not provide all the necessary information, they will raise questions which can be addressed later.



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Then, gather testimonies and descriptions, conduct a series of case studies. For that purpose, identify the right places to meet people and organise discussions, identify various concerns and queries, which will lead to reflection and dialogue.

1- Identification of survey target groups

Recommended actions: discussions with targeted groups, broken down as follows – women, men, young people and old people etc. Small groups, of similar people, are advisable to avoid any censure or embarrassment. In addition, these focus groups may enable cross checking of information.

2- Identification of appropriate places to conduct the survey

Identify places according to the targeted groups: i.e. choose a building dedicated to an association for young people, a house for women etc.

3- Topics

The questionnaire will be divided into specific topics to facilitate answers: specific needs of each panel, knowledge and practice in relation to disease, typical timetables of the participants, health resources available for the targeted population (current / traditional medical practice, care structures, associations / NGOs, mutual aid assistance), the impact of other NGOs and previous programmes ...

Examples of questions to be asked

- ❖ On the disease: Where does the disease / practice come from? What is it called in the local language? When does it appear? What are the supposed causes of this disease? Can you describe its symptoms? Is it a shameful disease? How do healers treat this disease? What kind of self-treatment is considered as a remedy for the disease?
- ❖ On family organisation: Describe a typical day of a woman / man / child? In the family, who usually takes important decisions about health issues? Who takes care of money issues? What are the most important constraints?
- ❖ To the traditional healer / marabout / shaman / birth attendant: What are the most common diseases? What are the needs of the populations? What are their difficulties? What are their expectations / fears about a specific action?
- ❖ About specific issues: Who is empowered to take decisions? Who usually deals with and controls projects? What are the economical issues? Who wins, who loses?
- ❖ What did the population retain from previous actions by other NGOs? What do they think about current actions? What do they think about the proposed activities?

4- Report back to the population



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It is advisable to gather all the focus groups and highlight, on an anonymous basis, any core points which have been raised by the different groups, in order to stimulate discussion and compare different points of view.

The implementation of a programme may give rise to different points of view among populations who may not share the same interests, and may help to identify the various causes of reluctance. This group discussion will help identify the various interactions among the targeted groups, such as power, or which groups are dominant and which are controlled. This information will be helpful afterwards to identify coordination agents and the integration of the project within the community.

Moreover, exchanges and discussions will give rise to a common knowledge. The common knowledge resulting from the discussion is more important than cultural differences in relation to health issues. Such discussions may elicit relevant information, which will be helpful towards the implementation of the project.

Wherever possible, in addition to the above focus groups, individual interviews (preferably semi-directive) should be organised:

On a given topic, such as a particular disease, an interview guide may help elicit a description of a treatment pathway for that disease.

Other ways to gather relevant information such as individual interviews, case studies and biographies will enable this information to be refined.

- 5- Restitution and synthesis of information followed by recording on files categorised by topic

Warning!!! The abovementioned data must be considered as information rather than pure truth: cultural issues cannot be standardised or indexed. Moreover, social background issues should not be reduced to a set of supposed beliefs shared within a target population, and, neglecting the heterogeneous nature of populations. The aim of this survey is the creation of a broad database which will enable better understanding of the population from different perspectives.

The abovementioned files may enable:

- To summarise significant and usable information on the populations and their expectations;
- To try to find appropriate connections between needs, beliefs and the project;
- To be aware of the vocabulary used by populations for the disease, the causes, the treatment, but also the body and how it functions, remedies and how they are thought to work etc. The use of the local language may enable an appropriate introduction to the study of cultural aspects of health and disease, and may also help improve the relationships between medical staff and patients.

2 - Intercultural strategies during project planning: finding a common language

Groups who are left out of the survey, may later be reluctant to get involved in the project.



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Consideration of cultural determinants should be cross-cutting and should be reduced to a simple 'social component' in the project.

Two specific objectives:

- Incorporation of information on socio-cultural background which has been gathered during project planning;
- Identification of possible activities that are considered useful by both medical staff and the population: taking into consideration the needs expressed by the population during the survey.

Methodology: the integration of socio-cultural information gathered during the survey can be done at different stages:

1. Situation analysis: integration of information gathered on norms, standards, practice and populations' knowledge as well as the availability of targets should inform the analysis of the situation, since these cultural aspects are crucial.

Appropriate beliefs and practice of the target population, once identified, may serve to implement the contemplated actions.

2. Identifying constraints: They may include the population's reservations.

It is also important to gain knowledge of other NGOs working in the area and of previous projects: a climate of competition, for example, may explain appropriation and misappropriation.

3. The first survey may enable to identify key people and miscellaneous influences: elected community representatives, village chief, shamans, birth attendants etc.
4. Selection of actions and priorities.

Once needs and expectations of targeted populations have been identified, it is advisable to assess how a programme could address the abovementioned needs and expectations. Hence, the proposed project may rely on adequate cultural and social data.

When deciding on project activities, finding common ground with the population can be a starting point for local involvement, particularly by proposing various methods and working with the community to choose the most relevant option.

5. Project set-up: vocabulary from the local language should be used to identify the project theme or relevant disease. The project's name may be in the local language.

3 - Implementation and follow-up

Three specific objectives:

- Training and subsequent follow-up of professionals working in contact with target populations: ethical issues, consideration of socio-cultural background and language used during the care process;
- Definition of indicators for how socio-cultural factors have been taken into account;



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- Mid-project evaluation to identify necessary adjustments.

Training

This involves training professionals how to use socio-cultural information to improve the services provided and to be more attentive to what populations say to improve their understanding of how these populations behave. The training session may provide some tools used by anthropologists but does not aim to turn health professionals into anthropologists.

In other words, training may prevent professionals from challenging local knowledge and beliefs, and instead lead them to a process of negotiation to be able to find a common understanding which permits both the populations' beliefs and medical activities.

At the end of the training session, professionals will have received appropriate information on the impact of social and cultural factors on the perception of disease, how it is described and treated (in both traditional and modern societies) and the importance of taking these factors into account in their day-to-day work. All diseases are subject to classification, beliefs and practice, and an adequate survey on those issues is essential.

For that purpose, professionals will be provided with data banks listing references (press articles, communications, references books etc.) on existing sociological surveys on the relevant geographical area and topics. After review of these data, the professional may then move on to empirical work observing, conducting interviews and analysis of these interviews. For practical reasons, this will be done with the aid of quick socio-anthropological surveys. A questionnaire will be prepared as well as appropriate interview guides for semi-directive interviews with families and medical staff. After this preparatory work, a day will be dedicated to door-to-door interviews of families and meetings with local officials or district meetings. Practically, this information is gathered on a day-to-day basis and will help understanding of how the populations' knowledge and practice may be linked to biomedical science and highlight their contribution to care and prevention issues. It is important to focus on information from notes taken during informal interviews between families or with the doctor (questions raised, remarks, comments...). This information will be kept in a "logbook" and will enable this information to be collated and compared with information gathered during the survey phase. This logbook information may also enable interview questions to be reworded or to go into more detail on certain points. Comments on the care process should be discussed during regular meetings.

A summary of these impressions, which will necessarily be partial and incomplete due to the lack of time, will however enable identification of ways of integrating socio-cultural background within the programme.

- Selection of appropriate questions on the key socio-cultural factors

At this stage, the professional, should be able to supply preliminary information on local cultural issues. S/he should be able to provide information on the following:

- **Practice:** why do they that, for how long, and why this is current practice etc....
- **Diseases:** corresponding word in local language, aetiology, traditional or modern treatment methods known by the populations



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- **Care pathways:** the reality in practice, compared to the different care options available;
- **Description of various categories of individuals:** social influence of healers, birth attendants and priests...

Professionals may also provide objective information on difficulties in implementing the project (discrepancies between work planned and work actually performed) and subjective information on the difficulties perceived by the team.

These data will be recorded with a view to being used and utilised as indicators on the impact of socio-cultural background on care.

- *Mid-project evaluation*

A qualitative evaluation of the programme will be needed to enable a proper critical review of one's own classification work, as compared to local practice, and prevent any underestimation of one's own actions.

We are of the opinion that a continuous assessment of the impact of socio-cultural background on the processes and implementation of projects all along the programme is advisable to identify, as the case may be, any changes noticed during the action. Any unforeseen side-effects may be considered. Moreover, estimations based on the process will most of the time provide answers to queries raised.

Ask the following questions: Which pernicious effects have arisen? Has the population started to appropriate the programme? Which conclusions can be drawn already?

For professionals, mid-project evaluations are recommended as a way of formalising and organising an informal training process and enable appropriate adjustments.

- ❖ Ask for information on actors' experiences.

Historical information on the project collected during interviews will enable discrepancies to be identified. Relevant information on experience, which may not have been included in the initial programme, may be collected during interviews on the whole history of the project to identify any possible misunderstandings. This will enable us to check how the planned project matches reality.

- ❖ Convert this information into concrete and practical proposals: what conclusions may be drawn from these discrepancies?
- ❖ Draw comparisons with other areas to identify recurring issues, which may arise from certain actions and hence lead to a general reflection.
- ❖ Gather information relevant for future training programmes during interviews, focusing on difficulties met by expatriates and record them on topic files.
- ❖ Identification of the project's strengths and weaknesses.
- ❖ Discussion: round table format.
- ❖ Capitalisation: the mid-project evaluation may be used to inform future projects.



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Mid-project evaluation: target populations' issues

This evaluation will focus on the consideration of target populations' appreciation of the programme (Olivier de Sardan, 1993). This may prevent any undesirable reinterpretation, or accordingly adjust intermediaries' beliefs relating to the population and their interactions. This will require the implementation of feedback mechanisms for the information resulting from the abovementioned adjustments.

- ❖ How are activities perceived and integrated into target populations' beliefs: How can populations' beliefs about the disease impact on strategies? Does the project affect beneficiaries' beliefs and practice? How do the beneficiaries understand and integrate the activities?
- ❖ Be able to identify sufficient parallels between traditional beliefs and biomedical science, even if there is no possibility of a simple translation. It is important to define what it is possible to convey using a particular language or particular linguistic context and to what extent.
- ❖ Ask populations to estimate the strengths and weaknesses of the project.
- ❖ Evaluate the involvement of local actors: surveys on their motivation and the difficulties they face.

How do they perceive the project? What motivates them? Which problems and needs do they express? How do they respond to the project? Is there any misappropriation of the actions?

Participatory evaluation

This evaluation can be made on a participatory basis by bringing together everyone who is involved in the project (coordinators and local agents, beneficiaries) through the creation of an evaluation team and involving them in all the decisions on the evaluation. In particular, all the actors may be involved in defining survey questions, selecting the appropriate information and identifying recommendations. The most important advantage of a participatory assessment is to create a network for participants to communicate and negotiate. In addition to ideological issues, making the evaluation open to the population explicitly recognises their impact on the programme direction and results. This mechanism will enable the exchange of information and potentially negotiations. Any actors represented will then draw information, which may be specifically useful for them.²¹

These workshops often boost motivation and cooperation, and lead to readjustments and mutual negotiations even if personal interests and strategies are also involved. This evaluation impacts positively on the process: enhancing professionals' credibility among populations and professionals and resource agents are obliged to take certain beliefs into account or, at the very least, it will be more difficult for them to ignore these beliefs. For the 'coordination agents', the evaluation will also help dispel the negative image of evaluations, which are often considered as a potential threat or form of control.

²¹ Lefèvre P. and Kolsteren P., 2007



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4 - Final evaluation: Detailed evaluation table (see Appendix 1)

This evaluation will enable an overall assessment of the project and the socio-cultural context in which it takes place. The evaluation should enable improvements in the comprehension of issues and enables us to step back and assess things in order to inform future work in relation to socio-cultural determinants and access to care.

The table may be **first** helpful to estimate discrepancies between objectives, which had been specifically defined, and their implementation. It may **also** enable consideration of the acceptability of a project and its subsequent integration within the different socio-cultural categories of the populations. By asking these two types of question, the actors may be able to assess what kind of relationship exists between the project and the target population.

This evaluation consists of:

- analysis of all the elements of the project and identifying, at any step, what may work or not;
- assessment of the local impact of the project;
- critical assessment of Médecins du Monde's methods for planning and implementing healthcare projects.



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Conclusion and prospects

All over the world, socio-cultural factors have a major impact on the way people perceive their body and manage their own health. Health programmes, which are dependent on relationships, will automatically generate conflicts between different beliefs about health issues, and these beliefs are often incompatible.

These perceptions, attitudes and beliefs will show the limits and impact of aid and may lead us to be more vigilant and cautious when developing and implementing programmes. Magic and religious protections, food beliefs and influences within families or groups constitute a series of constraints which may impact on access to care. The proposed project must be compatible with the values, beliefs and cultural practices of the target population. A good understanding of these socio-cultural determinants will enable effective interventions to be carried out among the beneficiaries. In addition to the acceptance of cultural disparities and observation of multiple practices, it is advisable to understand that from one culture to another, there are different ways of considering disease and care. A lack of awareness of the differences in practice and beliefs may be considered by populations as a refusal take them into account and may generate suspicion and reluctance towards projects, which then will not attract adequate support.

Because all development processes require acceptance and respect of cultural diversity, and health programmes cannot deny other ways of thinking about disease, recognition of socio-cultural differences in health also means taking others into account in our work and our interactions.



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On relationships between medical staff and patients

WE CARE FOR THOSE WHO THE
WORLD IS GRADUALLY
FORGETTING

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NOUS SOIG NONS
CEUX QUE LE MONDE
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Schedules

Appendix 1

Methodology guidelines for carrying out an assessment in relation to consideration of socio-cultural determinants in relation to access to care

The proposed survey on socio-cultural issues covers several topic areas. These particularly reflect the integration of cultural issues by professionals' diagnostics and may highlight socio-cultural factors in relation to access to care.

The following guidelines have been prepared not only for professionals, health structures and projects but also for target populations. Focusing on general beliefs and the ways the actors consider their own conduct will enable us to increase our knowledge to be able to implement culturally appropriate projects in any context.

It is, however, impossible from a practical point of view to cover all the issues affecting a target population, we suggest that the survey focuses on the following items: traditional beliefs about disease and how knowledge is spread, social and family organisation (especially gender issues), traditional medical practices, modern health systems, drugs and, finally, international aid. The aim of this work is not to set a definitive list of questions, but to make actors aware of the importance of socio-cultural factors in the various issues arising from the access to care. *Médecins du Monde* may take this opportunity to play a more important part in the promotion of this approach in the humanitarian and development sectors.

➤ Traditional beliefs on disease and transmission of knowledge

This involves assessing the population's knowledge about a particular disease relevant to a proposed programme, and how such knowledge and beliefs are spread. It may enable identification of discrepancies between biomedical science and traditional beliefs, which may help to anticipate misunderstanding and find an appropriate common approach.

It may be helpful to consider the following:

- Definition of disease and health
- Designation (how suffering is described)
- Identification of symptoms and signs pertaining to disease or health
- Explanation (what causes disease)
- Chosen treatment processes
- Social reactions to someone considered to be "ill" (exclusion, solidarity, integration in specific structures such as hospital or a holy place)



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- Transmission of knowledge

This survey diagnostic relies on the identification of the actors who usually convey information or traditional beliefs: the elders, healers, media. The indicators will also identify different information sources (transmission from mother to daughter, by healer, by TV /radio / newspapers, teachers, religious and community leaders).

List of questions:

What is the name of the disease?	
Do populations consider [*] as an illness or as normal?	
When do parents consider that their child is ill?	
What are the different information sources and means of transmission (family, healers, modern health system, media, NGOs...)?	
How symptoms are perceived? How serious is the disease?	
What is the social status of this disease? Is it a shameful disease? Have you noticed any stigmatisation/marginalisation of patients?	
How is the disease treated? Self-medication? Traditional treatment?	
Which diseases are supposed to be treated by a specific medical practice and why?	
To what extent relatives are involved in the treatment?	
What are the religious standards and principles relating to this disease?	
What are the most important sources of knowledge on health issues within la community? Religious leaders? Teachers etc.	
Do schools incorporate health education?	
Do the communities have access to media?	

Example of survey on reproductive health issues



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Which events may be considered as suffering or normal in reproductive health (conception, pregnancy, labour, contraception, etc.)?	
During the above processes, what is considered as normal and what is considered as a problem?	
In reproductive health, what conditions are considered as disease?	

Evaluating knowledge about contraception among men and women

How many kinds of contraceptives are known by the population?	
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Estimating women's knowledge of the physiology of reproduction

Can you provide an outline of the individual's knowledge of physiological and anatomical aspects of reproduction?	
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Teenagers' knowledge of family planning and STD/AIDS

How many teenagers know about condom use?	
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The above questions aim to assess the information held by target groups, and will enable identification of the population's knowledge and adapt accordingly one's own beliefs and incorporate common knowledge (ideas, causal principles and reasoning etc.) into a programme.

- **Social and family organisation**

The following questions address gender, place in the family (among brothers and sisters) and the socio-economic situation of the family.



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Example questions

Describe the family (monogamy / polygamy; enlarged family).	
Describe a typical day of a woman, a man or a child.	
Can you provide an outline on the typical relationship between man/woman, young people /old people, literate / illiterate (hierarchy, support, solidarity)?	
Can you list the different ways health issues are dealt with (within families)?	
Who takes important decisions on health issues in the family? In the community?	
Who will decide to refer a child or teenager to a doctor?	
Who deals with money issues?	
Provide information on housing (lack of privacy; modern / traditional)?	
What are their needs and expectations in relation to health issues?	

This means observing and objectively measuring the allocation of tasks (social and gender) in relation to health, roles and tasks assigned to women, to the young girl, to men and boys and subsequent education. This diagnostic may cover information from various authoritative or reference sources (religion, proverbs, media, school books, etc.) as well as from informal discussions (ideas and remarks made by individuals). The guidelines must include, depending on the nature of the problem to explore, information on gender, age and education etc.

In addition, it may provide information on the perception by community leaders and chiefs (for instance influential local people or religious leaders) towards a particular issue (eg. family planning issues).

- **Traditional practices**

How many healers?	
What are their respective areas of expertise?	



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How do they transmit their knowledge?	
For which disease in particular do the population consult them?	
What is their social and political status within the community? (influence)	
How are they organised?	
How do they cooperate with modern health system? Have they already received some training?	
Are you aware of any previous dialogue about their knowledge?	
What are their expectations and fears in relation to the contemplated action?	

▪ **Modern health system**

How long do population usually wait (in waiting room) to see the doctor? How long does a consultation take?	
For which kind of disease do people refer to the modern health system? (at which stage of the disease?)	
What are the reactions of medical staff towards a sick individual? (stereotypes)	
Describe the relationships with patients (empathy, violence, disinterest...)?	
What do generally people think about medical staff? (reputation)	
What is the salary of medical staff? Are there any sums paid, on an informal basis to access care?	
What are the difficulties (on a day-to-day basis) encountered by medical staff (lack of equipment, poor salary, heavy workload...)?	
What are the population's complaints about medical staff ?	



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Are medical ethics respected? Professional confidentiality?	
What do medical staff expect from the project and what are their needs?	

The aim is to improve understanding of what may or may not lead people to consult medical staff (doctor, nurse, chemist, etc.).

▪ **Medicines**

Name of the medicines purchased most often? For which purpose?	
What are the names given to the most common medicines?	
What do people know about the efficiency, side effects, dosage of a drug?	
Do medical staff take appropriate time to provide information on the treatment, side effects...?	
How do economic issues impact on purchase and compliance (price, free provision, resale, misappropriation ?)	
Are there religious, political or legal reservations in relation to specific medicines?	
How many distribution networks of drugs (either legal or illegal)?	
Where does illegal medicine selling take place?	
What is the importance of traditional drugs?	
Are they incorporated into the modern health system?	

We should be able to **provide information on the perceptions and use of medicines**



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▪ **International aid**

Example of questions on international relief:	
How many NGOs are active on site?	
Describe their actions? Who are the target populations?	
Is there any institution in charge of coordinating activities?	
How is international aid perceived by the population?	
What do populations think about previous programmes?	
What do they expect from the proposed programme?	
Who (among the community) has already been involved in projects?	
What may lead individuals to be involved in the project?	
How may the most vulnerable populations be involved in projects?	

These questions can help to give an idea of the impact of health programmes on populations (state and NGO), if these programmes are compatible with the socio-cultural background, the scope of programmes implemented on [*], populations' attitudes towards the programmes (acceptance, rejection or disinterest).

Conclusion

This section aims to provide information towards the creation of a series of qualitative indicators. As shown above, this means a questioning by the actors on the sense they usually give to their work programme. The notion of 'quality', as currently opposed to 'quantity' may not exclude the use of figures. Hence, we have reviewed some options in relation to key aspects of the populations and international aid. Among the various indicators raised by quality issues, we have focused our work on cultural indicators. This may be explained by the fact that these indicators are supposed to be used in the follow-up and assessment of the project. However, many areas of uncertainty remain about our proposals because this is a preliminary attempt at developing qualitative indicators and, given that we are in the early stages of this work, patience and experience in the field are required so that project staff can feed into this work.



DRAFT

Useful links

Research laboratories

- C R e C S S: Centre de recherche Cultures, Santé, Sociétés: www.mmsh.univ-aix.fr/crecss
- Institut de recherche pour le développement (IRD): www.ird.fr/
- CEPED, (Centre Français sur la Population et le Développement): www.ceped.org

Associations

AMADES - Anthropologie médicale appliquée au développement et à la santé: www.amades.net/
Nomad Recherche Soutien International: www.nomadrsi.org
Groupe URD: Urgence Réhabilitation Développement: <http://www.urd.org/>

Réseaux:

Doctorants Santé et Société: <http://doctorants.mshparisnord.org/>:
Réseau Epidémiologie et Développement (RED): www.red.ird.fr/:

Bibliographical researches:

Bibenligne: selection of catalogues issued by libraries and documentation centres specialized in social studies accessible on the net...
bibenligne.mmsh.univ-aix.fr/directory.asp
Anthropology and society: <http://www.erudit.org/revue/as/>
Journal des anthropologues : <http://www.afa.msh-paris.fr/journal.html>
Social sciences and health:
http://www.john-libbey-eurotext.fr/fr/revues/sante_pub/sss/sommaire.md