

Health, Culture and the Human Body

Epidemiology, Ethics and History of Medicine,
Perspectives from Turkey and Central Europe

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İlhan İlkılıç, Hakan Ertin, Rainer Brömer, Hajo Zeeb (Eds.)

Migration and Health, Infectious Diseases, Beginning of Life/Reproductive Medicine, End of Life, Human Body, and Interculturality and Ethics – these six main themes have been studied from historical, ethical, and epidemiological perspectives, keeping the sister disciplines in a transdisciplinary view.

The contributions reflect the themes of two meetings in Mainz/Germany and Istanbul/Turkey. The book is attempting at a synthesis of the different perspectives and methodological approaches with a focus on Central Europe and Turkey. The authors and editors have revisited the field and bring together a more comprehensive approach to *Health, Culture and the Human Body*.

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Preface

Medical interventions accompany the lives of humans in industrialised countries almost from the moment of conception, sometimes until after the declaration of death. The nature of these interventions is rapidly evolving, opening new approaches to diagnostic techniques, preventive measures and therapies that affect people's lives in many ways, extending the duration of a life of high quality for some while making others feel the pressure of having to be healthy, a life in a state of medicalisation. The impact of medicine on modern human life is not purely technical, though. The way a patient responds to medical treatment depends intimately on the cultural values he or she has internalised during their lifetime. Expectations and preferences of patients may be quite different from those of their doctors, who through their education (and often their social background) live in a distinctive culture of their own, cemented through years of medical education during which they were exposed to a characteristic set of rites and rules, from the dissection room to the ward rounds and "grand exams". The cultural distance between doctors and patients is greatly enhanced through the migration of persons from different majority societies back and forth between the continents. A German neurosurgeon, scion of an upper middle class urban family, may not always find the right words to explain to the daughter of a factory worker what is happening in her dying father's brain; if the daughter's first language is not the same as the surgeon's, and the culture and religion the family are living is drastically different from those of the majority society where this drama unfolds, communication becomes an even greater challenge. Is it possible at all for the surgeon to broach the subject of organ donation with a family that may not see the body in a mechanised way common in the science-based environment of the doctor? Or, at the beginning of life, how can a physician in reproductive medicine assess a family's wish to have a child conceived by the married couple themselves when there are physiological, or maybe psychological obstacles to conception which the doctor will be asked to help overcome? What is a neonatologist going to tell the parents of a severely ill newborn they insist to keep alive because their religion values life above all, even in the face of severe suffering, while the doctor would reduce therapy in a medically futile treatment?

Technical aspects are not the only content of the relation between doctor and

patient, and often not even the most important element. Many sophisticated medical interventions pose difficult ethical dilemmas. The notions of life and death are undergoing a profound change of meaning in an age of pre-implantation diagnostics and organ donation from brain dead persons *Hirntote Menschen*. Just as life is not generated through *in vitro* fertilisation, death has not completely taken possession of the organ donor's body – dead organs cannot be transplanted. Thus, in today's migratory population, a wide variety of cultural, often religion-based views on the most essential aspects of human existence are exposed to the rapid evolution of medical practices requiring a redefinition of ancient agonies.

Along with the advances in medicine, the population structure in many countries is changing profoundly, the ratio between birth and death rates leaves society with a larger proportion of elderly citizens requiring medical attention. After half a century of labour migration in Europe, with the fourth generation of immigrants now entering the education system, members of the first and even the second generation are thinking about retirement and sometimes nursing care or eventually the practicalities of funerals. Two of the countries particularly closely linked through the mid-twentieth century migration in Europe are Turkey and Germany. What began as an active recruitment of basic workforce in post-war (West) Germany, a rapidly growing economy short of hands, gradually expanded into all circles of society, including academic researchers and educators.

Thus, in the year 2006 Mainz University hosted a project aimed at supporting healthcare professionals treating Muslim patients in the context of the German health system, funded by an important foundation and implemented by members of the university's Department of History, Philosophy, and Ethics of Medicine (www.kultur-gesundheit.de). Research in the context of this project made clear that the processes of migration and multicultural interaction cannot be fully understood without applying a historical perspective, and at the same time when ethical decisions are becoming increasingly complex, the changing demographics of modern societies create new epidemiological challenges for the health system. This insight led to a contact between medical ethicist İlhan İlkılıç, epidemiologist Hajo Zeeb, and medical historian Rainer Brömer at Mainz University in 2010, who jointly initiated a working group

with wide-ranging contacts both in Turkey, especially with Istanbul Medical Faculty, represented by medical historian and ethicist Hakan Ertin, and in Germany and neighbouring countries, coordinating further investigation of the history, ethics, and epidemiology of health, culture and the human body. A first international conference on the topic was organised at Mainz University in September 2010, followed by a second conference at Istanbul University in September 2012, and in keeping with a biennial rhythm, the third conference will be held in September 2014, again at Istanbul University, in collaboration with the Beşikzade Center for Medical Humanities (BETİM) and two German institutions, Bremen University and the Leibniz Institute for Prevention Research and Epidemiology - BIPS Ltd. in Bremen.

This volume is meant to be a lasting document of the first two conferences and the contacts developed in their wake. The contributions reflect the themes of both meetings, attempting at a synthesis of the different perspectives and methodological approaches. Rather than being a mere reproduction of multidisciplinary conference proceedings, the authors and editors have tried to revisit the field and bring together a more comprehensive approach to *Health, Culture and the Human Body*. Six main themes have been studied from historical, ethical, and epidemiological perspectives, keeping the sister disciplines in a transdisciplinary view: Migration and Health, Infectious Diseases, Beginning of Life/Reproductive Medicine, End of Life, Human Body, and Interculturality and Ethics.

Like the history in the focus of this project, the book opens with the recruitment of “Gastarbeiter”, migrant workers from the Mediterranean countries and Anatolia. Topp analyses the medical selection applied in the recruitment process, looking at the “practice and function of medical examinations under the influence of economic and political interests in the Federal Republic of Germany, 1955–1973”. Topal-Cevahir uses the tools of oral history to explore the development of health conditions among female immigrants from Turkey to West Germany, while Kaelin looks at the specific example of care worker migration to Austria, largely arriving from Eastern Europe. A larger section examines the epidemiological aspect of the same issues arising in migration. Epidemiologists will have no difficulties in relating to the oral histories in the previous section when it comes to understanding

illness perception and the role of stories to create a narrative of the individual experience of illness and health (Brzoska et al., Glodny et al., Schayk and Hosper). Kressing looks at the “other party”, healthcare professionals being trained outside their cultural home at a time when migration no longer is a phenomenon of basic labour force, while Altıntop tackles the growing issue of care for elderly migrants. Not all migration occurs upon recruitment, though, and a significant number of migrants and refugees have no regular access to the health system of their country of residence at all, raising ethical as well as epidemiological problems. Wolf et al. present a voluntary network trying to cover the most urgent needs of undocumented migrants in cases of medical emergencies.

Infectious diseases also migrate, and sometimes rapidly. In the more recent history, we remember the enormous cholera epidemic of the 1830s, with aftershocks throughout the 19th century, which Yıldırım and Ertin are analysing from the perspective of the late Ottoman Empire. Another disease concerning especially the Ottoman military was syphilis, which had become endemic on the Black Sea coast, often transmitted from mother to child, and was then carried to the capital Istanbul mainly by conscripts, debilitating the armed forces to a worrying degree. This was a time when bacteriology developed in Europe, but antibiotics were still far in the future. The Sultan invited foreign doctors to apply their knowledge to syphilis control in the Empire. An important figure was the German dermatologist Ernst von Düring, whose career and achievements are presented in this volume through Ottoman and German sources in the chapters contributed by Sarı, Kümmel, and Yıldırım. Düring was however neither the first nor the last German-speaking dermatologist to be called to Anatolia, as Kümmel reminds us in his first chapter on Rigler and Marchionini, and the syphilis problem was still unsolved by the time of World War One (Yolun). The control of infectious diseases also requires the active collaboration of the population. Historian İlikan describes an attempt in early Republican Turkey to inform the people through a popular magazine. Epidemiologists Samkange-Zeeb et al. look at results of information on sexually transmitted diseases among migrants almost a century later. Toy studies policies dealing with Hepatitis B within migrating populations, and Dimitrova et al. analyse the communication between doctors and parents of children to be vaccinated

against the HPV, which is still a controversial issue. The ethics of dealing with people infected with an incurable disease is discussed in the chapter by Temel and Ertin on the first known case of AIDS in Turkey.

The beginning of life had been shrouded in mystery until the discovery of the mammalian egg cell in 1826. Infertility could cause grief in the past and still does. Popovska traces an old interfaith fertility ritual based on stone slabs in a Macedonian dervish lodge, while Stopfkuchen reports the development of keeping prematurely born babies alive. Ethical issues are very dominant in this fragile period of an individual's life, raising issues of dignity that have concerned all major religions (Sass), and following from Stopfkuchen's neonatological interventions, İlkılıç addresses the ethical aspects of having to decide about the ending of a life that has only just begun from a clinical perspective in Germany, while Ahmad draws on comparable experiences in the UK. Heyder talks about the legal aspects of egg donation in cases where a woman wants to have a child, while Hakeri documents the legal situation of not wanting a child in the case of abortion legislation in Turkey.

The end of our lives is an inevitable concern that individuals and cultures approach differently. Sarı traces death concepts in Turkish culture from pre-Islamic times till today. Gencer and Başağaoğlu delve into psychology and survey religious attitudes across cultures. Bobbert takes us to the current position of ethical debates regarding the end of life in the German context. A group of four papers deals with the experience of aging and the provision of services to geriatric patients (Şahne and Şar), dealing with a failing will to live (Kutscheid), ethical advice for palliative care (Doğan), and the tension between palliative care and euthanasia (Donev and Kaluđerović). To close the bracket from the beginning to the end of life, Heper asks about dignity from the perspective of philosophy of law, and finally, Ünver takes the reader beyond the patient's death to legal questions of organ transplantation.

The representation and self-image of the human body is examined by two papers with very different outlooks. Boeckmann lets us participate in the self-publishing world of feminist zines, while McKian writes from a therapeutic perspective about the construction of body image. And while interculturality has been emerging in almost all of the contributions to this volume, the last section addresses this aspect more explicitly, first with a concrete example

among Roma people in Poland (Strzaada), and finally in a more fundamental paper by İlkılıç analysing the term interculturality and in a study by Grützmänn on the application of the concept in clinical ethics consultation.

A lively debate ensued from these encounters, and the organisers are looking forward to further projects arising from the joint work.

It is with great sadness that we have to note the loss of two of our valuable colleagues, Şahin Aksoy from Şanlıurfa (1965-2012) and Franz Dumont from Mainz (1945-2012). Both were excellent colleagues dear to all who met them, and both made important contributions to a variety of research areas, including the one developed in this volume. They are greatly missed by all of us, most importantly of course by their families. They will not be forgotten.

Health, Culture and the Human Body would not have been possible without the tireless support by a great number of individuals, not all of whom we can mention here – you know who you are. The first conference in 2010 was kindly supported by two patrons, the German Minister of Integration Maria Böhmer and the Rector of Istanbul University, Yunus Söylet, who also granted his patronage to the second conference in Istanbul in 2012 and will again be patron of the third conference in 2014. The organisers and editors of this volume are most grateful for their support.

The Rector of the Istanbul University Yunus Söylet and the President of the Johannes Gutenberg University Mainz Georg Krausch, as well as the Deans of Mainz University Medicine, Reinhard Urban, and Istanbul Medical Faculty, M. Bilgin Saydam, provided their full personal and institutional support for the conferences hosted at their universities and faculties, for which the organisers are most grateful. Thanks are also due to the directors of the hosting institutes, Norbert Paul (Mainz) and Nuran Yıldırım (Istanbul).

The Municipality of Zeytinburnu helped with the logistics of the second conference in 2012, the organisers' thanks are going especially to mayor Murat Aydın.

The conferences in Istanbul would not have happened without the generosity of the Hayat Vakfı, a foundation sponsoring health and social services and also supporting the Beşikçizade Center for Medical Humanities (BETİM). A great vote of thanks to the foundation and its chairman Ahmet Özdemir and the board of the foundation, as well as the committee of BETİM. This volume, the

first book produced under the imprint of *BETİM Center Press*, also owes its existence to the support through the Hayat Vakfı.

For anything to do with design and printing, Galip Yılmazbaşar and Bärbel Mietzschke in Wiesbaden and Ahmet Yumbul of the Hayat Vakfı in Istanbul have been working creatively and tirelessly. The completion of this volume owes everything to Ahmet Yumbul's generous overtime. For the preparation of the manuscript and a host of organisational tasks, thanks goes to İnanç Özekmekçi (Kayseri) and Ayman Atat (Istanbul).

Rainer Brömer also made great efforts to make sure that this volume could be published. He tried to ensure editorial homogeneity as far as possible in a multidisciplinary volume with multilingual contributors, using his experience and knowledge of languages in the editorial process. Even if some authors may have found this procedure somewhat tiresome, we as the editors hope and believe that it has been worth the effort.

Apologies to whoever has been left out of these explicit acknowledgements, the conferences as well as the preparation of this volume have been a great effort of cooperation, thank you all very much.

An edited volume is of course the result of the contributing authors' work, so the last vote of thanks goes to all the colleagues who have shared their knowledge and insights, giving of their time and energy to produce the 41 articles assembled in this book.

İlhan İlkılıç, Hakan Ertin, Rainer Brömer, İnanç Özekmekçi, Hajo Zeeb
İstanbul, September 2014