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The Loving Care of Postcolonial Subjects Doctors, Medicine and Epidemiological Interventions in Cyprus

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Abstract

Cyprus has one of the highest incidences in the world of the mutations that cause thalassaemia. A very successful prevention programme was developed since the 1970s which deployed genetic screening of couples of reproductive age to reduce the number of thalassaemic children born. Against the backdrop of a personal account given by Dr. Minas Hadjiminias who is credited with starting the programme, the author inquires into postcolonial society as a context for epidemiological interventions. The article explores both socio-cultural and medical reasons for the success of the prevention programme. It argues that the civic epistemology of postcolonial Cyprus allowed for the medical profession to establish a paternalistic regime 'for the common good' that was also motivated by a strong 'love for the people of Cyprus' on the part of the medical practitioners.

Keywords: thalassaemia, prevention, Cyprus, biomedical platforms, civic epistemology

'Back in the 50s, there was a mother suffocating a thalassaemic child with a pillow. Another couple committed suicide. Lots of marriages were splitting up. Families with sick children were scared stiff to talk to their neighbours, because of the rejection. Fathers were afraid to go to the village kafenion. They were rejected from the community. That was the real situation existing in the 50s and 60s. We had to fight against prejudice, ignorance, poverty, lack of funds.'¹

The introductory passage is quoted from a personal account given to me in 2004 when I conducted a series of interviews with medical doctors in the Republic of Cyprus. I had become interested in the professional biographies of clinicians, medical researchers, and

† Stefan Beck passed away on 26 March 2015.

1 Quoted from an interview that the author conducted with Minas Hadjiminias in 2004 in Nicosia. In 2003, he had met Dr. Hadjiminias and interviewed him for the first time. See Beck 2005a. At the time of the interviews and the first publication of the article, Dr. Hadjiminias was still alive. He passed away in 2012 at age 92.

health policy-makers while doing research on the impact of genetics on social life and on the implementation of epidemiological programmes in Cyprus. Dr. Minas Hadjiminias, whom I am quoting here, is credited with having laid the foundation for one of the most successful epidemiological programmes in the entire world. It is dedicated to the prevention of thalassaemia, a severe hereditary haemoglobin disorder that is widespread globally, especially in many subtropical countries.²

Like most academics of his generation in Cyprus, Hadjiminias had received his professional training in the colonial 'motherland'. He went to medical school in England in the 1940s, and, after completing his studies at the university as well as his clinical training in 1952, he returned to Cyprus where he started to work for the Medical Service of the British colonial administration. Only four years later, at the instigation of the director of Health Services, he was sent to Birmingham on a scholarship to receive specialist training as a clinical paediatrician so he would be able to become the successor of the head of Paediatric Services in the public health system who was about to retire. In 1957, he did indeed take over this position in the colonial administration as planned. The way he told the narrative of his professional life did not leave much room for good fortune or coincidence; rather, it seems to have been a carefully planned and executed career. This was evidently not unusual during the colonial period.

At the time of our conversation, Dr. Hadjiminias had already been retired for more than 15 years, but had not yet stopped practising. Jointly with his son, he ran paediatric clinics for private patients in one of the well-to-do middle class residential areas of the capital Nicosia. At the same time, he proceeded to write an historical account of the development of his thalassaemia programme³ and continued to follow with great interest

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- 2 Cyprus has one of the highest incidences in the world of the mutations that cause β -thalassaemia: every seventh person in the population is a carrier of the trait and suffers from thalassaemia-Minor. These heterozygous carriers are generally healthy, but show symptoms of mild anaemia. However, there is a 25% chance that two carriers pass on their respective genes to their offspring. In cases of homozygosity or compound heterozygosity for a β -thalassaemia mutation, the child will develop thalassaemia. In 93% of these cases thalassaemia-Major as a very severe and lethal form develops, while only in the remaining 7% of cases patients with thalassaemia intermediate can lead a life without the need of major therapeutic interventions. According to the carrier frequency in the Cypriot population, almost one in every 160 newborns can be expected to suffer from β -thalassaemia-Major. The condition usually becomes manifest during the first year of life and – if untreated – leads to a series of severe clinical symptoms. Thalassaemia does not have a specific molecular correlate but includes several clinical abnormalities due to highly ineffective erythropoiesis. Most prominent symptoms are iron overload of the tissue, progressive dysfunction of liver, heart and endocrine glands, enlarged bone marrow resulting in an erosion of the bone structure from within and in pathological fractures. In the skull bones these changes transform the facial features. See Olivieri, 1999; Weatherall and Clegg, 2001, Cao and Wai Kan, 2013. See also Niewöhner and Beck, 2009.
- 3 See Hadjiminias, 1994. The account that Dr. Hadjiminias wrote on his campaign was published as a book in the year after Stefan Beck's article appeared (Hadjiminias, 2008).

the medical advances in the field of genetic therapies for hereditary blood disorders. Together with colleagues from Cyprus and abroad, he also acted on the advisory board of an acclaimed clinic for reproductive medicine recently established in Cyprus. Not a particularly tall man, but very energetic, Hadjiminias clearly is regarded as a towering monument of the Cypriot medical system. The contemporary generation of medical doctors acknowledges his achievements.⁴ At the same time, however, they are uncertain whether his methods are bio-ethically correct. His 'professional grandchildren' feel uncomfortable about his inclination to break taboos, and to do so with full intent and for strategic purposes. Quite a few of the younger medical doctors that I met during my research in Cyprus liked to tell stories about Dr. Hadjiminias, and when they talked about him to me, the Western European outsider, they did so with a peculiar mixture of shame and fascination, admiration and rejection.⁵ There was one anecdote especially, about how Hadjiminias sent a policeman round to a family's home 'to remind them', as he put it, of an appointment for a prenatal check-up that they had failed to show up for. Or another story about how the Archbishop, the head of the Orthodox Church of Cyprus, called Hadjiminias a murderer in front of the entire synod when Hadjiminias presented his plans for a comprehensive prevention programme to eradicate thalassaemia. On the occasion, Hadjiminias had advocated a termination of pregnancy whenever a prenatal examination showed that the children would be born with thalassaemia, an invariably lethal illness for which there was no cure.

For me, Hadjiminias was a fascinating person to talk to precisely because he had been so successful in defending the system of prevention that he had set up, and was able to steer it through a period of political change by mobilising a coalition of supporters both domestically and internationally. The initial steps towards developing the prevention programme were taken during his service in the British colonial administration. He proceeded to build it up during the politically turbulent period following the independence of Cyprus in 1960, and was able to keep it going through the period of intercommunal violence and war that culminated in the 1974 invasion of the north of the island, with the subsequent population displacement having a detrimental impact on the provision of healthcare. Finally, during the 1980s, he was able to forge a heterogeneous coalition of Orthodox clergy, patients' organisations, international experts, government and civil society actors, and firmly established the programme of thalassaemia prevention in Cyprus which drew attention from global agencies such as

4 Among others, see Angastiniotis *et al.*, 1986; Angastiniotis and Modell, 1998; Eleftheriou, 2003; Gill and Modell, 1998.

5 Michael Herzfeld and Vassos Argyrou, among others, have analyzed this stance as reflecting the subjective and collective feelings of 'shame' that result from being symbolically dominated by social actors representing Western modernity. See Argyrou, 1996; Herzfeld, 1997.

the World Health Organisation. When he retired, his successors took over what has been called the most effective medical prevention programme globally. There are three strategies that made this possible, the first of which were health information campaigns aimed at the general population and, in particular, at the schools. The second strategy was the implementation of a comprehensive system of haemopathological diagnostics combined with a premarital genetic screening of adults of reproductive age which informed them of their carrier status for the disease as well as of options that were open to them to prevent children with the disease being born.⁶ In 1983, the Church of Cyprus assented that before performing rites of engagement or marriage, clergy would require a certificate to prove that the couple had undergone a genetic test for carrier status.⁷ The third strategic pillar was the establishment of an efficient infrastructure, including a genetics laboratory, a quality control system for its operation, and the building up of well-equipped treatment centres for thalassaemia sufferers and specialized training for medical staff.

The programme was fairly easy to implement, as it did not require a huge expense or complex medical technologies, but at the same time, it was spectacularly effective – which is why it was recommended by WHO as a ‘best practice’ model to be emulated by developing countries around the world. Many countries’ populations exhibit a comparatively high frequency of the genetic disposition for thalassaemia: among them Pakistan, Indonesia, Burma, Malaysia and Iran. In Cyprus, by applying the recommended combination of measures, the number of children born with thalassaemia was reduced from about 150 annually in 1970 to virtually 0 births per year. This way, Cyprus was able to alleviate the social problems and to avoid the humanitarian hardship described at the outset of the article. It also averted a breakdown of its medical system that threatened to become dysfunctional under the heavy load of thalassaemia cases, a situation that was worsened by the postcolonial state’s lack of funds and the effects of the war, invasion

6 The results of the test – i.e. whether one or both partners were carriers – were not revealed to the church, of course, and the decisions of whether to get married and to have children was left to the couple. While the population complied with this measure and there was no resistance, as it appeared to make sense to all concerned, the fact that the screening was mandatory – i.e. in order to get married, prospective couples had to get tested – and the counselling that followed it was directive – i.e. telling couples to avoid having children or, later on, to make use of in-vitro fertilisation and pre-implantation diagnostics – raised a storm of indignation in international bioethical circles. Because the programme’s aim is to prevent sick children being born, it also qualifies as eugenic. For more detail on these contested issues and how they reflect on the programme, see Beck, 2006; Niewöhner and Beck, 2011.

7 In Cyprus, there was no civil marriage possible for Cypriot citizens prior to the Republic of Cyprus acceding to the European Union. Therefore, church weddings as well as the blessing ceremonies when couples became engaged provided ‘obligatory passage points’ (Niewöhner and Beck, 2011) working as a mandatory screening for all adults at reproductive age. For more recent developments in thalassaemia prevention internationally, see Cao and Wai Kan, 2013.

and division.⁸ It was precisely the fact that the number of patients that had to be treated was not increasing any more that made possible a marked improvement in the quality of therapeutic care. The medical system was now able to apply its resources towards treating patients born with thalassaemia and increasing their life expectancy. This approach – to significantly lower the number of new patients suffering from thalassaemia by way of the prevention programme – actually helped create a situation where the government was able to cover the cost for state-of-the-art treatment of all thalassaemia sufferers within a public health funding framework, which was what both the medical staff and the associations of thalassaemia sufferers and their families had been demanding for many years. This, indeed, was a complex, not entirely balanced trade-off between bioethics, epidemiology and medical economics.

Hadjiminias himself saw the reason for the success of the thalassaemia programme primarily in the fact that it was ‘rooted in the Cypriot way of thinking’. He asserted that it was not an American or English concept, or ‘something from Europe’. Rather, as he pointed out, while the programme adopted the recommendations of WHO experts, it implemented them in such a way that it complied with Cypriot society, its values and social orientations. In his words, ‘The programme implements what the people want, not what the international experts and bioethicists tell us. If one would try to push one’s own ideas on them, this would surely fail, because the people would not accept it. What they, the patients, want – this has to be your orientation. Then they will voluntarily do whatever you want them to do, and they will do it their own way, if you educate them correctly and guide them. You have to be with them.’ He exhibits a great deal of confidence in his medical expertise as well as a secure knowledge of the implicit cultural orientations of lay people. He is even certain of his ability to manipulate and patronize them in a benign way. In another interview passage, Hadjiminias elaborates on the importance of mutual respect – the doctor’s acknowledgement of ‘the common people’ and their attitudes, and laypersons’ respect for the expertise of the medical practitioner complement each other. According to Hadjiminias, this is a precondition for being able to convince people ‘in an enlightened way’ of the need to change their attitudes and behaviour. It is clear that he himself is always absolutely certain of what the correct

8 In the 1960s, it was discovered that blood transfusions could extend the life expectancy of thalassaemic children and adolescents. But because there was no system of voluntary blood donation in Cyprus, either relatives would have to donate blood, or families would have to resort to paid donors. Family budgets as well as kin relations were strained. Repeated transfusions, also, created the problem of life-threatening iron accumulations and damage to vital organs. Medication that counteracted this threat was extremely expensive, and the government anticipated that it would not be able to cope with the growing numbers of patients and the rising cost of blood replacement and iron removal drugs. The WHO was called in for counselling and advised the government urgently to find a way to reduce the number of births of affected children. See Niewöhner and Beck, 2011.

measure to be taken is – his stance is that of an enlightened paternalism which is quite typical for the field of medical prevention generally, not just in Cyprus.

Problematization: *Agápi pros ton plisíon* and Networks of Qualculation

In what follows, I will inquire into the material, knowledge-based and institutional conditions that make possible this degree of passionate engagement that doctors like Hadjiminias exhibit. I want to find out what enables them ‘to be with the people’ and to help them, but in an unmistakably paternalistic manner. I am interested in both the emotional resources and the epistemic infrastructures that help produce this specific type of medical-epidemiological care and this form of clinical love for the common people. The affective underpinning of medical care, its forms of expression and modalities, are quite different today, in late modernity and within the context of contemporary bioethical standards, from Hadjiminias’ earlier postcolonial paternalism. Yet, and this is my first assumption, even the most selfless love for the people (*agápi pros ton plisíon*) can only become effective in healing when emotions are left aside, when they are disciplined by deploying ‘biomedical platforms’, and by an objectification of human suffering. This means to combine pathos and logos in such a way as to subject the individual’s suffering to a calculative procedure, that is, to analyse it, measure it, and compare it – but to do so in an impassioned way. This indeed is reminiscent of a well-known dilemma, a dilemma that goes back to the controversy between holistic and reductionist approaches at the onset of modernity (Harrington, 1996) and resonates with the well-established distinction between abstract and personal relations in the social sciences.⁹ Applied to my inquiry into the ‘love for the people’ within the context of colonial and postcolonial medicine, the question can be recast as follows: How does altruism relate to self-interest?; What is the relationship between passion and calculative

9 On the history of this opposition in the social sciences, especially in Anglo-Saxon liberal philosophy, see Silver, 1990. From the perspective of cultural anthropology, James Carrier (1999) discusses the trope of ‘selflessness’ in regards to concept of friendship and the types of subjectivity that go with it. On reciprocity within social relations of friendship, see also anthropologist Maurice Godelier, 1999 and sociologist Peter M. Blau who wrote, ‘Love appears to make human beings unselfish, since they themselves enjoy giving pleasure to those they love, but this selfless devotion generally rests on an interest in maintaining the other’s love.’ (Blau, 1964, p. 76). This concept resonates with the Aristotelian notion of friendship: ‘Benefactors are thought to love those they have benefited, more than those who have been well treated love those that have treated them well, and this is discussed as though it were paradoxical. Most people think it is because the latter are in the position of debtors and the former of creditors; and therefore as, in the case of loans, debtors wish their creditors did not exist, while creditors actually take care of the safety of their debtors, so it is thought that benefactors wish the objects of their action to exist since they will then get their gratitude, while the beneficiaries take no interest in making this return.’ (Aristotle, 1999, p. 154).

practices?; and What is the specific social form that emerges from taking care of patients and being concerned with their well-being?

The exemplary case of the thalassaemia prevention programme in Cyprus suggests two interesting venues for further exploration. Firstly, within a short time span of 50 years, the practices that emerged in the colonial period and crystallized in a notion of medical care addressed to the entire populace as a collective entity have been transformed today into something else, into a type of late modern individualized medicine. This changes both the objective status and the subjectivities of those who are cared for as patients and of those who care for them as medical staff. Ultimately, this transformation redefines the love for the people as it produces a different notion of peoplehood, when biomedicine reconceptualises a social community as an epidemiological 'population'. This shift from peoplehood to population¹⁰ goes hand in hand with redefining what is considered legitimate in terms of interventions into the biological conditions of existence of this very population (Foucault, 2003).

The second exploratory venue is concerned with networks that combine experts, institutions, knowledge, practice, diagnostic instruments and technologies, all of which are being mobilised in order that the selfless love for the people can actually effect healing. Clearly, the success of an epidemiological programme such as thalassaemia prevention in Cyprus hinges on the complex interplay of very heterogeneous elements. The coordinated access to both the physis and the psyche of the population depends on their interaction. Social and cultural anthropologists operating from a Science Studies perspective have recently suggested a number of conceptual tools that help analyse how heterogeneous elements combine in the production and application of scientific knowledge. For instance, the conceptual model of 'biomedical platforms' engages with the ability of an interaction between 'material and discursive arrangements or sets of instruments and programs' (Keating and Cambrosio, 2000, p. 386) to actually coordinate practices that are used to define disease aetiologies and determine options for medical intervention. Only by way of such platforms, this approach argues, can biopolitical strategies such as public health programmes be developed and implemented successfully. Following approaches suggested by the British sociologist John Law and

10 The instrumentation of the programme – comprehensive information campaigns, developing reliable diagnostic technologies, controlling the population – is not all that different from the efforts undertaken by western European nations in social medicine and epidemiology. The biopolitical strategy constructed 'the population' that became its socio-political object, see among others, Hacking, 1990. In spite of these findings being widely discussed in the social sciences, they have yet to be applied to the analysis of the formation of nationhood and identity on the island of Cyprus. Greek Cypriot and Turkish Cypriot nationalisms, conversely, are discussed from a political science perspective, while more indirect infrastructural – in the sense of Foucault – forms of identity politics by way of biomedical interventions and their role in the formation of populations are not taken into account.

French anthropologist Michel Callon, I will attempt to elaborate how these platforms or arrangements work as 'networks of qualculation' (Callon and Law, 2005). This concept is linguistically awkward, as it combines qualification and calculation. However, it has the clear advantage of not being limited to the description of biomedical laboratory operations and actually can also be applied to practices other than those of scientific research. Actually, the concept highlights the fact that material-discursive arrangements which take the form of networks can be found elsewhere in modern societies as well. Another advantage of the term qualculation is its potential to underline that qualifying as well as quantifying epistemic practices are often closely aligned, especially in the medical-diagnostic sector. (Toulmin, 1976; Jordanova, 1995)

Following this line of argument, the question of how diseases emerge can be addressed in three distinctive ways. (1) Physiologically and materially, a disease is the consequence of a detrimental modification of one or more metabolic pathways as a consequence of often complex interactions between environment, genes and somatic factors, i.e. lifestyle. (2) A disease only becomes a scientific fact when it is actively classified as such. This is made possible by the establishment of diagnostic criteria, the differentiation of a range of symptoms, the building of aetiological models and pathological concepts as well as the development of therapeutic interventions. (3) Yet, only when the scientific fact of the disease is reported outside of science, by way of knowledge transfer, and spreads into the realms of everyday life and popular discourse, will it start to have an impact on body images and corporeal concepts, prevention practices and social classifications (Hacking, 2000). Conversely, this threefold production of diseases in physiology, science, and everyday life should also be taken into account when we reverse the inquiry and not only ask how diseases emerge but also how they are made to disappear. This may happen through public information campaigns and the overcoming of superstitions, or through the revision of medical aetiological models, or in interventions into the very interaction between genes, bodies, and environment. For all three dimensions, we also need to know about the trajectories of diseases' diffusion, meaning that any medical epidemiology needs to be combined with a social-cultural epidemiology that traces the history of thalassaemia, its introduction to the island of Cyprus and the procedures which attempt to make it disappear again from the island. Such an extended epidemiological perspective would help to (re)integrate notions of socially constructed geographic spatiality as well as concepts of social and imaginary time into medical concepts.

It is against the backdrop of these theoretical considerations that the Cypriot programme for the prevention of thalassaemia can be accounted for as a network of qualculation that gradually expanded and was improved over the years. In a sense, the programme can be considered as the result of a social evolution. This was powered by a medical ethos that was characterized by a passionate and caring love for the

people of Cyprus. In order to analyse such networks, we therefore need a threefold approach consisting of Agapology, Epistemology and Praxeology, meaning (1) an analysis of the forms and conditions of emotional loving affection, (2) an analysis of the forms of rational knowing and the production of epistemic objects (Knorr Cetina, 1999; Rheinberger, 1997), and (3) an analysis of the pragmatic conditions for action. Engaging two case studies, I will attempt to show how the threefold approach can be helpful in interrogating my research materials collected about the Cyprus thalassaemia programme.

The Production of Thalassaemia Sufferers: Dr. Fawdry and the Search for Cooley's Anaemia

In 1925, the journal *Transactions of the American Pediatric Society* published a short article that described a newly discovered disease. This form of anaemia occurred among the children of Italian immigrants in the United States. The anaemia disease was accompanied by an enlarged spleen and severe changes in the bone structure, negatively affecting the ability to produce blood cells. The disease was named Cooley's Anaemia, after Thomas Cooley, the physician responsible for the study. In following years, Italian researchers were able to describe a milder version of the same disease, and research from other circum-Mediterranean countries finally led to the conclusion that this disease was in evidence throughout the Mediterranean area. This is why the name thalassaemia – anaemia of the sea – was later adopted.¹¹ Up to this point in time, the deadly disease had not attracted any attention in the countries affected, as it had remained statistically undetected among the prevalent, fairly high infant mortality, and the limited diagnostic facilities had prevented detection. Especially in small children, the illness had often been mistaken for malaria, which was at the time also widespread in these countries. A reliable diagnosis was only possible after Cooley developed a method of examining blood samples by looking at the blood under a microscope to see if the red blood cells appear small, less vividly coloured or misshapen. Abnormally shaped red blood cells are a symptom of thalassaemia.

Cooley's Anaemia, however, emerged as an epidemiologically relevant health problem requiring disease management only after further studies in other Mediterranean countries, foremost in Greece and Italy, were conducted. In Cyprus as well, the disease had been completely undetected until the 1930s. But one paediatrician working in the British colonial health services in Cyprus, Dr. Alan Fawdry, changed that. In spite of

¹¹ See Whipple, 1936. Only later, research showed that the disorder is in evidence throughout the world in those regions where malaria was endemic, or else where there are immigrants that come from such regions.

-serving as an officer in a geographically marginal area, he was keen to follow the most recent international research publications. Cooley's article came to his attention and when he visited rural clinics and remote villages during his inspections throughout Cyprus, he asked for children to be presented to him whose symptoms were similar to those described by Cooley.¹² He started to do systematic blood tests and, by the early 1940s, published an article about the likely degree of prevalence of Cooley's Anaemia in Cyprus. His research was restricted by lack of funds, a limited hospital infrastructure and a low number of private practices that could have systematically taken in and documented cases of the disease. Moreover, there was widespread fear among parents about making illnesses of their children common knowledge in society. Especially in rural areas, the disease was regarded as God's punishment visited on the parents for sins that they had committed.

Indeed, the Cypriot people owe much to Fawdry's work. When the desperate parents of suffering children received the diagnosis, the illness was known by a Greek name that unmistakably identified it as a disease of the Mediterranean Sea or more precisely even as an illness of the Greek people. In popular imagination, thalassaemia came then to be seen – erroneously – as the tragic ethnic destiny of all Greeks, and as collective burden that joined Greek Cypriots in an existential way with their motherland Greece.¹³ More to the point, the correct diagnosis prevented children from being mistakenly treated with anti-malaria drugs, and instead, more effective cures could be initiated. Furthermore, the medical categorisation of the illness in conjunction with a public information campaign worked towards easing the social stigmatisation of the patients and their families. Because of the success of this campaign, medical expertise and scientific knowledge were increasingly deployed in public health education in Cyprus during the colonial period, to work as an antidote against superstition and stigmatisation, and were assigned an important role in public health, side by side with improving diagnostic techniques and treatment options.

While Fawdry's research made the disease real for Cyprus, he also made sure that the colonial administration took charge of this problem in their public health agenda, especially by way of developing a systematic framework for diagnosing thalassaemia. This in turn was made possible by an increasingly well-developed network of hospitals and clinics built up by the colonial administration, as well as by training doctors and nurses.

12 Cooley's papers were published in 1943 and 1944 in *The Lancet*. Applying his findings, Fawdry's estimate of the frequency of the mutation in Cyprus was proven by later testing. This was also confirmed in an interview conducted by the author with Michalis Angastiniotis in 2004.

13 This was, of course, not correct. The frequency of the mutation in the Turkish Cypriot population is fairly similar. Indeed, Greek Cypriots and Turkish Cypriots alike, exhibit comparable frequencies like the other populations that have been residing in the Eastern Mediterranean area for a long time. Clusters of genetic traits are not coterminous with cultural, linguistic or religious collectives.

Not least, Fawdry's studies also contributed to the formation of the newly emerging research field of blood diseases in biomedicine and thereby created new options for specialisation in the medical profession, which in turn would later motivate physicians like Hadjiminias to pursue additional training in the field of haemopathology, hereby improving their career options. Even more importantly, though, the colonial medical officer Alan Fawdry and his accomplishments set an example to emulate that continued to have an effect even after the end of the colonial period: namely by showing that scientific expertise, passionate curiosity, social engagement, objectified research, and that love for the (colonized) people can be effective in easing the suffering of patients. Hadjiminias and his successors were and are still full of admiration for Fawdry, the British paediatrician. In the 1940s, Fawdry had left Cyprus, because he had been transferred to Yemen and later to Bahrain, but he kept in contact with Cyprus. As Hadjiminias and his colleagues put it, 'He was a friend' – which is how they felt about him, but by extension this can also be taken to mean that he was a friend of the entire population, both Turkish and Greek Cypriots.

Creating Enlightened Subjects: Dr. Hadjiminias, Fava Beans and Thalassaemia

Minas Hadjiminias followed Fawdry's example right from the beginning of his professional career. As soon as he was appointed to his position in the colonial health service, he took up the habit of travelling across the island for inspection visits, adopted blood diseases as his specialisation, and devoted much of his attention to the development of the health system in rural areas. He was interested in reliable cooperation with the officers of the British administration, with whom he kept close official as well as personal contacts throughout the period of the Greek-Cypriot liberation struggle against the colonial power. As he put it, 'I think the relations were excellent. I was invited to all the parties in the government houses – even during the struggles I went there. I went even when the much-hated governor was there – I went and did my job. If you knew how to deal with them, you could get anything from the British. They did their best. Look: for example malaria. Because someone in the British colonial services showed an interest and started working on it' There he broke off, but it was clear what he meant: This is how malaria was eradicated on the island. He also implied that after independence, the new Cypriot government might not have been able to muster the expertise and successfully implement such a programme.

Against the backdrop of his training as a paediatrician and haematologist, it is not surprising that, in addition to thalassaemia, another disorder caught his interest that also carried an association with malaria, namely favism. This is an acute haemolysis that can be triggered by ingesting fava beans. In severe cases, especially in young boys,

it can lead to sudden death caused by kidney failure and circulation breakdown. In the meantime, molecular genetics have been able to explain that favism is caused by a defect in an enzyme which causes red blood cells to break down prematurely. It is inherited in a recessive pattern linked to the X-chromosome. As males only have one X-chromosome, one altered copy in each cell is sufficient to cause the condition.¹⁴ An acute, potentially lethal haemolytic crisis – i.e. the depletion of red blood cells at a rate greater than they can be replaced – can be caused by fresh fava beans, but also by green almonds, which contain glycosides. In the early 1960s more than 50 severe cases occurred annually, because fava beans were an important staple in the Cypriot diet especially among the poor rural population, and because almost 10% of the population are carriers of the mutation. But, as already Harry Harris, the ‘father’ of modern biochemically oriented genetics, asserted, while all affected persons have the gene (i.e. a mutant allele), they only get the disease by eating the bean (fava). (Scriver, 2001, p. 2) Favism, then, is a medical problem that can easily be avoided, at least in theory, by simply removing the beans from one’s diet. It is the culturally contingent co-factor, making the genetic condition potentially lethal, that has to be abolished.¹⁵

In the early days of his involvement, Hadjiminias was very confident that a comprehensive information campaign would lead a change in diet, eliminating fava beans, and thereby effecting a marked reduction in illness cases. With a slide projector he started travelling even to remote villages to give lectures in schools or coffee-shops in the evening where he had the local authorities – the priest, the village leader, and the teacher – accompany him. He also systematically enlisted doctors and nurses in his campaign to get the message across. However, even at the time of the interview he was

¹⁴ It is caused by a mutant allele that causes G6PD deficiency. Some researchers attribute favism with a decreased likelihood to experience severe cases of malaria. In this, it is similar to thalassaemia which is also thought to give carriers the evolutionary advantage of being less susceptible to malaria. This may explain its high frequency in areas that are malaria-prone because of anopheles mosquitoes who serve as a disease vector for the infection by plasmodium falciparum. For the analysis of the co-evolutionary processes involved, population genetics, social history, ecology and epidemiology need to be combined. See, for instance, Jackson, 1997.

¹⁵ On the one hand, favism is a typical genetic disorder, because it breaks out when the genetic disposition interacts with a specific outside influence – in this case: fava beans. On the other hand, it is quite untypical for genetic diseases precisely because the causal relationship is so simple and can easily be avoided. But precisely because its prevention is not complicated, favism became an ideal testing ground for the public information campaign that Hadjiminias conceived. He emphasized that at that point in time, nobody knew whether people would respond to the information in the manner intended and stop eating fava beans. Indeed, there had been evidence from similar campaigns in Greece that this would not work, and foreign experts, as well, had been more than doubtful. They thought that Hadjiminias’ claim was far too idealistic. As it turned out, they had underestimated the powerful social force of shame and familism – the emotions that Hadjiminias knew well how to make use of.

convinced that the campaign was only successful because he personally and informally addressed local men when he met them in the village coffee-shops after the lectures. Eventually, the number of cases occurring during the time of harvest of beans and of almonds markedly decreased.

From his point of view, the success of the campaign was due to a cultural trait that he prudently made use of for his purposes. He claims that – in his words – ‘the Cypriot is a different type from the English’ whom he also got to know during his medical training. From his point of view, this is the reason why the British colonial public health campaigns did not work, because, in his conviction, they were based on false premises. In the following quotation from my interview with him, he explains how he strategically used his intimate culture knowledge of social mechanisms in his own society: ‘When it is about illnesses, the Cypriot will do anything for his family and for his children. He does anything, because he wants to have a healthy family. He wants to sit in the kafenion in the evening and tell the other men about his son, how great he is, how successful he is, and that he has gotten married and given him many grandchildren. How can one go the kafenion and have to admit that one’s children are not healthy?’ It is significant that Hadjiminias rather astutely makes use of the fear of stigmatisation that pervades the social arena, and of the social competition that even increased when Cypriot society started to modernise. Hadjiminias is also familiar with the particularly male attitude of *eghoismos* that figures in many ethnographic accounts, and for his campaign, he enlists those attitudes that are geared towards sustaining and defending one’s family’s honour. These cultural patterns were alien to the thinking of the British colonial officers as well as to foreign advisors sent by the WHO, as Hadjiminias, but also his colleagues and successors assert. Only Cypriot medical professionals were able to develop and implement effective health campaigns because they were familiar with the cultural horizon of the people.

US-American cultural anthropologist Michael Herzfeld conceptualized this type of insiders’ knowledge of a society by coining the term cultural intimacy (Herzfeld, 1997). It forms the basis for contested forms of identity, as it is often rooted in collective feelings of awkwardness or guilt, or is based on a self-ascribed negative image of the group or population. To put it more succinctly, cultural intimacy appears to emerge from collectively shared feelings of shame over one’s group’s backwardness, poverty and lack of power in relations with dominant outsiders. When applying this model to the case of Cypriot health professionals, such as Hadjiminias, it becomes evident that it was their ability to mobilise the cultural intimacy that they shared with their compatriots in order to reach their goals. They did so by addressing individual families and engaging with their fear that their children may come to harm when eating fava beans. However, they also addressed families and individuals as members of a community that collectively

is marked by a health problem, in this case a genetic defect. This feeling of being at risk as a collective was greatly increased by the fact that even though only about 10% of the population were estimated to be carriers of the this dangerous genetic disposition, the campaign included the entire population and advocated that fava beans should no longer be cultivated in Cyprus.

Until today, Hadjiminis is very proud of his success in enlisting Cypriot families as agents for his prevention programme. Of course, he is not the first who did this. In Western Europe, from the 18th century onward, regulations based on medical knowledge started to pervade society, and the family was turned into a unit that not only joined two kin groups and privileged certain mechanisms of property transfer, but increasingly was regarded as providing a beneficial physical and psychological environment for children to grow up in. In 19th century Europe, the attenuated concept of nuclear family constructed the bond between parents and children as dominant and socially significant. To safeguard the health and well-being of one's children and to provide for the education of their character became – as Michel Foucault pointed out – the foremost task of the bourgeois family. The nuclear family also became an important agent of medicalisation. Starting in the late 18th century, this huge project of medical acculturation and normalization that reached its peak in the 19th century primarily targeted the family unit (Foucault, 1980, p. 173). Foucault points out that families were also made into tools of individualisation. The individual duty to safeguard one's well-being that grew into an 'ethics of health' could not do without a society-wide system of hygiene and scientifically-based medical care. It is interesting that Hadjiminis proposes a family-society relationship that operates in reverse order. He assumes that society's 'ethics of health' are produced by the family, in the context of familial concern and care for the family members. Moreover, Hadjiminis conceptualizes the state's 'biopolitical regime' as a mechanism where the authorities act just like a family towards its members. To put it another way: Hadjiminis is proposing genetic intimacy as a sub-category of cultural intimacy, and he goes ahead to make it work for the implementation of the prevention programme that he devised. The people who were the recipients of his care and the objects of his concern are regarded as if they were members of one extended family.

Mindful Married Couples and Civic Epistemologies: A Co-Production

It is amazing how resilient the programme established by Dr. Hadjiminis proved to be in the following years. His successors further elaborated it and applied its mechanisms to new prevention programmes that addressed other diseases that also had genetic causes (Beck 2005). Two aspects deserve further analysis. For one, the co-production of facts

and attitudes, of truth claims and normative orientations is a mechanism that can also be observed in the case of other scientific knowledge being implemented. Indeed, the prevention programmes developed in Cyprus since the 1940s are biopolitical projects that introduced new forms of control, surveillance and persuasion, and fundamentally changed the health sector along with the type of expertise required for its operation as well as the expectations of patients. Even more importantly, these measures were geared towards establishing new forms of mindfulness and responsibility that required couples intending to get married to take 'genetic precautions' and to act prudently in terms of family planning. Most of them had been familiar with thalassaemics in their social environs, in the village, among their relatives, at kindergarten and in school. Their immediate exposure to the suffering of those affected, combined with their access to information about the possibilities of preventing the disease, left couples about to marry no choice: before getting married, they would have to find out whether they were carriers of the mutation that causes the disease. And they may then decide against getting married, should both of them be carriers, or else make sure by way of prenatal diagnostic procedures and termination of pregnancies that no thalassaemic children are born. However, in the international arena, medical technologies and health policies that select for healthy individuals and, as in this case, prevent babies who have a disorder from being born are branded as eugenics and in many countries, outlawed by legislation. For the Cypriots, however, doctors as well as prospective parents, it appeared as a deeply moral practice that prevented suffering and fulfils the ideal of the good life.

The second important aspect is that the prevention programme initiated by Dr. Hadjiminias produced a social contract between scientists, the state and its citizens. In modern societies, the advances of science and technology have the potential to massively intervene in people's lives. 'Progress' becomes a contested issue, and in democratically constituted societies, citizens expect to participate in political decision making. US-American political scientist Sheila Jasanoff asserts that the current transformation of modern societies into so-called 'knowledge societies' creates new challenges as lay people increasingly have to assess the truth claims of experts and their prognoses, and in the course of doing so, have to be able to judge what counts as reliable scientific knowledge and codes of conduct, and what does not. In turn, as Jasanoff points out, scientists have to ensure that their research is accepted in society and have 'to conform to these established ways of public knowing in order to gain broad-based support – especially when science helps underwrite significant collective choices.' (Jasanoff, 2005 p. 249) In this context, Sheila Jasanoff introduces the term civic epistemologies to denote 'culturally specific, historically and politically grounded public knowledge-ways' that differ between societies.

In conclusion, I would like to suggest that Dr. Hadjiminias was able to implement his prevention programme so very successfully because it was highly compatible with the civic epistemology of rapidly modernising Cypriot society. His love for the people was both a tool and a product of his long-time intimate familiarity with his compatriots' values, convictions and social strategies. It formed a foundation on which a prevention programme was institutionalized that was spectacularly successful. It embodied his personal convictions: that only loving care of patients is effective, that the people themselves have a strong will to prevent suffering, and that they are able to achieve this by adopting a unique type of genetic mindfulness.

Postscript to Stefan Beck's Paper (Gisela Welz)

The article by Stefan Beck included in this issue of *The Cyprus Review* was originally written in 2005 as a paper to be presented at a conference titled 'Volksfreunde' (Friends of the People) organised by the eminent cultural studies scholar Bernd Jürgen Warneken at the University of Tübingen (Germany). It was later published in German in the conference proceedings (Beck 2007). The conference topic was 'the love for the common people', an attitude that - throughout Europe, since the 18th century – had motivated many aristocratic and bourgeois reformers, philanthropists, writers, and scientists who tried to improve the lot of the lower classes. The impetus of the conference had been to compare historical as well as contemporary case studies, and to elaborate culturally specific patterns as well as shared underlying mechanisms, such as the intimate connection between empathy for those less fortunate than oneself, and the hegemonic regimes of paternalism, discipline and domination. Stefan Beck chose Dr. Hadjiminias, the 'father of paediatrics' on the island of Cyprus, as the focus of the case study that he contributed to this venture. Because he anticipated correctly that the audience of the conference and the readers of the subsequent publication had no particular interests or expertise in the medical field, he left out biomedical terminology and simplified some of the genetic issues involved. He engaged with the genetic implications of the disease in detail in other publications and papers (Beck, 2006a, 2006b; Niewöhner and Beck, 2009; Beck, 2011a).

Stefan Beck's interest in the thalassaemia programme had emerged as a sideline of his case study of the genetic screening for cystic fibrosis in Cyprus in 1997-98. (Beck, 2005a) At the time, he had also done some archival work on the efforts of the British colonial administration to eradicate malaria on the island as well as on the development of the public health system in Cyprus during the colonial period and after independence (Lengwiler and Beck, 2007). He was particularly interested in the British administration's policies in the health field in terms of a paternalistic biopolitical regime

that shaped the inhabitants of the island of Cyprus as colonial subjects. In addition, the long-standing debate on whether Cyprus is inhabited by two genetically distinct ethnonational communities or, conversely, a population sharing many traits and being distinct from both mainland Greece and mainland Turkey had clearly fascinated Stefan Beck, and in some of his writings, he inquired into the ability of genetic screenings and epidemiological interventions to both make and unmake populations. For this reason, his research interest in tissue donation and organ transplantation coalesced around the bi-communal civil society campaigns to find bone marrow donors for children suffering from leukaemia and that mobilised thousands of people from both communities across the Green Line (Beck, 2011b). He was also interested in how patients' organisations and medical professionals on the island to become active on a trans-national scale. Even though it does not figure in the present article, the development of Thalassaemia International Foundation was one of Stefan Beck's case studies referred to in other published papers (Beck 2012).

For Stefan Beck, the globalisation of biomedicine was at best an ambivalent process. He inquired into the impact of the global circulation of expert knowledge and new biomedical technologies that became available on the island in the 21st century, arguing that specific local historical and social constellations influence the material and discursive practices within which genetic technologies are enacted. Throughout his life, Stefan Beck defended the Cyprus thalassaemia programme against criticism voiced by medical experts, policy-makers, and bioethicists from abroad. In a later paper co-authored with his Berlin colleague Jörg Niewöhner, he wrote:

'The obligatory screening and counselling for thalassaemia in Cyprus is one of the most successful public health programmes - but it is also arguably the most criticised in the international bioethical debate, mainly because the screening is compulsory and violates the "right not to know". This accurate bioethical critique, however, does not take into account that the programme was specifically designed to better a public health situation that was seen as unbearable, to de-stigmatise thalassaemia patients and their families, to overcome superstition and to provide carriers with a choice in a situation of discrimination. Also, the bioethical critique does not take into account why the programme is still unanimously accepted in the population more than 30 years after its inception.' (Niewöhner and Beck, 2009, p. 81)

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