

**THE
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REVIEW**

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DEDICATED TO STEFAN BECK

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GISELA WELZ is Professor of Cultural Anthropology and European Ethnology at Goethe University, Frankfurt/Main, Germany. In 2006, she co-edited the anthology *Divided Cyprus. Modernity, History, and an Island in Conflict* (Indiana University Press) with Yiannis Papadakis and Nicos Peristianis. Her most recent book, *European Products: Making and Unmaking Heritage in Cyprus* (Berghahn Books, 2015), inquires into the effects of the EU's regulatory regime on social practices and cultural knowledge. Gisela Welz is the widow of German anthropologist Stefan Beck (1960-2015) to whose memory this issue of *The Cyprus Review* is dedicated. Since the early 1990s, they visited Cyprus annually for their respective fieldwork.

INTRODUCTION

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Stefan Beck lecture on Thalassemia in 2007 at Humboldt University, Berlin

In Memory of Stefan Beck

COSTAS S. CONSTANTINOU, CONSTANTINOS PHELLAS, YIANNIS PAPADAKIS

This special issue of *The Cyprus Review* is dedicated to the memory of Professor Stefan Beck. *The Cyprus Review* is the most suitable scientific environment in which to host such commemorative work. It is a journal that publishes academic work on Cyprus, which Stefan Beck loved so much. This issue is also a review of Stefan's contribution to scholarship in Cyprus and of the people he inspired to take his work further and enhance the medical anthropology and sociology of Cyprus. Stefan was the first scholar who conducted systematic research in medical anthropology in Cyprus in the 1990s, which was a time when tertiary education and scientific research were becoming institutionalized on the island, but very few people knew what medical anthropology pertained to. He then collaborated for the following two decades with a number of social scientists in Cyprus and was an influential force in their academic careers. Though not many people in Cyprus specialise in medical anthropology or sociology, a good number of journal articles, books and research projects have been initiated; indeed, Stefan authored many of them and participated in others. Stefan Beck is deserving of the title 'The Father of Medical Anthropology in Cyprus', as he forged the path in the 1990s by influencing young scientists and continuing his research and publications for two decades. His work was thorough and his writing aspired, in the best tradition of anthropology, to reach the level of detailed, contextual 'thick description'.

Stefan Beck's work was primarily concerned with biomedicine, social and medical anthropology, and science and technology studies. He sought to enter into a two-way dialogue with medical experts and practitioners, and brought along key anthropological insights, something he achieved by dealing with people who were socially and historically situated, and who had their own priorities, needs, interpretations and ways of acting in their engagements with biomedical discourses and practices. In other words, he treated people as social agents, rather than just as passive biological medicalised bodies, and he tried to create a meaningful dialogue between the social actors and the experts involved. This is an approach that could make this process more democratic, interactive and hopefully also effective. He sought to critique the notion that experts have undisputed authority over human subjects, yet without rejecting the role that medicine and expert knowledge has to play. Thus, he also submitted the primary dogma of social sciences, namely social constructivism, to critical scrutiny. At times, moving stories emerged in the course of his research and writings, like the predicament of the parents who tragically kept secret their children's cystic fibrosis, in order to protect them from the knowledge that they were terminally ill and to allow them to enjoy their childhood.

Politics, of course, in its various forms, could not be left outside this domain, and one of Stefan's contributions was to show how politically, historically and culturally-specific such discourses and practices were. In terms of Cyprus's politics, which are obsessively focused on the Cyprus Problem, it comes as no surprise that Stefan would become interested in the bicomunal bone marrow campaigns. The Karaiskakio Institute's campaign to register donors was successful beyond the institute's highest expectations, and this is one of the lesser known stories about Cyprus yet also one of the most positive ones in its recent history. One of the reasons for this success was that bicomunal activists had campaigned energetically to encourage people from both sides to give samples in order to save children across the divide of Cyprus. While the campaign was a great success, in that it mobilised large numbers of people to come forth and that it led Cyprus to acquire possibly the largest donor register in proportion to its population, it did also create some risks. Inevitably, it embroiled the Karaiskakio Foundation in the politics of the Cyprus Problem. Even if this was all done in the name of humanitarian values, and even if one agreed with the particular bicomunal politics that fuelled the campaign (and our own sense is that Stefan himself would agree), this created other kinds of risks and complications that Stefan, as a sign of his academic integrity, was not averse to pointing out. Here one could also further ponder what it meant for Stefan to conduct research within the context of Cyprus's division, considering that he himself had grown up in a Germany that was, at the time, divided.

Stefan Beck's legacy and contribution to scholarship in Cyprus is presented in this special issue. At the beginning, Christophidou-Anastasiadou eloquently presents Stefan's work and his unique contribution to the medical anthropology of Cyprus. Christophidou-Anastasiadou reflects on Stefan's connection to Cyprus and his contribution to scholarship chronologically, starting from the 1990s and the study of cystic fibrosis in Athienou village to his more recent involvement in a thalassaemia study. Stefan did not only contribute to academic research and literature in Cyprus but also to important discussions about public health and bioethics in society. Christophidou-Anastasiadou also places emphasis on Stefan's personal qualities and the strong relationships that he developed in Cyprus. In the following article, Loizou *et al.* present the qualitative findings of a recent study of how patients in Cyprus experienced the thalassaemia disease. The preparation of this qualitative study was made possible with Stefan's help in order to finalise an effective interview guide and have well narrated accounts by research participants. The study showed that thalassaemia patients in Cyprus understood blood transfusion and especially iron-chelation therapy as restrictive experiences. Patients imagined that without thalassaemia they would have been able to regain what they had lost psychosocially as a result of their condition. Amelang explored patients' perceptions of organ donor-recipient relations in Germany, Sweden

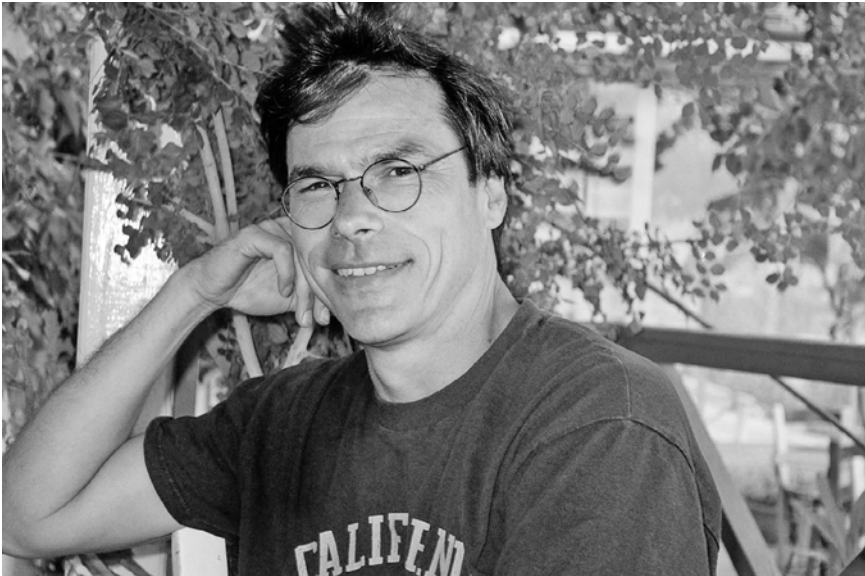
and Cyprus by analysing qualitative data. The data derived from the European project, which Stefan participated in and contributed substantially to the design of the study and analysis of results. Amelang explains that Cypriots understood organ donation in a context of producing further relationships, whereas Swedish and German participants denied donor-recipient relationships. This is an interesting finding, which Amelang understands as based upon the different cultural values within these European regions. Niewöhner *et al.* were inspired by Stefan's ideas and came up with a new methodological approach and analysis, namely phenomenography. By phenomenography, the authors refer to 'the ethnographic study of phenopraxis'. Phenopraxis is a term the authors use to understand how people socially interact in certain contexts. Phenomenography thereafter is a term which combines the phenomenological approach and ethnographic methodology. Stefan's writing style also inspired Dikomitis who highlights the importance of ethnographic research in medicine. Drawing from her experience in teaching social sciences to medical students and working on research projects with other scientists who do not deeply understand anthropology, Dikomitis unfolds the challenges she was faced with while trying to fit her writings and publication priorities to medical schools' academic mindset. Dikomitis concludes that ethnography is an essential framework of research and understanding humans and deserves a more respected position in medical schools. The series of articles concludes with the English-language translation of one of Stefan's articles which was previously available in German. Early on, he had become interested in the professional biographies of clinicians, medical researchers, and health policy-makers while doing research on the impact of genetics on social life and on the implementation of epidemiological programmes in Cyprus. The protagonist of this article is the late Dr Minas Hadjiminias who laid the foundation for the thalassaemia prevention programme of the Republic of Cyprus in the 1960s. The paper argues that the 'civic epistemology' of postcolonial Cyprus allowed for the medical profession to establish a paternalistic regime 'for the common good' that was in turn motivated by a strong 'love for the people of Cyprus' on the part of the medical practitioners.

In addition to the articles, this special issue hosts a list and summaries of Stefan Beck's publications, which are relevant to Cyprus. This list was compiled by Gisela Welz and shows Stefan Beck's notable contribution to the scholarship of medicine and health promotion in Cyprus. We would like to thank Stefan for his friendship, academic integrity, guidance and support! His legacy will live on through his writings of the social sciences of health in Cyprus.

**EULOGY
FOR
STEFAN BECK**

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Stefan Beck in Cyprus, 2006



Eulogy for Stefan Beck, 1960-2015

VIOLETTA CHRISTOPHIDOU-ANASTASIADOU

Introduction

Stefan Beck, born in 1960 in Germany, was a professor of European Ethnology at the Humboldt University in Berlin. He was one of the most active and productive researchers in the field of the social anthropology of medicine. He inspired and guided numerous students. He collaborated and exchanged views with people from various fields all over the world. He made many friends and forged strong relationships that lasted years irrespective of distance. Stefan sadly passed away unexpectedly on 26 March 2015. Despite his short life he left a legacy of scientific accomplishments. He is also well remembered for his great personal qualities.

Stefan Beck's Connection to Cyprus

Stefan Beck visited Cyprus numerous times and left his mark as both a scientist and a researcher but also as a sincere and compassionate human being who built many close, long-lasting friendships. He became an 'overseas citizen' by using the tools of media and technology to stay updated on news from Cyprus covering all aspects of local life as well as events relevant to his medical anthropology interests. He informed himself of global scientific developments – especially in the field of medical genetics – which he expected to impact on the health system and the practice of biomedicine in Cyprus. He was also interested in the Cyprus problem and followed the political debates and discussions from both a local and international perspective. He was interested in the arts and cultural scene on this small eastern Mediterranean island, and also monitored the risks that development posed to the environment, especially the threatened Akamas peninsula, which he knew so well.

Genetic Screening in Cyprus

Stefan Beck carried out one of his earliest research projects in Cyprus in 1997 and 1998. He focused on the cystic fibrosis genetic screening programme in the village of Athienou. It started when the media presented stories of mysterious deaths caused by a deleterious disease in the village. Actually two patients from the same family died from cystic fibrosis, a heritable disease with chronic multisystem manifestations. Researchers and physicians launched an initiative for a population screening programme which indicated that

the incidence of the disease in the village population was surprisingly high. When the researchers, geneticists and physicians reported their discovery, the media publicized the screening programme in a rather pronounced way, and it risked stigmatizing the entire population of the village, even though it probably was not done intentionally. Lefkos Middleton, currently professor of Neurology at the Imperial University Hospital, UK, and at the time the Director of the Cyprus Institute of Neurology and Genetics, invited Stefan Beck to do an ethnographic study of the local effects of the screening. Stefan interviewed several scientists and health professionals, including the key researcher Constantinos Deltas. During his fieldwork, he travelled to Athienou every day. With the assistance of Stavros Marangos, who acted as interpreter, Dr Myrto Azina and others, he conducted a series of interviews with inhabitants of Athienou village at the local hospital, as well as with community leaders and clergy. This fieldwork examined local perceptions of the body and disease, issues of family and kinship relations, and even conflicts, including pressure by the media, the local community or the extended family. Hidden feelings of anger and frustration, misunderstandings, and the fear of stigmatization came to the surface when the carrier status of village residents was determined. Interpretations of this fieldwork as well as comparative analyses, engaging other cases, were published over the years.¹

Thalassaemia Prevention in Cyprus

Cyprus has been reported in the medical literature as the country that introduced a national prevention programme for the genetic disease thalassaemia, which achieved exceptional coverage of the population that showed a very high degree of compliance with testing. The serious burden of the disease on the patient and the family, the limited therapeutic options at the time, such as frequent blood transfusions and chelation agents, and the tremendous need for blood units for the hundreds of patients, had an evident impact on public health authorities and their necessary actions. The local scientific community and patients groups at the time and today strongly support this programme of premarital population screening and option for prevention. In the early years of this programme and in the absence of advanced therapies and pre-implantation genetic diagnosis, termination of affected pregnancies, even though against religious values, was the choice of the majority.

¹ See Beck 2005, Beck and Niewöhner 2009. For a comprehensive list of Cyprus-related publications by Stefan Beck, see pp. 121-132 of this volume.

The thalassemia prevention programme was a controversial issue internationally, and several bioethicists continued to discuss it in international fora, in some cases accusing the programme of eugenics. But local as well as many international public health experts clearly supported the option of prevention through population screening. The programme remains rather sensitive even today when there are elective births of affected children as well as new methods of management are available.

Stefan became interested in the national prevention programme for thalassemia in 1998, and he proceeded to interview laypeople, healthcare professionals, and experts in the field. He was particularly keen on finding out about the process leading up to the establishment of the programme, and how it was related to the development of the health system of colonial and postcolonial Cyprus.² His publications contained analyses and views not always shared by the local community of experts, but still he managed to keep their appreciation.

Through the years, Stefan remained interested in thalassemia and the consequences of this disease on Cypriot society and the evolution of social behaviour. Until recently he served as a consultant and researcher for RUBSI's project Psychosocial Aspects of Thalassemia in Cyprus, funded by the Research Promotion Foundation 2012-14, cooperating with Dr Costas Constantinou and Dr Constantinos Phellas at the University of Nicosia.³

Comparative Studies of the Social Impact of Biomedicine in Europe

The collaborations and discussions from the previous projects produced ideas for further cooperation. Stefan was the main architect of a successful grant application to the European Union's 6th framework programme. This involved a highly interdisciplinary team from the fields of sociology, philosophy, anthropology, science and technology studies, political science, economics, religious studies and medical genetics in six European countries. Under the title 'Challenges of Biomedicine – Socio-cultural contexts, European Governance and Bioethics', partners from France, Austria, The Netherlands, Sweden, Cyprus and Germany and from totally different disciplines, backgrounds and cultures worked on this complex project and encountered many difficulties, but they

2 See Beck and Lengwiler 2008. This volume also contains an English-language translation of an article that Stefan Beck published in Germany, on the development of the Cyprus thalassaemia prevention programme. See pp. 99-120 of this volume.

3 A paper on this project is included in this volume, see Loizou *et al*, pp. 31-48.

also gained true fulfilment. Genetic testing and organ transplantation were the cases-in-point and we compared countries in terms of both the legal and institutional frameworks for healthcare and the notions of health and illness prevalent among the populations.⁴

I was responsible for the Cyprus subproject of the consortium in my capacity as the Clinical Geneticist at the Archbishop Makarios III Hospital, and I worked in close collaboration with Costas Constantinou, now a professor at the University of Nicosia, who developed his PhD thesis on organ transplantation. I look back on this period with great nostalgia as, beyond my interest in the project itself, I can recall the intensity of the discussions, the exchange of ideas and views and even the disagreements. The experience of interviewing laypeople and patients on everyday practices of medicine and genetics was extremely useful and eye-opening for me. Stefan and Costas had the patience to accommodate my busy clinic schedule in order to support our part of the project tasks. Volunteers, whom we interviewed, included patients at the clinical genetics clinic and their families, people personally involved in organ transplantation as donors or recipients, as well as laypeople. They have all been very enthusiastic about this project. As a reward for the long hours of work, we were lucky to share friendly outings for drinks and meze not only to continue discussing and exchanging ideas but even more to enrich a long-lasting friendship and respect.

Bone Marrow Donation and the Karaiskakio Foundation

Under the leadership of Pavlos Costeas, the Karaiskakio Foundation and the Cyprus Registry for Bone Marrow Donors (CBMDR) became one of the most prominent and successful registries around the world. In 2000 and 2003, calls for bone marrow donors to help children suffering from leukaemia on both sides of the Green Line mobilized tens of thousands of Greek and Turkish Cypriots to register at Ledra Palace as potential donors and to give tissue samples for further testing. Stefan was excited to be able to do research about these events. His interest was not only in the altruistic motive of donation as such, but how people from the two opposing communities, Greek and Turkish Cypriots, came together for the common goal of saving lives. Stefan conducted interviews with bi-communal activists in this context. In later research in 2004 and 2005, Stefan used bone marrow donation more generally for theoretical inquiries into the social basis of altruism and generosity. For this reason, in 2005, he conducted a series of interviews with individuals who had actually undergone operations to donate

⁴ See Amelang, Anastasiadou-Christophides, *et al.*, 2011. A contribution by Katrin Amelang, who worked as a researcher in the subproject led by Stefan Beck, is included in this volume. See pp 49-65.

bone marrow for people suffering from leukemia in Cyprus.⁵ Costas Constantinou (then working with the above-mentioned EU 'Challenges of Biomedicine' project) and Efi Avgoustinou (of CBMDR) assisted Stefan in this research in 2005. Stefan and Pavlos Costeas became and remained good friends from then up till Stefan slipped away from us.

Other Research Interests in Cyprus

In Cyprus, patients' role in the health system, and the pronouncement of their rights became topical when Christos Eliades founded the patients rights organization, KIDDA, back in 2000. Stefan became involved immediately. He also closely followed the initial steps of the establishment of the Cyprus National Bioethics Committee. He kept informed on opinions published on matters such as medical research and its regulation, assisted reproduction, surrogate motherhood, and pre-implantation diagnosis, and discussed matters with Pavlos Costeas, Christos Eliades and me, when we were active members of the first national bioethics committee.

Of course, besides his Cyprus-related work, Stefan conducted many other research projects in medical anthropology, most of them based in Germany. Assisted reproduction and the transnational medical mobility of patients triggered by different legal systems was one of the topics that he and his colleagues addressed. He was principal investigator of a research project at Humboldt University in Berlin that dealt with reproductive medicine in comparative perspective between Germany and in Turkey.⁶ For this reason, Stefan was interested in the development of fertility clinics in Cyprus. He conducted a number of interviews with experts in the field, among them Dr Dimitris Papapetrou.

For Stefan, medical anthropology was a lens through which he studied the modernization of Greek Cypriot society. He met a large number of people, laypersons, experts as well as politicians and administrators. It is my impression that although he had many good friends and followers, some people were able to appreciate his scientific broadness and wisdom and his personal qualities only rather lately. As he wrote in his article on reproductive technologies: 'Anthropology has a history of being uncomfortable with intervening in the cultures we study. And with good reason...'

⁵ Among others, see Beck 2011.

⁶ See Knecht, Klotz and Beck 2012.

Passing from Cyprus: A Personal Farewell

It is not easy to write or talk in memorial of a dear friend! If you also feel that this person's departure was premature, it makes it even more difficult since you feel it was not fair. Death is the only definite moment after birth we all know about, which very unwisely we keep refusing to acknowledge, or we remain in denial. Of course it is totally impossible to lead a 'normal' life under a permanent perspective of the unexpected expected death. Therefore, we keep postponing things until tomorrow! I do not know how much this applied to Stefan Beck, but I do suspect he did not take into consideration any physical signs he might have had of his illness, working through an increasing load of intellectual effort, and therefore always postponing rest and relaxation for later! I also always postponed for the future my plan to visit Berlin and spend promised days with my close friends Stefan and Gisela.

I had the privilege to thoroughly discuss with Stefan many subjects, starting from the cystic fibrosis project and moving on to thalassaemia. As an interviewer and researcher Stefan was very polite but at the same time very insistent, as he had masterful skills in questioning and getting answers. He had a true gift for ethnography. He would dig down to things and sometimes would make you disclose the truth that you had not wanted to share! He interviewed me as a health professional in the field of medical genetics and genetic counselling. We gradually became friends and this friendship extended to include his wife, Gisela, who is also an anthropologist, and my family. We shared crucial moments in life and accumulated many memories. I remember we were working together on a proposal on 11 September 2001. We had just walked home to have lunch with my children and as the TV was on we watched the Twin Towers in New York collapsing! Lives were never the same again as terrorism became and remained part of everyday news. A few days later I had to fly to Italy, where I was lecturing on cross-cultural perspectives in genetic counselling. Evidently sharing views and, at the same time, living through irrational historical events had a great influence both on my teaching and practice.

I was really fortunate to meet him and have him as a special friend. Bodily identity and related issues were often at the centre of our discussions. I appreciated him as a very good listener and advisor to me whenever I considered and reflected on the applications of new medical technologies and medical genetics. We did not always share the same views on many aspects but we did share a need for examining and analyzing behaviour patterns and decision-making.

As science and more specifically genetics and biotechnology develop rapidly, new knowledge is changing our own perception of health and disease. This progress and knowledge has bilateral effects, both promising and disastrous. The Pandora box is now open and nothing or nobody can take it away. The only way to move forward is

to try to behave in a very cautious, culturally relevant and wise manner. Stefan's work exhibited the way.

Arriving at the end of this eulogy, I can only conclude that we are here to celebrate Stefan's life.

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Stefan Beck in discussion, 2007

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How Life Would Be Without Thalassaemia: Patients' Perceptions

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Abstract

This article focuses on the experiences of patients with thalassaemia in Cyprus. Through a qualitative study of 10 patients and their spouses, this paper shows that thalassaemia is a restricting experience due to blood transfusions and especially iron-chelation therapy, while without such a disease, patients would be better able to fulfil their goals in life. The research participants indicated that thalassaemia impacts on patients' personal identities and the fatigue and stigma that they often experience can cause disruption to their routine, social life, and leisure activities. The study was part of a larger quantitative study of the quality of life of patients with thalassaemia and was co-funded by the Republic of Cyprus and the European Regional Development Fund (EU).

Keywords: thalassaemia, chronic illness experience, Cyprus

Introduction

Thalassaemia is derived from the Greek words *thalassa*, which means sea, and *haima*, which means blood. It refers to a kind of anaemia that presents abnormalities in α - and β -globin synthesis (Manchin, 2014). Adult hemoglobin is 97% α - and β -globin, and thalassaemias are autosomal conditions that consist of abnormalities in α - or β -globin chain production. The most common forms of thalassaemia are α and β -thalassaemia, and it is estimated that around 100 million people throughout the world are carriers of the trait (Hadjiminas, 2004). In Cyprus, the most common form of thalassaemia is β -thalassaemia and it is characterised by familial trait chains. Caused by defective β -globin genes, β -thalassaemia can be subdivided into the trait, intermediate and major types. Thalassaemia trait refers to a heterozygous carrier state, meaning a person has one defective and one normal gene-encoding β -globin (Manchin, 2014). Couples who are both carriers have a 25% possibility in every pregnancy to have a child with thalassaemia

† Stefan Beck passed away on 26 March 2015.

(homozygous) (Hajiminas, 2004; Hatzouli, 2012).

Hajiminas, in his book *Cyprus and Thalassaemia* (2004), pointed out that thalassaemia was known in Cyprus since around the 7th century BC. This is verified by studies of bones and skulls discovered in archaeological excavations in Cyprus. Furthermore, Haldane's theory (1948, as cited in Kyrii *et al.*, 2013) supported that thalassaemia trait carriers were immune to malaria, which until the first half of the 20th century was one of the major causes of mortality on the island. This is the reason that many thalassaemia trait carriers survived and why epidemiology on the island showed large numbers of thalassaemia carriers (Kyrii *et al.*, 2013).

Cyprus was under Ottoman rule for around 400 years before it was colonised by the British towards the end of the 19th century. The British Public Health Services were determined to combat the huge problem of malaria and ultimately to identify and study thalassaemia (Hajiminas, 2004). After Cyprus became an independent state in 1960, one of the major public health problems that the public health services had to manage was that of thalassaemia. In the late 1970s a population screening programme that allowed the testing of students at school for the detection of the thalassaemia trait was planned and implemented. Thus it allowed couples who were both carriers to know in advance, through a prenatal examination, whether their child would be born with thalassaemia and to take the necessary measures. In this way, the number of children with thalassaemia dropped dramatically. In the past two decades the number of children born with thalassaemia fell to almost zero. The drop in the number of births and the low life expectancy of the people living with thalassaemia resulted also in the reduction of the number of the people who live with β -thalassaemia down to 650.¹

This study aims at presenting the impact of β -thalassaemia on both persons living with this chronic disease as well as on their spouses. More specifically, it will focus on how they experience thalassaemia and how they imagine their life would be without the disease. The analysis is based on the findings from in-depth interviews conducted with five men and five women living with thalassaemia in Cyprus and 10 interviews with their spouses.

Thalassaemia in Cyprus

Until the middle of the 20th century there was no long-term cure for people living with thalassaemia. Treatment was primarily based on blood transfusions without any successful method of chelation. These caused deformities in the body and facial bones, delayed sexual and reproductive development, and triggered complications, such as

¹ Latest statistics were provided by the Thalassaemia Centre, Ministry of Health. Republic of Cyprus.

cardiovascular disease, diabetes and other chronic conditions (Hajiminas, 2004). Because these serious problems were caused by old chelation therapies, life expectancy was very short and people died quite young. With modern chelation therapies, complications are prevented, life expectancy has been increased, and people with thalassaemia can survive as long as any other healthy person.

Because of the high morbidity of the thalassaemia patients and because of the high prevalence of the chromosome carriers (estimated at 12.4% of the population in the 1960s), the government decided to implement a population screening programme in schools, so as to detect thalassaemia in youths and to prevent births of thalassaemia homozygous children (Hajiminas, 2004; Kyrri *et al.*, 2013). The Church of Cyprus supported this campaign and asked couples for a certificate of thalassaemia before issuing a marriage permit, and it recommended that people who were both carriers should not get married or should not have children (Hajiminas, 2004).

Quality of Life and Complications

Hours of blood transfusions, hours of chelation, body harm, social stigmatization, mainly because of deformed external features, and social exclusion are some of the factors that might cause a poor quality of life for people who have thalassaemia (Hatzouli, 2012). Studies show that bad chelation is associated with bad quality of life, mainly because of the complications, and that the modern method of chelation contributes to a better quality of life (Gollo *et al.*, 2013). Especially, long hours spent in hospitals for blood transfusions and other diagnostic tests pose a problem for people living with thalassaemia (Telfer *et al.*, 2005).

Furthermore there is a social stigma associated with thalassaemia (Hatzouli, 2012). This is associated with the general beliefs about what is considered normal and what is considered different regarding health, but it is also associated with health beliefs and the way thalassaemia is managed and treated by the individuals and their families.

Bad chelation can lead to complications due to hyperperfusion, which can cause several other conditions. Complications involve skeletal deformations of the skull, in which the person's cheek bones are more prominent whereas the bridge of the nose is depressed. Also the thorax bones can become deformed and the spleen and liver can become enlarged. Furthermore, there is skin and eye discoloration, as well as bone marrow dysplasia (Hajiminas, 2014).

It is important to be aware of the possible complications and chronic conditions encountered by patients with thalassaemia, also due to hyperperfusion. GPs can help support patients to coordinate their care between haematologists, cardiologists,

hepatologists, psychologists and genetic counselors to promote a better quality of life and improved survival (Manchin, 2013).

Because thalassaemia is a chronic condition, it is imperative here to outline some basic concepts in the sociology of chronic illness, which will be helpful for understanding our participants' accounts.

Chronic Disease: Some Basic Concepts

In the past few years infectious and acute diseases have given way to chronic conditions, described as health transitions, mainly because of the great advancements of the medical science (Manderson and Smith-Morris, 2010). These changes are also attributed to the high level of industrialization and urbanization that has altered the lifestyle of people around the world. Chronic conditions account for around 60% of global mortality, and in many cases they co-occur, causing a huge burden on political and economic conditions globally.

According to Nettleton (2015) the onset of an illness means that the person's everyday life is disturbed both physically and mentally. This disturbance has an impact both on the patient as well as on the family and carers, the latter in the case the person cannot self-care. Illness reminds us that the 'normal' functioning of our minds and bodies is central to social action and interaction, especially between the body, the individual and society. At another level, the degree in which the person depends on others to be able to perform self-care and duties contrasts the well-recognized social values of independence, which is related to self-image and self-confidence. Moreover, Lazarus and Folkman (as cited in Fitzgerald Miller, 2000) recognize a series of function coping procedures which are jeopardized in the case of chronic illness. Such procedures include the maintenance of equilibrium, sound decision-making, maintenance of autonomy and freedom, meeting social demands, controlling stressful factors that can become a threat and avoiding negative self-evaluation.

Talcot Parsons (1951, as cited in Nettleton, 2015) analysed what he described as the 'sick role', making a distinction between the biological and the social basis of illness. On the social level he describes illness as a form of deviance from what is considered normal. However, the sick person is allowed certain rights and privileges, but also obligations. Privileges include the right of the sick person not to fulfill everyday normal social obligations. The person is not held responsible for his/her illness. However, the person has the obligation to want to get well and must seek medical help in order to treat the condition of sickness. Furthermore, as Friedson argues (1970, as cited in Nettleton, 2015), the sick role is related to a wider social context and therefore it is also associated with the changing identity of the person because of this very experience of

illness. Friedson also distinguishes three types of legitimacy of the sick role. The first type refers to when the sick person's condition is temporary and curable, and therefore his access to the sick role is temporarily legitimate. The second refers to when the patient suffers from a lethal disease and cannot take action to overcome illness, in which case the patient's access to the sick role is legitimate. The third case refers to when the illness is stigmatising (e.g. AIDS) and societies do not encourage the person to have access to the sick role and to seek help in order to become well. (Constantinou, 2014).

According to Bury (1997), chronic illness can cause biographical disruption in two ways. First, patients may experience disruption of routine. Such disruption may cause feelings of uncertainty because lack of routine is linked with lack of sense of safety and predictability. Second, patients may experience disruption of their biography in the sense that the person's identity is lost or changed. This is associated with the fact that the person is adopting a new self, based on the new adopted role that is inevitably acquired with chronic conditions or disabilities.

Methodology

This qualitative sociological study was part of a bigger survey that explored the psychological and social needs of people living with β -thalassaemia in Cyprus, which is the most common form of thalassaemia found on the island. The qualitative part is based on in-depth interviews with 10 people with thalassaemia and their spouses which were conducted between 2013 and 2014. The sample was randomly selected from the list of members of the Cyprus Thalassaemia Association and it included persons living in urban and rural settings in the area controlled by the Republic of Cyprus. The in-depth interviews were based on a semi-constructed questionnaire that contained basic questions that were used for comparison purposes. Furthermore, there was a free discussion between the researcher and the interviewee that allowed the interview to take the form of a narrative.

The questions were based on the impact of thalassaemia on everyday life of both the person as well as his/her family. In particular the interviewees were asked about the burden caused by the need for frequent blood transfusions and the chelation methods, the anxiety or stress that the interviewees perceived they suffer from because of the treatment methods, but also from the possibility of suffering future complications that is quite often the case for people living with this condition, the impact that thalassaemia has on planning for the future, and the social stigmatisation that they may have encountered over the years. The interviews were recorded and transcribed and they were then coded and analysed using the Atlas-Ti software. The study was conducted after being evaluated and approved by a national bioethics committee. All interviewees signed an informed

consent, but all information was treated anonymously, for purposes of personal data protection.

The sample consisted of five men and five women who have thalassaemia and are between 31 and 58 years old, and their spouses. All of the persons with thalassaemia perform blood transfusions and chelation. The older persons with thalassaemia present the characteristic external physical features that are the result of bad chelation methods of the past. The younger people do not have these features because modern chelation methods (usually oral) do not cause deformities of any kind.

This paper focused primarily on the question posed both to the person living with thalassaemia, as well as his/her spouse, asking how they would imagine life without thalassaemia.

Findings

All the persons living with thalassaemia who participated in the study are treated with blood transfusions and chelation. There were three different chelation methods used by the group. The majority performs chelation with a pump; two of them use a pump in combination with oral chelation, and two of them use only oral chelation.

Blood transfusion is commonly performed once a week or twice a month depending on the needs of each patient. The patient has to visit the specialist thalassaemia centre where the transfusion is done, and it can take up to four hours. The length of time required to complete a blood transfusion places a huge burden both on the person as well as the family, as admitted by both the person as well as the spouse.

Time Scheduling

The hours spent on blood transfusion seem to cause a problem regarding the fact that scheduled days need to be very well programmed. One man described the time lost as being booked for the whole day:

‘It is not so much the suffering; it is that I have to go every week and I need about 2 hours to transfuse one bottle of blood. You somehow get out of your general schedule, because you need to have one whole day blocked specially for this purpose.’

Another woman stressed:

‘You do miss a day from your life. It is not just the two or the three hours you will lose, but you need to also schedule the children not to have any classes, because who will give them a lift? I need to finish early if nobody else can pick them from classes.’

Time schedules seem to also have a certain impact on the work life of some people, especially since the work hours often coincide with the transfusion hours. One

participant pointed out that it was necessary to make special arrangements with his bosses at work so that he can leave earlier:

‘The transfusions are usually in the afternoon. I need at least three to four hours each time. Now I have a problem at work as the civil service has changed the work schedule and I get off work at 15.30 the earliest. The thalassaemia clinic closes at 19.00. You understand that I cannot get there at 16.00 and have two bottles transfused. I would have to make it very quickly and this might have an impact on my health condition. I am still negotiating with my superiors on how to arrange this matter. They tell me not to worry, but when you have to leave earlier all the time, you can understand that it is an issue.’

This is also combined with the fact that sometimes there is no blood available on the day scheduled for transfusion, which is something that also poses a problem at work. Some people get off work later, especially in the private sector where work hours are different than the civil service, and they need to take time off for the transfusion. This means that they need to alter days off, something that causes additional problems with work schedules.

Fatigue

Fatigue seems to be an important factor, which could potentially have a negative impact on patients’ daily life and integrity. One lady described the level of the fatigue she feels:

‘You won’t know what fatigue means. I feel that I am tired, especially when it is due time for a transfusion. I feel weak, I feel tired, I feel that I cannot cope with everyday chores. In the old days, when I was alone, I could maintain my haemoglobin at the same level, but I would come back home (from transfusion), sit and rest. Now I have the children, I have to help them with homework, to take them to afternoon classes, to do this, to do that...to... There are so many things to do and you get even more tired. And when night comes, the only thing you want to do is sleep early, by 10 p.m. the maximum.’

On the other hand, transfusions do not seem to bother the spouses, but they point out that they empathise with their spouse for having to go through this whole procedure:

‘It does not bother me personally, because it concerns him as an individual. It bothers me to see him come back at 7.30 in the afternoon tired from the transfusion, after a whole day’s work; it does bother me at the psychological level that what he is doing is so tiring and difficult, however he never complains. But to be bothered personally otherwise, no, it doesn’t. It is just the sentimental thing It is only that I know that he suffers.’

Another problem that arises due to blood transfusions is travelling abroad, as people need to schedule their travelling around their blood transfusions. This means that it is difficult to be away for more than a week, because as time passes, the body has a greater

need for transfusion, and the more fatigued the person tends to get. Also it is not easy to have blood transfusions in another country, as there is a lot of bureaucracy involved. The problem with travelling abroad was mentioned by the persons with thalassaemia themselves as well as by their spouses.

Fatigue is not only caused by blood transfusions, but it is also associated with the chelation methods that were used in the past, although chelation methods have been modernised since then. Pump chelation, according to the participants, means that on a daily basis a pump is inserted with a special needle into the body and has to remain there until the long process is completed. One woman, who was the oldest of the participants, focused on the fatigue that was caused mainly by the discomfort of having to pierce the body every day to use the pump:

‘Look, I have been using the pump since the age of 10. For the past years, a period of 30 years, I used the pump. Eh, I reached a point that my body could not take it any longer. I mean that I could not endure it any longer psychologically. I was disturbed mainly by the piercing and the swelling of my feet, because it is administered subcutaneously and it makes your feet swell and everything.’

Another woman, who is a teacher, said she prefers to use the chelation pump only in the summer, because the pump is visible under the clothes and she does not want the students to ask questions about it:

‘It is a 24-hour thing. When I go to school, because life at school is very active, I sweat a lot and the pump causes extra perspiration. It also causes me itching as it is administered under the skin. So I prefer to do it in the summer when I am at home, although the doctor insists that I do it year-round. I only do it in the summer and in the winter I prefer to take the tablets, which, of course, is not sufficient. However this safeguards that the pump, which is covered in plastic, will not slip away from perspiration, running the risk of the children noticing it. It might fall out of my pocket, or the wire might hang out.’

The chelation device also causes problems for people who want to participate in outdoor activities during the summer, especially swimming: ‘I refused the device because it is quite thick and you cannot conceal it if you wish to. And of course I cannot deprive my child from going to the sea in the summer to swim, because of the device.’

The spouses also seemed to realize that chelation processes are an additional source of inconvenience for their husband or wife, but they thought that the person is accustomed to it, although, in combination with transfusion, it seems to have a physical and psychological impact mainly on the persons themselves:

‘Yes, ok. Definitely it is something that affects her (his wife), because surely she would feel differently if she did not have this additional burden; the visits to the doctors, the

chelation, the transfusion. All of these are definitely negative, but she accepts them. They are incorporated in her life.'

Further Treatment

Medication and tests are another factor that is part of the life of a person living with thalassaemia. They need to be constantly alert for both medication as well as further testing:

'... You take a lot of pills. Every 15 days you need to go to the hospital to have blood tests in order to be able to determine further treatment, when you have to do your transfusion, how much blood you need to transfuse. You understand that this is a constant friction, from the moment you discover that you have the anaemia, until your time comes to leave this earth.'

In addition to blood transfusions and chelation, people living with thalassaemia have tests to do, which are related to transfusions (for example as stated above, they need to check their blood before the next transfusion), as well as to complications of thalassaemia (Hajiminas, 2014). Such complications can be cardiovascular, diabetes mellitus, and osteoporosis. Persons living with thalassaemia have to go through regular testing, either in order to prevent such complications, or in order to treat them if they are already present. This means that our participants have to spend additional time in hospitals for the testing or to get further treatment: 'Diagnostic tests have to be done with other specialists, for example with a cardiologist. I have to have MRIs, thorax X-rays, abdomen ultrasounds, etc. You can realize that these are morning appointments; I have to leave from work again.'

Childhood Experience of People Living with Thalassaemia

Most participants admitted that they had a difficult childhood due to the need for blood transfusions and the bad chelation methods. When they were children, they were different from their peers because they frequently suffered from fatigue and they were considered very frail, due to their weakened immune system. Some of them admitted that they often had infections. For these reasons they were frequently marginalized and bullied. Also, they were stigmatized, mainly due to the fact that people with thalassaemia often died young from complications caused by poor chelation methods. This negative situation was also reinforced by the general public's lack of awareness on what thalassaemia really is and how it is treated.

A man, who is now in his 40s, described his life when he was a child:

'In my school life there were many things that my classmates could do and I could not For example gymnastics, sports, going out in the evenings. I was young and I felt confined. I did not go out 3-4 times a week like my friends did, or go around every day.'

I knew that I had to study, go out and play a bit, come back and take my bath and install my pump, so that I would finish my chelation early enough to be able to go to school the following day. I couldn't for example go to the amusement park.'

One woman said that she had wanted to take ballet lessons when she was a girl, and another man said that he had wanted to follow a football career, but both of these were unthinkable, especially for their parents who always felt they had to protect them.

The general public's lack of awareness about thalassaemia was also an issue, since quite often people were bullied and mocked. A woman described the conditions she had to live through during her school years:

'I was mocked at school. There was this girl that kept chanting at me that I am anaemic and that I will pass it on to her (she thought it was contagious). I told my mother and she said I should not listen to what they say....but I was extremely frustrated and so I beat her and pulled her hair out. I was deeply offended, but after that nobody dared say anything to me.'

Stigma

Many of the above experiences are associated with social stigmatization. As Alonzo and Reynolds (1995) define it, stigma refers to a category of people who are devalued by the broader society and whose life chances are lessened, with an ultimate consequence on their social intercourse (Green, 2009). Literally, stigma is 'a mark branded on the skin', and in another dimension it is a 'distinguishing mark of social disgrace'. According to Irving Goffman (1963), stigma is a social product generated by social interactions involving usually two individuals in separate roles, one of the normal and one of the stigmatized (Nettleton, 2015).

In the case of thalassaemia, the person's deformed external features, as well as being more susceptible to catching infections, and having to curtail various activities, play a crucial role in the social stigmatization of the individual. Moreover, as mentioned above, for many years thalassaemia was associated with a short life expectancy. The other significant thing is that for those who are trait carriers, others refer to them as 'having the stigma', meaning they have the particular chromosome, in layman's language. The whole stigmatization process has been reinforced by the population screening programme, which, according to some interviewees, it has contributed to the definition of thalassaemia as something evil, a disease that we should get rid of, so as to avoid people dying young. Hatzouli (2012) describes social stigmatisation of people who are heterozygotes as 'having the stigma', as the beginning of social stigmatisation for those living with thalassaemia.

One woman described the severity of the impact that social stigmatization had on the family:

'Parents need to be supported, so that they will be able to help their child to hold on, to adhere to the treatment without feeling embarrassed. Too many thalassaemics, just because they lacked support and they did not have the right treatment, their parents were too embarrassed for this thing; the children grew up in a closed home. They even closed the windows and stayed indoors in order to get their treatment and they came out the following day and neighbours and relatives never knew.' The same person faced discrimination and bullying from her boss, who felt obliged to employ her, although she never wanted to.

Especially regarding employment, some of the interviewees stressed the fact that it was difficult to get a job in the first place because of their external appearance. In their opinion, because of the small-sized communities in Cyprus, people are more prone to social stigmatization. The following statement by a man who was often bullied by peers is very characteristic:

'As it happens in most peer groups of youngsters, there are some people who want to present themselves as "chiefs", who are more crazy, who like to mock other people... Even if your ear is a bit small or big, they would mock you for it. Just think of me having this huge problem with my health, being bullied that I have this problem with my health. They mocked me that I was the "bloody guy" (because he had to have the blood transfusions). This is still in my mind very vividly after so many years. Many years might pass, but this will always be in my mind, because when they did this I was deeply disturbed.'

Imagine Life without Thalassaemia

Participants were asked to try to imagine what their life would be like if they did not have thalassaemia. The first thing that would make a huge difference is that they would not have to have the blood transfusions, the chelation and the medication that cause inconvenience in their life:

'I would not have to take so many tablets early in the morning. I would not have to get stressed about whether I have to take the tablets for thalassaemia, because if I do not, I will have problems with my iron levels and possible complications from there onwards. I would not have to spend my time in hospitals, to do my treatment, the blood transfusions, the blood tests, the MRIs, the CT scans, the osteoporosis tests, etc.'

Possible complications of course play their role, since they are a source of stress and anxiety, as described by one man:

'Ok, the only thing that is sure, no matter what you might think, I would not have all these worries: doctors, hospitals, transfusions. I would have more time and less worry that I have to do all this in order to stay well. And of course, because of thalassaemia

there were other complications, like osteoporosis, like the one that old people have. And for this I have to take medications and have tests all the time.'

Time seems to play a crucial role, as many of respondents stated that they would not need to spend so much time in hospitals for blood transfusions, tests and treatments and they could be spending all this time doing other things. The matter of fatigue was also emphasised, as it also causes difficulties with coping with all family obligations and their everyday duties and housework. However, there were some positive things said that mainly had to do with thalassaemia being an important contributing factor in their upbringing and in the way their character was formed. One person feels that his character would not be so good without thalassaemia:

'...For me thalassaemia has been a form of blessing; I feel it has protected me, it has made me a bit wiser and sensible, a bit more humble. I think if I did not have thalassaemia I might have followed other routes, more wild. I think it has helped me become a better person than if I didn't have it. I am saying this in the sense that it has made me think more of others. My lifestyle might have been a bit more...if I did not live with thalassaemia, I would have a more lewd life. My passions would be more intense, like gambling for example. This means that thalassaemia has kept me away from all this. I became a better person.'

Travelling seems to be an important factor for people living with thalassaemia. One man described what it means to be able to travel for someone who lives with thalassaemia and how different travelling would be without it:

'Only one thing would be different, that I am sure of and this is the capability to travel. Thalassaemia deprives you of the possibility to go on a long journey...this is because you need blood. If I decide to go to another country and stay a month, I cannot really do that, because I need the blood transfusion. If you wish to go to study abroad, as I did, you need to talk to doctors in that country, locate hospitals and everything else. Apart from that, there is nothing else I would wish for.'

Studying abroad is something another man emphasised, who decided not to go abroad to study because of his thalassaemia:

'Ok, you can make some thoughts for example. I might have gone to another country to live if I did not have thalassaemia. I might have studied further abroad, if I could continue my studies. Now just with the thought of going abroad, you would need to think of your circumstances: blood transfusion elsewhere, chelations elsewhere, new things, and more difficult. Your whole life would be more difficult. Ok. I am now working in our family business and I am doing well.'

Some of the respondents reported that taking part in sports activities would also be different. There are two factors that contributed to them not getting involved in sports

activities – one being the requirement to provide a health certificate to sports officials to be allowed to join a group:

‘I would certainly engage in sports. I did engage in sports up to the age of 18....It was impossible to continue, as a health certificate was required. Otherwise your team cannot cover for you. For example what will happen if you collapse on the sports ground? You do understand that these people would be in a lot of trouble, won’t they?’

The other reason for not getting involved in sports is that the persons themselves were persuaded that they could not do it. One woman described her own experience:

‘I continuously felt that I could not be involved in anything. For example I became 30 years old and I still wished that I could climb a tree, because I could not climb when I was a child. This is actually what stigmatised me: that I was 30 and I still wanted to climb a tree because I never did it when I was little. I went to the sea and did water ski, after my thirties. I went twice. I went to do things that I could not imagine before.’

Spouses also gave their own opinions of how life would be without thalassaemia. One of the things that seem to be important is the freedom of movement, as now they feel that this is limited, mainly due to the treatment schedules:

‘Freedom of movement is the most important thing. We are limited because when we go abroad we need to hurry back because of the blood transfusion in 15 days. Then theoretically it is ok, but as the day of the transfusion approaches, she cannot get up easily, she has pain in her bones, she is nagging, she complains. I know it is her own matter, but I am also disturbed as a human being. I cannot tell her that I want to go out today, if I see that she cannot do it, neither could I leave her alone at home. Of course you get accustomed to some things over time....When you decide to get into this relationship; you know all of this from the beginning. You compromise. I knew that and I still chose to proceed.’

One spouse was concerned about her husband because he had developed diabetes as a complication, since he frequently suffers from hypoglycemia. Living without thalassaemia would also spare the person from such worries.

Time planning was a factor that respondents said would be different if there was no thalassaemia:

‘It plays an important role in the sense that if there was no thalassaemia we would probably not have to do so much planning in our family life. This is because when he knows that on the scheduled day he will have to have the blood transfusion, we know in advance that we can schedule nothing else for that day. This strict need for planning

does of course affect the whole family. We all need to follow a certain schedule. Other than that thalassaemia has not really deprived us of anything.'

Discussion

Thalassaemia is a chronic illness that needs special treatment throughout the individual's life. Unlike other chronic diseases that might appear later during one's lifetime, the onset of β -thalassaemia appears soon after a person is born. It can even be detected during pregnancy. Therefore it is not easy to assume that, as a chronic illness, β -thalassaemia is expected to disrupt the person's biography, as described by Bury (Nettleton, 2015; Constantinou, 2014, 2012). Beta-thalassaemia is incorporated into the person's life from their childhood and their life course is planned and scheduled depending on the treatment and the course of therapy, and on their competence in the management of their condition. As for spouses, as soon as they entered into a permanent relationship with the person living with thalassaemia, they become aware of all the consequences and complications that thalassaemia carries with it and they have willingly and consciously taken on the 'burden' of living with a person with thalassaemia.

Both the attitude of the individual who lives with thalassaemia as well as that of the spouse seem to contribute to a smooth coexistence, acceptance and successful management of the situation. This is probably due to the fact that they might be sharing common beliefs and values about health and illness that have helped them to face hardships and cope with the condition. Årestedt, Benzein and Persson (2015), in a qualitative study on family beliefs on health and illness, show that 'when illness was viewed as a natural part of life, being aware of and prepared for new situations caused by illness was included' (p. 223). The results of their study also showed that families have beliefs that illness is a family affair, and therefore it was a matter of course to be there for each other within the family. It can also be the case that the couples that participated in the study share family beliefs that do contribute towards a positive attitude of the management of thalassaemia. These attitudes and beliefs also seem to contribute to the willingness of the spouses to take on additional responsibilities in order to secure the smooth function of their family and household.

The theme under question, which was how people with thalassaemia and their spouses imagine their life would be without thalassaemia, revealed that one of the most important barriers that thalassaemia poses is the number of the hours needed for the treatment and management of thalassaemia. Blood transfusions and chelation treatments take many hours, which means time away from work and from family life. In a study by Telfer *et al.* (2005), which examined the quality of life of 119 people living with thalassaemia in Cyprus and in the UK, nearly 40% in both surveys were

missing a great deal of time from work or school because of their transfusions or other thalassaemia treatments. In that study, patients suggested that arranging for transfusions during the evening, overnight, and on weekends would reduce absence from work or school and would enhance social integration.

Although many patients in our sample, as well as some of the spouses stated that life would be the same without thalassaemia, there are still some parameters that might be different and that would contribute to a better quality of life for the persons living with thalassaemia and their families. Such features were not mentioned before in other studies and it is the first study that explores the attitudes of both the patient and the spouse on this matter. In this sense, freedom of movement seems to be valued, meaning that thalassaemia would not be a barrier to travelling and to being involved in sports and physical activities. Another patient also mentioned that if she did not have thalassaemia, she would not be stigmatized, as she has been since her childhood.

It is also understood, and this agrees with other findings (Hatzouli, 2012; Telfer *et al.*, 2005;), that chelation methods in the past posed a hardship to patients, resulting in complications and deformities of their physical appearance, whereas new chelation methods prevent these complications. Thus, younger patients do not face the same problems as the older ones, and life without thalassaemia for them would not be that different.

Limitations of the Research

This survey has studied people living with thalassaemia and their spouses. It is apparent that over the years these people have developed a positive attitude towards their condition and that it has not had a negative effect on their self-esteem. This is probably the reason that they have proceeded with their life and enjoy good working and family lives. It would be interesting if an additional investigation could look at the lives of people living with thalassaemia who did not get married or did not progress with their lives in the way expected by Cypriot society. The sample that we studied had no problem in revealing the condition of their thalassaemia and the various parameters that give their lives a different dimension. However the participants themselves stressed that many patients with thalassaemia, with the cooperation of their families, conceal their condition, feel stigmatized and are ashamed about their situation, thus resulting in low self-esteem and no self-confidence in planning and living a meaningful and productive life, including getting married and having a family. It is the suggestion of the researchers that these people should also be studied, and it is a limitation that such cases were not included in the sample in the first place.

Conclusion

People living with β -thalassaemia undergo the same experiences as in any chronic illness. In the course of their lives the need to treat thalassaemia prevails, meaning that they must spend a great deal of precious time in hospitals and having treatments, which are often painful for the subjects. Time lost in treatments means time deprived from family, work and social encounters. However a positive attitude seems to play an important role in combating all negative situations that may arise from their conditions. This is possible also with the support and understanding on behalf of the spouses.

Life without thalassaemia then would not be that different except for where the various treatment requirements and their restrictions pose obstacles to a person's freedom of movement and ability to engage in activities.

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Anonymous Grafts and the (Un-)Making of Relatedness: Ideas of Donor-Recipient Relations in Cyprus, Germany and Sweden

KATRIN AMELANG

Abstract

Organ transplantation creates relations between persons (donors and recipients), but also filters this connection by producing de-personalized organs in an anonymous exchange. This article deals with grafts (transplants) as mediator of social connections. Differing ideas of the socializing effects emanating from organ transfer are comparatively explored on the basis of empirical material from Cyprus, Sweden and Germany. While Greek Cypriot respondents embraced the idea of donor-recipient relations more easily, German and Swedish respondents rather challenged it. As will be shown, this contrast presents two narrative modes of making sense of grafts and its binding effects. The article argues that the two modes address locally different cultural rationales as well as transplant medicine's ambivalent rationale of dealing with the socializing effects of (de-)personalised 'gifts'.

Keywords: Organ transplantation, organ donation, Cyprus, Germany, Sweden, donor-recipient relation, anonymity

Transplantation medicine creates human bodies as a site and source of medical intervention: Organs are extracted from one body, are in most cases transported over long distances, and are inserted in another, matched body, in which they have to be integrated as foreign body parts. In this respect, transplantation medicine establishes relations between bodies – by describing them as similar (e.g. regarding blood group, body size or tissue-type) and by transferring material substances. But organ transplantation also creates relations between persons – in most cases anonymous relations between dead donors or their relatives and recipients. The following article investigates the socializing effects emanating from organ transplantation by exploring how transplanted persons interpret the kinds of social connections that emerge from transferring vital body parts: Who, according to these views, is connected by organ transfer and what is creating the connection? What kind of social relation is established and what binding effects do grafts (organ transplants) have for recipients?

Asking how people think of themselves and their bodies as linked and affiliated

to others as a result of organ transplantation evokes cultural understandings and concepts of bodies as well as concepts of being an individual and of social relatedness. In Western cosmology the individual is thought of as a unique and autonomous entity, which is intimately linked to but at the same time easily distinguishable from other individuals. And it is clearly demarcated against abstract entities like society or a persons' environment. However, anthropological research reveals that these presumptions that are so deeply embedded in Western cultural common sense and that serve to stabilize the individual are culturally highly contingent. Contesting the universalising assumption of the person as an autonomous, free-standing individual, Strathern (1997) shows that Melanesian concepts of personhood are based on the idea of intimate interactions and material entanglements with other persons and things. There, the as 'dividual' thought person is clearly not the 'individual' of Western cosmology (Deleuze, 1992; Sahlins, 1996; Overing and Passes, 2000). Transplantation medicine intervenes into individual bodies but equally challenges this 'dividuality' in material as well as ideal dimensions. The transfer of organs thus serves as a probe into concepts of relatedness between individual persons (donor-recipient-relations) and between individual persons and society (social relations). Based on empirical research in three European localities the following article reconstructs concepts of donor-recipient relationships as social forms which reflect cultural concepts of how social relationships are imagined and associated obligations are managed.

The article's argument is based on comparative team research that took place in the EU project 'Challenges of Biomedicine: Socio-Cultural Contexts, European Governance, and Bioethics' (2004-2007).¹ The analysis draws on data from ethnographic interviews and focus group discussions, which were conducted in the Greek-Cypriot part of Cyprus (9), the German capital Berlin (11) and the southern-Swedish university town Lund (7).² Among the 27 participants were 18 persons who had received transplants, five relatives of organ recipients, one of whom donated a kidney to her husband, and four persons

1 Project details at: http://cordis.europa.eu/project/rcn/73927_en.html. Participant researchers of the anthropological team within the interdisciplinary project were Katrin Amelang and Stefan Beck in Germany, Costas Constantinou and Violetta Anastasiadou-Christophidou in Cyprus, and Anna Johannson and Susanne Lundin in Sweden.

2 The respective local data was collected by Costas Constantinou (Cyprus), Anna Johannson (Sweden) and me (Germany) in 2005. I thank my dear colleagues for the permission to use their material in this article and for our vibrant collaborative analysis and discussions during the project. It was Stefan who brought us all together. His sad death provided an occasion to revisit unpublished project material and to remember his sharing with us his intellectual curiosity for Cyprus and the cultural embeddedness of biomedical practices.

on the waiting list for an organ.³ Although not representative in the strong sense, the exploratory results of comparison reveal a striking contrast between Cypriot respondents and respondents from northern Europe with respect to ideas of social relatedness and dependencies resulting from the transfer of organs. While the assumption that a donor-recipient relationship is established by means of organ exchange was predominantly challenged by German and Swedish respondents, Cypriot respondents embraced the idea of donor-recipient relations more easily. To understand this difference in the ways how people describe and manipulate connectedness resulting from organ transfer is what the following article is all about.

In order to unpack issues of donor-recipient (dis-)entanglements in organ donation, I will comparatively analyse the variety of imagined donor-recipient relations in Germany, Sweden and Cyprus the backdrop of divergent social and cultural rationales. For a better understanding of the context, I will start by shortly outlining how the anthropological research literature situates the practice of organ transplantation socio-culturally. Then the (Greek) Cypriot material will be introduced to show local ideas of donor-recipient entanglement and invented relatedness. Afterwards the previously mentioned differing and opposite ideas of a disentanglement or denial of possible donor-recipient relations in the Swedish and German material will be explored. Finally, the findings will be discussed with respect to the costs resulting from the two different narrative strategies and rationales for dealing with the binding effects of grafts.

Situating Organ Transplantation as Cultural Practice

In the last 20 years transplantation medicine's basic rationale of how to define meaningful life and death has been equally put into question by anthropologists regarding the neutrality of its application in different cultural settings. Drawing on research literature I will show that transplantation medicine does not simply use available organs but makes grafts by transforming persons and bodies in a specific way, and by framing transplanted organs as gifts.

3 Participants were recruited via public flyers, key persons and the snowball system, hospitals, and patient associations, and were selected to be preferably diverse and balanced regarding criteria such as gender, age, education and religion. Regarding the latter, less variety existed: Swedish participants were mostly Protestant and all Cypriot respondents were Greek Cypriots and Christian Orthodox. The variety in the kinds of transplants – in Lund (heart, lung), in Nicosia (kidney, bone marrow), in Berlin (heart, kidney, liver) – did depend on the local transplant centres. All participants survived at least two years after receiving a transplant.

Making Anonymous Grafts – Transplantation Medicine as a Process of Depersonalisation

One focus of anthropological interest has been the particular view of the body organ transplantation is based on, namely the idea of a mechanistic and ‘replaceable’ body that is composed of ‘spare parts’ (Fox and Swazey, 1992). This understanding of the body is as much informed by the Cartesian legacy of separating mindful self from body (cf. Scheper-Hughes and Lock, 1987) as by the diagnosis of brain death preceding every post-mortem organ donation. Yet, given the ambiguous status of grafts, which symbolises simultaneously live-saving objects and life-donating persons, clear-cut distinctions between body and person remain challenging. Organ recipients and relatives of brain-dead organ donors might have difficulties in dealing with the particular segmentation of body and person when trying to solve the integration of their subjective body perception within the objectified view of body (cf. e.g. Kalitzkus, 2003a). Also the popular idea of dead donors ‘living on’ disagrees with the depersonalized conception of donor bodies and rather contradicts the Cartesian dualism by allowing some essence of the individual to survive in some form (Sharp, 1995, p. 364). Moreover, Lock’s study of the concept of brain death in Japan and North America shows both the negotiation of the re-definition of death within medicine as well as the different irritations with ambiguous entities like ‘living cadavers’ resulting from this specific location of a person’s death in the brain (Lock, 2002). Whereas Hogle points to the many efforts and ambivalences of separating body and person in organ procurement in Germany and partly the US when closely examining how dying bodies are technically and socially translated into ‘therapeutic tools’ (1999, p. 4), i.e. life-extending grafts. Both studies reveal the various actors, general infrastructures and specific local contexts that enable the liaison between organ donors and recipients in the first place.

What is important for the perspective of this article is an understanding of the making of disembodied grafts as process of objectification or depersonalisation. Persons are converted into brain-dead bodies and sets of organs that are depersonalised, object-like entities, which are dissolved from their former histories (cf. Hogle, 1999; Hauser-Schäublin *et al.*, 2001; Lock, 2002). While transplantation medicine creates connections between donors and recipients, it also filters this connection in a particular way by producing purified organs as standardised, anonymous entities. As abstracted a graft after these strategic purifications might be, in the end it is relocated into a new body and thus has to be re-embodied and re-personalized. Against this background I am interested in the graft as a mediator of social connections. The procedural efforts of purifying the organ can be interpreted as disentanglement of the organ’s personalised side and of the organ’s past position within the donor’s network of relations. The subsequent question is how research participants manage the relations ascribed to the organ, more specifically how they (dis)entangle the organs’ social relations.

Framing Donated Grafts – Organ Transplantation as Gift-Exchange

Another focus of anthropological critique has been the public representation of organ replacement. The technical relocation of body parts is, on a legal and social level, framed as a specific kind of transaction, namely donation, and thus it is marked as a non-commercial, altruistic act of giving. Questionable is not only the rhetoric of altruism and solidarity as legitimisation for the collective usage of individual bodies (e.g. Strathern, 1997; Sharp, 2001) but also the wrapping of organs as ‘gift-of-life’ and the implicit assumptions and moral implications inherent to the gift-metaphor (Ohnuki-Thierney, 1994; Fox & Swazey, 1992). Drawing on Mauss’ (1990) classical notion of ‘gift-exchange’ and its linkage to social relations and mutual obligations (of giving, receiving, reciprocating), several anthropologists note that local ideas and practices of reciprocal gift-exchange relations are impeded by the rule of anonymity. The anonymously donated graft ‘lacks the most critical element of gift-giving and exchange: social relationship’ (Ohnuki-Thierney, 1994, p. 241, accentuation in original). Giving and receiving generate social bonds of mutual interdependence, and the act of giving creates a (gift) debt and accordingly the obligation to reciprocate (giving in turn) (Mauss, 1990). Since anonymity prevents not only personal relationship but also possibilities of reciprocity, organ exchange is rather viewed as ‘incomplete exchange’ (Kalitzkus, 2003b). These critical observations on organ donation as gift-exchange shift the focus from social relations per se to the obligations resulting from these relations. Yet, there have also been critical comments questioning whether, in the transaction that is constructed as donation and intermingles gift, commodity, altruism and money, the interpretative focus on reciprocity is not once more concealing ‘what is missing’ (Strathern, 2012).

Invented Relatedness and Donor-Recipient Entanglements (Cyprus)

Before outlining Cypriot respondent’s views, some local specifics have to be kept in mind regarding the different local transplantation situation which is mirrored in the recruitment of persons and points of references respondents draw when discussing transplantation medicine. Besides local variation in size of population and thus absolute numbers of transplantation, differences concern the mode of donation. Swedish and German respondents mainly refer to deceased donors of solid organs, which is, despite current increases in living donation of kidneys and part-livers, the main form of donation. Cypriot respondents, in contrast, more often refer to living donation of kidneys and

bone marrow.⁴ Questions of a graft's binding effects arise differently depending on whether one firstly has a living or deceased donor in mind when approaching the issue. Yet, this difference presents in addition distinctive local preferences of living or deceased donors, which are based on local ideas of social relatedness and dependencies resulting from organ transfer. In other words, Cypriot respondents prefer living donors, whereas Swedish and German respondents favour deceased donors – as will be shown – exactly because of their contrasting ideas of donor-recipient relations and obligations.

Imagined Relatedness – Binding Substance?

That there is a relationship between donors and recipients appeared to be common sense among Cypriot respondents. All of them spoke about a special bond grounded on feelings of closeness. The question was rather how to classify this specific relation. Several Cypriot respondents picture an intimate, kinship-like connection between donor and recipient. Kinship relations function as reference point to designate the donor's specific status and articulate intimate relatedness. Moreover, kinship-vocabulary provides a tool to express the different nuances of imagined donor-recipient relations. For example, when the donor is imagined by one respondent as a cousin, familial relatedness is clearly marked as one of second-degree. But what exactly is creating the intimate connection? Is it, as the reference to kinship suggests, the shared bodily substance?⁵

Asked what actually binds donors and recipients together, a 50-year old dialysis patient from Cyprus inquiringly says from the perspective of a donor: 'What else from giving a part from my body, would I need anything else?' Depending on interpretation, either the bodily part, or the act of giving it, is emphasized in his statement. Imagined donor-recipient relations are thus created biologically and socially. In several Cypriot accounts, intimate feelings of connectedness are associated with both substance and the act of exchange. What a recipient is given is not simply a graft in the sense of technical object or mere body part, but as one Cypriot respondent put it 'life' and thus 'something inestimable'. It is because of this, continues the 25-year old, that '[f]or your whole life, you will be indebted to this person.' What connects, in his and other Cypriot respondents' opinion, is the life-generating capacity of the graft and hence the

4 Except kidney transplantation, which is often based on living donation, transplantation of other solid organs is rare in Cyprus: In 2014 there were 22 transplants from living donors and nine transplants from five deceased donors (<http://cyprus-mail.com/2015/10/16/cyprus-tops-living-donor-list/>). In contrast, bone marrow donation is much more present in public discourse, and the Cypriot Bone Marrow registry is, with 100,000 registered volunteers, one of the most successful bone marrow registries internationally (Beck, 2004, 2011).

5 Despite its extension to 'elective affinity' or 'social family members' kinship is, in the 'Euro-American' context, still prominently based on shared bodily substance (blood, genes).

effects of the substance exchanged, less the substance itself. Similarly and with respect to kidney transplantation, Constantinou (2010, p. 3) shows that a graft is understood in Cyprus as an enormous gift, because it allows the recipient to return to normal life and to become a social person again.⁶ The immeasurability of 'life' has consequences for the ways respondents conceptualize the donor-recipient relation and above all its associated implications.

Negotiations of Anonymous Intimacy

If one follows Mauss (1990), the bond between the two gift-exchanging parties does not result from the gift itself, but from the relation of the one receiving to the one giving. This emphasis on the exchange relation resonates with the difference Cypriot respondents draw between giving and receiving when discussing the kind of relation anonymous but intimately entangled donors and recipients might have. Most of them grant 'their' donor rather than the recipient an exceptional position in terms of relatedness. Conversely, a donor can 'choose' which closeness of relationship he or she desires, whereas a recipient cannot – because s/he may feel or is expected to establish a long-standing relation of exchange in order to reciprocate. Cypriot respondents thus point to the different positions donor and recipients have within the exchange relation.

Many of them frequently expressed from the perspective of recipient the wish to meet the donor or the donor family and have a good relation with them. Interestingly, the Cypriot bone marrow donors whom Stefan Beck spoke to expressed a similar desire: They, too, wanted to know about 'their recipients' and struggled with the 'unfamiliar type of relationship' established by organ transfer (Beck, 2011, p. 108). He suggests that this relationship, which 'is characterized by an anonymous intimacy and an existential entanglement with strangers', does not only include ambivalences but also 'the potential to engender new visions of the social, the self and the biological' (ibid.). Beck based his optimistic view of 'alternative social ties that lies below or beyond the "ethnic social"' (ibid., p. 113) on bicomunal donor-drives, in which Cypriots from both parts of the divided island demonstrate humanitarian action and altruistic behaviour by their willingness to register and eventually become a bone marrow donor exchanging bodily substance with the 'other side'.

Shades of Indebtedness and Fractured Reciprocity

Nonetheless, the Cypriot material from our project indicates that in face of the 'Cyprus problem' the balancing of reciprocity in imagined donor-recipient relations can become

⁶ The quality of post-transplantation life (did one really restore one's former self) influences how the relationship is articulated and feelings of indebtedness are expressed (Constantinou, 2010, p. 117).

a delicate issue. While all (Greek) Cypriot respondents would unhesitatingly donate a graft to a Turkish or Turkish Cypriot person, they expressed far more reluctance regarding the thought of receiving a graft from a Turkish Cypriot and especially from a Turk. This hesitation with respect to receiving was based less on a fear of physiological 'pollution' with the critical 'other', but the perceived outcome of receiving a graft in terms of the position one has within the exchange-relation. If, as outlined above, emerging relationships and feelings of affinity between donors and recipients are assumed, one would have to picture a long-standing, intimate relationship with a Turk – which would be contrary to what many Greek Cypriots would wish or dream of. On the one hand, the hesitation might be seen as articulated prejudice and stereotypes based on a political conflict. On the other hand, the distinction between giving and receiving shows, according to Beck and Constantinou (2006), that Cypriot respondents are quite aware of what Pierre Bourdieu (1997) labelled 'legitimate domination' resulting from giving, or 'inescapable submission' following receiving. Likewise, these constellations which define different positions and dependencies of the two parties involved in the exchange-relation can be found in the preference of relatives to strangers as donors some respondents expressed.

The reason given for this preference is, according to a 55-year old respondent, who received a kidney from his wife, 'the Cypriot attitude'. Explaining what he meant by that, he said one feels less obligated when the donor is a family member: 'If it is your brother, then it is your brother; will blood turn into water?' Earlier he had noted that 'In Cyprus we have not learned saying "okay, we found an organ from an accident", it sounds like they are afraid.' In this logic, what Cypriots are afraid of are anonymous intimate relations and prevented reciprocity. Constantinou (2010) explores the expectations and obligations of family members and strangers with respect to organ donation as gift-exchange in more detail. Because family members are viewed to be in a constellation of constant exchange and interdependence, gifts given within the family do not create any obligation to reciprocate. Since, reversely, strangers are not considered by Cypriot respondents to be obligated to donate, their giving is praised as precious, exceptional or even 'sacrifice'. For this reason Cypriot respondents or recipients feel more indebted and obligated towards an unfamiliar donor or the unknown donor relatives (Constantinou, 2010, pp. 110-113).

The rule of anonymity in transplantation law precisely aims at preventing the potential exploitation resulting from the wish to reciprocate the immeasurable. Yet, as has been shown, for Cypriot respondents there are no gifts without expectation to return; for them the intimacies entered with organ transfer cannot be separated from issues of reciprocity. Because the donor cannot be identified, for Cypriot respondents both, the wish to meet the imagined intimate, just like possibilities of reciprocity, fail.

In a way, one could say Cypriot respondents refuse to forget the silent bond created by the act of exchanging bodily substance; what their statements do not conceal but address are the binding effects of grafts.

Denied Relatedness and Disentanglements (Sweden, Germany)

Only a Romantic Thought

The assumption that a special bond between donors and recipients is deriving from organ transfer was predominantly challenged by Swedish and German respondents. The issue at stake was if there actually is or can be a relationship. ‘Actually, there is no relation, of course. But it’s an object that you receive’, notes for example, a Swedish respondent in her sixties who has no personal experience with transplantation medicine. The objection of the interviewer, that this object is still part of another person, is immediately corrected by her: It ‘is not’ but ‘used to be’. As the interviewer thereupon reminds her of her earlier view that organ donation is a way for the donor to prolong his or her life, she puts the issue straight: ‘That’s also a romantic thought. It’s not a realistic thought. [...] just like you prolong your life through children – those are the same kinds of romantic thoughts.’

A 57-year-old German liver recipient knows that her donor was a 42-year-old man.⁷ Asked how she would describe her relation to him, she says: ‘Odd question. My relation...? I have no relation to him at all. I don’t’. Despite shortly wondering if it is better to know anything about the donor or not, she emphasizes: ‘I’m not superstitious, I like the organ, and I regard it as mine. I’m glad to have it because he [the donor] couldn’t use it anymore, anyway.’ In both statements the graft is dissociated from the donor as person without any problems and thus viewed as object. While the donor of the German liver recipient is present to a certain extent, the relation to him is at the utmost describable as a matter-of-factly and de-emotionalized thought. The graft is not only detached from the donor but rendered dispensable from the dead donor’s perspective. The graft becomes an independent object of personal usage; its ownership is shifted or reassigned with the transfer into another body.

The two selected reactions are typical among Swedish and German respondents, transplanted and non-transplanted alike. Grafts are viewed as object-like entities

⁷ She learned this information from her patient file, which had been left unattended while she was waiting to be transported. As she reported this story in the focus group, a short discussion arose between two participants if this ‘opportunity’ was a mistake and a violation of anonymity or a ‘coincidence’ that had been arranged to let the recipient know at least about the donor’s sex and age. In Sweden organ recipients can learn about the sex and age of the donor if they wish to do so. Not all of the Swedish organ recipients have used this possibility, since this kind of knowledge was mostly considered irrelevant.

independent from persons and possible binding effects these bodily substances and their histories might create are negated. In order to untie the organ from the donor and his or her history and thus to disentangle donor and recipient, Swedish and German respondents most often employed 'rationality' to legitimise the presentation of individual (normative) standpoints as factually 'true'. To be more precise, they differentiated between 'romantic', 'superstitious' or 'implausible' thinking on the one hand, and 'realistic' or 'rational' thinking on the other hand. In doing so they emphasized that a donor-recipient relation is, if anything, only imagined and thus unreal. Within this 'rational' argumentation the circumstance that the donor is dead and anonymous was an important point of reference.

Too Much Emotion

Coexisting with the de-emotionalized claims were nonetheless more contemplative statements about the binding effects of grafts. A 47-year-old Turkish migrant, who has lived in Berlin since the 1970s and received a liver transplant in 1996, started his argument like so many: 'No, there is no relationship, no relationship at all. You can never forget. You know, you owe your life to someone, but that's it. There is nothing else. How could there be anything else? You won't find out!' The phrase of owing one's life to another person introduces a strong ground for a social relation and points to the notion of indebtedness. Yet, the indicated bond is cut off in the light of anonymous donation. That this cut is controvertible is evident in his continuation: 'You wouldn't want to bother with it too much yourself, and destroy [yourself] because it's also connected with a lot of sorrows on the other side. And you don't necessarily want to know all about their [donor relatives'] sorrow.' Implicitly referring to the 'troubling paradox of organ transplantation' (Hogle, 2003, p. 62) – the death of the donor as precondition for one's own survival – the negation of donor-recipient relations becomes in this account a product of denial or non-bothering. The object-like graft is connected to donor relatives' unspecified sorrows, i.e. their material and social loss of the donor as a person. This kind of bothering is viewed as bearing the risk to be unbearable and even destructive. To cut the social ties of the graft and disentangle with the donor or donor relatives can hence be interpreted as a strategy to prevent unsolvable pondering – as the above quoted respondent put it: '[Y]ou'd rather hide your head in the sand, and won't hear of it.'

The death of the donor indirectly links recipients and donor relatives. Anonymity becomes in this context a welcomed rule because it obstructs a relationship that is conceptualized by most Swedish and German respondents as a complicated connection of sorrows. While organ recipients repeatedly acknowledged their gratitude towards the donor and donor relatives, more unease resonated in their statements about ideas of contacting donor relatives. Like a Swedish respondent, who underwent lung

transplantation, many think there would be ‘too much emotion involved’ if recipients and donor relatives would know about each other. ‘And’, the respondent added, ‘I guess it could mess things up.’ What exactly it is that could be messed up is left open. This kind of vagueness and circumnavigation around the issue of the donor’s death or the relation between recipients and donor relatives can frequently be found. Yet usually, these lingering thoughts of the binding effects of grafts were discarded by recipients as unsolvable burden and not very long-lasting. In face of the demanding treatment regime following organ replacement (Amelang *et al.*, 2011), such pondering or inquisitiveness about the donor was, maybe understandingly, outweighed by a pragmatic approach of getting on with life.

Some Sort of Connection?

Beyond the pragmatic untying of donor-recipient relations, there exists – at least in the verbalized footnotes and side comments – another level that rather tends to entangle than disentangle donors and recipients. One Swedish respondent in his fifties, who ‘feel[s] some sort of connection’ to his donor, knows that the heart transplant he received nine years earlier is from a Finnish donor. On the one hand, he laughingly betted his ‘Finnish heart’ enables him to learn Finnish, implying in a joke the neighbourly bias of Finnish as an extraordinary odd and complicated language as well as the non-seriousness of his claim. On the other hand, he spoke about his wife’s cousin being married to a Finn, his travelling around Finland and checking out passers-by on the streets, wondering how that person looked like who had ‘my heart’,⁸ and his lightening a candle for his donor in a Finnish church. Regardless of this preoccupation with the donor as person, he immediately classified the created donor image as a fictive image. At another point, he referred to an organ recipient who had told him that her donor appeared to her during the night wanting his heart back, but states that her story is solely a fantasy: ‘It’s in your brain. It’s nowhere else [...] It’s a lot of imagination’.

But what is wrong with imagination? Do the described imaginary practices not exactly address the ‘nameless relations’ (Konrad, 2005) transplantation medicine creates? Besides rationalizing donor-recipient relationships by declaring (and devaluing) them as imaginary exercise, the usage of jokes and someone else’s stories were typical instruments that Swedish and German respondents used to present ‘irrational’ thoughts on possible donor-recipient relations. These jokes and stories allow distancing oneself from one’s

8 Like several organ recipients in all three localities, he speaks of ‘my heart’, rather than the donor’s heart. While the graft is dissociated from the donor, it is clearly repersonalized by the recipient. What is suggested here are the limits of objectifying and rationalizing body parts when it comes to the perception of ones’ own body (see also Sanner, 2003).

statement and can be read as narrative strategies.⁹ They function as contrastive examples to underline one's own position as rational, but at the same time allow expressing dissenting thoughts and hidden insecurities on the topic. Even if marked as 'unreal' these imagined donor-recipient bonds are grounded on ideas of relatedness.

Shades and Ambivalences of Gratitude

While German and Swedish respondents repeatedly acknowledged their gratefulness towards the donor or the donor relatives, issues of indebtedness were granted less importance. For many of them anonymity and the death of the donor diminish issues of relatedness as well as of indebtedness. Since the donor is unknown and dead, consent to donate is assumed,¹⁰ and organs are for him/her rendered 'useless', the death of the donor seems to neutralize feelings of indebtedness. Even those few Swedish and German respondents who regretted not knowing who was the donor, out of curiosity, said they would 'rationally' accept the secrecy. Like other respondents they evaluated anonymity positively because knowing who the donor is would support establishing a relation with the donor and would therefore increase feelings of debt as well. Accordingly, the organ from a living donor was more often viewed by German and Swedish respondents as grounds for a complicated relation, as the recipient would be more indebted to a living donor – regardless if it would be an anonymous or a family-related donor.

Although reciprocity was ruled out due to the principle of anonymity, there are some hints in the Swedish and German material that can be interpreted as signs of gratitude or forms of doing some kind of abstract reciprocity. For example, some viewed the pragmatic getting-on-with-life as obligation or means to show respect to the donor. This included taking good care of the organ, i.e. living a healthy life, in order to demonstrate that the precious graft is highly valued and served its purpose. Here expectations of society that transplantation medicine restores health and normality loom large and leave little room for organ recipients' possible deviant experiences of post-transplantation life. Besides addressing societal norms and the level of individual and society, some respondents mentioned their engagement in the promotion of organ donation or their

9 Olivia Wiebel-Fanderl analysed the narrated experiences of persons with heart transplants in Germany with special attention to the function of specific narrative forms and patterns: Jokes are used as 'intelligent weapon[s]' to deal with everyday experiences, personal conflicts and especially external, curious questions after transplantation (2003, pp. 306-310).

10 This point was especially made by respondents in Germany, where legislation is based on the consent model: the donor (or the donor's family) has actively opted-in. In many countries there is the presumed consent model (opt-out system), which means that unless the deceased has refused during their lifetime to become a donor then consent will be assumed. Even though according to Swedish and Cypriot law the donor families' wish will not be overruled, the consent legislation might make a difference for organ recipients with respect to solving feelings of indebtedness towards a donor who had opted-in.

going back to work, paying taxes again, referring to symbolic forms of reciprocating the donation or the healthcare system one had profited from. A more institutionalized version of showing gratefulness, that organ recipients in many countries are encouraged to do, is the possibility of writing a thank-you letter to the donor's family, which then is forwarded by the transplant centre and organ procurement agency. Not all recipients knew about this possibility or did eventually use it. Ambivalent attitudes towards such a letter concerned not only the above mentioned risk of increasing donor relatives' sorrows but the challenge to write about an emotional issue in an anonymised form (letters are checked for personal information, which then is blackened) and in a context where feelings of relatedness and indebtedness are silenced or rendered unproblematic. Here, if not before, it becomes clear that the at once depersonalized making of grafts and the framing of grafts as gifts create a tension for organ recipients regardless of their opinion of anonymity.

Conclusion – Two Modes of Narration and What to Make of It

The exploration of how people from three European localities describe connectedness resulting from organ transfer shows how meaning is given to organ exchange in different ways with respect to ideas of donor-recipient relations and its social implications. Confronted with the same problem – how to make sense of anonymous grafts and its potential binding effects – respondents from Cyprus, Germany and Sweden drew locally different conclusions concerning the question of what is at stake. While Cypriot respondents struggled with the questions how to best classify the perceived intimate donor-recipient relation and how to negotiate obligations associated with the relatedness of donors and recipients. In contrast, Swedish and German respondents struggled with the question if a donor-recipient relation is actually possible and with the untying of suggested notions of connectedness. How can one make sense of this contrast?

Anthropology has been teaching us that an answer using cultural stereotypes, i.e. of a 'level-headed' approach by Northern Europeans and a far more 'emotional' approach by Cypriots, would only invigorate them rather than be explanatory. Even though Swedish and German respondents employ 'rationality' as important means of denying or unmaking donor-recipient relations, this indicates by no means that Cypriot respondents' arguments are less 'rational'. In fact, both groups argue rational – with respect to their cultural background and with respect to the vocabulary of organ donation. Both local argumentations follow the ambivalent rationales of transplantation medicine: The altruistic and anonymous framing of organ exchange entails both entanglements and disentanglements, invented and denied donor-recipient relationships, associated

and dissolved reciprocities. Cypriot, German and Swedish respondents' ways to deal with their social meanings of grafts reflect these ambivalences – albeit within their local contexts respectively.

Anonymity spells out differently in the small society of the Republic of Cyprus (800,000 inhabitants, excluding the North) and the larger societies of Sweden and Germany (9.8 m and 81.3 m inhabitants). The reasons for this are not so much unequal population figures but the varying sociocultural constellations in which forms of (anonymous) solidarity are practised, experienced and framed. In the historically specific welfare states of Sweden and Germany, people are used to being part of anonymous communities of solidarity, anonymous social relations and dependencies of the state when it comes to the provision of welfare and particularly healthcare. Whereas in view of the comparatively relatively weak Cypriot welfare system, many people rather avoid being dependent on the welfare system and first and foremost rely on their families and wider kinship-networks when it comes to the provision of social needs. Extended families (Argyrou, 1996) can be viewed to be the most dominant and stable form of solidarity in Cyprus. Moreover, as Constantinou (2010) has convincingly shown, the rule of anonymity in organ donation unfolds in Cyprus in a gift-exchange society where a graft cannot be a free gift but is a matter of negotiating multiple reciprocities and hence relationships. The examination of donor-recipient relationships tells us thus about how people think about themselves and their bodies as related through organ exchange and more generally about how social relationships are locally conceptualized.

Swedish and German respondents invented donor-recipient relations more likely in stories of other people than in their own personal experiences, where relatedness was denied. Yet, entanglement hazards had to be continuously disentangled by means of narrative strategies that attempt to keep individuals and things separate. In contrast, Cypriot respondents immediately understood donor-recipient relations as exchange-relation balancing connectedness and sameness. For them obstacles of anonymity were two-fold – with respect to feelings towards their imagined intimate 'counterpart', and with respect to impeded possibilities of reciprocity. As different as the two rationales may be, a central moment in both is a certain horror of how to articulate what is at stake when discussing donor-recipient relations: on the one hand a horror of anonymity (Cyprus), on the other hand a horror of irrationality (Sweden, Germany).

The de-personalisation of the donor within the procedures of transplantation medicine emphasizes the abstract relation of individual and society: donation does not follow distribution lines of personal relation, but a collective distribution system of generalized solidarity (Hauser-Schäublin *et al.*, 2001, p. 227). While this form of

abstractions is rather appreciated than regretted by Swedish and German respondents, it is bemoaned by Cypriot respondents as painful, wrongful and unfair. Although the outlined mode of 'Cypriot' entanglements might not challenge the distinctiveness of the 'individual' in Euro-American cosmology completely, it contests the way relations among 'individuals' are in transplantation medicine thought of, namely, not as free-standing but invariably attached. The examined contrast of how 'individuals' are conceptualized when thinking about the socializing effects of anonymous grafts presents two different attempts of broaching an inherent dilemma of transplantation medicine, namely how to articulate the inexplicabilities of what a graft as 'given life' is and which impact it has. Swedish and German respondents make an effort to sidestep entrapments of this dilemma, which Cypriots rather allow. What is shared, regardless of the used narrative strategy, is a lack of appropriate vocabulary to describe and narrate one's experiences.

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Phenomenography: Relational Investigations into Modes of Being-in-the-World

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Abstract

This paper introduces the notion of 'phenomenography'. Phenomenography is an ethnographic research practice that attempts to combine practice-theoretical approaches (praxiography) to investigations of human-environment-technology relations with phenomenological perspectives on knowing and experiencing these relations. It is rooted within relational anthropology (Beck, 2008). The paper introduces a set of basic premises guiding phenomenography before relating four short empirical sequences, the analyses of which suggest specific analytical sensitivities: mind, brain and body in social interaction; knowledge and experience in psychiatric treatment; reproductive technologies in shaping sociality and kinship; (digital) infrastructures' impact on ways of being-in-the-world. The paper concludes by defining phenomenography as a co-laborative research practice that aims to curate concepts jointly with research partners and that aims to provide a new form of reflexivity within anthropology.

Keywords: phenomenography, relational, practice theory, modes of being-in-the-world

Introducing Phenomenography

The study of 'humankind in all its aspects' is a difficult task. Ongoing debates within the American Anthropological Association about its statement of purpose, from which this phrase is taken, point to the many fault lines that run through anthropological terrain and that obstruct the passage to unifying approaches (most prominently perhaps Scheper-Hughes, 1995, and the ensuing debate): the separation of nature and culture the deepest and most suspiciously guarded among them. Yet it has also been pointed

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out that straightforward questions such as ‘How do people live in groups?’ are asked of anthropologists – biological and social/cultural alike – and that it is of little use to pretend that these are somehow not legitimate questions (Kuper and Marks, 2011). Productive answers to these questions can neither take holistic form nor can they insist on the primacy of any singular epistemology or ontologically primitive analytical unit. They need to navigate and speak to different thought styles, scientific practices and research fields. Answers will necessarily fall short of comprehensiveness and are likely to encounter strong resistance from many sides. It takes humble anthropological engines of discovery (Hacking, 2006) to find answers that are good to think with (Strathern, 2002).

This paper develops the notion of phenomenography as a contribution to such engines. The paper does not list Stefan Beck as a co-author, because it has been written after his death. Yet his thinking, his critical questioning, his relentless scepticism and his wit have shaped every sentence. So the ‘we’ in this paper refers to the authors and always includes Stefan Beck. And it is only fitting that we start our line of argument from one of his key concerns: phenopraxis, the constitution in practice of being-in-the-world. It marks an entry point into investigating how processes of social ordering unfold, i.e. how people live in groups within specific environments. And it is an attempt to bring into productive dialogue practice theoretical thinking and science and technology studies with phenomenological questions, all against the backdrop of a keen interest in materiality in action.

Stefan Beck never used the term phenomenography. Even the notion of phenopraxis (*Phänopraxie* in German) has not been published, but was only pondered within work-in-progress lab sessions in Berlin. Yet rather than reviewing what has been, we try to carry his thinking forward. By phenomenography we thus mean the ethnographic study of phenopraxis. Perhaps pheno-praxiography would be the more accurate term as it retains praxiography as the more established ethnographic study of socio-material practices (Mol, 2002). Yet we take our cue from ethnomethodologist Michael Lynch, who responded to the recent debates in science and technology studies about the ontological turn by arguing that rather than presupposing multiple ontologies, scholars should be concerned with studying how such onto-logies are produced. He referred to this approach as ‘ontography’ (Lynch, 2013). We much appreciate the humble ‘graphein’ in the face of the daunting ‘logos’. Analogously, we suggest phenomenography as the practice theoretical investigation into phenomena as they are being enacted, i.e. into modes of being-in-the-world.

We proceed to flesh out the notion of phenomenography in two steps. First, we briefly outline four basic premises of phenomenographic research. Second, we proceed in the main section of the paper to present four facets of phenomenographic concern

rooted within empirical material taken from recent and current projects conducted within our group and with Stefan Beck.

1. Thought Styles

‘What actually thinks within a person is not the individual himself but his social community. The source of his thinking is not within himself but is to be found in his social environment and in the very social atmosphere he ‘breathes.’ His mind is structured, and necessarily so, under the influence of this ever-present social environment, and he cannot think in any other way.’ (Fleck, 1935/1979, p. 47ff.)

This quote from the Polish physician and immunobiologist Ludwik Fleck decentres the individual subject as the origin of knowledge and the production of truth claims. Instead Fleck suggests that we think of knowledge production as a social process; one where individual thinking is constrained by a social collective trained in conducting lab work in a specific way, joined by a shared language, shared concepts and shared paths of argument and thought. Phenomenographic research rests on this understanding of scientific practice as enacted within collective thought styles.

2. Practice and Relations

Phenomenography is part of a relational anthropology (Beck, 2008). Relational anthropology focuses on the practices – epistemic and otherwise – within which nature and culture are hybridised in continuously changing configurations of sociality. Its basic unit of analysis are ‘relations between relations’ in practice (Beck, 2008, p. 197). It is a symmetrical form of organised scepticism: symmetrical in the sense that it doubts any simple methodical or epistemic reductionisms within the natural sciences, while at the same time asking the social and cultural sciences to re-engage with materiality and letting go of the notion of biology as the enemy of critical thought. (Tsing, 2000)

3. Reassembling the Social

Phenomenography does not centre on the self-evident individual of idealist philosophy, but rather concerns itself with always already partially connected ‘dividuals’ (Strathern, 1988) or thoroughly ‘socialised’ forms of practice within which individuality may be enacted. Yet while we endorse a Durkheimian understanding of sociality as a unit of analysis *sui generis* (Beck, 2013b), we also appreciate research in the science and technology studies and feminist critique over the last 20 years that has reassembled ‘the social’ as continuously co-produced from the entanglement of human and non-human agencies (Latour, 2005). Bodies, material artefacts, technologies and material environments are important sources of agency.

4. Ecologies of Expertise in the Contemporary

While heavily infused with thinking from science and technology studies, phenomenography is not about understanding the production of knowledge and truth claims for their own sake. Rather knowledge practices or ecologies of expertise are a central element of processes of social ordering and how knowledge and experience change modes of being-in-the-world and modes of being-done-in-the-world (Beck, 2012; Beck, Niewöhner *et al.*, 2012). Very much in line with an anthropology of the contemporary (Rabinow, 2004; Rabinow, Marcus *et al.*, 2008), the human and technical sciences, understood as forms of practice, play a central role in shaping the concrete sets of practices within which ‘humankind in all its aspects’ is being done. Phenomenography is thus a research practice aimed at producing reflexivity within the epistemic, social and material architectures of late modernities (Law, 1994; Boyer, 2015).

The following sections portray research from four very different contexts within which Stefan Beck was centrally involved. We present them here to illustrate four important facets of phenomenographic concern: the role of cognition and the brain in social practices, the role of knowledge and experience in shaping (disease) classifications, the role of technology in reconfiguring kinship and sociality, and the role of digital infrastructures in mediating social practices. This is, of course, by no means a comprehensive list. Yet all four contexts provide insights into current vectors of truth claims (Rabinow, Marcus *et al.*, 2008) and how they contribute to modes of being-in-the-world.

Neuroscience: Enculturing Brains – Enbraining Cultures

From fieldnotes taken during a joint project involving anthropologists and computational neuroscientists in Berlin:

It is one of these grey autumn days in Berlin. I am sitting in a laboratory-like room in front of a screen, wearing what can only be described as a wired bathing cap, a rubber thing with cables running from it, disappearing from my view. The screen soon begins to show two faces that explain to me some kind of path or route I will later have to trace on a paper map. Rather than being positioned side by side on the screen, the two faces are superimposed onto each other and so is the audio track. My two experimenter colleagues, who are sitting next door watching me through a window pane, instruct me that it is my task to focus only on one of the faces and the voice that goes with that face. Luckily it is a male and a female face. Still, the task is amazingly difficult. I realise just how difficult it is when one of the experimenters tells me to relax, as my tense neck muscles are distorting the signal that we are after in this pilot for an experiment: my electroencephalogram (EEG), i.e. the electric currents produced by my brain-at-work

trying to master a particular task. The point of this procedure is to find out whether my EEG (listener) relates to the face's EEG (speaker) recorded earlier when narrating the story. Hypothesising that speaker and listener coordinate with each other during communication, can we detect that process of coordination using EEG? The short answer is: Yes, we can. The coordination of neural activity between two individuals is directly linked to verbally communicated information (Kuhlen, Allefeld *et al.*, 2012).

What is the point of being part of developing and running such an experiment from a phenomenographic perspective? There are four aspects to an answer to this question:

1. The neurosciences have been expanding at an extraordinary pace, particularly driven by developments in technology, method and analysis. Functional magnetic resonance imaging (fMRI) and related analyses are key elements of current research. Ambitious projects around the globe set out to decipher the way human brains function. 'Watching the brain think' is one of the slogans explaining this type of research in the popular press. Social and cultural neuroscience is a subfield of these neurosciences. It is of interest to social and cultural anthropologists, because it considers humans to be animals that interact amongst each other in complex ways and that live in groups that share a set of key values, i.e. humans live in cultures and the fact that they do supposedly shapes their brain functionality in specific ways – and is shaped by it, too. Such truth claims about human group life are a matter of concern to anthropologists. They need to be examined critically to better understand the experimental systems, the genealogy of current concepts, the philosophical underpinnings of these concepts as well as the wider political economy of neuroscientific research (cf. Callard and Margulies, 2011; Hasler, 2012; Roepstorff, 2013). Of particular interest to social and cultural anthropology are the notions of 'the social' and 'culture' that operate within current experimental systems. Both tend to be brain-centric. They position the brain at the centre of an autonomous individual self that engages in rule-based interaction with other autonomous individuals. These brain-centric individuals live in cultures understood as value systems. Much of this brain-centred reduction of the complexity of actual human group life and social interaction is driven by the methodological individualism built into current experimental systems through the fMRI machinery that really only allows the investigation of individual brains working in immobilised bodies. Most neuroscientists are very aware of the limited ecological validity of many of their assumptions. They are pragmatic reductionists (Beck and Niewöhner, 2006). Yet relational anthropology shares with Foucault the concern that neuroscientists do something that neuroscience itself might not be entirely aware of. Critically observing and analysing the discursive and practical consequences of neuroscientific research for medical practice, changes in biopolitics and the notion of the self in late

- modern society is an important element of relational anthropology.
2. As the above experiment shows, relational anthropology attempts to produce a different kind of reflexivity to that of critical deconstruction. It tries to develop experimental paradigms, the findings of which act as a kind of reverse *Widerstandsavis* within the neurosciences (Fleck, 1935/1979). They are meant to counteract dominant brain-centric and individualist thought constraints. Three aspects are key: the role of the human body in coordinating social interaction (Beck, 2013a; Niewöhner and Beck, forthcoming), the social as an emergent phenomenon *sui generis* that enters into feedback loops with interacting individuals (Niewöhner, Kehl *et al.*, 2008), and the reassembled social that constitutes itself within specific material environments and with the use of material artefacts and technology (Latour, 2005). Enculturing brains within patterns of material-semiotic practice, is an agenda that is critical towards much of the mainstream thinking in the neurosciences (Roepstorff, Niewöhner *et al.*, 2010). Yet it is generative in its critique (Verran, 2013) trying to develop understandings of cognition as distributed and embodied that align better with current thinking in social and cultural anthropology. (Hutchins, 1995; Beck, 2013a)
 3. To any social anthropologist sitting still in front of a screen watching superimposed faces certainly marks a very specific form of 'social' interaction. Social neuroscience is a long way away from doing experiments in actual social situations, let alone within thick ethnographic contexts. It is not even clear whether they have any interest in getting there. Anthropology does not learn from the social neurosciences about the brain in social situations in a way that could be straightforwardly integrated into ethnographic analysis. Yet the experimental *Widerstandsavis* works symmetrically. Experimental work with the neurosciences challenges anthropological theorising: What is the role of perception, cognition and cooperation in human group life? Can an advanced cognitive anthropology interact productively with social anthropology? Why is social theory so disembodied and a-material (Beck and Niewöhner, 2006)? Current new materialisms are beginning to address this, but few even attempt to work with the knowledge that is produced by the disciplines that know much more than ethnographers about the material world and the human body (Knappett and Malafouris, 2008; Timmermans and Haas, 2008, but see also, Dolphijn and Tuin, 2012; Lock, 2015; Niewöhner, 2015a). Relational anthropology in this context does not mean buying into experimental findings and reifying complex and contingent socio-material phenomena. Rather it means thinking with experimental findings and challenging the social and cultural reductionism built into social anthropological comfort zones.

4. In such an approach, the experiment is not only a natural scientific method, but also an object of ethnographic study and a particular research aesthetic – one where materiality, technology and experimental systems are appreciated as good to think with (Roepstorff and Frith, 2012). Relational anthropology is thus an approach to social and cultural anthropology that collaborates with disciplines that do research about the human body and appreciates the productive confusions that emanate from it (Niewöhner, 2016).

A phenomenographic perspective onto and with the neurosciences thus aims to rematerialise social and cultural theory as a way of inducing new reflexivities into ethnographic research. It understands cognition as a distributed and embodied process inherent to shaping social interaction and inherently shaped by situated epistemic practices.

Psychiatry: Ways of Knowing, Ways of Experiencing

Our second facet of phenomenography takes us from controlled laboratory experiments with the brain into urban settings and psychiatric care. With partners from psychiatry, we have engaged in a collaborative research process over the last six years. The initial aim of the project was to enquire into the ‘production of chronicity in mental health care and research’. How is the classification ‘chronically mentally ill’ used in everyday psychiatric and bureaucratic practices and what are the respective effects, specifically for people classified as such? At first glance, the situations and phenomena we encountered during this research seem to be the very opposite of the ‘artificial’ experimental situation described above. Conducting fieldwork in mental hospitals and other institutional care settings and especially following patients outside the walls of institutions into their private lives meant dealing with unpredictable and often uncontrollable situations. Yet the two fields both hybridise nature and culture in their own ways. Our collaborators in the field of psychiatry use the label ‘social’ to define their position within (or rather on the edge of) mainstream psychiatry. The label ‘social psychiatry’ in the German medical setting describes a critical stance towards increasingly biomedical explanations within mental health research and treatment programmes. Put to the fore is an understanding of mental illness as systemic, comprising social relationships, environmental conditions and processes of adaption to a social milieu – with positive as well as negative consequences (Schmiedebach and Priebe, 2004; Dörner, 1995). Somatic mechanisms, specifically brain functions and pathologies, are certainly not seen as the main target for therapeutic interventions. From their perspective, chronicity, i.e. the long-term persistence of a set of symptoms and experiences, is co-produced by a complex set of factors, including, first and foremost, mental health care infrastructures, diagnostic and

treatment regimen with their labelling and looping effects and the challenges of urban living, including poverty and social exclusion. Being chronically mentally ill in a city is thus something that is not reducible to a brain dysfunction, but rather marks a very particular mode of being-in-the-world that is heavily shaped if not structured by medical knowledge, bureaucratic practices and requirements, and the entrainment of particular social routines within urban settings – a process we have elsewhere described as ‘niching’ (Bister, Klausner *et al.*, 2016). At the same time, however, most social psychiatrists share the view that phenomena such as acute psychotic states contain corporeal elements, i.e. are materially anchored somehow. Their particular form is not determined by or based on a material defect and it varies with treatment, social context etc. It might even be the case that psychosis is an entirely misleading category. Yet medication is routinely used to establish a situation where patients are able to enter into talk-based formats of interaction, showing that somatic interventions do have an effect and implying for most psychiatrists that psychiatric symptoms have corporeal components. For us, it is a phenomenographic question how the experience of being a psychiatric patient is situated within particular choreographies and wider infrastructures of care. (Klausner, 2015; Klausner, Bister *et al.*, 2015)

The particular social psychiatric perspective that we encountered is less grounded in universal standards, scientific evidence and best practice guidelines. Instead, it is described and enacted within clinical contexts as a form of expertise that is gained by practical experience or *enskilment* (Ingold, 2000) and very much situated in local ‘ecologies of expertise’ (Beck, 2015a) through practical engagement in social as well as environmental settings. This ‘experiential expertise’ was considered a key resource to meet the uncertainties of individual cases in clinical practice and to choreograph treatment trajectories with outmost flexibility.

What is of interest here from a phenomenographic perspective is how this ‘experiential expertise’ is legitimised and mobilised in mental health care, thereby producing specific practical consequences. Rather than understanding these processes in terms of ‘medicalisation’, i.e. non-medical life-worlds coming under the jurisdiction of a medical regime, the phenomenographic perspective, in a first step, differentiates ways of knowing and pursues their grounding in specific socio-material co(n)texts (Beck, 1997). In a second step, it asks how certain ‘thought styles and habits order (new) forms of sociality’ (Beck, 2010) – how psychiatric expertise transforms the being-in-the-world of people living with a diagnosis.

Experience in this context needs to be considered in two different ways. It not only serves as legitimation for the ‘doings and knowings’ of the social psychiatrist, but is also considered the core therapeutic object. A keyword in recently developed treatment programmes in social psychiatry is the notion of ‘expert-by-experience’: the patient

becoming an expert of his / her experience in the course of mental illness. Therefore, the patient is considered as a partner in the treatment process, centring on his / her individual illness experiences and his / her 'coping skills'. Treatment in this sense is about a patient learning to transform the uncontrollable and wearying experience of mental problems into a conscious experience, which then becomes accessible to rational reflection and skilful re-working. In the everyday therapeutic practices, this was pursued in a mode of collective inquiry (comprising the patient and the professional, as well as other patients, e.g. in group therapy sessions), where experiences were exchanged, probed and interpreted and thereby transformed into a more stable experience. Following the pragmatist John Dewey (1934), phenomenography problematises this process as the transformation of experience (in German: *Erlebnis*, as something someone lives through) into experience (in German: *Erfahrung*, as a reflective moment of 'closure') (Beck 2015a). In this process, 'having a psychiatric disorder' is slowly being transformed from a process of labelling to a way of being a person (Hacking, 2006) and into a specific way of being in the world. What at first glance appeared to be an analysis of the inventory of clinical expertise was slowly turned into a more general investigation of 'ways of experiencing': how the experts' know-how is legitimised as an experience-grounded and artful skill as opposed to simply a mechanistic application of diagnostic and therapeutic standards, and at the same time, how patients learn to express and reflect their experiences and transform them into something meaningful.

Experience from a phenomenographic perspective is thus never an authentic phenomenon that ethnographic work needs to pay particular attention to and even tries to empathically emulate. Rather 'experience multiple' is enacted as therapeutic tool and object carrying very specific meanings of mental illness, of the pathological in general, understandings of what it means to be a good 'patient' and choreographing ways of being-in-the-world as a mental health patient.

Two points follow from this:

Firstly, experience must be analysed as practice, as experiencing, constituted by and in situations. We argue in favour of addressing 'the interactive, ecological nature of experiences that are the outcome of a mutual, self-amplifying adaptation of actors and their natural, social, and cultural environments' (Beck, 2015a, p. 20). Experiencing then is performed in the collective inquiry of patients and therapists, in concrete spatial arrangements and daily routines, drawing from historically evolved therapeutic concepts, hospital infrastructures and embedded norms of 'good care'. This dissecting of experience into different modes of knowing and being-in-the-world has at the same time fundamental consequences for an anthropological framing of experience which is commonly assumed as universal to human beings (cf. Desjarlais 1994). Rather than taking 'the subjective experience' as the unit of analysis, the social

and material conditions and practicalities of experiencing move to the centre of phenomenographic analysis.

Secondly, analysing 'ways of experiencing' substantially merges being, doing and knowing. While in a phenomenological approach the experiencing subject (in its relations with the world) tends to assume central position, a combination of an ecological-anthropological version of practice theory with the phenomenological interest in 'being-in-the-world' enables phenomenography to address 'humankindness' as a process and as an empirical problem.

Reproductive Medicine: Techno-Science and Techno-Sociality

The partially connected 'dividual' is at the heart of much of current anthropology. This becomes most obvious in the new kinship studies investigating the effects of reproductive technologies on kinship and social life more generally (e.g., Strathern, 1992; Franklin, 1997; Edwards, Franklin *et al.*, 1999). Within a series of projects, within which Stefan Beck was centrally involved (e.g., Beck, Cil *et al.*, 2007; Knecht, Klotz *et al.*, 2011; Knecht, Klotz *et al.*, 2012), phenomenographic attention was turned to kinship as a classical domain of the social, as a form of social meshwork, as 'diffuse and enduring solidarity' (Schneider, 1968) and as such a key element in ordering the social: What happens to everyday solidarities when something as self-evident as biological kinship becomes questioned? And how is this domain stabilised – normalised – once again, during and after repro-technological interventions? How does scientific knowledge about genetics and reproductive technologies contribute to this? And how does one conceptualise a 'techno-sociality' were human life has literally been made on the lab-benches of a trans-nationalised medicine and where family life rests on notions of nature modelled on culture as practice (Rabinow, 1992)?

A phenomenographic perspective approaches kinship as a set of practices (e.g., Franklin and McKinnon, 2001) or 'structuring structure' (Bourdieu, 1996), instead of a hidden grammar of society (e.g. Beck, Hess *et al.*, 2007). It asks how patterns of 'doing kin' emerge, sustain themselves, develop structural properties or, to the contrary, vanish again. It thus turns a topographic interest in mapping structural givens, into a topological interest for the concrete and situated workings of the multiple looping effects between everyday (family) life as lived, technology and expertise, and a diverse set of formal and informal institutions and regulations.

Istanbul, Berlin and London harboured the field sites within this series of projects conducted by Stefan Beck. They all foregrounded analytically an inherent mobility: of people, professionals, artefacts, and concepts navigating an increasingly thick palimpsest of knowledge, experience and regulation (Beck, 2007, 2012b). Take the Turkish branch

of the US-American Johns Hopkins hospital in Istanbul as an example, where Turkish doctors trained in the United States were treating patients from all over the world after strict US standards for clinical practice, within a physical environment completely imported from the US; or mobile patients, dodging the strict regulatory constraints of national bioethics, being treated by German-Turkish doctors migrating back to Istanbul after life and medical school in Germany. Such mobility can only be sustained through the flexible and often pragmatic use of religious, scientific and regulatory concepts to make and stabilise familial solidarities after technologically assisted reproduction.

This key role of mobility in co-producing particular practices of regulation and lived experience underlines an aspect of conceptual importance to phenomenography and relational anthropology more generally. It demands a re-conceptualisation of biopolitics in times of ever-intensifying transnationalisation and globalisation. How does one come to terms with biopolitical phenomena, such as standardised clinic equipment travelling around the world to “make life” in standardised ways in highly different places? Stefan Beck pointed out how Foucault developed his notion of biopower on the basis of the European welfare state. Today, however, the relationship between state and citizenry is constantly shifting and it is domains such as biomedicine and reproductive technology within which these shifts are negotiated. In fact, ethnographically following these highly mobile ‘patients’, it becomes clear that territorially bound nation states are today but one element acting on processes of social ordering. Patients navigate regulatory and epistemic landscapes heavily shaped by a globally operating capitalism and a thoroughly economised medicine, and they adhere to, reproduce and alter highly individualised sets of normative assumptions and rules, defying in practice any straightforward understanding of the nation state, populations or a body politic. While the critique of commodification always looms large in this field of anthropological research, Beck was more interested in the meticulous ethnographic, or indeed phenomenographic, surveying of the degrees of freedom engendered by the co-constitutive shifts in regulatory, epistemic and experiential reproductive practices.

Technology in Practice: Mediating Ways of Being-in-the-World

Phenomenography is interested in better understanding how ways of being-in-the-world are being done in practice. As the previous section has demonstrated, phenomenographic sensitivities are attuned to the practices of partially connected (in)dividuals. Technologies and their developmental hinterland play a key role in these practices. Here, phenomenography reveals its allegiances with science and technology studies, new (relational) materialism and feminist critique (Haraway, 1988; Barad, 1999; Law and Mol, 2002; Pickering, 2010; Beck, Niewöhner *et al.*, 2012; Dolphijn and Tuin,

2012). Technology is never simply used or appropriated. Neither can it be sufficiently understood as material object inscribed symbolically with culture. Technological agency is an inherent part of material-semiotic practices.

In his last public lecture on digital practices in January 2015, Stefan Beck related the following fictitious story of his arrival by train that day to his audience:

‘I got on the train to come here. To do this legally, I operated the application “touch and travel” via the touchscreen of my smartphone in order to buy a ticket. Hence, the program sent the data of my GPS tracking to a central server. To calculate my travel route, the means of transportation and the appropriate fare, my data were compared to the ideal timetable. Interestingly, the same was done with the GPS data of the train, but its data were compared to the ideal timetable in order to measure the train’s divergence. Via another interface I was able to recall the ‘delay’ live through another application of my phone. Thus, I could send a text message to apologise in advance: “I am at Hesse memorial [Hessendenkmal; a tram stop between railway station and lecture hall].” (Beck, 2015c)

This simple example does not only show that everyday lives are always already technologically mediated. It tries to make the point just how deeply human practices are shaped by and embedded within digital infrastructures in often implicit ways. Practices are continuously being infrastructured (Niewöhner, 2015b). Trying to understand these digital infrastructures, research draws on yet further specialised technology; hence not only ways of travelling but also ways of knowing are technologically mediated. Instead of separating a ‘technological’ from a ‘social’ and trying to find meaning in matter between technological determinism and cultural pessimism, the relational and practice-theoretical perspective asks ethnographically how routinised practices are mediated through technology over the course of time. How can habitus, body techniques or local biologies be conceptualised as practiced within specific material environments including technological artefacts and their hinterland? The ethnographer needs to carefully follow the web of significant infrastructural relations, which have been socio-technically constructed and in which people are suspended and enmeshed, thereby producing an analytical thickness that is ‘not localized in the way that either Geertz or Latour thinks it is’ (see also Rabinow, Marcus *et al.*, 2008: 81; Beck, 2015a).

Phenomenography extends this thinking to include analytical sensitivities towards the human body and to material environments writ large. Here, phenomenography differs from others in anthropology who have suggested that the analysis of technology ought to be integrated into a wider understanding of material culture – including particularly mundane, everyday objects – to avoid an unwarranted a priori analytical primacy of the material (e.g. Hahn, 2015). The consistent focus on practices marks a somewhat different if perhaps complementary strategy to avoid such risks of fetishising

technology not through integration into the multitude of objects of the lifeworld, but through turning into an empirical question how relations of all kinds are forged through material-semiotic practices within specific environments.

In its most fundamental sense, this perspective also dissolves the implicitness of the corporeal and mindful human being as the inhabitant of an object-populated lifeworld. The human self does not end with its skin, but is being conceptualised as a dynamic product of or even vector within material environments including infrastructures and mundane objects (Bentley, 1941; Bateson, 1972). Human beings are never autonomous users of objects within detached surroundings. Bateson was perhaps the anthropologist who most clearly articulated his difficulties with attempts to distinguish *a priori* and categorically between self and environment without being able to observe how this division is produced.

‘If you ask anybody about the localization and boundaries of the self, these confusions are immediately displayed. Or consider a blind man with a stick. Where does the blind man’s self begin? At the tip of the stick? At the handle of the stick? Or at some point halfway up the stick? These questions are nonsense, because the stick is a pathway along which differences are transmitted under transformation, so that to draw a delimiting line across this pathway is to cut off a part of the systemic circuit which determines the blind man’s locomotion.’ (Bateson, 1972, p. 318)

The human self, as well as that self’s experience as and knowledge and understanding of itself, is always constituted in socio-material environments and thus varies across situations: Human beings then are the effects of their substantial entanglements with their surrounding environments. Where cybernetic thinking conceptualised this entanglement systemically, Stefan Beck insisted on practice and process. In the lecture cited above, he continues, ‘I am differently at Hesse memorial compared to Constable guard-house.’ This grammatically dubious statement reveals a difference in the process of ‘being’ that is induced initially by a difference in infrastructure. Picture yourself on this tram ride from the railway station to the lecture hall where you are meant to give a plenary lecture. As your phone tells you in real-time how you are being delayed and that you are unlikely to make it. Your mind-set and experience of that ride will change with every update of your travel app on your mobile phone. You may respond to this by sending a text message to the host or you may make a call. The point is: the availability and operation of this infrastructure changes how you go about your day, how you experience a particular set of practices, but also how your body responds to a situation (stress, communication). Analysing this set of practices, it is not sufficient to operate with object, user and meaning. What about the affordances built into the travel app by software developers within their respective programming and marketing environments? What about the manifold looping effects between technology, body and self that may

bypass hermeneutic processes? What about the multiple ways of responding to this situation technically, socially and emotionally? What about the discursive, epistemic and political contexts of such situations?

Phenomenography is about carefully attempting an answer to these questions – and returns us to the opening statement: studying humankind in all its aspects. Phenomenography certainly does not consider all aspects of human existence. It provides an attempt to hybridise nature and culture in analyses of everyday practices by diffracting analyses of doing human-technology relations through analyses of knowing and experiencing human-technology relations (compare Ihde, 1979). It extends practice theory into questions of experience without giving primacy to authenticity or reifying human subjectivity. And it extends phenomenology by dissolving the human subject/self into a set of material-semiotic processes and relations; relations between body, technology and material/social/political/historical environment. Phenomenography thus contributes to a relational anthropology that asks how the human body, forms of subjectivity and ultimately humankind are constituted in practice and over time, and how these practices are shaped by knowledge and experience always conceptualised as relational phenomena.

Conclusions

We have provided brief insights into four research fields where phenomenographic attention creates a productive tension between practice theory and phenomenology, i.e. between doing and experiencing nature culture relations and their hybridisation. We conclude by insisting that phenomenography is a co-laborative research practice (Niewöhner, 2016) that engages in joint epistemic work with its research partners in the respective fields, e.g. social neuroscientists, psychiatrists, reproductive medicine practitioners or infrastructure and technology developers (see also Marcus, 2010). Co-laboration is necessitated by the degree and nature of expertise and institutionalised reflexivity in these research fields. Phenomenography risks having little to add to the natives' point of view unless engaging in jointly curating concepts that are good to think with (Rabinow, Marcus *et al.*, 2008). This form of co-laboration, studying sideways (Boyer and Hannerz, 2006) or modest witnessing (Sørensen, 2009) tries to induce new forms of reflexivity to anthropology and to the research fields by providing a protected space within which scholars can try other disciplines' and fields' ways of knowing and ways of being-in-the-world through scientific method. It applies phenomenographic attention self-reflexively to generatively irritate established thought styles and collectives and increase thought caprice.

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Reflections on Ethnography in Medicine

LISA DIKOMITIS

Abstract

After conducting many years of 'classical' ethnographic fieldwork among refugees in Cyprus, I started field research in hospitals, community settings, and medical schools in Belgium, England, and Cyprus. My collaborations with clinical and biomedical scientists have led to an ongoing dialogue about ethnographic fieldwork and ethnographic writing. I discuss, through some ethnographic vignettes from my own research journey, some challenges that academics who work in medical research units may face in their engagements with ethnography. Stefan Beck's work speaks to researchers from different social, biomedical and clinical disciplines. I show that ethnographic work, such as that by Beck, raises the profile of social scientific work in medicine and demonstrates the potential of ethnography in medicine.

Keywords: Anthropology, Stefan Beck, medicine, ethnography, social sciences, biomedical sciences, interdisciplinarity

In Memory of Stefan Beck

It was a shocking blow when Stefan's wife, Gisela, called us from Australia, in the first week of spring 2015, with the devastating news of Stefan's death. His untimely loss coincided, for me, with the start of a large study on death and memorialisation.¹ Stefan's death and my research for this project have since been intertwined and I am grateful I can 'memorialise' Stefan and his work through my contribution in this special issue. One of the many messages in the online Book of Condolence for Stefan Beck read: 'He was good to think with'.² It was posted by Jörg Niewöhner, Stefan's friend, colleague and long-term collaborator (see his contribution in this issue). It saddens me that I am not able to 'think with Stefan' in person anymore. I fondly recall conversations in our Kaimakli garden near the jasmine tree, brought by Stefan and Gisela, or over lunch at the *mairko* Mattheos, in the heart of old Nicosia, which Stefan frequented.

1 An interdisciplinary study, funded by the UK's Arts and Humanities Research Council, on dying, death and memorialisation: *Remember Me. The Changing Face of Memorialisation*, more on <http://www.hull.ac.uk/rememberme> (last accessed on 18 May 2016).

2 See obituary and condolences on <https://easst.net/article/obituary-stefan-beck-1960-2015/> and the complete online Book of Condolence on <https://ethnoserver.hu-berlin.de/kondolenz/> (last accessed on 18 May 2016).

Stefan Beck was both a friend and a truly inspirational fellow anthropologist. I feel academic kinship with Beck for three reasons. Firstly, he was a scholar who thought deeply about anthropology, and social science more broadly, and especially how social anthropology intersects, or could intersect, with other disciplines. Beck was working across different fields and it is his engagement with medicine in particular that strongly resonates with me. For six years or so, influenced by both professional and biographical events, I have focussed my research on the social and cultural dimensions of health and illness. Secondly, Stefan Beck wrote in multiple languages, his native German and English, and worked in different academic traditions (see, for instance, Beck 2008, in which he writes about German-speaking cultural anthropology). As required from an academic who worked for a decade in Belgian academia, I experienced the joys and struggles of writing in more than one language and being embedded in a disciplinary tradition that differs from British social anthropology. Finally, Stefan Beck conducted multiple ethnographic studies on Cyprus and has been instrumental in establishing a medical anthropology hub on the island (Amelang *et al.*, 2011; Beck, 2005, 2008, 2011). I started my academic career with a long-term ethnographic study of refugees on Cyprus (Dikomitis, 2012).

It was a biographical event that sparked my interest in studying medicine. When I was pregnant with our daughter, and still inexperienced in all things related to pregnancy and childbirth, I was confronted with contrasting discourses. What follows is one example about how childbirth was differently perceived by our Belgian and Cypriot gynaecologists. I asked our gynaecologist in Nicosia for his advice on giving birth. He said to us:

We are not barbarians here. We do not let women suffer. Without any doubt you should ask for an epidural. In fact, I recommend a C-section. This is best as it is painless and has the best outcomes for mother and child.

When I returned to Belgium at the end of that summer to start teaching, I asked the Belgian gynaecologist the same questions. She said something along these lines:

You are here in the best hands. We try to do everything natural here. If you insist, you can have an epidural, but not a caesarean unless it is absolutely unavoidable. We don't cut women open if it is not necessary. It is always best to let nature run its course.

I wrote an extensive research bid on cultures of pregnancy and childbirth (Béhague *et al.*, 2002; Ivry, 2009; Johanson, 2002; Sargent and Bascope, 1996; Walsh, 2006). I was especially interested in the turn toward the 'natural', or 'traditional', and the views I encountered around 'de-medicalisation' in pregnancy and childbirth, but also around breastfeeding and childhood vaccinations. I never obtained sufficient funding

that would allow me to carry out long-term fieldwork in this area, but by that point medical anthropology had caught my attention! I started research on the socio-cultural dimensions of health, illness and the organisation of healthcare.³ My venture into the field of medicine came with some unexpected joys, but also with its own challenges.

When I was conducting ‘classical’ ethnographic fieldwork I did not encounter many scholars who considered ‘the social and cultural’ of insufficient importance to be studied at length or in-depth. I did not have to defend why I thought an ethnographic approach was the way forward. I was not in need of the kind of encouragement that my doctoral students, who work at the interface of social and medical sciences, often seek from me. I conducted my fieldwork and wrote up my ethnography, rather blissfully, as an anthropologist among anthropologists. My colleagues and collaborators were all scholars who shared the same ‘academic world view’ and who did not question my methodology or critique the narrative style I used in my writings. However, my collaborations, in more recent years, with clinicians and medical scientists have led to an ongoing dialogue about ethnographic fieldwork and ethnographic writing.

My contribution to this special issue is simple enough. I do what anthropologists do as a matter of course: I use precisely the incidental every day of my academic life to discuss some of the practical challenges I faced around ethnography in medicine.

Medical Anthropology

There is a large ethnographic literature of medicine. Medical anthropology includes a wide range of topics and specialist areas, including work on the socio-cultural aspects of health and illness, the organisation of healthcare, the social nature of biomedicine and public and global health. To name but three examples of recent work with superb ethnography: Elizabeth Davis’ (2012) ethnographic study of psychiatry in northern Greece; Karen Nakamura’s (2013) ethnography of mental illness in Japan; and Alice Street’s (2014) ethnographic account of how biomedical practitioners work and struggle in a public hospital in Papua New Guinea. In addition to ethnographies of medicine, there are many ethnographic accounts of medical education and medical students (see Atkinson and Pugsley, 2005, for an overview of this ethnographic tradition). The classic is Howard Becker’s *Boys in White* (1961), followed by contemporary work by, among others, Rachel Prentice (2013) who turned her attention specifically to the

3 This included a study on the evolution of mental healthcare in Flanders, a project on health inequalities in the north of England (Dikomitis, *et al.* 2014), an evaluation of the use of electronic risk assessment tools in primary care (Dikomitis, *et al.* 2015) and different studies on primary headaches (Dikomitis, *et al.* 2013; Ahmed, *et al.* 2014; Dikomitis, *et al.* 2015).

training of surgeons. This sub-field also includes two monographs by medical doctors who became anthropologists: Simon Sinclair (1997) conducted participant-observation in a London medical school, and gynaecologist Claire Wendland (2010) worked among Malawian medical students. The fast-growing body of ethnographic work on medical topics has, on the whole, been produced by anthropologists, social scientists and clinicians who received anthropological training (and who often take up positions in universities' Anthropology departments). The most well-known of such clinicians-cum-medical anthropologists are Arthur Kleinman (1980, 1988, 2008) and Paul Farmer (2001, 2004). Stefan Beck (2008) was particularly inspired by Farmer's activist research agenda for medical anthropology.

Stefan Beck, in turn, was an inspiration to many social scientists working in the medical field. I highlight below some of his many contributions to the field. Beck (2008, 2011) collected rich ethnographic data around a social gathering of Cypriot organ donors and recipients of bone marrow grafts. He conceptualizes the relationships between these donors and receivers as 'biosocial relationships', which have 'the potential to engender new visions of the social, new visions of the self, and new visions of the biological' (Beck, 2008, p. 26). In a next paper, Beck (2011) focuses on one such biosocial relationship. He puts forward a compelling ethnographic account of a young Turkish Cypriot man who saved the life of a young Greek Cypriot girl through the man's anonymous donation of bone marrow cells. Beck analyses the relationship between the donor and the recipient through the 'biomedical platforms'⁴ of bone marrow transplantation and immunophenotyping. Such bone marrow donations create a biological and a social relationship, which can also be heavily invested with political meaning, which is the case here. Indeed, in combining resources, patients, NGOs, volunteers and biomedical experts create a new type of 'body cosmo-politic', which can confront the 'state-centred type of biopolitics' (Beck, 2011, p 115). Beck was engaged in a cross-cultural comparative study on genetics in Cyprus and Germany. Through his ethnography Beck (2005) demonstrates the influence of biomedicine on concepts of health and how biomedicine can also determine marriage strategies as was the case in Cyprus. Throughout his work Stefan Beck analyses the complex relationships and interconnections between the social and the biological. The thread that binds his multiple studies is a strong engagement with ethnography.

In what follows I will discuss some of the challenges that academics who work in medical research units face in their engagements with ethnography.

4 The term was introduced by Peter Keating and Alberto Cambrosio (2003) to analyze the transformation of medicine into biomedicine since the 1950s.

Ethnography in Medical Research Environments

I strongly believe in the importance of such ethnographic research, perhaps increasingly so in this era of growing disinvestment in anthropology. I have witnessed, in Belgian and British academia, the gradual disappearance of Anthropology departments (now often only small 'units' in larger schools) and the withdrawal of several Anthropology degrees. If the discipline is not expanding but contracting, it seems paramount that researchers find a way of *doing* ethnographic fieldwork and writing ethnographically outside these disappearing departments.⁵

I am specifically concerned here with ethnographers who work outside the welcoming homes of Anthropology or Social Science Departments. These include academics conducting ethnographic work who are employed in medical schools or medical research environments (such as clinical research centres or hospitals). Medical fields, both in and outside academia, habitually have very different epistemic traditions in which, often, a positivist paradigm dominates, and where quantitative social research methods are still privileged over qualitative approaches.

What follows is a short account of some of the challenges I faced with regards to methodological issues when I conducted 'hospital ethnography'⁶ in a psychiatric hospital in a provincial town on the Belgian-French border. My informants were no longer Cypriot refugees who, on the whole, always welcomed me and liked the idea of me 'writing a book' about them. In fact, I do not recall discussions about the particularities of the ethnographic method with my Cypriot informants. My methods were not questioned or critiqued. The Turkish-Cypriot Kozanlılar laughed when I insisted on getting up at five in the morning to get the fresh goats' milk from the shepherd, and they were grateful for an extra hand when making cheese and going to the local markets to sell the bread we made. They all knew I was an academic and was planning to write a book, and although they might not have been familiar with the term 'ethnography', they understood it as Ruth Behar (1995:3) defines it, 'a strange cross between the realist novel, the travel account, the memoir, and the scientific report'. Things were very different in the hospital. I was confronted with complex ethics procedures to gain approval from different ethics committees. I was asked, time and again, what exactly it was that I wanted to do. Why was it important that I should do the night shift as well? Surely,

5 There is indeed a growing body of ethnographic knowledge being produced by non-social scientists. For instance, Ball and Ormerod (2000) discuss how ethnographic methods can be applied in engineering design and Maginn (2007) highlights the potential of applied ethnography in urban regeneration partnerships. See also Peto's recent book on applied ethnography (2013).

6 The journal *Anthropology & Medicine* devoted a special issue to 'hospital ethnography' (see Long, *et al.*, 2008).

many claimed, I could get *all* the information for my research during the day. And why did I want to spend a week with the cleaners' team, or in the kitchen? Did I *really* want to talk to the porters? What could they possibly have to say about the reforms in mental health care, or about staff's perceptions on the evolution of psychiatric care? 'But they are all staff of this hospital and some have worked here for decades,' I argued. 'Cleaners, cooks, porters and administrators are part of the social structure of the hospital. If I want to write about the complex culture of a mental health institution I need to spend time in that social setting, with as many people who live and work there and observe, and where possible participate, in their everyday lives.' Can you not just ask people about their lives? My replies always paraphrased Blommaert and Dong (2010, p. 3, emphasis in original):

People are not cultural or linguistic catalogues, and most of what we see as their cultural and social behaviour is performed without reflecting on it and without an active awareness that this is actually something they *do*. Consequently, it is not a thing they have an opinion about, nor an issue that can be comfortably put in words when you ask about it. Ethnographic fieldwork is aimed at finding out things that are often not seen as important but belong to the implicit structures of people's life. Asking is indeed very often the worst possible way of trying to find out.

Ultimately, I was granted permission and I started fieldwork. Many of my informants in the psychiatric hospital, however, were highly educated individuals who had been trained to think about the world in a particular way, and consequently some had strong views on how I should conduct my research and what the end results would be. A survey and a quantitative approach would surely be more professional? More scientific? More true and more objective? 'But there is no such thing as objectivity,' I objected, and I tried to explain, while I politely accepted print-outs of a large numerical dataset of hospital admissions. It was the first time that I needed, and wanted, to explain that ethnography is a social form of research, that it is predicated on my personal commitment, and that I was really committed to sharing the everyday life with staff and patients. It was a different kind of trust that I needed to earn in this medical environment. With the Cypriot refugees I had also been confronted by issues of acceptance because of my ethnic background, the fact that I was a *Greek* Cypriot refugee's daughter (Dikomitis, 2012, p. 29-33). This time it was my professional background, and specifically my methodological approach, that was questioned and not understood.

At present, there are only a few studies on how medical and social scientists relate to each other. Albert *et al.* (2008) examined the perceptions about social sciences through in-depth interviews with 31 biomedical scientists who are members of peer

review committees at the Canadian Institutes of Health Research.⁷ The majority of their respondents questioned the rigour of social science methods and the validity of data collected via those methods. Quantitative methods were perceived as more ‘objective’ and ‘reliable’ and their respondents argued that qualitative studies need a quantitative element for data verification (Albert *et al.* 2008, p. 2526). The research team describe that most of their participants had limited, and occasionally inaccurate, knowledge of social sciences. My experiences in the medical field echo this. One example is how medical students think about social sciences. I examined this through fieldwork in one medical school, where I was teaching optional health sociology and medical anthropology courses. The students showed great enthusiasm, but simultaneously expressed concern and unease with the material and ‘the way social scientists think’, as one student put it. After long-term participant-observation among medical students, I obtained a good insight into both the formal and the hidden medical curriculum. Institutional slang is one of the areas through which a hidden curriculum can be ascertained (Hafferty, 1998). The term ‘fluffy stuff’ is a good example of such slang used in the medical school where I conducted fieldwork. Here is how students understand it:

Fluffy stuff: the aspect of medicine that is repetitive and easily understood using common sense. E.g. patient has been diagnosed with cancer – how does that make them feel? Obviously awful. Or what are the social effects on an elderly lady who has broken her hip and is now not as mobile as she was before? She is not as independent at home so she may need help doing this she used to do, which might make her depressed and even embarrass her or she may even need to go into a home and lose all independence, etc. These are very easy to understand, obvious and often self-explanatory topics. (Charlotte)

The fluffy stuff is something that is a bit more common sense where you can sort of talk about it without researching it. (Ashak)

The ‘fluffy stuff’, according to my informants, includes learning content from the medical humanities, sociology, psychology, professionalism, ethics and public health.⁸ My data show that sociological knowledge is perceived as ‘common knowledge’ which ‘you can Google’ and it is always left to last, by clinical tutors to teach it and by students

7 Biomedical scientists usually hold a high status in the health research field. See Clarke (2001) and Clarke *et al.* (2003).

8 An editorial in the *British Medical Journal* (1980) was entitled ‘More anthropology and less sleep for medical students’ and it reflects on a possible place of anthropology in medical education. The (unnamed) author divides the subjects in the medical curriculum into two distinct categories: the ‘lions and tigers’ (including surgery, anatomy and physiology) and the ‘alleycats’ (including psychology, sociology, epidemiology, statistics, anthropology). Social sciences have now been more robustly integrated in the undergraduate medical curriculum (BeSST, 2016), but it is still unusual to find medical anthropology as a stand-alone core subject.

to study it. This understanding is reiterated by each new cohort, and, worryingly but not surprisingly, is also very much alive among staff in medical research environments. Such staff includes, in addition to social scientists, academics from different scientific cultures who engage in distinctive research practices: basic scientists, clinical scientists, epidemiologists and medical educationalists. I believe it is fair to conclude that the majority of scholars working in medical academic units do not have a robust understanding of ethnographic methods. This is evidenced by the regular contributions in medical and clinical journals which outline the basics of ethnography – sometimes in sweeping generalised terms – and highlight ethnography’s potential for medical research (see, for instance, Dixon-Woods, 2003; Goodson and Vassar, 2011; Greenhalgh and Swinglehurst, 2011; Pope, 2005; Savage, 2000; Reeves *et al.*, 2008; Van der Geest and Finkler, 2004).

But where does that leave the social scientists in medicine, and especially the ethnographers among them? The same Canadian research team subsequently examined perceptions held by social scientists working in medical research units (Albert and Paradis, 2014; Albert *et al.*, 2015). They conclude that most social scientists working in Canadian medical schools and medical environments perceive themselves ‘misfits or outsiders in their work environment’ (Albert and Paradis, 2014, p. 380):

For most of our participants, being in medicine implies something similar to moving to another country, a country with its own rules, expectations, value system, and legitimate strategies to establish reputation. For all participants in our study, adaptation was necessary. For some, adaptation was successful, for others it failed. (Albert and Paradis 2014, p. 381)

Sociologist Maria Tsourouffi (2012) paints an even bleaker picture of her professional experiences in a British medical school – which she describes as a ‘war zone’ and ‘battleground’. She felt marginalised as a feminist academic and as a social scientist with expertise in qualitative methodology: ‘I was told that as a social scientist I should understand that most things were a matter of perception and I should not get upset’ (Tsourouffi, 2012, p. 474).

I do not experience working in a medical research environment in such a negative way, although I have changed my research practice. The main difference is that I now mainly work in a research team, whereas before I carried out all research activities on my own. The main challenge for me, however, concerns the writing style of my academic work. I always had time and space to write ethnographic narratives and that has changed and is, for me, the major challenge now that I work in interdisciplinary health research teams.

Writing Ethnographically

During a professional development event at a medical school we were asked to list our priorities to develop our careers. I explained that completing my second ethnography was my top priority. After all, during my time in a social science department it had been drilled into me that monographs were essential for academic promotions. At that event, however, I was told by a very senior academic that I should revisit my priorities. 'Books, certainly ethnographies, are not valued in medical schools. Books are things you write on Saturday mornings.' This view was echoed by many biomedical and clinical scientists present at the event. Since then I have not written another book. I focussed on journal articles and research reports. Much of my research time has also gone into the writing of bids for external income, research protocols, ethics applications and study materials. Indeed, in many countries, there is an encroachment of the science publication and research model on a large number of disciplines.⁹

The publication benchmark in medical research units is set by the massive productivity of biomedical scientists and epidemiologists who write 10 to 15 papers per year. The standard template of such journals do not allow much space for writing articles in the narrative style characteristic of such ethnographic texts 'that everyone can read'.¹⁰ Clinical and medical journals generally adhere to a fixed format with set sections which are on average each 600 words long: 'Background', 'Methods', 'Findings', 'Discussion', 'Strengths and Limitations of this Study'. This template is increasingly being used in social science journals too, especially in those journals that focus on quantitative research. Anthropology is, in that respect, more situated on the boundaries of social sciences and humanities. Albert and Paradis (2014, p. 382) suggest that many social scientists in medical schools shift their academic production:

Several have had to compromise or dilute their work to fit the dominant publication model in medicine, that is articles in the range of 3,000–4,000 words, characteristically without theoretical grounding or substantive literature review and discussion.

An additional challenge is that ethnographic studies rarely find their way into clinical, medical and healthcare journals. It remains indeed challenging to publish such research in leading medical journals. The recent debate around the rejection policy of the *British Medical Journal* (BMJ) is a good case in point. The BMJ rejects, according to

9 Of course, also academics in social science departments are increasingly engaging with these different writing genres: administrative texts, audit forms, feedback reports, to name but a few. A recent collection (Wulff, 2016) explores the wide range of writing genres anthropologists are expected to master. One reviewer pointed out that books are increasingly devalued also in the humanities.

10 I refer here to Kristen Ghodsee's (2016) recent book, *From notes to narratives: writing ethnographies that everyone can read*, in which she explores the craft of ethnographic writing.

Greenhalgh *et al.* (2016, p. i563), qualitative research on the grounds of 'low priority' and 'unlikely to be highly cited'. The BMJ's editorial team responded to Greenhalgh and colleagues as follows: 'We do not prioritise qualitative research because, as mentioned in our information for authors, qualitative studies are usually exploratory by their very nature and do not provide generalisable answers (...) We have chosen to focus our efforts on quantitative research that reports outcomes that are important to patients, doctors, and policy makers' (Loder *et al.*, 2016: i641).

To conclude, I have used anecdotal evidence in this reflective piece to highlight some of the challenges that social scientists in medicine, who are engaged with ethnography, may face. There is of course much more to explore, especially about the different ontological and epistemological views researchers in medical research units hold and how these views may act as barriers to the full acceptance of ethnography. It seems essential that social scientists in medicine join efforts to ensure that ethnographic research acquires more visibility and scientific authority in the medical field. For me, it is precisely scholarly work such as that by Stefan Beck that raises the profile of social scientific work in medicine and demonstrates the potential of ethnography. Beck's research speaks to researchers from different social, biomedical and clinical disciplines precisely because it goes beyond what Beck (2008: 17-18) called 'fashionable interdisciplinary conversations'.

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

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Translated by Gisela Welz

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.

Hadjiminas 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, Hadjiminas 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 Hadjiminas, 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 plisión* 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 plisión*) 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, Hadjiminias 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 Hadjiminias 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, Hadjiminias 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: Hadjiminias 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. Hadjiminias 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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Stefan Beck's Contribution to the Medical Anthropology of Cyprus: Selected Publications

COMPILED BY GISELA WELZ

The following bibliography lists only those publications by Stefan Beck that are based on original fieldwork that he had conducted in the Republic of Cyprus since the late 1990s. A complete list of his publications on the Anthropology of Biomedicine as well as other fields can be viewed on the website of Humboldt University Berlin: <https://www.euroethno.hu-berlin.de/de/institut/personen/beck/publikationen>

Wherever possible, the original English-language abstract has been quoted, to give some information on the publication's contents. English translations of titles in other languages as well as additional summaries were provided by Gisela Welz.

Beck, S. (1999) 'Blut, Schweiß und Gene – Anmerkungen zur Belebung der Künstlichkeit und zur Industrialisierung der Biologie' [Blood, sweat, and genes. Notes on vital artificiality and the industrialisation of biology], *kuckuck - Notizen zu Alltagskultur und Volkskunde*, Vol 14. No. 1, pp. 11-16.

In 1998, Stefan Beck engaged in an in-depth ethnographic study of a genetic screening for cystic fibrosis (CF), conducted by the Cyprus Institute of Neurology and Genetics in the village of Athienou. Against the backdrop of the history of science and the anthropology of knowledge, the first publication related to this research project discussed different diagnostic techniques to detect the illness in terms of their social impact, starting with historic sources on popular knowledge in Germany and other Northern European countries where CF was prevalent. There, midwives determined whether newborn babies suffered from cystic fibrosis by tasting their sweat. The high chloride content of babies' sweat, in fact, provided the basis for developing the first generation of chemical tests to be administered to newborns. Only with the advent of genetic testing, predictive diagnoses became possible, and the option of prevention became more pressing. In this short paper, Stefan Beck pondered how the production of certainty – i.e. to know for sure about the carrier status of prospective parents, or whether an unborn baby will suffer from the illness – generates new types of uncertainty and decision-making dilemmas.

Beck, S. (2000a) 'Die Denaturierung des Labors. Anmerkungen zur Erforschung der Arbeitskultur in den Naturwissenschaften' [Taking nature out of the lab. Notes on doing research in scientists' professional culture], in Götz, I. and Wittel, A. (eds) *Arbeitskulturen im Umbruch. Zur Ethnographie von Arbeit und Organisation*. München: Münchner Beiträge zur Volkskunde. 2000, pp. 175-196.

Starting with ethnographic observations of daily routines in a genetics laboratory at the Cyprus Institute of Neurology and Genetics (CING), this article explores genetic research as a type of knowledge production, arguing that geneticists' professional practices constitute a specific culture of expertise. From the perspective of cultural anthropology, laboratories indeed are 'cultural' spaces where experts are engaged in constructing reality. In contradistinction to earlier approaches of social constructivism and symbolic interactionism, Stefan Beck developed in this paper a 'realist constructivism' which takes into consideration economic and political factors as well as technologies and material settings. The paper also discussed the establishment of CING, in the context of postcolonial Greek-Cypriot society, and emphasized the importance of transnational networks of biomedicine and genetics for its inception.

Beck, S. (2000b) 'Rekombinante Praxen, Wissensarbeit als Gegenstand der Europäischen Ethnologie' [Recombinant practices. Knowledge work as a research topic in European Ethnology], *Zeitschrift für Volkskunde*, pp. 218-246.

'From a praxeological perspective, the article explores knowledge cultures typical for late modernity. Drawing on fieldwork studying a genetic screening in Cyprus, and hospital practices in Germany, the interplay of different kinds of professional knowledges employed by medical experts – geneticists, physicists, genetic counselors – is analysed. Special attention is given to the different epistemic settings of knowledge production and processes of knowledge transfer in professional settings as well as to the appropriation of knowledge by actors in everyday contexts. The article proposes to study different modes of knowledge production, storage, transfer and appropriation as defining practices for modern knowledge societies. In order to do so, the modification of fieldwork practices and theoretical assumptions of cultural analysis is needed. The argument is developed in part by critically examining earlier work in the German Volkskunde tradition.' (Original abstract)

Beck, S. (2001) 'Reflexible Körper. Anmerkungen zur Transformation von Gesundheitsverständnissen und Verwandtschaftsverhältnissen durch humangenetisches Wissen' [Re-flexible bodies. Remarks on health attitudes and kinship relations being transformed by human genetics knowledge], in Brednich, R.W. et al. (eds.) *Natur - Kultur. Volkskundliche Perspektiven auf Mensch und Umwelt*. Münster, pp. 31-45.

Based on a paper presented at a conference in Münster, Germany, in 1999, Stefan Beck framed his fieldwork in Cyprus within a larger debate on how advances in human genetics will impact on lay people's attitudes about what counts as being healthy, and how they are expected to also change culturally embedded notions of kinship. He discussed findings based on interviews with adults who took part in the comprehensive genetic screening of the population of Athienou in 1997-1998. After a series of inexplicable deaths of children, it was unexpectedly discovered that the village was home to a number of families suffering from the genetic disease which is extremely rare in the Eastern Mediterranean. Stefan Beck deployed this case study also to discuss the status of biomedical and specifically genetic knowledge in Cultural Anthropology.

Beck, S. (2004a) 'Fryst altruism, varm solidaritet och kall etik. Om en biobank på Cypern' [Frozen altruism, heated solidarity, and iced ethics. About a biobank in Cyprus], in Lundin, S. (ed.) *En ny kropp. Essäer om medicinska visioner och personliga val*. Lund: Nordic Academic Press, pp. 43-76.

'In 1998, the Cypriot Bone Marrow Donors Database took up its operation as a charity under the name of Karaiskakeio Foundation. [...] In its first two years of operation, Karaiskakeio Foundation registered the impressive number of 15,000 potential donors. However, these figures hugely increased in March 2000, when in the time span of only three weeks, almost 60,000 volunteers registered. This unprecedented donor drive was started by a press release issued by Karaiskakeio Foundation that it was searching for potential bone marrow donors for two boys suffering from leukaemia, one a Turkish Cypriot living in the north, the other a Greek Cypriot residing in the south. The article takes ethnographic observations, interviews and the analysis of media discourse surrounding this one as well as a later bicomunal drive for bone marrow donation in Cyprus as a point of departure, to inquire into how political activists, representatives of patient organizations, biomedical experts and ordinary citizens infuse biomedical practices – bone marrow donation – with meanings that reach from manifestations of altruism to political statements for a common, cosmopolitan humanism. In doing so, participants also supersede a nationalist bio-politics instituted by the Turkish- and Greek-Cypriot governments in power at the time.' (summary from an unpublished English-language draft)

Beck, S. (2004b) 'Alltage, Modernitäten, Solidaritäten. Soziale Formen und kulturelle Aneignung der Biowissenschaften – Plädoyer für eine vergleichende Perspektive' [Everyday lives, modernities, solidarities. Social forms and cultural appropriations of biosciences - an appeal for a comparative perspective], *Zeitschrift für Volkskunde*, pp. 1-30.

‘The article analyses emergent social forms and divergent cultural modes in which knowledge and options, produced by the life sciences, are integrated into everyday routines and vernacular thinking. Drawing on the example of a Cypriot bone marrow database, a ‘biomedical platform’ is observed in operation. The article argues that it not only brings into existence new biological objects but also disseminates new forms of instituted altruism and de-/re-politicized solidarity. Applying the concept of multiple modernities, developed in Post-Colonial Studies and Cultural Anthropology, and drawing on Science and Technology Studies the article calls for comparative inquiries of the complex dynamics and interdependencies of vernacular culture and recent advances in the production of genomic knowledge.’ (Original abstract) This article is based on Stefan Beck’s inaugural lecture at Humboldt University on the occasion of his appointment to an Associate Professorship in 2003.

Beck, S. (2005a) ‘Putting Genetics to Use’, *The Cyprus Review* Vol. 17, No. 1, pp. 59-78.

‘On the basis of empirical research using a screening program 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 program 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 program for thalassaemia on the island, most participants felt a pervasive moral obligation for all-compassing ‘genetic transparency’. While this might constitute a bio-ethicists’ 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 genetisation.’ (Original abstract) This article is based on a paper presented at a conference at the University of Nicosia / Intercollege in 2001.

Beck, S. (2005b) ‘Dicke Bohnen. Zur Ko-Evolution eines gefährlichen Genusses’ [Broad beans. On the coevolution of a dangerous pleasure], in Muri, Gabriella et al. (eds.) *Die Alltagsküche. Bausteine für alltägliche und festliche Essen*. Zürich: Schweizerische Gesellschaft für Volkskunde, pp. 65-68.

For a collection of essays on food culture, Stefan Beck contributed this short piece about favism, an acute haemolysis that can be triggered by ingesting fava beans. Favism is related to a genetic defect in an enzyme which causes red blood cells to break down prematurely. In severe cases, especially in young boys, it can lead to sudden death by kidney failure and circulation breakdown. In Cyprus 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.

Beck, S. (2006a) 'Enacting Genes – Anmerkungen zu Familienplanung und genetischen Screenings in Zypern', [Notes on planned parenthood and genetic screenings in Cyprus] in Graumann, S. and Grüber, K. (eds.) *Biomedizin im Kontext* (= Mensch, Ethik und Wissenschaft, Vol. 3). Münster 2006, pp. 221-237.

This article evolved in the context of a large-scale research endeavour that Stefan Beck conducted between 2003 and 2007, with the objective of comparing Germany and the Republic of Cyprus in regards to political regulation and societal responses to challenges posed by new biotechnologies, in particular, genetic testing and IVF technologies. The genetic disease of cystic fibrosis constituted a focus of research in Germany and Cyprus alike. When Stefan Beck was appointed Full Professor at Humboldt University Berlin in 2007, other projects and obligations started to claim his time, and he abandoned the full-scale comparative research design. In this paper, historical and ethnographic data from the Cyprus case study is engaged with only, analysing contemporary attitudes and social practices in regards to genetic prevention programmes against the backdrop of society's historical experience of the colonial period. The paper also inquires into the social construction of ethnic group identity and how it both tries to enlist and is contested by the findings of population genetics

Beck, S. (2006b) 'Wissenschaft und die Transformation des Alltags – sozialanthropologische Anmerkungen zur Variation biopolitischer Regimes' [Science and transformations of everyday life – social anthropological remarks on the variability of bio-political regimes], in Liebig, B. et al. (eds.) *Mikrokosmos Wissenschaft. Transformationen und Perspektiven*. Zürich: Universitätsverlag, pp. 205-226.

This paper scrutinized the development of the Thalassaemia Prevention Programme in the Republic of Cyprus. Since the 1970s, its implementation significantly reduced the number of births of children suffering from thalassaemia. This was achieved by the Church requiring couples to be tested for carrier status before getting married. While the decision of whether to get married and to have children was left to the couple on learning of their potential risk to have thalassaemic children, the fact that the screening was mandatory raised a storm of indignation among international bio-ethicists. In this article, Stefan Beck proceeded to explain that from the perspective of the Greek Cypriot population, conducting the test, conversely, represents a deeply ethical act that demonstrates one's responsibility towards one's family as well as to society as a whole. Importantly, this paper argued that anthropological findings may be conducive to

understanding culturally-specific barriers to the implementation of universalistic global bio-ethics.

Beck, S. (2007a) 'Medicalizing Culture(s) or Culturalizing Medicine(s)?' in Burri, R. V. and Dumit, J. (eds.) *Medicine as Culture. Instrumental Practices, Technoscientific Knowledge, and New Modes of Life* (= Routledge Studies in Science, Technology and Society, Vol. 6). London: Routledge, p. 17-33.

This paper took as its starting point a celebration arranged by the Cyprus Bone Marrow Donor Registry (CBMDR) where all donors and recipients of bone marrow grafts came together as a group, but the individual donor-recipient-relationship was not disclosed. Stefan Beck contrasts this policy with the US-American practice of letting recipients know who donated bone marrow to them and saved their lives. By explaining why CMBDR chose a different route, he shows that human beings 'do not simply turn into objects of biomedical regimes' but instead, new subjectivities are produced that 'draw on specifically Cypriot conceptions of community, solidarity and altruism that make the Cypriot Bone Marrow Donor Registry one of the most successful biobanks worldwide' (Beck 2007a, p. 21). The chapter critically engaged with the notion of medicalization as it is prevalent in medical anthropology and sociology, and inquired into the advantages and risks of deploying 'culture' as an explanation when observing differences in social actors' appropriations of biomedical knowledge and technologies.

Beck, S. (2007b) 'Die liebevolle Behandlung postkolonialer Subjekte. Medizin(er) und epidemiologische Intervention in Zypern' [The loving care of postcolonial subjects. Doctors, medicine and epidemiological interventions in Cyprus], in Warneken, B. J. (ed.) *Volksfreunde. Historische Varianten sozialen Engagements*. Tübingen: tvv-Verlag, pp. 319-338. [re-printed in translation in this volume]

Cyprus has one of the highest incidences in the world of the mutations that cause thalassemia. 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, Stefan Beck inquired 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.

Beck, S. and Lengwiler, M. (2008) 'Historizität, Materialität und Hybridität von Wissenspraktiken: Die Entwicklung europäischer Präventionsregimes im 20. Jahrhundert' [Historicity, materiality, and hybridity of knowledge practices: The emergence of European regimes of prevention in the 20th century], *Geschichte und Gesellschaft*, Vol. 34, pp. 489-523

'The article analyses the emergence of European regimes of prevention by focussing on the history of knowledge practices as a distinctly modern form of social and political rationalities in Western Europe. While the targets, means, logics and institutional forms of preventative interventions differed significantly in European national contexts, the authors also trace the elements of a convergent trajectory in the development of prevention regimes. Based on a case study on Cyprus, the article also highlights how European colonies such as Cyprus provided a crucial 'laboratory' for the development of innovative approaches in prevention, revealing a 'histoire croisée' of prevention practices.' (Original abstract) The sub-chapter on Cyprus is based on archival work on the efforts of the British colonial administration to eradicate malaria on the island that Stefan Beck originally conducted in 1998. In this article, he considered the British administration's policies in the health sector in terms of a paternalistic bio-political regime that produced the inhabitants of the island of Cyprus as colonial subjects, and even today, continues to shape the prevalent civic epistemologies on the island.

Beck, S. (2009). Προσωπικές συνδέσεις: δημιουργώντας αλληλένδετες μορφές ζωής στη δωρεά μυελού των οστών. in Κωνσταντίνος Ν. Φελλάς (Hg.) *Κοινωνία και Υγεία*. Athens: Εκδόσεις Κριτική, pp. 249-276 [Inabstractable Connections. Creating enchaind forms of life in bone marrow donation]

'Onur, a young Turkish Cypriot, saved the life of a little Greek Cypriot girl, Andrea, by donating bone marrow cells that were transplanted to Andrea when she was suffering from leukaemia. The extraordinary relation between Onur and Andrea [...] is based on histo-compatibility: by sheer coincidence their tissue types are highly compatible. The incidents that led to the identification of Onur as a "match" [...] and their political ramifications' are exceptional, as is this new type of 'biosocial intimacy' between these two individuals who are separated by the Green Line which divides the island of Cyprus. 'The chapter explores the implementation of global regulatory frameworks for organ / tissue donation in Cyprus as a practical and pragmatic reflection of Cypriot cosmologies and understandings of sociality and solidarity, of belonging and possessing. Tissue donation in Cyprus reflects particularly well the effects of the coloniality of power and the vitality of local ethical motivations for new forms of a globalized sociality. In the last section of this chapter, the views of donors and recipients of bone marrow grafts are discussed. How do they perceive the relations that are instigated by transplantation? How can this peculiar relationship be conceptualized socially, culturally and emotionally,

what are the social models that people draw on, in order to make sense of the close bond with a person whom they do not know and most likely will never meet? It is suggested that these donor-receiver-relations represent a new type of biosocial relationship that is characterized by "anonymous intimacy".' (Excerpt from the original abstract)

Beck, S. and Niewöhner, J. (2009) 'Localising Genetic Testing and Screening in Cyprus and Germany. Contingencies, continuities, ordering effects and bio-cultural intimacy', in Atkinson, P., Glasner, P. and Lock, M. (eds.) *The Handbook of Genetics and Society: Mapping the New Genomic Era*. London: Routledge, pp. 76-93.

'Genetic testing and screening and their implementation in the context of increasingly complex genomic knowledges marks a vast field of practice and research. To attempt a systematic and comprehensive overview across the different technologies and their contexts is far beyond the scope of this chapter. Instead, as social anthropologists we focus on three areas of problematisation: (1) Local biologies and medicines in their historicity: Tests and screens are situated in specific temporal-spatial contexts. These entail not only specific (regional, national, supra-national, e.g. EU) regulatory regimes and medicinal cultures (i.e. belief-systems) but also specific local biologies. The complexity of their interaction increases with the intensification of migration. (2) Performing tests and screens: The practices of testing and screening need to be conceived of as relating specific technologies and knowledges to a range of actors and their respective familial, professional and socio-cultural contexts. These socio-material networks operate before a backdrop of legal, political and moral discourse with a strong historico-cultural dimension. (3) Translations and biosocial assemblages: the outcomes of tests and screens cannot be adequately understood in terms of information production and transfer. Rather, we suggest that these processes should be conceived of as entangled in complex translations, which can be analysed along at least three axes: individual to collective; purified to hybridised; local to transnational. To discuss these aspects, the chapter draws on examples from the US, Cyprus and Germany including cystic fibrosis and thalassemia.' (Original abstract)

Amelang, K. and Beck, S. (2010) 'Comparison in the wild and more disciplined usages of an epistemic practice', in Scheffer, T. and Niewöhner, J. (eds.) *Thick Comparison. Reviving the Ethnographic Aspiration* (= International Studies in Sociology and Social Anthropology, Vol. 114) Leiden, Boston: Brill, pp. 155-179

'Our analysis of the usages of comparative practice derives from a retrospective consideration of our participation in the EU-funded research project "Challenges of Biomedicine – Socio-Cultural Contexts, European Governance, and Bioethics". Our empirical basis consists of interviews and focus group discussions which we produced

in the context of this research project, which analysed how lay people in six European countries perceived and discussed recent developments in biomedicine, namely genetic testing and organ transplantation. The project took a comparative perspective on three levels: between the different national contexts, between the two biomedical technologies, and between lay people generally and affected persons more specifically who had more direct experiences with one of the two technologies, for example as patients. We concentrate on three research locations, namely on Lund, Sweden, Nicosia, Cyprus and Berlin, Germany.' (Amelang and Beck 2010, pp. 156ff.)

Amelang, A., Anastasiadou-Christophidou, V., Constantinou, C., Johansson, A, Lundin, S. and Beck, S. (2011) 'Learning to eat strawberries in a disciplined way. Normalization practices following organ transplantation' *Ethnologia Europaea*, 41/2, 2011, pp. 54-70

'The article concentrates on the accounts of transplant patients and their relatives in a comparative perspective. Starting from narratives of normalization of respondents in Sweden, Germany and Cyprus, we examine more closely what we call normalization practices as they are embedded in different social situations and contexts of living with chronic disease. The narratives are analysed as a crucial part of highly selective and individually constructed meaning-making practices, which – most of all – serve to establish continuity with the past and the expected or desired future. The article inquires what counts as normal in the eyes of our respondents, what strategies they apply to normalize their conditions for living, and – on a more general level – which social and cultural mechanisms of in- and exclusion they have to face in doing so, our case-based analysis will explore these narratives by analytically differentiating between three "levels" of practices normalizing illness experience: (1) a personal level, (2) a level of the intimate and (3) anonymous sociality.' (From the original abstract)

Beck, S. (2011a) 'La politisation et la moralisation d'une pratique médical: le don de moelle osseuse comme referendum' [Politization and moralisation of a medical practice: Bone marrow donation as a referendum], in Vailly, J., Kehr, J. and Niewöhner, J. (eds) *De la vie biologique à la vie sociale*. Paris: La Decouverte, pp. 51-77.

'In March 2000 – in a time span of only three weeks – more than 57,000 volunteers from both the Turkish and the Greek communities in Cyprus registered as potential bone marrow donors following a call in the press to help two boys suffering from leukemia, a Turkish-Cypriot, Kemal Saraçoğlu, and a Greek-Cypriot, Andreas Vassiliou. While the vast majority of registrants were Greek Cypriots living in Cyprus, there was a significant number of Turkish Cypriots as well who used the UN-controlled Ledra Hotel, where a make-shift sample office was established, for registering and giving blood samples for

further analysis. Most reports interpreted the huge success of the donor drive in 2000 against the backdrop of the stalling political negotiations between representatives of the two communities on the island. According to these interpretations, the volunteers expressed their solidarity and commonality not just with their own ethnic group but also with members of the other community on the island, demonstrating that humanitarian considerations can overcome the political divide.’ (Quoted from the English-language draft of the original presentation in Paris)

Beck, S. (2011b) ‘Anthoullas Gefühl für Gene. Leben, Heiraten und Kinderkriegen im Zeitalter genetischer Transparenz - in Zypern, zum Beispiel’ [Anthoullas Intuition about Genes. Living, Getting Married, and Having Children in the Age of Genetic Transparency – in Cyprus, for instance], in Moos, T., Niewöhner, J. and Tanner, K. (eds.) *Genetisches Wissen. Formationen und Übersetzungen zwischen Wissenschaft und Gesellschaft*. Konstanz: Röhrig Universitätsverlag, pp. 115-140.

Against the backdrop of the many years of research that Stefan Beck conducted in Cyprus on genetic testing and prenatal diagnostics, this paper inquires into the impact of genetic information on social actors’ everyday lives and relationships. How do they negotiate the moral implications of results of genetic testing, and how do they cope with the challenge of translating abstract information – such as their own or their spouses’ carrier status for a genetic disorder – into making life decisions, such as getting married or having a child? The case studies discussed in the paper are of Greek-Cypriot men and women who in the course of their lives have undergone genetic tests for both thalassaemia and cystic fibrosis. Taking recourse to the anthropology of knowledge as well as to practice theory, Stefan Beck asserted that lay people are capable of transforming scientific knowledge into a tangible resource for (re-)considering and potentially modifying the course of their lives. Rather than leaving such topics to social psychology, he argued that a ‘praxeological’ anthropology, informed among others by pragmatist philosophers, such as John Dewey and William James, is well-placed to inquire into how scientific knowledge is made meaningful for and by lay people.

Beck, S. (2011c) ‘Staging bone marrow donation as a ballot. Reconfiguring the social and the political using biomedicine in Cyprus’, special issue ‘Medical Migrations’, *Body & Society*, pp. 93-119

‘The article analyses practices, perceptions, and political dramatizations of bone marrow donation in Cyprus. Based on empirical data from an ethnographic study on practices of organ and bone marrow transplantation in postcolonial Cyprus, forms of oppositional biopolitics are analyzed that are not bound by the modern, statist regime of governing populations but capitalize on new developments in biomedicine,

on new political movements, as well as on transformations in the political sphere. These reconfigurations are interpreted as instances of an emerging bio-subpolitics that transcends national borders and produces new complexities, inter-relations, associations and social forms that come into being alongside biomedicine. At the same time, these developments co-produce cosmopolitan citizens and new subjectivities, transcending nationally bound regimes of political deliberation and identification. These forms of bio-politics mobilize local historical experiences and take advantage of affordances provided by biomedical platforms operating on a global scale that make available an opportunity structure for a cosmopolitan bio-subpolitics.' (Original abstract)

Beck, S. (2011d) 'Knochenmarkspende als Volksabstimmung - oder: die Politisierung des Organischen und die Moralisierung der Medizin in Zypern' [Bone marrow donation as a popular referendum – or the Politicisation of the Organics and the Moralisation of Medicine in Cyprus], in Niewöhner, J., Kehr, J., Vailly, J. (eds.) *Leben in Gesellschaft. Biomedizin - Politik - Sozialwissenschaften*. Münster: transcript-Verlag, pp. 54-82.

This paper asks what the political and cultural reasons were for the remarkable success of a number of campaigns for bone marrow donation in Cyprus. How is the globalized altruism of Cypriots produced locally, which social forms provide an underpinning for this high rate of registration as potential donors? To what extent is a society-based altruism scalable to reach out into the global domain? This paper analyses a series of interviews that Stefan Beck had conducted with Greek Cypriot bone marrow donors in 2005. At issue were the imagined relationships that are thought to emerge between donors and recipients of bone marrow cells. In Cyprus, these remain anonymous but are considered to be bound to each other by sharing living substance, i.e. bone marrow stem cells.

Beck, S. (2012) 'Biomedical Mobilities – Transnational Lab-Benches and Other Space-Effects', in Knecht, M., Klotz, M., Beck, S. (eds.) *Reproductive Technologies as Global Form. Ethnographies of Knowledge, Practices, and Transnational Encounters*. Frankfurt and New York: Campus Verlag, pp. 357-374.

'The article sets out to explore a challenge posed by recent developments in late modernity that for some time has been constituting a predicament for the social sciences and especially for socio-cultural anthropology: The intertwined questions of how to conceptualize and of how to make methodologically accessible the new spatio-temporal arrangements, the new modes of ordering or structuration of institutional as well as vernacular practices that are commonly labeled as being transnational or global. The article analyses instances of biomedical mobilities in the domain of in-vitro fertilization and reproductive medicine as a prominent example of these developments. I use the term biomedical mobilities to analyse three examples of these emerging patterns

in the domain of biomedicine; the term mobilities underlines the heterogeneity of elements set in motion: people, knowledge, ideas as well as things are mobilized to travel beyond borders. As will be argued in the following, biomedical platforms as they are in operation in reproductive medicine afford an opportunity structure for new types of mobilities and new transnational practices, that are in conflict with established regimes of governing over a territory and a population demarcated by well defined national borders: biomedical platforms afford not only the mobilization of cells, patients, medical equipment and knowledge, but also of moral convictions, of imaginations, of desires and of feelings of solidarity that travel beyond borders. This mobilization of material-discursive “things”, new relations between discursive practices and material phenomena, entanglements of human and non-human forms of agency, threaten to escape attempts of “national encompassment”, giving rise to a dialectic of globalization and attempts to re-localization.’ (Original abstract) Thalassaemia International Foundation (TIF), an transnational NGO based in Nicosia, Cyprus, was one of the case studies in this article which was written in the context of the Berlin-based multidisciplinary Collaborative Research Centre ‘Representations of Social Order – Intertemporal and Intercultural Comparisons’, German Research Council. Stefan Beck was Principal Investigator of a long-term comparative study on the implementation of IVF-technologies in Germany, Turkey, and Great Britain (2004-2013).

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**BOOK
REVIEWS**

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NUMBER 1

European Products: Making and Unmaking Heritage in Cyprus

GISELA WELZ

Berghahn Books (Oxford, 2015), 190 pp.

ISBN: 978-1-78238-822-7 (hard back)

Whilst reading Gisela Welz's new book, I was reminded of a walk I had taken in Nicosia more than 10 years ago. With Haşmet Gürkhan's book *Düñkü ve Buğünkü Lefkoşa* (Nicosia Yesterday and Today) in my hand, I was on a 'heritage quest', looking for a street whose life and residents he had written about, and which had been divided and cut off by the wall marking the division of the city post 1974. Finding the street and the shrine of Kara Baba as he had described it, I was amazed to discover a boat yard right up against the wall, with sailing boats in various stages of construction and repair. What was, to my eyes, an entirely unexpected and eccentric local urban economy had emerged in the gaps created by the coastal bias of Cyprus's tourism and the spatial politics of the Cyprus conflict. With 'heritage' now a dominant mode of production, driving the transformation of urban and rural economies across Cyprus, there will be little room available for such idiosyncrasies in the commodified spaces of the island's towns and villages, as Welz's careful analysis of the material processes of heritage making and unmaking in Cyprus reveals.

Welz's book is the product of a decades-long engagement with Cyprus which is both personal and professional. Out of this long-term engagement emerges an eye for what links such, at first sight, unrelated practices as the restoration of vernacular architecture, cheese production, and city makeovers. These she locates in the particular form of globalisation Cyprus has signed up to through accession to the European Union, mediated by a major shift to managerialist procedures and technologies of governance. 'Heritagization', argues Welz, comprises not only a 'massive reorganization of public memory' (p. 27), but is at the same time a 'vector of Europeanization' (p. 151), a channel for the harmonisation of laws, policies and practices through which Europe is effectively enacted and becomes part of daily life for at least a section of the population. Each chapter of the book offers a vignette of these practices in relation a particular heritage case, and these specific examples are topped and tailed by the introduction and conclusion, which set the political context of the argument.

The seven chapters of the book are organised under three headings – 'Heritage Regimes' concerns rural heritage making and projects aimed at the revival of villages and the rural economy through conservation and rural tourism. 'Food, Culture and

Heritagization' explores the 'full meze', which has become a staple of tourism hospitality, and the controversial listing of halloumi as a protected 'origin food'. 'Ambient Heritage' examines the commodification of landscapes and townscapes – the former in relation to the protection and exploitation of the Akamas Peninsula, the latter in the context of the 'European Cities of Culture' programme, in which cities compete for the title by demonstrating how successfully they can embody an idea of European urban cultural space. By tracing the paths of European legislative and policy practice across each of these chapters, a picture emerges of the tensions and contradictions, not only between the ambitions of a Europe-wide project and its local realisation in Cyprus, but between different policy arms. This results in the paradox, for example, of a food origin-listing regime that favours the commercial interests of big halloumi producers over small-scale 'craft' cheese makers, driving another nail in the coffin of rural economic viability, and exacerbating the problems of decline that other European-funded rural heritage and tourism projects are trying to address. The concluding chapter brings the situation right up to date with a critical reflection on the effects of the financial crisis and the impacts of the Troika and austerity measures on the Republic of Cyprus, which highlights the neoliberalism implicit in the European project. This, for me, was one of the most fascinating parts of the book, opening up questions concerning the role of elite classes in driving and capitalising on investment flows within a globalised heritage economy, which the usual preoccupation with the uses of heritage in projects of ethno-national identity and state formation tend to obscure – particularly in the context of Cyprus. Whilst these processes are by no means unique to the European Union, the EU, as Bianchi (2005) points out, plays a decisive role in pushing liberalisation measures in its neighbourhood and trading partner countries, in order to open up and extend the free European market in services, which is so far incomplete, and which offers rich pickings from the privatisation and commodification of the public realm.

This is not a book about the Cyprus conflict. Nevertheless, its contestations inevitably surface in this account of cultural heritage production, and, without wishing this to become the focus of the book, I should have liked to see some of the issues raised, for example, by the Protocol 10 arrangements for the suspension of the *acquis communautaire* in the north, dealt with more fully, rather than relegated to parentheses and footnotes. This, however, should not detract from the book's achievement, as Welz, moving between interlocutors in Brussels and Cyprus, and reflecting on developments spanning 25 years, delivers a fascinating insight into the multiple layers of heritage practice and the making – and unmaking – of Europe in Cyprus.

JULIE SCOTT

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*Narratives of Cyprus:
Modern Travel Writing and Cultural Encounters since
Lawrence Durrell*

JIM BOWMAN

I.B. Tauris (London and New York, 2014), 183 pp.

ISBN: 978-1-84885-918-0 (hard back)

Jim Bowman's book *Narratives of Cyprus, Modern Travel Writing and Cultural Encounters since Lawrence Durrell*, offers analysis and critique on travel narratives in English by a number of writers from 1955 to 2005.

Bowman, who spent an extensive period living in north Cyprus, begins his book with the two chapters discussing what is, or should be, a modern travel narrative, calling upon various theories of rhetoric, approaches, styles and cultural contexts. He claims that travel narrators deliver their texts to their public in order to achieve different purposes and thus shape international and domestic politics resulting often in asymmetric relations of power. Bowman tries to present and explain travelogues as "cultural works" which have an effect on how people see and understand themselves, but also remain a synthesis of a travellers' experiences, motives and narrative style. Central to his analysis and critique is the "ethos" which should be found in each traveller's text. He questions whether ethos is the result of the interaction or an a priori position of the traveller. He concentrates on what the travellers have omitted and why they write as they do under the circumstances.

Not much has been written about Cyprus recently, says Bowman. Perhaps that is because of its position, too far east in the Mediterranean, or perhaps because travellers were worried about security due to the militarization of the country. A simpler explanation should perhaps have been considered by Bowman: Cyprus, during the last 20 years or more has been competing with new markets and is being marginalised due to high costs and saturated product.

The dire circumstances in Cyprus and the political situation conspires against the independence of the traveller, confuses him and makes him feel insecure as to his personal assessment, continues Bowman. As a result, the north part of Cyprus (unrecognised, illegal area for many years) has not been clearly recognised, researched and understood by most travellers. And this is the niche which Bowman wants to explore and do justice to since it is lacking in most travelogues. In doing so he introduces himself as the ideal person to present the case, as he has lived in Turkey and in north Cyprus and visited repeatedly south Cyprus. He, in effect, lays out how

ideal his position is in relation to the work he is about to embark on, the *Narratives of Cyprus*, perhaps blowing his own trumpet a bit too loudly, especially when it comes to understanding the Greek Cypriots. The fact that he had worked with them, as a US government official in education, already places him in an awkward position with regards to the subjects of his study. It should be remembered that US was much blamed by Greek Cypriots for the situation in Cyprus in 1974, and in 2004 it was also blamed for the 'demonic' Annan Plan. So, Greek Cypriots are often apprehensive and suspicious of most Americans when it comes to politics and consequently do not talk honestly and openly with them.

In chapter 3, Bowman starts his cultural encounters with *Bitter Lemons* (1957), by Lawrence Durrell. In a nutshell, the book is treated as a political exposé camouflaged as a travelogue. Bowman has taken an obvious dislike to Durrell's narrative and does not accept him as the good spirited writer who aims at informing his readers about his own emotional experiences in Cyprus. Durrell is not forgiven for omitting obvious political realities such as the tensions between the two communities on the island in 1953-56, omitted, according to Bowman, purposely, so as to be likable to the domestic readers. Nor is he forgiven for purposely avoiding to mention the responsibility of the British government for the tragic situation in Cyprus. But his greatest fault, claims Bowman, is, contrary to Durrell's own contention that human beings are the expression of their landscape, the fact that, in *Bitter Lemons*, Durrell constructs both the landscape and the character of the people. Durrell is accused of embracing the differences between Greek Cypriots and Turkish Cypriots because he does not know the latter, to whom he attributes myriads of oriental tropes, and thus his text lacks ethos.

It is rather hard for anyone to question the traveller's intake of the country, the result of which was *A Journey into Cyprus* (1975). Being much kinder to Thubron, Bowman understands that the writer follows Don George's school of thought, which dictates 'don't tell what your characters are feeling but show it and let the reader draw conclusions'. Bowman, embracing postmodern theories, does not agree with this method, which he labels 'intimate distance' and which he believes creates dangerous asymmetric qualities in the narrative.

Further into his analysis Bowman returns to his defence of the Turkish Cypriot and claims that historically even the word Cypriot does not include the Turkish Cypriot. But why does it not? 'Cypriots' usually means a conglomeration of ethnicities living on the island, and when spoken of historically, in the Middle Ages Cypriots referred more to Venetians or French than Greeks. Just as Turks were referred to as Muslims during the Ottoman period, Greeks were referred to as Christians or 'infidels', but both were thought of as the population of the island which, in fact, was often called

Turkey.¹ Indeed, Bowman rightly notes that the use of Cypriots appeared mostly in the 20th century and proved uncomfortable to both the Greek and Turkish communities. Further on, while using a series of episodes from *Journey into Cyprus*, such as Thubron's observance of the Turkish women at Hala Sultan Tekke, his encounters with Hussein, Kemal, and the Greek peasant, Bowman asserts that Thubron misunderstood the Turks, made assumptions and used distant intimacy, which led him to the wrong conclusions. He rounds up his arguments that Thubron's text implicitly posits "the supremacy of western secularism, culture and political hegemony of the UK and the West over societies like Cyprus and Turkey." Towards the end, mellowing down, in his last remarks in the chapter, Bowman admits that Thubron, when abandoning his distant intimacy, produces noteworthy results within his narration and grants him 'a text that stands up fairly well to the tumult that has shaken Cyprus and Europe in the decades since its creation'.

Bowman exaggerates dangerously when he declares that the north appears as the 'dark other' of Cyprus in the narratives post-1974. Obviously he has not spent time exploring the feelings of both communities, and his own ethos is at stake here. Sanctions and embargo for the north, blamed by Bowman for 'the darker other', were requested by the Republic of Cyprus, but were these really adhered to? And if so, to what extent and for how long? Travel writers visited and visit the north, travel guide books in fact often contain descriptions of the north and not the south (I should point out here that this is not always the editors' choice). Guilty feelings, attributed to writers going into an illegal state, writing about occupied areas, buying or renting properties of the Greeks who lost part of their country, did not seem to stop either visits or travel writing during the last decades. After 2003 direct flights to the north and easy crossings through the Green Line have made visits to the north routine. The fact that a number of travellers choose to visit the north through arrivals to the south, which seems to bother Bowman, is nowadays a matter of convenience: they may thus visit the south as well, where they find better tourist infrastructure, better communications etc. But it is important to note that the vast majority of travellers declare that the north is the better half of the island and offers a more interesting landscape. Orientalising tropes regarding the north need further analysis by both the travel writer and Bowman. Furthermore, according to Bowman 'the north of Cyprus only sporadically finds itself fully included in symbolic constructions of an inclusive Cyprus'. Although not exactly true, especially in recent years, how can north Cyprus be included in 'Cyprus' when it advertises and proclaims itself as the 'Republic of Northern Cyprus', an 'independent

1 While researching early 19th century paintings of Cyprus in repositories of libraries or museums, I often found these under Turkey or Ottoman Dominions.

state', having its own tourist policies and having nothing to do with the south?

Hitchens' book *Cyprus, Hostage to History* (1997), a political narrative, probably justifies Bowman's bitter criticism. In fact Hitchens' a priori political stand poses obstacles towards a just exposé. He does not devote enough time to understanding the people nor in analysing the socio-economics of the landscape. The book though stands on its own merits independent of the usual travelogues. Bowman proceeds to examine two books, by foreigners living in the south and visiting the north, British expatriate Libby Rowan-Moorhouse's *In the land of Aphrodite* (2005) and the Irishman Seamus MacHugh's travelogue *Cyprus an Island Apart* (1999). Throughout his review, Bowman insists on finding tropes for the Turk as 'the dark other, pitiful, poor etc', questioning the knowledge and understanding of the writers but also pre-empting any possible understanding of incidents other than through his own explanations. 'Unhopeful smiles' cannot be interpreted this or that way! Angry Turkish youth shouting obscenities to the Greeks can only be bored conscripts! Wearing a moustache signifies a Turk! (I never knew my father was a Turk!!). The Turkish Cypriot Cuma does not want to go back to his village in the south because of the deprivations and hostilities of pre-1974, although he speaks fondly of his Greek friends and wants the Green Line to disappear. It has never occurred to Bowman that Cuma would not want to go back because he is better off in material terms compared to pre-1974: ethos is questionable here. Another 'incomplete' narrative, according to Bowman, of 'day tripping in the north' is *Dispatches from the Dead Zone*, by Anderson and Junger (1999). Cyprus is constructed as a sad place suffered in by decent people, people who cannot dream anymore. Certain readers might in fact agree with Anderson and Junger who paint a gloomy picture of Cyprus and a population trapped in its own petty politics rendering the island hostage to their immaturity and stubbornness. In claiming that the horrific construction boom around Kyrenia was done pre-1974, I suggest Bowman should have a look at photographs of that period.

The Infidel Sea, Travels in North Cyprus, by Oliver Burch (1990), enjoys Bowman's approval. Burch and his family lived long enough in the north part of the island and acquired enough cultural experiences to be able to give a decent voice to the Turkish Cypriots. According to Bowman, Burch offers an ethical narration. But Burch skilfully avoids analysing the relations between Turkish Cypriots and Turks. Bowman mentions this but he does not delve into it. Another case of ethos not prevailing? Further on, we are told that 'the dark other' appears due to qualities like anti-materialism and poverty and has political and economic justifications: after living through so many hardships Turkish Cypriots prefer to sacrifice prosperity for security. The validity of this argument can be challenged. Perhaps more explanations can be sought within Turkey's influence/power in Turkish Cypriot affairs, or the relation between the Turkish Cypriot

administration and Turkey.

For Bowman, the apogee of travel narratives on Cyprus seems to be the book by Yiannis Papadakis, *Echoes from the Dead Zone* (2005). More global in his approach, having visited north, south, Turkey, Greece, UK and US, Papadakis's narrative is a challenge to travel writing. He establishes an ethos based on responsibility, revelation and personal rigor, goes across the divide rather than cement it and tries to bridge differences and respond to people fairly. The writer involves himself in the encounters with his subject and opens up to them. Furthermore, he addresses the points of social distance between Turkish Cypriots and Turks. To Bowman's credit, while Hitchens was criticised as a biased observer (married to a Greek Cypriot), Papadakis's background, a Greek Cypriot from Limassol, is accepted with no qualms because of his overwhelming narrative.

I ought to admit that I found *Narratives of Cyprus* interesting, although at times I felt the language was complex and tiring and in general the text too theoretical. Bowman speaks authoritatively about Cyprus and in his book he assumes the role of the apologist for the Turkish Cypriots. To a Greek Cypriot it is apparent that the author does not know enough or understand well the Greek Cypriots. Once too often, I felt I had to defend and answer on behalf of the Greek Cypriots, I felt the need to clarify misconceptions and answer to criticism. This led me to question Bowman's purpose for his book. On the one hand it is surely a critique of the aforementioned narratives, but an apologist's ghost lurks between the lines of his script.

RITA SEVERIS

Cyprus: The Post-Imperial Constitution

VASSILIS K. FOUSKAS AND ALEX O. TACKIE

Pluto Press (London, 2009), xviii + 110 pp.

ISBN: 978-0-7453-2935-2

This book is a polemic. Its primary objective is 'to criticise the imperial arrangements that have governed Cyprus from 1958-60 to date ...'. However, an ancillary objective is to 'propose some sensible steps as to what the Cypriot Left, both Turkish and Greek, can do to reach a post-imperial constitutional understanding' (p.1).

The authors are two respected academics who have produced a distinctive contribution to the academic literature on what they depict as 'the Cyprus issue' (p.2). One of the authors, Vassilis K. Fouskas, hails from the field of international relations, while the other, Alex O. Tackie, has a background in economics. Not surprisingly, the authors have adopted a refreshing cross-disciplinary approach aimed at a wide readership within and beyond academia.

With the aim of fulfilling their primary objective, the authors fire a metaphorical scattergun. At the same time, they do little to disguise their ideological starting point which is ostensibly located on the anti-imperialist 'left' of the political spectrum. An inevitably mixed picture thereby emerges.

On the one hand, the authors do not appear to have drawn upon the wealth of primary source material available in various archives, not to mention published collections of declassified documents. No less seriously, the polemicism of the authors has prompted them to make some sweeping assertions and simplistic generalisations. To take one example: 'Imperial powers have always used proxies in history in order to achieve their aims, disregarding human suffering and international law' (p.28). The reality is much more nuanced than that.

On the other hand, the polemicism of the authors has enabled them to transmit an unequivocally clear set of messages. Of these, a number stand out as being particularly significant and, indeed, relevant to the present when 'the two leaders' of 'the two communities' are immersed in a secret 'leader-led process' (as the United Nations describes it) with the underlying aim of implementing the long-standing objective of Turkey. This is the transformation of the Republic of Cyprus ('the Republic') into 'a bi-communal, bi-zonal federation'.

Firstly, the authors make a shrewd point about the birth of the Republic on 16 August 1960: 'geo-strategic imperial interests' were 'encoded' in 'the Cypriot Constitution' which the authors define as 'an immense body of treaties, laws, agreements and other arrangements' (p.2). In turn, 'the Cypriot Constitution' forms the core of a bigger bundle

of texts which the authors brand as an ‘illegal Cypriot *acquis*’ (p.6). What they seem to mean by this is that the ‘*acquis*’ is morally repugnant, legally dubious and tainted with neo-imperialism.

Not without reason, the authors insinuate that the aforementioned ‘*acquis*’ was conceived in 1958, the year in which the ill-fated Macmillan Plan was published. The authors rightly highlight the critical role of Harold Macmillan, the prime minister of the United Kingdom from 1957 until 1963. When he presented the Macmillan Plan to the House of Commons on 19 June 1958, Macmillan envisaged ‘an adventure in partnership – partnership between the communities on the island and also between the Governments of the United Kingdom, Greece and Turkey.’ As events were to transpire, the Macmillan Plan bit the dust, but the ‘partnership’ concept did not. Indeed, it formed the foundation of the Zurich-London Agreements of February 1959, together with the instruments introduced in August 1960 and the ill-fated Annan Plan of 2004. Even today, the word ‘partnership’ continues to spew out of the mouths of politicians who wish to renew the neo-imperial ‘partnership’ framework articulated by Macmillan in 1958.

Secondly, the authors remind us that the Republic was established as an endemically divided ‘bi-communal’ state. Interestingly enough, the authors prefer to use the noun ‘vivisection’ (e.g. at p. 3) to portray the ethno-religious division initiated in August 1960. This ‘vivisection’ was achieved by various means, including a new quasi-Ottoman ‘bi-communal’ constitution, the preservation of pre-existing structures of division, such as the segregated school system, and the envisaged introduction of new forms of division, such as segregated municipalities. All of which was inimical to effective governance, an integrated society and any sense of inter-ethnic or inter-faith solidarity.

The divisions built into the newly-born Republic were no accident. They were firmly in line with the policies of Turkey and the United Kingdom. Both wanted to frustrate the principle of majoritarian democracy and replace it with the crude concept of ‘bi-communalism’. The upshot was all but inevitable. During the turbulent period from 1963 until 1964, the Republic was afflicted with a constitutional crisis ignited by communalism, inter-communal upheaval polluted by communalism and acts of external interference which exacerbated communalism.

According to the authors, ‘the Cypriot Constitution’, as defined above, was ‘invariably imposed by outside imperial interference’. Worse still, this ‘Cypriot Constitution’ has ‘been regulating not only the governance of the island from 1960 to date, but also the solution to the Cyprus question as such.’ In this respect, the authors make a telling point: ‘From the partition plan envisaged by Macmillan’s government in 1958 to the Ghali ‘Set of Ideas’ (1992) and the Annan plan(s) of 2002-04, the solution to the Cyprus issue has in great part been built on constitutional and other arrangements that go against the

spirit of international and European law.’ (p.2) Indeed, the secret ‘leader-led process’ of today not only seeks to perpetuate and adapt the divisive ‘bi-communalism’ enshrined in 1960. By means of ‘bi-zonality’, the ‘process’ also envisages the metamorphosis of the Republic into a peculiar entity out of kilter with mainstream European norms and democratic values.

Thirdly, the authors contend that the ‘garrison-prison state’ theory is useful in terms of understanding the extraordinary state of affairs prevailing since August 1960. This theory was advanced by Harold Lasswell (1902-78), a political scientist and professor of law at Yale University. According to Lasswell, a ‘garrison-prison state’ is one where power is wielded by ‘experts on violence’ (p.40). With this in mind, it is arguable that the Republic effectively became a ‘garrison-prison state’ when veterans of EOKA and TMT respectively came to assume positions of power in August 1960. However, as the authors indicate, the Republic became a ‘garrison-prison state’ upon its establishment for other reasons associated with neo-imperialism: because it was militarised by Turkey, the imperial ruler of Cyprus from 1571 until 1878, the United Kingdom, the imperial ruler from 1878 until 1960, and Greece, a pliant state branded by the authors as ‘a protectorate of the USA’ since 1947 (p.92).

Thus, from the moment it was born, the Republic played permanent host to foreign military forces from Greece, Turkey and the United Kingdom. The latter three likewise became ‘guarantor powers’. To this end, they undertook to ‘recognise and guarantee the independence, territorial integrity and security of the Republic, and also the state of affairs established by the Basic Articles of its Constitution’. They likewise reserved for themselves the unprecedented ‘right to take action with the sole aim of re-establishing the state of affairs created by the present Treaty [of Guarantee].’ To cap it all, the Republic was established subject to two British Sovereign Base Areas and the reservation by the United Kingdom of numerous neo-imperial treaty rights. These included the right to retain several sites, installations and training areas situated on the nominally sovereign territory of the Republic. Seen in this light, the Republic was indeed established as a ‘garrison-prison state’, although not quite in the sense described by Lasswell.

Today, all these years later, the veterans of EOKA and TMT have all but left the political stage. Yet the three guarantor powers have not. Indeed, not only is the Turkish military presence far larger than the one inaugurated in 1960; Turkish forces are illegally occupying an area governed by Turkey’s *de facto* subordinate administration, an illegal entity which evokes chilling comparisons with a Lasswell-type ‘garrison-prison state’.

One is therefore obliged to ask an inevitable question. Will the ‘leader-led process’ in Nicosia do anything, in substance, to undermine the neo-imperial arrangements introduced in 1960? Time will tell. Nevertheless, if the ill-fated Annan Plan of 2004 is any guide to what is being negotiated amid the secrecy engulfing the process, the answer

is an unmistakable 'no'. This seems to be the view of the authors. They conclude that the Republic has been condemned to remaining as a 'garrison-state endorsed by the UN' (p.39). This vivid phrase speaks volumes and, thanks to this book, it has rightly entered the lexicon of 'the Cyprus issue'.

Fourthly, the authors draw attention to an interesting juxtaposition. The Republic is a member of the 'European family', yet 'at the same time, by location, default and design' it is 'a pawn in the strategic calculations of the West's Middle Eastern and Central Asian policies' (p.11). This has enhanced the vulnerability of the Republic, as dramatically demonstrated during the fateful summer of 1974. On the back of an unconstitutional coup engineered in Nicosia by the American-backed *junta* governing Greece at the time, Turkey launched an unlawful invasion of the Republic and the United Kingdom failed to prevent or reverse these naked acts of aggression. Put another way, the three guarantors forming part of 'the West' failed miserably to honour their duties.

Instead of clamping down on egregious violations of law at odds with the post-1945 legal order and the cherished values of liberal democracy, 'the West' turned a collective blind eye. Turkey was effectively granted impunity to infringe international law by occupying, ethnically cleansing and colonising the northern areas of the Republic. In consequence, 'Greek Cypriots, Turkish Cypriots, Christians and Muslims, were unmingled totally, for the first time in their modern history' (p.27). Worse still, the United Nations responded to the invasion by lending its authority to a protracted diplomatic initiative with the unspoken aims of preserving 'bi-communal' division, legalising illegality and regularising segregation. The current 'leader-led process' is a product of this deeply unethical initiative, yet it is firmly in line with the wishes of Turkey.

Finally, the authors put their finger on another regrettable development: the widespread deployment of 'humbug'. What is 'humbug'? To quote the authors: 'Humbug is not a lie. It is far more serious and dangerous. It is the conscientious attempt of the dominant ideology to produce such forms of mass subjecthood which will reflect the scope of the humbug: indifference to, and/or distortion of the truth and subservience to imperial rule as the only rule.' The authors illustrate their contention with reference to the misleading phrases which have crept into day-to-day 'humbug discourse' thanks to 'humbuggers'. According to the authors, these 'humbuggers' include 'all sorts of intellectuals, journalists and activists' (pp. 81-82), as well as diplomats, politicians, the European Union and the United Nations.

The authors have a point. To take one example, it is an Orwellian abuse of the English language for anybody to summon the mantra of 're-unification' in the same breath as the proposed transformation of the Republic into an inherently disunited 'bi-communal, bi-zonal federation'. Besides, the Republic was never unified in the

first place. Indeed, it is impossible to ‘re-unify’ the Republic by perpetuating the ‘bi-communal’ division introduced in 1960, by legalising the illegal ‘bi-zonality’ effected in 1974 and by preserving so many existing structures of separation, segregation and supremacism. Put another way, the misuse of the word ‘re-unification’ is the height of ‘humbug’. Even so, the word ‘re-unification’ regularly trips off the tongues of academics, diplomats and others who ought to know better than to engage in ‘humbug’ of this nature.

The authors end their book by expressing hope that ‘the Cypriot Left’, including AKEL, should strive to compose ‘a Cypriot post-imperial constitution’ which results in ‘the liberation of Cyprus’ (pp. 88 & 89). Be that as it may, AKEL has come to form part of the vanguard in support of the divisive ‘partnership’ identified by Macmillan in 1958, the retention of the Republic as a ‘garrison-prison state’ and its proposed transformation into a ‘bi-communal, bi-zonal federation’. In other words, in tandem with some other parties and institutions in the Republic of Cyprus, AKEL has aligned itself with neo-imperialism. That is not humbug. It is the unvarnished truth.

KLEARCHOS A. KYRIAKIDES

Ireland and the End of the British Empire: The Republic and Its Role in the Cyprus Emergency

HELEN O'SHEA

I.B. Tauris (London, 2015), xviii and 288 pp.

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In April 2004, in the weeks leading up to the referendum on the Annan Plan, numerous events were held across Cyprus to discuss the relative merits and, more usually, drawbacks of the proposals for the island's reunification. One of these events, which took place in Nicosia, involved the then Irish Ambassador to Cyprus. Like many other European Union diplomats based on the island at the time, he openly supported the Plan. He therefore used the opportunity to call on people to vote 'Yes' in the forthcoming poll. At the end of his speech, a Greek Cypriot man got up from his seat and launched in to a full scale condemnation of the ambassador's position. In doing so, he uttered an immortal line. In all seriousness, he asked the ambassador what he could possibly know about conflict and division. The rest of the audience was left utterly dumbfounded. It simply defied belief that anyone could have made such a comment. Indeed, it was almost impossible to quite take in what had just been said. If anything, most Greek Cypriots were more than aware of the apparent commonalities shared by the two islands. Indeed, to most Greek Cypriots, it is almost as though the people of Cyprus and Ireland are spiritual kin.

Against this backdrop, it is perhaps surprising that there has been remarkably little written on the relationship between Cyprus and Ireland. Certainly, there are those who have sought to cast a comparative eye on the countries' respective conflicts. However, few have investigated bilateral ties between them. In truth, as 'Ireland and the End of the British Empire' shows, the relationship between the two countries is based on more than simply a shared sense of grievance. Rather, it has been shaped by very real encounters. In this light, this book is an important effort to correct this by examining the part played by Ireland and the Irish at one of the most crucial periods of modern Cypriot history – the 1955-59 EOKA uprising against British colonial rule.

One of the most interesting aspects of the book is the way that it takes a rather different approach to the subject matter than one might usually expect. Typically, such books would tend to take a broadly chronological approach. Ireland's reactions to the events taking place in Cyprus would have been traced in a fairly linear manner. However, this book instead adopts a thematic approach. In doing so, it feels more like an edited volume than a single authored work. While this could seem rather disjointed in some

situations, in this case it works rather well. It allows the author to explore a range of themes and topics with the range of detail that they deserve, but because it is written by a single author there is a single voice and a welcome evenness in terms of quality. It is also excellent inasmuch as it allows the author to truly reveal the wonderful range of oddities and paradoxes in the story.

Chapter 1 sets the stage by examining the way in which Ireland and Cyprus interacted from the start of British colonial rule, in 1878, through to the start of the EOKA rebellion. Thereafter, the book develops a number of themes. From the very start, one is confronted with a fundamental contradiction that lies at the heart of the relationship. For while many Cypriots have long sympathised with the Irish, few realise just what an important role Irishmen, and occasionally Irishwomen, played in the colonial administration. This is brought out very strongly in the book. Indeed, it seems as though British rule on the island was a rather Irish affair. And yet, over in Ireland itself, there was clear sympathy for the efforts of the Greek Cypriots to divest themselves of British rule. But then again, many Irish officials and members of the Irish establishment were rather more sympathetic towards, or at least uncritical of, British actions in Cyprus.

This sympathy is emphasised very well in Chapter 2, which explores the way in which the Irish press responded to the uprising. The chapter also notes a rather fascinating ambivalence of the Irish. On the one hand, they understood and supported the wish of the Greek Cypriots to be rid of British rule. However, the support many Irish may have had towards Cyprus was also tempered by a deep aversion towards Communism amongst many deeply Catholic Irish, so much so that at the early stages of the crisis there were even suggestions that Britain should retain control in order to see off the 'Red Menace'. What is particularly interesting is that the growth in Irish sympathy towards the Cypriots as the EOKA campaign wore on was actually down to the British press. As is shown, many people in Britain, were also deeply opposed to British colonialism. This was reflected in parts of the British media, which were widely accessible in Ireland. It was critical British media coverage that in many instances fed Irish criticism of British policy.

Chapter 3 looks at how Irish republicanism viewed the campaign to end British rule. Here an interesting story emerges concerning the very high degree of cooperation that developed between EOKA and the Irish Republican Army (IRA). However, this did not develop because either of them went looking for the other. Instead, it was inadvertently fostered by London after it decided to start sending EOKA fighters to jails in Britain. Also, while one might expect that EOKA learned a lot from the IRA, in fact, it seems to have been the other way around. EOKA, under George Grivas, drew on the experience of anti-Nazi resistance in Greece during the Second World War. In many ways, this was even more formidable than the IRA's experience of fighting Britain – something

recognised by the Irish. However, while the Irish Republicanism was building up strong links to Greek Cypriot fighters, the attitude of the Catholic Church was rather different. As is shown in Chapter 4, the Catholic Church remained distinctly unsupportive of the Greek Cypriots. This was in part down to the antipathy between Catholicism and Orthodoxy. However, it was also shaped by a deep concern about AKEL's strength. There was a view that if Cyprus and Greece united, they would fall to Communism. And if Greece and Cyprus fell to Communism, then Italy would follow. Instead, it was actually the Church of Ireland, the branch of the Church of England in Ireland, which expressed far greater public criticism of the British policy in Cyprus. It seems hard to believe that it was therefore more in line with popular Irish sentiment on Cyprus than the Catholic Church.

The next two chapters explore the ways in which Ireland approached Cyprus on the international stage. Chapter 5 takes a look at how it responded to efforts to bring the matter of Cypriot self-determination before the United Nations. As is shown, at first Ireland took a very cautious approach to discussions on Cyprus – not least of all due to its exceptionally Anglophile representative at the UN. However, as time continued, the temptation to use Cyprus as a means to open up discussions about the partition of Ireland became just too great, especially after a change of government in Ireland in 1957. Nevertheless, its position was more moderate than many may have expected. Following on from this, Chapter 6 looks at how Dublin addressed the Cyprus question within the context of the Council of Europe. This may sound a rather obscure angle to explore until one realises that, following Ireland's exit from the Commonwealth in 1949, this was Ireland's only outlet for international multilateral engagement until it joined the UN in December 1955. Here again, a fascinating tale emerges as Ireland's two delegates to the Council held rather different positions. One was broadly balanced in his views towards Britain. The other was vehemently Republican and staunchly anti-British. This became important inasmuch as the Council became heavily involved in examining allegations of human rights abuses by the British colonial authorities in Cyprus.

Finally, the last two chapters take a closer look at the role played by Irishmen on the island at the time. Chapter 7 explores the part they played in the Colonial Legal Service. Once again, this produces some very surprising and unexpected insights. For example, both of the Chief Justices of Cyprus during the Emergency were from Catholic Irish families. The first of these, Sir Eric Hallinen, oversaw the trial of the first Cypriot to be tried and executed. Meanwhile, the second death sentence handed down was by a Judge Shaw – a cousin of the famous Irish playwright, George Bernard Shaw. Understandably, Greek Cypriots found very it very hard to reconcile this with popular Irish sympathy for their cause. Lastly, Chapter 8 explores Irish involvement in the British counter-insurgency efforts. Through a series of examples, the author shows how

Irish soldiers serving in the British Army, both Protestant and Catholic, came to play an important part in the fight against EOKA. Indeed, the exile of Archbishop Makarios to the Seychelles was planned and implemented by an Irish RAF officer.

Overall, the author has done a marvellous job in outlining the Irish involvement in the Cyprus Emergency. The book is meticulously researched and full of wonderful and surprising pieces of information and anecdotes. Most importantly, the degree to which Ireland and the Irish were involved in Cyprus during the period, and the often astounding paradoxes and contradictions that this created, are brilliantly brought to the fore. As is shown, in many instances, Irish views on Cyprus were not just fed by anti-British sentiment, but, given the close cultural ties that existed between the United Kingdom and Ireland, drew on strong criticism of British policy expressed in Britain itself. Meanwhile, elsewhere, there were many instances where Anglophile tendencies reduced the degree of official criticism of Britain. The book simultaneously confirms the view that many Greek Cypriots have of the Irish as natural sympathisers. And yet it manages to convey the extent to which the British colonial rule in Cyprus was so strongly influenced by so many Irish. Overall, this is a fascinating and absolutely excellent addition to the historiography of Cyprus. And Ireland.

JAMES KER-LINDSAY

Μια Εποχή της Βίας: Το Σκοτεινό 1958

[A PERIOD OF VIOLENCE: THE DARK 1958]

NIYAZI KIZILYÜREK

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Despite its small size, Cyprus has a rich history, but many aspects of that past have yet to be researched. A study by Niyazi Kızılyürek, entitled *Μια Εποχή της Βίας: Το Σκοτεινό 1958* (in Turkish, *Şiddetin Mevsiminin Saklı Tarihi*), adeptly fills in an important bibliographical gap in the history of the island.

As mentioned by the author (p. 11), the study is part of a larger project concerning the history of ethnic and political violence on Cyprus. In an eloquent and masterful manner, Kızılyürek provides a rare account of the violent events of 1958 that took place on the island. Although those events had a major impact on bicomunal relations as well as on the recent history of the Turkish Cypriot community, an analysis of that history has been lacking. Considering that the tragic events of June 1958 resulted in the deaths of many people, events which led to a much bloodier period, this lack of research is even more notable if we take into account the fact that other periods (1964-1967 and 1974), during which time the Greek Cypriots committed numerous acts of violence against the Turkish Cypriots, have been researched to a much greater extent.

The present study is a rare work¹ that exclusively deals with those influential events through which the political elites of both communities framed the collective memory of the people. Furthermore, with great dexterity the study sheds new light on obscure periods in that history, assessing the violent events that erupted between the two communities. Kızılyürek manages to bring ‘forgotten’ or ‘neglected’ memories back to the forefront in a way that I would say make it possible for the Turkish Cypriot community to face past events by debunking myths, deconstructing narratives, and disassembling the dominant Turkish Cypriot ‘grand narrative of victimization’.

The book consists of six chapters which in a masterful way take the reader through a ‘day-to-day’ account of those violent events, while at the same time providing hard facts about the role of the ‘TMT’ (Türk Mukavemet Teşkilatı), whose goal was to promote

1 A much shorter account of the events of June in Turkish is presented in Ahmet An, *Kıbrıs'ta Fırtınalı Yıllar (1942-1962)*, Galeri Kültür Yayınları, Lefkoşa, 2005 [1996], pp. 100-126.

Turkish nationalism and thus partition (taksim), and the 'TMT knot' is revealed in a way that discloses its actual agenda.

The narrative starts with the first Turkish Cypriot clashes with the colonial administration on the 27 and 28 January 1958 and the setting of the blood feuds that would develop in the following months. The events that occurred in January, similar to the anti-Greek riots that happened in September 1955 in Istanbul, were set in motion through the publication of fabricated news, this time suggesting that 'the British had accepted Partition' (p. 21). The author brings to light the various discourses which sought to legitimize the violent uprising of the period, including those of both right-wing supporters and leftists alike, as with the case of Hikmet Madid Mapola, a prominent author of the time who saw the events as an act of 'anti-imperialism' (p. 23). In a sophisticated manner, Kızılyürek debunks the Turkish account of 'freedom fighters' by demonstrating its manipulative and well-planned strategies, as well as the instrumental role played by the TMT in undermining any attempts to find a solution. The author also brings Great Britain into the narrative, as in the end it was Britain which accepted the partition of the island and hence sparked enthusiasm among the Turkish Cypriots in an attempt to undermine the negotiations regarding the Foot Plan. However, the author's account brings yet another perspective to the Turkish/Turkish Cypriot story: the British were actually not in favour of the partition of Cyprus as that would have a negative impact on its own interests. Such a stance initially led the British to distance themselves from discussions regarding the partition of the island even though they were quite firm in that regard, which led to shaky relations with Turkey. The British response even caused Turkish Prime Minister Adnan Menderes to openly threaten Selwyn Lloyd, the British Foreign Secretary, by saying that in the case of a Turkish Cypriot insurrection, the Turkish Armed Forces would 'not be far' (p. 25), implying that the Turkish armed forces were prepared to intervene. Furthermore, it was made clear that if the plan were implemented, the Turkish Cypriots would not assist the British (p. 30). The discourses employed by the Turkish Cypriot elite, notably Rauf Denktaş, presented British policy as a vindictive response brought about by the British defeat at Gallipoli in 1915 (pp. 31-33) and stirred anti-British sentiment among the people, a discourse reminiscent of the discourse used by Menderes prior to the events of 6-7 September.

The second chapter of the book takes up the TMT's persecution of Turkish Cypriot leftists, which it seemed were competing with EOKA regarding which of the two was the most anti-communist. But due to the fact that there was not a strong and independent Turkish Cypriot leftist movement, the TMT turned against Turkish Cypriots workers, who, due to a lack of an alternative way to organize, found refuge with Greek Cypriot syndicates and trade unions. Although enosis for Turkish Cypriot leftists was also out of the question, that did not prevent the TMT from taking violent action against them. For a non-Turkish audience, the author's short but extremely useful account of the Turkish Cypriot leftist movement, which is a little known issue, adds much to the study. The discussions between Turkish and Greek Cypriots, especially those related to the KΤİBK (Organization of Turkish

Cypriot Workers' Union) and PEO (Workers' Federation of Cyprus), the relations between Turkish and Greek Cypriot leftists, and the political differences among them (p. 42-43) are presented by the author in a way that also provides background information about those topics and exemplifies, at least in part, why they were targeted by the TMT. Following 1 May 1958, the TMT announced that all Turkish Cypriot members of the PEO who took part in celebrations with the Greek Cypriots should abandon the trade union, as the TMT was painstakingly trying to prove that it was impossible for the 'two communities to live together' (p. 44). Notably, armed attacks against Turkish Cypriot leftists took place right after Dr. Fazıl Küçük and Rauf Denктаş travelled to Ankara on 22 May 1958. Kızılyürek extensively explores the Turkish Cypriot press and news about the killings of leftists, including armed attacks that were carried out as a means of thwarting perceived threats to Turkish plans for partition. Dr. Fazıl Küçük, realizing that all the blame would fall on the TMT, stated that the TMT was not a 'cadre of murderers' but an 'organization that protects the human rights and freedoms [of the Turkish Cypriots and Turks]' (p. 50). Other leading figures, such as Denктаş and Tremeşeli, prepared similar statements in an attempt to escape the spotlight, and they also blamed Greek Cypriots. However, Kızılyürek's account once again employs strong evidence to convincingly prove that that was not the case, revealing that the TMT was behind those killings and attacks. The state of terror created by the TMT drove some Turkish Cypriots to make signed declarations stating that they were not communists (p. 56-60) and that they were leaving the trade unions to 'align with the Turkish Cypriot leadership' (p. 55).²

The next chapter focuses on June, the month in which political and ethnic violence reached its peak. If we consider the fact that during this period Britain was preparing a new plan for Cyprus, the violent incidents that occurred cannot be seen as mere coincidence but rather as carefully planned action on behalf of the Turkish Cypriot elite supported by Turkey, action which sought to prove that the only viable solution, and the only way of 'safeguarding' the lives of the Turkish Cypriots, as claimed by the Turkish Cypriot leadership, was 'partition and only partition'. Rauf Denктаş and Dr. Fazıl Küçük had already made a joint statement the previous month expressing those views. Insisting on the impossibility of the co-existence of the two communities, whose lives were becoming more troubled since the British were unable to impose their decisions and administer the island, the Turkish Cypriot elite transformed the issue into something 'exclusively Turkish' by stating that Cyprus 'does not constitute a colonial issue anymore' (p. 71). The policy of partition was expected to lead to a more 'offensive' stance, as on numerous parts of the island people were gathering and the aim was to encourage demonstrations in favour of the partition of the island. At the same time, the British colonial administration was starting to find out about the demonstrations. Governor Foot correctly surmised that if Dr. Fazıl Küçük, who was in Ankara at the time and planned to return to Cyprus that same day, did not return, it was

2 A list of declarations can be found at: www.ahdr.com.

likely that demonstrations would take place. Dr. Fazıl Küçük postponed his return to the island and the demonstrations indeed took place.

On the night of 7 June 1958, there was an explosion at the Turkish Information Office in Nicosia. From that day onwards, violence escalated and became a daily fact. While Denktaş and the newspaper *Bozkurt* ('Grey Wolf') held EOKA responsible for the bombings, Kızılyürek shows through a close and objective analysis, as well as confessions from Turkish Cypriots (pp. 95-103), that the bombings were a provocative action instigated by the TMT with the support of Turkey, all with the aim of stirring up people's emotions and encouraging them to support partition. Yet again the bombings resembled, in both planning and rationale, the events of 6-7 September in Istanbul.

Following the attack, Turkish Cypriots responded almost immediately by turning against their counterparts on the island and attacking their homes and places of work. A few days later, the first mass killing took place on the island, which is the focus of chapter 4. The event was set into motion when 35 Greek Cypriots from the village of Kontemenos (Kılıçaslan) in the region of Kyrenia (Girne) were informed that there were plans for an attack against Greek Cypriots in the nearby village of Skylloura (Yılmazköy). The Greek Cypriots got in two trucks and travelled to Skylloura to help their compatriots. The British, however, stopped them and took them to another village, Gerolakkos (Alayköy), and then to Nicosia. In the meantime, the British authorities decided to punish the 'troublemaking' Greek Cypriots by using the technique of 'bussing', a type of mass punishment first employed by the British in Palestine during the 1940s. The 'troublemakers' were transferred by bus or truck to places far from where the incidents were taking place and then forced to walk home on foot (p. 112), leaving them exposed to attacks, as happened in the June events.

Kızılyürek's well-balanced and documented account of these events sheds valuable light on both the victims' and perpetrators' roles in the events. By gathering testimonies from both Greek and Turkish Cypriots (pp. 114-135), the author clarifies much about what transpired in this much debated story; firstly, the failure of the British to foresee what could happen to the 35 Greek Cypriots, and secondly, the nationalist fervour and fanaticism of the Turkish Cypriots, stirred up by the bombing that had occurred a few days earlier which led to the murder of eight and the injury of another five Greek Cypriots. Also notable is the report prepared by the British colonial administration which states among other things that 'the 35 unarmed Greek Cypriots were ambushed by the Turkish Cypriots, which were hiding and attacked when [the mysterious] motorcyclists appeared', while it also concluded that it was 'a premeditated action' (p. 146).

After these bouts of extreme violence, the Turkish and Turkish Cypriot side proceeded with the de facto institutional separation of the municipalities with the aim of moving forward with the implementation of the partition plan. In chapter 5, the author provides a comprehensive account of the developments that led up to and followed the separation of the municipalities, as well as the instrumental role of violence in the events that transpired.

In particular, the author shows how violence was critical in the unfolding of events,

as revealed through an extended interview with Salih Mahmut Kayasal, one of the first counsellors of the municipality of Limassol in 1990 (pp. 182-184). As Kızılyürek rightly argues, the de facto separation of the municipalities helped bring into being the Turkish/Turkish Cypriot plan, while in light of the proposal of a new plan and in need of their support, the British turned a blind eye to this illegal action (p. 184).

The final chapter of the study turns its focus to the counter measures used by EOKA and provides background information about the deaths resulting from the actions of EOKA and TMT. With close calculations, the author concludes that between 1 April 1955 and 17 August 1956, the EOKA refrained from targeting Turkish Cypriot civilians and only after mid-1957 did Georgios Grivas order attacks on Turkish Cypriots who were in the militia. Kızılyürek stresses the fact that although EOKA had been ordered to attack Turkish Cypriot militia members, attacks against civilians were not encouraged, and, furthermore, the Greek Cypriot community was told to refrain from making counter attacks (p. 191). Grivas wrongly surmised that there was a Turkish-British plot against EOKA, and therefore concluded that a counter-attack would expose the organization and could prove fatal (pp. 192-193). This state of affairs was about to change, however, in July of the same year, when Grivas dropped all restrictions in regard to attacks against Turkish Cypriots and soon a bloody attack was carried out on a bus filled with Turkish Cypriots. As the saying goes, violence breeds more violence. By August of the same year, Greek Cypriots and Turkish Cypriots had become entrenched in a vicious cycle of killing, leaving many people dead and injured. Although, as this study makes clear, we do not know exactly how many people were killed, the newspaper *Eleftheria* states that 59 people were killed on each side (p. 204), while the colonial administration (p. 205) provides a slightly different number. If we take into account the four phases of violent incidents that took place, the number of dead and injured is quite high and this demonstrates the extent of violence and the complete domination of blind aggressive nationalism that existed on the island. This state of violence on Cyprus ceased only at the end of 1959 when discussions about independence began, but again this was only temporary.

There are just a few rather minor issues in the book, such as some missing footnotes regarding the interviews on pages 119 and 160, and in other parts, the reader might have trouble locating the references the text refers to; some footnotes are lacking, as on page 21 where the footnote for the newspaper *Bozkurt* is missing. These small oversights do not detract from the core arguments, however, and the study adds to the body of work on the Cyprus issue. For scholars who study nationalism and ethnic and political violence, this work demonstrates that Cyprus provides more history than it can consume.

This is a well-documented, balanced study that is marked by in-depth analysis which sheds additional light on one of the darkest and most violent periods of the history of Cyprus, and it also notably debunks numerous myths and false impressions about the troubled past of the island, making it a book that I highly recommend.

NIKOS CHRISTOFIS