BIOMEDICALISATION OF DEATH IN BANGLADESH: AN ETHNOGRAPHIC STUDY OF HOPE AND TECHNOLOGY IN THE ICU

Sadaf Noor E Islam BSS (hons), MSS, MA

This dissertation is submitted for the degree of Doctor of Philosophy

September 2019

Sociology

Declaration

This thesis has not been submitted in support of an application for another degree at this or any other university. It is the result of my own work and includes nothing that is the outcome of work done in collaboration except where specifically indicated. Many of the ideas in this thesis were the product of discussion with my supervisor Dr Richard Tutton and Dr Dawn Goodwin.

Sadaf Noor E Islam
BSS (hons), MSS, MA

Contents

Preface **1**

Chapter One **1**

The Emergence of Life Support Technologies 2

Life Support Technologies and Changing Definitions of Death **3**

Life Support Technologies in Bangladesh **7**

The political history of Bangladesh: An overview of the health system **15**

Provision of Health Care in Bangladesh **20**

Research questions and structure of the thesis **24**

Introduction **30**

Medicalisation to Biomedicalisation: A Conceptual History 31

The Emergence of Medicalisation 32

The emergence of Biomedicalisation as a theoretical lens **42**

Biomedicalisation as a theoretical framework in the Global South context **46**

Key Concepts **51**

Biopower and biopolitics 51

Hope and Technology 52

Conclusion **54**

Introduction **57**

The hospital as a field of study: Understanding the unfamiliarity in a familiar place **59**

How it began: Access and Obstacles to the field **61**

Hospital Ethnography: Seeing, exploring, and understanding **63**

Observation: A way of understanding biomedicalisation in action 68

Interviews 72

Newspaper and health care service **75**

Analysing data **76**

The Three Hospital sites **76**

Going into the unknown – Challenging contexts **82**

Encountering the researcher's own identity: the 'White Apron' as a gate opener 84

Dealing with emotions 86

Ethics as a localised form 91

Conclusion 95

Chapter Four **97**

Introduction: First encounter with the waiting room **97**

The ICU Waiting room **101**

University Teaching Hospital (UTH) 103

BIRDEM (Bangladesh Institute of Research and Rehabilitation for Diabetes, Endocrine and Metabolic Disorders) 113

Phoenix Hospital Limited 117

Conceptualising Spaces of waiting **119**

Heterotopic space and ICU visiting hours 124

Practices and purposes of Waiting **127**

Waiting Room: The making of a temporary home 128

***"You are not alone"*: Universality of waiting** 130

Solidarities in Waiting 135

Conclusion **139**

Biomedicalisation in action - Ⅰ **141**

Death and Embodied Biomedicalisation in intensive care **141**

Introduction **141**

Technoscientisation, technologisation and the emergence of **142**

hybrid techno-social forms **142**

New ways to understand health and body 143

Biomedical technology and society- relatedness and interactions **146**

The ICU- A space of technologised treatment **152**

The technologised interactions between machines and humans in ICU 153

Bleeps and alarm in the ICU **158**

Technologisation of care **162**

Another side of the coin **168**

Hybridised and technologised death and dying in ICUs **169**

Machine confirmed death: *Not dead yet* 170

Machine predictable and decided death 175

Familiar vs. unfamiliar death 177

Life without creation is death 182

Conclusion **184**

Introduction 187

The political economy of hope and prolonging death **191**

Trajectories of Hope **196**

Hospital Emergency to ICU 198

Hope and the temporalities of death 207

Hoping for 'Quantity or Quality' of life 209

The quandaries of hope and unequal access to the resource **213**

Choice of no-Choice 215

Your pocket is what cures you 220

Hope and stigma 222

Conclusion **224**

Examining the "Bangladeshi Biomedical TechnoService Complex Inc." **227**

Introduction **227**

The 'Biomedical TechnoService Complex Inc.' **230**

Medical-Industrial Relation **231**

State, legislations and regulatory framework **246**

Oversight and Monitoring: DGHS **250**

Media reports, public discourse, and governance **258**

Updating Laws and their outcomes 262

Patient rights and health activism **266**

Conclusions **270**

Overview of the study **274**

Technology of self and denial **280**

The practices of life support are localised and globalised **282**

Regulation and enforcement **286**

Stratified Biomedicalisation of Death 288

Decolonising knowledge: Biomedicalisation in the local context 290

Limitations of the Study and Opportunities for Future Research 297

References 302

Appendix 310

Table of picture

Picture 1 The entrance to the University hospital ICU. 104

Picture 2 Designated waiting space at University hospital 104

Picture 3 Chatting and resting at UTH waiting area. A hybrid medical-domestic area 107

Picture 4 Relative's temporary home at UTH 108

Picture 5 The collapsible gate at UTH 111

Picture 6 Reception and Security Guard. 111

Picture 7 The rules for visitors, BIRDEM 113

Picture 8 BIRDEM waiting room. This is how relative takes rest. 116

Picture 9 Jam-packed waiting room at BIRDEM 116

Picture 10 Waiting room, at Phoenix Private Hospital 118

Picture 11 This is the ICU complex, at BIRDEM 135

Picture 12: An ICU bed waiting for patient UTH 156

Picture 13 Mr. Shafayet's room at his house. Few necessary machines are seen in the picture. 212

Picture 14 Mr. Shafayet's room with a few medical devices. 212

Picture 15 An ICU bed in an international free-standing chain hospital in Dhaka city 234

Picture 16 The ministry of Health, Dhaka 252

Table of Figures

Figure1 Map of Bangladesh showing major cities.....16

Figure 2 Population health indicators for Bangladesh 17

Figure 3 This is a screenshot taken from the home page of Square Group.....232

Figure 4 Excerpt from the Medical Practice and Private Clinics and Laboratories (Regulation) Ordinance 1982 250

Biomedicalisation of Death in Bangladesh: An Ethnographic Study of Hope and Technology in the ICU

Sadaf Noor E Islam

Thesis Abstract

The relatively recent developments of life support technologies, which were introduced in Bangladesh in 1978, have resulted in the production of new forms of life and death. The intervention of modern life support technologies gives rise to hope in relatives of patients but led to complexities and contradictions in the contemporary society of Bangladesh. I show how the intervention of life support technologies has resulted in hybridised technologised life and death, new technologised hope and care, and new forms of subjectivities. This thesis examines how 'decisions' about initiating life support technologies are made and how hope, the affordance of technologies, and economic context interplay in this endeavour. Life support treatment is very expensive in Bangladesh, where life support care is mostly privatised, and the government life support treatment is not entirely free, thereby, this study focuses on how economic status affects access to different levels of technological intervention and shapes different experiences of death.

This thesis examines the influence of a marketised profit-motivated health care service and the paradox of hope in the life support treatment choice. In some cases, relatives need to take the withdrawal decision of life support for not being able to continue the cost of life support treatment. Informed by the unequal access to resources, this thesis finds the process of withdrawal of life support as a negotiation, which also reflects the political-economic context of life support technologies. For the uneven access to resources, I consider that the biomedicalisation of death has taken the form of stratified biomedicalisation.

As there is still no state-provided standard guidelines, protocol, and legislation for life support care in Bangladesh, I critically explore how this complicates and impacts the public

perceptions of life support technologies. In a critical exploration of the use of life support technologies in both public and private intensive care units in three locations, carried out by anthropological ethnographic observation and conversations, I show the biomedicalisation of death in the context of contemporary Bangladesh. My ethnographic observation in the ICU and daily conversation with relatives, doctors, and health service providers enables me to understand seemingly insoluble tensions that exist in relation to the life-prolonging technology's relationship to the dying patient's family members.

The anthropological exploration of the biomedicalisation of death in Bangladesh is the first-ever study in this area to my knowledge. Thereby this study contributes to the scholarship of medical anthropology of science, technology and body, medical sociology, science, and technology studies as well to the understandings of policy and lawmakers. Providing ethnographic knowledge on the actions of life support technologies in life and death can also contribute to generating knowledge regarding the misuse and futility of life support technology.

Acknowledgments

I must express my sincere thanks to the numbers of people who throughout this study have kindly provided me with the support I needed: to all the patients' relatives, doctors, nurses, staff; to the Wellcome Trust for funding the project; to Charles Wallace Trust (Bangladesh) for the doctoral student award; the anonymous two hospitals and BIRDEM (who have allowed me to use their name) for allowing me to carry out my study; and to my friends and family who gave their support to reach respondents.

I want to express special gratitude to all of the patients' relatives of this study who have shared their lamentable stories of life support care with me. My thoughts and prayers go to those who lost their nearest ones in this journey.

I am very thankful to Dr Taufiq, Dr Rana, and Dr Shehan[1] for the enormous support they have given me by explaining medical terms, medical procedures, and many things beyond my understanding in the initial phase of my fieldwork at ICU. Even after my return to the U.K., they continued to help me with the information and clarifications I needed; my ICU understanding would have been incomplete without them. Their presence made my difficult time at the ICU easier and sometimes joyous.

My greatest debt is to Nahid, Shujon, and Samshed[2] (patient's relatives). They have been very helpful to me throughout my study and introduced me to other patient's relatives. Nahid was always there when I needed him for any clarifications or information.

My special thanks and gratitude to my teacher, mentor, and comrade Rahnuma Ahmed for inspiring me in doing an ethnographic study on death on life support. At every stage of my fieldwork, she provided an enormous amount of support. Words are not enough to thank her, without whom this study would not be possible. I would also like to thank Dr. Shahidul Alam for the encouragement; Nurul Kabir for helping me to get the most challenging hospital permission; and Dr. Zafar Ullah Chaudhury , Dr. Qamruzzaman, Dr. Mahmudul Islam, Farida Akhter, Shireen Huq, Professor Dr. Sayedur Rahman, and Jannatul Mawa for their valuable time and discussions.

[1] Pseudonym

[2] Pseudonym

I want to thank Professor Nayanika Mookherjee for stimulating ideas and helping me in the first stage of this research proposal.

I wish to pay heartfelt gratitude to my supervisors Dr Richard Tutton and Dr Dawn Goodwin, for their constant support even in difficult times. I am deeply indebted to Professor Bob Jessop for his valuable discussion; to Noel Cass for proofreading and stimulating suggestions on the thesis draft; to Dr Jonathon Beacham for commenting on chapter 4 and making valuable suggestions; to Lula Mackenzie, Andy Yuille, Cath Hill, Laura Clancy and William James for proofreading and commenting on the part of my thesis. I want to especially thank my friends Lula and Jane Fish to encourage me and walk with me in a difficult time. I also want to say thanks to my colleagues, Ala Uddin, Khadija Mitu, and all the well-wishers and friends who supported me in many ways to complete this study.

I cannot end without thanking my *amma* (mother) and *abba* (father) for whose constant encouragement and love I have relied throughout my time at Lancaster University, and most importantly, for tolerating my absence when they needed me by their side. I know they will be the happiest people to see me complete this thesis. I also owe a debt of thanks to my sister and brother, whom I have neglected during this study.

Thanks to Majida, Ramija, for keeping me fed during my fieldwork days in Dhaka and Rokeya *bua* for taking care of my younger child when I was away for fieldwork.

Most importantly, I express my sincere gratitude to my beloved partner Rashedul Hassan, for his constant support and unquestioning confidence in my ability, for taking care of the children, me, and everything single-handedly. Without him, I would not be where I am now.

Above all, I am indebted to my two beautiful children Aungshu and Riddho, for being so understanding, patient, and independent, which enabled me to concentrate on my study. I always feel sorry for the nice moments they missed in their childhood for me. Thanks for being my world.