

Inherited Hemoglobinopathies in the Sultanate of Oman.⁽¹⁾

Initial Results of Doctoral Research Conducted in Medical Anthropology.

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Translated from French by C. Welch

This publication presents the initial results of research toward a doctorate in medical anthropology on hereditary hemoglobin diseases in the Sultanate of Oman.

Increased knowledge in the field of genetics has led to new forms of treatment which in turn present certain ethical dilemmas; this constitutes an important basis to the present study. In effect, how can the practice of such innovations be overseen in a developing country whose healthcare system is relatively recent?

One of the objectives of the present study is to examine representations of heredity and filiation, as well as the state's role in regulating these practices; this is done by studying the social and medical management of two hereditary hemoglobinopathies (sickle cell disease and thalassemia). The Sultanate of Oman has been the locus of intense industrial, health, social and political development since 1970. In particular, this Muslim society, in which procreation constitutes a duty as much as a means of social existence for women, is currently putting into place procedures and protocols for diagnosing and treating certain hemoglobin diseases. Local authorities are very interested in studies of genetic pathologies because of the high percentage of consanguineous marriages, due in large part to a preference for marrying first cousins as well as to administrative obstacles associated with marrying a foreigner.

New information and techniques regarding reproduction are of considerable importance to this society because of the confronting factors of high fecundity rates and the social importance given to the number of children a woman produces on the one hand, and longstanding government attempt to slow the country's birth rate.

The methodology used here derives from standard anthropological investigative practices, combining observation with both semi- and non-directive interviews of healthcare professionals, patients, and their families, in order to apprehend the mode of transmission and understanding of genetic information in Oman.

Key words: Hemoglobinopathies, Anthropology, Genetics, Sultanate of Oman, Research Ethics

The purpose of this article is to present several aspects of on-going research on hereditary blood diseases in the Sultanate of Oman (Arabian peninsula).

Advanced medical technology is rarely studied outside of a European context. Moreover, the Gulf States are rarely studied from an anthropological perspective. Exploring this largely uncharted manifestation of modernity therefore constitutes a “double strangeness.” And yet, the study of genetic pathologies and their related technologies provides an effective basis for analyzing the results of thirty years of unbridled modernization in Omani society.

The Sultanate of Oman is an authoritative monarchy whose state leader is currently the Sultan Qaboos bin Saïd Al-Saïd, monarch to a population of approximately 2.4 million people.⁽³⁾

Since Antiquity, Oman has cultivated close relations with the Indian sub-continent and Oriental Africa, home to numerous Omani trading posts which made the state an important regional power. After the discovery of oil in the middle of the twentieth century, the father of the current

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⁽³⁾ On the authoritative nature of the Omani regime see Peterson, Wilkinson, and Valeri.

sultan dedicated a portion of the wealth from this new industry to modernizing the country. In 1970, he is overthrown by a palace revolution backed by the British and his son Qaboos takes over running the country and launches an initiative to modernize the country on a larger scale. He creates an administration and invests important sums in the sectors of health, education, commerce and communication. This triggers a massive influx of manual laborers, coming primarily from the Indian sub-continent. In addition, opening the country's borders allows for the return of those Omani declared undesirable by the previous ruler and exiled, for the most part, to Africa.

Modern Oman is a remarkable country on several of accounts: the locus since 1970 of exceptional economic and social upheaval, it is nonetheless an island of stability in its region.⁽⁴⁾ The state remains paternalistic, embodied by and centered on its monarch, despite several timid signs of democratization.

As for the biomedical sector of its health system, it is manifest in a relatively dense network of hospitals and clinics, including several healthcare centers in Muscat, the country's capital, which are technologically well-equipped.⁽⁵⁾ The private healthcare sector constitutes a small minority.

The sultanate's population (currently about 2.4 million) has increased significantly in large part due to improved medical response to epidemics which has placed life expectancy to over 73 years. In such a context, healthcare is a crucial domain, especially in its capacity for legitimizing the power of authority because of its initiatives in the public healthcare sector, a policy that lends itself well to favorable treatment by the media.

In northern countries, the field of genetics is no longer restricted to the domain of research and has a real place in healthcare systems.

In southern countries however, including those with a viable healthcare system, little attention is given to genetics. No doubt genetics is perceived as the "luxury branch of medicine" whose development is not a real priority. If Tunisia's first genetics laboratory dates back to 1980, such is not the case in many other southern countries.

In Oman, genetics has only recently begun to make incursions into the healthcare system. Although a few geneticists can be found the first laboratory dedicated to genetic screening tests opened only recently and at the moment focuses mainly on blood pathologies such as sickle cell. And this despite the fact that the government has officially promoted the study of genetic pathologies for several years. Unfortunately, efforts to raise public awareness have been limited to distributing pamphlets published by the Ministry of Health, which aim to explain the genetic

⁽⁴⁾ This upheaval is exceptional even by global standards and has led the political scientist John E. Peterson to remark that it is "surprising and admirable [to see] how the Omani have adjusted to the enormous changes of the past thirty-four years." [1]

⁽⁵⁾ The adjective "biomedical" and the noun "biomedicine" are used in the social sciences to designate the complex system and sometimes ill-named "modern medicine" or "Occidental medicine" and whose epistemological basis derives from biology and the experimental method.

transmission of diseases and to encourage consulting extended family when planning marriages in order to establish kinship and query elders on known family pathologies.

My research focuses specifically on hereditary hemoglobinopathies, in particular on sickle cell anemia and β -Thalassemia, in which a genetic mutation (due to recessive transmission) causes a malformation in the hemoglobin. In Oman these pathologies are grouped under the expression *faqr ad-dam*, poor or weak blood.

Symptoms include intense fatigue (due to anemia), high fevers (due to pain, polyuria, the reabsorption of large quantities of blood accumulated in tissues after transfusion), frequent infections (due to weakened vessels in the spleen, and secondarily to the deleucocytation and contamination of transfused products), severe bone and joint pain (vaso-occlusion and ischemia of small vessel tissues by malformed red blood cells), bone deformations (due to osteonecrosis associated with vaso-occlusion, and posture defects due joint pain), etc. Possible treatments include antibiotics, analgesics, anti-inflammatories, transfusions, etc.

In general terms, we could say that sickle cell anemia is prevalent throughout Africa while β -Thalassemia is more common in the Mediterranean basin and the Middle East. According to the Omani Minister of Health one neonate in 323 is born with a hemoglobin defect characteristic of sickle cell anemia. [4] Roughly 2000 Omani suffer from a severe form of β -Thalassemia, and 5000 from sickle cell anemia.⁽⁶⁾ Furthermore, 2% of the population carries the β -Thalassemia trait, and 6% carries that of sickle cell anemia.

One of the primary outcomes regarding these pathologies is a report which presents the results of a study of genetic blood pathologies occurring in Oman (hemoglobinopathies and enzymopathies). This study, in which roughly 6000 homes are consulted, is part of a larger health study conducted in all Gulf countries using the same questionnaire (the "Gulf Family Health Survey"). The study is officially presented as the initial action of a government initiative conducted in order to reduce the prevalence of these pathologies. Results have led its authors to attribute the particularly widespread presence of these pathologies in certain regions of Oman to a higher rate of consanguinity.

It should be noted that the preferred marriage statistically appears to be between first cousins; these constitute 35% of Omani marriages (the same as neighboring countries with a 2% margin of difference). More specifically, the Omani social ideal calls for the union of patrilinear first cousins. [5] When considering all degrees of filiation, the study shows that 55% of Omani couples are characterized by varying degrees of consanguinity. The study's authors affirm that "*the lack of potential alliances outside of the family due to tribal and cultural isolation*" is at the origin of this situation.

⁽⁶⁾ [5] – We might compare this to the presence of sickle cell anemia in France which is three times less, roughly 0.02%. Orphanet – www.orpha.net/data/patho/FR/fr-drepanocy.pdf.

Such conclusions, which underscore how closely related these pathologies are to numerous, important aspects of social life, clearly identify the need for an in-depth anthropological study.

WHAT IS THE ANTHROPOLOGY OF HEALTH?⁽⁷⁾ A METHODOLOGICAL PERSPECTIVE.

The anthropology of health (called Medical Anthropology in English-speaking countries) is a branch of anthropology that applies this discipline's methods to questions concerning health, illness, and healthcare. Anthropologists of health work in a large variety of contexts ranging from isolated villages to the administrations, operating blocks, and maternity wards of hospitals in the largest cities of France and abroad.

In the anthropology of health, primary areas of investigation include the development of informational and healthcare networks; the patient-doctor relationship; the integration of alternative therapeutic practices in diverse environments; how biological, environmental and social factors interact to influence health on an individual as well as a social scale; and, the impact of biomedicine and biomedical technologies on non-occidental societies.

An anthropological approach to health is neither medical nor biological. It is similar and different to those experimental sciences where research begins with the construction of an object of study, first isolated from its context then examined using deductive methods of analysis which may or may not confirm an initial hypothesis. In such disciplines factual observation must be validated by a theory and be reproducible. The anthropologist will distinguish between a pre-existing *subject* of research ("field") and the construction of an *object* of research to be studied in light of the milieu in which it is found. Consequently, the method used is inductive rather than deductive: lines of investigation lead to a field, which in turn leads to analysis, which itself leads to the formulation of explanatory hypotheses and the perspective from which the object of research will be examined. The periodic re-examination of one's field of research is necessary in order to evaluate the pertinence of one's preliminary hypotheses. While it is impossible to return to a field exactly as it existed at the time research began, re-examination of the same field over time or by different researchers will reveal its social dynamic.

To illustrate the anthropological approach to health let us examine the conceptual triptyque "illness, disease, sickness" which is subsumed in French to "maladie" and in English to "disease." This complex concept constitutes a paradigm that allows for analyzing disease from three perspectives: "illness" is construed as the personal subjective experience of disease, as experienced by a member of society; "sickness" refers to disease as a social construction, its social significations and the behavior expected of sick people; "disease" concerns objective physiopathological disorders such as they are defined by biomedicine. Anthropology addresses

⁽⁷⁾ Being fully aware that any support given to a research project in the social sciences on behalf of a medical society is a favorable gesture toward interdisciplinary studies, I have allowed myself to dedicate a few lines to defining my discipline, in order to clarify the conditions in which I have performed my research.

above all the components of “illness” as a socially determined behavior, and “sickness” as a sociocultural context.

In practice, to collect the field data necessary for my research I use several methods frequently combined in anthropology: participative or non-participative observation of consultations in diverse Omani establishments, semi-directive and non-directive anonymous interviews with practitioners, patients, and the patient’s family (at the place of treatment or the patient’s home) as well as the collection of data regarding the legal organization of screenings and medical treatment, provided by libraries and diverse public authorities including the Minister of Health and the medical school at the University Sultan Qaboos. This research, then, is in part descriptive and in part analytic and comparative.

The people included in my research are, on the one hand, the patients (people affected by sickle cell anemia, β -Thalassemia, or their traits) and their family. On the other hand, my research also includes the medical personnel involved in treating these patients. Because treatment is administered in various places, diverse types of professionals are involved: generalists as well as specialists, laboratory personnel, doctors and paramedics, coming from both the private and public health sectors.

The anthropological method does not use sampling since the purpose of qualitative research is not to construct a statistical model. Rather, it seeks to examine those individuals or situations most pertinent to a given set of questions. In this context, the term “sample” designates the specific set of people interviewed or observed, without any reference to the theory of sampling. Data collection, one might say, progresses in an arborescent manner, more or less as a result of the network created among interviewees who will suggest other people to interview.

The final goal of my current research is to conduct semi-directive or non-directive interviews with roughly thirty patients and at least one member of their family and three professionals in each healthcare facility they visit.

Anthropological data is characteristically heterogeneous. In the case of my current research they are composed of transcribed interviews, written accounts of ethnographical observation, official regulations, press clippings, medical files, etc. I am currently entering them in a quantitative data analysis program (Atlas.ti) which allows to account for this complexity and facilitate thematic analysis of all material.

My research began with two main questions:

- Are there specifically Omani aspects in the social representations of hereditary blood diseases?

- How are [these] social representations linked to the recent history of the Omani health system?

My goal then is to examine, on the one hand, representations of such things as causes, symptoms, blood, parenthood, and the effects of a given diagnostic from the patients' perspective, and on the other hand, to examine potentially different representations as perceived by healthcare professionals, and then to compare these results with publications that address other societies.

PRELIMINARY RESULTS: ASILA'S STORY

The example of a young Omani woman suffering from sickle cell anemia illustrates nicely the major avenues I explore in the current state of my research.

Asila is a young woman of roughly 20 years, the eldest of six children, three of whom suffer to various degrees from sickle cell anemia. Both of her parents are "African Omani", also called Zanzibaris, who returned to their ancestors' country from Tanzania when the current sultan took the throne in the 1970's.⁽⁸⁾ Asila speaks Swahili with her family and Arabic in public and with her husband. She has known for years that she is ill, and was treated until the age of six primarily with *wasm*, a traditional method of cauterization using a circular iron, of which she still shows scars. At the age of seven she suffered from a major occurrence which led to her to be hospitalized and diagnosed with sickle cell anemia. Since then, she has returned to the hospital for follow-up exams roughly every three months.

In 2005 Asila married a young Omani from a very religious family from inland Oman; she and her family hid the matter of her illness from her husband. It was only during her first pregnancy that Asila's illness was revealed to her husband.

She gave birth to her first child in early May of 2006 after having had seven transfusions throughout the course of her pregnancy; all transfusions were done in the country's only university hospital. Because of her pregnancy Asila began taking medication regularly for the first time in three years; the reason being that she was once again experiencing pain within her bones. Asila, however, considered herself fortunate to have had so few major symptoms considering the number of complications her doctors and family predicted she would endure. She claims to have spent her entire pregnancy in fear that her child be afflicted with the same pathology as her: "*You understand, my father, myself, my sister, my brother... and so perhaps my child as well.*"⁽⁹⁾

⁽⁸⁾ See explanation of this term below, p.8.

⁽⁹⁾ Interview, Muscat - Al-Mawaleh, June 1, 2006.

When it came time to deliver her child, Asila refused to return to the university hospital where she was scheduled to have a cesarean section; instead, she went to another prominent public hospital and concealed her illness from the emergency medical staff in order to avoid giving birth by cesarean section. Asila claims that from that point it was difficult for her to speak of her condition, and that only the dramatic decrease in her hematocrit levels and extreme fatigue alerted the maternity staff to her condition. She was released from the hospital three days later, after having been made to promise that she would return to consult with her usual doctor. Asila, however, sought her mother's care instead, claiming that her hibiscus infusions and legume purées are the best treatment possible for her.

Asila's son, still an infant, has undergone screening and been found healthy, but she knows that any children she may have in the future will be subject to the same risks. This awareness leads her to comment on the large variety of sickle cell anemia symptoms that differ from one afflicted individual to another, citing in particular the differences between herself and her brother, who is severely handicapped in daily life by extreme bouts of pain.

Asila's example raises a number of important issues concerning hereditary blood diseases found in the Omani Sultanate. I address a few of them here in order to show the various micro-sociological and sociopolitical dimensions of this subject.

The Therapeutic Itinerary

Asila's therapeutic itinerary is emblematic of the recently created Omani healthcare system: recourse to traditional medicine is present but rare, as it has been surpassed by modern medical praxis present in Oman since 1970. And yet, as with many of the patients I encountered in Oman, Asila makes important use of her own powers of decision by refusing to submit to the university hospital's planned course of action. By doing so she exposed her own and her child's life to the risks of severe anemia and obstetric complications.

With future research I will attempt to elucidate the determining factors of this common attitude by investigating it from two angles: first of all, the patient's defiance toward the healthcare system. This, according to the people I met, stems from what Carolyn M. Rouse would refer to as a case of "flawed access." In effect, although the WHO has ranked the Omani healthcare system among the best in terms of access to healthcare, this ranking is based solely on the "possibility that a patient be examined by a healthcare professional," and does not address the "*quality of the patient/practitioner collaboration.*"[6]⁽¹⁰⁾ According to Omani patients, the latter frequently leaves much to be desired.

⁽¹⁰⁾ Ranked 8th in 2000.

A second, equally important angle, is that of the patient's submission to his or her destiny; in Arabic this is referred to as *maktoub*. In effect, the prenatal diagnostic that could have been made for Asila's son might have "come across as a kind of victory over destiny," and therefore gone against divine will. This kind of behavior is a common source of grievance for the practitioners I have met and their main obstacle is often times eliciting their patient's cooperation.

Furthermore, pain management is another important factor. This is largely due to the dependency of certain drepanocytic patients on opiates because of their frequent need for morphine injections. Asila herself is rarely subject to pain, but for many of those who suffer from this disease "*the intensity of pain associated with an acute attack of sickle cell anemia is comparable to that of terminal bone cancer.*" Thus the risk of addiction, which along with the heavy financial burden of hemoglobinopathy treatment exacerbates the patient's sense of being stigmatized (over one third of the university hospital's emergency budget goes to treating hemoglobinopathies, a large part of which goes to transfusions). [6]

While completing fieldwork it became clear to me that secrecy plays a crucial role in the way Omanis who are afflicted with hemoglobinopathies manage their public lives. Any signs of sickle cell anemia and β -thassalemia can be virtually hidden from public view. Even when accompanied by few visible symptoms these diseases are considered to be disabilities and are in most cases hidden by the diseased and their families. The diseased themselves often live reclusive lives, especially if they experience frequent, violent attacks of pain.

DISCUSSION AND LIMITS

The "Ethnicization" of Pathologies?

The existence of an "African" group of Omani, which includes Asila, requires explaining. In effect, the structure of Omani society is complex. A few words borrowed from Marc Valeri will allow us to see things more clearly: "*When identified using the common generic terms of 'Swahilis' (in reference to their vernacular) or 'Zanzibaris' [...] African Omanis constitute a particularly heteroclite group which cannot be defined in terms of neither genealogical nor spatial criteria. In effect, families, even individuals, coming from the same clan may or may not be considered as "Swahili" depending on whether or not they are linked to Africa, and even this link itself is rather subjective. [...] speaking fluent English, and having been trained in European and Central or Oriental African schools, or schools located in other Gulf countries, African Omanis represent a precious source of labor for furthering modernization [...] It is important to note that whether or not one feels or is perceived to be "Swahili" is not associated with having African*

features [...] The total number of African Omanis has reached 100,000, of which 10,000 or so are Francophone [...]. [8]

The close relationship between hemoglobinopathies and an individual's origins was identified by Lainé et al. and dates back to colonial medicine and the practice of "ethnicizing" or associating these pathologies with certain ethnicities. In Oman as in numerous other countries efforts are being made to map hemoglobin mutations. Daar et al. point out the presence in Oman of mutations originally described in India, and attribute this to significant migration from Baluchistan. [10] Rajab and Patton, as well as Rajab et al. address Oman's relationship with Zanzibar, Africa and Asia Minor, as well as the "Bantu and Benin" haplotypes found in the Omani population.

To date, my investigations have led me to observe that the Omani commonly associate β -thalassemia with the Baluch, who come from across the Gulf of Oman.⁽¹¹⁾

The scientific examination of these kinds of historical relationships which leave so few social traces must rely on the social categories established by the diseased and any consequences to which they give rise. For example, in the United States, sickle cell anemia is commonly associated with ancestors who were brought to the country as slaves; this association in turn is evoked in legal proceedings where damages are sought for the prejudice endured by one's enslaved ancestors.

Stakes at Play in the Screening Process

Because of the stigma associated with these diseases, the Omani ministry of health is likely to encounter a degree of resistance when they begin offering genetic screening in the near future. This much is evinced by Asila's reluctance to speak of her disease with her husband's family, and subsequently, by her decision not to seek genetic screening for her husband even though she was aware of the risk of passing the disease on to her children. Asila would not have had this choice in neighboring United Arab Emirates where screening has become a mandatory part of prenuptial arrangements since the spring of 2006. In order for this to be possible in Oman it is crucial that the social construction of these pathologies be analyzed first. The question of prenuptial genetic screening has become the object of public discussion for two reasons. First of all, because students are being targeted by university initiatives to raise awareness and make testing readily available. Moreover, required genetic screening in the Emirates has generated discussion on several Internet forums, such as Al-Sabla where members debated the importance genetic screening may have on their children's future, as well as ways of communicating results or pressuring reluctant families to consent to screening (one suggestion entailed differing the

⁽¹¹⁾ For more information on the Baluch in Oman, see [8].

official conclusion of a marriage by not presenting the dowry until screening was completed). [12, 13]

The possibility of required genetic screening leads, in turn, to other avenues of reflection. For example, what would be the consequences of wide-spread screening for diverse pathologies and how would this be regulated in a country where the organized representation of the diseased is not yet fully authorized and where patients' access to legal recourse is limited?

In this regard it is important to recall the discrimination that resulted from efforts to screen the African American population for sickle cell anemia in the 1970's. Furthermore, in a country like Oman where adoption is barely tolerated it is all the more important to consider the social repercussions of genetic screening when performed after conception.

Moreover, if "*the objectives of a pre-natal diagnosis [...] are to give women and couples at risk of producing an abnormal child the choice of different courses of action, and to reassure them and reduce any anxiety associated with the uncertainties of reproduction, as well as to encourage people at risk to reproduce and to guarantee the best treatment possible for fetuses diagnosed with disease,*" we have to ask what the consequences will be in a country where health-based abortions are forbidden and where there exists only one school for handicapped children and which is limited to 300 places. [7, 14]

Finally, it is worth asking what the social consequences of genetic testing might be. For example, how would people respond to a negative paternity test?⁽¹²⁾ Or, how would members of a small village community react to the positive diagnosis of a genetic pathology in one of the local families? In light of Asila's story it is also important to consider the possible influence of genetic screening on whether or not extended family members continue to marry.

Public Healthcare and Consanguinity

Unfortunately, Oman is no exception to the trend that public healthcare policies may generally exacerbate pre-existing social inequalities. A woman's access to advanced genetic screening techniques (pre-implantation diagnosis, for example) or even to the possibility of having an abortion for medical reasons, partly depends on whether or not she is financially able to travel to another country, as well as on how independently she can act. In addition, fieldwork has shown that there is no effective procedure for administering systematic pre-natal genetic counseling and as a result a majority of families are overlooked, including those in which 3, 5, or 7 children are already afflicted with some form of genetic disease.

⁽¹²⁾ See [15]. It may be interesting to see if there exists in Oman a notion similar to the Moroccan "sleeping child" or "bou mergoud." This refers to a child conceived by his mother's husband, but who is born much later than 9 months after his departure, or death. The child is considered to have fallen asleep in his mother's uterus, thereby disrupting gestation. This notion protects the mother from any unpleasant social consequences. See [16].

Related to this is the fact that consanguinity appears to be of real concern to Omani society (as indicated above, 35% of Omani marriages are between first cousins). Discussants on the Omani internet forum Al-Sabla address this sensitive issue above all from an esthetic point of view. [17] A primary concern is that if people refuse to “mix blood” this will lead to the birth of unsightly (“disgracieux”) Omani children. The matter of health is of secondary importance in their discussions.

Marrying within one’s family is common practice throughout the Arabic peninsula. In fact, because of its economic advantages—namely, that it prevents family wealth and resources from being dispersed—it is the preferred form of union. As Paul Dresch has observed “*it is said of a family in which the daughters have married their own kin that ‘their bread is in their own basket’.*” [18]

On the other hand, doctors and statisticians strongly disapprove of endogamy and link it to the prevalence of patients afflicted with hereditary hemoglobinopathies. Despite this, the marriage of an Omani citizen with a foreigner must still be authorized by the government. However, a recent change should be noted: Omanis are now permitted to marry citizens of other countries belonging to the Gulf Cooperation Council (GCC), Koweit, United Arab Emirates, Bahrein, Qatar, and Saudi Arabia.

Investigative Bias and Methods

When performing qualitative research bias is a problematic concept because, by definition, the researcher is an integral part of the investigative process. This “human factor” is often presented as both the primary strength and weakness of qualitative methods of research. In anthropology the goal is to minimize inevitable sources of bias by, for example, diversifying the places where and social environments in which observation is conducted for any given project. All unavoidable biases are of course always accounted for in a final report that relates how all used data was gathered.

The biases I encountered while conducting my doctoral research are very similar to those one generally finds in anthropology: the need to spend a long period of time in the field (10 months to date), to master the language of the people you will be observing (I hold interviews in English and Arabic) and finally, the need to increase and diversify places of observation.

Another source of bias which leads to a loss of time while researching in the field is the fact that the administrations with whom I collaborate are unfamiliar with anthropology and anthropological methods. I must therefore explain very clearly my research methods and deontological prerequisites, especially when working with the healthcare system.

In fact, French anthropologists are currently considering the possibility of elaborating a formal code of ethics for their discipline, as is the practice in some other countries. Since there is as yet no ethic specific to French anthropology I refer for the time being I refer to the code of the American Anthropological Association.⁽¹³⁾

Another key point concerns the use of written consent forms. These forms are required by local healthcare authorities when conducting routine clinic tests, however, they have little bearing in the context of a non-interventional anthropological study that deals primarily with illiterate people. These people are, in any case, free to refuse to be interviewed, or to respond to certain questions, and above all, to contact me if they wish to modify or consult their responses. In countries such as Oman the rights of the diseased are not respected as they are in certain northern countries. For example, there exist very few interest groups for the diseased and it is rare that they bring healthcare professionals to court. It is therefore crucial to protect the people one interviews. Sometimes this responsibility leads one to avoid certain interviews, or to use the results they generate selectively.

CONCLUSIONS AND FURTHER PERSPECTIVES

I am conducting this research despite a paucity of bibliographic resources on both Oman and non-infectious diseases in the South. The socio-political context of my research is complex, composed of several inter-related layers of meaning. My research is guided by the idea that an in-depth study of the perception, treatment, experience, and management of these pathologies in Oman would shed light on several things: the place of science (especially in the northern countries), the balance of religious and political powers, the impact of the new medical culture advocated by the government, and more generally, the major social divisions.

In effect, the distinction between “poor” and “rich” blood—which has yet to be thoroughly explored—adds an additional criteria to the already complex process of choosing the people with whom one interacts socially, one’s spouse, or even the people with whom one’s children interact.

Furthermore, from a strictly anthropological point of view, my research is of real interest to the study of cultural interpretations of technical innovations as well as to the exploration of current ethical questions regarding the relationships between healthcare professionals and women dealing with reproductive concerns, and to a “political anthropology of reproduction.”

⁽¹³⁾ Available on the website : <http://www.aaanet.org/committees/ethics/ethicscode.pdf>

REFERENCES

1. Peterson, J.E., *The Emergence of post-traditional Oman - Sir William Luce Fellowship Paper n°5*. Durham Middle East Papers, 2004.
2. Chaabouni, H. (2003) *La génétique dans les pays émergents : l'urgence de créer des réseaux*. L'Observatoire de la Génétique, Publication électronique : www.ircm.qc.ca/bioethique/obsgenetique
3. Omani Ministry of Health, *Knowing about genetic health. My mother and myself wish to know some hereditary secrets. [at-t'araf 'ala as-saha al-warâthiya]*, Health Education Department, n.d.
4. Rajab, A.G., M.A. Patton, and B. Modell, *Study of hemoglobinopathies in Oman through a national register*. *Saudi Med J*, 2000. 21(12): p. 1168-72.
5. Al-Riyami, A., *National Genetic Blood Disorders Survey*. 2000, Ministry of Health: Muscat.
6. Rouse, C.M., "Paradigms and politics: Shaping health care access for sickle cell patients through the discursive regimes of biomedicine". *Culture, medicine and psychiatry* 2004. 28(3): p. 369-
7. Renaud, M., et al., *Diagnostic prénatal et choix de société : le non-dit du développement technologique*. Santé Publique, 1991. 3-4: p. 37-48.
8. Valeri, M., *L'Etat Qabous - Identité nationale et légitimité politique au Sultanat d'Oman (1970-2005)*, PhD thesis, Political Science. 2005, Institut d'Etudes Politiques: Paris.
9. Lainé, A., et al., *La Drépanocytose : Regards croisés sur une maladie orpheline*. Homme et Société : Sciences économiques et politiques. 2004, Paris: Karthala.
10. Daar, S., et al., "Spectrum of beta-thalassemia mutations in Oman." *Annals of the New York Academy of Science*, 1998. 850: p. 404-406.
11. Rajab, A. and M.A. Patton, "Major factors determining the frequencies of hemoglobinopathies in Oman". *Am J Med Genet*, 1997. 71(2): p. 240-2.
12. www.englishsabra.com. *Understand Your Lab Results!*. 2005-2006 [consulté le 8 janvier 2007]; <http://www.englishsabra.com/forum/showthread.php?t=33495&highlight=blood+disorders>
13. www.englishsabra.com. *Sickle Cell vs. Thalassemia Carriers*. 2006 [consulté le 8 janvier 2007]; <http://www.englishsabra.com/forum/showthread.php?s=d2a1332661c0ea14d323d60e3d13c153&t=38958&highlight=sickle>
14. Beaudevin, C., *"Everything is kullû zayn !" L'échographie obstétricale au Sultanat d'Oman : pratiques, usages, représentations*. 2004, Master's Degree Thesis in Biocultural Anthropology [non published], Université de Droit, d'Economie et des Sciences d'Aix Marseille 3: Aix-en-Provence.
15. Mégarbané, A. (2002) *"Le serment d'Hippocrate et la fausse paternité"*. L'Observatoire de la Génétique. Publication électronique : www.ircm.qc.ca/bioethique/obsgenetique
16. Colin, J., *L'Enfant endormi dans le ventre de sa mère. Etude ethnologique et juridique d'une croyance au Maghreb*. 1998, Perpignan: Presses Universitaires de Perpignan.
17. www.englishsabra.com. *Should or Shouldn't pre-marriage blood tests be compulsory in Oman?* 2004 [consulté le 8 janvier 2007]; <http://www.englishsabra.com/forum/showthread.php?s=d2a1332661c0ea14d323d60e3d13c153&t=27092&highlight=sickle>
18. Dresch, P., *Debates on marriage and nationality in the United Arab Emirates*, in *Monarchies and nations. Globalisation and identity in the Arab states of the Gulf*, P. Dresch and J. Piscatori, Editors. 2005, I.B. Tauris: Londres. p. 136-157.

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