Jenny Schreiber

Politics, Piety, and Biomedicine

The Malaysian Transplant Venture

transcript Culture and Social Practice
The discourse on transplantation and brain death has become emblematic of conflicts between certain perspectives on adequate medical care, death and dying. Scientific and religious, modernising and traditional as well as academic and popular voices debate on how to approach these topics. This work captures the heterogeneous and often contradictory views on the Malaysian transplant venture and the treatment option of end stage organ failure from the Malay and Chinese population, physicians, state officials, and Muslim, Buddhist and Daoist clergy. It also addresses vital issues as to the use of and extent to which biomedicine and medical technology in contemporary Malaysia actually benefits its people.

Jenny Schreiber (Dr. med.) studied Cultures and Languages of Southeast Asia and Medicine in Hamburg and Sydney. Her research interests include ethical issues and decision-making processes in biomedicine. She is currently completing her specialist training in Neurosurgery.

For further information:
www.transcript-verlag.de/978-3-8376-3702-1
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>List of Figures, List of Tables, List of web-based Appendices</td>
<td>11</td>
</tr>
<tr>
<td>List of Figures</td>
<td>11</td>
</tr>
<tr>
<td>List of Tables</td>
<td>11</td>
</tr>
<tr>
<td>List of web-based Appendices</td>
<td>12</td>
</tr>
<tr>
<td>Abbreviations</td>
<td>13</td>
</tr>
<tr>
<td>Glossary</td>
<td>17</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>21</td>
</tr>
<tr>
<td>Preliminary Remarks</td>
<td>25</td>
</tr>
<tr>
<td>Preface</td>
<td>27</td>
</tr>
<tr>
<td>Abstract / Zusammenfassung</td>
<td>33</td>
</tr>
<tr>
<td><strong>1. Introduction</strong></td>
<td>37</td>
</tr>
<tr>
<td>1.1 Objective of the Study</td>
<td>42</td>
</tr>
<tr>
<td>1.2 Ethnicity, Culture, and Religion</td>
<td>44</td>
</tr>
<tr>
<td>1.3 Medical Pluralism</td>
<td>49</td>
</tr>
<tr>
<td>1.4 Bioavailability of Organs</td>
<td>52</td>
</tr>
<tr>
<td>1.5 Anthropological Problems</td>
<td>57</td>
</tr>
<tr>
<td>1.6 Overview of Healthcare Research concerning the Attitude of Malaysians towards Organ Donation</td>
<td>63</td>
</tr>
<tr>
<td>1.7 Fieldwork</td>
<td>68</td>
</tr>
<tr>
<td>1.7.1 Qualitative in-depth Interviews with Medical and Religious Experts</td>
<td>72</td>
</tr>
<tr>
<td>1.7.2 Quantitative Survey among the Rural Malay and Chinese Communities</td>
<td>81</td>
</tr>
<tr>
<td>1.8 Structure of the Present Work</td>
<td>87</td>
</tr>
</tbody>
</table>
2. **Politics, Piety, and Biomedicine** | 89
   2.1 Political Background and Context | 91
   2.2 The Transplant Venture and the Media | 104
   2.3 From Sporadic Transplant Activity to the National Transplantation Programme | 111
   2.4 Laws, Government Policies, and Medical Guidelines Pertaining to Transplantation, Organ Donation and Brain Death | 128
   2.5 Promoting Organ Donation: From Grass-Root Initiatives to Large Scale Government Campaigning | 134
   2.6 Making the National Transplantation Programme a ‘Muslim-Friendly’ Enterprise | 142
   2.7 Normative Islamic Obligations: Their Generation and Content | 153
      2.7.1 Generating Federal Fatwas under the National Fatwa Committee | 155
      2.7.2 The Content of Federal Fatwas Concerning the Transplant Venture | 158
      2.7.3 Generating State Fatwas under the State Mufti Department | 160
      2.7.4 The Content of State Fatwas Concerning the Transplant Venture | 164
      2.7.5 IKIM, the Institute for Islamic Understanding and Their Viewpoint on Transplantation | 165
   2.8 Normative Obligation in Chinese Realms: The Generation and Content of Buddhist and Daoist Normative Obligations | 169

3. **Malaysian Lifeworlds, Medical Pluralism, and the Transplant of Organs** | 181
   3.1 Malay Lifeworlds | 184
   3.2 Chinese Lifeworlds | 191
   3.3 End-stage Organ Failure between Traditional Medicine, Supernatural Healing, and Biomedicine | 205
   3.4 Local Perceptions on the Practice of Transplanting Organs | 219
      3.4.1 Experience with and Practices of Organ Donation and Transplantation | 224
      3.4.2 Knowledge about Organ Donation and Transplantation | 226
      3.4.3 Attitudes towards Transplant Practices | 229
      3.4.4 Attitudes towards Organ Donation | 233
      3.4.5 Local Perceptions on Increasing the Organ Donation Rate | 237
      3.4.6 Attitudes towards Certain Organs, the Body, and the Corpse | 240
      3.4.7 Religious Aspects on Organ Donation and Transplantation | 247
      3.4.8 The Role of the Family in Organ Donation | 252
      3.4.9 The Concept of Brain Death | 254
4. Conclusion | 259

Epilogue | 271

References | 273
Books, Book Chapters, and Journal Articles | 273
Newspaper Articles | 285
Statutes, Government Publications, and Publications from Medical Professional Bodies | 289

Brief Biography | 293

Web-based Appendices | 295
I was thrown into a Chinese Malaysian family when I had just turned sixteen. My keluarga angkat, my adopted family, lived in a small house in a rural area in Selangor. It was constantly hot, sticky, and humid. Chinese and Indian households shaped our neighbourhood, here and there Malay houses were scattered. It was terribly noisy everywhere – the rain forest on the other side of the street sounded weird, the ancient looking fan made a dangerous noise as if it would drop off any second. On top there were agitated clinking snatches of Chinese words – Hokkien and Hakka – as I was later to learn. Conversation – if any at all – was mainly possible through gestures and signs, only the youngest of my many siblings conversed with me in English – or better Manglish, a pidgin English that follows its own rules.

Very soon I realised that no one was ever physically alone here. We constantly had visitors – the extended family came and would not leave for months, friends and acquaintances came and went, neighbours were always present. Nonetheless I often felt lonely with my thoughts, feeling as though the time stood still: I observed every single thing – the way they acted and communicated with one another, the way they did things – I meticulously noted every aspect and eventually enjoyed mimicking the way they acted. To me Malaysians were so much alike and after some months they would tell me how well I would blend in.

During one of my first school days I was instructed that in fact Malaysians were not alike at all: a chocolate brown boy asked me whether I could tell if he were Malay, Chinese or Indian. In fact, at first I did not understand his question, as I thought it would be redundant to categorise someone, instead of getting to know him. He elucidated in a lengthy monologue that one could tell from the appearance which ‘race’ they belonged to, and that they – the Malays, Chinese, and Indians – would differ considerably from one another. I felt that this was such rubbish – especially because I felt so very different from the Malaysians: to me they seemed to be so similar in their mindset and actions. From my European point of view they had so many more commonalities than distinctions. The boy was obviously amused that I was not able to tell which
‘race’ he belonged to, and proudly ended by telling me that everyone thought
he was Malay, because of his appearance, but in fact was Chinese. He was
obligated to comfort me by letting me know that I would soon learn how to
properly categorise Malaysians according to their ‘race’. My experience shows
that the Other only emerges in segregation to one self and may be perceived
differently according to one’s own personal contextualisation or identity.

My German identity gradually vanished and became less important. ‘Kat
rumah, at home, I discovered the Chinese world, embracing the exciting social
and religious life, including their spirituality – when for example kaima,
mother, felt sick and went to see the tiaotong, the spirit medium, or when
one of us had fever. Then the horn of a rhinoceros was slowly rubbed off in a
shallow dish and taken as a remedy. While kaima, a Hokkien born in Malaysia,
would often use Malay loanwords in her everyday language, father belonged
to the first immigrant generation, who virtually exclusively spoke Hakka, a
different Chinese dialect. On the other hand I merged into the Malay world
‘kat sekolah, in school and at a friend’s house, were I soon became anak angkat,
an adopted daughter. I stayed over for long weekends in their wooden house
in the deep jungle. Their social and religious life was gentle and calm. I spent
hours, lepak, hanging around enjoying the kampung, village life. In short, I
blended in, felt secure, and truly enjoyed my new Malaysian life. Only once
in a while was I reminded of my German identity, usually when Malaysians
communicated their images of Germany: great cars, crazy Nazis, excellent
soccer, and impressive engineering.

All of a sudden, one night my seemingly beautiful Malaysian life was
interrupted: People were up and about running up and down, children were
crying. I got up to take care of one of them and realised that kaima, one of my
brothers and his wife were trying to get father in the car. They had called an
ambulance, but no one came – this was rural Malaysia. He died in our car on
his way to the nearest hospital – as we later learned due to a heart attack. Never
before in my lifetime had I seen a corpse, and I cried hysterically when he
was laid out in our living room for an entire three-day period. I was horrified,
because someone had just simply ceased to be. Moreover, I was unsure about
the appropriate behaviour, so I felt insecure. When we dressed him for the
public viewing, blood ran out of his mouth when my sister and I tightened
his tie. For days on end I felt like I was in a trance, the air was filled with the
fragrance of burned incense sticks, leading to the burning of eyes that were
unable to stop crying. We constantly prayed and burned incense paper, and
other paper-made things such as houses that he would need in the afterlife.

The corpse was moved into a small transporter and we, the family,
accompanied him on his last journey. I was dressed in traditional mourning
clothes, the patch on my right arm showed me to be his daughter-in-law, a
position that made me more than just an adopted daughter, it made me part of
their family ties. We arrived at the cemetery where we once again kneeled down as a family and prayed. My face was drowned in tears. At the crematorium, we saw him slowly sliding into the furnace, my heartbeat raised to infinity, and my breath got stuck in my chest. Whereas I was reminded of my German identity – images of concentration camps with stacked emaciated dead bodies carelessly thrown onto one another – my family seemed to be alleviated by the burning of father. We picked a particularly good space for the urn at the nearby pagoda and had an appointment the next day to pick out left bones with chopsticks from the residual burning – it is said that bones that survive the crematorium stand for a strong character.

Back home in the afternoon a giant rama-rama, a butterfly, sat on the altar in front of father’s photograph. You sometimes catch a glimpse of those large rama-rama when they fly in and instantly out again. This one just sat there, we would head towards it, but it would calmly stay. It seemed that everyone knew something I did not. Kaima smiled contentedly and told me that father had come back for one more time to bid farewell and wish us well. When dusk arrived, the rama-rama left and father’s soul was free. Even though my inner German voice told me that I do not believe in souls, it allowed me to let go peacefully.

Many years later a lecturer at the Department for Austronesian Studies was pleased that I had had the opportunity, even the luck, to watch a traditional Chinese funeral. I was confused about this statement, as the lecturer had obviously not understood what had happened to me. I had become part of that family and the Malaysian life, and I would rather not have attended that funeral. To me this was not an interesting anthropological observation, to me this was the loss of a faithful companion.

During my time in Malaysia, I experienced life in an extended family; living together in a limited space, accepting each other as we were and being sure of each other’s care when it was needed. Many friendships resulted from my life in Malaysia. Those friendships were not so much about having the same opinion or having the same Weltanschauung, worldview – which was virtually never the case – it was more about shared experiences, being engaged in one another’s lifestyle, and at the start being the Other that enriched our mutual friendships. My very special thanks with all my heart therefore go to kaima, Fong, Ah Peng, Peng Peng, and my overwhelmingly large family and to my dearest friends Soon, Hui Ching, Lea, Chee Keong and Salmi, and all of 4G and JG – without whom I would have been lost in what seemed to me to be a strange world.

Retrospectively, I often felt the need to give something in return to the Malaysian people that enabled me to be part of their life while at the same time allowing me to be different. Often, material gratuity somehow did not meet my needs. After many years I feel that this piece of work may be my very own
way to give something in return. I do this from multiple perspectives: as an ‘outsider’, a mak saleh, a Westerner, a trained physician; but also as an ‘insider’, a Malaysian anak angkat, be it in the realm of the Chinese or the Malay world, who has experienced traditional medicine, be it spiritual or herbal, and the ordinary klinik kesihatan, the rural health clinic.

As my personal experience indicated and this piece of work further expounds, there are politically desired demarcation lines between Malay and Chinese Malaysians and the health sector is no exception to this. Chinese people are labelled as being attached to urban life and ‘modern’ medicine, willing to donate organs and accepting brain death. Malays on the other hand, are ascribed to being attached to their village life, viewing ‘modern’ medicine with suspicion, hence virtually never giving up their organs and are said to have not yet ‘understood’ the concept of brain death. Although it is true that Chinese Malaysians donated organs more often than Malays, the overall donation rate in Malaysia is extremely low. In the past 15 years there have been between four and forty donations from brain-dead, heart-beating donors each year and to conclude the above-portrayed picture would be overly simplistic, given the absolute, small numbers of deceased donations per year.

The aim of the present study is to overcome the simplicity of this polarising dichotomy between Malay and Chinese Malaysians regarding their willingness to donate organs in presenting a more differentiated picture of why Malaysians are reluctant to donate their organs or unsure about the concept of brain death and take their concerns seriously. This new picture may not draw a demarcation line between ethnic groups but in contrary exposes that attitudes towards organ donation and brain death are strongly dependent on personal identity in this ever more complex world, which increasingly disrupts the positioning of individual identity along ethnic lines or religious affiliation.

The process of this work has not only generated ‘academic outcome’ in the form of this account, but has enabled a transformation of myself from a staunchly biomedically trained physician with an interest in culture and its people into a passionate clinician appreciating the world through the anthropological lens. Not least because of this, I was confronted with what Peletz (2013: 604) has described as a “challenge, ... related to our readership, [that] has to do with the fact that many of us write for, or are held accountable by, multiple audiences: professional colleagues straddling different academic disciplines; variably situated interlocutors and friends in the field; and religious [and biomedical] authorities and bureaucrats in the countries that host our research and sometimes vet our publications”.

I am well aware that I cannot meet the often contradictory demands which I encountered from people in the field. Even though, I imploringly hope to contribute to entangling some of the complexity of the Malaysian ‘venture of transplantation’ with its manifold actors who frequently pursue conflicting interests by providing a fine-tuned and detailed account of the multiple told
and untold stories of transplantation, organ donation, and brain death in the Malaysian context. By writing this thesis in English rather than in German, I would like to make this piece accessible to a broader audience, including those Malaysians who are affected by this topic.
Transplanting organs under the premises of diagnosing brain death have become emblematic of the possible conflicts between scientific and religious, modernising and traditional, and academic and popular views on adequate medical care and death and dying. In Malaysia there is the perception that the Chinese population readily and often donate due to the positive attitude of Buddhist scholars, whereas Malays are sceptical towards post mortem organ donation and donate seldom due to a reserved Muslim clergy. This thesis aims to capture the heterogeneous and often contradictory views on transplantation, organ donation and brain death in the context of Malaysia. Therefore, I make use of the analytical construct ‘global assemblage’, a concept that grasps well the complexity of discourses and practices that biomedicine entails.

Based on a total of 15 weeks of ethnographic fieldwork conducted between 2009 and 2014, this work delineates how the global assemblage of the transplant venture has played out in Malaysia. That research included informal conversations with representatives from the Malaysian Ministry of Health, NGOs, and transplant recipients and their families. The findings reveal the dynamic interplay between local and global influences, highlighting the challenges faced by organs for the underserved populations in Malaysia.

Zusammenfassung


Basierend auf insgesamt 15 Wochen ethnographischer Feldforschung zwischen 2009 und 2014, beschreibt diese Arbeit, wie sich die globale Assemblage des Transplantationsvorhabens in Malaysia manifestiert hat.
Health and 19 semi-structured interviews with transplant physicians, and Muslim, Buddhist and Daoist scholars. In addition, medical policies, contemporary laws, information leaflets from government agencies, and religious edicts were consulted to further characterise the official religio-political stance on transplantation and brain death. Furthermore, structured interviews with approximately a hundred Malay Muslims and a hundred Chinese of Buddhist and Daoist faith living in a rural area of the Malaysian state of Selangor were conducted. Two semi-structured interviews, one with the district imam and one with the abbot of a local Chinese temple supplemented those insights. The work shows how the National Transplantation Programme has come into being through medical professional bodies and the National Transplant Resource Centre, an agency under the Ministry of Health and how it has developed further. The aim of the established transplantation programme is the nationwide treatment of end-stage organ failure by means of increased transplantations from brain-dead donors. To establish post-mortem organ donation in Malaysia, physicians and state officials from the Ministry of Health have successfully convinced Muslim clergy from JAKIM, the federal Department for Islamic Development and from State Mufti Departments about this practice. Buddhists elites initiated the first transplants in the country themselves and have since supported the state-run transplant system. This official

religio-political stance is in great contrast to the dismissive view towards the practice of transplanting organs from donors diagnosed as brain dead from the minority religion of Daoism and the surveyed Malay and Chinese population, who are sceptical towards this practice and express their concerns about the renegotiation of the moment of death and an institutionalised transplant system that may well lead to a coercion to donate.

This work shows that the opinions of such communities, the Daoist community and the rural population, are excluded from the national discourse on transplantation, organ donation, and brain death; a discourse that to date has been dominated by the views of the medical, governmental, and religious establishments. At the same time, the preserved picture of 'good/laudable' Chinese who donate and 'bad/ungrateful' Malays who object to donating, leads to the distortion of reality, namely that both sides are reluctant towards this practice and seldom donate their organs after death. This non-participation of Daoist scholars and the Malaysian populace on the national discourse, however, obfuscates unresolved concerns about transplanting organs and the disputed concept of brain death from a considerable part of the population and nullifies any attempt to address wider, vital issues as to the use of and extent to which biomedicine and medical technology in contemporary Malaysia actually benefits its people.
1. Introduction

We are going through a radical contemporary change of social, cultural, and economic life around the globe, which is felt to have profound but uncertain and confusing implications for human life (Collier and Ong 2005: 3). This transformation is often loosely referred to as ‘globalisation’ and in the Muslim world many transformations are all too quickly concealed under the label of ‘Islamisation’ (Collier and Ong 2005: 3 and Peletz 2013: 626f.). Both notions discourage the recognition of the complexity of this all-encompassing societal shift. The “almost unavoidable marker” globalisation does not capture those “heterogeneous and often contradictory transformations – in economic organization, social regulation, political governance, and ethical regimes” (Collier and Ong 2005: 3). Likewise, as Peletz (2013: 627) rightfully notes, Islam is not even related to many of the transformations currently affecting the Muslim world. And yet to those transformation processes that are influenced by Islam, such as the transformation of the Malaysian sharia judiciary system, Peletz (2013: 625) denounces the generalising term Islamisation as “a woefully incomplete and otherwise misleading gloss – partly because it is so reductionist”. Even though Peletz has made clear that the term Islamisation can by no means comprehensively grasp the manifold transformations in the Malaysian sharia court system, or for that matter any other system in Malaysia, few observers would deny that over the past four decades Islamic symbols and idioms have become a much more prominent feature of social, cultural, and political relations in the country, and there are indications that biomedicine has not been excluded from this process. Ormond (2013: 71ff.) for instance describes parts of the Malaysian healthcare system as having become ‘Muslim friendly’.
To capture the vicissitude of the Malaysian medical system, I use the notion ‘global assemblage’ in the sense of Collier and Ong (2005: 3), and in analogy to Peletz (2013: 603ff.), who regards the Malaysian sharia judiciary system as global assemblage. So, what is global about the Malaysian medical system or in this particular case, what is global about transplantation, organ donation, and brain death in the Malaysian context and why is it helpful to consider it an assemblage?

Biomedicine and experimental science, both attended by the production of high-technology equipment, have emerged in Euro-America and are nowadays not only practised, produced and utilised, but even developed further in virtually every corner of the world.1 Biomedicine – be it clinical medicine or medical research – is, so to say, a global enterprise, or assemblage that plays out at a certain locality, yet it has to be viewed in its global connectivity. This ensemble of often heterogeneous elements under the umbrella of biomedicine is “articulated in specific situations – or territorialized in assemblages – they define new material, collective, and discursive relationships” (Collier and Ong 2005: 4). The machinery of biomedicine, specifically the venture of transplantation – be it in form of material technology (e.g. ventilators) or specialised scientific expertise (e.g. surgical skills) – is organised in a global space, for example through scientific publications. Academic publications regarding transplantation, organ donation, and brain death are generated from around the world, and are easily made available to an entirely different locality.2 Potentially, presuming that bodies are biologically the same everywhere, research findings regarding transplantation that emerge in a specific locality would be valid anywhere around the globe (Brotherton and Nguyen 2013: 288 and Collier and Ong 2005: 4). But the body “is inseparable from evolutionary, historical, cultural, and sociopolitical contexts”, thus there is no “standardized ‘universal’ body”, though Lock recognises that this “entity … is indispensable to medical practice today” (Lock 2013: 296, 302).3

---

1 | I should note that I use the term biomedicine to describe mainstream modern medicine with its basis in science and emphasis on the (physical) body. Some use the term ‘Western medicine’ or just plain ‘medicine’ as opposed to ‘traditional medicine’ to refer to biomedicine. But precisely because biomedicine is not exclusively shaped in Western societies, I avoid the disorientating term ‘Western medicine’.

2 | A multitude of biomedical articles from diverse localities have dealt with ‘transplantation’, ‘organ donation’, and ‘brain death’ and are pooled, for example, under the search engine Pubmed: www.ncbi.nlm.nih.gov/pubmed.

3 | There is in fact evidence that social events can become embodied, in that they alter the molecular makeup of the epigenome and therewith influence gene expression. This means environmental factors may well have durable and even transgenerational influence on many health issues. See for example Kuzawa and Sweet (2009) and Labonté et al. (2012).
Global phenomena like biomedicine are entrenched in established historical, cultural, social, and political structures, but at the same time “they have a distinctive capacity for decontextualization and recontextualization, abstractability and movement, across diverse social and cultural situations and spheres of life” (Collier and Ong 2005: 11). They are not limited by the vagaries of a cultural field, but limited in the sense that specific technical infrastructure, administrative systems and ethical regimes have to be in place to practise biomedicine, in this case to transplant organs from one site to another (Ibid: 11, 13).

Thus, biomedicine is usefully viewed as being global in the sense that it features and forges relationships to a multiplicity of global discourses and practices. Here, the global is “abstractable, mobile, and dynamic and replaces the sweeping and seemingly outworn terms ‘society’ and ‘culture’” (Ibid 2005: 4). Yet, transformations in the realm of biomedicine are contradictory and are subject to inherent tensions. While the “global implies broadly encompassing, seamless, and mobile; assemblage implies heterogeneous, contingent, unstable, partial, and situated” (Ibid: 12).

This means the global assemblage of the Malaysian transplantation system is composed of certain biomedical conditions, specific systems of political administration, ethical regimes, and the laity. Biomedical conditions involve techno-scientific developments, which have made possible the availability of organs. On the political side, the Ministry of Health and its multiple sub-agencies are concerned with the venture of transplantation. The ethical regime largely consists of the religious domain, an extremely heterogeneous field in Malaysia. Non-government religious umbrella organisations and prominent individual religious scholars have long been involved in the matter of blood and organ donation, but to an increasing extent state-run religious ministries, think tanks and committees have also emerged on the scene. Perhaps most important in this ensemble and sustainably pertaining to the availability of organs is the role of Malaysian laity that comes into play on at least two, if not three occasions: as potential consumers (organ recipients) and givers (organ donors), and as a public raising a moral voice, or as Collier and Lakoff (2005: 28) put it, the “‘society’ emerges as a central ethical subject in modernity”. This public and its appreciation to current transplant practices is as important as voices from the biomedical, political, and religious domain are, because the practice of organ donation and brain death directly pertains to their body (Leib) and life. This increasingly informed public has, as we will see, its very own agenda on the matter.

Within this assemblage, the producers of expertise – be them physicians, scientists, bureaucrats, religious authorities and to some extend the laity – ‘go global’, in that they are mutually linked to their peers at remote sites. As such, Malaysian transplant surgeons and nurses are sent for international transplant conferences and transplant coordination courses around the globe. Likewise Malaysian bureaucrats from the Health Ministry work in close cooperation
with transnational administrative bodies, like the World Health Organisation, an agency that also has its own agenda on the issue (i.e. pushing the practice of transplantation in a defined regulatory framework but banning organ trade). Muslim and Buddhist clergy in Malaysia also attain a global quality in that they are sustaining strong international ties. For example, Muslim scholars sitting in national committees are in close contact to the transnational operating Islamic Fiqh Academy. Buddhist clergy, on the other hand, has intimate links to Sri Lanka, a country known to be one of the world’s largest cornea exporters. In this ensemble, not only the bearers of specialised expertise in the field of biomedicine, governance, and religion are ‘global’, but technical devices such as medical equipment or tools to deduce religiously virtuous conduct also attain a global quality. Laity, on the other hand, is global in the sense that their identity is not merely based on localised ethnic or cultural belonging, but progressively personal identity and individual religious practices are shaped by a multiplicity of global discourses, which negotiate the constitution of modern earth dwellers anew. Stivens (2013: 153), for instance, argues that family networks operate across national borders. Likewise, Hoffstaedter (2013: 273) points out that Islamic theology is part of a global discussion in that “Muslims in Malaysia today consume theology on the internet, watch lectures and sermons via Youtube [sic] and engage with these international theological debates as well as interact with the local imam (preacher) and ustad [sic] (religious teacher) and missionaries”.

This sketch of the global assemblage is not self-contained nor do the actors necessarily agree on how to deal with the venture of transplantation and its entailing issues. The assemblage is united in the sense that all involved parties raise the question as to how one should handle this relatively new opportunity to receive or pledge organs upon death, but individuals and collectives are coming up with a multiplicity of suggestions, opinions, trends, and actions, which are often contradictory and pose a variety of diverse intentions and targets. This tension within the ensemble is what Collier and Ong (2005: 4) call a domain “in which the form and values of individual and collective existence are problematized or at stake, in the sense that they are subject to technological, political, and ethical reflections and intervention”. They view those assemblages as sites for the formation and reformation of anthropological problems whereas anthropological problems are best understood as problems concerning the social and biological existence of human beings rather than isolated theological or philosophical reflection on human life per se (Ibid: 4, 6). This study demonstrates that the global assemblage of the Malaysian transplantation system clearly is a site of the formation and reformation of anthropological problems, as for example the question of donating an organ in the state of brain death or opting for a human organ to treat end-stage organ failure.

The concept of global assemblage helps us to comprehend features of the Malaysian transplantation system and its nascent anthropological problems.
As such, it illuminates how civil servants and religious scholars have generated policies and religious obligations towards the transplantation of organs and the concept of brain death and how Malaysian laity has valued those predefined political and religious concepts. In the following, my aim is to entangle the complexity of the Malaysian venture of transplantation and illustrate the significance it has for individuals and collectivities by empirically unpacking this global assemblage in providing a detailed account of the multiple told and untold stories of organ donation and brain death in the Malaysian context. I thereby follow the tradition of Ong and Collier (2005: 15) to delineate the trajectories of change by giving a fine-tuned and thorough ethnography that addresses “the ‘big’ questions of globalisations in a careful and limited manner”.

The first subchapter of the introduction outlines the objectives of the present study in detail. In the second subchapter, I argue that external labelling of ethnic and religious belonging provides little information about the actual lifeworld of a Malaysian individual. Therefore, to make an assumption about the influence of ethnicity and religion towards the attitude of organ donation and brain death, it is necessary to take personal identity and actual religious practices into consideration.

The third subchapter describes medical pluralism in Malaysia. Here I locate organ transplantation and brain death in the biomedical system, while health beliefs of Malaysians⁴ are highly influenced from concepts that have emerged from locally developed traditional medicine. The subsequent part discusses how organ transplantation and brain death have historically emerged within biomedicine and experimental science in Euro-America. Here, I show that the practice of post mortem transplantation has become feasible due to certain techno-scientific developments, notably the advent of brain death. I show that the practice of transplantation and therewith diagnosing brain death have become adopted in the biomedical setting throughout the world, including Malaysia. At this point, I argue that the procurement of organs from brain-dead donors is not only controversially debated in the Euro-American context by certain people, but increasingly organ donation and its emerging anthropological issues are on everyone’s lips in Malaysia.

In the fifth subchapter, I then come to delineate two underlying anthropological problems in the scope of the Malaysian transplantation system. From the government’s point of view, the main problem of the transplantation programme is the severe ‘scarcity’ of organ donors, calling the Malaysian public to come forward and donate organs upon death. The Malaysian laity on the other hand remains reluctant to donate organs upon death, indicating that they view organ donation and brain death at the least as ethically disputable

⁴ The term Malaysian refers to people who possess the Malaysian citizenship, whereas the term Malay describes the ethnic belonging.
practices. Furthermore, all involved parties associate ethnic belonging with a different willingness to donate organs. As such, Malay Malaysians are labelled to be reluctant to donate, while Chinese Malaysians are considered to readily give away their organs. Here, I argue that this assumption is impossible to maintain, given the absolute and extremely low numbers of organ donation upon death each year.

The sixth subchapter then summarises current research publications regarding the attitude towards organ donation and brain death among Malaysians. Here I show that previous studies have unilaterally focused on cultural and religious beliefs and ‘misunderstandings’ as the major barrier to an increase in the post mortem organ donation rate in Malaysia. Thereby previous studies have sidelined the forces of the ‘biomedical battery’, government agencies, and religious authorities in the venture of transplantation. Furthermore, underlying religious perceptions and practices that have been held responsible for the reluctance to donate organs were not investigated in all their breadth and depth. This is especially true for followers of the syncretic religion of Shenism, a blend of Buddhism, Daoism, Confucian ethics, and folk beliefs, but to a lesser extent also applies to Malaysians who view themselves as Buddhists or Muslims. Another shortcoming of previous studies is the negligence of how Malaysians assess and value the concept of brain death against the background of ‘conventional’ death and the practice of organ donation. This is of specific importance as knowledge about brain death and its validity greatly influences the attitude towards donation upon death.

The seventh subchapter addresses the fieldwork in a reflective manner and delineates the qualitative and quantitative approach to capture the complexity of the Malaysian transplantation system. The final subchapter outlines the organisation of the present work.

1.1 Objective of the Study

The objective of this study is to present a thorough account of how the venture of transplantation, the flagship of biomedicine, has played out in the distinctive Malaysian setting. This means the work explores the relationship between political governance, religious administration, and biomedicine and takes into account the views of the rural Malay and Chinese communities on transplantation, organ donation, and brain death. The account delineates how organ donation became a politically and to a large extent a religiously motivated mission to be spread to all Malaysians alike and unveils motives of why certain people in Malaysia writhe in pain when asked for a donation, while others virtually fetishise organ donation as a religious deed. In the beginning, the work was based on two hypotheses: First, Malays are reluctant to donate organs
due to a reserved Muslim clergy and secondly, Chinese are willing to donate organs due to a supporting Buddhist clergy.

However, during the fieldwork two issues gradually became apparent: firstly, certain Muslim clergy were indeed very keen to support national efforts to build up a transplant service, and secondly the majority of Chinese turned out to be reluctant to donate organs after death, a circumstance that seemed to involve certain Daoist teaching and Confucian ethics. Therefore, the main objectives of the present work were (1) to unveil the relationship between biomedical forces, political governance, and the religious domain within the venture of transplantation, (2) to delineate attitudes regarding organ donation and brain death among a selected religious clergy, (3) to explore the lifeworld of Malay and Chinese Malaysians in order to locate end-stage organ failure in view of medical plurality, and (4) to explore attitudes towards organ donation and brain death among a selected rural Malay and Chinese community. To reach these four main objectives, the following questions will be addressed:

1. Unveiling the relationship between biomedical forces, political governance, and the religious domain in the venture of transplantation.
   a. What are the operating structures of the state-run organ transplantation programme?
   b. What is the government’s policy on transplantation, organ donation, and brain death and how is it promoted?
   c. How are normative religious obligations generated in the Malaysian context?
   d. What are enunciated Islamic, Buddhist and Daoist obligations regarding organ donation and brain death?

2. Delineating attitudes regarding organ donation and brain death among a selected religious clergy.
   a. What are the attitudes towards organ donation and brain death among Muslim, Buddhist and Daoist clergy and what are they based on?
   b. Are attitudes regarding organ donation and brain death among Muslim clergy in contrast to normative Islamic obligations?
   c. Are attitudes regarding organ donation and brain death among Buddhist and Daoist clergy in contrast to normative Buddhist and Daoist obligations?
   d. Are there different attitudes towards organ donation and brain death between local (regionally active) and high-ranking (nationally active) religious scholars?
3. Exploring the lifeworld of Malay and Chinese Malaysians in order to locate end-stage organ failure in view of medical plurality.
   a. What beliefs and practices make up the lifeworld of Malay and Chinese Malaysians?
   b. Where is end-stage organ failure located within the pluralistic medical field?
   c. How does the therapeutic option ‘transplantation’ compete with other options from biomedicine and with treatment regimes from other medical systems?

4. Exploring attitudes towards organ donation and brain death among a selected rural Malay and Chinese community.
   a. What are the attitudes towards organ donation and brain death among the rural Malay and Chinese population?
   b. Which attitudes regarding organ donation and brain death are similar or divergent between the Malay and Chinese study population?
   c. Are attitudes regarding organ donation and brain death among the rural Malay study population in contrast to normative Islamic obligations?
   d. Are attitudes regarding organ donation and brain death among the rural Chinese study population in contrast to normative Buddhist and Daoist obligations?

To answer these questions it is necessary to explain how I understand and define the terms ethnicity, culture, and religion to then approach the biomedical therapeutic option of transplanting organs for end-stage organ failure and delineate ramifications of the current transplant system.

1.2 Ethnicity, Culture, and Religion

In print and audio media, including advertisement, in politics and during casual conversations, Malaysia is often described as a multi-ethnic, multi-cultural, and multi-religious, sometimes even as a multi-‘racial’ society. The meanings of those terms are vague and the usage is frequently inconsistent. Therefore, I make some brief comments on ‘race’, ethnicity, culture, and religion and their relationship to one another.

Ethnicity is frequently confused with ‘race’ or even wrongly used interchangeably. ‘Race’ refers to a group of a species that shares distinct biological features that are presumed to be different to those of another ‘race’. Applied to human beings, the concept of ‘race’, where humans are separated into biologically distinct ‘races’, is a scientifically false notion. On the basis of current scientific knowledge, all human beings belong to the species Homo sapiens and originated from Africa (Müller, Kluge and Heinz 2013: A314). The
concept of ‘race’ is most controversial for two reasons, as Eriksen (1993: 4) points out: “First, there has always been so much interbreeding between human populations that it would be meaningless to talk of fixed boundaries between races. Second, the distribution of hereditary physical traits does not follow clear boundaries”. In fact, human beings do not have different genes, as often discussed in the lay press, but populations differ regarding their frequency of gene variations, which are either called mutations, or when they occur with a frequency above 1% are referred to as polymorphisms (Müller, Kluge and Heinz 2013: A314f.). This means, “there is often greater variation within a ‘racial’ group than there is systematic variation between two groups” (Eriksen 1993: 4). Therefore there are no definitive ‘races’, but gradual gene variations between or within a population which have emerged through the migration of the *Homo sapiens* throughout the world (Müller, Kluge and Heinz 2013: A314). The gradual change in both, traits (phenotypic characteristics) and gene variation of a population, usually correlates with environmental or geographical transition and is referred to as clines. The term cline describes the complexity between genetic determination and physical appearance much more accurately than the former categorical classification of ‘race’ (Ibid).

Ethnicity differs substantially from the term ‘race’ in that it “refers to a way of socially grouping persons on the basis of historical or territorial identity or by shared cultural patterns” (Crawley 2005: S59), although “cultural difference between two groups is not the decisive feature of ethnicity” (Eriksen 1993: 11). An ethnic group is rather “created through a process of ‘othering’ [and ethnic] identity is a product of comparison and contrast with others who are deemed to be different” (King 2008: 131). This means ethnic identity is transformed, negotiated, and reinterpreted constantly, thus it is not a static entity. In addition, it is important to note that ethnic groups are internally diverse (Ibid: 129). That, however, does not prevent the Malaysian government from recording ethnicity in official documents. This poses problems to citizens that do not fit in any precast ethnic category as for instance children from mixed marriages. In addition, once an ethnic entry has been made it is virtually impossible to change in retrospect. Hoffstaedter (2011: 31, 60) gives an example of a doctor who must have perceived the parents of a newborn baby as Muslims, and subsequently documented the newborn to be ‘Malay’, whereas the parents were actually of Indian descent. The now grown-up adolescent is still categorised as ‘Malay’ with “all the positive discrimination”, but then he is also confronted with the unpleasant interference of religious police in his life (Ibid: 60). The Malaysian Department of Statistics documents ethnic belonging in the form of a census, most recently in 2010. The total Malaysian population of 28.3 million consists of 67.4% ‘bumiputeras’; 5

5 | *Bumiputra* literally means “son of the soil”. The Malaysian government uses this term to refer to the Malay ethnic group and indigenous people (*orang asli*) living in Malaysia. *Bumiputra* enjoy certain privileges from the government.
mostly ‘Malays’ (63.1%), and 24.6% ‘Chinese’, 7.3% ‘Indians’, and 0.7% belong to ‘other’ ethnic groups (Malaysian Census 2010: 5). This means, according to the census, Malays make up the largest ethnic group, followed by the Chinese.

Ethnicity may get confused with the term culture. “Culture refers to patterns of explanatory models, beliefs, values, and customs. These patterns can be expressed materially (as in diet, dress, or ritual practices) or nonmaterially (as in language, social or political order, or kinship systems)” (Crawley 2005: S59). Although ethnicity and culture are similar, they are distinct in their concepts. “For example, we can think of the culture of Western medicine with its own specific language, values, and practices ... [But w]e do not think of medicine as having ethnicity” (Ibid). Analogue to ethnicity, there is great diversity within a cultural group and a member of any group may inhabit multiple ethnic and cultural identities (Ibid).

Religion may be the term that is most difficult to capture. Religion is embraced by culture, and interwoven with society so that it can hardly be viewed as an isolated entity that exists next to culture (Schmidt 2008: 1ff). Moreover, not all beliefs and rituals that are found within a certain culture can be attributed to religion. Currently, no definition of religion is universally accepted and captures all of the depth of religion (Schmidt 2008: 22 and Eller 2007: 28). Eller gives the following broad, but encompassing description: “Every religion makes a (more or less integrated) system of claims about the ‘supernatural’ world and its relationship with the natural, human, and societal worlds” (Eller 2007: 52). He suggests that it is more meaningful and accurate to speak about ‘religious fields’ instead of a certain religious type “recognizing that any religious field may contain some and not other elements, may elaborate some elements more than others, and may mix elements in ways that at first would seem ... unlikely or incompatible” (Ibid). Moreover, “[w]hile we are accustomed to thinking of a world religion as a monolithic, homogenous entity, the truth is that it is really an assortment of more or less closely related local variations” (Ibid: 204). In the context of Malaysia, where Islamic, Buddhist, and Daoist groups are internally diverse as previously described by Lee and Ackermann (1997), talking about religious fields indeed seems more accurate.6

6 The term ‘religious field’ based on Eller solely describes the diversity within a certain religion and has to be distinguished from the ‘religious field’ coined by Pierre Bourdieu (1991). Bourdieu’s genesis and structure of the religious field first and foremost is a sociology of Catholicism and the French Church (Dianteill 2003) and thus cannot be transferred to the Malaysian context. Furthermore, Bourdieu makes a rather strong hierarchical distinction between religious specialists and the dispossessed laity. “For Bourdieu, the authentic religious producers are the official institutional specialists who “consciously” reinterpret religion, as opposed to the “dispossessed” consumers/laity, who can merely “demand” but not “supply” religious meanings” (Dillon 2001: 414). But lay people can and do manipulate religious symbols to allow change within religious