# PUTTING GENETICS TO USE

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#### Abstract

On the basis of empirical research using a screening programme for a genetic disorder (Cystic Fibrosis) in a Cypriot village as a case-in-point, the paper evaluates the influence of genetic information for concepts of heredity and kinship practices. Far from being simple receivers of biomedical knowledge, participants of the screening programme blended traditional, analogous concepts of blood relations between kin with scientific, digital concepts of 'passing-on genetic information' from generation to generation, creating a new mode of hereditary thinking, bodily concepts, and practices of relating oneself with others. On the backdrop of the unique experiences with the established screening programme for Thalassaemia on the island, most participants felt a pervasive moral obligation for al/- encompassing "genetic transparency". While this might constitute a bioethicist's nightmare, it is argued that Cypriot modernity produced a unique "genetic citizenship" which might afford critical resources for coping with the prospects of an ongoing geneticisation.

## Inquiring into the Interface between Scientific Knowledge and Vernacular Culture

Instead of dismantling holistic systems through inappropriate analytical categories, then, perhaps we should strive for a holistic apprehension of the manner in which subjects dismantle their own constructs.

(Strathern, 1992, p. 90)

In October 1996, the Cypriot press reported the discovery of a deadly disease in a village near the capital Nicosia. The gist of these messages that were placed prominently on the radio and television news as well as in several Greek Cypriot newspapers was more or less identical: They celebrated the scientific achievement of the Cyprus Institute of Neurology and Genetics whose research effort of some years in cooperation with local physicians had yielded an explanation for a number of mysterious deaths in this village. Large parts of the population - according to the reports - were affected by a genetic disease that so far had not been known to exist in Cyprus. In order to assess the threat that Cystic Fibrosis - the name of the disease - was posing to the population, geneticists in accordance with the Ministry of Health had decided to collect and to analyse saliva probes of all 170 school

children in the community. On the basis of this representative sample the experts were able to determine the frequency of 'carriers' in the village population, healthy persons that carry one copy of the gene. In those cases where both the father and mother are carriers, the chances that their children will develop the disease are 25%. These research findings, establishing the frequency of the gene in the village population, provided the impetus for the Health Ministry to offer genetic tests to all villagers to establish their individual carrier status; the aforementioned press reports were based on a press release informing the public about the findings and announcing the option for tests.

## Line of Inquiry

The press reports mark the beginning of a sustained argument involving a number of parties – human geneticists, medical doctors, health policy makers, and lay persons – in the course of which the validity of scientific findings, the power of human geneticists' practices, the assessment of social and cultural effects of genetic procedures and aggregate knowledges as well as the collective identity of the villagers were contested. In the following, I am going to highlight some aspects of this conflict that point to a more general constellation of problems.<sup>1</sup>

The study serves as a case-in-point to show how in Cyprus, as in other societies, social actors are appropriating universal scientific knowledge and are integrating it creatively with local knowledges to apply in social situations that are no longer static and predictable but have become fluid and highly uncertain. The case under discussion is a good example of a development that has been diagnosed by sociological risk theory: Genetic knowledge transforms the danger of being threatened by a mysterious illness into a calculable and controllable risk (Luhmann, 1997) that demands affected persons to respond actively, namely by using the option of genetic testing, an option that, once it is known and available, presents itself as a moral obligation. German sociologist Elisabeth Beck-Gernsheim has pointed out that in the process of modernisation, health has been constructed as a project to be realised by the responsible individual (Beck-Gernsheim, 1994). Inquiring into the situation in the USA, Carole H. Browner and Nancy Ann Press (1995) argue that human dispositions and behaviours are more and more perceived through a "prism of heredity" which - in addition to the tendency that every pregnancy be seen as an extraordinary risk - would heighten the readiness to rely on genetic testing on a routine basis.

I propose to use the Cypriot case as a focus to inquire cross-culturally into this construction of health as a project of individual actors. This question will hopefully cast light on the following problematic: Does the accelerated popularisation of scientific knowledges – the "prism of heredity" – alter the culturally specific perceptions of body, disease, family and collective identity? How are older, culturally

highly familiar concepts of affliction that are known "to run in the family" blended with genetic concepts of (Mendelian) heredity? Or more pointedly: How does nature enter into culture when it comes to the popularisation of genetic knowledge?

#### Two Kinds of Constructivism

Some clarifications seem necessary beforehand. In most of the social sciences, a constructivist perspective has become prevalent in recent years. This perspective emphasises that there is no perception of reality that is not socially biased and culturally shaped. In keeping with the sociology of knowledge of Peter L. Berger and Thomas Luckmann, "reality" then is consistently put in quotation marks and conceived of as a product of social practice. However, while Berger and Luckmann in their 1960s studies addressed the domain of quotidian knowledge that is jointly and consensually produced by human beings in their everyday face-to-face interactions, by the 1990s, this approach began to be applied to scientific knowledge as well: In Anglo-American Cultural Studies or in Science and Technology Studies in particular, the objectivity claim of the natural sciences was challenged by employing methods from textual analyses against the backdrop of what one might call a universalist constructivism?

This attack on scientific authority constitutes the core issue of a debate between natural sciences and the humanities that erupted in the United States in the 1990s. Labelled "the science wars", it has to some extent been characterised by mutual misunderstandings of terminology. Positioning themselves on a battleground between conflicting claims of objectivity and relativity, a number of excellent anthropological studies of the practices of laboratory scientists have been brought forth on the basis of extraordinary ethnographic work that discloses how certain social practices are able to produce facts while others are not.<sup>3</sup> Scientific practices in the laboratory setting – according to the findings of these studies – are predicated on something one might call a "realistic constructivism", a pragmatic sense of reality that takes into account that it can always be proven wrong by new and conflicting experimental evidence.

In the face of these contrasting constructivisms that are based on different assumptions and use different methods, there is a need for a conceptual distinction between what can and what cannot be subject to construction processes, a distinction that also allows for closer scrutiny of the "how" of construction processes (Hacking, 1998). The disease Cystic Fibrosis that I introduced in the beginning can serve as an example of how such a distinction works. Individuals who have this disease will die from a highly complex set of problems, often during their childhood, no matter whether they themselves or other people know or do not know what this disease is. As a bodily syndrome consisting of chronic infections of the respiratory system, an insufficient intake of vitamins and nutrients by the digestive system,

chronic inflammation of the spleen, and a heightened salt content of the sweat, this disease as well as the genetic codes that cause it, are independent of the ways they are conceptualised scientifically or socially. At the same time, however, the disease of Cystic Fibrosis is a social and cultural phenomenon that can be responded to in a multitude of possible ways always contingent on available knowledge and available options of action to take – and that indeed requires that people respond to it. Within this social dimension, illness is dependent on extensive knowledges, procedures, and experiences, and therefore is always historically situated.

For instance, in the handbook of German folk beliefs and superstitions,<sup>4</sup> similar to collections by folklorists in other countries, there are several entries regarding the occurrence of a newborn's sweat tasting of salt – a high salt content in the perspiration is one of the symptoms of Cystic Fibrosis. To ward off bad spells, thought to be the cause of this condition, traditional proverbial wisdom in several north-western European regions recommends the following: The mother should lick the perspiration off the brow of the child three times and spit out behind her back. Contemporary medical manuals, however, demand somewhat more complex management techniques to cope with the illness: A permanent treatment using antibiotics, a continuous medication of digestive enzymes, three hours of physiotherapy per day and finally lung transplantations might prolong the life expectancy of Cystic Fibrosis sufferers well into their thirties or early forties.

In this case, modern biomedicine brings two types of construction to bear: On the one hand, the "objectifying" practices of the scientific laboratory and the clinic, on the other hand, the socialising and culturalising practices of the medical system. Both are constructions, in both cases taking construction to mean literally a complex system in which knowledges, procedures, options for action, social practices etc., are interdependent. However, in the first case, the facts of natural science are being produced, while in the second case, it is social relations and moral obligations which are being produced. Both kinds of construction operate by classification. Yet the subjects/objects of classification are of a different kind: In the laboratory, a segment of a genetic code is identified as the cause for the complex syndrome of a medical disorder; in the medical system, people with a disorder are diagnosed as suffering from Cystic Fibrosis, a diagnosis that requires a specific treatment that in turn requires a high degree of compliance from the person thus diagnosed and at the same time positions him or her socially: as a patient.

In this context, a suggestion of the Canadian philosopher of science, Ian Hacking, is helpful. He proposes to distinguish constructions on the basis of the classifications they rely on. This allows him to distinguish interactive classifications from those of a non-interactive kind. The classifications of the sciences – for instance, sub-atomic particles in physics – are non-interactive, because what is

classified is not capable of modifying its behaviour or traits as a consequence of the classification. Classifications in the social domain, however, Hacking terms "interactive" precisely because those classified can change their behaviour in accordance (Hacking, 1999). When you apply this distinction to the phenomena associated with the human body, it becomes obvious that one has to expect a combination of non-interactive and interactive classifications. This is what makes scientific discourse on bodily practices so interesting and so fraught with difficulties. Against the backdrop of this distinction, we can also surmise that to talk generally of the "social construction of the body" has limited value if one does not at the same time distinguish between the different domains of construction, namely classifications of interactive and non-interactive kinds.

This distinction, itself belonging to the field of abstract logic, does have a distinct advantage in making clear what social and cultural practices serve to achieve, namely, to evolve strategies of socially coping with a medical disorder on the basis of such a classification, and, also sometimes, to manipulate such classifications. Referring back to the village introduced in the beginning, and to an actual event there, I would like to describe the least complicated of these strategies – to keep silent on and not disclose the nature of an illness, – that is, the manipulation of an interactive classification by partial denial, and attempt to show the serious implications that such a simple manipulation may have.

## Manipulating Constructions

The press reports quoted initially remarked that the mystery of a series of inexplicable deaths in the village had been solved by the scientists. The confusion and concern that these reports instilled in the village in part reflected the fact that there was no public knowledge of any deaths of mysterious causes in the village. Only collective investigations brought to light the fact that geneticists had referred to the deaths of two children within the same family, deaths that had occurred a number of years ago. The parents had successfully kept the information from the local community that both children suffered from Cystic Fibrosis.<sup>5</sup> Also, they kept the chronic and fatal nature of the disease secret from the children themselves who thus did not know that they were terminally ill. With this policy of secrecy towards both their children and the village the parents attempted to let their children have a childhood as undisturbed and as 'normal' as possible, and - by the same token save their siblings and the entire family from being stigmatised. In order to do so, however, they chose to deviate from some of the physicians' suggestions whereby the 'normality' of their children's lives might have been interfered with. To that extent, the active and full compliance with the management of the disease, suggested by the physicians, was refused by the parents: The medical construction of an ideal patient was contested by the parents who - to put this in a pointed manner - posed their morality of granting a light hearted childhood to the little

patients and of keeping the family life intact against the medical morality of prolonging the life of an individual patient. Indeed, the parents had to confront an insolvable dilemma since even perfect compliance to the medical regimen would not have saved the children from certain death, only postponed it.

As pointed out earlier, recent sociological discussions of risk imply that biomedical knowledge is operational in transforming those dangers that were once considered fate into risks that the individual is required to respond to by taking action as soon as such an option is known to him or her. However, as the above example shows, there is no simple one-to-one relation between knowledge and agency. Social actors interpret new knowledges – including scientific knowledges, social diseases – against the backdrop of already existing quotidian knowledges, social practices and narratives of a good life.<sup>6</sup> This observation also cautions us against the supposed homogenisation of different cultures that is thought to be effected by the global availability and application of scientific knowledge.

Disciplines such as Social and Cultural Anthropology, Folklore, and European Ethnology that engage in "thick descriptions" can reconstruct the cultural logic of quotidian practices that is not co-terminus with the logic of official discourse. In what follows, it is not the semantics of official biomedical representations and procedures that is being deconstructed, nor do I aim at analysing how media images are employed to transmit notions of nature, the body, and health that are intended to popularise biomedical knowledge or the findings of Human Genetics. Instead of engaging in deconstruction along those lines, I am more interested in addressing the strategies of everyday life in order to find out about how people actually make use of both the official semantics and of vernacular notions, thereby reconstructing both in order to pursue their own goals. In order to be able to consider both the complexity of these de- and reconstructions and their effects, of necessity the scope of observation has to be rather broad.

#### Kinship as Biologically Hardened Social Fact

For a number of reasons, here I will focus on kinship, partly because notions of kinship act as mediating agents for a number of diverse domains of social behaviour and agency - marriage, children, inheritance, family solidarity. In addition, kinship as a "social fact" (E. Durkheim) represents social relations between generations, between the sexes, and between individuals by establishing a classifying matrix of great precision: Not only does it designate unequivocally who is the uncle and who is the nephew, but also which privileges and obligations arise from such positions within the kinship network.

Within the framework of European cultures, these social facts are often legitimated by referring to "natural facts" that supposedly make them stable and

durable. Cross-cultural studies in the anthropology of kinship point to the fact that European notions of kinship are quite "exotic" because they use biological knowledge of reproduction and heredity as a basis, a relationship that is conventionally summed up in the metaphor of "shared blood": Kinship relations are supposed to be social relations of a special kind, because blood is considered to be "thicker than water",<sup>7</sup> a liquid that 'draws people together'. It is truly fascinating how this self-evidence of kinship relations is achieved by short-circuiting the completely separated domains of nature and culture. What is even more relevant is what the possible effects of such a switching of the grand notions of Nature and Culture might be.

In European cultures, kinship appears to be a "hybrid concept" (Strathern, 1992, p. 16) that joins social, i.e., interactive classifications with biological, i.e., noninteractive classifications. Both elements contribute to a formation of kinship as an instrument well suited to defining persons not only as individuals but as positioned in a network of relations (Strathern, 1993, p. 154). By the same token, this kinship concept divests these relations of their socially constructed and therefore always contingent character.a As kinship relations are being denied their basis in the social, kinship is privileged as a seemingly pre-social and therefore particularly stable mode of integration in modern societies (Pina-Cabral, 1992). This essentialising move has proved so successful that its operation has been expanded beyond the family to bigger social units. In complex societies, a "politics of blood" – as Birgitta Hauser-Schaublin has called this transfer of the blood metaphor (Hauser-Schaublin, 1995) – serves as one of the "intermediary" mechanisms that define, institutionalise and legitimate social and national boundaries.<sup>9</sup>

Kinship as a concept certainly will keep on promising this kind of stability in the face of the challenge that Genetics is posing. However, some important changes are to be anticipated, as kinship in its European formation – because of its recourse to biology – is very susceptible to changes that occur in the biological knowledge base. Scientific advances in genetics might conceivably lead to a situation where no longer "shared blood", but "shared genes" are being emphasised.<sup>10</sup> And this metaphorical switch indeed can cause decisive shifts in how proximity and distance in kinship networks are being calculated. I will illustrate this with some observations on how, in the village introduced above, genetic knowledge acts on kinship relations, for instance, in the context of arranging marriages, or concerning decisions on whether to have oneself tested for carrier status of CF (Cystic Fibrosis) or not.

## **Kinship In Action**

The transformations affected by this new knowledges, however, have to be contextualised with other, competing processes of modernisation that during the

past thirty years have caused massive changes in conventional practices, normative orientations, and everyday life worlds in Cyprus. The specific effects of genetic knowledges on Cypriot notions and practices of kinship and on Cypriot vernacular culture generally will be approached in two steps, first, some words on traditional marriage strategies and concepts of blood relations, as well as on notions of heredity and the marriage restrictions that result from them. Secondly, I will use some of my fieldwork findings to show how biomedical knowledges impact on actual marriage strategies as well as on concepts of health.

These fieldwork findings are part of a cross-cultural comparative study in Cyprus and Germany on production of scientific facts in Human Genetics laboratory settings, those facts being communicated in genetic counselling and the media and being read by and made sense of by lay persons. In this paper, however, the comparative dimension of the study remains implicit; it is based exclusively on findings from two periods of fieldwork in Cyprus in 1998 and several follow-up studies since then. In addition to observations in laboratories and in medical facilities I conducted interviews with physicians, officials in the health care sector, and, in particular, with residents of the village.

These interviews were conducted against the backdrop of the genetic screening of school children having resulted in the detection of an unexpectedly high incidence of carriers of the gene for CF.<sup>11</sup> As a consequence, the health authorities in cooperation with the Cyprus Institute of Neurology and Genetics (CING) proceeded to initiate a "prevention programme", to some extent modelled upon the successful screening for Thalassaemia in Cyprus.<sup>12</sup> All community residents between the ages of eighteen and forty-five, the segment of the village population belonging to the "reproductive" age-group as defined by the experts, were asked to participate in a second genetic screening in order to allow them to make decisions concerning their "reproductive behaviour" on the basis of the results. My interviews with community residents were scheduled about two months after the results of these tests were made available to the testees. The interviews included persons belonging to three groups, with fifteen interviews per group: people who had participated in the test and had been told of their non-carrier status; people who had been diagnosed as carriers of the CF gene by the testing; and people who for various reasons had not participated in the testing. The interviewees were between the ages of eighteen and forty-five, men and women were represented in equal numbers.13

The village with its four-thousand residents, all of them of Greek orthodox faith, is a community larger than many others in Cyprus. Because of its geographically advantageous setting in the central plain, and especially because it always had plenty of water supplies, the village emerged as an economically prosperous community already in the nineteenth century which kept out-migration at a minimum for a long time. Nearly all marriages are between people born in the village;<sup>14</sup> young couples prefer to settle in the village. This marriage strategy of staying within the village was accompanied until recently by negative sanctions against those who violate this principle of endogamy: If a young man married a girl from elsewhere, he and his family were likely to hear diatribes intended to hurt their prestige: Namely, that he was not good enough for a marriage candidate in the village itself.<sup>15</sup> What villagers themselves interpret primarily as an expression of localist pride, is a social strategy partly anchored in the agrarian economy and predicated on a complex interplay of social and symbolic factors.

Marrying within the village ensured that the land that the groom receives upon marriage,1s and the dowry house constructed on another piece of land by the bride's family, together would provide a subsistence basis in the village sufficient for the future family. Middle aged interviewees emphasised that until not long ago, marriages exclusively were arranged by the parents, often without the knowledge and consent of the young people concerned. Since the early seventies, first young men, then the girls as well were able to veto the decision of the parents.<sup>17</sup> The economic, social, and moral status of the respective families were the most important criteria for successfully arranging a marriage, with one criterion potentially taking the place of others in order to make upward mobility possible: lack of wealth could - given the right circumstances - be made up for by social and moral prestige. In order to arrange a marriage, both families would need to scrutinise the others' economic and social standing very closely, which entailed confidential and secretive negotiations to be pursued. After all, a rejected marriage candidate could mean loss of face for the entire famil y.<sup>18</sup>In the agrarian society of Cyprus where conspicuous consumption until recently was largely impossible, the marriage market served as the primary arena for social distinction<sup>19</sup>.

The incidence of medical disorders in a given family was a factor drawing attention even before actual negotiations began. Most of the people I interviewed reported that families were constantly on the look-out for other family's health problems: "They look at the family line *(gennia)*. You know what the others have in their houses."<sup>20</sup> Against the backdrop of families constantly keeping each other under observation, it no longer comes as a surprise that - like in the example presented before - a family should attempt to hide the health problems of its members even from its own relatives. The wish to keep illnesses a secret is also linked to the conviction that many illnesses, especially hereditary ones, are the result of a mixing of blood among relatives. That these convictions are still held today is evinced by the answers given by all persons interviewed when asked what had caused the cases of CF in Athienou. They said: because of *eímomiksia*.

*Eimomiksia,* which can be translated approximately as incest, results from marriage or sexual intercourse between relatives (*soi*).<sup>21</sup> Who counts as a relative for whom the incest taboo is in effect is defined by the canonical law of the orthodox church of Cyprus. Marriages between persons who are related up to the fifth degree are sinful relations and therefore forbidden. This means that a second cousin or the son of a first cousin cannot be considered as a potential partner in marriage.<sup>22</sup> This regulation is not contested; quite the contrary, lay persons tend towards an even stricter interpretation according to which the blood relation remains in effect even between more distant relatives. Even relatives beyond the seventh degree are thus considered to be joined by shared blood. Connected to this there is the conviction that the blood in order to renew itself progressively through the generations requires the admixture of "foreign" blood. It is therefore considered dangerous for distant relatives to marry because thereby the circle is closed again and the blood returns with disastrous results: Misfortune, death, and passing sickness to the family are the consequences.

Only against the backdrop of these beliefs and the practice of arranging marriages within the village, does the severe impact of the news about the discovery of a dangerous hereditary disease in Athienou become understandable. The community residents assumed that the disease had been caused by a social practice and that, even though allowed by the Church, it nevertheless is considered morally problematical. The scientific explanations made available by the geneticists in effect seemed to provide credence to this interpretation: According to the scientists, the frequency of CF cases in the village is evidence of a so-called "founder effect", with centuries of village endogamy causing the accumulation of the gene in the population. The practices of human genetics strengthened the interpretation relying on the metaphor of blood as well: The researchers had taken blood samples and had sketched out pedigrees. For them, this was a standard procedure to identify the paths of Mendelian heredity. The villagers, however, imagined that the research intended to disclose incestuous links. While the concept of the founder effect in population genetics works as a purely statistical explanation of a biological phenomenon devoid of any moral undertones, the blood metaphor, applied by the lay persons - reflecting on the same phenomenon - implies a negative moral evaluation of their collective practices.

These contrasting interpretations of the high incidence of a hereditary disease – one based on genetics, the other based on the notion of shared blood – belong to separate "domains". Domain, as a term coined by the British social anthropologist Marilyn Strathern, connotes a coherent set of practices and extensive knowledge that allow for a distinctive conceptualisation of phenomena and experiences (Strathern, 1993, p. 134). While scientific domaining strategies are characterised by strictly rational styles of reasoning and practices specific to each domain, in

everyday life, however, analogous and metaphorical styles of reasoning are common, as are imaginative combinations that transcend the clear-cut boundaries of individual domains. Natural scientists, as a rule, find such vernacular styles of reasoning deeply disturbing: For the human geneticists involved in the Cypriot case the fact that many lay persons interpreted their findings as the disclosure of a moral failing constituted an irrationality at the very least - to restore conceptual order they filed this phenomenon away under the heading of "misunderstanding", thereby also excluding it from their area of competence and concern.23 That the scientific and the vernacular styles of reasoning turn out to be incompatible is linked to their different modes of domaining - and by extension, of constructing reality. These differences should be viewed against the backdrop of processes of knowledge transfer that so far have not been sufficiently explored by the Humanities. Again, the case study can illustrate what inquiries could productively be pursued by anthropology and related disciplines. Two aspects I would like to emphasise in concluding: first the changing notion of "blood" and relatedness, and second the impact of genetic knowledge on marriage strategies.

## Analogous and Digital Proximity in Kinship Relations

According to the beliefs of Cypriot lay persons, blood constitutes a non-interactive substance that anchors the social relations between kin in a specific way. Shared blood progressively should be mixed with foreign blood so that over the course of many generations the family blood as well as kinship undergoes a process of "thinning out". Blood, obviously, is conceptualised as a substance with analogous attributes: the closer the kinship-link, the higher the degree of similarity of the blood, and vice versa. Conversely, human genetics operates on the basis of a "digital" concept of heredity. Genes are conceptualised as disembodied units of pure information that have no substance-like qualities at all.<sup>24</sup> According to this concept, drawn from information theory, genetic information is either present or absent, but it cannot be found in varying degrees of intensity. While blood as metaphor makes it possible to view the relative *proximity* between affines as analogous with the degree to which shared family blood flows through their veins, population genetics, on the contrary, privileges *distant* relations – for example between a mutational event in the past and the spreading or accumulation of this mutation in a given population.

This concept of heredity introduced by human genetics weakens the bloodbased notion of kinship but conversely also works to reinforce some of its aspects. While close kin relations lose importance, more distant ones can suddenly become more relevant. For instance, many carriers of the CF gene were perplexed as to why their siblings were not carriers as well – because they considered themselves to be of "one blood" (*efnai afmo*) with their brothers and/or sisters. Now they were provoked to investigate their relatedness to other carriers whom they had not

previously considered as kin, or even to reconstruct their descent from the imaginary figure of the "founder" that the geneticists had alluded to. Such "constructions of the genetic self" surely have an individualising effect on the actors involved, as they set them apart from the immediate family: at the same time, however, new notions of belonging are produced as they begin to consider themselves as members of a population of carriers of a gene that goes back many centuries but is, of course, a purely abstract aggregate. Hereby, the innocent dealings with the far from innocent concept of "shared blood" are being irritated to the core. Also, the biological basis of social relations, that so far had determined proximity and distance unequivocally, is no longer unambiguous.

The question remains as to how people respond to these irritations of established notions of kinship and heredity. Interestingly enough, the results of the geneticists' research were taken by many of the interviewees as proof that their own world view is correct: namely, as a 40-year-old family head explained, that nothing is secure. In particular, people found it disturbing that the practice of marrying endogamously in the village - in itself a strategy to exclude unpleasant surprises by way of possessing secure information on the economic and social status of the respective families – should now turn out to be extremely risky, even when taking the precaution of not marrying anyone even distantly related. However, this realisation did not cause the villagers to want to abandon the practice of intra-village marriages. Quite the contrary – after all, other villages may also have a CF problem, people argued, but it might not be known yet because systematic tests have not been carried out in other villages. What is more, there is a new advantage in keeping up the tradition of marrying within the village as all young people have previously been tested for Cystic Fibrosis prior to marriage and already know who is a carrier and who is not.

British cultural anthropologist Charlie Davison attributes such attitudes to the increasing prevalence of a culture of "measure and manage" that invades all areas of life, meaning that more and more decisions in life are taken on the basis of biomedical test results in an attempt to rationally assess what dangerous or beneficial consequences any decision may entail.<sup>25</sup> I would like to add however, that every critique of this "measure and manage" culture resonates with standard assumptions in the social sciences, which may also deserve some critical scrutiny. To name three of them: It is assumed that the criteria people apply when making decisions generally are less than rational; it is also assumed that it is science that then will supply the rational criteria. And, finally, if one applies the statement to the Cypriot case under discussion, the impression is created that to Western biomedical sciences falls the task of modernising a non-Western society.

#### PUTIING GENETICS TO USE

However, as I have tried to show above, what characterises traditional marriage strategies in Cyprus is precisely that they are far from irrational, but on the contrary mobilise an immense concern with rational decision-making based on primarily economic as well as social criteria. Therefore, in Cyprus, many middle-aged parents tend to view the notion of "romantic love", adopted by the under thirty age group, as a dangerous or at least disconcerting import of Western irrationality. Most of the middle-aged interviewees in my study were doubtful as to whether one could actually build a lifelong relationship on such a transient sentiment. Those interviewed who were about thirty years of age, however, showed understanding as to the desire of the adolescent to take decisions independently. Alas, the intergenerational struggle that becomes evident here is not merely symbolic or the manifestation of young people trying to claim autonomy. Rather, the economic criteria that in the past determined what would be a "good match", today have become less important in restructuring the Cypriot service economy. Different criteria have begun to take their place, such as an academic degree acquired abroad, or the cultural competence to come out on top in the turmoil of social transformation. Land holdings or the ability of a family to uphold its honourable status no longer affords the security it once did. However, without exception all parents and young people I interviewed in the village agreed that genetic testing should precede marriage. For the parents, the test in a sense helps reintroduce an element of rationality into proceedings that have almost totally succumbed to "the power of love"; for the young people, conversely, the test helps exclude any problems that might cloud their future happiness as a couple.

While it remains to be seen whether "love" will eventually become a socially accepted criterion for marrying that is deemed rational,<sup>26</sup> what can already be detected today is that the secrecy that used to surround all health matters is being abandoned. Without exception, the interviewees had heard of marriage scams in the past where parents had kept the health problems of their children from the family of a prospective spouse. Today, however, uncompromising honesty in such matters is required and also practiced - not so much between the parental parties, because they no longer have exclusive responsibility in the marriage arrangement, but between the partners in marriage themselves because they are now morally obligated to mutual sincerity according to the code of love. In effect, the strict and from the perspective of bioethics dominated by scholars in North-European or North-American universities – debatable policy of the Thalassaemia programme enforced by the church (Angastiniotis et al., 1986) was highly influential in establishing such mutuality by creating an *obligatory passage point* for every prospective couple. By granting its blessing only to those couples who present a certificate confirming that tests for Thalassaemia have been undertaken, the church has made the genetic condition a public family affair and in turn ensured that prospective spouses must declare openly whether they are carriers or not.<sup>27</sup>

## Conclusion

In Cyprus, similar to other societies, we can observe how social actors are appropriating the wider knowledge produced by human genetics, and are using it in the context of social situations that are no longer static but have become fluid. Thus, the process of introducing such a far from "neutral" corpus of knowledge into a society is always accompanied by processes of appropriation that in turn are guided to varying degrees by personal goals, cultural values, and social patterns. What follows is that the impact of this new knowledge on cultural practices cannot be of a simple, cause-and-effect-like linearity.

Rather, both, on conceptual and on practical grounds, the genetic practices associated with modern biomedicine - such as genetic testing - as well as genetically-based concepts of heredity make available new options that affect a transformation of the body that can be captured in the intersection of two terms: flexibility and reflexivity. The flexibility of the body refers to its malleability when social actors take up new options and develop new practices. And bodies also become increasingly reflexive, as scientifically produced knowledge on the body is employed by social actors and other or older types of corporeal knowledges are added on to, modified, or replaced. Human Genetics is transforming the human body both in terms of its cognised models and in terms of everyday practices; according to the medical anthropologist Nancy Scheper-Hughes the body at the end of the twentieth century has become a "primary action zone" (Scheper-Hughes, 1994, p. 229). In the course of this transformation, the refashioning is not without bounds. Rather, it comes up against immutable biology as well as against established practices, conventional styles of reasoning, and persistent normative orientations. The outcome of the complex interplay between these factors I provisionally label as "reflexible bodies".28 This term, at least, seems more accurate than simply speaking of socially constructed bodies, and, because it is such an unwieldy term, also has the distinct advantage of constantly reminding us that we urgently need to explore this new world order empirically and come to terms with it theoretically.

Because of the way in which modernity has established itself in Cyprus, people have already had the opportunity or rather, were forced to grapple with issues that only now are confronting populations in Northern and Western Europe. For instance, in Cyprus young couples unquestioningly deal with the imposition of having to draw conclusions from a mandatory genetic test for Thalassaemia carrier status. In this, they are being helped by the fact that the (traditional) notion that decisions for marriage should be based on purely rational criteria has not yet disappeared from social experience.<sup>29</sup>

Faced with revolutionising developments in gene technologies, can people in Northern European countries learn from the Cypriot experience, and if yes, what can they learn from it? A few years from now, so-called "bio-chips" will become widely available that allow for quick, reliable and inexpensive simultaneous testing for a variety of genetic dispositions and traits, thereby creating a complete "risk profile" of an individual. Up until now, such testing had to be performed in costly and complicated testing procedures for single traits and could only be carried out by experts, whereas bio-chips can also be handled by non-expert personnel. Social scientists are expecting the *promise of transparency* offered by these bio-chips to turn all too soon into an *obligation to transparency* especially in the middle classes of western industrial societies, a challenge which is not yet balanced by any ethical or normative regulations. Conversely, it is quite possible that Cypriot modernity has accumulated the kind of social experiences and moral practices that might constitute a critical resource in this context.

#### Notes

1. For the generous help provided during the research I would like to thank the Cyprus Institute of Neurology and Genetics, namely Dr. L. Middleton and especially Dr. C. Deltas, who – as principal investigator – granted access to his data, made contact with study-participants possible and supported this study in many respects. Dr. M. Azina-Chronidi and Dr. A. losiphides supported me in arranging meetings with respondents and made the village hospital a hospitable place for me. I am grateful for generous feedback and critical comments especially by Dr. V. Christophidou-Anastasiadou, Prof. V. Argyrou, S. Marangos, Prof. Y. Papadakis, and Prof. G. Welz.

2. See for example Gross (1990, 206f.): "rhetorical analyses show how the sciences construct their specialized rhetorics from a common heritage of persuasion. By means of these, the sciences create bodies of knowledge so persuasive as to seem unrhetorical – to seem, simply, the way the world is."

3. See for example the seminal study of Latour/Woolgar (1986); in addition, research in the tradition of classical studies on/in History of Science and Sociology of Science have been influential in shifting the focus from analyses of histories of scientific theories to analysing scientific practices especially in the laboratory. See for example the reader of Cunningham/Williams (1992).

4. This Handbuch des Deutschen Aberglaubens (1935/1936) was one of several large scale projects German folklorists were devoted to at the end of the nineteenth century. Like in similar projects, compiling information and editing was done by academic folklorists, who relied solely on information collected by questionnaires, which had been sent out before to "amateur folklorists", most of them schoolteachers or clergymen. The aim was to secure vernacular culture and folk beliefs which were doomed to "disappear" in the dynamic processes of industrialisation and modernisation. Whether the Handbuch comprises sound information or is most of all a projection of the educated bourgeois class in Wilhelmine

Germany is a much-debated issue – nevertheless, some of the information given can be considered as a useful historical source.

5. Keeping health-related information a secret in small communities seems not to be a culturally specific phenomenon as such. Jutta Dornheim (1983), a German Medical Folklorist for example found a very similar pattern of behaviour in a village in the southern part of Germany in families with cancer patients. Nevertheless, the reasons for this behaviour seem to be highly context specific: In the case of the German village secrecy about cancer cases was a result of a connection the villagers made between cancer and contagious tuberculosis, a serious health problem in the community in former times not only for the people but – because the cattle could become infected – for their economic subsistence. In the village under study in Cyprus, secrecy seems more related to the organisation of kinship and marriage; this point will be examined below.

6. On the significance of such narratives which are often drawn from popular culture see a study by The Wellcome Trust {1998).

7. Cf. Zonabend {1996} for the cultural specificities of the European kinship system and the influence of the Christian Church in its development.

8. Social agency is muted – which aligns these everyday strategies nicely with some theories of structuralism; see, e.g., Herzfeld (1997, p. 113).

9. For the important role of the family as an "intermediary institution" in modern and latemodern societies see Luckmann, 1998.

10. Although the notion of "genes" was applied as early as the end of the nineteenth century – as in Galton's "eugenics", – racist ideologies (especially the German variety) drew heavily and exclusively on the blood metaphor. This line of inquiry cannot be pursued here any further.

11. The mutation tested was AF508, a mutation which homozygously causes a very severe form of CF. Other mutations, which account for more than 50% of CF mutations in the Cypriot population either homozygotically or in combination with the AF508-gene will result in a much milder symptomatology; see Deltas 1997.

12. In the context of this paper it will not be possible to discuss the important - and for an ethical evaluation critical – differences between screenings for Thalassaemia and Cystic Fibrosis; important aspects would be the totally voluntary character of the CF screening, the marked differences in the symptomatology of the disease and – most of all – the different carrier-frequencies. Also, the highly controversial literature regarding the benefits and risks of a population screening for Cystic Fibrosis cannot be discussed here; cf. – e.g., – Honnor et al., 2000; Haddow et al., 1998; Koch et al., 1994; Danayer et al., 1997; Levenkron, 1997.

13. Due to the fact that respondents had been granted confidentiality of their data, the procedure of arranging meetings was rather complex. The protocol agreed upon was the following: GING provided a list of names of testees to the local hospital; the physician at the hospital then approached the people on the list to ask whether they would be interested in participating in this study. The physician gave the names of those who had expressed their willingness to be interviewed to me; the aims of the study were explained at each meeting extensively, all respondents contacted agreed to participate. People who chose against a genetic test or who missed the opportunity were found by personally approaching residents at random. In a number of cases, such persons would also approach me with the explicit wish to be interviewed.

All of the interviews took place in the village hospital, because as a rule, the interviewees

preferred this "neutral" setting. For setting up the appointments and making it possible for the interviews to take place, I would like to thank Dr. C. Deltas (GING), Dr. M. Azina-Chronidi and A. losiphides. For assisting me in the interviews I wish to thank Stavros Marangos.

14. Only very recently the proportion of marriages between villagers and "Outsiders" has risen significantly but nevertheless stays even in the perception of villagers on a low level compared to other villages in Cyprus.

15. Interview 12/7; for similar findings see Sant Cassia. In his case study of Peyia, marriage partners originating from neighbouring villages were considered as "morally suspect" mainly because their social status could never be known with certainty: "They were referred to, jokingly, as shillokualima (a dog brought to the village), and their position was emphasized in a whole series of rituals, the most important being a mock beating of the groom's party ...." (Sant Cassia, 1982, p. 645).

16. According to Sant Cassia (1982), the practice of transferring land to a son upon marriage increasingly replaces earlier practices where property transfer was tied to inheritance after the death of a parent (see Loizos, 1975).

17. For similar findings see Loizos, 1975, p. 511.

18. See Loizos, 1995, 513f. This secrecy at the same time opened up options for fraud (see Sant Cassia, 1982, p. 655): the strict gender-separation for young people in the traditional village in addition to prohibiting the appearance of young women in public (Loizos, 1995, p. 508) made the "bridal switch", that elderly people often alluded to, possible, i.e., the groom was under the impression that he was going to get married to a chosen girl while at the wedding he would find out that she had been replaced by a less attractive older sister. "I have been betrayed" is even today a frequent saying by which some Cypriot husbands mockingly express their displeasure about their spouses.

19. See Argyrou, 1996, for an analysis of the fouartas (the "big spender"), a male strategy of conspicuous consumption which might generate social capital but not necessarily result in enhancing social status.

20. Interview 6/7. Very often, the vocabulary chosen was not as "neutral": a common expression used was *kalo ratsa.* 

21. See also Du Boulay, 1984.

22. In recent years, the Church holds the position – relying on genetic knowledge – that marriages to second cousins can be allowed but it is not willing to promote this new point of view publicly.

23. This strategy was much criticized by other experts involved in genetic services in the Cypriot tertiary health-care system; this conflict between different groups of experts, related styles of reasoning and between private (research) and public institutions (health-care sector) cannot be elaborated upon here.

24. Fox Keller, 1995. The well known population geneticist Lee Silver for example states that the sequential code stored in chromosomes as well as in databases *is* the gene, which can be transmitted via biological reproduction or via the internet.

25. Davison, 1996; similarly, Dorothy Nelkin und Laurence Tancredi (1989) are predicting the emergence of an "actuarial mind-set" in everyday culture.

26. For young Cypriots today, love is the primary reason for marriage, and they prefer friendships they have chosen themselves over kinship ties they have inherited. See also the study by Argyrou (1996, 104f.): "There are several visible signs that wedding celebrations may be scaled down in the future. In fact ... members of the elite are already having close

weddings attended only by a few hundred guests." Argyrou interprets this as an attempt on their part to visibly represent their modernity, and also as a consequence of the socially secure status they have achieved that allows them to step outside of the "extended networks of social relations". For the context discussed here, however, statements by younger people are pertinent, who are no longer interested in the social revenue of big weddings and claim to prefer small celebrations in the circle of close friends.

27. Conflicts about marriage arrangements in former times arose mainly between the parental parties, the married couple seems to have been rarely involved; see Loizos, 1975.

28. Emily Martin's (1994) excellent study on the impact of scientific knowledge on the everyday-perception of immune systems by lay people emphasises the element of flexibility of late-modern bodies; conversely, I would like to stress the reflexivity of flexible practices.

29. The "romantic love complex" is informed by a different mode of rational practices and judgements that are grounded in *aesthetics*, a socially distinctive "Urteilskraft" that makes criteria like economics, social class or status topical in a more indirect manner – by means of *aesthetic judgements*, cf. Bourdieu's (1979) concept of "habitus".

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