

ACCÈS AUX SOINS

**>> LES DÉTERMINANTS
SOCIOCULTURELS**

ACCESS TO HEALTHCARE

**>> SOCIOCULTURAL
DETERMINANTS**

ACCESO A LA SANIDAD

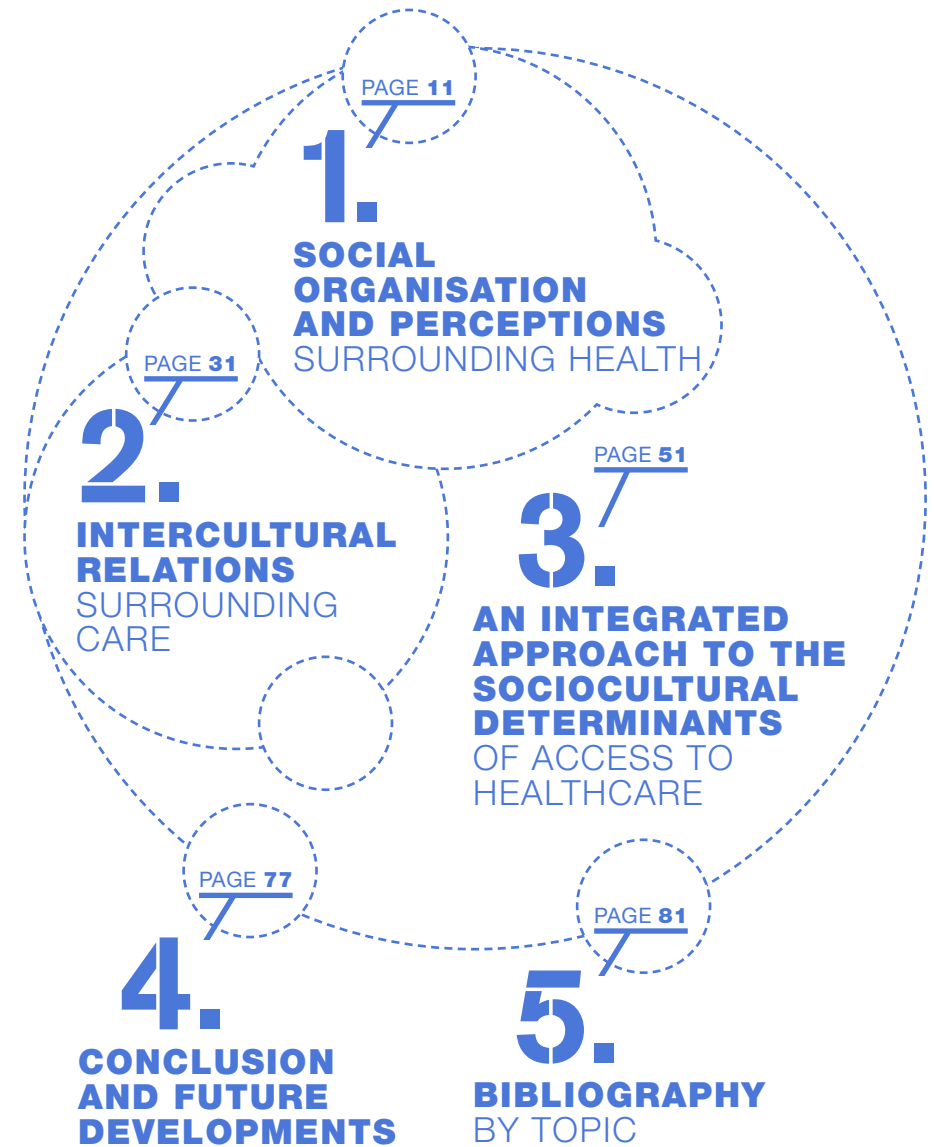
**>> LOS DETERMINANTES
SOCIOCULTURALES**





**ACCESS
TO HEALTHCARE
& SOCIOCULTURAL
DETERMINANTS**

TRADITION



Access to healthcare >> sociocultural determinants /
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INTRODUCTION

Médecins du Monde Project on ‘Access to healthcare and sociocultural determinants’

Central to the ethics and practice of Médecins du Monde (MdM) for over thirty years, the **issue of access to healthcare poses questions for our capacity as human beings and professionals to listen to and respect others.** These same concerns and intentions are evident in the various approaches — community health, participative, de-westernising — developed at MdM. By increasing the professionalism of their activities, humanitarian organisations, including MdM, have successfully developed their logistics, human resources and communications. Today, professionalisation involves **incorporating the ethical and operational added-value of social sciences, to improve the quality of international solidarity work.**

Four years ago, the work led by Médecins du Monde in Latin America and the Caribbean represented the beginnings of a response to this issue. Projects in Mexico, Bolivia and Nicaragua implemented intercultural awareness-raising activities, in partnership with the ministries of health and civil society organisations. In response to this **demand from field staff**, this reference framework and the AS-DSC project now form part of these

ongoing operational initiatives as implemented by programmes and local partners. It is now important that Médecins du Monde should build on these to promote a new appreciation of the role of sociocultural determinants among professionals, so that they are aware of the issues involved.

Defining the sociocultural determinants of access to healthcare

What is meant by sociocultural determinants? Why are they of interest when considering access to healthcare? What contribution can a study of the sociocultural determinants of access to healthcare make to the dialogue between practitioners and beneficiaries?

For many professionals working in international solidarity organisations, these questions arise from witnessing the way project strategies regularly have to confront complex behaviours and perceptions of health of the populations targeted. Projects are not always understood simply because it is impossible to implement them systematically for a variety of reasons, including those which demonstrate the influence and determining nature of culture¹ and social² factors.

Thus, **sociocultural determinants may be defined as all popular norms, values, knowledge and practices associated**

with health and governing actions and thinking about health, illness and also care. To understand these is to try to explain how cultural specificities and social inequalities are ‘transformed’ into health inequalities, and thereby help us find suitable long-term solutions. “The way in which these determinants develop and succeed each other refers to theoretical models but, ultimately and above all, refers to political choices relating to social justice.”³

From an international solidarity point of view, this key notion helps us analyse the source of our motivations and actions. It also improves our understanding of our national teams and partners, providing a means to interpret how we interact and to establish a basis for genuine dialogue.

The international context: sociocultural determinants, a common concern

In recent years, the abandoning of free healthcare (the Bamako initiative), and the exclusion from the healthcare system of the poorest populations, have been the basis for many discussions of the issues surrounding access to healthcare. While several initiatives are striving to improve financial accessibility and levels of health service use, the importance of sociocultural determinants in limiting access to healthcare is still only barely acknowledged.

While consideration of social and cultural factors in humanitarian health projects is nothing new, it still represents an unmet challenge. Emergency-related issues or force of habit may mean that sociocultural concerns are subject to constraints in terms of time, budget and human resources. While some stakeholders wholly appreciate the relevance of these types of study, without necessarily having the resources to implement them, others put forward the argument that these anthropological analyses are often too complex, or that the recommendations are out of step with operational constraints, etc. There is, however, a noticeable and **growing demand from medical and field staff for clarification relating to sociocultural matters**, as is borne out by the rise in the number of people from the field of anthropology involved in healthcare staff training. A lack of understanding of different health practices, the relative effectiveness of medicine in tackling certain diseases and ethical concerns about ‘cultural’ aspects of the patient/health practitioner relationship are some of the many factors of significance to health projects.

One of the responses to the growing demand for consideration of sociocultural determinants is a strategic document on traditional medicine published in 2002 by the World Health Organisation (WHO).⁴ This document is intended to improve recognition of traditional forms of medicine, to help integrate them into

1. *Culture* introduces notions of heritage and transmission as distinct from *nature*.

This concept of culture encompasses a range of areas including the description and analysis of perceptions, behaviours, skills and knowledge and material creations, as well as institutions and means of organisation.

Both these notions refer us back to the image which we project of others and, consequently, of ourselves.

2. The *social phenomenon* to which this refers is understood as all factors characterising the collective (and not personal) sphere of a population. These social factors apply in time and space to the individuals making up the collective grouping which, more or less consciously, internalises the rules.

3. Moleux M., Dr Schaetzel F. Scotton C., *Les inégalités sociales de la santé : déterminants sociaux et modèles d'action*, [“The social inequalities of health: social determinants and models of action”], report by the Inspection générale des affaires sociales [French social affairs inspectorate], May 2011, p.3.

4. *WHO Traditional Medicine Strategy 2002-2005*, WHO, Geneva 2002, http://http://whqlibdoc.who.int/hq/2002/WHO_EDM_TRM_2002.1.pdf

other healthcare systems and to preserve and protect the knowledge and skills of traditional medicine. That having been said, **the WHO stresses the complexity of the issue by adopting an extremely cautious approach** to any attempt to integrate traditional healers into primary healthcare projects.⁵ Other studies place greater emphasis on exploring the social context, as is the case with the report by the WHO's Commission on the Social Determinants of Health. Health is now viewed through daily living conditions (childhood, education and also work), alongside issues of purchasing power and resources, to bring about understanding and to provide skills which will help "build a global movement" aimed at "closing the gap in a generation".⁶

Respect for human rights and, therefore, for the right to cultural diversity emerges as a need that is ever more clearly stated by the UN system, by governments⁷ and all those working in development.

Discussion surrounding the sociocultural context is certainly one of the major areas of a new policy on international aid.

The culturalist vision and the lure of ethnocentrism: two pitfalls to avoid

Exchange between a doctor (D) and an anthropologist (A):
D: "As medical students, we went off to set up a small maternity clinic in the depths

of Senegal; the clinic never got off the ground for one very simple reason: the person put in charge was a Wolof while the community itself was Toucouleur. And I said to myself, 'Well aren't we the ignorant doctors, if we'd had an anthropologist that wouldn't have happened.'
A: "You said 'for one very simple reason', but there's never a very simple reason why a project fails. I'm pretty certain that it's not because the person in charge was Wolof, at least that can't be the only reason. (...) It's true that it's a bit of a hobby-horse among anthropologists who say 'Beware of ethnic conflicts' but, me, I have my doubts."⁸

In reality, are there any health projects which are unsuitable because of people's devotion to their 'gris-gris'?

Before focusing on what is at the core of this issue, **we need to guard against falling into the trap of viewing and perceiving populations from a culturalist perspective, which nurtures stereotypes in the minds of aid and development workers.** Such a perspective tends to use the cultural to justify difference and the absence of dialogue, instead of using it to open up communication. While no one should ignore the extent to which the cultural is integral to the behaviours in populations who come in contact with humanitarian activities, it is on the other

hand too easy to use the cultural as a catch-all when explaining why projects fail. Finding a balance between analysing sociocultural determinants and systematically using the cultural as an explanation involves encouraging every practitioner to engage in a process of self-reflection with regard to his/her own practice. Such an approach is intended to avoid an ethnocentric – and thus subjective – reading of the norms of the other and a culturalist interpretation of the issues encountered.

Take the case of an anthropological study⁹ commissioned by an institution in response to the problems arising from the failure of a local population to take ownership of a project to reduce maternal mortality in Ecuador. The institution was hoping to use the study to explain the reluctance among women from working-class backgrounds to attend antenatal consultations, to give birth at the maternity units and to use methods of contraception. It suggested that this reluctance was based on the women's attachment to traditional practices and values (care of pregnant women by traditional midwives, preference for large families, etc.) and on a rejection of modern knowledge and norms (medicine, contraceptives, etc.). In actual fact, the study showed that the analyses carried out by experts at the institution rather than reflecting reality were more an expression of their own perceptions of the populations concerned. On the one hand, the attachment here by rural populations in the Andes to a particular tradition did not imply the

systematic adherence solely to traditional behaviours and conceptions. On the other hand, far from being rejected by the rural populations, the westernised world was incorporated by them as was manifest both in the efforts made to send children to school and in the purchase of urban consumer goods.

This study shows that **the tendency to produce culturalist interpretations replaces questioning of how projects are run and, most especially, how healthcare activities are carried out.** By focusing on the traditions of Indian women, discussion of issues such as the patient/health practitioner relationship or the principles and choices affecting the humanitarian action can be avoided.

It is essential in the field to bear in mind that practitioners are also individuals with their own values, references, behaviours, habits and ways of doing and perceiving. The social and cultural specificities of practitioners are sometimes far removed from those of the population they are working with. Moreover, the question of interculturality is also posed by different cultures coming face to face within the teams of practitioners themselves (international staff/local colleagues).

When trying to understand how projects and populations interact, clearly it is extremely helpful to analyse the perceptions of those involved in international solidarity work and the ways they think. This self-reflexive analysis of our own practices is part of a scientific approach as defined by D. Fassin and Y. Jaffré: "Critical work differentiates scientific

⁵ Foster, G.M., "Introduction to ethnomedicine",

in *Traditional medicine and healthcare coverage*, Geneva, WHO, 1983, pp. 17-24.

⁶ *Closing the gap in a generation: health equity through action on the social determinants of health:*

final report of the Commission on Social Determinants of Health, 2009.

⁷ Venezuela undertook particularly important initiatives to promote the involvement of Latin America and the Caribbean in preserving their identities.

⁸ This is an exchange between Didier Fassin, Director of Anthropological Studies at EHESS and a doctor attending one of his seminars.

⁹ Fassin D., *Les enjeux politiques de la santé: études sénégalaises, équatoriennes et françaises*

["Political challenges of health: studies in Senegal, Ecuador and France"], Karthala, Paris, 2000.

knowledge both from common sense and ideological discourse: continued questioning by the self and others, not only of results but also, and most especially, of the more or less implicit concepts which serve to produce these results, also appear as a precondition for them to qualify as science.”¹⁰

In addition to the often culturalist view which avoids questioning one's own practices, a cautious approach also has to be adopted with regard to the status of ‘aid worker’ which encourages ethnocentricity. Indeed humanitarian workers have often been reproached for trying to normalise cultures through the medium of health and for contributing to the “moralising enterprise”¹¹, legitimised by emergency situations. While humanitarian action has evolved considerably by taking a more decentered view and reflecting on its practice, **those involved in aid and development work must not be influenced by ideological extremes.**

The populations targeted by humanitarian aid are too often thought of as “victims”, masking their social and cultural specificities: “This man who is a victim of a tsunami or a dictatorship is no longer primarily a Balinese or Burmese person belonging to a social or ethnic group or to a party: he is a victim [...]. Victims rarely think of themselves as victims. It is the outsider's eye which defines them as such.”¹² **The humanitarian relationship must not be a monologue, avoiding the issue of culture as a result of the demands imposed by an emergency.**

Reference framework content

Intended for those involved in humanitarian work in France or abroad, this reference framework should assist them in their work with populations of diverse cultural origins by making them aware of the issues surrounding the influence of sociocultural determinants of access to healthcare. The framework document aims to **strengthen the relevance of the dialogue and the quality of encounters between those working on health projects and their beneficiaries**, by taking greater account of the values, norms and needs of the populations involved.

Viewed alternately from the standpoint of the populations and that of the practitioners, the themes developed set out to examine the different ways of ‘doing’ and ‘thinking about’ health, illness and care. It is about providing practitioners with an interdisciplinary openness so that they may look critically at the encounter that humanitarian action represents. This often poorly understood dimension has consequences in the field that should not be underestimated.

This guide is structured around the central theme of access to healthcare and sociocultural determinants. It thus contains a first part devoted to identifying and defining the ‘sociocultural determinants’ of accessing healthcare, as a way of understanding what the challenges are to improving our knowledge and also the issues involved.

A second part suggests how to decipher populations’ and health workers’ individual and collective behaviours and aims to respond to the questions most frequently asked by practitioners in the field. These questions relate to perceptions of illness (illness as a social factor, as an individual experience and as a collective cultural phenomenon with its norms and constraints), forms of treatment and care (the patient/health practitioner relationship), sociocultural aspects of treatment (care pathways), the social dynamics of traditional medical systems and the connections between medical systems (medical pluralism).

The third and final part tackles the socio-cultural issues arising from implementing a project and then sets out some proposals regarding methodology. These internal procedures and various tools should enable each individual to reveal the influence on his/her everyday practice of the social and cultural dimension within healthcare. These methods are intended to add to discussion surrounding improving healthcare and the patient/health practitioner relationship. At the same time they seek to hone the critical eye of those working in international solidarity, so that it is systematically focused on their own practice and so that they take a qualitative approach to considering the sociocultural determinants when defining, setting up, monitoring and evaluating projects.

This guide proposes to improve the encounter which takes place as part of the humanitarian aid process, not as part of a utilitarian vision but from an ethical standpoint. This approach, which respects the cultural richness of the target populations, reveals the role it has to play in ensuring the effectiveness, quality and sustainability of a project. The questions, considerations and actions that reflect the significance of sociocultural determinants of access to healthcare are in the process of being discovered. It is believed this change

of attitude and of practice might prevail and may ultimately become rooted in all of MdM's work in France and internationally, as well as in all solidarity projects in general.

10. Fassin D. and Jaffré Y. (edited by), *Sociétés, développement et santé* [“Societies, development and health”], Paris, Ellipses/AUPELF, 1990.

11. Hours B., *Domination, dépendances et globalisation – traces d'anthropologie politique* [“Domination, dependency and globalisation”], L'Harmattan, 2002, p. 110.

12. Hours B., “L'anthropologie est-elle soluble dans l'action humanitaire global?” [“Do anthropology and global humanitarian action mix?”], in *Anthropologues et ONG : des liaisons fructueuses ?* [“Anthropologists and NGOs: a profitable partnership?”], *Revue Humanitaire HS* No. 4, Autumn/Winter 2007, p. 72.



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**SOCIAL ORGANISATION
AND PERCEPTIONS SURROUNDING HEALTH**

➤ Using an anthropological approach, this first part is intended to raise field workers' awareness of the social context and culture, as encountered in other countries and in each individual. An individual's pre-existing sociocultural determinants evolve with contact and persist over time; they inform us in advance of our own perceptions and intentions, by offering keys to help us understand others. A better understanding of the social organisation and a questioning of the perceptions surrounding health create the necessary basis for a humanitarian approach to evolve – including at the level of everyday practice.

ENVIRONMENT AND COLLECTIVE MANAGEMENT OF HEALTH

➤ While in the West our management of health is increasingly focused on the individual, the same does not go for all parts of the world where aid workers are deployed. It is, therefore, worth examining how health can be collectively managed in relation to the environment, strategies of the group concerned and community-based health projects.

1 / THE SOCIAL, ECONOMIC AND POLITICAL ENVIRONMENT

“Health deprivation is really the most central aspect of poverty.”¹³

There are diseases for which ‘environmental’ factors are as important as biological factors

and which undoubtedly hamper any medical approach. Among existing diseases, this applies to malnutrition and diarrhoeal illnesses. **Poverty and hygiene problems make living conditions precarious and the more the environment in which a population lives promotes development of disease the more difficult it is for them to follow advice and take action.**

As regards the social environment, J. Brunet Jailly explains that individuals in situations of extreme poverty in countries of the South are subject to the decisions of their institutional representatives (partner, head of family, village leader, etc.) and that individual

consent is not autonomous.¹⁴ **What we have here is the collective management of health which influences individual pathways.** A woman never presents without her husband, a husband without his wife and parents without one of their children or children without either father or mother. It is not a single individual but part of the family unit which travels as a group to obtain a diagnosis, to enquire about the proposed treatment and to decide what should be done. The length of time a sick person is cared for depends on agreement between the family (as payer) and the doctor.

“All my young diabetics die of acidoketosis before reaching adulthood because insulin is too expensive and the parents cannot pay or consider it too great an investment. If his father doesn’t buy it, where is a child of nine going to find insulin? It’s often in families of five or six kids and the insulin for just one of them costs what it takes to feed the family for a week, they quickly make their choice, or rather they have no choice – they let the others live and leave the treatment of the sick child in the hands of God.” **A doctor**

Whatever the issues examined, that of economics plays a part within the social and cultural environment of the patient. Thus,

following health education sessions¹⁵, women are aware of the fact that they must vary their diet and eat ‘rich’ foods.¹⁶ But due to a lack of means or the influence of certain people (notably the mother-in-law), these women cannot alter their dietary behaviour and content themselves with eating what is available or prescribed by family habits.

The same goes for treatments for chronic illness, as **people without welfare benefits are led to look for the least expensive solutions.** Faced with diabetes, the doctor has no option but to propose an expensive medicine for life, simply to control the symptoms without offering a cure. The limitations of the proposed treatment, in addition to habit, prompt the patient to turn to traditional healers who claim to provide rapid and definitive treatment.

While the local dynamics of the socioeconomic context must be examined, those experienced by the patient must also be considered in relation to how they overlap with international issues associated with poverty. In an article on tuberculosis in Haiti, A. Castro and P. Farmer are interested in a paradoxical situation concerning the treatment of this disease where the existence of effective medicines is failing to prevent a rise in its prevalence. The increase in the number of resistant strains is, in fact, due to a whole host of factors relating to the international situation (globalisation and the cost of medicines) and to local conditions: poverty, the state and limitations of local

13. Amartya Sen, in address on “Health in Development” to the 52nd World Health Assembly, 17th-25th May 1999, Geneva, quoted by Adrea Mach, “Amartya Sen on development and health”, in *To our health, WHO*, 1999.

14. Brunet-Jailly J., “Une éthique de la recherche médicale immédiatement universelle : un moyen de protéger la recherche médicale des pays du Nord ?” [“Instantly and universally applicable ethics for medical research: a way of protecting the medical research of countries in the North?”], in Doris Bonnet (Ed.), *L’Éthique médicale dans les pays en développement* [“Medical ethics in developing countries”], Paris, Autrepant / IRD – Éditions de l’Aube, 2003. Autrepant (28), 2003, pp. 37-53.

15. Bouchon M., “Les soignants en souffrance : les difficultés émotionnelles des soignants en interaction avec la douleur, la maladie et la mort, dans un service de pathologies lourdes et chroniques à l’hôpital national du Point-G, Bamako (Mali)” [“Medical staff in pain: emotional issues for health service staff when dealing with pain, disease and death in a serious and chronic diseases unit at Point-G National Hospital, Bamako (Mali)”], in *Face à face, regards sur la santé*, No. 9, 2006.

16. The lack of an adequate diet is most often associated with a modest standard of living.

healthcare systems, difficulties in accessing healthcare and an increase in social inequality. These factors cast doubt on biomedical theories which attribute the advance of tuberculosis to overly narrow cultural theories.¹⁷ The authors have emphasised the **economic conditions as a “pathogenic force”**. According to them, any analysis of the role of medicines must therefore **take account of the general social conditions and the investment needed to improve the system of healthcare, diagnosis and access to medicines.**

Although they comply with biomedical health norms, recommendations made about what action to take often depict situations which do not conform to the material and environmental reality of the target social groups, who are generally the poorest in society. **The constant discrepancy between the activities envisaged and the real possibility of their implementation** (suggestions for nutrition in situations of extreme poverty, individual mosquito nets where 15 people live to a room, hygiene where there is a lack of water, etc.) **leads to demands being made for greater effort from those who are already the most deprived.**

Consequently, it must be remembered that the **sociocultural and economic and political spheres are closely inter-related**. The introduction of fee-charging for healthcare, the level of household

incomes, the cost of transport and the power structures operating within healthcare establishments may also, therefore, be determining factors in the use made of healthcare services.

2 / STIGMATISATION, BREAKDOWN OF FAMILY COHESION AND ACCESS TO HEALTHCARE

“If my mum saw me with a condom in my bag, straight away she’d think that I was hanging about on the streets, I can’t take even those that are given out free, it’s too risky. I’ll get belted by my parents and my friends will make fun of me, say lots of things about me...”¹⁸

Anthropological research carried out in collaboration with epidemiologists studying malnutrition illustrates the scale of the social dimension of health behaviours. The study focuses on stunted growth in Brazzaville¹⁹ in order to understand the impact on children’s health of inequality caused by material living conditions. The study was designed to test a theory

that is so commonplace it appears obvious: namely, measuring the correlation between children’s state of health and parents’ level of income. Given that numerous pieces of research undertaken in Europe, the United States and countries of the developing world have shown that the poorest populations were those with the poorest health, the question might be asked as to whether it was worthwhile pushing again at a door that was already open. That having been said, the conclusions of this study turned out to be paradoxical. Researchers observed that seriously malnourished children belonged to households whose socioeconomic level seemed satisfactory, thus raising questions about the evidence for a relationship between poor nutrition and standard of living. **An explanation was therefore sought in the breakdown of family cohesion**, which placed the mother in the position of being unable to take proper care of her child.

When it came to the epidemiological survey, certain questions included in the questionnaire were formulated with the case studies in mind in order to identify indicators of breakdown in family cohesion (distance of mother’s bloodline from that of the head of household, exact marital status of the mother, etc.). The processing of these statistics revealed a population of seriously malnourished children for whom the usual risk factors²⁰ ceased to be significant, whereas data relating to the family and marital status of the mother became so. Thus, while social factors influence serious growth delays, projects need to be adapted to different at-risk groups, particularly by proposing to redefine such groups on the basis of sociological criteria.

This type of study shows that certain models for action do not take account of the social dimension experienced by patients, who are subject to the collective management of health.

Models drawn up concerning child survival also focus on the personal determinants of the mother. This approach means that the major roles played by the father, child and other members of the family are only rarely examined. The institution of the family occupies a central place in the management of health, in so far as it is the social group to which the child belongs. That having been said, each culture leaves its imprint on disease, or rather confers a status on it within the group. **There are illnesses which have to be dealt with alone and whose social consequences are marginal.** A study of cholera in DRC revealed that it is a disease which is viewed as a “personal illness”, and so “the attention of the population is focused more on [individual] healing practices than on the importance of preventative habits adopted by the group as a whole”.²¹

Other diseases, such as STIs, or problems with fertility, involve relationships and upset the social status quo. Some only require a single treatment while **others, which carry greater stigma, bring the patient’s identity into play, as they involve both the pathological and the social.**²² HIV/AIDS continues to be marked by a sense of blame, viewed as a disease that is ‘shameful’. With the exception of cases where infection is transmitted by transfusion, AIDS is seen as pointing to sexual instability or drug use. In some countries, prevention is hampered

17. cf. Sub-section “The culturalist vision and the lure of ethnocentrism: two pitfalls to avoid” in the Introduction.

18. Bouchon M., “Savoirs et pratiques préventives : des campagnes d’informations sanitaires aux conceptions locales” [“Knowledge and practice of prevention: locally designed health information campaigns”], doctoral research carried out in Senegal, 2005.

19. Gruénais M.E., “Mariages en villes et malnutritions aiguës” [“Urban marriages and acute malnutrition”], in *Sciences sociales et santé*, III, 3-4, pp. 57-83, 1985.

20. In particular, among these can be found a physiological factor such as birth weight, or other factors to do with the overall socioeconomic level of households.

21. Staro F., *Entre savoirs experts et mauvais sort, pratiques d’utilisation de l’eau et perception de l’épidémie du choléra dans le district du Tanganyika* [“Between expert knowledge and fate, practices in water use and the perception of the cholera epidemic in the district of Tanganyika”], MdM, March 2011, p.8.

22. Bouchon M., *Enquête qualitative sur le projet VIH/Sida et Santé sexuelle et reproductive du district de Chipinge, Zimbabwe* [“Qualitative survey of the HIV/AIDS and reproductive and sexual health project in the district of Chipinge, Zimbabwe”], MdM, July 2011, pp.25-26 and 52-58.

by these perceptions and buying or accepting a condom is synonymous with sexual 'vagranity'. As a result, **benefiting from the provision of a treatment facility does not mean actually being able to use it: in practice, service provision may come up against the private spheres in individuals' lives.** Confrontational relationships and conflicts can be seen to arise from changing a habit or practice within a family or group: the authority of older members challenging certain innovations, a fear of becoming marginalised by taking the action suggested.

It is clear, therefore, that while **these health-related activities have a biomedical basis, for the population their application extends beyond the dimension of health into the social sphere.** Thus food is governed more by social norms (age difference, gender, food taboos and dietary customs) than by strictly nutritional concerns, just as hygiene may be related to aesthetic norms or prestige.

There is a real link between partial or non-adherence to an action and the constraints operating within or outwith a family or social group. **Healthcare practices are surrounded by social issues and are integrated into a system of relationships based on power.** Projects must, therefore, pay special attention to social organisation as a central characteristic: compatibility between development work and local mechanisms must be sought and areas of common ground relied on.

3 / COMMUNITY HEALTH: A RISK OF SUBSTITUTION?

Community health means the population managing its own 'health capital', assessing its own needs and seeking its own solutions. A new way of organising healthcare, community health has spread as systems of treatment provision in developing countries have been transformed. This type of organisation puts the notion of participation at the centre of any initiative, transforming the public—referred to as 'beneficiaries', 'targets' and even 'victims'—into stakeholders. Encouraged by the 1986 Ottawa Charter, this participative approach requires the relationship between international solidarity stakeholders and individuals in the community to be redefined. That being said, defining what community is represents an exercise imbued with subjectivity, which depends on the context and those involved. **This notion of community health is based on an ambiguous view of the community** and starts with the premise that a tradition of collective property management exists. In reality, this is not always the case, or at least there is an idealised perception of it. Conflicts, unequal systems and pressures on minorities are an integral part of daily life in villages and neighbourhoods.

"We were supposed to set up a community project but we saw that we could not work out whether the notion of community existed for them, as each family described itself as a community!" **A volunteer on returning from abroad²³.**

Lastly, as a way of legitimising their lack of engagement or of encouraging autonomy and participation in democracy, **governments have invoked the capacity of communities to take responsibility for themselves and to provide solutions which are closest to the needs of individuals.** According to this 'communitarian' view, individuals and families become responsible for their health and wellbeing. The concept of empowerment can be used to disguise the fact that a **government is abandoning its active and decisive role in determining the living conditions of the population,** particularly of those who are poorest.

The community health system, even when artificially created, may provide a lever for humanitarian action. This is provided the practitioner takes account of the influence of strategic groups, pressures and conflicts affecting access to healthcare for the poorest, whether within the community prior to a project's implementation or within the dynamics that the community-health model produces. It is therefore important to understand how the healthcare system is organised, how hierarchies are structured (management committee) and how the health establishments are viewed by the population. A community health centre that is not approved of by the population will undermine their willingness to take ownership of any project in which the centre is involved. On the other hand, a community health centre that is well received by the population can provide an appropriate and long-term interface between it and the project.

23. Debriefing following project in Colombia, MdM, 2008.

CULTURAL PERCEPTIONS OF HEALTH

➤ We need to take a step back to be able to understand the relationships between the social sphere and the individual's care pathway. As has been shown, social norms need to be viewed in the context of the individual's environment so that the aid worker can avoid transposing his or her own. Factors relating to the social context are interlinked and need to be cross-checked against an analysis of the cultural determinants to improve understanding of how health is perceived.

1 / LAY KNOWLEDGE VS BIOMEDICAL KNOWLEDGE AND PRACTICE

"Illness may be passed on in a look."
 "Drinking-water is clear water drawn from not just anywhere."
 "A healthy child is a fat child."²⁴

Depending on the particular cultural context, there are many different ways to gain an understanding of the issues surrounding health, disease, the body and pain. The example of food alone generates **many different beliefs and perceptions** and underlines the gap between lay knowledge, which arises out of everyday experience, **and scientific knowledge**. There is no need to look to the Papous or the Yanomamis to grasp the cultural dimension of food. In Europe, at the time of Pasteur, people believed in the virtues of consuming fresh blood to combat anaemia or weakness. This belief owed nothing to the nutritional

properties of blood but related principally to **thinking by analogy**. According to this way of thinking, red meat and wine fortified the worker and the white meat of chicken was good for those convalescing. Until quite recently, those with big appetites were admired and were popularly depicted as healthy, which was seen as synonymous with having enough to eat. Lastly, in many regions of the world, bouts of diarrhoea are not seen as an illness but as a natural mechanism for purging the body of toxins originating in food ('It cleanses the stomach, it clears out dirt').

Nowadays in Europe, beliefs surrounding food and health are perhaps no longer so much about 'Red meat + fresh blood = strength' but more about 'Fish is good for the memory', 'Eat up your soup and it'll make you grow' and 'Carrots help you see in the dark', and so on. Alternative medicine, equally fertile ground for such perceptions, also plays a great deal on values that are imagined or extrapolated from food and which often draw on analogous thinking. In other words, **we transform the nutritional properties of food into moral, even magical pro-perties**. Vitamins, trace elements and antioxidants heard about on television or read about in magazines are part of the vocabulary. They become abstract if not miraculous concepts, since consuming them guarantees – depending on the advertisements – youth, long life, resistance to illness in winter, beautiful skin, etc. Through food, **these cultural perceptions of health constitute a general basis of lay knowledge**. It is interesting that, in order to be credible, this knowledge may acquire the thinking, or at least the language, of science which will be 'twisted' and reconstructed. Armed with this scientific terminology, we are made to believe in its properties, even if we do not have the slightest idea of the whys and wherefores.

In the West, as in the countries of the South, the idea that 'the food of our forebears was healthier' is common (even though food quality and controls have continued to improve with, for example, the introduction of pasteurisation and cold storage), and that the traditional is better and more reliable. This expresses an attachment to the land or the earth and corresponds to perceptions of the world and its natural classifications. There is also a loyalty to the values of older generations: we do not reject what older people say even though we know that it is not wholly accurate. **It is important therefore to recognise that innovation, such as the introduction of technologies or biomedical principles, may be viewed as an act of aggression.**

Hence, some infant health prevention messages (malnutrition, exclusive breast feeding) directly conflict with food taboos popularly considered as a way of safeguarding health. One of the specific perceptions associated with pregnancy and early infancy in Africa states that pregnant women should not eat red meat to avoid haemorrhaging during labour. Another involves not eating bananas to avoid having a 'weak baby', while certain citrus fruits are said to produce an ill-tempered child. **Populations will not subscribe to a project if their socio-cultural health-prevention practices (magic, religious, etc.) are hampered by modern health standards, which they see as unconventional**. Thus, the practice of *tohenthal*, which consists of making a newborn baby drink water blessed with verses of the Koran, is incompatible with the principles of exclusive breast feeding.

These elements show the importance of cultural perceptions in any transfer of technology: **the way to introduce biomedicine is not on the basis of a 'knowledge-versus-ignorance' relationship**. Instead, new information

24. Bouchon M., "Savoirs et pratiques préventives : des campagnes d'informations sanitaires aux conceptions locales" ["Knowledge and practice of prevention: locally designed health information campaigns"], doctoral research carried out in Senegal, 2005.

must be incorporated into pre-existing belief systems. This is known as “*bricolage*”, or a makeshift arrangement, between the two forms of knowledge. That is to say **the content of health projects is neither rejected nor accepted as such, but rather partially integrated in a collective exercise to redefine meaning.** Questions must be asked about medical practices, which might challenge established cultural principles and which could potentially overturn popular perceptions and distort the scientific meaning. This could give rise to situations where, for example, women think they are immunized against malaria²⁵, refuse vaccination for fear of being made sterile or want latrines built to prevent the spread of measles.

The question must be asked: What happens to popular knowledge about health and disease when it comes face to face with our health projects based on biomedical norms? Medical discourse, which has a tendency to generalise, must question its own practice, so that the response of a population is not solely to resist. Such resistance limits the extent to which new practices, capable of meeting needs, can be incorporated.

2 / HOW IS DISEASE PERCEIVED AND HOW ARE SYMPTOMS INTERPRETED?

“Disease strengthens.”²⁶

How do perceptions of disease work?

A lay person’s knowledge of health corresponds to the perceptions he/she has gathered and developed about disease, health, treatment, and so forth. The sick person is aware of various conditions and symptoms, such as diarrhoea and vomiting, and understands the importance of food and diet. **A lack of biomedical knowledge is made up for in the lay system by translating the confused physical experience of the patient into an accurate description of the symptoms of the disease.** The ‘language of ailments’ (or symptoms) in each culture describes suffering, abnormalities, signs and disorders. It often pairs a part of the body (the organ that is presumed to be affected) with a sensation: to have a headache, to have heartburn, or to have lockjaw for tetanus, etc. These examples show that **popular perceptions are generally based on different signs that are immediately visible on the sick person’s body.**²⁷

During consultations, medical practitioners are confronted on a daily basis with **these popular perceptions, which have an unknown impact on the extent to which patients are willing or unwilling to be treated.** In general, lay knowledge does not correspond to medical knowledge and involves extremes and omissions. On the one hand, people will sometimes interpret a range of symptoms as completely separate illnesses, as is the case with fever among the Madagascan populations in the district of Maroantsetra. “We understand that cases of meningitis, malaria, influenza and various infections are not necessarily detected as the link between symptoms is not made.”²⁸ The study which led to these conclusions showed that, where fever is combined with a disease, it is believed to be of supernatural origin, the result of bewitchment or possession.

On the other hand, where the biomedical diagnosis points to gastro-intestinal and gynaecological diseases, these may be popularly perceived as one single illness. Visible symptoms are interpreted and grouped together according to apparent similarities of type and form. People speak about “the illness which causes lumps” and include in that description hernias, tumours and haemorrhoids. These differing interpretations explain why, for some diseases where the relationship between treatment and disease is not clear to the patient (for example in cases of chronic illness), the care pathway is based on popular remedies rather than biomedical science.

Conversely, there may on occasion be a correlation between popular perceptions and biomedical science, where the latter observes and diagnoses an ailment in terms

of a symptom. Measles, for example, is often correctly identified and accurately named. This correlation between popular and biomedical names facilitates dialogue between doctor and patient who will then be talking about the same illness. In addition, cultural perceptions also identify what is associated with illness or a normal state of health. In some cultures, what western medicine sees as evidence of a disease is not considered to be a symptom at all. For example, some peoples believe tapeworms are an essential aid to digestion.

Lay knowledge is founded on learning from experience, giving weight to what can be seen and felt. Using principles of analogy, perceptions are based on sensations and similarities. Popular beliefs group together like with like: in the absence of scientific terminology, disorders of the body are explained by matching them with everyday words and thereby acquire a credibility based on the evidence of the familiar and usual. Often this leads to confusion between cause and symptom: for example, a cough resulting from a cold is believed to cause tuberculosis.

The causes of disease

In many regions of the world, traditional beliefs about the causes of disease are based on a **dual principle** involving both the natural/material and supernatural/spiritual. These beliefs accept the existence of a variety of specific and simultaneous causes. Social causes are seen as fundamental and determining factors, as **disease is often viewed as the troublesome result of failing to observe social norms.**

25. Jaffré Y., 1989, *Le forgeron, la pintade et la vaccination : enquête sur l’acceptabilité des vaccinations dans la province du Houet* [“The blacksmith, the guinea fowl and vaccination: study of acceptance of vaccination in the province of Houet”], Bobo-Dioulasso, OCCGE, 1989.

26. Bouchon M., “*Savoirs et pratiques préventives : des campagnes d’informations sanitaires aux conceptions locales*” [“Knowledge and practice of prevention: locally designed health information campaigns”], doctoral research carried out in Mali and Senegal, 2004-2007.

27. However a balanced approach is needed: since the time of the writer Marcel Pagnol and his character César, we have known that “to break a heart” is not to be taken literally. While the expressions ‘melancholic’ or ‘phlegmatic’ come from an ancient medical theory (theory of the humours, see Hippocrates), people do not attribute their distress to an excess of black bile. See Jaffré Y., 1996.

28. Bouchon M., *Analyse qualitative de l’organisation communautaire et de la santé, district de Maroantsetra* [“Qualitative analysis of how the community and healthcare are organised in the district of Maroantsetra”], MdM, 2010, p.19.

Differences do exist between urban and rural, literate and illiterate, settled and nomadic populations, for example. In the rural district of Chipinge in Zimbabwe, a study conducted in July 2011 reveals the prevalence of supernatural interpretations. Partly explained by a need for spiritual protection, these interpretations are also fed by instances of “inaccurate diagnoses, chronic diseases and opportunistic infections.”²⁹ The **coexistence of different interpretations of disease** has been observed in the urban environment, with neighbouring groups borrowing elements from each other’s cultures.

Different ways of seeing things are not mutually exclusive: beliefs and how they are put into practice are juxtaposed. Depending on the community, the ways in which diseases are perceived are both disparate and closely interrelated.

Understanding behaviours

“In some countries, many people, having been bitten by mosquitoes since they were very young, carry malaria, like a persistent ‘flu, and therefore do not believe that they are affected by the disease. In particular, they say that the symptoms referred to in health prevention messages have nothing to do with them, that it’s a foreign disease, implying that the disease is to be found where the symptoms are most acute, most apparent.”³⁰

29. Bouchon M., *Zimbabwe : enquête qualitative sur le projet VIH/Sida dans le district de Chipinge* [“Qualitative survey of the HIV/AIDS and reproductive and sexual health project in the district of Chipinge, Zimbabwe”], MdM, 2011.

30. “Les représentations autour du paludisme” [Perceptions surrounding malaria], interview by Magali Bouchon, Head of Project entitled “Accès aux soins et déterminants socioculturels” [“Access to healthcare and sociocultural determinants”], MdM, 29 April 2009.

Faced with the fear of the unknown, popular interpretations assign diseases a name based on **‘coded’ perceptions of the body, associated with the affected organ or with outward signs. This naming provides a basic diagnosis** and identifies one or more ailments in terms of a familiar illness, such as heartburn. But these popular interpretations may also assign a disease a name **in terms of how serious it is considered to be:** in Wolof, malaria is called *sibiru*, from *sibir* which means ‘to come back tomorrow’ to emphasise the everyday nature of the disease. The translation of popular names for diseases may provide a means of understanding behaviour, as in this instance where it shows how behaviour may affect the length of time it takes to access healthcare and delays in seeking treatment.

How health services are used certainly depends on how diseases are popularly viewed and on comparisons made with the way biomedicine interprets the same diseases. For example, if the seriousness of a disease is popularly seen in terms of how chronic it is, people have a problem accepting lengthy treatment that does not involve drugs, as in the case of hepatitis, for example. **The way in which a disease is interpreted leads to its identification.** Depending on the interpretation and the choices/possibilities offered, the sick person, or immediate family, will decide on the appropriate practitioner. Along with economic factors, the characteristics of the disease are used to decide whether it is an illness treated locally or treated with ‘white medicine’.

Traditional perceptions explain diseases based on observations of the body and its suffering, but they may equally rely on the way a disease is transmitted, how long it lasts and how effective the treatment is.

It is important for health practitioners to know the popular names for diseases and the translations of these in order to understand how diseases are perceived and subsequent behaviours. Popular descriptions of a disease are always linked to locations on the body, types of pain and treatment, duration, etc. How seriously a disease is viewed and ideas about how long it lasts and the way it evolves are therefore relevant factors in understanding health behaviours.

3 / TRADITIONAL AND MODERN MEDICINE: WHERE PROVISION OVERLAPS OR FALLS SHORT

“Patients will ask ‘white medicine’ to remove the symptoms of the disease and traditional medicine to identify the root causes of the illness and to find ways to fight it.”³¹

31. Salem G., *La Santé dans la ville, géographie d’un petit espace dense : Pikine (Sénégal)* [“Urban health, geography of a densely populated corner: Pikine (Senegal)”], Karthala, 1998.

Despite the important role played by modern healthcare systems, they are not the exclusive source of treatment. Other methods are consulted in the individual’s quest for health. In many countries, including those in Europe, **patients increasingly move between different ‘therapeutic worlds’ which have absolutely nothing in common.** Indeed, despite the authority wielded by biomedicine in treating disease in contemporary societies in the West, it must be acknowledged that a growing proportion of their populations make use of a variety of different treatments.

Traditional medicines precede, replace, support or follow other forms of treatment. Terms such as bonesetter, ‘fire purger’ (*enleveur de feu* in French), shaman, marabout and also traditional therapist are used. Recourse to traditional medicine has often been wrongly attributed solely to deficiencies in the healthcare system. Yet, people **genuinely believe that it is effective and that both systems complement each other.** Treatment deals only with the bodily aspects of an illness, whereas the culture, symbolism and values of a society are also relevant. How can modern medicine effectively appease angry spirits or re-centre vital energies? Lastly, relationship and communication problems, complex medical jargon and uncertainty surrounding diagnosis in situations where there are few facilities for x-ray or diagnostic tests mean that **patients cannot be offered treatment that is considered on a par with that of traditional therapies.** The gap between modern and traditional healing practices grows even wider when the patient’s anxieties and need for spiritual reassurance (both excluded from the medical sphere in biomedicine) are taken account of in the treatment.

Although modern biomedicine predominates, certain factors encourage medical pluralism which “far from disappearing in the face

of modern medical practice draws greater strength from it" (Benoist, 1996). As doctors withdraw from the sphere of human fears and suffering and employ increasingly technical methods of treatment, the trend towards consulting traditional forms of medicine and religious groups for the treatment of so-called diseases of the spirit becomes ever more popular (Jacquemot, 1996). Diseases are divided into those affecting "whites" and those affecting others. **The popular view is that patients and traditional therapists are more in tune with each other:** they speak of symptoms and interpret the causes of an illness, or the active ingredients used in medicines, in the same way. The patient does not feel excluded from the treatment process as he/she and the healer share the same references based on popular knowledge. How a diagnosis is reached and what the patient expects in terms of treatment are thus based on a shared knowledge, making it easier for the patient to accept the treatment and to see it as effective. In this context, sorcery may sometimes act as a "medium for understanding and establishing a relationship with the patient."³²

In putting forward a diagnosis and treatment, people and healers 'pick and mix' (the French term used is bricolage) from several different and available ways of thinking.³³ **Today, the language of traditional therapists and individuals reveals a degree of syncretism between popular beliefs and biomedical classifications.** Consider, for example, the following syllogism: Chloroquine cures malaria; this disease has been cured using chloroquine, therefore this disease was malaria. Many healers use terms borrowed

from biomedical science and apply them to traditional ways of thinking about disease. Words such as 'germ', 'virus' and 'bacteria' are frequently used to describe a condition. Several factors are behind this, such as health education campaigns, proximity to a hospital and attendance at healthcare facilities by individuals or by close family members.

As care pathways show, patients take a practical approach to managing their health which does not mean complete and exclusive attachment to one form of medicine, but involves switching between different practices (from homeopathy to allopathic medicine, from plants to pills, from acupuncture to surgery, etc.). **There is only one tenet which is widely shared and to which the different treatments hold: that of alleviating suffering and providing a cure.** Various corresponding treatments will be offered for the same disease and patients will choose some or all of these. **Opting for different forms of treatment, both modern and traditional, is common.**

Moreover, in countries such as Brazil, the wide range of cultural influences also serves to explain the use of different forms of medicine. **Any reference to traditional medicines must therefore include a historical, geographical and, in particular, a pluralist perspective.** When inhabitants of favelas turn to traditional medicine, self-medication or religion, it is a reflection of the different ways they relate to the society in which they live. These relations are socioeconomic and traditional in nature and also depend on how accessible health services are. **Relations between medical staff and patients and**

deficiencies in health service provision encourage people to continue to seek help from traditional medicine and religion.

Sometimes, however, there is no correlation between traditional and modern medicine and there is resistance from populations to systematic biomedical procedures, such as immunisation. The indigenous Amazonian Madjia-Kulina group in Brazil views the act of vaccination, for example, in terms of how they perceive the body. Their medicinal plants can either cure everyday ailments (accidental injury, stomach ache, headache, etc.) or bestow the power to cure more serious illnesses (so-called 'wise' plants). They consider pharmaceutical drugs capable of curing common ailments (headaches with no supernatural causes), while vaccines are seen as being able also to bestow the power to cure more complex diseases. In addition to initiation and apprenticeship, shamans derive their power from the dori, a substance that is introduced under the skin. The power of the shamans opens the door to the abstract world of the spirits, which ought to be foreign to the world of biotechnology. However, the substance of the vaccine is perceived as bestowing such powers. The wisdom attributed to certain plants like the dori may be transferred to injectable substances used in vaccines, which also penetrate the body and alter its state. Universal immunisation, involving injecting a 'wise' substance into the body of each inhabitant of the villages, would thereby

deprive the shaman of one of his essential and special characteristics, namely that of being the only one able to incorporate the knowledge of wise plants. Does immunisation therefore interfere with the specific ability of the shaman to inflict and to cure disease? The Madjia-Kulina shamans do indeed confirm that they have lost their power to practise due to these biomedical procedures: the power of immunisation has made them lose the dori. Vaccination, as a form of intrusive new technology, thus violates tradition. The inherent wisdom of the vaccine enables all immunised inhabitants in the villages to avoid the disease without the shaman's intervention; at the same time, just as the wisdom of the dori or other plants mixed by the shaman can do, the vaccine can also inflict illness. The people of the Madjia-Kulina consequently fear the power of vaccines in the same way that they fear the power of the shaman. When an immunisation campaign is announced, many inhabitants flee the villages or prefer to go about their daily tasks rather than to take any risks.³⁴

For several years, WHO has recommended that traditional medical practices be incorporated into modern healthcare establishments.³⁵ **To take on board the notion that 'therapeutic knowledge and therapist are indivisible' means devising ways of bringing two different worlds together.** But such collaboration seems problematic on several counts. Extracting plants from a context in which their use is

32. Staro F., *Entre savoirs experts et mauvais sort, pratiques d'utilisation de l'eau et perception de l'épidémie du choléra dans le district du Tanganyika* ["Between expert knowledge and fate, practices in the use of water and the perception of the cholera epidemic in the district of Tanganyika"], MdM, March 2011, p.22.

33. The concept in anthropology that it is possible to analyse how meanings are arrived at by encouraging "consideration of the relationships between metaphors and concepts and the construction of analogous relationships, which direct the way social science models of intelligibility are drawn up", Mary, A., "En finir avec le bricolage..." ["Putting an end to bricolage..."] in *Archives de Sciences Sociales des Religions*, No. 116, Oct.-Dec. 2001, p28.

34. Laplante J., Bruneau J., 2003, "Aperçu d'une anthropologie du vaccin : regards sur l'éthique d'une pratique humanitaire" ["Overview of an anthropology of the vaccine: a look at the ethics of humanitarian practice"], *Historia, Cienias, Saude-Manguinhos* Vol.10, 2003.

35. WHO *Traditional Medicine Strategy 2002-2005*, WHO, Geneva 2002, p.7.

subject to specific codes to put them to 'scientific' use is often an impossible task. The same plant will have different properties depending on when it is picked, where it grows and the way in which it is mixed with other substances. Moreover, certain practices are dangerous and could be difficult to control.

Asking healers to agree to use only that part of their practice considered safe for patients runs the risk of the remainder being used in secret. Lastly, shamans and marabouts see themselves as more than just healers and to incorporate their practice into a project would be **to incorporate their social and political status too** (prestige and power).

Practitioners must not draw hasty distinctions between traditional and modern practices in a world where allopathic drugs are now available in even the most remote locations. They must recognise the range of care pathways available, the existence of therapeutic syncretism and the expectations and frustrations associated with attending hospital facilities. All these factors provide proof of medical pluralism. But care must be taken when attempting to incorporate traditional practices, as they are not risk free. **The social, economic and political issues associated with different forms of traditional medicine and their practitioners must be identified.**





INTERCULTURAL RELATIONS
SURROUNDING CARE

USE DOTS

**COVER
THE MOUTH AND NOSE
WHEN COUGHING OR SNEEZING**



**INTERCULTURAL
RELATIONS
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**INTERCULTURAL RELATIONS
SURROUNDING CARE**

➤ Following the explanation of the sociocultural dynamics surrounding disease and treatment, it is important to see how such knowledge and perceptions emerge in care pathways. This second part is aimed at tackling aspects relating more specifically to the attitudes of the person dispensing treatment as well as **patients' recourse to treatment and the patient/health practitioner relationship in particular.**

2 A

ACCESS TO HEALTHCARE AND CARE PATHWAYS

➤ The issue of traditional medicine has highlighted the medical pluralism of care pathways, with the guiding rationale being a search for effectiveness which combines the different options available. We thus view management of the disease in terms of its chronological development, in relation to pain, perceptions and degrees of suffering, as well as the (economic and social) resources available.

1 / HOW COMPLEX ARE CARE PATHWAYS?

"I lose heart when I see women arriving for their first appointment with bone metastasis: I ask their families why it took so long and why they didn't come to the hospital before. They reply that at first they thought it was an evil

curse and they went to see the healer who said it would pass, it would pass. Then they had no money left, so had to wait a bit longer to sell an ox in order to come here." **A senior doctor in a haematology department in Mali**³⁶.

Cancer in West Africa is a disease which has not shed its image as the 'devil's work', leading patients to seek ineffective treatments which can cause the condition to deteriorate, sometimes irreversibly. This view of the

disease as devilish comes from a traditional interpretation: the cancerous tumour is believed to be a curse inflicted with the aid of a poisoned arrow. The lump form of the tumour is a sign that the curse has taken hold.³⁷ For the curse to be lifted, a traditional healer must be consulted. This interpretation of the disease is more persistent in rural areas, where people's access to health information is more limited. Few patients associate the appearance of a tumour, and their declining state of health, with cancer. The pain, initially seen as a passing symptom, will be the main reason for consulting. **Those who are ill will leave it to the discretion of their local community and the treatment sought will be the result of asking friends, neighbours and family for advice.**

If the symptom is seen at the outset as being the 'devil's work', the patient will look to traditional medicine, going from healer to healer. After a series of unsuccessful attempts to find a cure and time has passed, the patient will come to the hospital to the appropriate department, but often not before it is too late. Therefore, in addition to being badly advised in the first instance, the individual has to cope with the complex array of treatments sought, which, as they do not guarantee the best treatment for a particular bout of illness, can prove very costly for the person concerned.

THE EXAMPLE OF A CASE RECOUNTED BY A DOCTOR FROM MALI:

"My patients arrive with their financial resources completely depleted because they've spent them elsewhere. They have lost time, and they don't have any money left to obtain a diagnosis or to get treatment once they have the diagnosis.

I think that there are two reasons for this: the first reason is, I think, to do with the way the disease is perceived. This means that people start getting treated in their local communities; generally what happens is that the person will go and chat to someone else who'll say 'Oh, I had that and the local healer cured me.' So they start there and the healer repeatedly attempts to cure the person and fails. That's one way of looking at the illness and another way, sometimes suggested by others, is: 'that illness is witchcraft so you have to start with this treatment first', and so time is lost.

Another aspect is that people begin with the local doctor because he has been recommended by an acquaintance saying 'I had a similar illness and it was the doctor who cured me'. They go off to see the doctor who takes some time over the diagnosis because he's not qualified. In many cases we see people take prescriptions and they have no idea what they're for, or they go from one appointment to the next and from one surgery to another because the treatment didn't work and then they meet someone else who says 'Go and see him' and that wastes more time and the problem is one of incompetence on the part of the CSCOM³⁸ and medical staff.

Take the example of Mr X, an elderly gentleman, who had a myeloma and what happened? He didn't go to the healer when his neck was sore following a minor accident but went straight to see a doctor who prescribed painkillers and that was it. And when the pain came back, he went to see another doctor who prescribed

36. Bouchon M., "Les soignants en souffrance : les difficultés émotionnelles des soignants en interaction avec la douleur, la maladie et la mort, dans un service de pathologies lourdes et chroniques à l'hôpital national du Point-G, Bamako (Mali)" ["Medical staff in pain: emotional issues for health service staff when dealing with pain, disease and death in a serious and chronic diseases unit at Point-G National Hospital, Bamako (Mali)"], in *Face à face, regards sur la santé*, No. 9, 2006.

37. See the [principle of analogy](#) at page 17 : "How do perceptions of disease work?"

38. CSCOM: Centre de santé communautaire [Community Health Centre].

painkillers again. Again the pain came back, but it was too specialised a case for the doctor who didn't know how to refer him to the appropriate department. And then, when the patient was about to go back to his village after three consultations, he saw a young doctor who referred him to me. In telling the story of this patient, it's clear that there is a problem of communication and diagnosis even among the doctors!"³⁹

A study of care pathways may also be useful for understanding issues surrounding prevention. It is difficult to put preventative measures in place based on the initial symptoms of a disease. In many countries, for economic and practical reasons, **the initial response to the first signs of a disease is observation.** The patient takes time to observe how the illness develops, given that health, or at least being a health-service user, can be costly, both in terms of money and time. In short, **people do not go to see the doctor if an illness is felt to be mild.** Moreover, no one goes to a health-care establishment unless they are ill (even if treatment is free of charge, the time spent waiting is time not spent trying to earn a living).

Discussions with mothers from different cultural backgrounds have revealed that they view their children's wellbeing in a radically different way from current child growth and development monitoring practices.

39. Bouchon M., "Les soignants en souffrance : les difficultés émotionnelles des soignants en interaction avec la douleur, la maladie et la mort, dans un service de pathologies lourdes et chroniques à l'hôpital national du Point-G, Bamako (Mali)" ["Medical staff in pain: emotional issues for health service staff when dealing with pain, disease and death in a serious and chronic diseases unit at Point-G National Hospital, Bamako (Mali)"], in *Face à face, regards sur la santé*, No. 9, 2006.

40. *Éducation pour la santé, guide pratique pour les projets de santé* ["Education for health: a practical guide for health projects"], MdM, 2010.

41. Suremain (de) C.-E., "Dynamiques de l'alimentation et socialisation du jeune enfant à Brazzaville (Congo)" ["Dynamics of diet and socialising in young children in Brazzaville (Congo)"], in *Variations*, Éditions de l'Aube, IRD, 2000.

The mothers' understanding of child health and the highly technical information put out by health education programmes are seriously mismatched.⁴⁰

In many cultures, the absence of illness combined with plumpness (a fat child is believed to be a robust child) is evidence of good health in a child who is growing and developing normally. For mothers, starting to walk and weaning from breast milk to a more varied diet of solids are the key stages in growth and development. The significance of these stages and the practices associated with them (proscribed foods and magic and religious protective rituals) show that mothers want their children to become independent as quickly as possible. These two stages—starting to walk and eating solid food, along, perhaps, with starting to talk—are their indicators of healthy growth and development.

Research carried out in West Africa⁴¹ demonstrates that, while acute forms of malnutrition (marasmus and kwashiorkor) are recognised as a problem, various other forms of malnutrition—chronic, moderate and mild—are in contrast seen as a child's normal state of health. When a problem is acknowledged (as in acute cases) by the parents, they rarely see it in terms of a nutrition-related disease. **How the causes of disease are identified by local populations differs from biomedical scientific theory in that diseases are seen as natural, supernatural or related to social upheaval.** No link whatsoever is made between malnutrition and what a child eats. These perceptions affect the care pathways as, in some cases, malnutrition

will be seen as having a supernatural source and the marabouts will therefore be the first to be consulted. In the light of this, **it is absolutely essential that the way medical staff address patients and the messages directed at the public and at healers are appropriate in order to improve the patient/health practitioner relationship.**

There are several fundamental points to consider in understanding care pathways: pain as a starting point, cultural interpretation of the problem, confiding in family and the many treatment options offered locally.

2 / CARE PATHWAYS: A RATIONAL APPROACH

"There is a 'resistance' as people don't like modern treatments and don't even respect vaccines; they come once, twice and then stop. They always put it off and go first of all to a traditional healer."⁴² **Nurse in the district of Chipinge, Zimbabwe.**

The care pathway generally follows a particular course according to a series of choices relating to medicines, doctors, doctrines and beliefs. **The order of the patient's choices and how his/her demands evolve depend on how diseases are viewed, the degree of anxiety, how effective and powerful**

42. Bouchon M., *Zimbabwe : enquête qualitative sur le projet VIH/Sida dans le district de Chipinge* ["Qualitative survey of the HIV/AIDS and reproductive and sexual health project in the district of Chipinge, Zimbabwe"], MdM, 2011.

the treatment is considered to be (Benoist, 1996) **and the resources available.**

The care pathway reflects the way the disease is experienced and always comprises an individual and social dimension. In general, **relief from pain may be considered as the prime motive for seeking treatment.** Patients will take a practical approach to evaluating and choosing the possible options depending on how effective each is at stopping the pain. Modern medicine is sought more often in areas where it seems most effective, namely in the treatment of acute diseases. Extensive use of modern analgesics testifies to this. At a linguistic level, this preoccupation with pain is confirmed by the existence of numerous expressions to describe diseases in terms of the pain's anatomical location (stomach ache, headache, etc.).

The example of managing fever provides a useful case study for the practitioner seeking to understand perceptions of disease and its treatment.

1. The person perceives the **first signs** of fever (or notices that he/she has a 'hot body': **naming**). Fever, like diarrhoea, is an example of an 'everyday' illness, seen as something ordinary due to the fact it recurs frequently, is easily dealt with using paracetamol and is recovered from naturally. Seen in this way, the illness will initially be treated at home, as this is the cheapest and easiest option. This first stage varies depending on the person's social status: women and children are more likely to be treated at home than men. During this time, we may observe three elements in how the problem is managed: a **cultural determinant** (how the disease is perceived), an **economic determinant** and a **social determinant** (self-medication, more frequent in women and children).

- When the fever gets worse, the way the disease is perceived will influence which treatment is chosen as the most effective: the sick person, seeing that he/she feels worse, will turn to family to explain the problem. **Family members, neighbours and those close to the sick person all have some influence on his/her choice.**
- Depending on the way the sick person describes the fever, **a theory will be formulated and the disease named and ascribed either to natural or supernatural causes.** The patient will take account of each person's view and interpretation of the problem when choosing which of the options is the most suitable for treatment. In societies in the South, if fever is accompanied by convulsions, by 'fits', the healer is most often consulted, as a fit is seen as separate from the high temperature preceding it and is ascribed to supernatural causes. The patient will therefore be taken to see the healer, even if it is acknowledged that the clinic cures lots of other cases of fever and is in some cases cheaper.

A fourth stage may be added which involves how the failure of the therapist to cure the patient (given that the problem persists) is perceived and the change of healer and/or medicine/health provider. It is important to understand that **the choice of a particular form of treatment is not made at the exclusion of others.** People switch from modern to traditional health providers where results are not achieved quickly, and are ready to go back and forth between them. People's perceptions of disease are not set in stone and rapidly alter if three days of treatment pass without any improvement. **The choice of care path is determined on a trial-and-error basis,** and is also influenced by word-of-mouth and personal recommendations from those close to the patient. From this point

onwards, the quality of communication and the establishment of a climate of trust have an impact on the effectiveness of the treatment prescribed and whether the patient follows it.

When trying to understand people's approach to healthcare, it is important to realise that the option chosen — modern or traditional — is to an extent determined by its capacity to achieve results.

To conclude, **health-related behaviour is pragmatic and rational:** people use what they can, depending on what they can afford. In practical terms, modern treatments and commonplace know-how have everything to gain from the 'added value' of the protective powers of magic.

To understand the pathways chosen in response to a disease, it is essential to consider how that disease is perceived (which does not always correspond to how it is understood by biomedical science), its naming (among or by relatives), criteria such as how long the bout of illness lasts (onset and deterioration), and how treatments are viewed (effectiveness). Consequently, to understand why patients delay before coming to a clinic and to successfully convey health prevention messages about what to do in the event of illness, all the elements mentioned above must be taken into account to ensure that medical staff and patients are talking about the same thing from the start.

2 B

THE PATIENT/HEALTH PRACTITIONER RELATIONSHIP

➤ It should be remembered that, however complex or straightforward a patient's previous care pathway, difficulties still remain once a relationship with a doctor has been established. These issues become pressing where a health practitioner comes in contact with populations in a different sociocultural context in which language, and also terminology, may pose problems.

1 / ISSUES OF LANGUAGE AND TERMINOLOGY

"I've a pain outside but not inside."⁴³; "You have bilateral homonymous haemianopsia."⁴⁴

The language used when a patient is being treated is problematic, as it often involves the **introduction of new concepts:** how many languages have a term for 'asepsis'? A command of local languages is thus a significant determining factor in the patient/health practitioner relationship and thus in gaining access to healthcare. **In order to be understood, the patient uses a language and concepts that belong to his/her linguistic register.** In this situation, if the health practitioner is not of the same nationality, ethnic group or culture,

43. Consultation at a Centre d'accueil, de soins et d'orientation [CASO – Healthcare and Advice Clinic], Saint-Denis, MdM.

44. Bouchon M., "Savoirs et pratiques préventives : des campagnes d'informations sanitaires aux conceptions locales" ["Knowledge and practice of prevention: locally designed health information campaigns"], doctoral research carried out in Mali, 2004-2007.

he/she will lack the keys to understanding and interpreting what the patient is saying. Hence, patient/health professional communication is limited to what each manages to grasp in a in a fog of lexicography, semiotics and semantics.

Moreover, what does it mean to a patient to be told: “You have bilateral homonymous haemianopsia”? And for the health practitioner, what does “I’ve a pain outside but not inside” signify? **In both the written and oral context, modern healthcare is complex: patient and health practitioner come face to face and, even though they may use the same words, they are not ‘speaking the same language’.**

The patient talks about pain and symptoms and may suggest the aetiology, or may think it is obvious, but may not be able or willing to express it; he/she may ask for treatment while being unwilling to reveal anything more.

A health practitioner will employ biomedical terminology, which does necessarily correspond to the cultural references used by the population and thus leads to a series of semantic and cognitive difficulties. Having access to medical practices does not mean that these practices then make sense as part of a coherent discourse. **Biomedical discourse and its subjects are often reinterpreted, even distorted. Each action to dispense healthcare is a signifier and medicine in practice is always a process of interpretation.** The doctor interprets the symptoms experienced by the patient and reinterprets them according to categories of medical knowledge, based on concepts of biology. The patient too has a point of view regarding his/her state of health and has formulated his/her own ‘explanatory model’: this may in part be a personal view, but it is also rooted in collective perceptions.

In Madagascar, the care pathway studied in the district of Maroantsetra reveals patients choosing inappropriate treatment for their illnesses due to poor communication, which led to misunderstandings and to symptoms being incorrectly interpreted. For example, a patient encountered in a village during the survey had been given “a first injection at the centre and then went off with four further injections to administer herself. She didn’t know who to ask to give her these intramuscular injections and so went to see the traditional birth attendant. She thought she was suffering from ‘nerves’ but didn’t know exactly.”⁴⁵

What a health provider says will always be interpreted by the patient and what the latter understands will depend greatly on the way the health provider formulates his/her message.

2 / CASE HISTORIES AND THE HEALTH PROVIDER’S APPROACH

“At the hospital during training, you learn not to let anything show, even if you’re disgusted or depressed: it’s like an unwritten code.”⁴⁶
A junior doctor.

In the patient/health practitioner relationship, the way the health provider perceives the disease often differs from the way the patient does. There is a discrepancy between the knowledge and practice of medical staff, based on a biomedical approach to health, and the popular perceptions and practices of patients, which reflect concerns not wholly limited to biology. The system of identifying and classifying diseases cannot always be simply superimposed on that used by the populations served.

While science talks of ‘controlling risk factors’, popular belief relies more on ‘placing oneself under the protection of’.⁴⁷

Training health practitioners

How can this wide communication gap between health practitioners and patients be explained? To understand the principal causes behind miscommunication between medical staff and the populations they serve, the best place to look first may be at medical training. At present, the professional training received by medical students tends to follow the **Pasteur model of cause, disease, treatment.**

Medical training is also characterised by its delivery within **a hierarchical environment, where the focus is on technical aspects and where emotional objectivity and maintaining a distance in dealings with patients and their suffering are seen as proof of professionalism.** This approach to training unfortunately underestimates the importance of cultural and social aspects

and patients’ expectations are often perceived as a hindrance to identifying the medical cause of problems. Indeed, in difficult situations (palliative care, civil war, etc.), medical staff are **paradoxically supposed to support patients in distress, while not allowing themselves to really listen, participate or familiarise themselves with this suffering, so as to be in a better position to alleviate it.**

The medical training curriculum in hospital requires doctors to behave “correctly” in the presence of patients, channelling their responses to the body and disease. Wherever treatment is dispensed, doctors are supposed to maintain this **objective approach to the body as required by their university medical training.** To behave like a professional — to show emotional objectivity, maintain a protective distance and exercise self-control — means not letting one’s feelings show, at least not on the surface:

“When she died, no one spoke about it, we continued working as if nothing had happened.”
A nurse.

Conventional medical training requires the patient to ‘disappear’ behind the disease. The patient to some extent loses his/her identity, is no longer a social being, far less an emotional one, as the body’s anonymity enables the health practitioner to guard against becoming too emotionally involved.

45. Bouchon M., *Analyse qualitative de l’organisation communautaire et de la santé, district de Maroantsetra* [“Qualitative analysis of how the community and healthcare are organised in the district of Maroantsetra”], MdM, 2010, p.17.
46. Bouchon M., “Savoirs et pratiques préventives : des campagnes d’informations sanitaires aux conceptions locales” [“Knowledge and practice of prevention: locally designed health information campaigns”], doctoral research carried out in Mali, 2004-2007.

47. Jaffré Y., *op cit.*

Healthcare institutions: too much technology and not enough humanity?

In traumatic situations, the institution and administration it generates act as a filter for the health practitioner: the patient is no longer the woman suffering from HIV/AIDS with young children, but a number allocated to her bed or case notes. **Technology shifts the focus and allows practitioners to hide behind their knowledge**, to place themselves 'one step removed': **the patient becomes the image of disease and suffering** that he/she conveys. It is nevertheless difficult to remain neutral and impassive when dealing with patients on a daily basis. One of the major problems in the relationship with the patient is to do with keeping just the right distance – becoming neither too involved nor too detached. It is difficult to find the appropriate attitude to adopt when constantly confronted with pain and at the same time fulfilling the essential role of medical practitioner as healer. In C. Mercadier's view⁴⁸, health practitioners are **subject to the 'mirror effect'** in their relationship with patients and their pain. This phenomenon becomes all the more difficult to cope with when the patient has something in common with the health practitioner, such as profession, age, neighbourhood, etc. For Y. Jaffré,⁴⁹ the personal history of the health practitioner affects how he/she interacts with the patient.

Conventional medicine needs to maintain the personal contact, because care that is too technology-oriented can have disastrous

results: it transforms the patient into an anonymous individual and the doctor into a technician who intervenes on the basis of machine-derived results. Dispensing care is not just a question of technical expertise any more than medical staff are technicians. Patients must be involved in discussions and subsequent decisions about treatment, or must give their consent. **Quality of care therefore also covers interpersonal relationships between patients and medical staff. How patients are received, empathy, respect for the individual, time accorded, information provided and professional integrity all contribute to quality as perceived by patients.** It is precisely because of the physical contact with patients (sounding the chest, palpating, etc.), with such contact forming part of the ritual, that traditional healers are liked, and even preferred, by people.⁵⁰

The relationship with the health practitioner is crucial for maintaining the trust of the individual who is sick and for whom receiving treatment is not necessarily enough. To improve communication, medical staff must therefore anticipate any potentially negative impact of the failure to take a patient's culture into account, by extending their knowledge of rules of propriety, values and norms relating to dispensing care. The medical practitioner must allow enough time for a consultation at the request of a worried patient.

48. Mercadier C., *Le travail émotionnel des soignants à l'hôpital*

["The emotional job of hospital medical staff"], Éditions Eli Arslan, 2002.

49. Jaffré Y., "La configuration de l'espace moral et psychologique des personnels de santé"

["The configuration of the moral and psychological space of healthcare staff"], in *Une médecine inhospitalière* [Inhospital Medicine], Jaffré Y. and Olivier de Sardan J.-P. (ed.), Karthala, Paris 2003.

50. Bouchon M., *Enquête qualitative sur le projet VIH/Sida et Santé sexuelle et reproductive du district de Chipinge, Zimbabwe* ["Qualitative survey of the HIV/AIDS and reproductive and sexual health project in the district of Chipinge, Zimbabwe"], MdM, July 2011, pp.34-35.

3 / THE PATIENT / HEALTH PRACTITIONER RELATIONSHIP: EXPECTATIONS AND BEHAVIOURS

"Social conventions govern the practice of seeing."⁵¹

In both North and South, people often complain about the quality of healthcare and, more particularly, the inability of health practitioners to communicate with them. Health practitioners can be removed from patients' fears and anxieties and more concerned with their responsibilities and with avoiding mistakes in diagnosis. **In the complex relationship between medical practitioner and patient, disease plays a pivotal role in how they interact.** While, on the one hand, the disease influences the duration of the interaction, it also has an impact on the form that interaction takes. Acute diseases do not involve medical staff and patients in the same way as serious, chronic diseases. As the latter require lengthy treatment, practitioner and patient are able to get to know each other better.

In public health centres dealing with acute diseases in West Africa, previous studies⁵² have revealed unfortunate and serious failings in the way patients are received, as well as in their treatment and care. In general, despite health-system reforms

and health-provider training, there continue to be extensive obstacles to the smooth-running of services. These obstacles include a wide social disparity between provider and patient, poor quality reception, withholding of information about patients' health, as well as a widespread lack of attention to the quality of treatment provided. Apart from in the case of a privileged few, dealings with the health service are often brief and sometimes brutal.

It is clear that the patient – the other – does not exist as a person and this way of dealing with people has a profound effect on the way those who are ill behave. It explains why they may be slow to seek treatment and why they might prefer a traditional, more humane, system.

People's complaints reflect their expectation that they will be better listened to, understood and informed in order to be able to participate in decisions about their own health. These communication problems mean that patients are often unfamiliar with the workings of the modern healthcare system.

During an observed consultation in a medical department, a female patient arrived with stomach pains. She had had scans but had not collected them as no one had asked her to. The doctor tried to find out if the results had been explained

51. Le Breton D., *Anthropologie de la douleur* [Anthropology of pain], Métailié, 1995.

52. Jaffré Y. and Olivier de Sardan J.-P., *Une médecine inhospitalière* ["Inhospital Medicine"], Karthala, Paris, 2003.

to her and what previous doctors had said. She then tried to remember scraps of information she'd grasped to pass them on to the doctor:

- They told me I had biliary segments.
- What are biliary segments???
- Well, I don't know. You're the doctor. They told me I had an inflamed appendix.
- ? Right. And when was this?
- In January I think.
- OK. You'll have to have the tests done again and then come back (...).⁵³

As in this case, the first exchange often has an impact on what follows, notably any subsequent consultation. Too often the patient gets discouraged, having failed to get a response during the initial consultation. If the failure is repeated, the patient begins to doubt the doctor's efficiency and may become disillusioned with the hospital as a whole. **The patient, who was pinning all hope on modern medicine and who obtains no tangible results without being informed as to why, will gradually become discouraged.** He or she will turn to other practitioners and other forms of medicine: "The doctor did not take away the disease" is a recurring complaint in West Africa.

The patient/health practitioner relationship is therefore extremely important in the treatment process, as it will undoubtedly influence the confidence the patient has in the doctor and his/her efficiency. The same applies to the reception given to families, whose confidence in the system has an impact on the whole treatment process and on the future use made of both preventative and curative services:

"We don't have enough time to talk to patients and that affects their trust. After having attended hospital, patients often go to consult the healer because they haven't understood or they've not been properly received. Take, for example, the case of sickle cell anaemia: it's a chronic disease that the patient needs to know is genetic, cannot be cured by a healer and, as long as measures are taken to control it, the patient will suffer no discomfort. But the patient who doesn't understand, who continues to suffer having been to the doctor once, twice, and whose bouts of illness have not abated, is going to believe in something else, is prepared to try anything and, in general, that's the healer."⁵⁴ **A doctor.**

In the patient/health practitioner relationship, attention must be paid to how care is dispensed, the physical surroundings, the staff, the manner in which the patient is addressed and the treatment offered. Poorly explained chronic illness will, over time, alienate patients and make them seek other types of treatment seen as more effective. As well as offering the hope of being cured, these alternatives offer individual support and some peace of mind.

53. 54. Bouchon M., "Savoirs et pratiques préventives : des campagnes d'informations sanitaires aux conceptions locales" ["Knowledge and practice of prevention: locally designed health information campaigns"], doctoral research carried out in Mali, 2004-2007.



20

MEDICINES AS SOCIAL AND CULTURAL IDENTIFIERS

➤ In the majority of countries in the South, every market has stalls offering a range of leaves, potions and chemical products which claim to cure ('priced by the pill'). Hence, talking about access to healthcare must include questions about medicines, since they are at the heart of the medical process, from the privacy of the consulting room, where medicines relieve symptoms and/or confirm diagnoses, to the open market where their sale raises major socioeconomic issues.

1 / NON ADHERENCE AND INTERRUPTIONS TO TREATMENT

"When they stop, they're asked: 'Why have you stopped?' And they

reply: 'I've not stopped but the packet was empty', and they haven't been able to buy another packet." **A doctor**
 "When we look at the prescriptions, we see that medical staff have put the right quantity but, because of the cost, the patient has bought only what he could and it's only part of the medicines prescribed as he's just bought the cheapest."⁵⁵ **A nurse.**

55. Bouchon M., "Savoirs et pratiques préventives : des campagnes d'informations sanitaires aux conceptions locales" ["Knowledge and practice of prevention: locally designed health information campaigns"], doctoral research carried out in Senegal, 2005.

The cost of medicines and the expectations they raise of a cure mean that patients often stop taking them, as is seen in the case of serious, long-term diseases like HIV/AIDS. Failure to adhere to a treatment is complicated in the case of diseases where treatment is of indeterminate length and involves taking a large number of medicines daily. **After an initial phase of treatment, patients feel better and, with this improvement in their health, they stop the treatment.** Prescriptions are therefore followed on an ad hoc basis, for one ailment after another. Chronically ill patients behave as if their disease was acute, wanting the immediate results seen with painkillers. They cannot conceive of having to manage their disease on a long-term basis, except where they have the financial means to do so.

2 / ACCEPTANCE AND MISUSE OF MEDICINES

"This disease (HIV/AIDS), once it's in your system, it can never be cured. The person has it for life and the patient is totally dependent on ARVs."⁵⁶
A community leader, district of Chipinge, Zimbabwe.

Rumours surrounding the effectiveness of a remedy, a product's name, how it is presented and the healing properties it is rightly or wrongly perceived to possess (of no relevance once faith in it is established)

56. Bouchon M., *Enquête qualitative sur le projet VIH/sida et santé sexuelle et reproductive du district de Chipinge, Zimbabwe* ["Qualitative survey of the HIV/AIDS and reproductive and sexual health project in the district of Chipinge, Zimbabwe"], MdM, July 2011, p. 51.

57. Bouchon M., *Analyse qualitative de l'organisation communautaire et de la santé, district de Maroantsetra* ["Qualitative analysis of how the community and healthcare are organised in the district of Maroantsetra"], MdM, 2010, p.18.

may help with understanding the ways patients behave in relation to medication. Hence, dexamethasone and falditone are corticosteroids which are bought by women who think that their figure is not shapely enough. In Mali, these medicines are called dafurukubanin or bobarabanin, which mean 'fat cheeks' and 'fat thighs' respectively. Similarly, the stimulating effects of ephedrine make it an accessible 'drug', while mild tranquillizers heighten the effects of some drugs. Aureomycin is used as a vaginal lubricant by women to simulate sexual desire and antidepressants are taken as stimulants. Antibiotics have been the subject of an advertising campaign explaining that they should not be 'systematically used'.

The study carried out in Madagascar also shows the extent of self-medication, ranging from traditional remedies to modern medicines, as an initial stage on the care pathway.⁵⁷ In addition, one of the sociocultural phenomena surrounding treatment worth mentioning is the popularity of injections in some developing countries. In the wake of mass immunisation programmes, injections continue to be firmly perceived as effective.

The use and misuse of medicines reveal more about people's preoccupations with health, appearance and mental wellbeing than any survey. Medicine usage also reveals the ways in which health information is obtained and these may pose serious health risks. Without the necessary medical advice and knowledge to understand the composition of a product and its specific uses, consumers cannot rely on a product's visible effects to evaluate it. In other words, **the reference used is**

not the active chemical molecule but the anticipated or experienced effect.

Reinforced by advertising, the medicine becomes an attractive substance, consumed both as image and product.

3 / A SOCIAL IDENTIFIER

"It's difficult to take my medicines at mealtimes as members of my family can see me; the same goes at work."⁵⁸

In addition, there are medicines which become 'identifiers', as is the case with treatments for HIV/AIDS. **The experience of following a treatment is affected by the process of selection for treatment and by the stigma attached to taking it. "Taking a medicine is a statement of one's disease.** Many people do not want to or cannot take their medication openly for fear of revealing their illness to those around them."⁵⁹ This study in Zimbabwe highlights the fact that decentralised distribution of antiretrovirals breaches confidentiality and stigmatises people suffering from HIV/AIDS. This means people stop their treatment or go to a distant distribution point, all of which has an impact on adherence to treatment.

Many of those buying from markets or unregulated 'bush pharmacies' cite **financial reasons** for doing so, along with the opportunity to buy medicines in single units. Moreover, going to an ordinary pharmacy involves more complex procedures, notably obtaining a prescription. The hustle and

bustle of the market seems to **protect the confidentiality and privacy of purchasers** who would be ashamed to go to a hospital to explain their disease. Such procedures draw patients into relationships of knowledge and power, which are to varying degrees unequal, within the healthcare system and social networks.

Despite the advantages they offer, medicines may still be **negatively perceived** (lack of information, powerful effects and side effects). These negative perceptions are also an **expression of a political stance.** Resistance to medication may take the form of non-adherence to treatment, reflecting scepticism towards the medical profession and its prescriptions. **The rejection of medicines is demonstrated by alternative medicines continuing to be available to and chosen by patients,** particularly in countries where traditional medicine is well developed and proclaimed as an expression of a spiritual knowledge that seeks **a harmony and balance absent from Western medical treatments.**

What populations understand by medicine must be examined by health practitioners as it raises specific questions. Clearly it involves more than merely compiling lists of traditional remedies and is about understanding the uses of these medicines and the perceptions associated with them. Health practitioners must not attempt to understand traditional remedies as simply infusions or other solutions, but as embodying meaning, such

as that assigned by people to ordinary injections. It is essential to appreciate the place occupied by medicines in daily life in order to understand health behaviours. How medicines are used would seem to offer a 'window' on fundamental aspects of a culture, such as relationships with knowledge and the concept of order or of authority.

58. Consultation at a Centre d'accueil, de soins et d'orientation [CASO – Healthcare and advice clinic], Saint-Denis, MdM.

59. Bouchon M., *Zimbabwe : enquête qualitative sur le projet VIH/Sida dans le district de Chipinge* ["Qualitative survey of the HIV/AIDS and reproductive and sexual health project in the district of Chipinge, Zimbabwe"], MdM, 2011.



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AN INTEGRATED APPROACH TO THE SOCIOCULTURAL DETERMINANTS OF ACCESS TO HEALTHCARE

➤ The social and cultural environment influences perceptions of disease and, consequently, the questions posed by those working in international humanitarian aid in their approach to healthcare. Deliberations on sociocultural determinants involve reflecting on their operational dimension, integrating them into humanitarian aid project methodology. Following some preliminary comments on the provision of aid today, this section tackles the **sociocultural dimension of projects and the participative approach**. In addition to those determinants associated with culture or with the social context (Chapter I) and those concerning the patient/health practitioner relationship (Chapter II) are those which result from the specific dynamics of a project and which must be examined in advance for the **deliberations to become an integral part of a project's operational cycle**.

PROBLEMS ASSOCIATED WITH THE PROLIFERA- TION OF HUMANI- TARIAN AID

“Yesterday I went to an awareness-raising session about micronutrients but couldn't have my child vaccinated.”⁶⁰

Among the major humanitarian aid problems emerging today, that of inadequate coordination between players and a lack of project continuity are of particular interest here. These two factors, and the solutions proposed, often reflect the differing ways in which commitment, time, space, authority, etc.⁶¹ are viewed in the West, cradle of humanitarian ideology, and how they are viewed in the various contexts in the field. Poor coordination between development and humanitarian actors, and between them and institutions, local authorities, etc., sometimes means that the different players are completely unaware of what each other is doing or planning to do. These factors influence how aid is perceived. In addition, humanitarian aid is now going through a period of competition, combined with a loss of credibility and legitimacy. **The compartmentalisation of humanitarian action, associated in particular with the 'vertical' approach to aid (HIV/AIDS, TB, immunisation, etc.) and tensions surrounding competitiveness, prevent areas where projects are complementary being exploited**

and potentially make inadequate management of healthcare services even worse. The question may legitimately be asked whether the range of aid offered in some areas, and the problems of coordinating those involved, do not in many ways confuse the populations served. **As a result, some forms of humanitarian action may be poorly understood:**

“They give our pregnant women pills to sterilise them.”
(Burkina Faso)

When a project is set up, there is a significant risk that it will duplicate or be at odds with previous or ongoing projects. A checklist needs to be drawn up of all projects in the area, which will then serve as the basis for coordinating those involved and for capitalising on their work.

In view of all the constraints hampering access to healthcare, it is essential to understand the sociocultural determinants involved as a way of improving the quality of the intervention for the populations concerned. If these different determinants are successfully explained and evaluated, we can then make our humanitarian work even more relevant. Clearly, a greater understanding of popular knowledge is essential for those working in the field. This knowledge influences people's practices and perceptions relating to how they manage health on a daily basis, as well as how they use health facilities and project resources.

60. Bouchon M., “Savoirs et pratiques préventives : des campagnes d'informations sanitaires aux conceptions locales” [“Knowledge and practice of prevention: locally designed health information campaigns”], doctoral research carried out in Senegal, 2004-2007.

61. “Travailler avec les communautés” [“Working with Communities”], review of discussion evening held on 26 May 2011, MdM, 2011.

3 A

PARTICIPATION: ITS CHALLENGES AND STRATEGIES

➤ We may ask whether NGOs, in their current drive to develop arguments for a participatory approach, are always aware of their role in, and the impact of a project on the social equilibrium of a community. The socioeconomic and political space created by a project undeniably alters aspirations and relationships with authority and with others. On a social level, a project may also, through stigmatisation, lead to the breakdown of social structures.

1 / POWER AND INCLUSION: THE CHALLENGES OF PARTICIPATION

“It's because they agreed to take part in the project that their organisation now has premises and ours doesn't.”⁶²

Project approach and power games

The participatory practices of various projects reveal that, in the area of health, they offer populations the chance to become involved in decision-making and in implementing the projects, thereby improving their quality. **Where participation plays a determining role, the complexity of such an approach should not be underestimated.** Projects must be seen as a space in which issues of politics, economics, status, etc. are played out and which may result in a conflict of individual

62. Bouchon M., *Rapport de mission d'évaluation interne par le S2AP, projet recherche action plaidoyer* [“S2AP internal evaluation report, advocacy action research project”], MdM, Niger, February 2010.

interests. Where these issues are not identified and processed, there is the risk that public opinion will turn abruptly against the project. Thus, **everyone who has a stake in the project** (target population, village leader and also professionals) **will implement strategies and behaviours designed to defend their own personal interests.**

Involvement in a project means being associated with the various resources it brings into play and may reflect personal motivation or strategic family interests.

These resources may be economic (the most obvious being money, a job and daily allowance), cultural (new expertise, training, etc.) and social (networks of resources/people, personal relationships, contact lists, access to administration, etc.). **The project is therefore not merely about implementing a healthcare intervention, but also involves challenging the hierarchy of the positions and roles, categories and groups of stakeholders in the society.**

The project may become the opportunity and focus for a whole range of struggles about the division/possession of resources, in which one of the key issues is the distribution of power to some and not to others. Those working on a project have the strategic ability to modify the activities in which they are involved or with which they are confronted.

The fact that these factors may increase people's motivation helps us understand their interests and behaviour in response to a project in which issues of power and restructuring of hierarchies are brought into play. By examining, within the newly created social space, the popular conception of what the action is about, a greater understanding can be reached of

individual interpretations and behaviour. The following questions may be asked in relation to these power games: What interest do populations have in taking part in the project? How is this interest perceived by populations? How can target populations – namely those who are most vulnerable – get involved in the project?

Identifying a representative cross-section of stakeholders

Previous experience of projects, the political and administrative context, prior relationships among project team members in the village and intermediaries, with whom particular links are established, will greatly influence the possibility of identifying individuals who represent the population and of identifying priority needs. During information gathering, **one particular group is often seen to dominate at the same time as the points of view and perceptions of minorities are excluded.** These minorities do not get the opportunity to have their interests and opinions considered as worthy of general interest. This is particularly the case for women, who are seen as being concerned with the private and domestic spheres. Essential information may be missed, as the information gathering and needs assessment focus on a convenient view of interests that irons out any differences. This problem should not be underestimated when examining the reasons for a project's success or failure.

Case studies reveal⁶³ that **target groups are extremely heterogeneous and sometimes view projects in radically different ways from other stakeholders.** Contributions must

therefore be encouraged from the weakest groups. In some contexts, when choosing who should participate in a project, it is important to consider what might influence a person's ability to speak and it may be advisable to avoid bringing together people who are from different levels of the social hierarchy.

When a village's needs are being assessed, it is essential to find out who is present, who is not and why. Therefore practical factors, such as time and distance, and social ones such as factions and alliances, which determine whether or not a person will be present, need to be identified. **Non-participation by certain stakeholders and the skewed information that emerges as a result must be taken into account.** As many issues are involved in the information flow and how that is controlled, it is important **to avoid making the information-gathering situation too formal.** It is the responsibility of the project organisers to ensure that the weakest groups (in terms of social status or the ability to express themselves) have an effective voice and are able to defend their point of view.

2 / INTERMEDIARIES⁶⁴: THE INTER-FACE BETWEEN POPULATION AND DEVELOPMENT

"It's not easy as people in my village believe that because I work for an NGO I want to behave like the Whites, and then they think that I'm going to get rich and they ask me for things."⁶⁵ **Community health worker, Senegal.**

One of the key ways to compensate for any deficiencies in a project and to ensure the community takes ownership of it is to involve intermediaries, essential links in the chain. **These individuals represent an alternative means of socially integrating projects and of bringing them in line with emerging theories of empowerment and local participation.**

Intermediaries are a form of bridge between a community and a project, working at the point where biomedical and popular belief systems overlap. They are in a privileged position as they offer a point of entry to the medical world, as well as being familiar with local cultural perceptions and practices. But the fact that their role is **generally unpaid raises questions, given the challenging**

63. Olivier de Sardan J.-P., *Anthropologie et développement, essai en socio-anthropologie du changement social* ["Anthropology and Development, an essay in the socio-anthropology of social change"], Paris, Karthala, 1995, p. 221, see section by Olivier de Sardan J.-P. on the "passeurs de l'innovation" ["transmitters of innovation"].

64. *Ibid.*

65. Bouchon M., "Savoirs et pratiques préventives : des campagnes d'informations sanitaires aux conceptions locales" ["Knowledge and practice of prevention: locally designed health information campaigns"], doctoral research carried out in Senegal, 2004-2007.

living conditions (can the poorest really be asked to commit to a volunteer role?) **and the problems of comprehension and communication.** This is why previous research into the legitimacy of such intermediaries has not produced clear-cut answers. **The scant material and support provided to intermediaries** (who receive little training) **results in them making their involvement in projects a tool for their own benefit, and even encourages them to do so.** Moreover, they often suffer the same social constraints as the rest of the population:

“In one project, one of the best intermediaries to be trained was a woman who had to give up because her husband said she was not at home enough. Other intermediaries gave up because they were caught up in political and religious conflicts between catholic and protestant communities, leading to the latter becoming isolated. Lastly, some intermediaries left to find seasonal work.” **Results of a survey in Ecuador.**

Thus the work of a project also comes up against the problem of how to implement it by those individuals selected as intermediaries. **Issues of power and the misuse of resources result in conflict within projects and turn intermediaries into mere service providers.** Each project produces specific challenges and conflicts, which vary from protagonist to protagonist, depending on his / her position in relation to others (power struggles).

Consider the following issues raised by a project:
→ Social issues

A good relationship with others in a neighbourhood or village and with the local administration and/or authority enables

individuals to become intermediaries for projects and the people they serve and, as a result, to increase their personal authority in the community. For example, an intermediary may exploit his / her new-found prestige to become a candidate in local political elections and will have to return the favour to those who helped him / her achieve this status.

→ Material issues

The intermediary's role will increase the standing of a particular social group (acquiring premises for an organisation, for example). This involves specific prerogatives and privileges, one of the most obvious being the 'company car'.

→ Economic issues

The use of incentives risks undermining the continuity of the project's work. When external funding comes to an end and these incentives stop, staff may refuse to continue working. Thus maintaining the daily allowance is seen by those running projects to be one of the major preconditions for ensuring the long-term future of activities. It is argued that a project will not succeed unless daily allowances are paid. This causal link between a daily allowance and the success of a project places an additional constraint on NGOs.

As with any acquired position, **intermediaries legitimise their power through their capacity to redistribute something** (daily allowance, better access, etc.), **thus demonstrating the social value of their new status.** If this capacity is too limited, they must look elsewhere for what the project does not directly provide: namely unofficial activities and misappropriation aimed at improving their lives.

When too rigidly applied, a project's methodology does not take sufficient account of the social environment and political power

struggles and their impact on the way the project operates. **The various stakeholders involved in a project, while contributing knowledge of the culture and society and a potential legitimacy to it, also have their own agendas. Consequently, what they bring to a development project and the ways in which they collectively and individually alter it, change it in relation to the initial planning.**

The social impact of a project is complex and the way in which those at whom it is directed appropriate it, transforming and even twisting its objectives, makes implementing it a delicate operation. Nevertheless, local volunteers and intermediaries may be effective at bridging the gap between project teams and populations, provided that they take popular knowledge into account. Unfortunately, their new status and perceived upward social mobility often distance them from this role as go-between in practice.

“The people in my neighbourhood are old-fashioned and behave like old people. They haven't moved on and don't understand that things have to change; (...) as for me, I was chosen and I've had training, so I can explain to them now.” **An intermediary with health-education training.**

It must always be remembered that any new development takes place in a public arena where there are various groups with differing agendas. Intermediaries are involved in a local community where

they have their own issues and they are sufficiently familiar with how the 'development world' works to be able to use them to their own ends. Thus, when a project is drawn up and monitored, account must be taken of the divisive effects of rivalries, quarrels and antagonism between individuals.

3 / THE DANGERS OF CATEGORISING TARGET POPULATIONS

“Marking out a group inevitably leads to exclusion and stigmatising.”⁶⁶

Defining a target group would seem to be an essential step prior to any project. But questions need to be asked: is the choice of target always relevant? Can groups really be defined? And, most importantly, what are the consequences of this targeting?

Some target groups (people at risk of HIV/AIDS, sex workers, drug users, mothers of malnourished children, etc.) may find themselves extremely marginalised once so labelled. This action places them in the role of accused, suspected of having brought about disease. Such potential 'blame' attached to their present or past conduct raises questions about their morality and lifestyle. For example,

66. Taverne B., “Sida et migrants au Burkina Faso : l'illusion d'une prévention ciblée” [“HIV/AIDS and migrants in Burkina Faso: the illusion of targeted prevention”], in *Médecine d'Afrique noire*, 43 (1), 1996.

in many areas tuberculosis is synonymous with poverty and poor living conditions.

The process of targeting certain groups, and the blame potentially associated with it, may also lead to these groups being stigmatised and even excluded.

The process of identification is therefore a delicate one and its potentially negative consequences must be avoided:

in countries where health prevention once focused mainly on heterosexual transmission of HIV/AIDS, women were seen as the source of the epidemic, while in North America HIV/AIDS was seen as a 'gay disease'. Although part of a public health initiative, work aimed at wider acknowledgement of the greater physical and social vulnerability of women to HIV/AIDS has had a similarly unwanted impact: the demonisation of sex workers and other 'sexually immoral' women, who are seen as dangerous and infectious.

These reworked popular perceptions are seen to have a negative impact on the work of a project: if, as is necessary,

resources are focused on women and HIV/AIDS, the popular impression that this disease is a women's problem is reinforced, thus deflecting attention away from the roles and responsibilities of men. So in Nepal, for example, HIV/AIDS now has connotations relating to race, class and also gender. In Africa, women do not want to be seen with condoms at home as that would indicate that they were working in prostitution.

Care must be taken in identifying the target group. Being specially singled out as a key interested party involves a process of differentiating individuals within their social group.

3 B

DATA COLLECTION AND QUALITATIVE METHODOLOGIES⁶⁷

➤ This section sets out the qualitative methods for data collection developed in social sciences and in anthropology in particular. While this framework neither claims to be a method that is universally applicable by all those working in the field nor to transform those same field workers into apprentice anthropologists, it does seek to provoke curiosity about, and to raise awareness of, the culture of "The Other" in the development worker/beneficiary relationship.

It is essential that these methods provide a way of looking at things differently, of questioning certainties, to make the encounter in the field — with different ways of thinking about illness and healthcare — easier to deal with. This approach improves the relationship, ensuring it is not just one-way but genuinely two-way communication.

Important! It must be clearly understood that information gathered is a tool that cannot under any circumstances be interpreted as established fact: cultures are not fixed and cannot be pigeon-holed. Moreover, it would be risky to identify the social context of a population solely in terms of a handful of

⁶⁷. For more detailed information on the methodology surrounding these three types of qualitative survey, please refer to the guide *Data Collection: Qualitative Methods*, MdM, Paris, 2009, 2nd edition 2012.

supposedly commonly held beliefs. This would be to brush aside the heterogeneity of populations. Instead it is more a matter of creating a wide-ranging database which provides insight into the population from several perspectives.

1 / A FIRST STAGE: COMPILING EXISTING INFORMATION

This step is designed to precede, orientate, stimulate and coordinate data collection in the field (interviews, observations and focus groups). As part of this process, it is essential to identify the information that is required: **What is it we want to know?**

To answer this question, it is useful to carry out a review of the sociocultural literature relating to the target population and to draw up a bibliography of available sources.

The data compiled must deal with the sociocultural organisation of the population in question, the extent of the problem, its consequences and characteristics, as well as any action already taken in response to it.

Certain questions must be asked to clarify the context of the action. For example:

- How is the family unit organised (patriarchal / matriarchal society)?
- What is the place of the child?

- What taboos are there relating to the project's theme (forbidden foods for example)?
- What is the hierarchy within the group?

While a bibliography will not answer all these questions, it will highlight issues to be subsequently examined.

Depending on the data it is intended to collect, the next stage involves direct contact with the concerns and needs of the population and is based on a series of questions setting out the sociocultural framework of the chosen theme. Using methodologies borrowed from social sciences (focus groups, individual interviews and observation), case studies are used as a means of accessing testimonies and descriptions taken from direct experience.

2 / OBSERVATION⁶⁸

This qualitative method is based on **careful monitoring** of observable data, with no aim of modifying them, using an appropriate protocol. It has several objectives, which are adapted depending on the phase – situation analysis, implementation or evaluation – of the project.

Observation makes it possible, among other things, to grasp the reality of a context, individual or issue with one's own eyes. The observer can identify 'ways of doing' and factors linked to environment – social, material, economic, etc. – which have an impact on behaviour and, in particular, on the care pathway. Another advantage of this method is that it provides the tools needed to assess the **discrepancy between what is said and what is done.** In this way, observation complements the two other

methods (see below), namely focus groups and interviews, as a way of confirming or disproving what has been said. For example, where an interview on the patient/health practitioner relationship has been conducted beforehand, it may be assumed that observation will provide corroborating evidence during a consultation.

The first stage of a successful observation is to draw up **a table to establish what it is one wants to observe.** For example, in the case of an observation aimed at highlighting data relating to malnutrition, the following questions could guide the observer in his/her study: At what time of day is the child fed? Do mothers prepare food specifically for the child? Etc.

While observation on its own gathers an initial volume of qualitative data, certain **subjects remain difficult to access and explore via this method**, such as domestic violence, sexual practices, drug addiction, etc. **In addition, fluency in the language** is sometimes crucial for grasping subtle and subjective elements of interaction between people.

Advantages

- This method can work without an intermediary, particularly where participative observation is involved, since one's own role in the project is used to collect information.
- Observation produces information on real practices, which interviews and focus groups are not always in a position to provide.
- It reveals discrepancies between what is said and what is done.
- It requires little in the way of resources.
- It provides insight into ways of interacting, norms and attitudes among the groups observed.
- It provides an understanding

of the physical, geographical and social context which may interact with the project.

Disadvantages

- It may be necessary to speak the language to be able to grasp the meaning of exchanges between individuals.
- Participatory observation is a difficult technique, as the observer must be capable of understanding his/her own impact while this method is being employed.
- If an observation table is poorly designed, there is the risk that important information will be missed or the results influenced.
- It is an often time-consuming method: occasionally it involves following an individual's pathway or observing the running of an establishment throughout a whole day, so as to take all parameters into account.
- Some spheres of study are difficult, even impossible, to gain access to: domestic violence, sexual practices, etc.

3 / INDIVIDUAL INTERVIEW

The individual interview is another qualitative method of data collection which goes hand-in-hand with that above and which takes the form of a more structured discussion. It focuses on a particular issue, with interview guidelines drawn up in advance.

This form of data collection **captures perceptions, knowledge and practices**

⁶⁸ Various types of observation may be employed. Participatory observation is a form which can be adapted in a project to stakeholders in the field, who already participate in community activities. The observer here abandons the role of outsider and must therefore take into account his/her own position as an insider. For all types of observation, the forms of bias introduced by the observer simply being present must be taken into account.

which, when combined with the results of other methods, enable the information to be **examined in depth and confirmed or disproved**. As a means of analysis, the individual interview helps **identify specific needs**, notably among minority populations. It offers the opportunity to tackle **difficult or personal subjects** for which focus groups or observations are not appropriate, particularly those relating to female victims of violence or risky behaviours, etc.

While the individual interview provides subjective insights to broaden the qualitative approach, it is an exercise which undeniably **requires time**. The interview guidelines have to be prepared, individuals identified and interviews conducted (a minimum of 40 minutes to 2 hours) and then transcribed. In addition, it is crucial to oversee the choice of interpreter to ensure that the linguistic filter is as nuanced as possible, can be used throughout the study and is included in the decoding process. It is also a question of **limiting the introduction of bias**, which may translate as a **discrepancy between what is said and what is done**. Lastly, the results provide a point of view but it is one which **cannot be generalised**.

For an interview to be successfully conducted, a guideline (maximum of six questions) needs to be prepared in advance focusing on: **What is it that we want to learn?** For example: What shows a child is healthy? What are the signs of normal / abnormal growth? The choice of people interviewed must be based on **'who possesses the information'**.

Advantages

- This is a very useful method as it provides an opportunity to spend time with individuals, sharing their

- deeply rooted perceptions and practices, which may only rarely be voiced in a quantitative survey or group discussion.
- It is a data collection method that is generally well received by individuals and is particularly well suited to populations with an oral tradition.
- A well-conducted interview obtains subtle and detailed information, if the subject is well explained and developed.
- Subjects which lend themselves to being explored in interviews are very wide ranging. The most sensitive of information may be tackled, unlike focus groups which do not allow for discretion and anonymity.
- It is a form of interaction which subsequently establishes more personal contact with populations.
- This method does not require extensive resources or staff.

Disadvantages

- While the interview helps reveal perceptions, it does not necessarily help reveal reality: again there is a gap between what people say and what they do. For this reason, this method must be supplemented by in-situ observation.
- The interview is a difficult technique to prepare and implement: it is difficult to step back from the 'questionnaire' reflex, where the impulse is to pose the questions in order, instead of conducting a real conversation with potential digressions.
- This method risks directing responses (introducing interviewer bias).
- It often requires time – to identify the right people, to carry out the interview (individuals have to be

- persuaded to give 1 to 2 hours of their time) and to transcribe it.
- Care must be taken over interpreting the interview when it is analysed, as it is difficult to extract what is relevant from what is not in relation to the subject.
- Lastly, the choice of interpreter is problematic as he/she risks altering or subjectively interpreting what is said, or even responding on behalf of the interviewee.

Methodology: In so far as is possible, individual interviews (preferably semi-directed) supplement focus groups on the chosen topic. Along with other means of understanding popular knowledge, such as case studies, biographies, etc., individual interviews provide a means to refine information.

4 / FOCUS GROUP

This further qualitative method of data collection accompanies those above and enables triangulation of the information to arrive at objective analysis. This method involves a formal, structured **discussion group** focused on a particular issue. The focus group is also accompanied by a guideline questionnaire, drawn up in advance and facilitated by a moderator with the help of an observer, who remains apart from the group.

Using this method, information can be obtained **to gauge public opinion of the main problems experienced, priorities**, etc. During the analysis phase, the focus group helps **identify beneficiaries**, as well

as increase knowledge of networks. At any stage of the project, it is thus possible to identify 'what is said' in the community as well as what is considered 'the proper thing to do'. More generally, the focus group reveals **current norms**: interactions between men/women, etc.

Advantages

- Focus groups generate a significant amount of information much more quickly and more cheaply than other methods of qualitative data collection.
- For fairly straightforward subjects, they may comfortably be led by trained individuals with little experience in qualitative data collection methods.
- Flexibly worded questions help reveal attitudes and opinions which other methods would not be able to uncover.
- They are generally well received by communities, as they are akin to discussion groups, which are a fairly natural form of communication in the majority of communities.
- They are not expensive to run and do not require much preparation.
- They demonstrate the ways communities interact and indicate how key people and the project will interact in the future.
- They help reveal current norms, 'the proper thing to do'.

Disadvantages

- The results cannot be extended to the community at large: they provide a range of points of view and opinions.
- Care must be taken with interpretation: participants may have come to an amicable arrangement over the responses to give (notably

as regards sensitive subjects or those relating to magic and religion).

- If the moderator is not well trained, there is a risk the answers will be directed.
- Focus groups will depict what is, socially speaking, acceptable in a community rather than what actually happens. This problem may be easily mitigated by selecting participants in small groups and comparing responses. Moreover, this helps minimise the problem minorities have in expressing their points of view.
- There may be problems with expressing diverging opinions in societies where confrontations and debates are considered ill-mannered.
- Sensitive subjects — such as casual prostitution, drug addiction, STIs, etc. — are not easily tackled given that an individual's personal experience is revealed in a group situation.
- Qualitative data are difficult to interpret and analyse.

3 C

SOCIOCULTURAL DETERMINANTS OF ACCESS TO HEALTHCARE WITHIN THE PROJECT CYCLE

➤ Following the theoretical basis set out in the first parts and the qualitative data collection methods presented above, it is now a matter of seeing how these may be incorporated into the various stages of the project cycle.⁶⁹ These theories and methods enable us to understand the subjective dimension of the issues raised by the population, local healthcare professionals, local and national elected representatives and authorities and, lastly, by aid workers. While the data may be subjective, the analysis resulting from triangulating the three qualitative methods does, nonetheless, achieve a certain degree of objectivity. This analysing of sociocultural determinants within a project includes consideration of those determinants affecting access to healthcare and may be incorporated at all stages from initial analysis to final evaluation.

⁶⁹. For further detailed information concerning project methodology and planning in general, please refer to the work *Guide de planification de projets de santé* ["Health Project Planning Guide"], MdM, Paris, to be published in 2012.

1 / ANALYSING SOCIOCULTURAL DETERMINANTS OF HEALTH BEHAVIOUR: UNDERSTANDING IN ORDER TO ACT

Initial analysis identifies intermediaries and maps power structures: representatives elected by the community, village leaders, marabouts, traditional birth attendants, etc. This prior analysis is an essential precondition for drawing up the strategy for implementing a project.

Sociocultural analysis of context

The first stage of the project, contextual analysis, is also the first time that sociocultural determinants emerge through qualitative methods. Contextual analysis is based on factors which are grouped into six types⁷⁰ and which influence a given situation and the health of populations in particular.

Sociocultural determinants belong to one of these six groups of factors:

- Level of schooling, education, literacy rates (men / women), approach to and means of transmitting knowledge;
- Organisation of social and family networks (relationships regarding men / women, elders, ethnic minority / majority, existence of civil society, etc.);

- Types of accommodation, individual / collective living;
- Working conditions and way of life;
- Perceptions of health: normal and pathological, perceptions of severity of principal diseases and local names for them;
- Presence / importance of traditional medicine and modern medicine;
- Religions and animism;
- Local languages;
- Etc.

The elements gathered relating to norms, values, practices and popular knowledge are taken into account and they, along with people's availability, should make it possible to **identify common points of reference among the popular perceptions and practices which are understood by all protagonists**. At this point, the field worker should be beginning to understand the local culture. He / she should be able to provide answers to questions about:

- Practices: why something is done and since when; why such a practice is approved, etc.;
- Diseases: what they are called in the local language; their aetiology; traditional or modern means of treating them known to local populations;
- Care pathways: actual practice in the face of a range of treatment options;
- Profiles of various categories of individuals: social role of the traditional therapist, traditional birth attendant, religious leader, etc.

Prioritising collective health problems

Prioritising is done on the basis of pre-

defined criteria, as well as by **negotiation**⁷¹ between the various stakeholders. This establishes a **common language**. While the initial analysis collects populations' needs and demands, possible common ground must then be identified to enable the project to be culturally and socially integrated.

The criteria for establishing the priorities of a chosen population are identified in terms of three aspects of a problem: its severity, frequency and extent and consequences. While consideration of sociocultural determinants sheds light on all three of these aspects, the closest scrutiny is directed at consequences. Thus, bibliographies and field studies can provide a perspective from which to grasp the fundamental dynamics operating at various levels, including the cultural, social and psychosocial.

These initially abstract-seeming concepts become much more concrete when, at the end of the situation analysis phase, an appropriate intervention strategy has to be drawn up. Various models of the intervention strategy are subsequently produced and applied during the project programming phase.

2 / PROJECT PROGRAMMING STRATEGIES: FINDING A COMMON LANGUAGE

The involvement of so-called 'beneficiary' populations is both an ethical and a technical prerequisite. People excluded from the programming process will not bring their vision to the project and will, legitimately, withdraw

when it is implemented. Taking sociocultural determinants and, consequently, individuals into account, is by its nature a transversal act which cuts across the various phases of the project. To achieve this, a common language must be found. This may be done by employing, for example, **elements of vocabulary** used by populations when talking about the theme of the project or about the disease. In particular, the name of the project may be in the local language.

Integrating SCDs into project programming

- 1 / Incorporate sociocultural elements gathered at various stages of planning.
- 2 / Identify possible activities undertaken jointly by the project and populations: needs expressed by populations during the analysis phase are taken into account.

Formulating objectives, results and constraints

From the very outset, the idea of participation must be meaningful in order to make the project relevant, feasible and sustainable. As when formulating objectives and results, the definition of constraints should take the views of the population into account—particularly any misgivings which have been expressed—in order to minimise potential constraints. In addition, an attempt must be made to understand the influence of other NGOs on the ground or of previous projects (climate of competition), which might explain any takeover or instances where a project is used (or misused) to meet someone else's agenda.

70. The six groups of factors are: 1/Sociocultural, 2/Health policy and organisation of healthcare system, 3/Geographical 4/Historical, political, regulatory and security, 5/Socioeconomic, 6/Demographic and health

71. See summary report of workshop on "négociations socioculturelles des pratiques professionnelles" ["Sociocultural negotiations relating to professional practice"], Kenya, 2011.

Identifying and selecting indicators for taking sociocultural factors into account⁷²

Those responsible for putting the project programming into effect identify and then select the criteria most appropriate to the context from the panel of indicators for taking sociocultural factors into account.

Examples of indicators

- % of consultations where protecting the privacy of the patient is guaranteed by appropriate measures (presence of a privacy screen, option of being treated by a health professional of the same sex, etc.).
- % of assisted births that respect birth position wanted by pregnant woman.
- % of births that take account of the wishes of the mother concerning the placenta following birth.
- % of healthcare staff who are familiar with at least three sociocultural taboos (e.g. caesareans, blood transfusions, drips), shared by the community, relating to treatment of obstetric complications.
- % of population aware of a harmful procedure associated with birth and care of newborns (e.g. cutting the cord).
- % of women who consult only traditional therapists (traditional birth attendants and midwives, etc.) for emergency obstetric treatment and neonatal health.

- Perception of effectiveness of service offered by the centre for emergency obstetrics in dealing with complications relating to labour and newborns.
- Perception of level of seriousness of obstetric emergencies and of treatment for newborns.
- % of consultations for which the means are in place (training and interpreter) for the local dialect to be understood and used by the health practitioner.
- % of local ethnic groups represented by link persons within the project.

Defining activities and resources

During the phase to identify activities, it is essential to find common ground with populations for the intervention. If this has not already been done, it may provide a 'catalyst', prompting a desire to participate, notably by offering a variety of methods and by deciding with the population which one seems most suitable.

Such participation must extend to the various stages at which the activities are defined⁷³, from identifying them to checking their consistency within the project and externally. In particular, those involved must remain open-minded about how long the process will take. Excessive short-termism in projects increases problems resulting from a lack of knowledge of the context, issues of power and discrepancies in how work is perceived, as well as a lack of participation by populations and of negotiation in the drawing up of projects.⁷⁴

Resources are also subject to negotiation, as, while they will undoubtedly be determined in relation to what is needed to carry out the project, they must also take into account what the community has the capacity to absorb and what the community itself might provide. In addition, the issue of human resources (and their remuneration⁷⁵) is without doubt one of the first that the field worker has to face.

3 / IMPLEMENTING AND MONITORING

The process to set up the project and finally put it into practice must be done in parallel with setting up project monitoring and use of the data which emerges.

Integrating SCDs into project implementation

- 1 / Those involved in international solidarity projects must be trained and monitored so that they listen to populations: ethical issues and taking account of the socio-cultural context and language in the healthcare process.
- 2 / Indicators revealing that consideration is being given to sociocultural elements must be incorporated into the programming.

Training to ensure integration of project

At this point, previous studies and the participative element of the analysis phase

become important as preparations are made to launch the activities and implement the project and to update information and issue communications relating to the project.

Training

This involves training those working in international solidarity to use sociocultural data to improve the healthcare offered. It helps them to be more attentive to what populations are saying and thereby improves understanding of how populations behave. Training must be able to offer some of the tools used by anthropology, without claiming to turn development workers into anthropologists.

Training must ensure humanitarian workers do not dismiss popular beliefs and local knowledge, and at the same time do not blindly accept them. It is a process of negotiating to find the middle ground where popular beliefs and medical interventions are both given space.

At the end of the training, the person must have been made aware of the influence of culture and social organisation on the ways in which disease is perceived, must be able to explain it and deal with it (both in traditional and modern societies). He/she must also be aware of the importance of taking these into account in day-to-day practice. **All diseases are subject to classifications, perceptions and practices and, in this respect, constitute important subjects of enquiry.**

72. An indicator is a quantitative and/or qualitative measurement (pointer, figure, fact or perception) which describes the status quo or changes to the status quo, when observed over time, and which helps reveal deviations in relation to other comparable elements or in relation to norms, standards or fixed objectives.

73. For further detailed information concerning project methodology and planning in general, please refer to the work *Guide de planification de projets de santé* ["Health Project Planning Guide"], MdM, Paris, to be published in 2012.

74. "Travailler avec les communautés" ["Working with Communities"] report on evening debate on 26 May 2011, MdM, 2011.

75. Bouchon M., "Diagnostic socioculturel de la mission du Medio Atrato" ["Sociocultural Analysis of the Medio Atrato project"], Stage 2, MdM, 2010, p. 23.

Once those working in the field are trained in collecting and using data gathered by qualitative methods, they will be able to compile a dossier comprising all the information. Passed from team to team, the dossier is intended to be added to and regularly updated. Ideally, it contains references (articles, communications, book references, etc.) to works of social science, which deal with the teams' geographical areas and with the subjects of their projects and which provide a theoretical basis for the collection of data.

The dossier also includes questions to ask and guidelines for semi-structured interviews, which are drawn up and organised for conducting a 'day-to-day' socioanthropological study involving families and health practitioners. This dossier of information collected provides a means of examining how knowledge and practices dovetail with biomedical knowledge and of detailing their contribution to health practices and prevention. For example, observation of the care process must be as extensively reported back on both in writing and verbally during regular meetings. A summary of this information, which will, of course, be partial and fragmentary given the amount of time accorded to it, should nevertheless make it possible to set objectives and to monitor the extent to which sociocultural determinants are being taken into account.

Participative monitoring: analysing together

Involvement of local stakeholders and consideration of sociocultural determinants, both in the method adopted and in interpreting the data, are fundamental to the relevance and running of the project. The monitoring process systematically and continuously examines the extent of the project's progress,

evolution and outcomes. It must also identify any deviations and make the necessary adjustments. This consideration of cultural and social aspects must enable adjustments to be made to the practices of humanitarian workers and, by extension, to the expectations of donors, in order to adhere more closely to reality and to the aspirations of the population. The project is monitored using systematic indicators (see above), adapted to suit the requirements of the project and the reality of the context.

Monitoring may take the form of a **participative study**, involving all those associated with the project (headquarters and local project workers and beneficiaries). In particular, all stakeholders take part in drawing up questions, in selecting how the information gathered should be interpreted and in formulating recommendations.

The data collected during the various phases of the project play a fundamental role in what happens next in a project. An approach based on sociocultural determinants tends to **encourage information to be safeguarded in every way possible and to be used sparingly**.⁷⁶ In the situations in which projects evolve, information **may constitute a risk for the patient or the person providing evidence**. As such information gathering is usually conducted on the basis of mutual trust, individuals' participation and transparency of the process in which they are involved are crucial.

The data in question are put to various uses. From a management point of view, they enable adjustments to be made to the project. While respecting codes of confidentiality relating to data use, they may also serve in communicating and **reporting for internal monitoring and donor purposes**. This information thus helps **improve knowledge**

and expertise in support of social change, whether among political decision-makers, media, partners, general public, etc.

4 / EVALUATING: DETAILED EVALUATION TABLE⁷⁷

As a participative exercise, evaluation represents a tool for communicating and negotiating between the different parties. **As well as being done for ethical reasons, opening up evaluation to the population explicitly acknowledges their capacity to influence project proceedings and results**. A process is established to enable the exchange of information and potential negotiation. All stakeholders represented will be able to draw a certain amount of information from this process, which may be useful in relation to their particular interests.⁷⁸

Participative evaluations can be seen to (re) motivate, to boost group dynamics and to result in adjustments and mutual negotiation, even if personal interests and agendas continue to be a factor. This type of evaluation has the advantage of **enhancing the credibility of professionals in the eyes of the population**, with whom closer links are forged. In addition, it obliges professionals and intermediaries to take some of the ideas expressed into account, or at the very least it makes it more difficult to ignore them. From the intermediaries' point of view, **it counters the negative image of the evaluation process**, often seen as a potential threat or a form of control.

The final evaluation provides an **overall assessment of the project and the sociocultural context in which it takes place**. It enables project actors to take a step back when considering **the directions of future work in which the sociocultural determinants of access to healthcare will play a role**.

The table⁷⁹ assesses any discrepancy between stated objectives and actual outcomes. At the same time, it questions how acceptable a project is and how it may be integrated into a population's sociocultural groupings. The relationship between the project and those it is aimed at may be analysed using this twofold questioning, based on a comparison of predetermined criteria (see below).

Integrating SCDs into project evaluation

- 1/ Analyse all elements of the project by demonstrating at each stage what works and what does not.
- 2/ Try to understand what impact the project has at local level.
- 3/ Question the practices for designing and implementing the project and the healthcare practices of aid workers.

Evaluation criteria and sociocultural determinants

Motivated by various different quality initiatives, the humanitarian sector has, in recent years, witnessed the adoption of

⁷⁷. For a copy of the table, please see the annexes on the CD-ROM. ©

⁷⁸. Lefèvre P. and Kolsteren P., "Le développement comme arène : implications pour l'évaluation des projets" ["Development as public arena: implications for project evaluation"], *Bulletin de l'Apad N° 8*, 1994, published online on 22 November 2007. URL: <http://apad.revues.org/1823>.

⁷⁹. See annexes on the CD-ROM. ©

⁷⁶. For *Ethics in the Field, Sensitive Personal Data Management*, McM, Paris, 2010.

standard evaluation criteria. Virtually all of the criteria can be grouped or expanded using the principles set out by the sociocultural determinants of access to healthcare.

To clarify, it is worth examining six of these criteria in relation to the sociocultural determinants of access to healthcare:

1 / Firstly, 'relevance': this measures how well **the aims of the development work correspond with the expectations of beneficiaries**, the needs of the country, overall priorities and partners' and donors' policies. Looked at in retrospect, the issue of relevance often involves asking whether the aims of the activity or its conception are still appropriate given the evolving context.⁸⁰

2 / 'Effectiveness' assesses whether a project's objectives have been or are in the process of being achieved. It asks fresh questions about the feasibility of the objectives at a sociocultural level, in order for any potential adjustments to be made to the follow-on from a project. This involves questioning the nature of the intended effectiveness, weighing it up against the sociocultural context.

3 / The various evaluation tables also include **'viability'** (longevity and sustainability), which, after the end of the intervention, **calculates the ongoing benefits resulting from development work. This requires participation and appropriation**, which in turn must be supported by detailed understanding of the society and culture, in order to create a common dialogue prior to negotiation and commitment.

4 / The sociocultural determinants of access to healthcare contribute as well to assessing

the **long-term impact** of an intervention—positive and negative, primary and secondary—whether direct or indirect, intentional or unintentional. While it is not a question of transforming the culture and the social context into a fixed, uniform whole, an assessment of the impact of a project in the social and cultural spheres seems **necessary at both an ethical and a technical level.**

5 / Assessing a project's impact from the perspective of sociocultural determinants closely relates to another of the criteria, namely **'equity'**. This refers to the fair distribution of healthcare services among the population's different groups. Equity in healthcare is the absence of any systematic disparity between groups which have varying underlying levels of social advantages/disadvantages (wealth, power and prestige). An assessment of healthcare equity implies **comparing the health and social determinants of health of more or less advantaged social groups.**

6 / Lastly, if **'acceptability'** is another of the criteria considered, parallels with the sociocultural determinants of access to healthcare are unavoidable. Acceptability here **is presented from the social, psychological and ethical angle of healthcare**; each of these aspects needs to be backed by the qualitative methods used in social sciences, and anthropology in particular, as part of the various evaluations carried out.

Capitalisation, or not reinventing the wheel

Of the various forms of evaluation available⁸¹, the one which now needs to be examined

differently in the light of sociocultural determinants is that of evaluating the process, or capitalisation, which is crucial for gaining an understanding of the history of a project and its context. Moreover, this capitalisation **supports a process of innovation**, by encouraging future activities to be based on previously acquired skills. During an intervention, capitalising on **knowledge of the sociocultural environment** is a process that develops systematically and **establishes the relevance and legitimacy of the action.** This knowledge also makes it possible to **anticipate and facilitate potential emergency interventions** in contexts which are recognised as unstable and where an approach that capitalises on sociocultural determinants constitutes a key form of participative support.

In concrete terms, this capitalisation involves **comparing how the project was planned to operate and how it actually operates** in terms of activities, use of resources and participation by partners and communities. It helps reveal why a project worked or why it did not. This 'why' should be examined particularly in relation to **documenting the implementation of new types of project to be able to reproduce them.** For a project to be successfully concluded, it is essential to **describe accurately and in detail** all the elements, particularly sociocultural, which have contributed to its implementation. In this way, levers and barriers may be identified, along with the specifics of the local context.

⁸⁰. Please refer to part 3C/1/ dealing with the analysis and, in particular, the contribution of sociocultural determinants of access to healthcare in analysing context.

⁸¹. *Guide de planification de projets de santé* ["Health Project Planning Guide"], MdM, Paris, to be published in 2012.



CONCLUSION AND FUTURE DEVELOPMENTS



CONCLUSION AND FUTURE DEVELOPMENTS

► In all societies, there are sociocultural factors which profoundly influence the way in which people perceive their bodies and manage their health. Healthcare activities involve complex situations arising in the relationships between the various (sometimes incompatible and even conflicting) ways health is perceived.

These perceptions, attitudes and beliefs reveal the limitations and impact of aid projects and invite us to be more vigilant and careful in drawing up and implementing our activities. Magic and religious protective rituals, dietary taboos, relationships of power in families and groups constitute constraints, which may have an impact on the ability to access healthcare. It is **vital that projects are compatible with the cultural values, beliefs and practices of those they address.** Acknowledging cultural difference is not simply a matter of recording the host of ways in which things are done, it is also about understanding that, from one culture to the next, it is the way of thinking about things that changes, particularly the way of thinking about disease and healthcare. **Ignoring differences in how things are done and thought about may thus be seen as akin to a rejection of knowledge and a refusal to acknowledge. This may provoke mistrust in, and resistance to, projects** that do not make sense in the culture of the beneficiaries.

As all development processes involve recognition of, and respect for, cultural diversity and as health development projects must not represent a refusal to understand the ways of thinking about disease, recognition of sociocultural differences in health is also **recognition of the other in a project's approach, exchanges and encounters.** This is why theoretical reflections must be inseparable from operational methods, such as data collection by qualitative methods, for the benefit of the whole project cycle. These tools designed for the field develop an attitude and approach among international aid and development workers which help them develop their questioning of ethical issues.

5

BIBLIOGRAPHY

BY TOPIC

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GENERAL WORKS

Adam Ph. et Herzlich C.,
– *Sociologie de la maladie et de la médecine*, Nathan Université, Paris, 1994.

Benoist J.,
– “Une anthropologie médicale pour les anthropologues et les médecins”, *Bulletin d'ethnomédecine*, Paris, 33 (1), 1985, pp. 85-96.

– “Sur la contribution des sciences humaines à l'explication médicale”, *Anthropologie et Sociétés*, vol. 5, n° 2, Québec, 1981, pp. 5-15.

Fainzang S.,
– “L'anthropologie médicale dans les sociétés occidentales. Récents développements et nouvelles problématiques”, *Sciences sociales et santé*, 2001.

Good B.J.,
– *Comment faire de l'anthropologie médicale ? Médecine, rationalité et vécu*, Les empêcheurs de penser en rond, Institut Synthélabo, Le Plessis-Robinson, 1994.

– “Problèmes théoriques et méthodologiques en anthropologie de la santé dans les pays d'Amérique latine”, *Sciences sociales et santé*, Toulouse, 17 (1), 1999.

PUBLIC HEALTH

Brunet-Jailly J. (éd.),
– *Innover dans la santé. Expériences d'Afrique de l'Ouest*, Karthala, Paris, 1997.

Dozon J.P et Fassin D. (sous la dir. de),
– *Critique de la santé publique. Une approche anthropologique*, “Voix et regards”, Balland, Paris, 2001.

Fassin D.,
– *Les Enjeux politiques de la santé. Études sénégalaises, équatoriennes et françaises*, Paris, Karthala, 2000.

Fassin D. et Defossez A.C.,
– “Une liaison dangereuse : sciences sociales et santé publique dans les programmes de réduction de la mortalité maternelle en Équateur”, *Cahier des sciences humaines*, 28 (1), 1992, pp. 23-36.

Hours B.,
– “Du droit à la santé aux droits de l'homme : le retour de l'ethnocentrisme”, *L'Homme et la société*, n° 3-4, 1987, pp. 13-23.

Hours B. (en collaboration avec Selim M.),
– “Santé et marché en Asie”, *Mondes en développement*, t. 24, n° 93, 1992.

Massé R.,
– *Culture et santé publique : les contributions de l'anthropologie à la prévention et à la promotion de la santé*, Gaëtan Morin, Montréal, 1995.
– *Éthique et santé publique : enjeux, valeurs et normativité*, Presses de l'Université Laval, Québec, 2003.

Tavares Soares L.,
– “Les transformations du système de santé et leurs répercussions sur les femmes : le cas du Brésil”, in Saillant F. et Boulianne M. (sous la dir. de), *Transformations sociales, genre et santé*, Presses de l'Université Laval, Québec, 2003, en coédition avec L'Harmattan, pp. 39-53.

SOCIOCULTURAL DETERMINANTS OF DISEASE

Albrecht J., Asif A.,
– “Father's perception of child health in a squatter settlement, karachi”, *Health Transition Review*, vol. 5, n° 2, 1995.

Baxerres C., J.-Y. Le Hesran,
– “Recours aux soins en cas de fièvre chez l'enfant en pays Sereer au Sénégal : entre contrainte économique et perception des maladies”, *Sciences sociales et santé*, vol. 22, n° 4, 2004, pp. 5-21.

Benoist J. et Cathebras P.,
– “The body: from an immateriality to another”, *Social Sciences and Medicine*, vol. 36, n° 7, 1993, pp. 857-865.

Bonnet D.,
– “Identité et appartenance : interrogations et réponses moose à propos du cas singulier de l'épileptique”, *Cahiers des sciences humaines*, (2), 1995, pp. 501-522.

Desjeux D., Favre I., Simongiovani J.,
– *Anthropologie d'une maladie ordinaire. Étude de la diarrhée de l'enfant en Algérie, Thaïlande, Chine et Égypte*, Nutrition et santé, L'Harmattan, Paris, 1993.

Early E. A.,
– “The logic of well-being: therapeutic narratives in Cairo, Egypt”, *Social Science and Medicine*, vol. 16, New York, 1982, pp. 1491-1497.

Gruénais M.E.,
– “Mariages en ville et malnutritions aiguës”, *Sciences sociales et santé*, 1985, vol. 3, pp. 57-83.

Good B., Good M.-J. Delvecchio,
– “Au mode subjectif ; la construction narrative des crises d'épilepsies en Turquie”, *Anthropologie et sociétés*, 17 (1-2), Québec, 1993, pp. 21-42.

Jaffré Y. et J.-P. Olivier de Sardan.,
– “Tjiri, la naissance sociale d'une maladie”, *Cahiers des sciences humaines*, 31 (4), 1995, pp. 773-795.

Laplantine F.,
– “Maladie, guérison et religion dans les mouvements pentecôtistes latino-américains contemporains”, *Anthropologie et sociétés*, 1999.

Mitrani P.,
– “Salud y enfermedad en la concepcion Yaruro (Ensayo de Antropología Médica), Santé et maladie selon la conception Yaruro (Essai d'anthropologie

médicale)", *Montalban Caracas*, vol. 8, 1978, pp. 329-390.

Ong A.,

– "The production of possession: spirits and the multinational corporation in Malaysia", *American Ethnologist* (Arlington), 15, 1988, pp. 28-42.

Zempléni A.,

– "La 'maladie' et ses 'causes'. Introduction", *L'Ethnographie*, 96-97, 1985.

PREVENTION

Aiach P., Bon N. et Deschamps J.-P. (éd.),
– *Comportements et santé. Questions pour la prévention*, Presses universitaires de Nancy, Vandœuvre-lès-Nancy, 1992.

Cherubini B.,

– "L'apport de l'anthropologie à la mise en œuvre d'une politique de prévention : du vécu de la maladie à l'analyse du raisonnement préventif", *Autrepart*, 29, 2004, pp. 99-115.

Decache A., et Meremans P.,

– "L'éducation pour la santé des patients : un carrefour de la médecine et des sciences humaines", in Sandrin-Berthon B. (éd.), *L'Éducation du patient au secours de la médecine*, PUF, Paris, 2000, pp. 147-167.

Jaffré Y.,

– "Éducation pour la santé et conceptions populaires de la prévention. À propos d'un programme d'amélioration de la couverture vaccinale au Burkina Faso", *La Revue du praticien-médecine générale*, t. 5, n° 154, 1991, pp. 2489-2494.

Jaffré Y., Banos M.-T., Kabo M., Moussa F.,

– "Prévention et communication dans le cadre d'un programme de santé oculaire", *Cahiers santé*, 3, 1993, pp. 9-16.

MATERNAL AND CHILD HEALTH/NUTRITION

Bonnet D.,

– "Présentation. La notion de négligence sociale à propos de la malnutrition de l'enfant", *Sciences sociales et santé*, vol. 14, 1996, pp. 5-16.

Desclaux A.,

– "De la mère responsable et coupable de la maladie de son enfant", in J. Benoist (sous la dir. de), *Soigner au pluriel*, Paris, Karthala, 1996, pp. 251-279.

De Garine I.,

– "Aspects psychoculturels de l'alimentation : motivation des choix. Interdits et préférences", in Froment A., De Garine I., Bikoi C.-B., et al. (éd.), *Bien manger et bien vivre. Anthropologie alimentaire et développement en Afrique intertropicale : du biologique au social*, L'Harmattan, Paris, 1996, pp. 345-346.

Farmer P.,

– "Bad blood, spoiled milk: bodily fluids as moral barometers in rural Haiti", *American Ethnologist* (Arlington) 15, 1988, pp. 62-83.

Gojard S.,

– "L'alimentation dans la prime enfance. Diffusion et réception des normes de puériculture", *Revue française de sociologie* 41-3, 2000.

Hoérée T., Kolsteren P., Roberfroid D.,

– "La prise en charge de la malnutrition chez les enfants préscolaires : le rôle des services de santé locaux", *Cahiers d'étude et de recherches francophones : santé*, vol. 12, n° 1, 94-9, Approches multiples, janvier-février 2002.

Laurer L.-J., Habicht J.,

– "Concepts about infant, health, growth and weaning: a comparison between nutritional scientists and maduresse mothers", *Social Science and Medicine* 29, 1989, pp. 13-22.

Rezkallah N., Epelboin A.,

– *Chronique du saturnisme infantile (1989-1994) : enquête ethnologique dans des familles parisiennes originaires du Sénégal et du Mali*, L'Harmattan, Paris, 1997, 261 pp.

Suremain C.-E.,

– "Dynamiques de l'alimentation et socialisation du jeune enfant à Brazzaville (Congo)", *Autrepart* 15, 2000, pp. 73-91.

MALARIA

Agyepong I.A.,

– "Malaria: ethnomedical perceptions and practice in an Adangbe farming community and implications for control", *Social Science and Medicine* 35 (2), 1992, pp. 131-137.

Asenso-Okyere W.K., Dzator J.A.,

– "Household cost if seeking malaria care. A retrospective study of two district in Ghana", *Social Science and Medicine* 45 (5), 1997, pp. 659-667.

Audibert M.,

– "Lutte contre le paludisme, approche économique des obstacles à son contrôle", *Sciences sociales et santé*, vol. 22, n° 4, 2004.

SEXUALITY AND STIS/HIV/AIDS

Balandier G.,

– "Le sexuel et le social, lecture anthropologique", *Cahiers internationaux de sociologie*, vol. LXXVI, 1984.

Bardem I., Gobatto I.,

– *Maux d'amour, vies de femmes ; sexualité et prévention du sida en milieu urbain africain*, L'Harmattan, "Santé et sciences humaines", Paris, 1995, 174 pp.

Benoist J.,

– "Le sida entre biologie, clinique et culture", in Benoist J., Desclaux A., *Anthropologie et sida, bilan et perspectives*, Karthala, Paris, 1996, pp. 5-10.

Desclaux A.,

– "L'observance en Afrique : question de culture ou "vieux problème" de santé publique ?", ANRS, *L'Observance aux traitements contre le VIH/sida. Mesure, déterminants, évolution*, coll. "Sciences sociales et sida", 2002.

Desclaux A., Crochet S. et al.,

– "Le 'choix informé' des femmes séropositives qui doivent alimenter leur enfant : interprétations locales, limites et nouvelles questions", in *Sexualité et procréation confrontées au sida dans les pays du Sud*, Ceped, Paris, 2006.

Fassin D.,

- “Idéologie, pouvoir et maladie. Éléments d'une anthropologie politique du sida en Afrique”, in **Cros M.**, *Les Maux de l'autre*, L'Harmattan, Paris, 1996.

Farmer P.,

- “AIDS and accusation: Haiti, Haitians and the geography of blame”, in **Feldman D.A.** (ed.), *Culture and AIDS*, New York: Praeger, 1990, pp. 67-91.

Goldin C.S.,

- “Stigmatization and Aids : Critical Issues in Public Health”, *Social, Science and Medicine*, vol. 39, n° 9, 1994, pp. 1359-1366.

Hancart Petitot P.,

- “Mortalité maternelle au Ladakh : de la santé publique à l'anthropologie”, in **Pordié L.**, *Panser le monde, penser les médecines. Traditions médicales et développement sanitaire*, Paris, Karthala, 2005, pp. 123-143.
- “Une perspective “intime” sur les soignants. Prévention de la transmission mère-enfant du VIH dans un hôpital de district en Inde du Sud”, in **Desgrées du Loué A.** et **Ferry B.**, *Sexualité et procréation confrontées au sida dans les pays du Sud*. Ceped, Paris, 2006, pp. 190-207.

Vernon D.,

- “Un exemple d'anthropologie adaptée : un programme de prévention contre le sida pour les Noirs Marrons de Guyane”, in **Benoit J.** et **Desclaux A.**, *Anthropologie et sida, bilan et perspectives*, Karthala, Paris, 1996, pp. 117-126.

COMMUNITY HEALTH AND POPULATION PARTICIPATION

Blundo G.,

- “Les courtiers du développement en milieu rural sénégalais”, *Cahiers d'études africaines*, XXXV (1), 137, 1995, pp. 73-99.

Bruyn (De) M.,

- “Women and Aids in Developing Countries”, *Social Science and Medicine*, vol. 34, n° 1, 1992, pp. 249-262.

Chauveau J.-P.,

- “Le modèle participatif de développement est-il alternatif ?”, *Bulletin de l'Apad*, 3, 1992.

Laurent P.-J.,

- *Une association de développement en pays mossi. Le don comme ruse*, Karthala, Paris, 1998.

Laurent-Beq A.,

- “Éditorial. Les forums-citoyens : une contribution à la “démocratie sanitaire” ?”, *Santé publique*, vol. 11, n° 1, v. 3-4, 1999.

Lavigne Delville P.,

- “Groupements villageois et processus de transition”, *Cahiers des sciences humaines*, 28 (2), 1992, pp. 327-343.

Paul B.D. et Demarest W.J.,

- “Citizen participation overplanned: the case of health project in the Guatemalan community of San Pedro La Laguna”, *Social Science and Medicine*, vol. 19, n° 3, 1984, pp. 185-192.

Saillant F.,

- “Transformations des systèmes de santé et responsabilité des femmes”, in **Hours B.** (sous la dir. de), *Systèmes et politiques de santé. De la santé publique à l'anthropologie*, Paris, Karthala, 2001, pp. 221-247.
- “La part des femmes dans les soins de santé”, *Revue internationale d'action communautaire, prendre soin, lien sociaux et médiation institutionnelles* 28, 68, 1992, pp. 95-105.

Tessier S.,

- “Le diagnostic communautaire comme outil pédagogique”, in *Interventions sanitaires et contextes culturels*, Amades, Toulouse, 1990, pp. 39-46.

DEVELOPMENT/NGOS

Atlani-Duault L.,

- “Ethnographie de l'aide”, in *Ethnologie française*, 2011/3, PUF, Paris 2011, pp. 389-520.

Bauber T.,

- *Les Enfants des rues d'Antananarivo et les morts : culture, psychopathologie, et intervention humanitaire*, 9 (1), Prisme, Québec, 1999, pp. 24-33.

Bouchon M.,

- “L'éducation pour la santé au Sénégal”, in *WHEP, Académie des sciences*, IAP, Paris, 2006, (en ligne).

Bourdier F.,

- “ONG et puissances publiques dans la lutte contre le sida en Inde : enjeux et répercussions sociopolitiques”, *Revue Autrepart*, IRD, Paris, juin 1999.

Brunet-Jailly J.,

- “Une éthique de la recherche médicale immédiatement universelle : un moyen de protéger la recherche médicale des pays du Nord ?” in **Bonnet D.** (dir.), *L'Éthique médicale dans les pays en voie de développement*, Autrepart, Éd. de l'Aube, 2003.

Copans J. et Freud C. (sous la dir. de),

- “Les sciences sociales au miroir du développement”, in *Cahiers d'études africaines*, 202-203, Éditions de l'EHESS, Paris, 2011.

Delauay K.,

- “Des ONG et des associations : concurrences et dépendances sur un “marché du sida” émergent. Cas ivoirien et sénégalais”, in **Deler J.-P. et al.** (éd.), *ONG et développement*, Paris, Karthala, 1998, pp. 115-141.

Dozon J.-P.,

- “Le dilemme connaissance-action : le développement comme champ politique”, *Bulletin de l'Apad*, n° 1, 1991.

Fabbrizio C., Desjeux D., Dupuis X.,

- *La Dimension culturelle du développement, vers une approche pratique*, Unesco, Paris, 1995.

Fassin D.,

- “La production locale de la santé publique”, *Prévenir, numéro spécial “Ville et santé”*, 31, 1996, pp. 9-20.

Fassin D. et Jaffré Y. (éd.),

- *Sociétés, développement et santé*, Ellipses, Paris, 1990.

Forde O.H.,

- “Is imposing risk awareness cultural imperialism ?”, *Social Science and Medicine* 47 (9), 1998, pp. 1155-1133.

Hours B.,

- “Les politiques de santé du village à la planète : dépendance ou intégration” in **Crousse, Delville, Mercier (éd.), Les Politiques de santé, De Boeck, coll. “Savoirs et santé”, Bruxelles, 1988.**
- *L’Idéologie humanitaire ou le spectacle de l’altérité perdue.* L’Harmattan, Paris, 1998.

Hours B. et Selim M.,

- *Une entreprise de développement au Bangladesh : le centre de Savar,* L’Harmattan, Paris, 1989.
- “Anthropologues et ONG : des liaisons fructueuses ?”, *Humanitaire, hors-série n° 4,* éd. Médecins du Monde, Paris, 2007.

Laplante J., Bruneau J.,

- “Aperçu d’une anthropologie du vaccin : regards sur l’éthique d’une pratique humanitaire”, *Historia, Ciências, Saúde – Manguinbos*, vol. 10, 2003.

Lefèvre P. et Kolsteren P.,

- “Le développement comme arène : implications pour l’évaluation des projets”, *Le Bulletin de l’Apad*, n° 8, “Les sciences sociales et l’expertise en développement”, décembre 1994.

Naudet J.-D.,

- *Trouver des problèmes aux solutions, vingt ans d’aide au Sahel,* Éditions de l’OCDE, Paris, 1999.

Olivier de Sardan J.-P.,

- *Anthropologie et développement. Essai en socio-anthropologie du changement social,* Karthala, Paris, 1995.
- “L’anthropologie du changement social et du développement comme ambition théorique ?”, *Bulletin de l’Apad*, n° 1, Montpellier, 1991.

Olivier de Sardan J.-P., Paquot E., (sous la dir. de),

- *D’un savoir à l’autre. Les agents de développement comme médiateurs,* La Documentation française, Paris, 1991.

Sanchez-Arnau J.-C., Desjeux D., (éd.),

- *La Culture, clé du développement,* L’Harmattan / Unesco, Paris, 1994.

Zempleni A.,

- “Réflexions”, in *Interventions sanitaires et contextes culturels,* Amades, Toulouse, 1990, pp. 98-99.

TRADITIONAL MEDICINE, MEDICAL PLURALISM AND INTERCULTURALITY**Benoist J.,**

- *Soigner au pluriel : essais sur le pluralisme médical,* Karthala, Paris, 1996.
- “Soigner dans des sociétés plurielles : les leçons du monde créole”, in **Hazaël-Massieux M.-C. et Robillard (de) D., Contacts de langues, contacts de cultures, créolisation,** L’Harmattan, Paris, 1997, 475 p., pp. 333-348.

Bibeau G. et Tremblay J.,

- “Résistance et soumission face à l’émergence d’une autre conception de la santé”, *Union médicale du Canada*, 109 (5), 1980, pp. 789-790.

Boy D., Michelat G.,

- “Qui y croit ?”, *Autrement*, n° 85, Paris, pp. 93-97.

Desjeux D.,

- *Le Sens de l’autre. Stratégies, réseaux et cultures en situation interculturelle,* L’Harmattan, Paris, 1994.

Dozon J.-P.,

- “Ce que valoriser la médecine traditionnelle veut dire”, *Politique africaine*, n° 28, 1988.

Dozon J.-P., Sindzingre A.-N.,

- “Pluralisme thérapeutique et médecine traditionnelle”, *La Santé dans le tiers monde*, Prévenir, Paris, 1986.

Fainzang S.,

- “La cure comme mythe, le traitement de la maladie et son idéologie à partir de quelques exemples africains”, in *Cahiers Orstom, série “sciences humaines”,* vol. 18, n° 4, 1981-1982, pp. 415-421.
- “La “maison du blanc” : la place du dispensaire dans les stratégies thérapeutiques des Bissa du Burkina”, *Sciences sociales et santé*, n° 3-4, 1985, pp. 105-128.
- “Les stratégies paradoxales. Réflexions sur la question de l’incohérence des conduites des malades”, *Sciences sociales et santé*, vol. 15, n° 3, 1997, pp. 5-23.

Fassin D.,

- “L’internationalisation de la santé, entre culturalisme et universalisme”, *Esprit*, n° 229, février 1997, pp. 83-105.

Gonseth M.-O.,

- “La fracture : médecine sacrificielle et médecine occidentale chez les Ifugao des Philippines”, *Ethnologica helvetica*, 17/18, Berne, 1993-1994, pp. 505-532.

Lock M.,

- “Rationalization of Japanese herbal medication: the hegemony of orchestrated pluralism”, *Human Organization*, 49, Washington, 1990, pp. 41-47.

Loux F., Saillant F.,

- “Saigner comme un bœuf : le sang dans les recettes de médecine populaire”, *Culture*, 20 (1-2), Québec, 1991, pp. 151-163.

Pordié, L.,

- *Panser le monde, penser les médecines,* Karthala, Paris, 2005.

Saillant F.,

- “Les recettes de médecine populaire : pertinence anthropologique et clinique”, *Anthropologie et Sociétés*, vol.14, n° 1, Québec, pp. 93-114.

Tedlock B.,

- “An interpretive solution to the problem of humoral medicine in Latin America.”, *Social Science and Medicine (Oxford; Cambridge)* 24, 1987, pp. 1069-1083.

Sturzenegger O.,

- *Le Mauvais œil de la lune. Ethnomédecine créole en Amérique du Sud,* Karthala, Paris, 1999.

Van Dormael M.,

- “La médecine coloniale, ou la tradition exogène de la médecine moderne dans le tiers-monde”, *Studies in Health Services Organisation and Policy* 1, 1997, pp. 1-39.

Young J., Garro L.,

- “Variation in the choice of treatment in two Mexican communities”, *Social Science and Medicine (Oxford; New York)* 16, 1982, pp.1453-1466

Zimmermann F.,

- *Généalogie des médecines douces : de l’Inde à l’Occident,* PUF, Paris, 1995.

PATIENT/HEALTH PRACTITIONER RELATIONSHIP

Bouchon M.,

- “Les soignants en souffrance : les difficultés émotionnelles des soignants en interaction avec la douleur, la maladie et la mort, dans un service de pathologies lourdes et chroniques à l'hôpital national du Point G, Bamako (Mali)”, *Face à face, regards sur la santé*, n° 9 (en ligne), 2006.

Dujardin B.,

- *Politiques de santé et attentes des patients. Vers un nouveau dialogue*, Karthala, Paris, 2003.

Cook J., Dommergues J.-P.,

- *L'enfant malade et le monde médical : dialogue entre familles et soignants*, Syros, Paris, 1993.

Jaffré Y.,

- “Dissonances entre les représentations sociales et médicales de la malnutrition dans un service de pédiatrie au Niger”, *Sciences sociales et santé*, vol. 14, n° 1, 1996, pp. 41-71.

Jaffré Y. et Prual A.,

- “Le corps des sages-femmes, entre identités professionnelle et sociale”, *Sciences sociales et santé*, vol. 11, n° 2, 1993, pp. 63-80.

Jaffré Y. et Olivier de Sardan J.-P.

- (sous la dir. de),
– *Une médecine inhospitalière. Les difficiles relations entre soignants et soignés dans cinq capitales d'Afrique de l'Ouest*, Apad-Karthala, coll. “Hommes et sociétés”, Paris, 2003.

Mercadier C.,

- *Le Travail émotionnel des soignants à l'hôpital*, Serli Arslan, Paris, 2002.

Pouchelle M.-C.,

- *L'Hôpital corps et âme*, Serli Arslan, Paris, 2003.

METHODOLOGY

Bierschenk T. et Olivier de Sardan J.-P.,

- “ECRIS : enquête collective rapide d'identification des conflits et des groupes stratégiques”, *Bulletin de l'Apad*, n° 7, 1994, pp. 35-43.

Desclaux A.,

- “Le RAP et les méthodes anthropologiques rapides en santé publique”, *Cahiers santé*, n° 2, 1992, 300-6.

Estry-Béhar M.,

- *Guide des risques professionnels du personnel des services de soins*, Lamarre, Paris, 1991.

Goldberg M., Melchior M., Leclerc A. et Lert F.,

- “Les déterminants sociaux de la santé : apports récents de l'épidémiologie sociale et des sciences sociales de la santé”, *Sciences sociales et santé*, vol. 20, n° 4, 2002, pp. 75-128.

Jaffré Y.,

- “L'interprétation sauvage”, *Enquête. Interpréter, surinterpréter*, 1996.
En ligne, URL : <http://enquete.revues.org/document513.html>

Myers G.E. et Myers M.T.,

- *Les Bases de la communication interpersonnelle. Une approche théorique et pratique*, Mc Graw-Hill, Québec, 1984.

Peneff J.,

- *L'Hôpital en urgence : étude par observation participante*, AM Métallié, Paris, 1992.

Ruszniewski M.,

- *Le Groupe de parole à l'hôpital*, Dunod, Paris, 1999.

MEDICINES

Ankri J., Le Disert D., Henrad J.-C.,

- “Comportements individuels face aux médicaments, de l'observance thérapeutique à l'expérience de la maladie, analyse de littérature”, *Santé publique*, n° 4, 1993.

Benoist J.,

- “À propos du rapport entre dimension technique et médiation symbolique dans le médicament”, in Faure O. (dir.), *Les Thérapeutiques : savoirs et usages*, Fondation Marcel-Mérieux, Lyon, 1999, pp. 383-394.

Cunningham C.,

- “Thai 'Injection Doctors', Antibiotic Mediators”, *Social Science and Medicine* 4, 1970, pp. 1-24.

Desclaux A.,

- “L'observance en Afrique : question de culture ou 'vieux problème de santé publique' ?”, in Souteyran Y. et Morin M. (dir.), *L'Observance aux traitements du VIH/sida : mesure, déterminants, évolution*, ANRS, coll. “Sciences sociales et sida”, Paris, 2001, pp. 57-66.

Etkin L.,

- “The Negotiation of 'Side' Effects in Hausa (Northern Nigeria) Therapeutics”: 17-32, in Etkin N.L. et Tan M.L. (dir.),

- Medicines: Meanings and Contexts*. Amsterdam et Quezon City, University of Amsterdam et HAIN, 1994.

Fainzang S.,

- *Médicaments et sociétés. Le patient, le médecin et l'ordonnance*, PUF, Paris, 2001.

Faure O. (dir.),

- *Les Thérapeutiques. Savoirs et usages*, Fondation Marcel-Mérieux, Lyon, 1999.

Greenhalgh T.,

- “Drug Prescription and Self-Medication in India: an Exploratory Survey”, *Social Science and Medicine* 42, 1987, pp. 1155-1161.

Hardon A.P.,

- “The Use of Modern Pharmaceuticals in a Filipino Village: Doctor's Perception and Self-Medication”, *Social Science and Medicine* 25, 1987, pp. 277-292.

Haxaire C.,

- “'Calmer les nerfs' : automédication, observance et dépendance aux médicaments psychotropes”, *Sciences sociales et santé*, vol. 20, n° 1, 2002, pp. 63-88.

Kamat V. R. et Nichter M.,

- “Pharmacies, Self-Medication and Pharmaceutical Marketing in Bombay, India”, *Social Science and Medicine* 47, 6, 1998, pp. 779-794.

Laure P., Binsinger C.,

- *Les Médicaments détournés*, Masson, Paris, 2003.

Lévy J.-J., Pierret J. et Trottier G. (dir.),

- *Les Traitements antirétroviraux : expériences et défis*, Presses de l'Université du Québec, Québec, à paraître.

Mcvea K.L.S.P.,

- “Lay Injection practices among Migrant Farmworkers in the Age of AIDS: Evolution of a Biomedical Folk Practice”, *Social Science and Medicine* 45, 1997, pp. 91-98.

Ngokwey N.,

- “Home Remedies and Doctors Remedies in Feira (Brazil)”, *Social Science and Medicine* 40, 8, 1995, pp. 1141-1153.

Okumura J., Wakai S. et Umenai T.,

- “Drug Utilization and Self-Medication in Rural communities in Vietnam”, *Social Science and Medicine* 54, 2002, pp. 1875-1886.

Saradamma R.D., Higginbotham N.

et **Nichter M.,**

- “Social Factors Influencing the Acquisition of Antibiotics without Prescription in Kerala State, South India”, *Social Science and Medicine* 50, 2000, pp. 891-903.

Taverne B.,

- “Enjeux individuels et collectifs autour de la circulation des antirétroviraux”, *Transcriptase Sud*, n° 6, 2001, pp. 32-36.



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Ce **cadre de référence** des déterminants socioculturels de l'accès aux soins montre la richesse qu'un regard décentré peut apporter au processus d'aide humanitaire. Résolument orienté sur l'ouverture interdisciplinaire, il propose différentes entrées pour mieux comprendre la diversité socioculturelle des populations auprès desquelles Médecins du Monde intervient. Analyses, définitions, méthodes de travail : autant d'outils proposés dans ce document établi par une anthropologue de la santé, qui permettent aux acteurs de la solidarité internationale d'identifier et prendre en compte l'influence des **déterminants socioculturels** dans la manière de faire et penser le soin, d'améliorer la pertinence des projets et leur mise en œuvre pratique.

This **reference framework** for the sociocultural determinants of access to healthcare shows just how much a 'decentred' look can enrich the humanitarian aid process. Firmly oriented towards the openness of an interdisciplinary approach, it offers various routes to gaining a better understanding of the sociocultural diversity of the populations with whom Doctors of the World works. Written by a health anthropologist, this document sets out a range of tools – analyses, definitions and methods of working – designed to enable international solidarity stakeholders to identify and take account of the influence of **sociocultural determinants** when dispensing and thinking about healthcare, to increase the relevance of projects and to improve their implementation.

Este **marco de referencia** de los determinantes socioculturales del acceso a la sanidad muestra la riqueza que puede aportar una mirada "descentrada" al proceso de ayuda humanitaria. Claramente orientado hacia la apertura interdisciplinar, ofrece distintas entradas para entender mejor la diversidad sociocultural de las poblaciones en las que interviene Médicos del Mundo. Este documento, redactado por una antropóloga de la salud, ofrece distintas herramientas (análisis, definiciones y métodos de trabajo) que pueden ayudar a los agentes de la solidaridad internacional a identificar y tener en cuenta la influencia de los **determinantes socioculturales** en la manera de hacer y pensar la sanidad, así como a mejorar la pertinencia de los proyectos y de su aplicación.

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