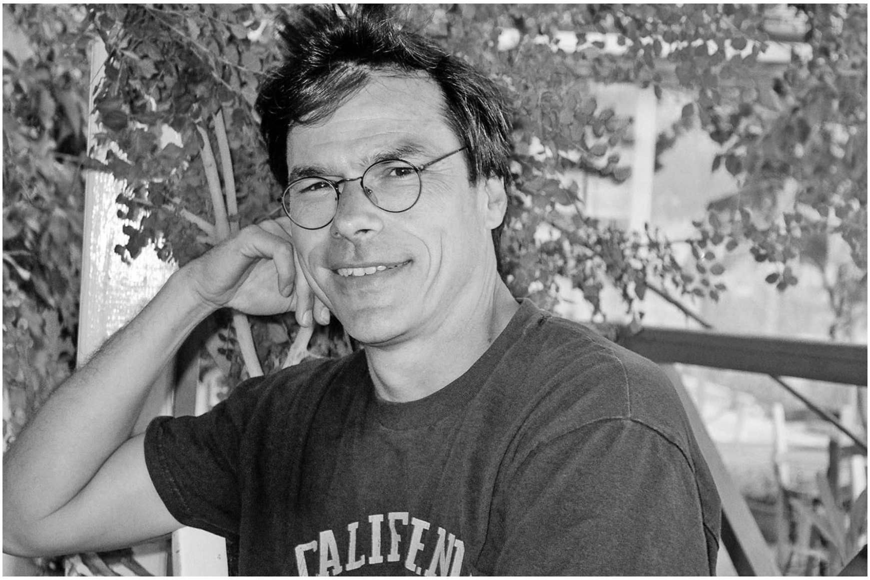
EULOGY
FOR
STEFAN BECK

VOLUME 28
NUMBER 1



Stefan Beck in Cyprus, 2006

Eulogy for Stefan Beck, 1960-2015

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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.

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[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

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[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

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[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…'

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[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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