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



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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.

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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.

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¹ Pseudonym

² Pseudonym

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Preface

Some of my acquaintances were surprised and somewhat unhappy when they learned that I would study 'death,' considering death to be a melancholy and mournful topic. However, the further explanation of 'death on life support in intensive care units' made them curious. I can identify at least two separate but related instances that have made me think critically and left me inquisitive about death on life support in the intensive care unit.

A while after the recent death of my acquaintance's spouse, on life support at the end of her terminal disease, my friend said that the doctor took half a day to declare his spouse's death. He thinks that the doctors' delay was intentional, thereby incurring an Intensive Care Unit (ICU) bill for the whole day when she had actually died earlier in the morning. I realised, this kind of accusation against doctors and hospitals had become more visible in daily discussion and even in the media in Bangladesh.

In a different circumstance, my relative told me that her mother in law died '*naturally*' on life support; they (the family) did not *withdraw* it. During that time, I had no clear idea about how death occurs on life support. However, I could clearly hear my relative's emphasis on the 'natural death' and 'not withdrawing' the life support machine (mechanical life support).

These two instances made me think that life support technologies are not only used in the most critical health condition to prolong life with mechanical supports: life support

technologies have more impacts on the surrounding networks of people. I also realised that life support and associated death and dying have various understandings in contemporary Bangladeshi society.

The first case, of 'delaying the declaration of the death intentionally,' cannot be judged without examining the particular case. Nevertheless, this situation intrigued me, causing me to ask – why has this kind of allegation increased in numbers, and why does it even exist? I wanted to understand the reasons behind this contestation of life support technologies. Generally, regardless of differences in beliefs and cultures, people have their way of perceiving death. I was further thinking, is the reason because death occurs 'on' a machine? Then, what does the machine to death and dying that make people react? Why do they point out that doctors are doing business? It is intriguing why my relatives emphasised that she died 'naturally on life-support, we did not pull out the machine.' Her statement suggests a cultural way of accepting and denying death, what we can do, and what we cannot do. At the same time, do we not feel compelled to negotiate with death while approaching life support technologies, as life support also needs to be withdrawn sometimes? I am also curious to know how and why the privatised health care service is considered a susceptible element in the discourse of life support technologies.

Chapter One

INTRODUCTION

This thesis is about death and dying, life support technologies, and the experiences of dying patients' relatives in Bangladesh. It is also about the people associated with life support technologies and treatment procedures and the health sector's rules and regulations, which define and shape death and dying at intensive care units (ICU). This thesis explores the ambivalent realities that arise from the interaction of life support technologies with users and service-providers in Bangladesh. The ambivalence is rooted in the culture of familial responsibility, the expectations and understandings of biomedical knowledge practices, and the way life support technologies work in the market-driven health care system. In this process, I want to understand the biomedicalisation of death, through which the increasing uptake of life support technologies brings both hope and economic hardship.

I begin this introduction by outlining the emergence of life support technologies, their influence on changing definitions of death over time, and their transfer to and uptake in the Global South and specifically Bangladesh. I go on to review the development of the Bangladeshi health system in the context of its political history and outline the availability of and issues with the provision of health care in Bangladesh. With this background established, I then describe the research objectives, my research questions and give an overview of the thesis.

The Emergence of Life Support Technologies

The invention of the 'iron lung'³ marked the first widely used form of an artificial ventilator. From the middle of the nineteenth century, many breathing machines were made, among them one group known as 'iron lungs,' first invented by the Danish Physiologist August Krogh in the 1930s, which were extensively used for patients whose lungs had collapsed because of paralysis caused by poliomyelitis (Lock 2001; Nevena et al. 2012).

In this thesis, I define life support technologies to mean the artificial ventilator and other life support equipment and procedures such as defibrillators, artificial nutrition, and cardiopulmonary resuscitation (CPR), without any of which humans in a critical health condition cannot survive. However, most of the discussion about life support technologies in this thesis is centered around the mechanical ventilator. The mechanical ventilator and cardiopulmonary resuscitation (CPR) are the most used and primary life-sustaining procedures and technologies. Other life-saving treatments are given to people who are not necessarily attached to mechanical ventilators or given cardiopulmonary resuscitation⁴, such as kidney dialysis, tube-administered feeding, and antibiotics. Life support technologies are most commonly used in intensive care medicine.

³ The patient body used to keep in a large airtight metal cylinder except the head and neck to be exposed to the room air. The negative pressure was generated in the metal box with an electric pump which caused the patient chest rise (Nevena et al. 2012)

⁴ People can choose between CPR or DNR (Do not resuscitate) at the end-of-life for trying to sustain life. So, CPR is an 'option' if the resuscitation decision has already been taken by the people, otherwise it is a life sustaining procedure.

The emergence of life support technologies began in the 1950s in Copenhagen, Denmark, in response to the outbreak of a poliomyelitis epidemic, which led to the creation of the world's first intensive care unit in December 1953 (Reisner-Sénélar 2011). The formation of the intensive care unit consisted of bringing together a group of medical specialists - cardiologists, critical medicine, nutritionist, physiotherapist, and critical care nurse. The ICU provides round-the-clock care and monitoring under the specialists, generally known as intensivists. Apart from the doctors, ICU nurses play a crucial role in constant patient monitoring, along with the medical devices attached to the patient's body. Thereby, the ICU became a place where assemblages of intensivist health professionals, carers, and technologies work together to restore dying patients' lives. Thus, life support technologies and procedures are not only an assemblage of medical technologies and devices but also an assemblage of care, support, monitoring, techniques, and procedures provided by a group of people who have special skills and knowledge for handling critically ill or injured patients whose life is at stake, which are assembled in/by intensive care units.

Life Support Technologies and Changing Definitions of Death

In *Twice Death* (2001), Margaret Lock uses the term biological death, which delineates the different stages of death defined by medical knowledge and practice, which I will discuss later in this section. In the mid 19th century, death was increasingly systematised and determined by newly invented technology. The absence of respiration, blood flow, or the electrical activity of the heart was recognised as the major signs of death. Rigorous scientific endeavours in the assessment of death started to take place in hospitals and medical settings in the U.S. and

Europe from the 20th century (Kaufman 2005) by which the social meaning of death started to become less significant and transform death as more a biological event in biomedical practice. Through this scientific knowledge about death, biomedical doctors acquired the authority to pronounce death as laypeople do not have the expertise and 'objective' knowledge (Lock 2001; Illich 1975).

The invention of life support technologies, principally the artificial ventilator, has brought dramatic changes in defining death medically. The mechanical ventilator and other life support technologies and procedures are not only able to sustain life to some extent, but also they can prolong death and create stages between life and death. Apart from defining various stages of death, the mechanical ventilator also posed questions regarding 'when to pull the machine?' 'how to pull the machine?' These questions entail ethical and moral dilemmas and issues regarding the withdrawal of or sustaining life support. Because the development of critical care medicine and advanced life support technologies necessitate determining when to stop life support for patients who will 'never' recover or who are in an irreversible condition which only can be ended by 'biological' death (Lock 2001; Kaufman 2005).

With life support technologies, the extension of vital bodily functions made extending life possible, but at the same time complicated the definition of the life of and death, as this stage presents as being in between life and death - as without life support, the body is unable to maintain the life functions, and would have otherwise died. Life on life-support eventually led to a reconsideration of the conventional medical understanding of death and life with the major signs of life. The dubious condition of life and death occurs when the heart is still

beating, but a person is 'functionally' not alive in the absence of major brain functions. Given organs stay alive in such body conditions, procuring organs from this body organ transplantation was become possible. However, it was necessary to declare a person in this state as dead to enable organs to be procured for transplanting to avoid legal problems. Brain dead as a new type of death has emerged for the first time from the context of organ transplantation (Lock 2001; Lock, Young, and Cambrosio 2000; Lock and Nguyen 2010).

In 1968, an Ad Hoc Committee of Harvard Medical School⁵ set a new definition of Brain death in response to two new technologies⁶-organ transplantation and mechanical ventilator or respirator (Kaufman 2005). The ethical dilemma around the declaration of brain death as the end of life has developed since then, though differently in different places in the world. Brain death is defined as death when the whole brain permanently and irreversibly loses both consciousness and reflexivity. According to the Harvard Ad Hoc Committee, respiratory failure and brain death are two criteria for defining death legally and clinically in the U.S. While in the U.K., the 'whole' brain death has been modified into brain stem death (BSD), which means an irreversible loss of generating capacity of both consciousness and respiration (Wicks 2017). The dilemma arises when public perception differs from this conceptualisation of death. Orthodox Judaism, Japanese culture, and Native Americans, for example, declined to accept the

⁵ "A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death", *Journal of American Medical Association*, 205 (1968), p. 337.

⁶ A Ciba Foundation Symposium in London in 1966, the 1968 meetings of the World Medical Association in Sydney, Australia in 1968, The second International Congress of the Transplantation Society, and the New York State commission showed their concerns and the urgency to solve the problem of determining death to make organ transplantation legally possible (Youngner, Arnold, and Schapiro 2002)

definition of brain death as death as such (Wicks 2017). The troubling condition arises for family and relatives as brain death on life support 'does not look like death' as the person still breathes even though on life support (Lock, 2001). In this regard, Kaufman says, apart from the definition of death, mechanical ventilators create another new problem of 'what to do about death' (Kaufman 2005). Furthermore, biomedical knowledge and life support technologies categorised and created stages between life and death, with different conceptualisations of death including being 'Brain dead,' Brain Stem Dead (BSD), being in a Persistent Vegetative State (PVS), all being based on the pathological condition of the dying person.

These differences between understandings of death between laypeople and medical experts have led to various ethical, moral, cultural, and religious dilemmas. In this context, this study wants to understand how life support technologies and practices deal with these dilemmas and the negotiations that take place in Bangladesh; and how relatives understand the new definition of life and death when death can be to some extent delayed, prevented, or even quickened by the technological intervention (Kaufman 2005). Life support technologies have developed not only with modern techniques and functions but also with a new hybrid, technologically created entity between life and death, and contradictions and confusions which are subsequently created in response to technological endeavours in end-of-life care. The advent of life support technologies makes these stages between life and death, as a site of biomedical intervention, visible and complex when 'laypeople' understand death differently. The predicaments of defining life and death also come with public perceptions of quality of life, suffering, and dignity that eventually beg the question of where and when to draw the line of life-prolonging interventions (Kaufman 2005; Kaufman 2015; Clark 2002; Franklin and

Lock 2003), alongside the financial context of dying people and their families. A set of scientific standards determines biological death, but what constitutes death for relatives, and how is it understood while a patient – a family member – is on life support between life and death?

Following this line of argument, understanding the relations between death and life-support technologies requires investigating the social relationships and moral and ethical dilemmas emerging from this encounter. Addressing and understanding the dilemma is one of the major areas that this research explores.

Life Support Technologies in Bangladesh

The first intensive care unit in Bangladesh was established in 1978 at the National Institute of Cardiovascular Diseases (NICVD) (Faruq et al. 2010). According to a study conducted by the Department of Critical Care Medicine, BIRDEM General Hospital in 2007, there were 424 ICU beds in 40 ICUs in Bangladesh, 80% of the ICU beds were located in the capital city of Bangladesh. Since then there is no government statistics available regarding total ICU facilities in Bangladesh (Faruq 2011). According to DGHS Health Bulletin (2018) there are 221 ICU beds in the government hospitals, without having any information about privatised ICU facilities. A media report (Tazmim 2019) mentioned about more than 1000 privatised ICU beds all over the Bangladesh. Generally ICU treatment is very expensive in Bangladesh (Faruq and Habib 2018).

The major breakthroughs in biomedical technological advancement that brought diagnostic, therapeutic, and prognostic developments in biomedical practice in the Global North, over time, have extended to the Global South. As a result, the advanced life support technologies which have redefined life, death, and body in the Global North also have implications in the Global South. The movement of biomedical technologies from North to South has been more complicated than predicted as it requires human support, skills, knowledge, expertise, and resources; furthermore, there is a wider social context in which the changes and transformations are to be accepted or denied. However, the history of technological development tends to be depicted only as a story of progress and the betterment of individuals and society (Lock and Nguyen 2010), where technology is often seen uncritically in terms of logic, rationality, autonomy, prosperity, and liberating the human from mundane constraints to fulfill basic human needs for living. In this study, I consider biomedical technologies as technologies of biomedicine. While by biomedicine, I understand that professional medicine originating in the Global North profoundly emphasises biological medicine. Kleinman and Hahn (1983) mentioned that biomedicine widely spread to the rest of the world as 'Western,' 'Allopathy,' 'Modern,' 'Scientific' and 'Biomedicine.' Biomedicine exhibits hierarchy by devaluing other medical practices such as ethnomedicine; it posits itself as 'beyond the influence of culture' while other medical systems are considered culturally biased and have no scientific relevance, hence little or no efficacy (Gaines and Davis-Floyd 2004). By agreeing with medical anthropologists and sociologists (Gaines and Davis-Floyd 2004; Franklin and Lock 2003; Lock and Nguyen 2010; Hahn and Kleinman 1983; Good 1993), I also find this single authoritarian position of claiming truths and facts problematic. This theoretical position influences me to understand biomedical technologies in practice, their differential development, relationship to culture and financial consequences, values, and their impact on individuals.

My focus in this thesis is not on the controversy of defining death on life support, rather its consequences for how death and dying are managed and experienced. I investigate the socio-economic factors of death and dying in the intensive care unit in Bangladesh.

Given that technology can play differently in different places, Lock (2001) shows how public debate on brain death, such as that took place in Japan, never occurred in North America. Although Japan is a secular society, equipped with complex medical technologies, the Japanese appeared to resist the new medical concept of 'brain death actively.' Lack of trust in medical professionals and different conceptualisations of personhood⁷ are posed as reasons for Japanese resistance to accepting brain death as the end of life. From this cultural lens, Japanese people rejected brain death as the death of a person and made the declaration of brain death *as* death controversial and questionable. Lock's work is relevant for Bangladesh, as it is for other countries, because it addresses the moral and ethical issue of life and death in a much larger context of modernisation, industrialisation, and Westernisation, in conjunction with cultural values, traditions, and notions of the self and personhood, as exhibited in the Japanese context. This ambivalent situation of identifying death is created by the life support technologies that blurred, extended, and complicated the boundary between life and

⁷ The brain-dead controversy poses several questions regarding the personhood of the dying person; 'when an organism as a whole ceases to exist as opposed to its parts'; also when, 'personal existence ceases' (Penrick 1988: 27). By personhood I understand not only the biological quality of being a person but also a culturally ascribed person understood by family, relatives and others (Lock: 2001). I discussed personhood later in this thesis.

death and makes this 'a matter of choice.' It is important to understand the 'choice' to identify the root cause of 'choice' as being problematic.

This complex phenomenon of 'choice' coexists with the discourses of 'natural' death prevalent in Bangladeshi culture, where death is understood and celebrated in their cultural way 'sometimes influenced by cultural understanding' (Joarder, Cooper, and Zaman 2014); 'death comes when God wishes,' 'life and death are decided only by God', 'if God wishes to keep someone alive, no one can end her/his life' 'as long we breathe, we have hope (*jotokkhon shahsh totokkhon ash*)' - those are embedded in the moral, religious and social beliefs. Along with these assumptions, people also understand and simultaneously are influenced by modern scientific knowledge. Thereby, as such, Bangladeshi society and culture define death through science, biomedicine, religion, and/or cultural beliefs such as funerary rites, afterlife beliefs, mourning rituals, and concepts of good/bad deaths. Sometimes, the acceptance of new knowledge stemming from the new technology is easy and smooth, and sometimes it gets complicated when the new knowledge contradicts deep-rooted values and beliefs about death (Lock 2004). Thus, the socioeconomic and cultural context of individuals tends to make this situation more complex and problematic.

Regardless the complex situation, why do many Bangladeshi people opt for the most expensive life-prolonging treatment for their close kin? With its enormous force of free trade, privatisation, and free-market, the neoliberal economy opens many apparent 'options' and 'choices' to people who can avail themselves of them. Even those who cannot fully access these options have the 'desire' to acquire the choice. Kaufman contends that 'choices' are constructed and

limited within the clinical reality in the context of choice in biomedical technologies. There is no way to escape using this technology as a routine part of the biomedicalisation of death. Regardless, the choice of treatment with the possibility of withdrawal is fundamentally a political question rooted in the distribution of wealth and social justice (Kaufman et al., 2004). Nevertheless, this raises the question of unequal access to the resources – who can avail themselves of these options? At what cost?

Nevertheless, the expanding marketised health care service creates the illusion of health matters as a choice (Lock and Nguyen 2010) and responsibility (Marsland and Prince 2012). Marsland and Prince (2012) argue, in this way, medical technologies produce inequalities and create a situation where some people's lives become more valuable by accessing the hope and opportunity of new life than others who do not have that access. In this light, my research examines how economic status affects access to different levels of life support technologies, and therefore impacts on different experiences of death. The biomedicine-dominated health service has reached ever-larger parts of the world, but only a relative few can afford the whole range of technologies it offers. Clearly, biomedical technology entails inequalities in accessing the health sector (Lock and Nguyen 2010; Marsland and Prince 2012; Prince 2018; Shim 2010). To examine how the economy based on biotechnology manifests in Bangladesh, I must examine how the boundaries of life and death are constructed, redefined, and negotiated in the context of the marketised health care sector.

The anthropological and sociological scholarship regarding life support technologies engages with various predicaments related to decision making considering 'good death' and 'bad

death' (Geest 2004; Clark 2002; Lock and Nguyen 2010; Franklin and Lock 2003; Kaufman 2005). Mainly in the Western world, there are also stories of lengthy legal disputes with the state, who sometimes want to withdraw mechanical support, while families want to sustain it. The opposite scenario also presents the picture of dying patients' families want to withdraw life support, while states and doctors will not allow it on ethical and legal grounds (Gedge, Giacomini, and Cook 2007). In Bangladesh, life support technologies appear in a very different scenario. Instead of legal disputes regarding the withdrawal of life support, patients' families accuse doctors and hospitals of using life support unnecessarily and purposefully to raise medical bills (Transparency International Bangladesh (TIB) 2018; Ain o Salish Kendra (ASK) 2013; Barkat and Maksud 2003).

How and why life support withdrawal decisions are taken in hospitals and get institutionalised and legalised as a declaration and certification of death are another point of concern for the state as it requires and information documenting births and deaths. According to Foucault (2010), life and death are also a matter of measurement at the level of population in the context of a modern state. The modern state apparatus needs to know not only the number of its population but also when and how people live and die to assess the birth rate and mortality for the sake of the development agenda of a modern state. The modern state also wants to know about people's lifestyles, criminal and other activities, health, and illness for creating the demographic datasets necessary for disciplining the population to achieve its sovereign political goals. In Foucault's term, this situation is described as biopower, which links micro and macro scales: individuals as a member of a population also become a part of national policy (Foucault and Miller 2010). Considering the socio-political-economic context of Bangladeshi

society, this research explores how death and dying on life support and the withdrawal decision go beyond the boundary of family and hospital and interact with state apparatuses, and how they are negotiated in the emergent situation.

Bangladesh is comprised of various religious, ethnic, and socioeconomic groups. Born and raised in Bangladesh as a woman, I can say that kinship ties are omnipresent in social life, and family members are expected to come together in times of illness (Zaman 2013; Aziz 1979). Today, many private hospitals with advanced life support technologies have appeared in the major cities in Bangladesh. Access to these private hospitals is remarkably expensive and beyond the reach of most people. However, due to a lack of, or insufficient standards of healthcare services in public hospitals, nearly 70% of the population depends on these privatised hospitals (World Bank 2003, Rahman 2019). Private health care operates as a profit-making industry. Often, people sell everything they have or are trapped in debt in order to bear the cost of life-prolonging treatment, which they consider the best option for their close kin. A seemingly insoluble tension arises concerning life-prolonging technology and the dying patient's family members. On the one hand, there is a strong desire to keep a loved one alive with modern technology. On the other hand, financial and/or other constraints restrict the continuation of long-term treatment, which prompts deciding whether or not to end life.

The biomedical technologies are deeply intertwined with the political economy as scientific research into new treatment and medications is expensive, requires capital intensive investment, and is dominated by private corporations and the market. Thereby science, biomedicine, technology, and capital are omnipresent and becoming available to the population (Rose

2007b; Marsland and Prince 2012; Sunder Rajan 2006) through marketisation, another significant aspect arising from recent developments in life support technology. When technology travels to new settings, it creates economic markets and networks among people and organisations (Hardon and van Der Geest 2006; Tsing 2000; Petryna 2009). Therefore, the promotion and provision of life-prolonging technologies require creating international networks and markets, linking together people, places, resources, objects, and information. This project will examine how the marketisations of life-prolonging technologies affect death and dying in Bangladesh.

The innovation and advancement of biomedical technology have demonstrated that life and death can be changed and transformed (Franklin and Lock 2001; Kaufman 2005; Langdon 1998; Lemke 2011). In this light, I want to consider not only the way that medical authority has been extended over death but the ways in which life support technologies have transformed death and dying. In this thesis, therefore, I look at the biomedicalisation of death in contemporary Bangladesh (Clarke et al. 2003). I also examine what Clarke et al. (2003, 2010) call 'stratified biomedicalisation' by paying attention to economic inequalities and differential access to healthcare technologies and services. Through this research, I explore how family members manage the end-of-life decision regarding close kin who are on life support in hospitals. I will also explore the specific biomedical protocols governing the support of life and the determination of death. What is the impact of contemporary trends in biomedical practices in this field on decision-making and the definition of death? What are the elements that play significant roles in this decision-making? What is the political economy of this phenomenon in Bangladesh?

This study adds to existing knowledge by engaging with the biomedicalisation theory concerning death and dying in the global south, which few authors have done to date (Kaufman, Shim, and Russ 2004). It does so in the social and cultural context of Bangladesh, where little social scientific research has been done on biomedicine, death, and illness. Although there is some scholarship on the medicalisation of reproductive technologies (Islam and Sultana 2007) and organ transplantation (Moniruzzaman 2012) available in the context of Bangladesh, the ambivalence of life support technologies in Bangladesh is yet to be investigated. This study provides information on the impact of life support technologies on different people's lives in Bangladesh. It contributes to understandings the influences of hegemonic biomedical knowledge and ethnographic knowledge on life-prolonging health-seeking behaviour together with biotechnological facilities in Bangladesh.

Before moving to the structure of this study, I want to focus on some aspects of the Bangladeshi health system that constitutes the 'field' (A Gupta and Ferguson 1997) and context of the study.

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

To understand the development of Bangladesh's health system, it is important first to examine the political history of Bangladesh, which only became an independent country in 1971 after more than 200 years of British colonial rule and Pakistani post-colonial rule. From its

foundation in 1971, Bangladesh faced successive political, economic, and environmental crises.



Figure1 Map of Bangladesh showing major cities.

After the nine-month-long war of secession from Pakistan, Bangladesh experienced floods, famine⁸, and two political assassinations in the first ten years of its independence. A period

⁸ In 1974 the President, Sheikh Mujibur Rahman, made a business deal with Cuba, as a result of which, the United States cancelled food aid to Bangladesh for the sake of American foreign policy. Beside this external factor, internal mismanagement of food distribution, floods, and food-smuggling were the causes of the famine. A recently war-torn country was unprepared to manage food scarcity through the market, and as a result, rice was

of political instability ensued, with four different governments in the office between 1971-1990, followed by a military coup and an autocratic government. The volatility of politics in Bangladesh eventually impacted various aspects of social, economic, and political life, including the health sector (Rahman 2007, 2019).

Country description	Bangladesh
Continent	Asia
Population (in thousands) ¹	160 000
Gross national income per capita (\$)²	1 580
Adult literacy rate(%)¹	53.5
Life expectancy at birth (years)¹	65
Infant mortality rate (per 1000 live birth)¹	43
Under-5 mortality rate (per 1000 live birth)¹	54
Maternal mortality ratio (per 100,000 live birth)¹	340
Per capita total expenditure on health (PPP int. \$)¹	42
Government expenditure on health as percentage of total health expenditure¹	33.6
Government expenditure on health as percentage of total govt. expenditure¹	8.0
Hospital beds (per 10,000 population)¹	4
HRH (physicians, nurses and midwives) density (per 10,000 population)³	5.8
Density of physicians (per 10000 population)³	3.0
Density of nurses and midwives (per 10,000 population)³	2.8

PPP int. \$, international dollar purchasing power parity.

Source ¹WHO: Global Health Observatory

²World Bank: Data: 2017

Figure 2 Population health indicators for Bangladesh

first Government of independent Bangladesh wanted to establish a public health care system for the population. Sheikh Mujibur Rahman's 1972-1975 Government's commitment was to develop a public health care system according to the Constitution of Bangladesh that provided a right to healthcare and treatment [Articles 15(1) and 180 (GOB)].

priced out of the reach of most of the population. Hence, Bangladesh experienced a 9-month long (March 1974-December 1974) famine and the consequent health deterioration continued for another year.

In the first five-year plan of Rahman's Government, the vision was to improve the population's health by establishing at least one public hospital in every district and, where possible, mother-and-child care at every sub-district level. After his assassination, the military took control of Bangladesh and formed a government, with Major General Ziaur Rahman serving as President from 1975-1981. His Government encouraged the expansion of private health care through low-interest loans, and the private sector became an increasingly important component of how people accessed health care (Rahman 2007, 2019). In the second five-year plan, the Bangladeshi Government became a signatory to the Alma Ata treaty⁹ in 1978 (Rahman and Caulley 2006; Rahman 2019) and, during President General Hussain Muhammad Ershad's regime (1982-1990), the Government legally recognized private health care by adopting the Medical Practice and Private Clinics and Laboratory Ordinance of 1982. Successive governments, regardless of their different political ideologies, encouraged the building of private clinics and hospitals. The World Bank and other donor agencies also influenced governments to support the private health sector, mainly in those sectors of health services where the Government was unable to provide necessary services and support due to not having resources and skills (Rahman 2019). Nonetheless, Sheikh Hasina's Government (2007-present) now wants to take a combined approach, developing both private and public health care services(2020)¹⁰.

⁹ The declaration clearly stated that primary care was the cornerstone of a country's health system and that governments have a responsibility to citizens for providing effective and well-resourced primary healthcare in order to sustain an economically productive life.

¹⁰ Health Bulletin 2019 published by Directorate General of Health Services (DGHS, Bangladesh) which is under Government of the People's Republic of Bangladesh Ministry of Health and Family Welfare (MoHFW).

The 'Seventh Five-Year Plan Fiscal Year 2016-2020: Accelerating Growth, Empowering Citizens' commits to ensure that poor and marginalised people are able to access and utilize health services. Acknowledging the existing deficiencies in per capita health expenditure, the share of the national budget for health and quality of care, alongside high out-of-pocket expenditure (OOP), it proposed to reform health-financing to address equal access to health services for disadvantaged people.

In practice, despite their manifesto promises, governments have never succeeded in fully implementing their policies (BHW 2010). Even the promise of Universal Health Coverage (UHC) made by the Sheikh Hasina Government was said to be merely an 'election promise,' which was made just before the end of their last (2013-2018) ruling period. The Government has started UHC as a model in three Upazilla¹¹. At the time of writing, many shortcomings in the proposed UHC have been identified by various reports so that, even if the model succeeds, it will take time to get implemented across the country .

Moreover, initiatives and plans adopted by one Government are usually overturned by the next (Rahman, 2014). In opposing the UHC, the former health secretary in the previous administration said in a newspaper that UHC is nothing more than an 'empty promise,' as the previous Government had developed a community-based health care service to address rural needs and disadvantaged people. The former health secretary condemned the present Government for abandoning the project and starting a new one instead.

¹¹ Sub districts

Despite such problems at the policy level, numerous studies, including those by the World Bank, have shown that Bangladesh has achieved vast improvements in critical health indicators (life expectancy, child mortality, child health - shown in Figure 2) in the recent past (World Bank report 2013; Health Watch 2015). Along with the Government's initiatives, NGOs and private providers have also expanded their services over the past four decades. They have worked together on immunisation programmes to combat diarrhoea and provide family planning, amongst other things. Despite the improvement in indicators (Figure 2), the goal of a majority of people accessing publicly funded primary health care services has not been fully met, with most still paying 'out-of-pocket' for treatment (Health Watch 2015). The number of private clinics and hospitals has grown in the last four decades, with the most growth in the last two decades. According to the health ministry report 2019(2020)¹², the number of registered private hospitals and clinics has increased from 33 in 1985 to 5,321 in 2018. However, it is also likely that the exact figure of private hospitals and clinics is even greater as there are many unregistered clinics and hospitals which remain out of the Directorate General of Health Service's (DGHS) knowledge. Before discussing the rise of private clinics (as I am studying state ICUs along with private ICUs in this research), I will first describe the health care system in Bangladesh.

Provision of Health Care in Bangladesh

¹² Health Bulletin 2019 published by Directorate General Health Services, Bangladesh.

Health care services are mainly provided by the government, private hospitals and clinics, Non-Government Organisations(NGOs), and other local alternative medical systems¹³. A World Health Organisation (WHO) statistical report (2009) on health care services provided by the Bangladesh Government underlines their inadequacy and how this situation remains almost unchanged. According to the Health Bulletin of the Ministry of Family and Health Welfare 2019, the numbers of primary to tertiary level hospitals and health care services have increased, but, at the same time, the population also has increased over the years, so the existing per capita of health care has only slightly changed. Although primary health care such as vaccination, family planning, tuberculosis treatment, and maternal health care has reached remote villages, critical care remains out of reach for people who live outside of major cities. One hundred sixty-two million people are living in Bangladesh, and the level of Government-provided health care is unable to meet the health needs of most of this population. For example, the physician-patient ratio for every 1000 people is 0.356, and hospital bed ratio 0.6 for every 1000 people (see figure 3 below). Hence, people turn to private health care, even though they cannot afford high-cost private treatment.

According to a World Bank survey, 70% of the population depend on private hospitals or private health services in Bangladesh. However, most of the economically disadvantaged groups in the country generally go to Government hospitals for their treatment first (if not taking homoeopathic remedies, see fn. 13). However, they also need to access some services from

¹³ Such as homeopathy, Ayurveda, religious belief-centred health care [holy water, tabeez (an amulet or incantation), herbal medicine and the like].

private hospitals and diagnostic centres, as Government hospitals are often unable to provide various diagnostic tests, medicines, or other medical supplies.

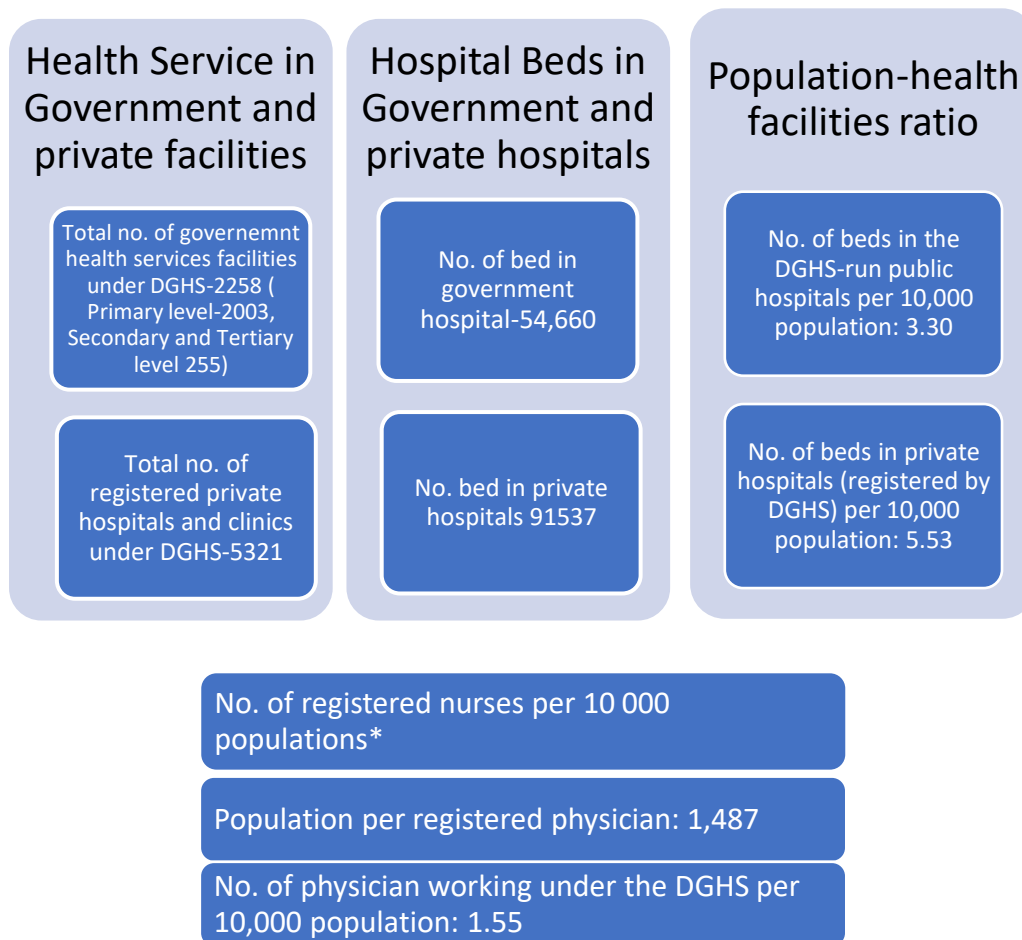


Figure 3 The government and private hospitals and staffing

Source: Health Bulletin 2019

*Health Bulletin 2016

In the first five years of this century, Bangladesh witnessed the development of privatised international chain hospitals along with other ‘modernised’ hospitals (Rahman 2019; Transparency International Bangladesh (TIB) 2018). In the beginning, this kind of hospital was limited to the capital city Dhaka but has started to spread even to small towns. Despite this, many people travel to Dhaka for advanced treatments that are not available locally. This is a symptom of developmental growth in a society that has grown to attend to the needs of a

specific class and a specific economic group. In a promotional video for an international chain hospital, the chair of the company says that they aim to avoid patients going abroad for treatment; to achieve this goal, they maintain the same high standards of quality found in foreign hospitals¹⁴. The chair's statement indicates who the main intended consumers of the hospital are the affluent group of middle-class Bangladeshis who could otherwise afford to travel abroad.

Another significant feature of the Bangladeshi health care system is the role of *Dalal*, who are brokers who aim to divert patients from government hospitals to private hospitals (Directorate General of Health Services 2015; Ain o Salish Kendra (ASK) 2013; BHW 2010). They collect patients for the private clinic, and in return, receive a commission from them. They often target those who come from outside Dhaka or major cities as they find it easy to draw them away from the Government hospitals by suggesting that they will not get prompt treatment there and that if they pay a little bit more, the patient can get better and more prompt treatment at a private hospital (BHW 2010; Barkat and Maksud 2003; Transparency International Bangladesh (TIB) 2018). Despite this, there are allegations of mismanagement in private hospitals. The lack of skilled, trained nurses, health-carers (Ward boy¹⁵, *Aya*¹⁶), inadequate numbers of permanent doctors, and the lack of essential medical equipment are major criticisms levelled at the private hospital, in addition to complaints about a profit-

¹⁴ <https://www.youtube.com/watch?v=Qzu4DXnUVGQ> last accessed 28.09.2019

¹⁵ The ward boy generally assists patients in and out of bed, bathe, dress, undress and otherwise assist with patients' hygiene needs helping them exercise, help maintain a clean, comfortable environment for patient, change linens and sheets.

¹⁶ *Aya* is female health carer who helps cleaning, changing, and carry out the order from nurses.

oriented approach, being more likely to prescribe unnecessary medicines and pathological tests, undertaking more caesarean deliveries and other surgery, and unnecessarily hospitalising people or extending their treatment at hospitals as such (Ain o Salish Kendra (ASK) 2013; Transparency International Bangladesh (TIB) 2018; Directorate General of Health Services 2015, 2018). This is not to say that there is no mismanagement in Government hospitals, for which there is ample evidence (Barkat and Maksud 2003).

The health system of Bangladesh exhibits several principal differences from health systems in the Global North, from where life support technologies and associated knowledge and practices have originated. The key characteristics of the Bangladeshi health system include lack of resources, skills, infrastructural capacities, health coverage, and dependency on the privatised health sector, and biomedical practices originating in a colonial context. While many of these features may appear similar to the health system of a First World country, Bangladesh, as a Third-World country, stands apart in terms of resource scarcity, level of poverty, and political and bureaucratic culture.

Research questions and structure of the thesis

Below are the research questions of this study that guided my fieldwork:

1. How do changing biomedical practices and increased technologisation create various types of death and its consequences?

2. How is the 'decision of taking and withdrawing life support' made? What are the major influences (a doctor's or family's decision, popular practice) on making the 'choice'?
3. How do families negotiate the complex demands of ethics and emotions in making end-of-life decisions for family members on life support?
4. How have medical institutions and practices arisen to deal with the problem of declaring a person dead on life support systems dead?
5. How are life-support treatments being commercialised in Bangladesh, and what are the moral and ethical implications for families?

I set out the thesis in three main parts comprising:

1. Introduction, theoretical discussion, and research methods.
2. Empirical chapters.
3. Discussion and conclusion

The first part, Chapters 1, 2 and 3, present my research context, the questions that guided my fieldwork, and the theoretical framework of the study (which formed the basis for the analysis of my empirical findings), and finally, the research methods by which I collected the empirical data for this study.

The second part is based on my empirical findings. This part consists of four chapters: 4,5,6, and 7. Chapter 4 is entitled 'The Waiting room: the world within the world,' where I will consider the waiting room as a hybrid medical-domestic space that emerges as occupied by relatives. This empirical chapter discusses the patient's relative's lives in the waiting room, while chapters 5 and chapter 6 are 'Biomedicalisation in action' parts I and II. Chapter 5 discusses the embodied relations of care, responsibility, and death and dying with life support

technologies. Chapter 6 discusses hope, inequality, and political economy in the processes of the biomedicalisation of death. Chapter 7 critically describes the concept of a 'Biomedical Techno Service Complex Inc.' in Bangladesh in the domain of life support technology. This chapter also discusses the governance of and legal and regulatory framework in the health sector and analyses media and research reports in the discussion of health governance.

The final part includes discussion chapter 8 with the concluding remarks of this thesis. In chapter 8, I further develop my analysis of the biomedicalisation of death, in which I position life support technologies as creating new hybridised socio-technical forms of hope, care, death, and dying.

Brief information about the patients and relatives mentioned in the thesis

1. Shamoly : Mother of Tareen- 12 years, F, Brain Tumor, Unconscious from July 15, 2015) Shamoly's husband is a migrant worker in the Middle East. They took loans and charity from friends and family for Tareen's treatment.

Samshed Maternal Uncle of Tareen.

2. Hosne Ara: Mother of Tuhin) Tuhin is a 17-year-old boy. He had Guillain Barre syndrome (GBS) and respiratory distress when he got admitted at UTH. His father is a headmaster of a high school in Feni. They sold their land property to cover the treatment costs. Furthermore, they are also financially supported by their friends and family.

3. Md. Harunur Rashid: Father of Rohan who is 19 years old. He was injured in a road traffic accident when he was with his friends on a motorbike. He is the eldest son in the family. He is unconscious from September 2015. He was shifted from Apollo Hospital. Doctors in Chittagong declined to accept him soon after his accident. Harunir Rashid is a third-grade government employee. He sold his land property and a shop for Rohan's treatment. Mr Rashid's colleagues and family are also helping him with the treatment cost. They are from Chittagong.

4. Nahid: Brother of Shimul who is 35 years old. Shimul was a lecturer in a government college when he was injured in a traffic accident in Char Fashion, Bhola. He was married and the father of 2 minor children aged 5 and 2. He was admitted to Alpine Hospital in Dhaka after being refused by Barishal Government Medical College Hospital. This family is economically solvent (Family property and business) and belong to a politically renowned family in Bhola. Shimul's grandfather is a former member of parliament.

Shuman: Brother in law of Shimul.

5. Shobuj: Son of Abdur Rahim. Abdur Rahim is 70 years old. He was injured in a road accident when he was on his bicycle in Rajbari. Abdur Rahim is a 4th class employee of a Government college. He expired on 16.11.2015. Despite the financial constrain, his relatives continued the treatment until the end.

6. Zahirul Islam: Father of Siam. Zahirul Islam is an accountant of a private company. Siam is an 11 years old boy. Siam was treated at a private hospital in Dhaka for GBS. He was shifted to UTH when his condition was deteriorating as he has asthma. Siam had a cardiac arrest while on life support. Despite economic constraints, they want to continue treatment till his last breath. Siam's family is getting support from family, friends, and his father's colleagues.

7. Ratna: Daughter of Faruk Miah. Faruk Miah is 72 years old. A man with respiratory distress and lungs problem. He was shifted from BIRDEM. Ratna's brother is working on a private farm, and her sister is a school teacher. Ratna is a housewife. They are unable to continue treatment for the financial crisis. Being conscious, Faruk Miah does not want to stay in the hospital as he is not comfortable living alone in the hospital. He never slept alone at home; he wants to go back to the village. However, relatives are not able to decide to take off Faruk Mia from the ventilator. Faruk Mia's children live in Dhaka, though he is from Comilla.

8. Faisal: Brother of Taufiq. Taufiq is a 15-year-old boy who had a brain injury in a road accident. He was hit by a bus when he was riding a bicycle with his friend. They are from Laxmipur. Taufiq's father is a migrant worker in the Middle East. They exhausted all their savings for the treatment. Taufiq was first taken to Dhaka medical Hospital after being refused at Shadar hospital at Laxmipur.

9. Mrs. Sharifunnesa: Wife of Shafayet Alam. Shafayet Alam is from a politically and financially established family in Chittagong. He was first taken to Alpine hospital by air ambulance from Chittagong. Again he was taken to Singapore by air ambulance. His appendicitis was busted. His family invested in a home setup which had all the equipment to supplement his post life support treatment.

10. Dr Monobendro Sen: Son of Shudhindra Sen. Shudhindra Sen was a famous singer in Chittagong. He was rushed to a private medical hospital in Chittagong, soon after had a haemorrhagic brain stroke. Mr Sen was in a coma for three days until his life support was removed with family consent. Being a doctor, Monobendro Sen understood that his father would not regain consciousness. Even though they had no financial constraints, they decided to withdraw Mr Sen's life support.

11. Abdul Alim: Brother of Shumi. Shumi was 25 years old when she died in a private hospital. She was pregnant and was infected by a hepatic disease. She was shifted from a five-star private hospital to another private hospital in Dhaka as her relatives thought five-star hospitals were not informing them of the actual condition of their sister and giving them false hope. They are economically very solvent.

12. Professor Fahad Ahamad: Son of Md. Akram Ahamad. Mr Ahmad was taken to a private hospital in Chittagong from Cox'sBazar after having a cardiac arrest. He was 78. Mr Ahamad's children are well established and financially solvent. Professor Fahad's wife is a doctor. They decide to withdraw life support as the doctors convinced them that Mr Akram Ahmad would not regain his consciousness. They thought the life support intervention would put their father in more pain rather than comforting him. Therefore, they decided on withdrawing life support to give him a 'peaceful' death.

13. Mohua Huq: (Wife of Khorshed Kamal, an eminent actor). Mr Kamal was suffering from a motor neuron disease while he had a cardiac arrest. He was taken to BIRDEM, 40 minutes after the cardiac arrest. Relatives decided to withdraw the life support after being confirmed Mr Kamal was brain dead by the standard medical protocol.

Shojol Kamal: Brother of Khorshed Kamal.

14. Anita Islam: Daughter in Law of Mr Noni Gopal, who was 80 years old. She gave the doctor consent to put his father in law on life support as her husband and brother in law were out of town.

15. Daisy Paul: Daughter of Andrew Gomez. Mr Gomez, who was 70 years old, had kidney complications before he was on life support. Daisy and her family decided to end the ineffective, invasive treatment as they did not want to see Mr Gomez in pain. They tried to give him a peaceful death. They decided after discussing with a doctor friend. They used their father's pension for the treatment, which was initially saved for his son's wedding.

16. Tarannum: Daughter of Nazli Khan, who was 68 years old. Nazli Khan had a cardiac arrest while she was travelling in Kolkata for her eye treatment. She went into a coma after having complicated heart surgery in a five-star international free-standing hospital in Kolkata. Mrs Nazli Khan had 18 months long life support treatment in Kolkata and Dhaka, which required a massive amount of money. Tarannum's both parents were university teachers. They used all of their savings and properties for the treatment cost. They received a large amount of financial support for Mrs Nazli's treatment, from a charity organised by university students. Relatives set up a room with necessary medical equipment for Mrs Nazli to continue her post-life support treatment since she was in an unconscious state.

17. Nasreen Noor: Daughter of Farida Huq who was 72 years. Farida Huq had liver Cirrhosis. Relatives decided not to take Mrs Huq to a private ICU as they knew it would linger Farida Huq's suffering.

Relatives treated her at a government hospital. They did not manage to get an ICU in the government hospital when Shahin's mother needed ICU.

CHAPTER TWO

Critical perspectives on Biomedicalisation of Death: From Global North to Global South

Introduction

To understand the complex relations between life support technologies, hope, and death-dying in the context of ICU in Bangladesh, it is necessary to characterise the scholarly context in which this study is situated. In this chapter, I draw on the work of social scientists in the Global North to theoretically examine the use of life support technologies in Bangladesh, a setting in the Global South that has received much less academic attention.

With regard to my exploration of how hope and technology interact with death and dying at the Bangladeshi ICU, I consider biomedicalisation one of the main theoretical concepts on which my study is based. To critically address this concept, I will first compare it to medicalisation, which closely deals with the taxonomic definition of social and biological phenomena by biomedical knowledge and reasoning to justify the significance of biomedicalisation theory and its point of departure in this study.

In the latter part of this chapter, I will further explore other key conceptual terminology of biopower, hope, and technology as these arise from the discussion on biomedicalisation.

These concepts help analyse my empirical data, with which I build up my arguments in this study.

Medicalisation to Biomedicalisation: A Conceptual History

Biomedicalisation, as a theoretical concept, reveals a broad historical shift that helps me to explain the transformation of death and dying brought by life support technologies in Bangladesh. However, I start with a discussion of medicalisation so that the distinctions between it and biomedicalisation can be set out. The distinction between two theoretical concepts is important to discuss as both have similarities yet differences. First, I discuss how authors such as Zola, Illich, Conrad, and Freidson developed ‘medicalisation’ as an analytical term in the 1960s and 1970s to trace changes in Western medicine practices. I engage with the discussion on medicalisation as an analytical concept as a way of explaining the expansion of modern medicine and its ever-increasing presence in social life. Then I proceed to the discussion of ‘biomedicalisation,’ which has grown out of the need to explain technoscientific extensions of medicalisation in an era of the increasing use of biomedical technologies. In this section, I engage with the challenges of medicalisation (Zola 1972; Illich 1975; Conrad 1975) and biomedicalisation (Clarke et al. 2003; Clarke 2010; Clarke 2014) and explore how authors use these analytical terms to identify and describe a specific set of phenomena in the arena of health, illness, and society. I also seek to outline the possibilities and shortcomings of these theories when extended to other cultural contexts.

The Emergence of Medicalisation

According to Rosich and Hankin (2010), in their celebration of 50 years of medical sociology, medicalisation has been one of the most important and enduring concepts that sociologists have contributed to understanding health and health care. As they observe, during this time, scholars writing on medicalisation have drawn attention to and helped to explain changes in the construction of health and illness and the role of medicine in society. Medical anthropologists, historians, STS scholars, and bioethicists also have taken up the concept of medicalisation to explain the complex relationship between health, illness, and medicine. Many scholars find the root of medicalisation as an analytical term in the radical health politics of the U.S. during the 1970s. It is not surprising that a powerful critique of mainstream medicine developed at the same time in the 1970s in the U.S. and Europe. At that time, a remarkably rapid transformation was underway in the public perception of doctors from 'life-saving scientists' to 'greedy monopolists' making heroes into villains and a doctor into a businessperson like any other (Stevens 1998XIV). However, as a historical process, medical anthropologist Margaret Lock argues that medicalisation emerged many hundreds of years before the 1970s. The early literate medical traditions of Europe and Asia, approximately between 250 BCE and 600 CE represent the first group of healers to treat professionally physical malfunctions and other health problems (Lock 2004). Birth, for example, had been attended previously only by women, until the 19th century in Europe and North America, when male attendants began to be trained to attend (only wealthy) women in the 'lying only' hospitals located in urban areas. She also mentions that by the end of the 19th century, the social consequences of medicalisation were visible. Mentally ill populations, 'morally unsound individuals,' and individuals living

in poverty were all subjected to forms of what Foucault termed 'Panopticism.'¹⁷ Lock thinks that technoscientific change is central to medicalisation. She also speaks of the 'hospitalisation' of citizens of all classes, from the mid-19th century onwards, which made it possible for medical professionals to exert power over patients in a way that had never happened before.

Bell and Figert (2015) trace the use of 'medicalisation' as an analytical term to the 1960s and the work of anti-psychiatrists such as Szasz (1960) and Laing (1961). These authors identified that Western medical professionals had the authority and power to reclassify 'normal' everyday feelings and behaviours and transform them into psychiatric illnesses (usually to the economic and professional benefit of psychiatrists and psychologists). Szasz's concern with medical power is also reflected in the work of Irving Zola (1972), who is one of the first medical sociologists to write about the institution of medicine as a form of social control in the western society, with specific reference to the United States.

Zola (1983) explores how medicine has become a major institution of social control, replacing more 'traditional' institutions of religion and law. He clearly defines medicalisation as a process whereby extended areas of everyday life have come under medical dominion, influence, and regulation. According to Zola, medicine has long had both *de jure* roles when doctors need to report about the contagious disease to higher authorities and *de facto* roles such as when medicine has focused on the disease of the rich and ignored the disease of the poor concerning institutions of social control. For example, since the 19th century, public health has been evident in states' programs regarding quarantines and vaccination. From the historical record, psychiatry has grown

¹⁷ The Panopticon is a mechanism of power devoted to surveillance (Foucault 1976).

to become the most dominant rehabilitative perspective in dealing with society's 'legal' deviants.

Like public health, psychiatry has also used the legal powers of the state to achieve its goal.

Zola (1983) identifies four elements of the medicalisation process:

1. The expansion of what in life is deemed relevant to the good practice of medicine.
2. The retention of absolute control over certain technical procedures.
3. The retention of near-absolute access to certain 'taboo' areas.
4. The expansion of what in medicine is deemed relevant to the good practice of life.

Zola argues that by labelling human behaviour as 'healthy' and 'ill,' physicians are 'medicalising' much of daily activities. Zola recognises that this process can be viewed as a way in which specific social 'problems' are potentially destigmatised or at least decriminalised. Conditions such as leprosy began to fall under medical jurisdiction and scientific scrutiny and to be established as objective and therapeutic categories as opposed to the consequence of God's judgment on individual sin.

Similarly, Peter Conrad (1992) an American medical sociologist, argues many diseases like ADHD (Attention Deficit Hyper Disorder), anorexia, CFS (Chronic Fatigue Syndrome), PTSD (Post Traumatic Stress Disorder), panic disorder, SIDS (Sudden Infant Death Syndrome), and PMS (Pre-menstrual Syndrome) were previously non-existent, and even diseases like obesity and alcoholism were not considered as diseases even by the doctors. He thinks that medical professionals identifying and naming many such problems like illness or disorders are a development of the last thirty years. This is the context in which he discusses medicalisation, whose growth he sees as the most powerful transformation of the last fifty years of the 20th century in the West.

Conrad (1992) has continued to update medicalisation theory in its application to pharmaceutical and technoscientific changes that have occurred in medical sciences. He describes medicalisation in his early writings as a process by which non-medical problems can be defined and treated as medical problems. Through to the present, he upholds this primary definition of medicalisation; as a process through which problems become defined in medical terms, in languages understood through a medical framework, and are treated with medical interventions (Conrad 2008). Defining a problem as a medical problem by medical professionals is central to the process, no matter how the problem was previously conceived. Conrad says that through medicalisation, behaviours may achieve medical rather than normative meanings, transforming them from 'badness' to 'sickness.' He identifies several characteristics of medicalisation which help us to conceptualise medicalisation from a critical perspective. He says that there are different 'levels' of medicalisation.

On the one hand, we see that conditions and processes such as childbirth, severe mental illness, and death have become fully medicalised in society. On the other hand, opiate addiction or the menopause have become partially medicalised, while sexual addiction and spouse abuse are minimally medicalised. In his later work (2007), he discusses the 'engines' of medicalisation in the past and now and how these have changed. Furthermore, Conrad argues that by expanding medical jurisdiction, medicalisation increases the amount of medical social control. He also contends that greater social control comes from having the authority to define specific behaviours, persons, and things.

Conrad also points to the *bidirectional* nature of medicalisation, and therefore that 'demedicalisation' of a specific phenomenon can also occur. For example, conditions such as homosexuality were once considered as diseases and treated under medical jurisdiction, but they are no longer seen as such. He mentions several factors as setting the context in which medicalisation occurs. These include diminishing the social power of/belief in religion, faith in science, rationality, progress; and the increased prestige and power of medical professionals. He considers medicalisation as a form of collective action. Although historically, medical professionals were central to medicalisation, more recently, he sees not only doctors but also patients and laypeople as being active collaborators in the medicalisation process. He (2007) broadly states that the medicalisation of life problems has now become part of our professional, consumer, and market culture. Thus, he does not suggest that the expanding growth of medicalised categories solely depends on the result of colonisation by medical professionals. Instead, decreasing public tolerance for mild symptoms also accelerates medicalisation processes (Conrad 2007: 6). Besides, corporate entities such as the pharmaceutical industry, and the potential for people to be translated into 'patients' as consumers of their products, have begun to play more significant roles in medicalisation in recent times.

Ivan Illich, an Austrian philosopher and a catholic priest, is another theorist concerned with medicalisation. However, he condemns more the whole of industrial society explicitly as transforming citizens into consumers, and he thus expands the concept of medicalisation into the context of a critical analysis of industrial and consumer society. Illich's critical analysis of industrial and consumer society related to medicalisation provides me insights to understand the biomedicine practice that impacts the cultural way of understanding and managing health, disease, and body.

For Illich(1975), medicalisation is part of a more comprehensive critique of modern medicine in the West. In his writing, medicalisation is more than labelling behaviours as medical problems, but how medicine itself contributes to disease and disorder and has marginalised self-care. He argues that modern medicine has turned people into consumers, which, in a way, destroys their health. His opening statement about the medical establishment becoming a major threat to health (Illich 1995) reveals this critique. Illich does not suggest any specific forms of health care or propose any new medical philosophy. He also does not deal with any single medical technique doctrine or organisation. Instead, he explains prevailing ailments, helplessness, and injustice as the 'side effects of strategies of progress' in the modern period. Transformations brought by medical intervention also come into his analysis. Illich says that "once society is so organized that medicine can transform people into patients because they are unborn, newborn, menopausal, or at some other age of risk, the population inevitably loses some of its autonomy to its healers"(Illich 1975: 147).

In this way, Illich explains the medicalisation of life and the 'Medical Nemesis.' He says that the Medical Nemesis cannot be operationally verified. Rather, he wants to take it as a theoretical element in a broader theory to explain the anomalies of health care systems in contemporary society. According to him, fundamental to health is the ability to cope with pain, sickness, and death. However, modern medicine makes the whole population survive on inhumanly low levels of personal health.

Illich finds professional and physician-based health care systems problematic for three reasons; these are:

1. This system produces clinical damage, which outweighs its potential benefit what he terms 'clinical iatrogenesis.' In this category, he argues that clinical conditions, physicians, and hospitals are pathogens or 'sickening agents.' He also includes the attempts that doctors take to protect themselves from 'malpractice risks' to avoid litigation and prosecutions;
2. It obscures the political conditions which render society unhealthy, which he termed 'social iatrogenesis.' Social iatrogenesis is at work when health care is turned into a standardized item; when all suffering is hospitalized, and homes become inhospitable to birth, sickness and death;
3. it tends to expropriate the power of the individual to heal her/himself, and to shape his or her environment, which he terms 'structural iatrogenesis'. He argues here about the structurally health-denying effect of health professions, including the ultimate backlash of medical progress. He says that this backlash is a result of what medical professionals do with human weakness and vulnerability.

According to Illich, the new devices, approaches, and organisational arrangements, which are meant to be the remedies of clinical and social iatrogenesis, become pathogens of the new epidemic. In this regard, he explains why he has chosen the term "Nemesis" in the title of his concept of a self-reinforcing, negative institutional feedback inspired by Greek mythology. He argues that medical *nemesis* stands as resistance to medical care. Medical Nemesis can only be overcome by recovering a form of self-care, which he understands to consist of personal activities shaped and conditioned by the culture in which the individual grows up; the patterns of work and leisure, the

production of food and drink, family relations and politics. For Illich (1975), modern medicine has failed to incorporate self-care.

Illich identifies several categories of damage caused by specific forms of medicalisation. He argues that 'in each of these areas of over-medicalisation, professional presumption and public credulity have reached health-denying level' (1975). During the 70s, the triumph over tropical diseases took place. However, the realities of hunger and environmental degradations in developing countries were marginalised, and the belief in medicine's unlimited progress remained intact. Doctors were considered as cultural heroes. By 1975, Illich explains, the factors that affect health conditions became more evident to the general public, yet , people believed that levels of health would be improved if more money could be spent on it.

Illich's argument over 'killing pain' is fascinating. Here, his emphasis is on the *cultural* regulation of pain. He thinks that every culture has its way of dealing with pain. More precisely, culture provides a model for suffering and shapes the experience of suffering, such as what should be stated and what should be shared. However, medical civilization replaces the experiences of pain. Now, the pain has become a technical issue, resolved by the question of how to kill the pain. What was previously dealt with through cultural norms has become transformed by medical interventions. Thus, the suffering of pain has become an expression of consumer demand for medical attention. Considering pain as unnecessary eventually leads to a process of eliminating it, even at the cost of health. However, he thinks that it results in a new form of suffering, which has lost its referential character. He also thinks that only the recovery of the will and ability to suffer can restore health.

Illich suggests that medical interventions have not brought any changes in total mortality rates, somewhat they have shifted from one segment to another. In the last 100 years, a dramatic change has occurred, like diseases. He says the mortality rates of epidemics or contagious diseases have reduced during this time because of improved lifestyles, nutritious food, growing body resistance, shelter, and other factors that have lowered mortality rates. On the other hand, after the decline of those diseases, a set of new diseases such as coronary heart disease, hypertension, cancer, arthritis, diabetes, and mental disorders have taken their place as modern epidemics.

From the beginning of its emergence until the early 1990s, medicalisation theorists' general tendency was to define it in terms of transforming social, moral, and legal problems into medical terms (Bell & Figert 2015). According to Bell and Figert (2015), in the 1980s, this tendency changed, and U.S scholarship started to focus on the construction of diagnostic categories and professional processes and the social control of behaviours (Conrad 1992). Another critical turn was taken by medicalisation scholarship during the early period in the '80s when researchers started to identify patients as active agents. Medicalisation is seen no longer merely as a process *done* to people because the patient's agency (advocating or refusing) comes onto the scene for analysis.

Feminist scholars have contributed significantly to the study of medicalisation, focusing on women's bodies (Bell 1987; Catherine 1983) and documented cases of the gendered nature of medicalisation. Throughout the 1960s to 1970s, the Women's Health Movement emerged primarily from a concern with improving women's health care and focusing on women's reproductive rights during the 1980s. Women's self-help groups were formed in the late 1960s and early 1970s, generally out of dissatisfaction with health care for women. During this period, women

started to give birth with the self-help groups, but without medical intervention: a significant achievement by the Women's Health Movement. Women's Health Movements (Boston Women's Health Book Collective 1973, cited in Bell & Figert 2015) also emphasised the unique ways in which women's bodies were more susceptible to medicalisation through processes such as childbirth, PMS, and menopause (Catherine 1983; Bell 1987; Bell and Figert 2012).

It is said that the contemporary medicalisation era started with the growth of the professionalisation of physicians, as a consequence of the Enlightenment ideas of rational science (Cacchioni and Tiefer 2012). In their discussion of the medicalisation of sex, Cacchoioni and Tiefer explain medicalisation as an evolving conceptual framework that charts the increasing power of medical concepts, institutions, and individual figures of authority. However, the term medicalisation can be seen as standing for all the negatives aspects of the influence of modern medicine in life and society (Clark 2002). By the end of the 1990s, a group of sociologists found 'medicalisation' insufficient to capture the complex and multidirectional processes of a new era in medicine: that of late modernity and therefore developed the concept of *biomedicalization* (Clarke et al., 2003, 2010). In the following section, I turn to the emergence of biomedicalisation, how it differs from medicalisation, and why I find it an important theoretical concept to address the changes brought by life support technologies in Bangladesh.

The emergence of Biomedicalisation as a theoretical lens

Clarke and colleagues (2003, 2010) argue that medicalisation, as defined in the 1980s, is insufficient to understand the situation today. They say that, by the late 1990s, many sociologists found the term medicalisation inadequate to explain health, illness, risk, and identity framed through an intensifying and increasingly complex technoscientific biomedicine. These complexities involving technoscientific innovations have been developing since World War II.

Adding the prefix 'bio' before medicalisation denotes another layer of meaning; it signals the increasing importance to the medicine of biomedicine or biotechnology, in which technoscientific innovations such as molecular biology, biotechnologies, genomisation, and transplant medicine transform both human and non-humans. It also signals the centrality of Foucauldian questions of bio-power and bio-politics (e.g., Rose 2007). In *Biomedicalization: Technoscience, health, and illness in the U.S.* (2010), Clarke and colleagues define biomedicalisation as a set of situated processes within a dynamic and expanding politico-economic and socio-cultural biomedical sector. They elaborately present the historical transformations of practices of biomedicine and its organisations, led by technoscientific innovations in the U.S. since the late 19th century. Their aim in identifying these transformations is to show how biomedicalisation occurred in U.S. society in different periods. Clinical innovations are placed at the heart of biomedicalisation, but the theory also encompasses the emergent social arrangements that allow their implementation.

Clarke and colleagues most importantly specify that biomedicalisation is co-constituted and manifests through five central and overlapping processes. These are:

1. major political-economic shifts;
2. a new focus on health and risk and surveillance biomedicine;
3. the technoscientisation of biomedicine;
4. the transformation of biomedical knowledge; and
5. the transformation of bodies and identities.

They point out that conventional medicalisation practices emphasise exercising control over medical phenomena: disease, illnesses, and injuries. In contrast, biomedicalisation practices emphasise transformations of bodies by technoscientific means, not only for treatment but also for enhancement. Clarke and colleagues (2003, 2010) characterise biomedicalisation by a strong orientation toward the future. They argue that it speaks to ‘the public’s further scientisation’ driven by the fear of biology getting out of human control. They also suggest that biomedicalisation theory appropriates and transforms the concept of medicalisation.

Through biomedicalisation, technoscientific identities have been created, which are only knowable through the application of technoscience such as DNA testing. Such technoscientific identities may be taken up individually. However, they often branch out through families, which also leads to the creation of *biosocialities* collective identities based on biomedical phenomena in patients’ groups. Clarke et al. (2003, 2010) also present as an example the case of ‘biopsychiatry,’ where exhortations to, for example, ‘go online and take this short assessment test, to see if you suffer from X condition’ (p.38) illustrates the individualising tendencies of biomedicalisation in neoliberal times.

Crucially, Clarke et al. (2010) state that their account of biomedicalisation is neither inherently nor solely a critique of medicalisation. Like many others, they also perceive biomedicalisation as a 'miracle of modern medicine,' which has triumphed over pain and suffering and improves life in a significant way. However, for them, assessing biomedicalisation is complicated and a matter of uncertainty since they also observe the increasing questioning of the value and appropriateness of biomedicalisation by patients or consumers, and also among the clinical providers and producers of technoscientific interventions. Even the new technoscientific alternatives also produce anxiety, including around end-of-life care.

Clarke et al. (2010) identify the rise of medical tourism as a transnational development of biomedicalisation, a phenomenon relevant to this study. By medical tourism, they mean the seeking of highly scientific biomedicine in places where it was not previously available. This point is discussed throughout the thesis to comprehend how life support technologies have been developed, practised, and marketised in Bangladesh by those biomedical technologies which are imported from other countries. This discussion highlights the importance of context and that the movement of technologies from Global North to Global South is neither straightforward nor unproblematic.

Clarke et al. (2003, 2010) propose biomedicalisation as a historical and local concept, and thus its specificities vary across time and locations and need to be explored empirically. Therefore, I address the research gap identified by Clarke et al. that is gathering empirical data to understand the specificities of biomedicalization in the Bangladeshi context. Whether, when, and how biomedicalisation manifests depends on the historical relations of the institutional development of scientific medicine and medicalisation, which vary tremendously (Clarke et al.,

2010). With relation to the argument of historical relation to the institutional development of scientific medicine and medicalisation, I find it important to examine life support technologies in the Global South: specifically how their introduction impacts variably on death, dying, and life-prolonging treatment, institutional development in Bangladesh compared to the Global North, and how the practice of life support technologies enforces institutional change. In this study, biomedicalisation theory as an analytical term is used to identify the biomedicalisation process and associated institutional development in the context of life support technologies.

Biomedicalisation theorists emphasise discussing the transformation caused by the biomedical intervention. They want to theorise the changes to understand their meaning, material forms, and practices and demonstrate the changes as co-constitutive of the transformation process (Clarke et al., 2010: 71). Among the five interactive processes stated earlier, one is technoscientisation. In the context of the U.S. health system, Clarke and colleagues (2010) said that the social transformation of American medicine had been brought about by medicalisation in the U.S. Technoscientific advancement reached such a level around 1985 that the constitution and organisation of contemporary biomedicine practice were transformed. According to Clarke, the drastic transformation of the biomedical niche in this second phase caused biomedicalisation in the U.S. health context with technoscientisation at its core.

Due to technoscientisation, the meaning of life changes over time and according to circumstances. The advancement and innovation of science and technology gradually change the organisation of biomedicine, such as biomedical interventions, knowledge productions, and its objectives, but also instantaneously produce a new hybrid social form which is often hinged on computerisation, information technologies, and organisational development

(Clarke et al., 2010: 65). The technoscientisation of biomedical practices, which is contingent on sciences and technologies (Clarke 2010), occurred mainly in two ways in the U.S.: 1. treatment intervention for biomedical practice; and 2. by enhancement. Biomedicalisation theory, as a critical lens and analytical tool, helps to explore the technoscientific changes brought by biomedicine. Concerning the way biomedicalisation occurred in the U.S. by technoscientisation of biomedical intervention, this study identifies how technoscientisation has been taking place in a different geographical location with a limited resource.; and also identify the consequences of technoscientisation within the limited resourced health care service in Bangladesh.

Biomedicalisation as a theoretical framework in the Global South context

It can be argued that the concept of medicalisation is not fit for the challenge of discussing the transformation brought about by biomedical technology. Kleinman (2012) argues that medicalisation is no longer an exciting or useful concept because it applies to a process in which conditions move from one category (e.g., badness) to another (e.g., sickness). In contrast, Conrad, who still advocates for the use of medicalisation, argues that 'some critics often conflate medicalisation with over-medicalisation and use the term almost as an epithet' (2015: viii). He also says that medicalisation has produced some positive effects, such as recognising epilepsy as a disease, not a curse.

Conrad (2015) considers pharmaceuticalisation, biomedicalisation, and geneticisation to be new conceptual frames produced by medicalisation studies. According to him, these tools all

relate to medicalisation and expand the study of medically related concepts in new and different ways. Conrad argues against the need for a new concept, saying that, “*medicalization still does not occur without social actors doing something to make an entity medical, but the engines that are driving medicalisation have changed so that we need to refocus our sociological eyes*” (Conrad, 2015: 9). The question arises whether simply identifying shifting engines of medicalisation is an adequate response to an effort to understand and describe the interplay of science, medicine, and technology in society, specifically in the context of life support technologies in Bangladesh. Instead, should we look for another concept altogether, such as ‘biomedicalisation’ or something else? Shall we advance with a new set of questions with newer terms and analysis or remain with existing conceptual tools?

The authors of *Reimagining (Bio) Medicalization, Pharmaceuticalization, and Genetics* (Bell and Figert 2015) offer the view that medicalisation as a concept is not sufficient to understand the globalising world of the 21st century, precisely because it is rooted in modernity and categorical thinking. Since the 2000s, they say that the evolution of the fields of biomedicine, pharmaceuticals, and genetics have provided evidence of the need to understand how changes in medicalisation occur. Bell and Figert (2012) identify the intersections of biomedicalisation-pharmaceuticalisation and public health with ethnographic examples from Chile. Their study shows that by the year 2000, anti-depressants' consumption rates had increased by 470% in Chile. They say that the reasons behind the high rates of anti-depressant prescriptions are not merely a consequence of the medicalisation of mental illness but also the neoliberal policies of using pharmaceutical treatments to control both patents and economic costs to the state. Bell and Figert (2012) explain that the three processes which appear to be the most relevant additions to the concept of medicalisation are: biomedicalisation,

pharmaceuticalisation, and geneticisation. These three ‘-isations’ have been added as new concepts by Bell and Figert and bring these different processes into focus.

According to Rose (2007a), “medicalisation, which implies the extension of medical authority beyond a legitimate boundary, is not much help in understanding how, why, or with what consequences these mutations have occurred”(2007a, : 701). He suggests that medicalisation might be the starting point for analysis to understand the assemblages of life (2007): how medicine shapes our lives, makes the relations between us, establish ethical regimes, and so on.

In a similar vein, Lock (2004) suggests that medicalisation is an untimely word to explore the recent phenomena of medical niches. Concerning her cross-cultural research on menopause, she suggests that local biologies and cultures contribute to making parts of the life cycle problematic. She finds that the everyday bodily experiences of middle-class North Americans at menopause are significantly different from those of some women in other parts of the world (Lock 1993). She also disagrees with an account of medicalisation as enforced surveillance. She puts forward as an argument that the medications for HIV/AIDS are not universally available, which she calls a social injustice. Again, not all women decide on elective abortion, even when their foetus is diagnosed with a genetic ‘flaw’. Therefore, she proposes that,

an investigation of the forms taken by political economies, technological complexes, and the values embedded in biomedical discourse and practice and in popular knowledge about the body, health, and illness that situate various states and conditions as residing within the purview of medicine better indicates the complexity at work. (Lock 2004: 126)

Numerous scholars seek to understand the dynamics of medicine in our lives in a rather different way (Rose 2007b, :701; Kaufman 2005; Martin 1998; Rapp 1999; Clarke 2010). Gibbons et al. (2010) work on comparative perspectives on public health, the state, and the partial reproduction of neoliberal subjects. Their cross-cultural ethnographic research in Cuba, Greece, and Germany looks into the relationship between new genetics and identity. Using deconstructive and feminist analyses, they show through an ethnographic account how normative neoliberal patient subjects are only 'partially reproduced' in situated contexts, which are neither stable nor homogeneous. They also reveal how the culturally embedded values of health and caring, public health ideologies, and political rationalities all come to matter in the establishment of neoliberal discourse. As such, in the context of Cuba, the researchers found that women identify risk for breast cancer associated with genetic and dietary factors. Whereas Cuban women identify the dietary factors linked to a larger economy outside the mere individual buying capacity. On the other hand, Gibbon (2007), in another study in the U.K., found that women think heredity and individual lifestyle are the main reasons for breast cancer.

Similarly, David Sudnow (1967b) found in his ethnographic work on dead on arrival (DOA) patients that, at two hospitals (though both hospitals are similar in terms of services provided, one for affluent people and another for non-affluent people), patients suspected as DOA were treated differently. Sudnow said that DOA is not homogenous concerning the actual physiological condition of the patient; there was a strong relationship between the age, social background, and the perceived moral character of the patient for attempting the restorative procedures. Sudnow found that the stimulating attempt was not performed for a 'homeless

patient who arrived with the overdrunk condition, whereas several attempts were performed for an affluent patient who had fewer life signs on hospital arrival time.

These theoretical insights regarding cultural and social situatedness enacted in biomedical technologies help identify the complexities of the transfer of life support technologies from Global North to Global South. This also suggests that the way biomedicalisation occurs in the global West will not necessarily occur in the same way in Bangladesh. The forces of biomedicalisation are advanced, contested, mediated, and ignored in specific contexts and situations, for example, due to limited resources and local cultures of practice; hence 'users' of technologies make their negotiations within institutions act according to the situation.

Considering the debates over the usefulness of these two terms, 'medicalisation' and 'biomedicalisation,' it can be said that they have specific utility in explaining different processes in different eras that demanded new conceptual tools. However, we need to understand not only how medicine and knowledge change and penetrate our lives but also how they connect with the broader economy and social institutions. The main challenge for social scientists is to reveal how a new kind of medical knowledge (in the form of technology, health behaviour, and treatments) emerges in a specific social context. By exploring how a medical tool is legitimised in public perceptions to become acceptable and how the hope and expectation for life support treatment options develop among the public, this study also addresses the dilemma around the use of life support technologies. It explores the possibilities offered by these technologies. In the empirical chapters of the thesis, I use analytical tools based on the theoretical concepts discussed above. This study thus uses the concept of biomedicalisation with a particular focus on the driving forces that derive from the particular local context. In this study, I

show how the biomedicalisation processes mentioned by Clarke and colleagues occurred differently in Bangladesh compared to the U.S. and how the co-constituents of the biomedical transformation manifest in practice.

Key Concepts

Biopower and biopolitics

The 'bio' in biomedicalisation importantly signals its relatedness to biopolitics and biopower as these two theoretical concepts provide critical analysis in the biomedicalisation theory, which explains the relationship between the subjection of the body and the mechanism of power in the society at large. Biopower is a means of managing life and governing populations, while biopolitics is a new technology of power that emerged from the modernisation and industrialisation of Western society during the 18th and 19th centuries that replaced the form of power exercised by the sovereigns in the mediaeval time (Foucault 1976). Biopolitics is a variation of biopower that is used to control and subjugates and continues surveillance over the individual body as a part of the whole society. The modern state controls the population through biopolitical surveillance for the sake of development of the population, where the number of births, mortality rate, patterns of disease, vaccination, lifestyle, literacy, as such is needed. Hence, life becomes politics. According to Foucault (1979), power is not always an oppressive force exercised by the state, but generative and productive energy emerging from all social processes. The terms are associated with Foucault, and he argues that in modern societies, power is situated and exercised at the level of life itself; that is, at the level of our biological existence. Foucault's position on power and genealogy of knowledge

provides further insight into understanding biopower and biopolitics, which helped me conceptualise biomedicalisation in action empirically. Foucault (1975) says that through understanding the 'genealogy' of medical knowledge, we see how medical knowledge categorises and constructs a lens that reconfigures 'facts,' which eventually become normalised scientific knowledge and language elements. Foucault sees science as a 'truth game' by which humans develop knowledge about themselves''(1988), create new subjectivities, transform concepts regarding 'the normal' and 'the pathological,' and create strategies and procedures for governing the beginning and end of life. Foucault explores the development of new technologies and genealogies of power through the examples of mental institutions, prisons, hospitals, and processes of self-making (Foucault 1988). I used the Foucauldian notions of biopower and biopolitics in chapters 5 and 6 to analyse the way of understanding dying patients' physical condition through scientific facts and analyse the marketisation of health care service, which has a strong relationship with hope and modernised biomedical technologies.

Hope and Technology

As stated earlier, the main aim of this study to understand how life support technologies transform death and dying. I am concerned with the question posed by Clarke and colleagues, that the technologised biomedical interventions not only intrude on our body but also how it transforms the way we perceive the body, life, and death. I draw on and develop further theorising around medical technology, society, hope, and anticipation in undertaking the work. Following Faulkner (2009), it is worth noting that, in the neoliberal global context, the penetration of medical technology in society and its approval and acceptance is a process

influenced not only by the success and failure of medical practices associated with the technology but also the prevailing health system and health service market strategy which I specifically discuss in the chapters 5 and 6.

Further focusing on the context of life support treatment, this study attempts to understand how the process of penetration and acceptance works and how the different actors involved in this process interact with each other. Can technology alone be so influential in making a change in death and dying? How does society interact with biomedical technology? Scholars from various fields have shown interest in the importance of the societal relation with technology at large. Bijker and Law (1992) discussed how social elements are embedded in technology; that is, how technology is socially shaped. For them, there is no such thing as 'pure technology,' but somewhat technology mirrors our society. Hence, they say, 'we have the technology that we deserve.' Bruno Latour (1994) suggests that science and technology come together dramatically, explicitly creating situations that affect humans and non-humans. Both have brought non-humans (technology and associated knowledge) into the human world. This seems to suggest that, by introducing the non-human into the human world (which I define as society, culture, economy, and politics), science and technology create, change, and expand the social organisation and incorporate human connotations and organisation into the non-human world to create new arrangements of forces (Latour, 1994). Hope and anticipation are interdependently tied with the technology, significantly when it facilitates the process of prolonging life or prolonging death.

'Hope' carries utopian promise; it offers possibilities of a 'not yet,' a 'to come,' and an imagining of a life otherwise (Ehlers and Kruper, 2014). Hope is that imagined future, living in the

heart of the present: the anticipation of a better condition in the future than at present. The archaic meaning of hope is 'a feeling of trust'. In the Bangla language, *asha* (hope) and *protyasha* (expectation) are very close in their meaning, although *protyasha* is a more profound and strong expression of hope. Both words express the meaning of prospect, dependence, waiting, possibility, and desire. In the context of life support technologies, all the meanings of *asha* and *protyasha* describe the patient's family's world of thoughts. Similarly, Adams and colleagues (2009) define anticipation as, [...] the palpable sense that things could be (all) right if we leverage new spaces of opportunity, reconfiguring 'the possible' (2009: 246) that reflects the relative's motive of choosing an advanced treatment option.

While hope and anticipation are to be embedded in the technologies, in this study, I explore how they often exceed the capacity of technology, resulting in medical futility. I also explore how relatives decide to withhold and withdraw life support in a complicated situation between life and death. In doing so, I seek to make explicit links between the marketised health care system and hope-anticipation, which often ends in an unwanted and complex situation. These links are discussed with regards to how hope and technology work together in life support treatment to conceptualise biomedicalisation, and I argue that the process has a localised character.

Conclusion

Concerning the objectives of this study, the concept of biomedicalisation is more relevant than that of medicalisation. The medicalisation of death occurred after describing and

pronouncing death by medical jurisdiction. However, life support technologies follow specific protocols of treatment procedures involving withdrawal and withholding decisions. More often, this results in a new technoscientific identity, such as the in-between stages of life and death (as described in chapter 1) that require further theoretical clarification to identify the complicated relationship between biomedical technologies and associated knowledge enacted in the practice of life support treatment in Bangladesh. In this chapter, I discussed medicalisation, as a historical shift in the history of medicine, body, and society, which tends to categorise human behaviour or conditions with medical logic that were not previously thought to be included under the medical jurisdiction. In other words, medicalisation brings some 'conditions' under the medical gaze, which were not considered as medical conditions before. It can be said that medicalisation is a deviation from social to medical. However, I consider biomedicalisation as another level of medicalisation that focuses on body, health, disease, and condition at a more molecular, genetic level with which I analysed my empirical findings in this study. This transformation of biomedicine has occurred in the recent era with the development of digitalisation, computerisation, and technoscientific enhancement. As a result, body and health are not only to be described under medical jurisdiction but are to be cured, as well as enhanced, predicted, and monitored, with highly technologised biomedical interventions. The outcome of the transformation is a hybrid technoscientific social identity, which also requires a transformation in the health and medicine-related organisations to integrate biomedical technologies and interventions into the health care services. In light of this theoretical projection, I presented my analysis in chapter 5 and 6 to comprehend how the biomedicalisation of death has taken shape in Bangladesh. Chapter 7 particularly focused on the institutional response, which grew from the increased intervention of life support technologies in Bangladesh.

In this chapter, along with biomedicalization theorists, I discussed various other thinkers who have addressed the local context where the ‘-isation’ process occurs. This body of work suggests that, regardless of the origin of biomedical innovation in the neoliberal era, the local situation contributes to shaping the outcome of medical intervention and practice. I am particularly interested in unveiling this theoretical proposition localise to Bangladesh in this study.

CHAPTER 3

Research Methods

We are not looking for a thing; we are seeking to understand processes by which things, persons, concepts, and events become invested with meaning.

(Martin 1998: 36)

Introduction

Pointing to someone's green dress, Tareen's mother Shamoly was trying to describe me the particular colour dress Tareen wanted to buy the day she fell and never recovered consciousness. Shamoly was unsatisfied with the colour she was pointing at, "No, this is not the exact green she wanted; it was in between the dark green and leafy green, it is a very nice and bright green colour." For a while, I was also trying to imagine the exact shade Tareen wanted for her for Eid¹⁸ day. In the end, Tareen bought a purple dress, although she did not have the chance to wear it for Eid, as by then, she was in an ICU in Dhaka. Shamoly described the day to me with every little detail, without waiting for me to ask questions. She related details about going for Eid shopping, frustration about not getting the right colour dress, in the end, Tareen's fall at the shopping centre, and then the journey from Noakhali hospital to ICU at

¹⁸ Eid al-Fitr also called the "Festival of Breaking the Fast", is a religious holiday celebrated by Muslims worldwide that marks the end of Ramadan, the holy month of Muslim.

University Teaching Hospital (UTH)¹⁹ in Dhaka. I was able not only to hear about the places and the events that happened at the particular time in her life but also to feel her affection, hope, and desperation for her daughter's recovery. My reflection on this story is not merely an emotional stage of a mother, but it is a representation of the health care system in Bangladesh, where the mother had experienced this.

Similarly, Shamoly tells me about Siam, an 11-year-old boy who has been taken to UTH's ICU for GBS²⁰ treatment. Later I talked to Siam's father, Zahirul Islam, who described how every morning he used to help Siam to prepare for school, making his breakfast and school lunch, and how he loves and takes care of his first-born child. These persuasive narratives provide a moving and compelling insight into the desperation they experience and why and how relatives bear so much hope for recovery.

Therefore, I have chosen ethnography as my key method to carry out this doctoral research. Ethnographic research embraces a range of techniques to collect data, although some form of participant observation is considered an essential element. In this study, I carried out observations and interviews. The interviews have taken various forms considering the situation

¹⁹ Pseudonym

²⁰ Guillain-Barré syndrome is a disorder in which the body's immune system attacks part of the peripheral nervous system. This disorder is sometimes life-threatening and is considered a medical emergency. <http://www.ninds.nih.gov/disorders/gbs/gbs.htm>.

of the fieldwork context. I justify the research methods and techniques I used in a later section of this thesis.

In the first part of this chapter, I document the preliminary phase of my fieldwork, which describes how I managed to enter my research 'field' to carry out my study in Bangladesh. In the second part, I will document the research techniques that I applied in the ethnographic study. In the end, I will describe the three hospital settings where I carried out my fieldwork and the issues that emerged during fieldwork. I want to start my discussion, focusing on the hospital as a field of study.

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

My field of study is the hospital ICU ward located in my own country, where I was born and brought up. Thereby, the society is familiar to me, but the hospital ICU was unfamiliar to me as I never had the embodied knowledge about ICU as a researcher. In this regard, this hospital ethnography is a study of unfamiliarity in a familiar society. Ethnography is not merely a method of enquiry; it is a collective process of knowing, formulating, analysing and representing the research in a set style that follows a theoretical tradition (Denzin 2017). It can be said that ethnography is a 'naturalistic' way of knowing the unknown, presenting it in a manner that makes the description so 'real,' that it enables others to see the studied group before our eyes, which I wanted to do by conducting an ethnography in the hospital settings.

Hospitals are distinctive institutions. Historically, hospitals had their beginnings in charitable and religious institutions that looked after the poor in the West. The history of hospitals and clinics is closely related, therefore, to missionaries and colonial expansion *within* Europe. In their early establishment, ‘western’ medical care was widely given by missionaries from their self-established clinics to the people they wanted to convert. Similarly, the colonisers of India also set up hospitals to save the indigenous labour force and themselves from infectious diseases (Guha 1996; Arnold 1993; Chakrabarty 1988).

Toward the end of the 19th century, ‘the hospital’ became a recognised institution and a symbol of modernity. At the end of the 20th century, it incorporated ‘biomedicine’ as a scientific practice. The hospital has been considered as a place where established universal principles of biomedicine were practised uniformly across cultures with some local variation (Geest, 2004). It has also been said that a hospital is a place where the battle between life and death takes place with the intense focus of anxieties and hopes (Kaufman 2005; Davies 1930 cited in Long, Hunter, and van der Geest 2008; Sudnow 1967b). This view reflects the way I conceptualise hospital in terms of death and dying in the ICU. Particularly, Davies’ observation is as valid today as it was back in 1930.

Further, Geest et al. (2008) suggest that hospitals have been considered a place of social and anthropological interest for their enduring possibilities to reveal people’s values, convictions, and moral rules in the situations and processes of illness and recovery. Likewise, Lock reminds us that, “The study of health, illness, and medicine provide us with one of the most revealing mirrors of the relationship between individuals, society, and culture; it is an exciting task

which has only just begun” (1988:8). Thereby, I have chosen to do a hospital ethnography. My research field encompassed both government and private hospitals in Bangladesh, as I sought to understand the similarities and differences between them.

How it began: Access and Obstacles to the field

Getting access to the hospitals was not easy for me. I arrived in Bangladesh in the middle of July in 2015, intending to start my fieldwork at the earliest. Although I had started contacting people for access to hospitals to do my research while I was in the U.K., it took almost five weeks to start my observations at ICU in the first hospital after I arrived in Bangladesh. In the meantime, I kept pursuing permission from other hospitals. At the same time, I used these five weeks to contact people who have experienced life-support treatment for their close kin (i.e., mother, father, husband, sister) and started taking in-depth interviews as a backup plan. I identified them through my family, friends, and colleagues. They eagerly introduced me to relatives who experienced life support treatments for their close family members.

The obstacles that delayed attaining permission at different sites were numerous, ranging from not able to reach the ‘right person’ who would pursue my access to ICU; questions as to why I was not taking a local supervisor from the hospital I wanted to study, and suggestions that I should share my research’s authorship, to ‘disappearance of my application between desks’ and the like. Reflecting Geest’s observation of the protective attitude of hospital authorities and their hesitation in allowing observers to enter their workplace (Geest, 2004), permission was also denied, by a reputed private hospital, on the grounds of preserving the

privacy of patients, based on the assumption that wealthy patients had more expectations of privacy than others. A doctor, and member of the executive management of a private hospital, told me that,

“sometimes over-drunk or suicide-attempted children from rich parents get admitted in the ICU. The parents do not wish to disclose this occurrence to an outsider. If they get to see you inside the ICU, it will be a big problem for us. They might take legal action against the hospital.”

In Chittagong, I was repeatedly avoided by saying the hospital director who was responsible for permitting me, was not available in the office.

My mentors, friends of friends, acquaintances, relatives, my ex-student helped me to get hospital access and introduce me to people who have gone through the experience of life support for their near relatives. The list of people who helped me in this endeavour is longer than my interviewee's log. Whether a contact person was successful in helping me get approval or not, their meeting with me always ended up with a story of their own or stories heard from others dealing with death at the hospital.

Eventually, I gained access to the ICUs of three hospitals, which I have called University Teaching Hospital²¹ , BIRDEM²² , and Phoenix Private Hospital²³ in Dhaka, the capital city of

²¹ Pseudonym

²² (Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine and Metabolic Disorders) [actual name used by request] I was advised by the BIRDEM to use their hospital name in this study.

²³ Pseudonym

Bangladesh. These three hospitals are different in terms of their ownership: one is a public university hospital, one is a private hospital yet with government support, and the other is a 'five-star rated' private hospital. My first permission to research made it easier to get permission from other hospitals. I conducted the majority of my observation in this hospital. My access was granted on the basis that I would not identify any of the hospitals in the research by name and would not, in the course of my observations, attempt to interfere in the treatment process. I maintained all the promises I made to them. I also never said anything to relatives about what I have observed inside the ICU, despite being asked many times. I consider this self-imposed rule as a researcher's ethics as a researcher's morals to not pass sensitive information to the relatives to avoid creating any 'misunderstanding' between relatives and health service providers in ICUs. I was also adhering to the ethical rules of the Lancaster University Ethics committee and the Academy of Social Sciences.²⁴

I had to take all the necessary precautional steps against possible contamination in the ICU, such as dressing up in an ICU uniform (white apron, wearing a mask, head cover, ICU footwear). The same rules and ethical norms were applied to all research sites.

Hospital Ethnography: Seeing, exploring, and understanding

The fieldwork was carried out for 8 months, during which I wanted to listen to the story of life

²⁴ Academy of Social Sciences adopted 5 ethical principals for social research in 2015. The second principle is "All social science should respect the privacy, autonomy, diversity, values, and dignity of individuals, groups and communities" (<https://www.acss.org.uk/developing-generic-ethics-principles-social-science/academy-adopts-five-ethical-principles-for-social-science-research/> last accessed 29/08/2020)

support treatment from relatives' account. The 'ethnographic story' is not a story created out of the imagination, but a story that consists of 'real life in real-time.' This 'real-time presentation' is not merely a description of the happenings in time but is a description of 'situated knowledge'²⁵ that has a relatedness to society. A critical perspective on uncovering the 'real-life in real-time' has been put forward by *the Writing Culture* (1986) group²⁶. The writing culture group criticised classical ethnographic writing for various reasons, such as research ethics that classical ethnographers ignored by not positioning themselves in writings and 'timeless' 'apolitical' representation of people and society. The writing culture group deeply engaged their readers with reimagining anthropological contributions in ethnography, as well as the politics, ethics, and cultural representation of ethnography. Ethnography is not merely a method of enquiry; it is a collective process of knowing, formulating, analysing, and representing the research in a set style that follows a theoretical tradition (Denzin 2017). It can be said that ethnography is a 'naturalistic' way of knowing the unknown, presenting it in a manner that makes the description so 'real,' that it enables others to see the studied group before our eyes, which I wanted to do by conducting an ethnography in the hospital settings.

Hirschman (1998: 88) used the term 'empirical lantern,' by which he meant how we craft our explanations, openness, and intricacy in ethnography to present our argument about what

²⁵ By situated knowledge, Donna Haraway means to problematise both subject and object. Situated knowledge is based on an embodied vision and is more dynamic and hybrid than the claimed objectivity of 'scientific fact', which should not be treated as straightforward, but rather, all the positionings that creates such knowledge need critical examination (Haraway 1988)

²⁶ *The Writing Culture* (1986) consists of essays by a group of authors who are famous ethnographers, literary critics and a historian anthropologist. This group of writers raised critical questions regarding ethnographers' authority in describing culture, objectivity and 'partial truth', the politics and poetics of ethnographic text and representation. They tell us that ethnography is recently in political and epistemological crisis.

we learned from the field. Herewith an 'empirical lantern,' I wanted to represent the experiences, dilemmas and struggles around life support treatment. Mesman (2008) said, "technological development creates not only new treatment options but also new questions, new dilemmas, and new tragedies" (p, 3). I wanted to understand and identify the new dilemmas and questions raised by the life support technology from the narration of experiences by relatives. The relatives' experiences might have been located at an individual level, but they coalesce strongly around stories of anxiety, pain, care and hope. They shared their thoughts and experiences with other patient relatives. They created a communal sharing space derived from individual experiences. Hence the integral cultural system is developed and revealed within the bounded subject matter. An ethnographer depicts this space from the micro-level, which reflects the systems playing out at the macro level as a background. To link the biomedicalisation of death to the broader political economy of hope, the relatives' experiences are crucial to address through their narratives by doing ethnography. I want to define narrative as the way relatives described the events following their conscience, own logic, the way they believed the event has occurred (Hampshire et al. 2014; Segalo 2014; Gemignani 2011). Hence, the narrative is not only a description of an event but also an explanation.

I find it challenging to turn the details of relatives' narrations into anthropological text, but not impossible. This is the point where Clifford Geertz (1994) advises anthropologists, whom he says cannot create the truth, to go 'near to the truth.' Hence an anthropologist's challenge is to create a text by pulling together threads and tie them into a narrative, like weaving a piece of cloth. By privileging relatives' narratives, I want to highlight the embodied and experiential knowledge of hope, anticipation, mistrust, gaps, understandings in the journey of life-

prolonging treatment and to include the meaningful user voices into the use of life support technologies.

I have contextualised relatives,' health professionals' narrative to the broader context of the health system, and Bangladeshi society while listening to their narratives. I have not taken their accounts for granted without justifying them with the context and meaning. Through their narratives, I not only wanted to empathetically understand the situation they were going through for undertaking life support treatment for their relatives but also, I wanted to understand the embedded meaning and speculations of hope and expectation in the life support technologies.

To define the narrative approach, Clifford (1986) discussed ethnographic allegory, where he emphasised the need to understand the hidden meanings of reality and cultural norms through representing the experience of ethnographic investigation—using the example of *Nisa: The life and words of !Kung woman* (1983) by Shostak, Clifford explained how ethnographic text represents a macro system from a micro-level narrative, where Nisa's narratives on her experience of giving birth open up cultural norms (of a !Kung woman's childbirth) to our view and understanding. Nisa's narratives not only depict *her* experience of becoming a mother, but also its nature as a typical female experience. The narrative of Nisa conveys an individual story and as well as a story of a specific culture and a story of common humanity (being a woman giving birth). Good and colleagues (1994) note in the context of epilepsy in Turkey that stories not only tell of past events, but it directs them forward in time. My objectives of the study fit here, as I want to listen to relatives' stories to portray their hope and

expectation, which led them to carry out the treatment at their fullest capacity. In this collection, Good and colleagues (1994) elucidate how relatives' hope and expectation directed them to set activities to achieve their desired goal. In their words, "organizing our desires and strategies teleologically, directing them toward imagined ends or forms of experience which our lives...are intended to fulfil" (p. 139).

The narrative is also crucial for Roland Barthes. According to him, 'narrative is there where life is' (1968: 2). For Barthes, "*the narrative may incorporate articulate language, spoken or written; pictures, still or moving; gestures and ordered arrangement of all these ingredients*" (1968: 2). Relatives' narratives have been an essential source of data for my research; by listening to relatives' narratives of deciding whether to withdraw the life support or not, I learned the various phases of the decision-making process and its intensity in relatives' life. I also found the decision-making process is not personal *per se*; instead, their experiences, decision making for taking or withdrawal of life support treatment are embedded in the specific cultural, political, financial, and health system contexts. Why, how, when the decision was taken, what are the decisive factors that have been reflected in the relatives' narrations (Bhatia 2011; Segalo 2014; Chase 2018; Gemignani 2011).

The relatives' narratives I used in this study were produced in many ways, more often in the form of conversation and the way relatives described the situation or instances to me. I used to participate in conversations with relatives every time I visited ICU. At the beginning of the study, approaching a patient's family was a great challenge for me. Their sad and worried faces made me hesitant to approach them. Shamoly and her brother Samsed made this easy for me by introducing me to other patients' relatives. Eventually, I became familiar with them.

The same things happened in the other two hospitals as well. Often one patient's relative introduced me to another. I found the hospital space sometimes removes the class and other differences between the occupants and also create a relationship bond between patients' relatives. I found that relatives eagerly talked to me when they realised, I am not a doctor. Regarding the conflicting identity, I will discuss later in this chapter.

I did not audio record relatives' conversation with me at the ICU waiting room, as I assumed this device could disrupt the natural flow of their narratives. At our first meeting, I explained my study objectives and about keeping their anonymity. I found that informants became more comfortable when they know about anonymity. I took notes while I talked to them. I tried to take notes as detailed as possible. I let relatives speak about it from the first day when the treatment had started. I found that they often begin their narrations with how the person was and how loved the person was to them.

Observation: A way of understanding biomedicalisation in action

Ethnographic research embraces a range of techniques to collect data, although some form of participant observation is considered as an essential element. Participant observation requires long-term residence among the population being studied, participation in their everyday activities, knowledge of the language they speak, and the observation of events in their everyday context. Spradley (1980) categorises participant observation according to the degree of participation by the researcher. The highest level of participation is called *complete participation*, where a researcher observes events as a complete participant in the research situation. On the other hand, there is *non-participant observation* where a researcher's role

is confined only to observation. Some researchers, such as Caudill et al. (1952); Rosenhan (1973); Van der Geest and Sarkodie (1998), carried out their ethnographic research by taking the role of a patient. Martin (2009) conducted her ethnographic research while she was under treatment for bipolar disorder and deep depression. She was simultaneously a group member and a researcher, a strategy that Geest (2004) mentions as the last option for researchers on ethical grounds. For Wind (1958), doing fieldwork is more than 'being there and observing,' but rather by developing interactions among the actors at the research site, she was able to overcome the non-participation role in the field.

Similarly, neither the hospital setting nor the objectives of the study allowed me to take an *active* role other than as a non-participant researcher during fieldwork in ICUs. This study technically only involved direct observations at ICUs in the hospital settings, which would be termed 'non-participation' by Spradley (1980). However, I have not limited the fieldwork to passive observations and taking interviews; instead, I continued day-to-day conversations with doctors, nurses, caregivers ('ward boys' and *Ayas*), and relatives waiting in the ICU, and attended counselling or patient briefing sessions.

I chose to pursue observation in the intensive care unit to understand how life support technologies bring changes in death and dying. Without observation, I never would be able to fully understand relatives' critical and challenging journeys, the critical aspect of this health care encounter, and the broader context in which these people have been situated if I had not been in the hospital ICU for ethnographic study.

My observations began by understanding the general work carried out in ICUs in the first place. As a non-medically trained social researcher, I barely understood what was going around me in the initial stages. Even to enable me to carry out a 'non-participant' observer role required me to first learn about the ICU. Unfamiliar technical 'languages' of the ICU many times obstructed my understanding of ICU. However, it also helps me understand the medico-technical place from a social perspective, and it reminds me that 'ICU is a place of expert', which is very unfamiliar to laypeople. In this context, Wind (2008) proposed the term 'negotiated interactive observation' for ethnographic fieldwork in activities and events in highly specialised healthcare systems. She felt this was a more appropriate term to describe ethnographic fieldwork in a hospital setting, as the setting does not allow a researcher to take any strictly *participant* role such as a patient, visitor, doctor, or nurse. In that regard, my investigation should properly be considered 'negotiated interactive observation.'

I observed relatives' daily waiting at ICUs and listened to the stories of their 'journeys.' These stories are not only the narratives of their waiting, decision making, and 'emotional roller coasters,' nor do they only reveal everyday life at the ICU but represents the ICU health service system as centred on a 'new' medical technology domain—I undertook observations at ICU, doctor's rooms, and waiting rooms. Two hospitals' ICU had a central nurses' station, from where the whole ICU can be easily seen. I used this as my observational base. BIRDEM's ICU is divided into two wings. Both wings have separate doctors' and nurse stations. I covered both sides by changing my location. I observed daily routinised activities such as examining, monitoring, caring activities as well as in critical moments when life support was withdrawn and when the death occurred.

Generally, patients are seen by specific allotted doctors. As a part of the observation in the ICU, I joined the daily round with doctors (in two hospitals) who allowed me, which provided me with a better understanding of doctors-nurse-patient-machine interactions, which I have discussed through this thesis. However, not all doctors allowed me to join their rounds.

When I first started my observation at UTH, I made a list of 21 patients, with all their information given on the bedside chart. The next day, I found many of the patients on my list were no longer in the place (most of them either died, discharged, or shifted to another ward). Sometimes, even a nurse could not reply to me about a patient's whereabouts. S/he replied to me, 'maybe the patient died.' After a few days of observation, I found it challenging to maintain patients' list as they 'left' the ICU more frequently. As my objective is to talk to relatives about their experience, I decided then to adhere to the long-staying patients (which I could see their duration of hospital stay on the chart) and the relatives who eagerly wanted to talk to me.

I also visited several ICUs during the fieldwork time to get an overall idea about private and government ICUs in Chittagong and Dhaka. Even when I was travelling, my co-passengers shared their experiences when they found out about my study. I have found that, at the cutting edge of medical technology, everyone has a story to tell, embracing life, death, and medical technology.

Observing Counselling session

In the beginning, I was unsure whether patient relatives would accept my presence at 'briefing' sessions. These sessions mainly involved briefing about the patient's condition to relatives by ICU consultant doctors. This session is also called counselling as doctors not only explain the patient's condition to relatives but also 'convince' them about the further steps of the treatment process. After some time, doctors and many of the relatives invited me informally. I was able to observe 14 briefing sessions at UTH and BIRDEM while none at Phoenix Hospital, as I was not given permission. Only once I was able to be present in a doctors-relatives' conversation. I was standing at the doctor's room's door talking with him while a patient's family came to discuss the withdrawal of their father's life support. The doctor and relatives allowed me to remain when I asked for permission.

Interviews

I also conducted interviews. I did these in four ways. First, while observing in the ICUs, I regularly talked with doctors and nurses. Although these day-to-day conversations may not be formal interviews, they were an important source of knowledge that informed my understanding of the use of life support technologies and death and dying in ICU. These casual conversations often enlightened me about the ICU in action. Secondly, in addition to these informal conversations, I also undertook in-depth interviews with doctors and nurses to explore specific queries about the admission process, withdrawal process, declaring death and brain death, and their challenges in the ICU. Thirdly, I conducted (in total 24) open-ended interviews

with 4 health activists, 2 journalists from print and T.V. media, 2 DGHS (Directorate General of Health Services) personnel, 2 religious leaders²⁷ (1 interview was taken over the phone as per his wish), 1 ICU installer and, fourthly, 13 relatives whose kin have gone through life support treatments. These relatives are outside the hospital relatives' group, as I mentioned in the earlier section. Through my friends and family, I contacted these 13 relatives and arranged an interview time at their convenience. Sometimes I visited their home, and sometimes they came to mine or at a cafe. In these interviews, relatives narrated the episode of the treatment process, death, and dying of their close kin. It lasted a minimum of 45 minutes to 2 hours. While they were narrating their stories, I asked a few questions about the cost of treatment, and how it was arranged, why they had chosen the specific hospitals and life support treatment. I also asked about the process if there was any withdrawal decision involved in that episode. I listened to relatives' stories of hope and frustration and sadness. Over time, I became more familiar with some patients' relatives, which allowed me to spend more time with them.

I always tried to ask fewer questions. I recorded these interviews with the permission of the interviewee.

I met and talked with many patients' relatives²⁸ in the three hospital sites. Relatives are from different socio-economic backgrounds. However, none of the relatives is from the 'unprivileged' class. As I mentioned, it required to pay some advanced to get treatment in these

²⁷ I did not use these 2 interviews in the study as there was no scope for this.

²⁸ A brief description of relatives' I have spoken to and their relatives who were admitted to the ICU are given at the end of this chapter.

hospitals. Though the three hospitals are located in Dhaka, patients and relatives in this study are from different parts of the country.

In this thesis, I have used 30 particular patients' stories that relatives' have shared with me, and I often draw on 11 cases as the backbone of my study. These cases are selected for demonstrating a level of complexity typical in this environment and for strongly illuminating some of the issues focused on in the study. Moreover, I was able to create a better relationship with these people as they stayed longer in the hospital, and I had a chance to meet them more frequently. This allowed me to have a fuller account of these cases than others. Tuhin, Shimul, Nurunnahar, Momota, Mithun, Siam, Tareen, Faruk Mia, Rohan, and Abdur Rahim, Shafayet Alam, therefore, will be mentioned more often in the discussion, as their stories help to represent more fully the experiences of relatives.

I was even more unsure about making a working relationship with doctors than with the patients' relatives. This hesitation is rooted in the doctor-patient relationship that I have experienced as a Bangladeshi, where doctors usually maintain a distance from patients. To my surprise, with a few exceptions, most of the doctors became very friendly and helpful to me. The 'doctors' rooms' (where doctors take rest, eat, study, and watch television) were the places, where I got to know the doctors and explained many medical procedures, jargon, terms, and their perspectives well. Sometimes, I went to the café with them and listened to their stories too.

Newspaper and health care service

I wanted to understand the picture of health services as represented in newspapers as I was also keen to understand public perception about the health service, which also defines their reliance and reservation about the health system. During my fieldwork, two significant cases came up in newspapers. Hence, these two cases²⁹ are mentioned throughout this study. Newspapers across the country publish articles about treatment negligence, theft from patients, and 'mis- or lack of communication' between health professionals and patient families. I also incorporate analysis of media reports of end-of-life cases. I gathered life support-related news from print media published during my research and wanted to deepen my understanding by interviewing journalists. I have used Google News and Nexis search engines to find relevant news in Bangladeshi newspapers. I used keywords such as 'ICU,' 'Life support,' 'Health Care in Bangladesh,' 'Updating Health Law/regulatory framework', and 'Bangladesh' to search. Where I knew specific incidents or subjects in the news, I directly used them as search keywords. I tried to limit my news search from 2014 to 2016 for specific ICU incidents; however, I could not limit this search only to the specific time when I found news more relevant to my research. I have analysed the news regarding the two cases in chapter 7 in support of my arguments. Regarding the issue of updating law and the regulatory framework relating to intensive care and life support (discussed in chapter 7), I searched the news up until 2018 to get the most up-to-date information regarding the issue.

²⁹ The summary of the two incidents are given in Appendix 1.

Analysing data

First, I organised field data thematically from my fieldnotes, observational notes, and transcriptions. A few themes came directly from the relatives' conversation, in which they emphasised issues by repeating them, for example: the reason for choosing a particular hospital or treatment option, the withdrawal decision of life support, financial matters, and day to day experience at hospitals. Other themes came from my observation, such as the relatives' waiting, hope, and deception. I categorised my fieldnotes and marked them with different codes and colour manually. I then critically analysed these themes with the help of the theoretical positions that I adopted in this study and used them to support my arguments.

The Three Hospital sites

In this section, I will describe the three hospitals where I conducted my fieldwork.

When I finally met the Chairman (head of the department) of the Anaesthesiology Department at UTH to start my observation, I found him very busy treating patients, attending 'requests' for ICU beds, answering phone calls, advising his staff on matters from stolen door stoppers to the absenteeism of doctors in the evening shift and problems with patients' families' inability to pay bills. I did not observe such activities in the other two private hospitals called BIRDEM and Phoenix Private Hospital. They operated differently to this public³⁰

³⁰ Being a public University, it is an autonomous body and it has its own constitution.

university hospital, in that admission procedures were not done at the ICU complex. Instead, patients first came to the emergency unit, and if an ICU bed was available, then the patient was transferred to the ICU with the consent of an ICU consultant.

The ICU and HDU are in the newest building of UTH. It is in the very centre of the city. This university hospital was established in the '60s. This institute turned into a public university in the late 90s, considered the most specialized type of government tertiary level hospital. The university runs its administration and finance with rules, regulations, and assistance set by the University Grant Commission and the Ministry of Health and Family Welfare.

There are 21 ICU beds at UTH. I found as patients at its ICU upper-level government bureaucrats, the husband of a current minister, and a famous poet. As the cost of ICU treatment is relatively cheap compared to private ICUs (see table 1), there is always a very long waiting list. This hospital's surrounding areas look like a typical 'hospital area' with hundreds of pharmacies, medical and surgical equipment suppliers' shops, apartment-hotels, lodgings, restaurants, shops for patients' food, utensils selling vendors, and fruit shops are found around the hospital. This is very unlike the 'western' hospital area, which is generally expected to be quiet. The ICU and HDU at UTH are under the jurisdiction of the Anaesthesiology Department, while in the other two hospitals, the ICU is under the Critical Care Department.

The other two hospitals are different from the UTH. I got permission at BIRDEM in the last weeks of my fieldwork period, literally when I was about to give up hope. Hence, the fieldwork

there was intense and shorter. BIRDEM is a private hospital, although it receives funding from the Ministry of Social Welfare. Despite being a private hospital, it is much cheaper than the third hospital in this study. Because of its high reputation for quality treatment, yet being less expensive, ICU beds at BIRDEM are in high demand. Besides, 30% of the total in-patients' beds are free and subsidized at BIRDEM for disadvantaged diabetic patients, and those cases are of academic interest³¹. Because of this, people often think that BIRDEM is a government hospital. Visiting hours are more flexible than at the university hospital but still controlled. The ICU waiting room is located on the 1st floor of its building, while the ICU is on the 7th floor. There were 19 beds in this general ICU. There is another cardiac ICU in this hospital situated in a separate complex, though I observed only in the general ICU. As this is a diabetic hospital, most patients have diabetes-related complications, though there is no restriction for the non-diabetic patient.

Compared to the UTH, BIRDEM ICU is smaller; thereby, beds are closer to each other than UHT. However, the patient and the doctor-nurse ratio is higher than the UTH. Only in the BIRDEM, I saw a nutritionist visiting each patient every day. Medicine and other medical supplies are provided by the hospital, which is later included in the invoice. Relatives need to pay an advance to get the patient admitted. The amount of money owing to date is recorded against each bed number on a whiteboard hanged outside the ICU complex. Though the waiting room is on the second floor, relatives wait in the corridor directly outside the ICU, sitting

³¹ https://www.dab-bd.org/page.php?cat_id=5 (Last accessed on 22/07/2020)

on the floor. There is a restaurant, prayer room in the same building where the ICU complex is located.

My last hospital, Phoenix Private Hospital, offered the most expensive treatment. On entry, it gives an impression of a five-star hotel, rather than a typical hospital as they are known in Bangladesh. There is a food court, spacious prayer rooms for both (Muslim) men and women, washrooms, and waiting rooms with many amenities such as drinking water and television. It is located near the diplomatic zone in Dhaka. Foreigners are seen as outpatients in this hospital. The visiting hours are the most flexible in this hospital. The patient-nurse ratio is higher in this hospital, which is usually 2:1.

Nevertheless, sometimes they cannot follow the ratio when nurses are on leave or shortage in number for some reason. There are different types of ICU in this hospital, though I studied GICU (General Intensive Care Unit). At UTH, relatives must supply medications and other medical supplies, but at Phoenix, like BIRDEM, medicine and other medical supplies are provided by the hospital. There are sixteen beds in this ICU. There are a few cubicles with sliding doors, whereas other beds are separated by curtains, which are different from the other two hospitals where the ICU is open plan. At Phoenix, the individual cubicles were for VIP patients and the most critically ill patients. There are some designated stickers to be used to identify the most critical patient and to record information necessary for the care of that patient, such as a particular condition or contagious disease.

When a patient reaches the emergency unit of the Phoenix hospital, the doctors in charge primarily diagnose the patient. Based on the primary diagnosis emergency doctor calls doctors from the specialised units in which the patient should be treated. The doctor from the specific unit finally confirms in which unit the patient should be treated. The ICU has two telephone sets with two different colours-emergency calls that come to the red set and the general call received by the blue one.

Table 1 Description of services provided by the three hospitals studied

Name of Hospitals	Type	Numbers of ICU Beds	Facilities	Cost (Daily approx.)	Waiting room arrangement
University Teaching Hospital UTH	Public University Hospital	21	Medicine and other supplies should be provided by patient's family.	Minimum 7,000 BDT (GDP 66.84)	Only a seating area furnished with chairs is available. There is no other arrangement provided.
BIRDEM (Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine and Metabolic Disorders) [actual name used by request]	Private Hospital. (Receives donations from Social Welfare Ministry)	18	Medicine and other supplies are provided by the hospital.	Minimum 30,000 BDT (GDP286.45)	The waiting room for ICU patients is located three floors down. There is a water filter, mobile phone charging point, and lockers provided.
Phoenix Hospital	Private	16	Medicine and other supplies are provided by the hospital	Minimum 70,000 BDT (GDP 668.37)	A large screen television, Drinking water, seating arrangements, fully air-conditioned.

The three ICU wards in my research are different in terms of medical devices, and types of equipment, facilities (a comparative picture of three hospitals are stated in table 1) treatment costs as I have mentioned in the previous chapter; despite differences between the three units in terms of facilities, treatment costs, medical devices, and equipment, they are all identifiable ICUs as each bed is equipped with an assemblage of life supporting machines and devices, such as the patient's monitor, ventilator, BiPAP,³² suction machine and oxygen pipes. Each ICU will also have an ECG machine, a portable x-ray, an ultrasound scanner, a defibrillator, a dialysis machine, a blood thinner machine³³ , and a blood culture machine³⁴. Some devices and machines are taken to the patient's bed when needed, like the dialysis machine and portable x-ray machines. There is a pathology laboratory adjacent to the ICU at UTH, though, for some pathology and other screening tests, samples are analysed in different places in the hospital. However, the three hospital sites of this study are not equally equipped. UTH, a public, government-funded university hospital, has more modern machines than the other two hospitals. The Phoenix Hospital Limited and BIRDEM also have some new machines, but fewer than the university hospitals have. However, according to the other two hospitals' doctors, UTH might have more advanced technological resources, but they lack skilled doctors.

³² BiPAP (also referred to as BPAP) stands for Bilevel Positive Airway Pressure, and is very similar in function and design to a CPAP machine (continuous positive airway pressure). A BiPAP machine is a non-invasive form of therapy for patients such as who suffering from sleep apnea.

³³ Or INR test meter to monitor patient response to warfarin that may be prescribed for patients with certain types of irregular heartbeat, blood clots in the legs or lungs, and patients who have certain medical device implants such as artificial heart valves. (Source: <https://www.fda.gov/medical-devices/vitro-diagnostics/warfarin-inr-test-meters> Last accessed 22/07/2020)

³⁴ A machine that does the blood culture which is a laboratory test in which blood, taken from the patient, is inoculated into bottles containing culture media to determine whether infection-causing microorganisms (bacteria or fungi) are present in the patient's bloodstream. (Source: https://webcache.googleusercontent.com/search?q=cache:w87Edf1SJhEJ:https://www.biomerieux-usa.com/sites/subsidiary-us/files/blood_culture_booklet_-_prn_16_0097a_00_mk_approved13jul161.pdf+&cd=16&hl=en&ct=clnk&gl=uk Last accessed 22/07/2020)

I found the two ICU wards of UTH and The Phoenix were not congested. The Phoenix Hospital ICU ward (16 beds) is smaller than UTH (21 beds), but it has various specialised ICUs, such as coronary and General Intensive Care. BIRDEM hospital's ICU is overly crowded with 21 beds and has no isolation space for patients with contagious diseases. During my observation, one bed was identified with a piece of paper written on the wall as a contagious patient. One doctor told me that this kind of patient should be treated in an isolated cubicle, not in a congested space like this. He says, "the management overlooks the consequences of jam-packed ICU beds. They would add more beds if they could".

Going into the unknown – Challenging contexts

In this section, I will address the issues that emerge during the fieldwork. It was the most challenging part of my fieldwork when I started observing the ICU to understand biomedicalisation in action concerning death. My first encounter with an ICU took me back to the childhood memories related to the doctor and hospital: the injection needle, the distinctive smell of the hospital, chilling temperature, 'serious-unsmiling' appearance of doctors and nurses. Altogether the place was full of strange and unpredictable feelings; hence it was frightening to me as a child. Many things are similar now, apart from my presence, not as a patient this time, so it is no longer 'frightening.' Although being an anthropologist and not medically trained makes me feel unfamiliar and peripheral in this place, as I have mentioned.

In this section, I present the challenges I faced in conducting ethnographic research in the intensive care unit and how these challenges have shaped my study. The first challenge I had

to face was getting access to hospitals. A 'gatekeeper' often enables a researcher to attain a better understanding of the research setting (Denzin 2017; Bernard 2011; Burgess 2002). Zaman (2008) carried out his ethnographic research in an orthopaedic ward of a government hospital in Bangladesh. He considered his role as an 'observer as participant' in the empirical study. However, being a doctor and alumnus of the Medical College Hospital, where he conducted his research helped him significantly in obtaining access to the research site. He positioned himself as both insider and outsider, which simultaneously gave him advantages and disadvantages. In my research, my social identity as a faculty member of a public university and as a research student of a renowned foreign university helped me to approach the ICU department or/hospital authority to get access, but it was always my existing *social* connections (my undergrad professor, her friends, and their associates, relatives) with the people who had accepted in the hospitals, that acted as my gatekeeper to enter the field.

Here I will specifically focus on two challenges that have arisen in my research and consequently have enriched my ethnographic study. My challenges encountered in the field are grounded in my positionality and emotional engagement.

First, I have encountered challenges from my own identity. This challenge of identity is two-fold. One aspect is grounded in the authoritative knowledge system: the problem of studying biomedical space (the ICU) while being an anthropologist (social science background). Furthermore, the other is embedded in my researcher identity, which I have found is 'fluid' in the research context.

The second challenge comes from dealing with such a sensitive topic. During my fieldwork, I would spontaneously become emotionally engaged with informants, which eventually raised the question of how to engage my emotions in ethnographic research.

I discuss these two identity-related challenges below.

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

When I entered the hospital after gaining permission to conduct research, dimensions of my identity opened various dimensions and challenges. First, I am a Bangladeshi female academic that establishes my socio-cultural position. Second, I am a Bangladeshi resident, studying in the U.K. and conducting fieldwork in Bangladesh, which reflects my socio-cultural status. The first two dimensions of my identity helped to get my acceptance in the field. Most of the time, when I approached relatives, doctors, nurses, or anyone for the research with my identity, I got accepted. Third, I am a *social* scientist, but studying life support treatments in a highly technical medical zone confined to medical staff. Studying at ICUs while being a non-medical scientist has added a critical dimension to my researcher role in the field. I was only allowed to enter the ICU with a proper ICU dress and a white apron (the medical staff's dress), which adds to the 'confusion' of my identity. My identity as a social researcher was 'erased' apparently (not from inside but from outside as it is seen) when I entered the ICU with a blue dress and white apron.

Fourth, the final challenge relates to combating two different worlds. Inside the ICU, I am only an observer; outside the ICU, I listen to the patients' relatives, whom I have observed at ICU.

Relatives sometimes asked me about their relatives' health condition, whether the nurses were taking care of them, what the doctor said about their patients to me, or what I had overheard. I could not reply to a parent who asked me why his son had suffered a cardiac arrest, though I was told the reason by the medical staff of the ICU. I decided not to say everything to the relatives as it would change my position as a researcher and thought it to be disruptive of the existing relationships between relatives and medical staff if I recounted everything I saw. Often, I felt guilty for my silence. When Shabuj's father, Abdur Rahim, died, he had still not been informed about the death of his father, but he saw his father surrounded by doctors and nurses through the glass of the ICU door as nurses wanted him to bring some medicine. When he asked me about his father, I stayed silent, although I wanted to reply to him, and I went to the ICU to get the doctor's permission to convey the news to him. However, by the time I returned, the nurse had informed him about his father's demise.

Maintaining the 'confidentiality' of these two worlds, and overcoming the ethical dilemmas raised, was not seamless. I maintained the level of confidentiality practised by the ICU medical staff and tried not to get a reputation as a passer of information. I had to earn my place by not disrupting ICU activities; hence, I restrained myself from replying to questions which I was not supposed to.

However, within the existing hegemonic doctor-patient relationship, I was asked many times which side I wanted to take up, from both medical staff and relatives. This question indicates that I was also 'under scrutiny.' "Are you a doctor?" (meaning, I suspect, 'so what are you doing here?') - was the most asked question regarding my presence in the ICU. My presence

as a 'not-doctor' was always an intriguing matter. I tried as much as possible not to highlight and yet not conceal my non-medical presence at the ICU in front of medical staff.

At the beginning of my observation, I did not understand anything when a nurse or doctor started to explain any patient's condition to me, using 'medical terms' and assuming me to be a doctor. It reminded me that the ICU is a very much an expert place. Observing the sufferings, pain, and lonely - technologised – death, without expressing any emotion, sometimes made me feel that I was behaving like a medical staff. Two of my identities often transgress each other.

Dealing with emotions

Maintaining my 'observer' role also was not so easy. Kleinman and colleagues (2010) suggest that the unique contribution of anthropology is not in the culture concept or even in the literary form of ethnography, but in the ethnographer's vulnerability. They say, "It is in the capacity to experience emotions - one's own or sharing in those of one's informants - and to reflect on those emotions, that the ethnographer is able to produce compelling analyses of particular local worlds" (2010: 185).

Observing in the ICU at a hospital on such a sensitive topic – dealing with death, end of life decisions and withdrawal of life support – provoked in me deeply emotional experiences. Despite being prepared for potential challenges from the field, several times, I was devastated by the incidents that happened in the ICU. I was shattered by becoming emotionally involved

with the family members, who were struggling with the immense pressure of bearing the high costs of treatment, but also felt unable to take the life-ending decision to take a loved one off life support. Whenever I started speaking with patients' relatives, I realised that I inflamed their intense pain. Being a researcher did not prevent me from becoming emotionally involved. It could not stop me from thinking, "Why am I observing this enormous pain since I am unable to help them? Furthermore, how do I put this pain and suffering into words?"

When I saw a mother discharging her 12- year daughter from the ICU because of her inability to bear the cost of the treatment, being a mother of a child the same age, I could not stop worrying and imagining myself in the same situation. I often place myself in the position of this mother and try to imagine how I would feel if I had to do the same. Every morning I used to go to near her bed, to see how she was doing. It was the most challenging moment of my fieldwork. I could not control myself when the daughter (Tareen in the study) was taken from the hospital by an ambulance to her hometown, where she was admitted to a local private clinic. It kept resonating in my ears how her mother described to me the exact shade of the green dress which her daughter wanted to buy for *Eid*, and I worried the whole night about her safe journey to her hometown.

Another episode occurred when one of my distant relatives had been admitted to the hospital where I was undertaking fieldwork. He was at a critical stage with multiple health problems. He was eventually taken to the ICU, but his condition was not fit for 'intubation.' Despite the doctor's briefing about his condition, his children were divided as to whether to put him on life support. When the doctor wanted their written consent, they became very emotional, very hesitant, and still undecided. I could not reply to his elder daughter when she asked me

what I would have done in this situation. She was looking for my opinion, which I was not supposed to give as a researcher, but as a distant relation. She was expecting that I might be able to provide information on her father's condition more accurately. I replied to her to discuss this matter with her mother and siblings and to take the decision. Nevertheless, I felt numb intellectually, imagining what exactly I would do if it were my father.

I also felt tremendously helpless and found myself 'useless' seeing an old man struggling to breathe, even with an oxygen mask. The medical staff felt that the family should not have admitted him to ICU, instead they should have arranged a peaceful death without involving any aggressive life support treatment.

Not all mornings were grey and sad. Sometimes morning starts with bright sunshine, even in the ICU. On one occasion, I was approaching the elevator to the ICU, and when the door opened, I saw Tuhin's mother. She ran to me and hugged me tightly. She almost cried with joy while saying, 'I am taking Tuhin home. He is well now.'³⁵ He only needs physiotherapy, which we can arrange at a local hospital.' I saw Tuhin in the wheelchair glowing, fresh, and smiling at me. I had never seen him or his mother like this before.

All through, I was aware of the relative's situation when approaching to have a conversation with me. I tried to understand by observing the situation and mood, whether it is an appropriate time to approach them. It was understandable that not all relatives were in a situation

³⁵ After he was transferred to the HDU from the ICU when he was improving, I did not meet Tuhin's mother for some time. He had been admitted to the ICU because of suffering Guillain-Barre syndrome, although his asthma made his condition critical, which had resulted in his entering the ICU, and a tracheostomy.

to talk to a 'stranger' in such an intense moment of life and death. Those who agreed to talk about their experiences came forward passionately, as they were relieved to share their intense pain and frustration. Tarannum Jahan very eagerly responded to my request to interview her. She said, "I want to talk about my experience. I want people to know about it. Thanks to you that you want to know about this experience and study it."

Mrs Sharifunnesa, who had arranged life support equipment's at home for her husband's treatment, expressed her enormous anger and frustration to me, assuming me to be a doctor as her relative introduced me as 'doing doctorate training,' which she understood as 'doing doctor's training.' Her misunderstanding about me being a doctor, in a way, provided me with a glimpse of the intense feelings that exist within doctor-patient relations and health care services.

Each individual's story of their relative's life support treatment journey is unique and emotionally charged. Furthermore, health professionals who work in the fraught setting of the ICU have to develop their strategy to deal with emotions. I learned from them that they had been taught that their emotional involvement with patients ends with their shift. I learned from them that I should draw boundaries, regulate my emotional involvement. The emotional turmoil I encountered in these situations left a deep impression on my understanding of the impacts of life-prolonging treatment. Despite my attempt to regulate my emotional involvement, it became part of the 'field' since I found myself standing next to a patient's relative and feeling the same way, by putting myself empathetically in the same situation. Therefore, I realised my researcher's *state of needing* to be acknowledged in the research, as relatives'

emotions, sadness, frustrations have a profound impact on me, my data, and my interpretations.

In the history of modern fieldwork methods, we see ethnographers rejecting the idea that emotions or subjective experiences can have epistemological worth. However, this position has been criticised by scholars such as Clifford Geertz and others in the 1970s and 1980s. In the reflexive turns of the 1980s, the *Writing Culture* group in North America took up the issue. This theoretical and methodological turn also argued that objectivity in field research is both a myth and distortion (Denzin and Lincoln 2005; Davies and Spencer 2010; Gupta and Ferguson 1997). Since then, the emphasis has been on addressing a researcher's positionality and subjective experiences in ethnographic research. The subjective experiences of a researcher can be regarded as data with a new potentiality. Davies and Spencer (2010) argue that the emotional and empathetic experiences of a researcher can contribute to research if it is treated with more intellectual rigour. According to them, as much as we emphasise empirical work to understand the lifeworld, we should equally emphasise certain emotions, reactions, experiences those consistently invoking in doing fieldwork as this compels us to conceptualise the lifeworld (2010a:1). Following this argument, I emphasise to have the capacity to experience the emotions, and the subjective experiences spontaneously and unexpectedly arise in the field. I consider my emotional experiences to arise from the relatives' stories as necessary as my empirical data because these experiences helped me to understand the relatives' situation in a more profound way. To understand 'why relatives sell their everything for the dying kin who has a slim chance of recovery' or 'why does wife refuse to go back home without her husband and waits at the hospital despite knowing her presence is not needed

for medical supply (discussed in chapter 4)' requires a certain level of engagement with the situations (Smith and Kleinman 2010).

Ethics as a localised form

Ethics has become extensively institutionalised in the form of professional, ethical committees in the Global North and South. The idea of confidentiality, written consent form, anonymity as ethical rules to be applied in social research came from biomedical research (Atkinson 2009; Maril 2000; Strathern 2000; Fisher and Anushko 2008; Fluehr-Lobban 2012; Simpson 2004, 2011). These concepts have become so dominant because of the core principle of ethical code 'do no harm' and 'as openness and non-deception' to the research respondents (Fisher and Anushko 2008; Fluehr-Lobban 2012). Most of the ethical rules and instructions are for generally assumed and foreseen issues that arise during fieldwork, such as those related to confidentiality, sensitivity, consent, and anonymity.

There are some precise instructions and rules³⁶ that researchers in the field are expected to follow to maintain ethical research conduct. In 1971, the American Anthropological Association (AAA) published the formal code of ethics entitled *Principles of Professional Responsibility*. This instructs anthropologists about what is forbidden in research, such as doing a covert study. However, ethically or morally appropriate actions are not always guaranteed by merely following the rules. There may still be unexpected issues that arise as ethical dilemmas in any

³⁶ For instance, a researcher must adhere to the ethical code of the institution s/he is working/studying in.

qualitative research, particularly while dealing with sensitive issues such as death, dying, and the decision-making involved in life support treatments, critical illnesses, and like, even after considering research ethics. In this context, Goodwin and colleagues (2003) explore 'situational ethics,' in that despite rule-following, still, ethical dilemmas arose. They suggest: "Ethical dilemmas must be resolved 'situationally' considering the individual circumstances each dilemma encompasses" (Goodwin et al. 2003).

In the context of bioethics and new reproductive technology in Sri Lanka, Simpson (2004) finds arising conflicts while responding culturally in ethical responses to donor insemination and consanguinity counselling. Simpson finds that if infertility professionals act ethically in response to Sri Lankan people's (who are receiving IVF treatments), the request to take sperm from the husband's brother means going against the Sri Lankan cultural values that would result in rejecting the new reproductive technology. Simpson suggests, "this tension is not simply an East-West/First World-Third World/North-South split, but one that is found within 'societies' and 'cultures' as well as between them' (2004: 238).

Russell (2011) said, as time changes, ethics also changes. Therefore, he thinks it is hard to set ethical rules, though it is an inevitable part of the research. Burgess (2002) finds that sometimes the steps taken for maintaining ethics in research may not work in another specific social research, as ethical conduct is context-dependent; hence it is situational. For example, he discusses written consent forms, which were first used in biomedical research, often complicating issues of anonymity in social research. Respondents may feel insecure about losing anonymity by signing their names on the consent form. Many anthropologists find it problematic to get written consent, particularly in a non-western research setting for many

practical reasons such as respondents do not know how to write, deemed to be vulnerable, or feel uncomfortable with written documents for cultural reasons (Fluehr-Lobban 2012, 2015; Simpson 2011).

I found informed consent, privacy, harm, confidentiality to be concepts that carry different meanings in different situations, which also refers to its own localised form. My experience of dealing with ethics in research is similar to Burgess (2002) argument. I found that some ethical protocols from the North do not fit in the research context located in the Global South as ethics is situational (Goodwin et al. 2003) and also responsive to culture. The ethic protocol's inadequate response to local culture demands decolonising ethical protocols. In my study, I had to take the decision morally considering the situation as I discussed earlier regarding Shabuj's father's death. In the case of obtaining written consent, I found that most of the cases, respondents were more comfortable with verbal consent. Furthermore, sometimes written consent forms made them sceptical about the purpose of my research.

In dealing with participants' informed consent, I took them according to the situation. Generally, I used to talk with the relatives in the waiting room/area outside the ICU. I had to always bear in mind that these relatives were going through a very stressful time and so breaking the ice was always crucial. I tried to introduce myself to them in such a manner that they would accept me. If I had presented myself to them with a piece of paper that requires a signature, they would suspect me of being either a journalist or a police officer involved in an investigation. Generally, people consider troublesome or harassing to get involved with police or journalist are often seen as in Bangladeshi society. By satire, one of the relatives replied to me when I asked him about the written consent form, '*Apa (sister), will police come to interrogate*

me if I give my sign here? You are not a journalist, right?' By this, he meant whether I would use his interview as evidence against the ICU, which may take this 'case' to the police interrogation, as being occurred in the criminal investigation by journalists. It is another challenge for the researcher to gain trust by reassuring respondent that they would not be harmed for her/his given information to me.

Sometimes, I also found it awkward and insensitive to take out the consent form to get the signature before a conversation. However, I did so when I found the informant comfortable with written consent forms: as I asked them to choose whatever they like regarding providing consent. In some cases, they took my participant information sheet but gave me verbal consent. I found that ethical norms and procedures developed in the western contexts are not impossible in Bangladesh, but they are impossible for some.

In others, relatives mostly wanted to hear verbally about my research. Before every interview and at my first introduction to the respondents, I explained my intention for talking with them, informed them about the ethical principle of anonymity, and offered them the participant information form and consent form.

I have used pseudonyms for my respondents and hospitals to keep them anonymous. I tried to use recorders and camera-less, as often these two devices make respondents cautious as well as doubtful.

Obtaining ethical permission from Lancaster University Ethics Committee was a precondition for starting ethnographic fieldwork, and this required adherence to the institution's code of ethics. In some ways, this was helpful; for example, the assurance of anonymity for the hospitals facilitated my access to the field. However, obtaining written consent was also a complicated issue in my research at the institutional level. I could only obtain a written permission letter in one hospital, and this took seven months. The other two hospitals would only give me verbal permission, either to avoid bureaucracy or to remain anonymous.

In my fieldwork, I may not have been able to follow all institutionally prescribed ethical codes as the respondents have a different understanding of the codes of ethics. However, I adhered to the moral codes of Bangladeshi society, where "morality" refers to socially shared worldviews or conventions about right and wrong human conduct (in the context of medical care) when I was not able to follow the institutional ethics (Beauchamp 2019). Moral values are shaped by socio-cultural values and beliefs (Ember and Ember 2003). In this way, I adhered to a localised form of ethics in my research context.

Conclusion

I discussed the various stages of my field research, justification of choosing research methods and techniques, the way I gathered information, and the issues raised in the empirical study, in this chapter. These various parts all together shaped my empirical study. Carrying empirical study in three different types of ICU, delaying in getting permission, listening to relatives' stories, my emotional turmoil, following localised ethics, choosing informants are the particular factors that gave my research certain characteristics. As a researcher, I tried to adhere to my main research questions and objectives while included some which were not initially in my

research objectives. I could not include everything in this thesis I have done during my fieldwork. Despite the intense and fieldwork conditions, it was the most memorable and challenging 'training' I achieved ever in my academic career.

Chapter Four

WAITING ROOM: "WORLDS WITHIN WORLDS"³⁷

Introduction: First encounter with the waiting room

Tell her parents to take her back home. Her brain is not improving. Why are they wasting money³⁸ on this child? They might have more children. They need to think about their future. Nurse, please convince them, make them understand her condition. Another patient could get admitted into ICU if this bed gets emptied.

[UTH, 2015]

Dr Manosh³⁹ spoke these words to the nurse after seeing Tareen in the morning round. It was in the early days of my fieldwork in the University Teaching Hospital ICU when I got to know about Tareen. I looked at the chart kept on a table near the bed and saw that it was her 57th day in ICU. Tareen was a 12-year-old girl in (August 2015) who had a brain tumour surgically removed. From my position, I only understood that Tareen was unconscious, on ventilation because she cannot breathe by herself, and, according to the doctor, 'most likely' will

³⁷ Foucault (1986)

³⁸ Later I come to know from Tareen's mother about the costs per day in those days was approximately 6000 BDT to 7,000 BDT.

³⁹ ICU consultant

not regain consciousness. The nurse informed the doctor that her family had chosen to discharge her in a couple of days. There is no separate ICU for children in University Teaching Hospital, but Tareen's bed is one of the two beds in a separate cubicle⁴⁰ away from the adults. I wanted to talk to Tareen's family about the decision.

In the methods chapter, I described how I was introduced to Shamoly, Tareen's mother. Shamoly was my 'gatekeeper' who opened the door to the waiting room for me, and I began my exploration of the significance of the waiting room with her. She introduced me to the surrounding patients' relatives, and I came to understand that she knows them very well. I started learning about the stories of the relatives with whom I have talked, and at the same time, I began to understand the temporalities of living in the ICU waiting room.

While I was talking to Shamoly, another patient's relative asked me to move aside as he wanted to take something out from the box underneath the chair I was sitting on. I stood up, and as he pulled out a box from underneath, I saw water bottles, a small cooking pot, and a bottle of liquid milk inside it. He poured the milk into a pot and left. Shamoly told me that on the 7th floor, they could heat food in a designated place if needed. I noticed that under all the chairs, attendants⁴¹ had placed their boxes filled with personal belongings.

⁴⁰ These two separate cubicles are mainly kept for contagious patients, or those who have a high risk of being infected. However, I saw VIP patients being given these cubicles, as well other patients.

⁴¹ This term refers to relatives/visitors of the patient. Patients' brother, brother in law, sister in law, mother, father, daughter, son, and wife – all known as 'attendants' in Bangladeshi culture.

Another woman, the mother of a 16-year-old boy called Tuhin, was sitting on a chair beside us. She listened with patience to how Shamoly described her daughter's condition to me. Although they only came to know each other at the hospital, these two women live in nearby villages. Khadim's mother looked sad and worried: she told me how Tuhin had Guillain-Barre syndrome⁴² (GBS). She was in deep shock as a tracheostomy⁴³ was performed on him. She asked me time and again: "Will he recover?" "Will he recover?" I did not know.

Shamoly told me she wanted to keep Tareen on life support as long as possible. When I asked whether she wanted to take her back home, she said, *"How can I take her from the hospital? Doctors are trying to withdraw the ventilator, but Tareen is not able to breathe without support. We cannot take her out from the ICU."* [UTH]

I realised her account did not agree with what the nurse told the doctor about withdrawing Tareen from ICU. [This account also reveals the hierarchical position of a doctor who passes on the responsibility to convince relatives to keep or withdraw life support to a nurse, which I will discuss in chapter 5]. The clinical view held by Dr Manosh suggested Shamoly should remove Tareen from ICU, as she would not regain consciousness, but Shamoly's decision did

⁴² Guillain-Barré syndrome is a disorder in which the body's immune system attacks part of the peripheral nervous system. This disorder is sometimes life-threatening and is considered a medical emergency (<http://www.ninds.nih.gov/disorders/gbs/gbs.htm>).

⁴³ A tracheostomy is an opening surgically created through the neck into the trachea (windpipe) to allow direct access to the breathing tube and is commonly done in an operating room under general anesthesia. A tube is usually placed through this opening to provide an airway and to remove secretions from the lungs. <http://www.hopkinsmedicine.org/tracheostomy/about/what.html>

not follow a biomedical 'logic.'⁴⁴ She hoped for her child's recovery, which led to her continuing treatment despite the cost. She did not want to give up her daughter's battle between life and death.

In this chapter, I describe and analyse my observations of the ICU waiting rooms. I consider the waiting room is an integral part of the ICU, albeit separated by a physical wall. On one side of the wall, a critically ill person is living in the grey area between life and death, and on the other side, the patient's family is waiting with the hope of ending the waiting. To get a deep understanding of ICU, we need to look at both sides of the physical wall: the ICU itself where therapeutic acts play out, and the spaces of waiting, where relatives pass their time in waiting. Acts of both sides of the wall play a role in the life-prolonging treatment in ICU; therefore, I observed on both sides of the ICU to understand – and problematise – how death has been biomedicalised in Bangladesh.

My aim in this chapter is two-fold. Firstly, I seek to theoretically conceptualise spaces of waiting to show how the waiting room, as space, evolves with complex and diverse meanings of waiting; how the practices of waiting are invested with different meanings and responses to life support treatment. Secondly, the chapter aims to explore the *sociality* of waiting. These two foci develop an understanding of the relatives' on-the-ground ICU activities. Therefore, this chapter addresses relatives' depiction of waiting and their lived experience in the waiting

⁴⁴ I write biomedical 'logic' 'in inverted commas to highlight that these concepts are criticised for being rooted in modernist thought and invoke a hierarchical knowledge system by rejecting any knowledges which are not 'logical' and scientific (according to strict criteria).

room and beyond, which is a central concern of the study. Here, I reflect on conversations with patients' relatives, which took place in the ICU waiting rooms.

The ICU Waiting room

While sitting with Shamoly in the waiting room for the first time, I had the chance to observe the space and patients' relatives closely. I came to realise that the social and symbolic properties of the ICU waiting room space would be necessary for understanding the experiences of ICU patients' families. My observation of the ICU waiting room is a window into the structure of the health system in Bangladesh. Most importantly, I came to understand the waiting room as a space in which various socio-cultural practices of Bangladeshi society are enacted, such as demonstrating familial caring and attitudes towards familial responsibility or duty. In Bangladeshi society, family bonding is still evident by the existence of extended households (Aziz 1979; Gardner and Ahmed 2009; Chowdhury 1995; White 1992; Gardner 2002); family members reach out to comfort one another during the devastating time when someone loved is in hospital (Zaman 2013, 2005; Prince 2018; Brown 2012; Street 2014) or on life support. Family members feel it necessary to stay near to loved kin (who might be on life support and unconscious) to let them know that they are not alone. I found in this study that, besides the emotional support, relatives needed to stay near the ICU to provide medical supplies and to arrange some of the medical tests in the UTH. Bangladeshi Medical anthropologist Zaman (2005) found a similar situation in an orthopaedic ward at a government teaching hospital during his hospital ethnography in Bangladesh, and where he found that relatives performed a great deal of patient care, helping with dressing wounds, toileting, and feeding, all tasks that should be done by nurses and other hospital staff. The services and care hospitals cannot

provide due to lack of resources, relatives themselves fill the gaps. Zaman described the patient's relatives as 'silent saviours' (2013) as they carry out medical care duties. In doing hospital ethnography in resource-poor health institutions, researchers find relative's presence in the caregiving ubiquitous (Street 2014; Prince 2018; Brown 2012).

The constant presence of patients' relatives in the waiting room is seen as essential to life support treatment. The treatment incurs enormous expenses for the family. However, also it requires their presence to give consent for sustaining or withdrawing treatment when such a decision will precipitate the death of the patient. Until that 'final' moment arrives, the relatives wait in the waiting room. The presence and involvement of relatives in the process of life support treatment (albeit in the form of 'non-medical' support) highlights the embedded sociality of the life support technology.

The patients' families occupy the waiting room, and their presence is constituted with multi-layered realities of waiting with hope, frustration, incapability (of continuing treatment) in the world of life-sustaining treatment. The waiting room emerged as an integral part of my study of life support technologies, as the effects of life support technologies can be seen here, among the relatives waiting in this space.

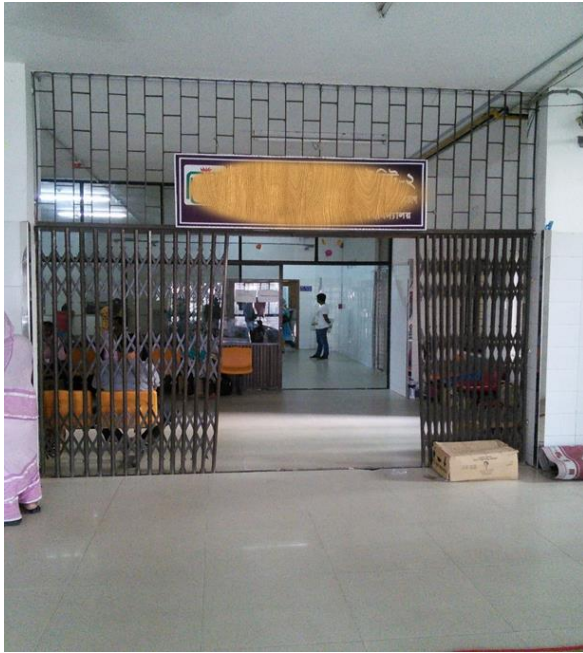
The purposes of waiting and the organisation of 'waiting spaces' at the ICU vary across my three fieldwork sites. As I briefly mentioned earlier, sometimes, patients' families need to wait *for* practical purposes such as bringing medicines and supplies, arranging pathological tests which need to be done outside the ICU unit (at UTH), collecting reports, giving consent,

and making decisions in life-prolonging treatment, and participating in doctors' briefings. The experience of waiting also differs from hospital to hospital, as different hospitals provide different kinds of facilities and amenities to the patients.

University Teaching Hospital (UTH)

When the lift door opens on the 6th floor, in front of me, I see an ample space occupied by patients' relatives. The gathering of relatives outside the ward is only seen in the 6th and 7th floor, where the ICU and HDU (High dependency Unit) is located in a newly constructed building known as the 'Cabin Block' building at the University Hospital. Attendants are not allowed⁴⁵ to stay with patients in the ICU or HDU on the grounds of transmitting infections. Every time I enter the ICU at University Hospital, I pass through this 'waiting room.' However, at the University Hospital, the waiting *space* is not limited to a room. It combines a specific waiting room with a considerable corridor in front of the ICU, both of which the relatives and I designate as the waiting room.

⁴⁵ There are a number of separate private rooms which are called 'cabins' for patients, in which relatives can stay officially overnight. However, these cabins need to be paid for. Moreover, cabins are not very easy get at University Hospital and BIRDEM. As the Phoenix Hospital is the most expensive among the three, no relatives whom I talked to stayed in cabins, instead they stayed at the waiting room.



Picture 1 The entrance to the University hospital ICU.

The area inside the collapsible gate with chairs is the designated waiting area.



Picture 2 Designated waiting space at University hospital

A 'collapsible gate'⁴⁶ (Picture 1) demarcates the ICU from the corridor. As this place is not very spacious, the relatives occupy the corridor area outside the ICU for waiting as well. Patients' families have transformed this corridor into a temporary home, which is overlooked by the hospital, as it is not officially permitted. As there is no storage or resting place for family members in the waiting room, they have no choice but to use this place to rest and to keep their belongings in. At night, the male family members staying at the hospital, sleep in the area outside of the designated waiting room, and the female attendants sleep inside the waiting room, where only chairs are provided. However, during the daytime, tiredness makes the gender segregation disappear. Both men and women rest in the corridor, as the designated waiting room (Picture 2) becomes occupied with other visitors or attendants during this time. Usually, at least one family member per patient stays at night, and other family members (if the patient is from Dhaka city or nearby) and friends come to visit during the daytime. In the busy schedule of daily life, this responsibility cannot be performed by all the family members equally. There is always someone who spends most of the time at the hospital, though other family members try to share the responsibility periodically. Doctors prefer to talk to the person who stays most of the time at the hospital as this member tends to be the most informed about the patient's condition.

It is prevalent to see attendants lying on mats trying to get some rest or sitting on the floor talking in a small circle with (probably) other family members. As seen in Picture 3, some are busy organising their bags and belongings. A low noise surrounds the whole space. Bedding

⁴⁶ Collapsible gates are a type of security gate that retracts to open and close. The word "collapsible" represents the way these conveniently conceal themselves in a very efficient way when opened.

and pillows, cups, plastic food storage boxes, flasks, plastic bucket-mugs, and many other things necessary for daily living, are kept behind rolled mats at the corners of the wall. These mats will be used as a bed again when relatives need rest. A few *gamcha* (traditional light-weight cotton towel) are kept on the window grilles to dry (Picture 3).

Soap, sachets of shampoo, and washing powder also can be seen under the window grilles, as if to keep them out of sight. I often see someone sleeping on the floor or chairs, or resting leaning on the wall, no matter how noisy the place is. Besides the sleeping person, some of the attendants eat together, discuss something, repeat the critical moments of patients, or just share good memories of the patients: giving emotional support to one another or sometimes just conversing with each other. I saw a female relative consoling the daughter of a patient by keeping her hand on her head and repeatedly saying to her to call Allah for help. The relatives make the best possible use of this space. I would often find someone saying a prayer at corners of the waiting room, lobby, or in the reception areas. Reciting from a holy book, saying *dua* (invocation), or counting beads for *tasbih* (prayer beads) are other standard practices in the waiting room, which denotes the coexistence of beliefs in medical practice and beliefs in religion in Bangladeshi society, which could commonly be understood as oppositional. Zaman (2005) found relatives to pray at an orthopaedic hospital in Bangladesh, while Pargament et al. (1999) also found that relatives' waiting for their kin's undergoing heart surgery at an American hospital are coping with the stressful situation by religious activities. Although biomedical practices are identified as non-cultural, objective, only based on scientific truth (as I discussed in the introductory chapter), researchers (e. g, Zaman, 2005; Pargament et al. 1999) did not find any conflict between biomedicine treatment and religion in relatives.

The coexistence of science and religion adds a further, specific layer to the realms of position-ality that meet and meld in the heterotopia of hospital/ICU space in my study.



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



Picture 4 Relative's temporary home at UTH

The floor of the whole space is unusually clean for a public hospital. It indicates the management of the anaesthesiology department at the University Hospital (under which the ICU and HDU operate), but also the relatives, are conscious of keeping this space clean. However, the way relatives stay in this waiting area with minimal facilities also reveals that the management of Anaesthesiology is not ready to accommodate patients' relatives as a part of life-prolonging

treatment. The constant presence of this group of people makes this ICU waiting area a little 'chaotic,' a common sight in Bangladeshi hospitals in general. I observed many times that ward boys and cleaners express their annoyance to the relatives for the way they occupy the space by mildly scolding. This is another manifestation of the medical hierarchy I confronted in this study. Early in the morning, before the doctors' arrive, ward boys, start to warn relatives to organise their belongings. They do the same when the chairman of the department or any high official of the hospitals or VIP comes to visit ICU.

A considerable signboard hangs over the gate, carrying the name of the ward in Bangla. It is a rectangular space furnished with colourful 3-link plastic chairs around the four corners of the room. The numbers of chairs are inadequate for the numbers of attendants that usually show up during the daytime, requiring a game of 'musical chairs' to get a seat. There is also an aluminium-glass partition that separates the waiting area from the reception lobby at the main gate of the ICU. Sometimes ICU management comes with an order to clear the space, which results in attendants hiding possessions and removing floor mats, although this happens only when a VIP comes to visit the ICU.

The reception lobby (Picture 6), just beside the waiting room with a reception desk, is a place for submitting applications for ICU admission. Security men are usually stationed at this place. Bipul, an office worker in his mid-20s, collects the applications in the morning around 8.00 to 9.00 and returns the forms with a decision around noon. The only electric fan hangs over the reception desk, which keeps the place cool. Bipul introduces me to the security guard to allow me to enter the ICU whenever I want. In the early days of my fieldwork, I needed to introduce

myself to different security guards every day as the guards' work in shifts. In time I was familiar with them all.

In the reception area, there are no chairs, discouraging attendants from waiting in this area. Nevertheless, small numbers of attendants always gather here. A guard asks me to sit on the only chair, thinking I am a doctor: all doctors at UHT undergo a minimum of 15 days of training in the ICU. I explain that I am researching the ICU for my PhD, and I am not a doctor. He looks confused but asks no more questions. Standing there allows me to see the whole area. The waiting space at University Hospital is not a place where only patients' family and friends come and wait.

I notice two other categories of visitors. One group works for pharmacies around the hospital area. The Raza Nagar area, where UTH and BIRDEM are located, is famous for having many medicine stores, pharmacy and medical equipment stores, and private boarding places. A fast-growing medicine market has been developed over the years by targeting these two large hospitals. This transformation of the area denotes the incorporation of the biomedicalisation process at large, as Clarke and colleagues say, biomedicalisation not only brings increased technologisation but also it brings a change in institutions and associated sectors involved in the process (Clarke et al.,2010). People from surrounding medicine stores approach patients' relatives to take medicine from their store. They provide service by delivering medical supplies directly to the hospital and selling medicine on credit.



Picture 5 The collapsible gate at UTH



Picture 6 Reception and Security Guard.

Guard stops relatives from going inside out of visiting time.

The other group of visitors is those looking for an ICU bed. Application for ICU beds is made in the reception area and returned here as well, after the chairman of the department has taken the decision. Those who are waiting to get a bed (it is often said 'seat') at the ICU gather here to find out the application outcome. They need to apply every day until they get a bed in ICU for their patients, meaning that the applications returned are usually unsuccessful. Frustration and helplessness become evident. Near midday, a young man of around 20 comes to retrieve his application. Bipul hands it to him. Bipul also introduced me to him in the meantime. The young man told me that he came here to look for a bed for his father, who was admitted in a private hospital after having a brain stroke.

Bipul: At present, there is no ICU bed free. Apply tomorrow morning again, and if anything comes up, you will get the bed.

Young man: Do I need to apply again? Why do you not you keep the application for consideration?

Bipul: No, we can't keep this as the decision has been marked on it already. You have to come with the new application for tomorrow.

Young man: How long do we need to wait for the bed?

Bipul: Actually, we cannot assure you when it will be available. Just keep in contact.

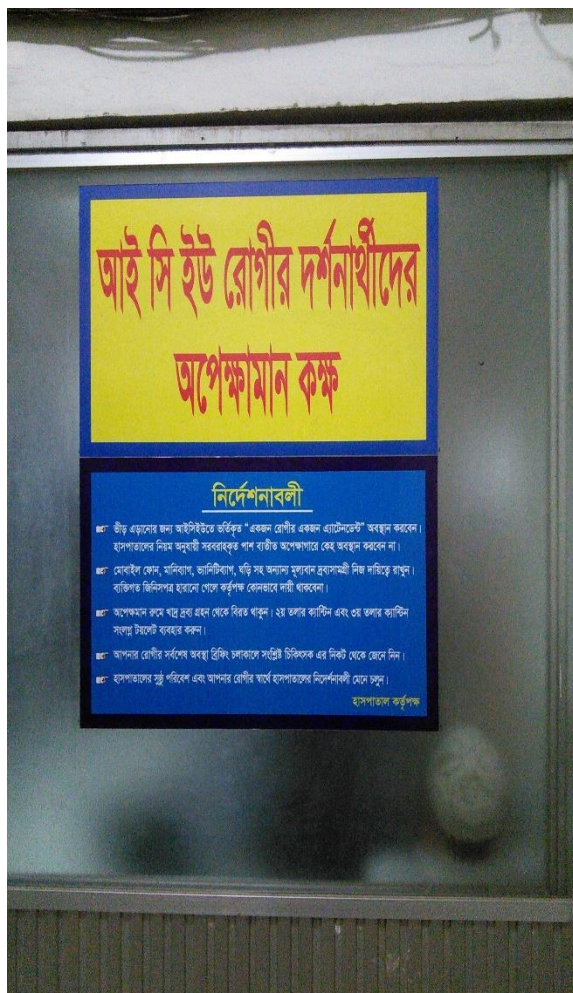
Young man: (surprisingly) What? My patient will die by then!

(UTH)

While the conversation was going between them, an attendant standing by the reception desk was curious about the health condition of this man's father. Asking this kind of question

to an unknown person is not unusual, nor is it treated as an intrusion in Bangladesh⁴⁷. I find this kind gesture to a stranger comes from the same experience they all are going through. The boy says that his family wants to shift him to University Hospital. Though he does not state it, I can guess the reason, as ICU treatment is cheaper in University Hospital than BIRDEM.

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



Picture 7 The rules for visitors, BIRDEM

⁴⁷ People often ask questions like this to an unknown person, for instance while they are waiting. Other common small-talk include "Sis/bro, how much are you paid?", "what is the salary of Dula Bhai (brother in law)?", "How old are you?" etc., questions which would generally be treated as a 'rude' intrusion into private life in the West. Recently, however, the modern, urban, educated middle class in Bangladesh have begun to avoid these types of question to an unknown person, adopting western attitudes towards privacy.

The waiting room at BIRDEM (Picture 7,8, 9) is in a separate room on a separate floor. It is furnished with eight 6-linked steel chairs, too many for the size of the room. A few essentials are provided for the attendants, such as a small storage cabinet, a water purifier, and a mobile phone recharging point (although most of the pins are broken). Attendants sleep on chairs and the floor irrespective of noise. Towels and clothes hang on the window for drying; bags, water bottles, and boxes are kept in the corners of the room, where someone is trying to fit into the space left, perhaps to take a nap. The place is crowded, full of people and objects (Picture-8). Like UTH, patients' families are also present all day long and overnight at the BIRDEM ICU waiting room. Unlike the UTH, however, the waiting room is *not* located on the same floor as the ICU. It is on the 2nd floor of the building, while the ICU is on the 6th. I learned from Dr. Qamrun that the waiting room had been moved there a couple of months earlier after a 'patient party created a nuisance.' The separation of the two spaces is to maintain the 'discipline' of the ICU, according to BIRDEM ICU doctors. However, Dr. Liza expresses her concern for the relatives. She tried to explain the relative's position, who made the 'nuisance' previously, logically, and empathetically. She said,

We cannot provide any amenities to the patient's relatives. They wait here day and night with zero facilities while their patient is in a very critical situation, and most of the relatives are under financial constrain. If we fail to reply to their queries properly, how would they be calm? [BIRDEM]

Dr. Liza's concern adds complexity to the discussion of a medical hierarchy. Her sympathetic concern shows that despite the hierarchical relationships, doctors are aware of relatives' agony.

In order to maintain the discipline, a notice (in Bangla) to be followed by the visitors is displayed at the visiting room entrance (Picture 7). The notice reads:

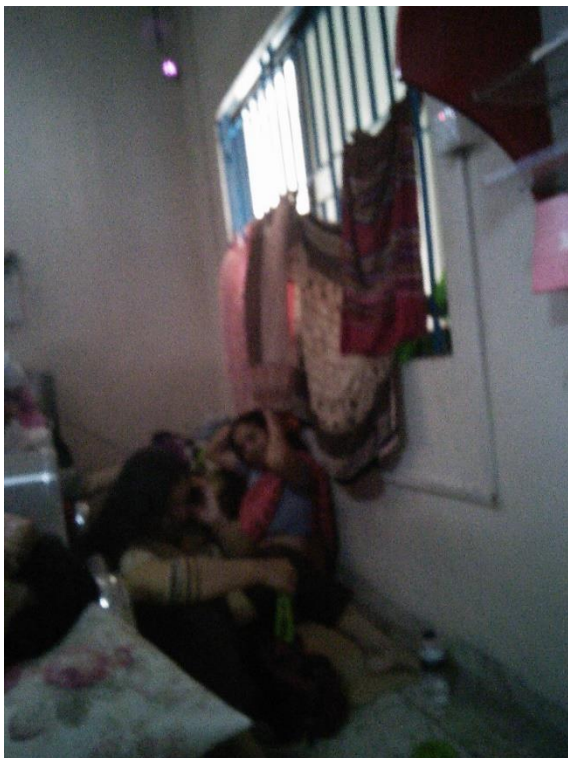
1. To avoid the crowding, 'one attendant per one ICU patient' is allowed. No one should wait in the waiting room without a pass provided by the ICU authority.
2. Take care of your valuable belongings, mobile phone, watches, moneybags. The hospital will not be responsible for any loss of belongings.
3. Avoid consuming food in this room. Use canteens on the 1st and 2nd floor, and toilets on the 2nd floor.
4. Check your patient's latest condition from the doctor concerned in the briefing session.
5. To ensure the healthy environment of the hospital and for the interest of your patient, follow the hospital rules.

Relatives meet doctors at counselling session usually takes place once in a day; nonetheless, relatives ask the duty doctors about their patient conditions whenever they get the opportunity. I have observed that doctors usually update relatives about the patient's condition. Nevertheless, relatives are not usually allowed to go to the patient's bedside outside the visiting hour; they can only enter the ICU to talk to doctors with doctor's permission.

A security guard is always seen at the waiting room entrance. The Public-Address (PA) system is used to communicate between the two places. If patients' relatives need to be called to the ICU, doctors convey messages to security guards to make the announcement using the PA system. This separation of ICU and waiting room reinforces the principle of heterotopic space—a Foucauldian concept to describe two spaces with oppositional characters, which I will discuss in the later section.



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



Picture 9 Jam-packed waiting room at BIRDEM

Nonetheless, some relatives are always seen in front of the ICU complex on the 6th floor, either sitting on the floor or standing with other visitors; usually the families of newcomer

patients and those in more critical condition. Sometimes, doctors call the family members of new patients to take previous treatment history or case history, or to arrange specific needs. For instance, if a patient needs a blood transfusion, the family is asked to arrange it, or if dialysis is needed, the family is asked to deposit the money⁴⁸ in advance.

Phoenix Hospital Limited

In my limited observation⁴⁹ at the Phoenix Hospital, the ICU waiting room (Picture 9) is the most comfortable of the three hospitals in terms of facilities and amenities provided for patients' attendants, but also the most expensive. A large-screen television, water filter, air-conditioning, and an adequate number of seats are provided. A sufficient number of clean and modern toilets (in terms of fittings) are located on each floor of the hospital.

⁴⁸ It costs BDT 3,000-7,000 per dialysis (GDP 28.6- GDP 66.84)

⁴⁹ I received permission to research two months prior to the end of fieldwork, as discussed in the Methods chapter.



**Picture 10 Waiting room, at Phoenix Private Hospital
Better arrangement for relatives**

Very few attendants stay at night in the waiting rooms, according to Priya (wife of Mithu Chakravarty). During my fieldwork at Phoenix Private Hospital, Priya stayed all the time in the hospital's waiting room. Priya has been waiting at the University Hospital since the first day of her husband's admission in ICU (when I talked to her, it was her 23rd day there) as she promised her mother-in-law that she would not return home alone, only with her recovered husband). The guard wakes them at 6.00 clock morning before the visitors start to come. There are plenty of washrooms on this floor; however, there is no place to take a shower. Priya says she manages to take a shower at other families' cabins by asking the occupants. She points to another visitor and says that she showers in their cabin's washroom. I see a couple of cushions on the chair, and a few luggage and travel bags kept either underneath the chair or on a wall rack. The waiting area is more extensive than at the other two hospitals.

It seems the management tries to provide maximum comfort to the relatives, presumably because they are paying the highest treatment cost.

Conceptualising Spaces of waiting

Often, 'waiting' becomes synonymous with the intensive care unit for relatives. The waiting carries the meanings of hope, care, and the reliance on medical technology at large, which motivates me to understand the word 'wait'. The word itself first appears in English in the early 13th century. As a noun, the meaning of a wait is rooted in 'a watcher, onlooker'. Interestingly, according to the Online Etymology Dictionary, from the late 14c, 'wait' also means 'an ambush, a trap' (as in lie in wait). It also says that the general senses of waiting include to 'remain in some place,' 'to see to it that something occurs' and to 'stand by in attendance on,' all in the late 14c⁵⁰. Concise Etymological dictionary (Weekley 1924) says that a wait is 'watch,' 'a guard, 'a being awake.' According to the Cambridge University dictionary (Dictionary 2008), the word wait means 'a period of time when you stay in one place until someone comes, or something happens, or until you can do something.' Another synonym for the word is to 'be patient.' In the following discussion, practices of waiting in the ICU waiting room carry various meanings of 'wait' outlined above.

⁵⁰ <http://www.etymonline.com/index.php?term=wait>

According to Tanner (2002), the waiting room is a temporary place where the length of stay is relational to the success of waiting. As she says,

by definition, [it] functions as a place we pass through on the way to somewhere else: a temporary stop rather than a final destination. By and large, time spent in a waiting room represents time wasted; the shorter the wait, the more successful our stay. A place where it would seem, nothing happens, the waiting room holds us only briefly before it sends us on to spaces more visibly marked by content.

(Tanner, 2002: 181)

However, for relatives, waiting at the ICU waiting room in a Bangladeshi hospital is not wasting time; for them, the waiting is a vital part of their 'hope for life.' The end of waiting means either the 'return to life' or the 'end of hope' (death). So long as relatives are waiting, there is a hope for life. The waiting room is where many dramatic situations evolve every day, always in relation to the situation of the critically ill relative in the ICU. When the ICU waiting room provides a space in which the caring, responsibility and familial bonding are enacted, then the ICU is represented as a place set off and isolated from everyday social space. The meanings and practices of waiting at the ICU waiting room are unique and evolve from the experiences of ICU patients' relatives involved in making life-and-death decisions for their close ones. This was reflected in a statement made by Samshed, maternal uncle of Tareen in a conversation with me: "*Only those who have experienced it first-hand will be able to understand it*" [UTH]. By which Samshed tried to express the immense pain of waiting in the ICU to me.

My ethnographic study follows the waiting room from Tanner's depictions of 'it seems nothing happens,' yet multiple meanings and purposes of waiting characterise it. It also broadens our understanding of the waiting room beyond being only a medical space.

The nature of the spaces themselves can be questioned. Geographers Mike Crang and Nigel Thrift (2000) discuss various accounts of the term 'space' from a wide range of disciplines. For example, in anthropology, *space* is a means of questioning how communities are constituted in an increasingly cosmopolitan world. In sociology and geography, space is "a means of questioning the materiality and its beyond ... space can be used to move closer to 'experience'" (2000:1). Nonetheless, Crang and Thrift (2000) find that common to all definitions is that space is considered to be very much within the social realm.

More specifically, for the space of hospitals, the concept of *heterotopia*, Michel Foucault (1986) usefully captures the complex relationships between order and disorder, stability and instability, that define the hospital as a modernist institution of knowledge, governance, and improvement. Foucault says that the *opposition* of the hospital to everyday life makes it an archetypal *heterotopia*, a space that is simultaneously real and imagined and constructed concerning all other spaces. Hence, I have taken the phrase 'worlds within worlds' in my chapter title from Foucault's work on '*spaces as heterotopia*'⁵¹ (1986), places that are different: '*disturbing, intense, incompatible, contradictory and transforming.*' In short, Foucault says that heterotopia is a space best described as 'worlds within worlds'. The Foucauldian notion

⁵¹ For details, see <http://www.heterotopiastudies.com/>

of heterotopia helps me to understand the space of the waiting room. Foucault also argues that hospital architecture and the situation of the hospital in an urban setting are crucial mechanisms in the politics of health (Foucault 2007). This argument also provides a way to understand the waiting room as being a part of hospital architecture as well as a crucial mechanism in the politics of health; for example, I found that the physical condition of the waiting room itself reveals the conditions of existing health care service, regarding the resources, amenities, and conveniences available for the patient and family, and how much consideration they are given. I, therefore, found the space of the waiting room as embedded in the sociality, which is as well situated in the highly technologised, 'sacred' place of a hospital: being separated and isolated from the 'as usual' domain of life.

According to Foucault, heterotopia presupposes:

A system of opening and closing that both isolates them and makes them penetrable. In general, the heterotopic site is not freely accessible, like a public place. Either the entry is compulsory, as in the case of entering a barracks or a prison, or else the individual has to submit to rites and purifications. To get in, one must have a certain permission and make certain gestures. Heterotopias are, according to such a view, intrinsically ambiguous spaces. They are both constituted by their relationship to other spaces and defined in opposition to them; they involve a complex ordering of opening and closing that both isolates them and makes them penetrable (Foucault 1986: 26).

Despite the distinct natures of the waiting room and the ICU, the waiting room functions as an extension space of the Intensive Care Unit. The ICU is, in one sense, a highly mechanised, organised, isolated, and restrictive space, equipped with technology and organised according to 'biomedical logic.' In contrast, the waiting room may be seen as a 'chaotic,' 'dis-organised', 'germ-infected', 'subjective' place according to therapeutic medical knowledge (Foucault

1986). Hence, while the complex relationship between the two spaces can be explained and defined in 'opposition' to each other, from my point of view, the realities of the therapeutic and waiting spaces of the ICU are intertwined, relational, and as an extended space of ICU occupied by patients' relatives in turmoil, facing life support technology. They should be understood in relation to one another, rather than separately.

My ethnographic study shows that despite the lack of sufficient amenities available in the waiting room, relatives transform it from a 'simple space of waiting' into a useful waiting space arranged according to their needs and convenience. Furthermore, from this generally considered 'disorganised,' 'chaotic,' 'place of infection' space, relatives perform their required duties for continuing the treatment process in the ICU (Zaman 2005, 2013; Brown 2012; Street 2014). My study reveals the importance of familial presence in the waiting rooms. It shows that relatives' presence is essentially needed in UTH and BIRDEM. However, the space of the waiting rooms where relatives are 'on stand-by' is not given much attention, nor is there regard for their physical and mental comfort as they go through a most critical time. The Phoenix hospital's waiting room is better than the other two hospitals, and their way of dealing with relatives is different. However, it is also vital to note that Phoenix Private is the most expensive hospital of the three, which may account for the difference. Phoenix hospital has better amenities, better counselling sessions with relatives, but very few people have access to this quality of health care in Bangladesh.

Heterotopic space and ICU visiting hours

The tendency to view the waiting room and its occupants as 'oppositional' to ICU is revealed during the visiting hours. This is a time when waiting places attain a lively mood; it seems as if the waiting is about to end. This is the only time (though very brief at UHT) when relatives get a chance to see their kin at ICU. Undoubtedly this is a temporal end or 'break' in the waiting for the relatives. More visitors - family, friends, relatives - start to arrive before visiting an hour. Of the three hospitals I conducted fieldwork in, the visiting policy is stricter in UTH than in BIRDEM or the Phoenix hospital. Relatives or friends can only visit UTH once a day during visiting hours. Expensive private hospitals such as Phoenix Hospital are not very strict about visiting hours. The Phoenix Hospital ICU generally allows relatives outside the visiting hours. Nevertheless, the basic principles of 'visiting hour' are the same across all the research sites. Visitors are allowed to stay only 5-10 minutes at the patient's bedside. At the weekend and holidays, the waiting area is typically more crowded.

The visitors stand in a queue to enter the ICU at UTH. The queue sometimes crosses the gate. The guard lets 2-3 visitors in at a time, also checking whether visitors have properly covered their head, mouth, body, and shoes with disposable covers.⁵² Wearing the covers is mandatory in all three hospitals. The guards maintain an air of authority. They also monitor the number of visitors for each patient, and sometimes stipulate: "no more visitors are allowed for bed no ...". The private hospitals in this study were more flexible in visiting hours than the

⁵² visitors need to buy these supplies

public university teaching hospital. Generally, visitors can come twice at BIRDEM. Though I have not seen any queue at the ICU complex at BIRDEM, the guard remains vigilant on visitor's entry to the ICU. Phoenix allows visitors all the time, as the ICU head confirmed it to me. However, I have not seen many visitors in the ICU there.

The waiting room/ICU space is thus characterised by a visiting policy regarding access, which denotes the rule of heterotopic space: the site is not as freely accessible as a public place, and the individual has to maintain the strict rites of purifications (Foucault 1986). A strict visiting policy controls relatives' movement between ICU and the waiting room. Despite their other commitments, some relatives wait all day to see their kin, and they consider this waiting to be 'taking care.'

Discipline, Foucault declares, is the key to separating the hospital as space, being 'above all an analysis of space' that is also evident in the context of the ICU waiting room. The separation of the waiting room from the ICU is presumably based on disciplining 'germ control' by not allowing visitors inside the unit very frequently, and by requiring them to adhere to infection control measures (i.e., wearing disposable covers on head, face, body, and shoes). Even touching is strictly controlled. I have heard nurses forbid the visitors to touch a patient. Despite the touching restriction, I also saw relatives touching their kin secretly.

There is a historical root of this attitude towards visitors. According to Mooney (2009), visiting the hospital has been a neglected theme in the western history of medicine. The reasons behind restricting visitors were the result of a gradual increase in medical control over all aspects

of the institutional experience and the fear of infection between the hospital and the wider community (Mooney, 2009). In the seventeenth and eighteenth-century, a hospital was not considered as a therapeutic space; instead, it was a place where poor people went to die (Foucault 1984). To control epidemics and contagious diseases, hospitals discouraged visitation outside the specifically allowed time, even after the emergence of the hospital as a (healing) 'medical-hospital.' In that period, only celebrities were welcomed as exceptions to hospital visitation policy to raise charitable funds (Mooney 2009; Finkler and Iedema 2008). Foucault argues that the 'question of the hospital at the end of the eighteenth century was fundamentally a question of space,' and the medicine of this time was, through its use of space, simultaneously one of the individuals and the population. A thread links these considerations with the practices observed in the ICU/waiting room spaces in my study.

I found that the waiting rooms themselves are a kind of liminal space – both domestic and institutional. The fact that the authorities do not attempt to 'clear' them reveals that they accept that these spaces, while within the institutional space, are not entirely governed by institutional rules. They are informal and hybrid spaces with their own 'rules' that arise from the interactions of the attendants with each other and with the institution's staff. The ICU is then a 'heterotopic space' (Foucault, 1986) because it is set aside from both the 'general' wards, the administrative spaces, and the hybrid domestic space of the waiting' room,' and entry, as observed above, is through ritual and purification. Although not all three waiting room spaces are equally 'chaotic' or 'disorganised' in terms of lacking an explicit 'discipline,' nonetheless, their occupants are similarly governed by and follow the rules of responsibilities, caring, and social bonding.

In the next section, I will discuss the different practices and purposes of waiting that relatives engage in these spaces.

Practices and purposes of Waiting

In this section, I discuss the various purposes for and practices of waiting by relatives at 'waiting rooms'. Life support treatment generally requires an extended stay at the hospital, and the condition of the patient can deteriorate at any time - a tension that requires relatives to wait close by. As, Nahid, a relative of Shimul says,

you understand, an ICU patient's condition is very critical. It can get worse at any time. So, we need to stay here all the time. However, we cannot see our patient very often, but still, we are very close to them, that make us more comfortable. [UTH]

Nahid's comment resonates with Henri Bergson's (1859–1941) reflections on *waiting* time, "*If I want to mix a glass of sugar and water, I must, willy-nilly, wait until the sugar melts*" (cited in Schweizer). Bergson's point here is that, whether one wants to or not, one has to wait for the result of an action (in this case, life support treatment), the precise point of which is hard to predict. Similarly, the waiting of the relatives, whether they want it or not, ends only when the critical condition of the patient comes to an end. Their staying near to the ICU gives relief to the anxiousness caused by the unknown resolution time and the ICU restrictions themselves.

Waiting nearby is also required to meet needs such as supplying medicines and arranging other requirements of treatment (in the University Hospital and, in some cases, BIRDEM). Nonetheless, temporary residence in the waiting room is also for emotional and financial purposes. Staying in the waiting room comforts relatives by being close to, although physically separated from their loved ones. At University Teaching Hospital, relatives supply medicine, blood, and food, and arrange pathological tests and other things required by doctors for treatment procedures. The patients' families need to provide copies of payment receipts before some tests, such as x-rays, CT scans as such that need to pay at the cashier counter located in a different place. At UTH, the family must provide everything from medicine to gloves, hand steriliser, and air fresheners to the ICU ward. Being a government hospital, due to a lack of resources, they are unable to provide all these supplies free to the patients. Requisition slips for medical consumables are given to an attendant in the morning shift, usually after the doctors' round. However, depending on the patient's condition, an emergency medicine/test/blood can be asked for by the ICU at any time. Hence, staying near to the ICU is necessary for relatives to be able to meet the needs of emergency supplies.

Waiting Room: The making of a temporary home

For some attendants, the waiting room turns into their temporary home. Sometimes financial reasons compel relatives to stay in the waiting room. Many patients come to the University Hospital from a different part of the country and do not have relatives in Dhaka. The patient may need to be in the hospital for an indefinite length of time, and financial hardship becomes a profound reality. Living in Dhaka is expensive, which exacerbates the cost of medical

treatment. Therefore, staying at the hospital relieves relatives of the cost of accommodation and transport. Shuman says that either he or Shimul's brother alternatively stayed at University Hospital since October 2015 (until I last visited the hospital on March 24, 2016). It is not practical for them to rent a house.

If I rent a house, I will need to buy all the household appliances, and someone to take care of the house, for cooking and other household chores. Alternatively, I need to bring my sister (Shimul's wife) or mother, who will not be able to stay at home alone. It is much better to stay here. At least I can stay near to him. [UTH]

Shumon's account reflects the nature of Bangladeshi society, where women do most of the household work. It also reveals the nature of urban housing arrangements, unlike those in the West. With very few exceptions, houses are rented unfurnished. To rent a house requires beddings, hobs, pans, utensils as such to be bought by tenants, meaning that arranging a household by one member is not an easy task, furthermore expensive.

Taufiq's brother Faisal, who is from the Noakhali district, and Rohan's father, who is from Chittagong district, both stay at University Hospital for the same reason, even though there are no necessary arrangements for attendants to stay overnight, let alone for extended stays. The washrooms are well maintained, but there is no place to take a shower. Sometimes they take a shower in the toilet. Nahid sometimes goes to a cousin's dormitory at Dhaka University to take a shower, which is not very far from the hospital. According to Nahid, "*we are sleeping on the floor, living like 'the average Joe' [am-janata] at the ICU corridor.*" [UTH]

Patients of this study who receive life support treatment are usually from at least the middle class, who can afford the cost of treatment at some level from their resources or with the help of friends and family and charity. Shumon's comment reveals that the mode of living in the ICU waiting room does not reflect their usual living standard. Living in the waiting room is a strategy of situational adaptation to a reduced, impoverished situation. I find here a specific way of 'temporary' living, in which relatives transform the ICU corridor and lobby into social spaces, and their corresponding bodily practices (modes of living in them) have become naturalised as per Foucauldian heterotopia. As Kohn says, space has consequences for how individuals and groups distinguish their place in the order of things (2001). The way patients' relatives occupy and transform the hospital waiting rooms imbue the space with social meanings of waiting. I would say, relatives, transform institutional spaces into domestic ones, albeit of unusual domestic arrangements. These social practices and meanings have emerged as a consequence of life support technologies and institutional rules. However, attendants are active in making their own spaces within certain affordances of the hospital authority and architecture. Thus, the ICU waiting room exists no longer as a mere medical space but becomes a social space, which is also a temporary home, which I refer to as a hybrid domestic-medical space.

"You are not alone": Universality of waiting

Waiting is universal, yet differences in the contexts of class, status, and position, disrupt the 'universality' of waiting. Above all else, relatives wait in the waiting room to stay near to their ill kin. Sometimes waiting is associated with hopes of recovery, such as in the case of Siam's

father, who has been waiting in the ICU corridor for a month when I started my fieldwork. The doctor says that being an 11-year-old child, Siam has a good chance of regaining consciousness. Siam has GBS but has also had a cardiac arrest. His father lives in Dhaka, not too far from University Hospital, but stays in the hospital corridor. He says,

nobody is now living at my house. I will return to the home with Siam (he bursts into tears). My wife, with my younger child, is currently staying at my sister's house. I try to stay at the hospital as long as possible. From Siam's childhood, I take care of everything. Feeding, dressing, everything. Even the day when he got GBS, I was preparing him in the morning, as he was feeling frail. I raised him for these 11 years.

[UTH]

This example reflects a desperate action emerging from love, leading him to stay in the corridor as long as he can. Through his presence, he seeks to review and be reassured about the care given by the ICU staff. As he says, he cannot imagine what would happen if he was not present there regularly. Siam's father stays to ensure that feeding and other regular care is adequately undertaken. He makes Siam a smoothie, as advised by the doctor, and hands it to a nurse only at mealtime. Siam's father's waiting is performed as subtle surveillance over caregivers in ICU. This surveillance is not merely questioning the dominant and authoritative practice of ICU caregivers, but a coping strategy of Siam's family with the medical system. As Siam's father says, *"I have to remain here as nothing is done properly without our monitoring."* Siam's father is not alone in finding ways to ensure proper care, as Nahid says, *"Nothing is done here without 'tipping' the ward boys."* The constant presence and 'tipping' are performed here to smooth the daily care of patients.

Priya's husband, Mithu Chakravarty, was taken to the Phoenix Hospital on the same day as he was shot in the throat by hijackers: on January 3, 2016. Since then, Priya has been staying at Phoenix Hospital in the waiting room. Her brother in law, Shubho, accompanies her during the night. Her father-in-law brings meals for her every day from Savar, on the outskirts of Dhaka. When I asked why she did not go home to rest, she replied with a smile, "my suffering in staying here is nothing compared to my husband's pain. My husband is suffering the real pain."

Not so many attendants stay at night in the Phoenix Private Hospital waiting room. Besides Priya (with her brother in law), only two or three other attendants of HDU patients stay overnight at this hospital. For example, I find that the wife of Mahmudul Huq, former attorney general, never stays overnight at the hospital waiting room, but is always present from morning to late at night. Her husband's condition is critical (intestinal carcinoma), and she wants to stay near to him by sitting in the counselling room. The management of the ICU at Phoenix Hospital cannot stop relatives from staying. As the lead consultant Dr Nur Ahmed says,

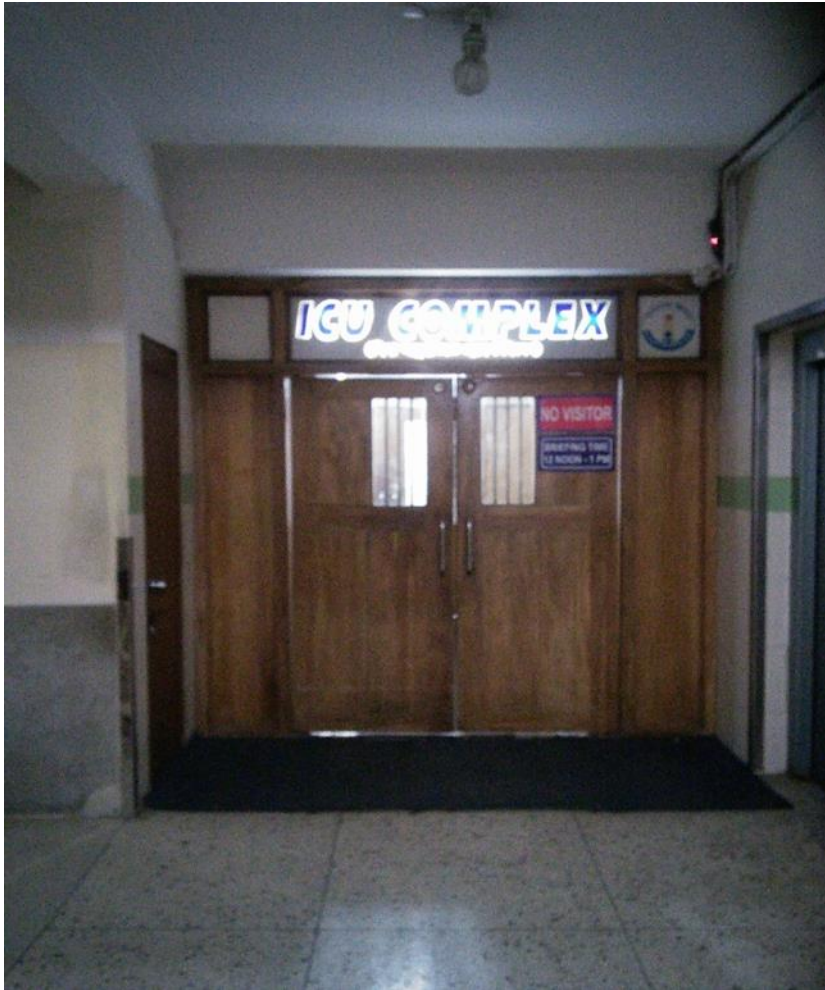
we say to the patient party that after admitting your patient here, it is our responsibility to take care of her/him. You can now go home and relax. If we call you, that indicates that something serious has happened to your patient. Until then, you can stay relaxed. [Phoenix hospital]

Here, it can be seen that waiting is a practice differentiated by social class and economic circumstances, and, as expressed by the doctor, with 'care' being 'delegated' to staff.

While the hospitals have different policies towards families being there, I have mentioned above that a strict visiting policy characterises the ICU and ICU waiting room. Nevertheless, I have not observed this visiting rule applying to *VIP* visitors. In reality, there is no such restriction for VIP patient's visitors. Even time constraints are not applied to them. If the patient is a doctor or a doctor's close relation, they are also treated like a 'VIP patient.' During my fieldwork, the husband of a political leader was admitted to ICU at UTH for about a month. Once a minister visited him with a group of people along with television camera crews inside the ICU. The chairman of the department, Vice-Chancellor of the university hospital with other consultants, also accompanied them. It was surprising to find that no one prevented these visitors from entering the ICU without shoe covers. Nor was there any floor cleaning after the group visit. Moreover, the minister and his group did not need to wait or queue to visit ICU, despite the consultants, doctors, and the whole ICU having waited a couple of hours for the minister to come. Therefore, the waiting of the politically dominant class takes a different shape than usual. I even heard from a 'ward boy' asking the head nurse if the general visiting hour should be cancelled. Such preferential treatment based upon political power is clearly expressed through the attitude of ICU management, at least at UTH. This incident parallels the mechanisms described by Akhil Gupta in *Red Tape* (2012), where he finds state employees through some regular bureaucratic practices construct boundaries between state and society that eventually gives them some 'advantage' to break the rules. Here, the dominant class can be seen breaching the universality of waiting that seemingly obliterates some hierarchies present in the outside world between attendants-in-waiting: the truly privileged do not wait, nor are their visits structured by the same rules that apply to others.

Patients' relatives are compelled to be present at the hospital waiting rooms for multiple reasons. Sometimes, they take it as a duty to stay nearer to the critically ill close one,

sometimes the situation demands it. Whatever the reason, for the sake of ill relatives, relatives ignore their suffering and agree to stay with the minimum facilities available to them. Relatives' constant presence and their practices of waiting denote the culture of responsibility towards critically ill kin. I want to stress how the waiting room space filled with people, carries the sentiments, anxiety, and emotions of those waiting and how patients' relatives share experiences and sufferings in this space. Thus, the ICU waiting room is also marked by affections, responsibilities, vacillation, rationality, and sometimes with hope and frustrations. Therefore, I consider the ICU waiting space as an extension of the ICU as the situation of the waiting room changes in response to patients' conditions within the ICU. Here, the two spaces are inextricably intertwined, as actions are taken in the ICU have a direct impact on the ICU waiting room. An intense, stressful situation manifests in the ICU waiting room when patients deteriorate. While patients' conditions improve, relatives waiting outside are happy and hopeful.



Picture 11 This is the ICU complex, at BIRDEM

Solidarities in Waiting

The waiting room demonstrates much about sociality. Solidarity forms among the group of people gathered for common reasons: that their kin is critically ill, dwelling between life and death. Following Bourdieu, we can understand the 'situational' bonding, which grows in the space:

All agents are located in space in such a way that the closer to one another in those two dimensions, the more they have in common; and the most

remote they are from one another, the less they have in common (Bourdieu 1998: 6).

This statement mainly seems to suggest the solidarity that developed among the relatives of ICU waiting rooms was based on class, gender, and culture, as considering the waiting rooms at UTH and BIRDEM, more sharing was found among the attendants who came from similar class background. I found a closeness between Shamoly, Tuhin's mother, Nahid, and Rohan's father. The financial constraints and critical conditions of ICU patient become the common phenomenon which keeps patient's relatives occupied and stressed. These common platforms of lived experiences unite attendants with each other. They find comfort by creating a common space of sharing since they have been in the hospital for a long time.

One evening after visiting the ICU, I come out to the waiting room looking for a place to sit with other visitors. The visiting hour is not over yet, so the place is crowded. The corridor and waiting room are filled with many 'unknown' faces - those who do not stay in the ICU regularly. Understandably, these visitors come to visit a patient when they get a chance. I am feeling a little uneasy in this crowd, as I cannot place myself anywhere in the waiting room. I feel relieved to see Samshed there. Fortunately, I find a chair beside him. His eyes seem like he just had a nap. Samshed, the maternal uncle of Tareen, has been staying at UTH for the previous 56 days when I meet him. Samshed has shared significant responsibility as a male family member. Most of the daytime, Tareen's mother attends ICU, while Samshed covers the rest of the time.

Samshed says,

I become friends with many family members of ICU patients in the last 56 days. We now feel like a family. Once, no ICU patient died for 20 consecutive days. That time, we used to say how wonderful it would be if all of our 21 patients come out from ICU on their feet! Then we would go for a picnic altogether! [UTH]

Nahid also sat with us says,

we are in fascinating social relations [indicating the relations between patients' attendants]. A few minutes ago, we all had lunch together. Bed number 1's family went to the village to arrange money for treatment. There is no one left to get the medicine for the patient. I brought the medicine from a pharmacy. We help each other in need, though we all are almost dead [mora]. [UTH]

Sharing food with the newly made friends at the waiting room is a pleasant scene to observe.

As my fieldnotes find,

I am sitting with Tuhin's mother in the waiting room. It is around 2 p.m. In front of our chairs, two girls are sitting, their mother having been admitted to ICU. One of their relatives has brought lunch for them in a large tiffin carrier. Both of the girls have lunch one after another. They request their father to have lunch as well, though he refuses to take it. Their father takes the Jainamaz (prayer mat) and goes inside to say a prayer. I can see from my chair that he is praying behind the reception desk. He again refuses to have lunch. After a couple of minutes, Harunur Rashid, father of Rohan (bed number 11), hurriedly comes to him, saying, "sorry I am late. I went to say a prayer ... Come,

come, brother, I have been waiting for you to have lunch together.” They both sit on the mat on the floor and start eating together. [UTH]

A reciprocal relationship like this develops mainly between attendants of long-term ICU patients. They comfort each other by giving suggestions, advice, sometimes receiving requisition slips or information on behalf of other attendants, taking care of possessions if anyone goes out, bringing medicine from the pharmacy, and so on. The nature of space, the purpose of living in the space, the people as a group who live in a particular space in a particular condition all develop a community feeling that might be temporary and situational. This community feeling can be identified as a ‘specific gesture’ developed in a heterotopic space, such as a waiting room.

A unique sense of solidarity grows among the relatives, that can be identified as a sociality. While I am at BIRDEM, a young man comes to me with whom I have not met before and says, *I am exhausted. I want to sleep for a while, will you please look after my mobile phone on the charger point?* He doesn’t wait for my reply, he lies down on the chair and falls asleep. He makes me wonder because trusting an unknown person with a valuable object is not common in Bangladesh. It made me realize that either his tiredness was too intense to bother who I am, or the nature of the waiting room space allows its occupants to feel togetherness or sympathy for each other. I saw this kind of request being made to Arzu by another attendant as well.

Arzu Akhter’s mother has been in the ICU (at BIRDEM) since early January 2016. Since then, Arzu has been shifted from cabin to ICU on and off. During the daytime, she stays at BIRDEM

until her elder sister comes to stay at night. As her mother is one of the extended-stay patients in ICU, Arzu Akhter knows other patients' relatives very well. She says,

Have you seen the patient of bed 17? A very young man had two children aged 14 and 5. He was on life support, and the doctor said there is no guarantee to his consciousness. His wife was a housewife. They had a flat of their own. That was the only property they had. When she started facing financial hardship to continue the treatment, her in-law relative advised her to sell the flat. Her in-laws were greedy for the flat. They didn't offer her any financial support. We advised her, 'do not do it, sister. You have two children to support their future. This is the only property you have, so don't sell it. Since there is no guarantee of your husband's improvement, take him home, and keep praying for his life. Do not waste money here'. Though she continued treatment for almost a month with the help of her husband's colleagues and a loan, in the end, she had to take him home. I still have a connection with her."

[BIRDEM]

I found this a common scenario in the waiting room, of sharing experiences and taking advice from one another, and relationships built upon trust and empathy. It is the collective experience that unites all the un-related relatives of ICU patients at the present moment.

Conclusion

In this chapter, I have focused on the various purposes and practices of waiting performed by patients' relatives in ICU waiting rooms. I intended to explore the various meanings

embedded in the waiting of relatives. It is impossible to identify a single reason for why they wait. Instead, my ethnographic exploration finds a complex world of waiting performed by relatives in the waiting room, where I find “worlds within worlds.” By describing the waiting room as a heterotopic space, this chapter, therefore, addresses how the waiting room becomes an extension and relational place to ICU. It discusses how bonding and sharing develop between relatives while waiting together for their kin and how their daily life is shaped in the waiting room in response to life support technologies. I wanted to show the ICU waiting room as a relational space of ICU, one that can be best described as a heterotopic space where the biomedicalisation of death has largely taken place. The waiting room has domestic aspects, caring aspects, and the attendants themselves perform ‘surveillance’ of the responsibilities of staff, this is what makes it hybrid medical-domestic space, and relational in that the care of patients depends on the actions of relatives, both through their waiting in the waiting rooms but also their actions to bring medicines and supplies, to arrange and pay for tests.

Despite the stressful general situation, the pictures of ICU waiting rooms do not merely present sad and worried faces, nor is the picture of ICU space of something static. As I have said, the ICU waiting room is a 'temporary stop' for the patients' relatives. For them, the time spent in a waiting room is not 'wasted' but a matter of hope for the future. Ironically, frustration and agony stand very close to hope. In relation to the argument, the next chapter chapters will be focusing on the interplay of hope, inequality at the cutting-edge innovation life support technologies in the biomedicalisation process.

CHAPTER FIVE

Biomedicalisation in action - I

Death and Embodied Biomedicalisation in intensive care

When a sophisticated new technique or instrument is adopted in medical practice, it transforms not only what doctors do, but also the ways people think about health, sickness and medical care.

(Winner 1986:58)

Introduction

Inspired by Winner's observation above, in this chapter, I am concerned with analysing how groups of health professionals and relatives talk about health, sickness, and medical care in the context of the ICU. I pay attention to how they work with the machines that keep patients alive and how these machines are embedded in certain everyday practices and relations. In particular, I explore how life support technologies are implicated in creating hybrid-technologised forms of life and death. In the following, I discuss my observations of doctors, nurses, relatives' experiences of life support treatment, and their accounts of this experience. With regard to relatives, I examine what they understand as possible and desirable treatment and their realisation of death and dying while their kin is in the ICU wards. My aim is to address the biomedicalisation of death in action through the practice of life support technologies in Bangladeshi ICU wards.

The first part of this chapter discusses the issues associated with the relatedness of and interactions between society and biomedical technology to understand the relative's perspectives. In the second part, I discuss the techno-social forms that emerge from interactions between life support technology and the associated domains. Finally, I conclude with the various techno-social hybrid forms of death in the ICU through which I discuss biomedicalisation in action.

Technoscientisation, technologisation and the emergence of hybrid techno-social forms

By *technoscientisation*, Adele Clarke and her colleagues (2003, 2010) mean the changes of 'life' over time and circumstances with the increased advent of biomedical technology. Following Clarke et al. (2003, 2010), I have chosen to use 'techno' and 'science' together as 'technoscientific' to be considered co-constitutive. By this conjunction, Clarke and her colleagues also intend to discard the idea that 'pure forms' of scientific or technological research are different from their practical applications (2010:16). The biomedicalisation theorists say that the new technoscience and the biomedical corporate enterprise influence not only how medicine is practised, but also how technoscientific discourses penetrate public discourse (Clarke et al. 2010). This study finds that technoscientisation occurs in medical practice and care⁵³ in life support treatments, which also influences public understandings and choices. The technoscientisation of life support treatments brings changes to the meanings as well as

⁵³ In Bangladesh, we can see enhancement in treatment process has grown narrowly, though for example infertility treatment by IVF is expanding its practice and gaining popularity Sultana, M. T. (2014) *Without a child my world does not end: IVF and childlessness in Bangladesh*. PhD Lancaster University.

essentialise certain types of death, dying, and care. Similarly, Sharon Kaufman (2005) showed in her ethnography how hospitals shape end-of-life care through further medicalisation in the US, where the central aim of hospital care is to maintain life.

In the sections below, I discuss the biomedical practices in the technoscientific area of ICU. I will explain how hybridised, and technologised forms of personhood, death, and care are being created and shaped with the advent of life support technologies in Bangladesh, and how through technologisation and technoscientisation of medical practice, biomedicalisation is organised and negotiated. I suggest that a new form of care, social responsibility, and understanding of life, death, health, and body emerges and creates new hybrid techno-social entities as a co-production of life support technologies. The subsequent sections use empirical findings to demonstrate how the changes occur in death and dying, and in relatives' understanding of these, by administering life-support technologies in ICUs, which eventually indicate the biomedicalisation of death in a localised form.

New ways to understand health and body

In my field notes, I noted the following:

Siam's father: Last week, Siam was doing better, his GCS⁵⁴ level was 8, but suddenly GCS has dropped today. I am frustrated.

⁵⁴ The Glasgow Coma Scale (GCS) is the most common scoring system used to describe the level of consciousness in a person following a traumatic brain injury. Basically, it is used to help gauge the severity of an acute brain injury. The GCS is the summation of scores for eye, verbal, and motor responses. The minimum score is a 3 which indicates deep coma or a brain-dead state. The maximum is 15 which indicates a fully awake patient

Nahid was comparing his brother's condition with Rohan by their GCS levels. He was saying,

Rohan's condition is much better. His GCS level is improving, but my brother's (Shimul) GCS is not improving anymore. [UTH]

Through my observation, I learned that measuring a patient's condition by using their GCS level is very common in the ICU. I realise that the patient between life and death on ICU bed loses personhood and is eventually represented by scores, signs, and numbers; categorised and presented as "*viable life, death in life or death*" (Kaufman 2005: 63). Often, the patient loses her/his name and becomes identified with bed numbers.

Here I want to argue that person is not only 'an autonomous conscious person' (Taylor, 1989) nor to consider personhood only as of the quality or condition of being an individual. Instead, I understand the personhood of the patient as being attributed by the culture, family members' understanding, expectations, and conceptualisations about the person, which is not a natural or innate quality (Bloch, 1993; Kaufman and Morgan, 2005; Lambek and Strathern, 1998). As most of the patients at ICU are in a deep coma, which reflects no apparent consciousness, regardless of the biomedical explanation of this stage, relatives conceptualise patient's personhood through the image they already had in mind about her/him with which relatives used to know the person, along with the new knowledge such as scoring, input-

(the original maximum was 14, but the score has since been modified). In UTH I found to use GCS score for other patient without traumatic brain injury but those who are in 'unconscious state' in the ICU.

output offered by the ICU practices - as in the above statement of Nahid and Rohan's father. Relative's new way of understandings about patients' health, illness, and personhood can be understood as a biopolitical subject, as discussed in Chapter 2 (Kaufman and Morgan, 2005). Relatives and health practitioners understand and describe the patient's condition in terms of GCS scores, numbers stated in the blood tests, input (feeding), and output (urine) measurements through the lens of 'truth game' as described Foucault (1975). Drawing on Foucault's proposition of genealogy of medical categorisation and their social impacts, we understand that relatives, during their extended stays at hospitals, adopt the medical terms, language, and the perception through medical categories, which led them to describe and understand the condition through the scores as used by doctors (and technology): they adopt a new, more medical gaze.

As the above statement of Nahid and Siam's father, Zahirul Islam reveals, they not only understand the condition but also compare the condition with numbers and scoring, which may be understood as a reduction of the personhood of the patient. However, relatives often concurrently have two opinions about doctor's explanations. Despite the medical gaze, relatives simultaneously use their 'own' perception to understand the patient's condition. For example, Zahirul Islam, differs from the doctor about Siam's reflexivity that he does not recognise anyone. Zahirul told me: *'I don't agree with the doctor. They say Siam cannot recognise us. When my wife or I touch him, he calms down, and he falls asleep. You saw in the morning when I was patting him, didn't you?'* [UTH]

He seems happy when I agree with him. Earlier that morning, I saw Siam very calm and comfortable when his father was giving him an oil massage and caressed him. So, there is always an ambivalence between medical categorisation of normalcy (that reveals which is normal and which is not, based on pathological standard) and people's understanding of it. Patient's relatives carry both opinions as they simply cannot ignore doctor's opinions by considering it as 'scientific truth,' but neither can they ignore their understanding regarding their kin's reactions and condition. When the GCS score improves, relatives, become happy and hopeful, whether or not the patient displays any 'visible' improvement. I find ambivalence very profoundly in relative's mind alongside the process of biomedical subjectification in the various part of the ICU treatment process, which I mention throughout this thesis.

The cultural aspect is also embedded in relative's perception regarding life support and biomedical intervention in the ICU. The following section is based on one of many situations in this research that reveals the coexistence of culture and biomedical knowledge, where biomedical knowledge is placed in a superior position. Furthermore, regarding deciding on further treatment or withdrawal of life support, the patient's relative often depends on and values the doctor's opinion, for as long as they can afford treatment costs.

Biomedical technology and society- relatedness and interactions

In this section, I present one of my observations at the ICU waiting room to present the relative's perception of life support treatment, sense of responsibility, morality, and 'god's will'

regarding the withdrawal of life support and death. The following observation also shows the relative's dependency on biomedical knowledge.

I was introduced to Farida by Arzu the previous day at BIRDEM. When I entered the waiting room, I silently greet both Farida and Arzu. I took a seat beside Arzu - a daughter of a patient admitted in the ICU, at BIRDEM hospital ICU waiting room, and observed the following conversation between Farida (daughter) and Rafiqul Bari (father). The father was lying on the chair as he was feeling dizzy. Farida was sitting beside him and trying to make him comfortable with a hand fan. Arzu had already told me that Farida's mother is on life support since the previous night, after having a stroke (she has type II diabetes). Gangrene has developed in her feet, which need to be amputated immediately to save her life, but her health condition after the stroke means she is not fit for the surgery.

Father: Why is she (his wife) on life support?

Daughter: As she cannot breathe properly even after giving her oxygen. So, she was put on the ventilator.

Father: Is your mother in pain?

Daughter: She is on life support. Probably, she is not feeling anything.

Father: Will she return from life support? Does anyone return from life support?

[Arzu joins the conversation at this point. She starts giving examples of other survivors from life support]

Daughter: She might. I heard someone lived 10 years more after returning from life support.

Father: What does the doctor say? Won't they perform the operation on her feet? Is it not possible, at all?

Daughter: No. I have told you before, the mother's condition is not strong enough for major surgery of this kind. The doctor said, if we want the surgery to be done, we should take her to another hospital as they do not want to take the risk.

Father: God [weeping], if she has the time (life), please let her pain go. If she does not have time, do not suffer her more, please take her.

[BIRDEM]

This conversation exemplifies the moral values, empathy, hope, dependency on biomedical practices, and death with a deep desire for remedy by the doctor's intervention. Rafiqul Bari indicates the general perception of life support, as he questions whether '*anyone returns from life support?*' In their conversation, the patient's husband or her daughter does not show their agency regarding the withdrawal of life support. Rafiqul Bari prays to God to relieve his wife's suffering. Nevertheless, the thought of taking her off life support by themselves - which (hypothetically) may let her pain go away by accelerating death - does not arise. Instead, he repeatedly asks about the doctor's opinion, as he still thinks surgery could be the best option for his wife's health condition.

Shimul and Tareen's family takes a similar position by not taking any withdrawal decision despite the doctor's advice. Nahid told me, "*My brother is breathing. He is still alive; how can*

we withdraw his life support. It will be like we are killing him. He has two small children. We cannot do that. As long God keeps him alive, we will continue his treatment." Their decision of not withdrawing life support reveals the juxtaposition of different moral⁵⁵ and cultural values as attached to life support technologies: that they could not decide on withdrawing life support; that they trust in God and fate; that only God can relieve their kin's sufferings and only God can take life. Relatives think they are responsible for continuing the treatment as long as the doctor says, and they thus depend on biomedical knowledge and practice. In this co-existence of society-culture and biomedical technology, Rafiqul Bari prays to God, does not take the initiative of withdrawing life support himself, and ultimately leaves the decision in God's hand they consider as fate. Relative's perception of death in most cases is such that it implicitly does not lie in people's hands.

The obvious and most intriguing questions for this discussion to arise out of the situation described is why and how medical technology acquires acceptability in society. Alex Faulkner (2009) suggests that the way society classifies technology has significant consequences for perceiving, constructing, and managing its risks and benefits. This also influences the acceptance of a particular technology (such as life support), regulation, and management. The social classification of technology highlights its specific characteristics foregrounded in the public sphere for public approval or concern. Faulkner's statement suggests a deep

⁵⁵ By moral behaviour I understand the socially and culturally defined conventions about right and wrong of human conduct which can be shaped by social, cultural and/or religious values (Ember, C. R. & Ember, M. (2003) *Encyclopedia of Medical Anthropology: Health and Illness in the World's Cultures Topics-Volume 1; Cultures*. Springer Science & Business Media.)

⁵⁵ For instance, despite the criticism and discussion of modern biomedicine or mobile phone, we cannot give up depending on them.

relationship between society and technology, in which social elements *enact* technology in a certain form by approving and adopting certain of its characteristics⁵⁶. Following Faulkner (2009), it is worth noting that in the neoliberal global context, where free-market capitalism is being encouraged and supported, the penetration of medical technology into society, and its approval and acceptance, is a process influenced not only by the success and failure of medical practices associated with medical technology but also by prevailing health systems and health service market strategies.

With reference to biomedical technology, medical anthropologists Lock and Nguyen (2010) describe the intertwined relations between technology and society by saying that: “[bio]medical technologies are, of course, designed expressly to facilitate human intervention into the workings of the body in health and illness; in implementation, they change us, and even as they are constantly modified, they change the world in which we live (2010: 20).”

Lock and Nguyen mention the social aspects of new health technology and the subsequent changes to both society and technology. They suggest that the implementation of medical technology does not depend only on its medical use but on existing medical and political interests and cultural norms, which are also found in this study. Leonardi (2012) made a very similar argument, which states that society is technologically shaped. In his view, technologies become part of the fabric of society, social structures, and culture. This means that technology significantly affects social roles and relations, political arrangements, organisational

⁵⁶ For instance, despite the criticism and discussion of modern biomedicine or mobile phone, we cannot give up depending on them.

structures, cultural beliefs, symbols, and experiences. These arguments convey the mutually constitutive nature of technology and society. This discussion also suggests that in the technoscientific era, technology and society work together. That is supported by the biomedicalisation theorists Clarke et al. (2010) by adding that the role of the social inside the technological, scientific, and medical domain also remains largely invisible.

As I mentioned in the theoretical chapter, biomedicalisation processes are not fixed but conditioned by the local settings. I find in this research that in many places in the context of life support treatment in ICUs, people as patients and as provider/health system workers respond to and negotiate biomedicalisation processes and create a new kind of 'practice' of the scientific innovations (life support technologies) and organisational forms to meet their own needs (Strauss, Schatzman, et al. 1964; Weiner 2000; cited in Clarke 2010:56). This also seems to suggest that the way biomedicalisation occurs in the global west will not necessarily occur in the same way in Bangladesh. The forces of biomedicalisation are advanced, contested, mediated, and ignored in specific contexts and situations, for example, in the context of Bangladesh, due to limited resources and local cultures of practice; hence 'users' of technologies make their negotiations within institutions, to act according to the situation. In the following section, as I discuss the enactment of biomedical technology and society, and how biomedicalisation creates new techno-social forms through the constant negotiations with the technologised form of life support treatment in the socio-economic specific context of Bangladesh. I will draw on the various aspects of the technologised treatment of ICU and the transformation of death by life support technology.

The ICU- A space of technologised treatment

This section examines the consequences of the interaction, involvement, and interdependence between life support technology and human (medical staff, relatives, and patient) involvement in life support treatments. The aim is to comprehend the interactions between machines and health professionals, how technologisation shapes a new way of understanding bodies, and how personhood emerges as a new hybrid socio-technical form.

I found in this study, isolation, restriction, medical devices, and high levels of observation and care are the characteristics of an ICU in Bangladeshi hospitals. The unique feature of an ICU, compared to other hospital spaces, is isolation and the much-reduced presence of relatives. Assemblages of beds in rows attached to monitors, machines, and tubes, the constant presence of doctors, nurses, and other health carers, differentiate the ward from other hospital wards. Generally, medical devices are less visible in most of the wards in typical Bangladeshi hospitals. In contrast, the ICU is intensively equipped with monitors, ventilators, portable x-rays, defibrillators, ultrasound machines, suction machines, pipes, and much more which I fail to recognise with non-medically trained eyes; it gives the impression of highly technologised treatment and care that is a powerful reminder of the technologisation and technoscientisation in medical domain brought about by biomedicalisation.

Often a person lying on the bed can barely be seen over the machines and pipes attached to her/his body. Moreover, the ICU has its unique type of sound. The sound comes either from medical staff or from machines, in most cases, not from patients. The medical staff does not even need to be aware of the loudness of their voices, as most of the patients are sedated

and unconscious. The constant monotonous bleeps and unharmonious alarms of the life support machines add another dimension to the place. Even after leaving the ICU, it keeps resounding in one's head. The assemblages of machines and devices remind me of a socio-technical hybridised place where machines mostly do intensive monitoring and care, and Intensive care as a concept does not exist until the machines could perform all these functions.

The technologised interactions between machines and humans in ICU

Jessica Mesman (2008), in her ethnographic study on NICUs,⁵⁷ follows post-phenomenologist Don Ihde's (1990) conceptualisation of artefacts (machine/technology) as playing a mediating role between humans and the world. Ihde refers to the first form of mediating role as *mediating relations*. According to Ihde, the relationship between humans and technology becomes so 'natural' it makes us forget its presence, for example, we forget about the glasses we wear every day, which help us to see the world seamlessly: we do not look *at* the technology, rather we look *through* it. The second type of mediation is referred to as a *hermeneutical relation*, which represents the world through technology itself, such as how the ICU bed-side monitor represents the patient. Here, technology makes explicit aspects of the world in which humans want to know about. Patients' monitors show information on the body mechanisms that are needed to understand the patient's condition. Therefore, nurses and other healthcare staff tend to rely on monitor readings to assess patients' conditions. It also requires specialised

⁵⁷ Neonatal Intensive Care Units

knowledge and experience to understand and read the information (Mesman 2008). As Mesman states regarding the medical staff's monitoring through the monitor in NICU:

In a single glance, the staff thus learns much about the child's condition. As such, this device mediates between staff and child. Staff members use the monitor as a lens through which they look at child up close. They watch the monitor but see the child- as if the monitor and child are one (Mesman, 2008: 94).

Smith et al. (2003) echo this view regarding the machine monitoring in their study on how "[e]lectronic monitoring offers an indispensable [...] form of knowledge about patients". The relation between healthcare staff and ICU monitors can be regarded as *hermeneutical relations*. Regardless of what doctors say about understanding the body by touching and feeling, the treatment and care provided by the ICU are technologically dependent on the information provided mostly by machines and pathology reports, and from the case history. As most patients are unconscious, no information can be gained from the patients themselves about their discomfort and pain.

Therefore, life support can be considered as (at least in part) a mechanical and technologised form of care. From the feeding tube to the urinal bag, from oxygen saturation to body temperature, or the probability of death based on a scoring system, everything is being measured and compared on 'standardised scales' in the ICU. As I have stated earlier, patient relatives also tend to understand improving and deteriorating in terms of these scores. These are forms of quantifying the body and health, which is itself a qualitative matter for the relatives.

In my research, I found that a significant amount of monitoring is done by machines attached to the patient's body by wires. The patient's face can barely be seen under the tubes and

wires. Nurses are expected to be always present by the patient's side, although expected staff/patient ratios of 1:2 cannot always be maintained at any of the wards studied. The machines connected to the patient's body notify the changes in their condition by making alarms and bleeps. Each bed-side monitor displays blood pressure, blood oxygen saturation, ECG, heart rate, and body temperature. This monitor is also connected with the central monitor kept in the central station in the middle of the ICU, as observed at UTH and the Phoenix Private hospital. I observed an ICU doctor explaining the readings on the monitor to the patient's relative at the Phoenix Hospital, which I did not see in the other two hospitals. I find this familiarising process indicates the following things: firstly, through the reading shown in the monitor, relatives establish a new form of hybrid mechanised communication with the kin lying on the ICU bed. This monitor, then, becomes one of the major sources of knowledge about the bodily function of the patient. This monitor, therefore, becomes the extension of the body, a hybrid entity *of* the body.

Despite the inevitably technology-based treatment in the ICU, interestingly, dependency on machines is not always encouraged by Professors teaching postgraduate medical students at UTH. I observed postgraduate medical students being told not to rely *entirely* on the device in their lessons, but also to touch the body. My observation in the morning shift finds the different stories of understanding bodies.



Picture 12: An ICU bed waiting for patient UTH ⁵⁸

One day, I accompany morning rounds by Dr Monoj, an assistant professor at UTH. He comes to bed 7 and holds the patient's hand to check the pulse, although the machine shows the readings of the vital signs of the body. He asks the nurse: *"How is he, sister? What is the output [the amount of urine in the bag]?"* Then he looks at the monitor and says, *"BP is low."* He also asks a student to check blood pressure with the manual blood pressure machine. Despite the blood pressure machine attached to the patient body, doctors often check the blood pressure with the manual machine. He also tells students, *"You should visit ICU often. Come and check patients with your hands and their medical reports, talk to a nurse about the patients. But you do not come. You won't learn much from the lecture. You have to get hands-on knowledge".* [

⁵⁸ The reason behind taking this picture at the University Teaching Hospital is, the empty ICU bed which is rarely seen. This bed was kept for a patient who was going through surgery to remove a tumour on the day of taking the picture.

UTH]. He then moves to the beds 6, 20, and 21 - to those under his treatment. Dr. Monoj repeatedly advises the students to visit patients and scrutinize their condition physically and corporeally, rather than through the mediation of machines and reports.

Another morning, Dr. Monoj, on his morning round, comes to bed 8 with postgraduate medical students. He starts asking a question about the patient's condition. Students start checking reports or looking at the monitor and trying to explain the patient's condition. Dr. Monoj stops halfway through and says with disappointment: *"Strange that none of you touches the patient with [your] hand but explains their condition by looking at the monitor!"*[UTH]. His statement reminds me of Mesman's statement mentioned above, that is, of looking at the monitor but seeing the patient. Mesman makes the point that monitor and patient become unseparated by this.

Dr. Monoj then starts checking the catheters of all his patients and finds pus in a tube. He becomes very frustrated to see this. He firmly advises the caregivers, nurses, and the students to check the patients' bodies by hand. However, during my observations, in most cases, nurses also measure the patient's condition by looking at the monitor reading and acting upon the findings, unless they have been asked to do otherwise. Goodwin et al. (2003) say that experienced anaesthetists integrate information provided by monitoring with other sources of knowledge about the patient, especially from their clinical assessment, and the ability to distinguish 'normal' and 'abnormal' findings is vital. They add that confidence in electronic information varies with experience, and while electronic monitoring brings new dimensions of understanding, it also brings the potential for new ways of misunderstanding. Likewise, in this study, I find that electronic monitoring can be the subject of concern, as the performance

of devices depends on an associated required chain of actions; its management and practice, and experience (Goodwin et al., 2003).

Bleeps and alarm in the ICU

In the early days of my fieldwork, I was often confused by the monotonous non-stop machine noises, which were strange to my ears and left me thinking about how one should react to an alarm? I later realised that the sound of the 'alarm' or rather bleep is associated with the 'regular' ICU environment. When medical staff starts working in ICU, they also need to learn to cope with the bleeping sound. Dr. Shajahan, a trainee doctor at BIRDEM, tells me that, *"after finishing 32 hours shift at ICU, the alarm still buzzes in my head even when I am at home. I feel like the alarm is rumbling in my head. Now I [have] become used to the noise. Sometimes I even miss it."* [BIRDEM]

The alarms and bleeps are the media of communication between machines and humans. The machine generates a signal when human intervention and attention are needed, as the machines are programmed with preset limits. The alarms are set to alert the medical staff about any 'abnormal level' of the vital signs of patient health, such as blood pressure, oxygen saturation, heart rate, and body temperature. Inevitably, alarms and bleeps have made monitoring easier in the ICU as, presumably, they previously had to check manually always.

There are two predominant types of noise in the ICU. One, by far the most common, carries no urgency to the medical staff because it conveys no new information, and so the

monotonous noise of bleeps become 'normal' to them. The other noise is the actual alarm, which requires an 'emergency' response. Mesman (2010) says in her ethnography at NICUs that: "To make devices function as designed, their scripts have to be followed systematically. As such, devices have a disciplining effect: the alarm of the monitor above the incubator makes a nurse jump up and check and, if needed, intervene (Mesman, 2010: 99)."

However, my initial observation is that medical staff (usually it is the nurse who first needs to act upon the alarms) do not pay attention to 'all' alarms from the machine at patients' bedsides. I often saw them look very casually at the monitor and pass by, or sometimes they checked the wires and oxygen mask; if not, it is a 'real' emergency. When I ask a nurse about it, they reply, "patients with a high fever have rapid heartbeats that make the machine alarm. However, it is not any sign of a heart problem or any severity." (UTH)

It is common for patients in the ICU to have a high fever, such as 105/106 degrees Fahrenheit. It is the staff's experience and knowledge that enables them to read and understand whether the alarm is a matter of real concern, as they know about the patients' conditions. Here, the interaction between machine and medical staff builds confidence as they know when to act and when not to. Even I eventually realise that occasionally the machine also makes false alarms for no good reason. There are numbers of research done on the excessive alarms in the hospital ward which cause alarm fatigue among clinicians (Cho et al., 2016; Sendelbach and Funk, 2013; Solet and Barach, 2012; Sowan et al., 2015; Ulrich, 2013; Wilken et al., 2017). The US Emergency Care Research Institute lists 'alarm hazards' in the top three of the Health Technology Hazard fatigue in 2016 (BRIEF, 2016). Researchers found that clinicians (often nurses) felt fatigued by the clinical alarms. Most of the cases, the alarms are false, such as

Wilken et al.(2017) who found in their study that out of 350 alarms in an ICU 150 are non-actionable or a false alarm. Researchers suggest that false alarms pose an obstacle in alarm management, perhaps resulting in missing a fatal alarm (Cho et al., 2016; Sendelbach and Funk, 2013; Solet and Barach, 2012; Sowan et al., 2015; Ulrich, 2013; Wilken et al., 2017).

However, through expert human monitoring, the performance of device monitoring gets better and fatal situations can be avoided (Parasuraman 1987). This is how human expertise, phenomenological experience with bodies, illness, and machine, combining with the affordance of the machine, create a technoscientific understanding of the bodies, illness, and death and dying in the ICU. This also tells us a story of human-machine dependence, which is possible by the technologisation and technoscientisation. Sometimes it ends up in a new type of technoscientific misunderstanding-as depicted by Smith et al. (2003).

Is there any need to draw the boundary line between technological dependence and human intervention? What makes us think 'when to rely on the machine, and when not to'? I have observed one incident that helps us address such questions. The incident I observed stands alone in my fieldwork. However, I find it important how machine-produced information alarms- as in this instance, was correct, but the nurse did not recognise the emergency, eventually complicates machine-human action in life support care. This reminds us that monitoring cannot be carried out depending on the machine alone (Smith et al., 2003).

The following case of Syeda Akter reveals the incident. According to my fieldnotes,

A new patient, age 65, gets admitted to bed 9 in the late afternoon at BIRDEM. I can see her from where I am sitting. She came to the emergency department with a cardiac arrest and

respiratory distress, from where she has been transferred to ICU. I have learned from the doctor's briefing to her son that her blood pressure is also down. She looks a little restless and uncomfortable. A nurse has raised the bed head to a sitting position as the lady could not breathe properly. The patient tries to take off the oxygen mask several times. Dr. Rima alerts the assigned nurse about the patient is attempting to take off the mask. Hence, the nurse ties her hands to the bedrail at 6.45 pm. The patient keeps trying to get her hands free and is asking for some water to drink. After some time, I saw the patient slowly 'calming down.' Dr. Rima has also seen that the patient is apparently 'calming down' and seems to be falling asleep. The doctor again tells the nurse to check the patient and tells her not to allow her to fall asleep as she seems drowsy. The nurse then moves to the patient's bedside and tries waking her up by calling her name, and then goes back to work she has been doing, writing something on the chart, arranging the medicines. By this time, the alarm has started buzzing non-stop, but the nurse did not go to the patient promptly. When another nurse brings this to her attention, she starts trying to fix the monitor alarm by saying, "it is broken, it is not stopping." The other nurse also came to the bedside. Within a minute, the situation becomes tense. By this time, the patient's head drops to the side, and she seems unconscious. The other nurse, who is at that time by the patient's side, shouts for help as soon as she understands that the patient is becoming unresponsive. At this moment, the first nurse realizes that the machine's alarm sounded because the patient's heart stopped beating. Almost all the doctors and medical staff of that evening's shifts run to bed 9 and start doing what they need to do. Dr. Lipi first jumped on to the bed and started giving CPR before Dr. Shajahan arrives. By rotation, doctors and nursing staff were giving CPR one by one until Syeda Akter's heartbeat returned after providing 30 minutes of continuous CPR. [BIRDEM]

This incident shows how a critical situation is handled by the critical care group of people, as well as also revealing the fact of the 'prevailing presumption' of alarms that lead to a crisis.

Not responding immediately to the alarm illustrates a crisis of ‘alarm fatigue.’ The mediation between machines and humans, therefore, requires constant work.

Another issue of concern is why the patient’s ‘restlessness’ and ‘drowsiness’ were not taken as a prompt for immediate action *before* the alarm went off, suggesting that machine mediations are prioritised above the staff’s senses and expertise, in this form of technoscientific care. Along with monitoring, care and responsibility are also shaped by the processes of technologisation in the advent of life support technologies in Bangladesh and has taken a socio-technical hybrid form. The next section focuses on how care has been technologised.

Technologisation of care

Throughout the thesis, I am exploring how the biomedicalisation of death has occurred in the context of life support in a local setting. To do this requires not only looking at machines but also their impacts on associated domains of social practices – care/ responsibility. According to Clarke (2010), biomedicalisation is the extension of medical jurisdiction over health, and commodification of health is central to the biomedicalisation. She says in this context,

health itself and proper management of chronic illnesses are becoming individual moral responsibilities to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help and biomedical goods and service (Clarke, 2010: 48).

For my study, the point of relevance here is that the improved access to advanced biomedical inventions like life support technology has made the management of chronic and critical

illness or injuries an individual responsibility that can be fulfilled by the use or consumption of biomedical goods and services. Life support technology, as a means of sustaining life, and access to medical inventions as a form of buyable service, have mutually constituted care and responsibility, within a specific socioeconomic context. This has resulted in a socio-technical form of care and responsibility.

I mentioned in the earlier chapter that Zahirul Islam, the father of an 11-year-old patient Siam, believes that he gets more response from his son and that Siam seems so happy when he and his wife are around. Zahirul also feels that Siam quickly fall asleep if they stroke his hair and touch his body, which healthcare staff do not usually do. Rohan's father similarly expresses his frustrations about the absence of touch in ICU care. This is another example of relatives missing themselves in the ICU care without which they find the care 'incomplete,' which stands opposite of the healthcare staff prioritising technologised information (discussed in the later section of this chapter). I find this realisation embedded in the relative's cultural perception about care and responsibility for their kin in medical care (Zaman 2005, 2013).

Before the visiting time at the public hospital, described in the previous chapter, I observed that nurses and carers tend to ensure that the patient and their surroundings look clean and tidy – providing a specific form of everyday routine care. However, patients' relatives not only expect care for the patient according to their bodily needs and requirements but also they expect the care to be performed respectfully according to cultural norms that are often difficult to follow in an ICU. Tareen's mother told me after she decided to take Tareen off the ventilator to their hometown that

My daughter is innocent, she didn't commit any sin. If she dies here, I don't know who will touch her? If a male nurse would touch Tareen's body after she dies, change her clothes? Why should I let this sin happen to my innocent daughter?

Though I have not found any explicit contradictions between religion and ICU treatment existing in relatives' decision about life support treatment, Tareen's mother statement reveals a moral judgment she used for an 'imagined' future of Tareen's death. However, this judgment was never used when Tareen's treatment was on-going. There is another sense of uncomfortableness that exist around the ICU care in relative's perception, which is linked to patient personhood, which explains this situation well. As Kaufman and Morgan (2009) said, the personhood of liminal subjects is assessed and negotiated through subjective knowledge. Like Kaufman and Morgan, I found a similar reflection in Tarannum's statement. Tarannum Jahan, whose mother required intensive care, told me of an incident that happened in an Indian hospital. She said, *"my mother has been a very decent and graceful lady, we even didn't see her knees. One evening I saw one male nurse was changing my mother's diaper. I know my mother would have never allowed it or like it. It made me very upset [Nikunjo, Dhaka]"*.

These episodes of uncomfortableness with ICU care are rooted in the socio-cultural context in which relatives and patients live. However, I did not observe such feelings playing a direct role in decisions to withdraw treatment.

In Bangladesh, it is culturally and socially expected that family members would do everything for the ill person, despite not having sufficient financial capacity to take responsibility. Failing

to take care of an ill person, at the critical or end-stage of life, is interpreted as neglect of one's social duties and responsibility (Zaman 2005, 2013). Fulfilling these is sometimes a social burden, sometimes considered a 'duty,' that *now*, because of the new affordances of technology, obliges relatives to go for the 'invasive' treatments offered by life support treatment.

To exemplify this, Anita Islam faced this burden of duty when her father in law, at 85, became critically ill. The Doctor asked her opinion instantly about whether to put her father in law on ventilation. Despite his age, a history of multiple strokes and internal bleeding, she felt that she could not refuse.

My husband is the elder son; he was out of the country at that time. My other brother in law, sister in law were not there for the decision. I am a daughter in law; I cannot decide to deny life support despite knowing his condition. If I would have said [no], everyone would have blamed me. They would have said, I wanted to save money, hence deny life support. [Uttara Model Town, Dhaka]

In light of this statement, it is worth noting that, to grasp the cutting edge of technological development and its consequences on people who use it, a cultural lens should be applied.

As Clarke and colleagues state,

biomedicine has become a sociocultural world and a potential lens through which we culturally interpret, understand and seek to transform bodies and lives. Fundamental evidence of biomedicalisation is the co-production of science, technologies and the new social forms within biomedicine and its related domain (Clarke 2010: 49).

The new social form stated in the above statement is evident in this study. I found interviewees deciding on 'aggressive' treatment on the ground of culturally-ascribed notions of responsibility, care, shame, and blame, without really thinking through the outcome of the interventionist treatment. This way, a new form of hybrid techno-social care and responsibility emerges and imposes the technologisation through the introduction of life support technologies to critical care.

There is, however, another kind of technologised care brought about by life support technology. In the Bangladeshi context, this type of care replaces 'hospice care' as it is known in the west. The following cases are reflections on this type of care, which are important to discuss here, as it represents the transformation of care from care at home to technologised care in a hospice. I write about one of these in my fieldnotes:

Tahera Begum (Age 76), a mother of three daughters and one son, has been brought to BIRDEM ICU a couple of times. She has diabetes and has respiratory dysfunction. Before admission to the ICU, she was taken care of by her elder daughter. For that reason, her only son living outside Dhaka blamed his sister's negligence for his mother's ailment. The son was reluctant to accept Tahera Begum being discharged from ICU. As a result, the other family members had to uphold their brother's decision as he is financing the treatment. Dr. Fahima wants to convince the family members that there is no more treatment left for the patient in the ICU, so she should be transferred to the HDU, but she fails to make them understand the disadvantages of staying longer. They are firm with their decision to keep their mother in the ICU as they are

afraid of accusations of negligence if she is moved to another ward and does not want to take any risk on the ground of their brother's constant blaming. The doctor tells them that the next time the patient develops such complications again, she should be treated at home, where she can spend her last days peacefully and not bring her to the ICU again. [BIRDEM]

Similarly to this, the case of Khadija Khanam (86 years) also provides an instance of using ICU care as a substitute for hospice care. Khadija Khanam (86 years old) has been staying in ICU for two months. Dr. Tauhid tells me the patient could have been taken home, but taking care of a patient with a tracheostomy is difficult (although not impossible). So, it was decided to keep her in the ICU since the patient's daughter is an employee at BIRDEM, gets a discount from the hospital and gets 'better care' as a result. In a discussion, Dr. Bijoy at UTH mentions the growing tendency of keeping patients in the ICU or HDU, for people who can afford the cost. He thinks that wealthy people who do not want to bear the 'burden' of taking care of elderly parents, choose this way of taking care. He also mentions some of his colleagues' names who take advantage of this. Reflecting on these choices, he said, though his mother has Parkinson's disease, he will not take her to the ICU, but will arrange non-invasive treatment at home to ease her discomfort and make her last days peaceful. I find these three examples important as these suggest death and dying from the point of medical jurisdiction by the logic of medical understanding. At the same time, these cases also suggest the co-production of new forms of socio-technical care and responsibility.

Another side of the coin

The story of Nasrin Noor's mother tells a contrasting story about refusing to use a private ICU. Nasrin and her family decided to admit their mother to the government Chittagong Medical College Hospital (CMCH), after withdrawing from a private hospital. CMCH doctors said it would be better if her mother could be taken to the ICU. She said,

We tried to get an ICU bed in the CMCH, but all the beds were occupied. We decided not to take her to the private ICU. We wanted to act practical and logical. My mother was suffering from liver cancer. We knew that there was no point in taking her to ICU. Rather we tried to give her comfort in those last days. If we could arrange an ICU bed at CMCH, we would have taken her there, but not to the private hospital, where the doctor would start to do so many things for no reason just to do business, which would, in a way, linger her sufferings and nothing else. [Mehedibug, Chittagong]

This story again tells how patients' relatives understand and perceive ICU. It was their decision not to take her mother to a private hospital and private ICU. However, there were some reasons for doing that. First of all, being a government officer, Nasrin received some facilities from the government hospital (free of a cost hospital room). Furthermore, they saw private hospital care as being driven by profit and for being an extreme interventionist.

These stories show that factors such as the perception of family responsibilities and care, and conflation of ICU with hospice care, can create a dependency on medical technology and a

technologised care system. Nevertheless, the dependence on and the expectations of medical technology also become ambivalent.

Hybridised and technologised death and dying in ICUs

According to biomedicalisation theorists, biomedical technoscience creates new categories of health-related identities and redefine the old ones (Clarke, 2010), such as becoming parents by in vitro fertilisation. In this study, I am using this set of ideas to define the various types of death created and made possible by life support technology. Life support technology has turned death into a 'problem' or 'dilemma.' Technology has introduced choice into what was a natural process. This dilemma comes in various shapes in different contexts. Generally, hospital care has transformed death into a "management problem, a part of life that needs to be ordered and orderly" (Kaufman, 2005: 68), and life support technology has extended this domain further. Life support technology has transformed death into a set of processes. Sharon Kaufman has shown how death has been shaped in hospitals in the US. In Bangladesh, it is difficult to pinpoint when and how death has been changed and shaped by hospital care, as no socio-medical history of death has been made to date. However, I suggest that at least five dimensions of the transformation of death can be identified that have been introduced by life support technologies. Those are the emergence of machine *predictable and decided death*; *machine confirmed death*; *'life without creation is death'*⁵⁹ and a state between life and death: *'death or not death'* and *'familiar and unfamiliar death'* discussed in the following. This way, within the hospital, the multiple enactments of death are thus added up and converge into a

⁵⁹ Relative's wording in defining death.

single narrative of death (Hadders, 2009). In the following section, I discuss these new socio-technical hybrid forms of death, which have resulted from life support technology.

Machine confirmed death: *Not dead yet*

My first ever experience of observing death in an ICU was the death of Mrs Momota. This death stands as a case of ‘dead but not *fully* dead until confirmed by a machine.’ This case also shows how death generally occurs in the ICU and how technologised moments of the end of life have become in ICUs.

My fieldnote reads that,

Around 11.00, I came to the ICU at UTH and was standing in the doctor-nurse station, located in the middle of the ward. From this place, I could see the EGK⁶⁰ monitor of bed 14 of Mrs Momota, which was just in front of me. It sounded alarms, but nobody around seems worried by the alarm. When I ask Dr. Karim about the alarm, he said, “actually the patient has died, it is the ventilator which makes her lungs go up and down. As the oxygen saturation is getting low, the machine bleeps the alarm”. According to Dr. Karim, Mrs. Momota had been admitted with a critical condition.

1.15 pm

⁶⁰ An electrocardiogram (ECG or EKG) records the electrical signal from the heart to check for different heart conditions (Source: [https://www.mayoclinic.org/tests-procedures/ekg/about/pac-20384983#:~:text=An%20electrocardiogram%20\(ECG%20or%20EKG,check%20for%20different%20heart%20conditions](https://www.mayoclinic.org/tests-procedures/ekg/about/pac-20384983#:~:text=An%20electrocardiogram%20(ECG%20or%20EKG,check%20for%20different%20heart%20conditions) last accessed 12/09/2020)

After seeing the readings of very low blood oxygen saturation and heart rate on the screen, the assigned nurse conveys this message to the duty doctor. The duty doctor walks away, says, "What can you do? Nothing can be done anymore" (Later, the nurse told me that it happened several times since morning). As I asked, the nurse replied, as she was given injections, Mrs. Momota's blood pressure was still not as low as her heart rate. Dr. Karim explained to me later that in this kind of situation, some injections are given to raise blood pressure and raise heartbeats. As long as medicine works, machines might show some signals. Sometimes, the patient returns, sometimes not. Being a non-medical person, I was getting to know how healthcare staff takes steps in this kind of 'end of life' situation.

1.20 pm

When I see the heart rate is 0 (zero), and nobody is even looking at the monitor, for the first time, I seek the attention of a nurse and show her the heart rate. Then she calls the assigned nurse who is then working on a file. She closes the file and says, 'we cannot do anything more.'

1.40pm A doctor tries CPR for a while and leaves.

I understood later that nurses and doctors had 'decided' not to resuscitate her anymore; that is why nobody joins the doctor while he was giving the CPR.

1.45 pm Another doctor instructs a nurse to do an ECG confirming the death.

1.50 pm The ECG is done. Mrs. Momota's death is finally officially declared.

[UTH]

Revealing disagreements on defining death, the death of Mrs. Momota shows how it is not merely a matter of moments but emerges as an event that needs to be confirmed by a machine. Dr. Karim told me 'she is dead' a couple of hours before the official death was declared: he actually meant 'she is dying,' rather than 'dead.'

I did not see any family members of the deceased by her side during the last moments of her life. I assumed the ICU rules did not allow them to come inside. I met Mrs. Momota's son at the doctor's room, where a doctor informed him about his mother's death. During the conversation with the doctor, the son speaks to someone over the phone, informing them of his mother's death. I realise he is unaware of the 'unofficial' death of his mother, as he is saying on the phone, "Mother died now." The death of Mrs. Momota represents a typical death in ICU, where death is expected, and its timing is arbitrary. Thus, a machine is used to determine and construct and sometimes to delay the moment of death.

Similarly, I found in the costliest private hospital [PPH], a patient was not declared dead until a machine determined complete death. The difference between the death at Phoenix hospital and the UTH hospital is that the Phoenix allows dying patient's relatives to visit as many times as they want until the patient is officially declared dead. In cubicle 10 of Phoenix Hospital, Abdul Huq (75 years) was admitted on 28/1/2016 with a sepsis infection, secondary to pneumonia, with HTN (hypertension). On 31/1/2016, the patient was visited by his relatives from the early evening. Earlier the same day, at 13:35, a nephrologist advised that he needed dialysis. His platelet count was very low, and ICU doctors were waiting for the family's decision. I came to understand from the conversation between Dr. Shanta and Dr. Nurul Ahmed that the

patient's relatives were not entirely convinced about the dialysis decision. Dr. Ahmed told Dr. Shanta that, *'we have to give some hope to the patient's relative to make them take the decision.'*

At 14:40, Dr. Shanta informed Dr. Asif that the family had given permission for the SLED⁶¹dialysis as advised. Dr. Asif telephoned the nephrology department to ask when they will take the patient for dialysis. By listening to the conversation, Nurse Rubi says with dissatisfaction, *"what will be the result of the dialysis? The money will be spent for nothing. The patient's family has money, what else?"* [Phoenix Hospital]

One nurse was constantly standing in the cubicle door, keeping the machine's reading up to date and monitoring the patient. Doctors are also visiting Mr. Huq. As the blood pressure was too low, he could not get the dialysis. Around 17:00, Abdul Huq's son came to visit his father, and other relatives visited one by one. Very silently, the death of Mr. Huq took place. There was no resuscitation. At 17.15, the nurse standing at the door has been asked to take the ECG. After taking the ECG, she starts taking off the tubes, wires, saline needles from the body, closes his eyes with tapes, and covers him with a white sheet. Another nurse takes back medicines from the bedside rack and asks someone to return them to the store.

⁶¹ Sustained low efficiency dialysis (SLED) is increasingly used as a renal replacement modality in critically ill patients with acute kidney injury (AKI) and hemodynamic instability (source: <https://bmcnephrol.biomedcentral.com/articles/10.1186/s12882-015-0123-4>: last accessed 19/01/2020).

17.55: Death certificate is being issued. One staff is helping to prepare a list on the computer in the nurse station.

18.00: All files are sent to finance for preparing the bill and discharge. By this time, one ward boy came inside to inform the nurse that, the deceased will be given the Ghosl

18.15 Relatives keep coming one by one to the cubicle of Mr Huq.

[Phoenix Hospital]

Not all deaths are the same in ICUs. Death at a ‘high-end’ private hospital has some differences to a Government-run ICU or a general private hospital like BIRDEM. One thing is evident that Phoenix’s doctors give more time to patients’ relatives to be present at the death. Nurse Rubi’s opinion on Mr. Huq’s SLED dialysis reveals that sometimes the necessity for a doctor’s treatment option can be questioned. I can relate to a conversation that I have with Dr. Shanta in this context. She tells me,

I did not want to intubate the lung cancer patient in bed 4. When he came to us, his heart rate was 30-40, and Oxygen saturation was 20. That means he was dying. I started cardiac hammering and wanted the patient’s family’s decision. Since they wanted ‘everything’ to be done, I had to intubate. Though after counselling they signed for the DNR⁶². There is no benefit (from intubation). Isn’t it giving him more pain? It is his prolongation of death. Isn’t putting a tube into the mouth painful? Even if someone put a finger into the mouth, how painful it is! There should be some admission criteria for ICU. Like, septicaemia⁶³ patient has less chance of a return to life, we should

⁶² Do Not Resuscitate

⁶³ Septicemia, also known as sepsis, is a life-threatening complication that can happen when bacteria from another infection enter the blood and spread throughout the body (source: <https://www.medicalnewstoday.com/articles/311589.php> last accessed 12/09/2020)

discharge them. Like Bed 12, she has no chance of a return to the life we should not keep her. However, when the patient party wants everything to be done, we have to opt for aggressive treatment. However, what is the meaning of this kind of life? Just living by breathing? I will tell my family not to do it with me. Who knows, I might want it. [Phoenix Hospital]

This conversation with an SHO⁶⁴ at Phoenix gives me one perspective of this hybridised, technologised and prolonged death. It prompts the question of why patients' families opt for this treatment, which will be discussed in the next chapter.

Machine predictable and decided death

An interviewee told me about his mother's last moments at a private hospital in Chittagong,

'it was early in the morning around 6 am when a doctor called me to come to the hospital immediately. When I rushed to the hospital, the doctor told me that the time has arrived to say goodbye to your mother. By this time, my brother came from Dhaka and other relatives as well. I touch my mother's cheek and said goodbye. It was so strange to see the doctor was writing my mother's death certificate while she was still breathing – at least I could see ups and downs of her chest'. [Chittagong]

This narrative presents a 'predictable' moment of death possible because of life support. This is an example of how life support makes death visible, tangible, and to some extent,

⁶⁴ Senior Health Officer

'controllable' (Kaufman, 2005; Kaufman and Morgan, 2005; Lock, 2001). A similar experience was narrated by Professor Farhad Ahmed while explaining his father's death. He said,

"We had decided to withdraw our father's life support. While the withdrawal process was taking place, but he was still 'alive,' yet his funeral time and the venue was being announced in our village. It was such a strange feeling as we say death is unpredictable, we do not know when it happens, but it is not such anymore." [Chittagong]

Following the death of Nadeem Gaffar in an ICU, the daughter of the deceased told me,

The doctor has informed me about my father's death. What kind of death is it? We could not say any dua' [religious prayer] to his ear, could not give him drops of water (the Islamic belief of providing drops of holy water to a dying person with the belief that the person will die with the name of Allah), even could not realize when he left us. It would have been more acceptable if he had died in front of us. We could have at least comfort ourselves by doing the last rites for him. [UTH]

From this statement of close kin of a deceased person, who has just died, I understand the emptiness and the resentment of not being able to perform the last rites for the dying person. Earlier that morning, the family members expressed their eagerness to transfer Mr Gaffar to the ICU from the cabin, to get better treatment. However, the doctor explained that there is not much hope for 'recovery' considering Mr Gaffar's health condition. Two things are occurring together: one is, Mr Gaffar's children had decided to seek treatment with biomedical technologies for medical conditions with or without knowing how this treatment will take place in practice, and the other is regret for not fulfilling cultural and religious norms. Hence, we see the contingent, complex, and multiple effects of life support technology in context. However, it is not clear from this what they would have done if there was no ICU at all.

Because, knowing or without knowing the consequences, relatives ended up in ICU for the best available treatment.

Familiar vs. unfamiliar death

With the life support technology, we are witnessing various kinds of death emerging, including the liminal situation *between* life and death, and the prolongation of death as a dying process, which are difficult to conceptualise by those who understand death in a culturally and socially informed way, not by framing of the biological death. Nonetheless, people also understand how doctors explain death to them, which suggests that biomedical knowledge and practice is seen to be dominant. In this situation, medical, cultural, and social understandings sometimes go together and sometimes contradict each other.

The determination of death by biomedical knowledge sometimes leads to ideological confrontations and mental suffering for families. The case of Naznin Akter (Bed-7, BIRDEM) reveals this tension of understanding the 'medically declared' death, which is sometimes unfamiliar for the patient's relatives. The emergent tension is located in the biomedical discourse, in opposition to the non-biomedical understanding of death. I argue this tension is not a shift in the perception of death brought by medical jurisdiction (by the logic of medical understanding). However, it is a new type of knowledge about death created by the emergence of technoscientific meanings. The following case of Naznin Akhter reveals the predicaments of understanding death. This case reveals how Naznin Akhter's family understand and conceptualise death from their experience, which contradicts with the condition of Naznin Akhter described by the doctor as not being dead.

A doctor asks Naznin Akter's son to sign a consent form for mechanical support. The doctor looks tense about Naznin Akter's health condition. He explains to the son,

We are not able to maintain her blood pressure yet, the oxygen level is too low, she might need life support, but we cannot confirm now. The situation can arise anytime. Hence, we might not get time to discuss with the family member if the critical moment arises. So please give the consent now. [BIRDEM]

While the son signs the form, the doctor keeps asking him about his mother. The son does not seem to respond appropriately to the doctor's queries. The doctor tells him to come back after some time. Meanwhile, the doctor intubates the patient and advises the nurses and other doctors about the need to raise the patient's blood pressure. The doctor again calls for the patient's son and tells him,

Still, BP is unreadable with our machine. We do not know how long she has been in this condition. Now she is on the machine. We do not know how much we can do to improve her condition. The rest is of Allah's will. It seems her condition had already deteriorated at home. [BIRDEM]

I came to understand later that Naznin Akter's family members condemned the doctors for keeping her in ICU and treating the patient as they felt that she had already died. It is a widespread allegation (discussed in chapter 7) that doctors keep 'dead' patients on life support to make money. Even though doctors and hospital management are two different bodies, since health care has become a profitable private sector, they remain 'one group' from the patients'

and their families' perspectives. There are some reasons to believe this,⁶⁵ and I will discuss this in chapter 7. Hence, allegations are made against doctors for continuing treatment or putting a patient on life support, and the accusations are based on a belief that bio-medicine has a 'business-driven attitude.' Despite the volatility, the family brought the patient to the ICU. Again, it clearly reflects their position (obligation) to try until the end.

In contrast, doctors have their own explanations regarding this situation. This indicates the existing unequal and opaque doctor-patient relationship. The doctor's advice to relatives expresses their defensive attitude in a complicated situation where they can be easily targeted for blame.

Dr. Tauhid explains later that,

We will not attempt any undue life-prolonging life. Ultimately, we know what is in her fate. By CPR or ventilation, we could save her for maybe a day. What is the value of this living? Instead, the family will be overburdened for giving her one-day life. That is why we did not counsel them very positively. I just told them to bring a bag of blood. It is a problem with our people; they misunderstand us. Now, she (The patient's niece) thinks that we are keeping a dead patient on life support. Our ICU is full of patients, yet so many patients are on the waiting list. We do not need to keep a dead patient.

[BIRDEM]

In the case of Naznin Akter, we find two enfolded realities. On the one hand, Naznin Akhter's family 'could not' or 'did not' deny the treatment option when they brought her to the hospital. Therefore, the patient was transferred to the ICU. As Mesman (2008) observes, it is hard

⁶⁵ TIB reports (2018), ASK reports (2013)

to reject the services of medical technology. On the other hand, when the family decided to discontinue Naznin Akter's treatment as they think she is already dead, they are dissuaded from doing so. They become sceptical about the doctors' attitude. They even start questioning why they have been asked to arrange blood since it is not being used. The situation reveals that there has been a lack of communication about the options available about their mother's treatment. The doctors and the patient's family have not been working in agreement. Callon(1986) said that the activity of technoscience is the work of understanding the interests of various actors and translating those interests so that the actors work in agreement. Here, Naznin Akhter's family members, medical staff, and ICU treatment (technology) are no longer working together as their common interest does not remain the same. In the case of Naznin Akhter, the option of life support treatment is imposed by the hospital and perhaps left the family with 'no choice' but to opt for the life support treatment, which causes enormous psychological, ethical, financial pressure at the end. Not everyone has to go through this stressful situation, yet, situations like this become common in the realm of life support treatment.

Both parties can be sceptical about each other in these decision situations. Mistrust intensifies (from both doctors and patient families) when the appropriateness of life support treatment for the patient is being discussed. This is for three reasons. One is related to inadequate information being shared with the patient's family about the consequences of life support treatment. Sometimes, doctors cannot or do not adequately explain the outcomes and limitations of life support treatment, such as how likely the patient is to survive, how long the treatment may be needed, as well as other health risks involved. Sometimes the patient's family cannot or do not know what to act on or act on the information available to them.

Often, the patient's family is asked to give consent about lifesaving treatment in minutes. In this brief time, it is hard to consider all the possibilities and shortcomings of the treatment unless they are well informed about the treatment and procedures. Mesman (2008) also points out these problems in the context of NICU in US hospitals. However, the US health system is different from Bangladesh regarding health insurance and the higher likelihood of litigation against hospitals and doctors.

The other problem relates to the existing multi-layered relationship between patient and health professionals. On the one hand, the relationship is historically unequal, with doctors being authoritative and hegemonic. The social status of a doctor in Bangladeshi society continues to be regarded exceptionally highly (Zaman 2005, 2013). It is almost a cultural norm not to ask a doctor any questions, and doctors often seem to be 'distant' from patients. The power of authoritative biomedical knowledge is undeniable in this context.

Another reason lies in the marketised health system in Bangladesh. As previously mentioned, popular discourses suggest that doctors get a commission for unnecessary tests on patients (which has been mentioned in the research reports I discuss in chapter 7); they give less time to each patient to maximize the number they see in their private chambers; hospitals are money-making places where unnecessary treatments (operations, C-sections, pathology tests) are done; and doctors are so powerful that if patients die from misdiagnosis or wrong treatments, they are apparently immune from punishment as the system of accountability in Bangladesh is weak (this will be discussed further in Ch 7). Thus, mistrust is exacerbated by suspicions about profit-seeking influencing doctors' and hospitals' actions.

Life without creation is death

Life support technologies can seize death for a while and are able to prolong life (Franklin and Lock, 2003). Life support technologies offer the opportunity to 'live' even with minimal signs of life (dependent on machines, bedridden, and non-communicating) for those who can afford it. This new form of life is a liminal existence. This way of living is a new, technologised form of life/death that has been created by the affordances of life support technology, but it is also informed by the notion of personhood, which I will now discuss.

The day when Khorshed Kamal got a heart attack was 'Victory day' of Bangladesh. Dhaka was flooded with people celebrating. Roads were blocked, and the popular actor, who had been suffering from motor neuron disease, suffered a massive heart attack while returning from a homoeopathic doctor with his relative by car. The car was stuck in severe traffic, unable to move. Traffic police failed to help, despite asking people to move. After more than half an hour, the relative of the actor managed to bring him to the BIRDEM emergency ward. The unit was ready to receive the actor as they were already informed about his condition. There was no heartbeat found when he was taken to the emergency ward. Doctors administered CPR until his heartbeat returned. However, the chances were too slim. According to the actor's brother Shojol Kamal,

I already have told [the actor's wife] that he is no more. He died at that time. Doctors were about to declare him dead. Maybe as he is a star, or maybe for some other reason, the doctor suddenly ordered to take him to ICU. With our consent, he was put on life support. [his wife] was very much optimistic about his return. So, we did not have

any other choice but to keep him on life support. However, he was already gone. It was very hard for [his wife] and [his daughter] that [he]is no more, and they should let him go [withdraw life support]. We couldn't even approach them to speak about it. Both just have shut down everything'. [Dhanmondi, Dhaka]

Three days later, his wife and later his daughter agreed to withdraw life support. His wife said to me in her interview

His face looks so sad. I realised as if he is telling me he doesn't want to live like this. He was not alive intellectually, mentally, consciously. Life can appear until the brain is being seized. But he never wanted life to live like this. I realize I should let him go. I whispered to his ears, go, and live a beautiful life. I am coming to join you. [Dhanmondi, Dhaka]

Here, the conception of personhood in a relative's mind plays a significant role in defining life and death. This withdrawal decision reveals the coexistence of multiple layers of persuasive thought: the possibilities of biomedical technology, realities of science, and the meaning of life, death, and personhood of the dying person conceptualised by relatives. While brother thinks Khorshed died when he was taken to the hospital, further action reveals the liminal stage between life and death, apparently as a course of time, that gives his brother's wife and daughter to make up their mind. These three days were very intense, and the family was not able to make a withdrawal decision. On the one hand, Khorshed's wife and daughter, who initially wanted to wait with the hope of Khorshed's recovery, did not want to withdraw life support. On the other hand, the rest of the family was dependent on their decision. However,

there was a whisper among the relatives and friends that Mohua and daughter should let Khorshed go (by withdrawal decision) as his soul is in great pain.

The actor's brother asked the doctor to do all the tests required for declaring brain death before withdrawing life support, and this was done to convince Khorshed's wife and daughter. This is the only case in my research where the biochemical test for declaring brain death was done. In other words, the actor's brother used biomedical knowledge, which is popularly considered as an 'undeniable truth' to confirm his death. The family members thus reconfirmed the understanding of death by biotechnical knowledge and technology. This particular case also reflects class and status differentiation compared to decisions on withdrawing life support, which stems from limited economic resources.

This underlines that death and technology are differently constructed and understood across classes, an analysis which will be elaborated in the next chapter.

Conclusion

In this chapter, I described how, despite saving a life, life support technologies in many ways reconstitute the perception of health, illness, care, death, and dying. This chapter showed that life support technologies have blurred the boundary between life and death and have created a hybrid technologised form of death and dying. Thus, death also becomes complex, fragmented, and paradoxical. Faulkner states (2009) it is impossible to prevent medical devices entering our family relationships, and that this changes how we understand health and

disease, and the way we take care of our health, values, and beliefs. It also alters our experience of healthcare systems.

This chapter tells a story about machine-human interactions, interdependence, and technologised life and death. It tells us a story about transformation, change, and encompassing complexities. Langdon Winner (1986, 1997) argues that “when a sophisticated new technique or instrument is adopted in medical practice, it transforms not only what doctors do, but also the ways people think about health, sickness, and medical care.” In the context of Bangladesh, life support technologies have brought many changes in life-prolonging treatment in the way Winner suggests. The changes occur in the treatment procedures as well as in the expectations of a patient’s family, in the zone of high-tech medicine. As a patient’s family pays a significant amount of money, they expect a positive outcome from the treatment. However, high-tech medical treatment is not able to assure anything, which also produces scepticism, mistrust, agony, frustration on their part. New kinds of death emerge: ‘machine confirmed death,’ ‘predictable and decided death, known and unknown death; life without creation is death’; a new type of care, a new sort of end of life is being created by the emergence of the life support technology in Bangladesh. This chapter opened up the diverse realities that can be grouped under the notion of biomedicalisation in practice.

This chapter shows the transformation in cultural practices, a new form of subjectification of the dying patient, and a new form of life and death have been brought about by the proliferation of biomedical options in Bangladesh. The stories in this chapter show how life support technologies shaped, renegotiated, and managed the boundaries of life and death are

being. In this study, cultural norms and the subject-making of personhood, body, hybridised techno-social death, and care are central to my argument, which emphasises how biomedical practices, together with discursive power arrangements (medical professionals, privatised health sectors, and government initiatives) and hegemony (of modernity and biomedical knowledge) shape and construct the end-of-life, personhood, and the creation of particular knowledge.

My analysis in this chapter demonstrates that the biomedicalisation process in Bangladeshi society has taken a particular localised form differently from how authors describe it in North America. Although life support technologies have been brought to Bangladesh *from* the West, their implementation has happened in the contexts of the economic and infrastructural capacities of Bangladeshi society. Their use reflects the specific interests of those investing in and regulating these technologies and is bound up with ongoing negotiations with pervasive cultural norms and values towards 'life or death' prolonging treatment in Bangladesh. I suggest then that there is a Bangladeshi form of biomedicalization that I now address further in the following chapter in which I focus on the creation of hope and its relation to limited and highly stratified access to medical technology in the Bangladeshi healthcare system.

CHAPTER SIX

Biomedicalisation in action: II Hope, inequality and stratified biomedicalisation

Khachar vitor, ochin pakhi kemne ashe jai!

[Look, how the strange bird flies in and out of its cage!]

Tare dhorte paarle mono beri, ditam pakhir paay.

[If I could catch it, I would bind it with my mind's fetter.]

A sacred song by Baul philosopher Lalon Shah⁶⁶

Introduction

This is a well-known *baul* song (a type of spiritual folk song) in Bangla that metaphorically depicts human birth and death and the endless desire for immortality; as Lalon continues, *mon tui roili khachar aashe, khacha je tor kacha basher* [O my mind, submerged in the desire of the cage, (alas) it has made of raw bamboo]. In the song, Lalon Shah, who is a mystic

⁶⁶ Lalon Shah (1774-1890) was a preceptor of Baul philosophy, and a composer and singer of Baul songs. Lalon had no institutional education. By his devotion he acquired deep knowledge of the religious doctrines of the Hindus and Muslims, the manifestation of which is found in the songs composed by him. He composed nearly 2,500 devotional songs. His songs are rich in mystic thought and artistic skill. His songs are significant and impressive, and are indicative of ideals of humanism and a non-sectarian attitude. His disciples used to sing his songs. Even in his life time, a colossal Baul community developed consisting of his disciples and their disciples. The main objective of Baul ascetic practice is to encounter the inherent and formless Supreme Being, which can only be achieved by divine love, devotion and meditation.

spiritual poet and *baul* philosopher, portrays the fragile body as a cage made of bamboo, and the bird symbolises the temporality of life, which is free to fly at any time. While the bird is free to fly, humans desire to chain the bird to control it. This is the desire to take control over death, despite it being the ultimate destiny of all creatures on the earth. Lalon's depiction of desire helps me to conceptualise relatives' hope towards life support treatment, using a culturally appropriate frame. Here I found that hope is not merely looking for something, but rather desiring for something that is sometimes nearly impossible.

I have touched on themes of hope, inequality, and stratified biomedicalisation in the previous chapter when discussing interactions between life support technologies and humans (health professionals, patients, and relatives) and its outcomes. The previous chapter showed how life support technologies create hybridised and novel technoscientific forms of personhood, death, dying, and care in ICUs. The most significant outcome of the human-medical technology interface in the biomedicalisation of death is the emergence of hope.

Relatives opt for sophisticated and technologised treatment with the hope of a cure. However, hope is also embedded in the broader context of the increasing availability of biomedical intervention, doctor-patient relations, affordability, family responsibility and care, and the marketised health care system. These are the issues discussed in the chapter around death and dying in the ICU. In this chapter, I argue that hope may originate in individuals but is provoked by these factors in existing health care systems. Hence, the treatment 'choice' made by relatives does not always refer to a relative's agency or autonomy; instead, it is constructed by external conditions.

The role and capacity of technology, and the expectations of it, often emerge as conflicting when ‘the hope’ of technology does not get fulfilled. Often, ‘hoping’ accompanies a techno-scientific meaning of ‘life’ (such as living in a vegetative state,⁶⁷ on mechanical ventilation, or being brain dead) as in the case of Khorshed Kamal, Tareen, Shimul, Taufiq, Siam, Rohan: where life does not exist without technological support. The patient’s family often consider this technological acquirement as a reward for their fight for life (Cases of Shafayet Alam, Tarannum’s mother as such of many). The hope provided by medical technology motivates the patient’s family to continue the treatment for as long as they can bear the cost. In the context of this study, the price of hoping often comes with an enormous financial and moral burden. Therefore, ‘the hope’ for life results in not only a ‘hybrid-technologised’ death (as the previous chapter has discussed) but also a technologised hope intertwined with inequalities and stratifications, which will be presented in this chapter. Stratification in health care is not a new phenomenon (Sudnow 1967b, a; Shim 2010; Clarke 2010). One of the significant changes brought by the increased biomedical interventions in health care is the latter becoming an object of consumption. Adele Clarke and colleagues (2003; 2010) identified the stratification of biomedicalisation in the means of distribution and unequal access to biomedical interventions.

It may seem that it is the relative who primarily decides to attain ‘aggressive’ life support treatment. In fact, after taking a patient to the hospital, many relatives feel they have minimal choice to make. Relatives depend on the doctor’s decision in the first place by saying, ‘do whatever is needed.’ The dependency between doctors and patients is hegemonic, cultural

⁶⁷ A vegetative state is when a person is awake but is showing no signs of meaningful awareness. Person may have basic reflexes like blinking eyes in response to loud noise <https://www.nhs.uk/conditions/disorders-of-consciousness/> last accessed 31/08/2020.

as well as historical, which lies in the emergence of Western medicine in the British Raj (Arnold 1993; Bala 1991) and the authoritative nature of biomedicine. However, the emergence of biomedicine or allopathy occurred in British India to protect the health of the British army and the Europeans in India, which also reflects the embedded power relationship that exists at the heart of modern medicine. During colonial times, doctors were mostly from the Empire; hence the relationship between doctors and local people has remained as 'coloniser and colonised' even after the end of colonial rule (Arnold 2000; Biswamoy 2001; Arnold 1993; Chakrabarty 1988; Guha 1996).

In light of this discussion, I intend to explain how hope, unequal access to resources, and biomedicalisation are entangled in the technologised living and dying at ICU in Bangladesh. In this chapter, I suggest how technologies create hope for the prolongation of life, how it impacts relatives' lives, and how they manage this expensive advanced technological treatment, through which I will identify the stratified nature of biomedicalisation in Bangladesh.

The following discussion is divided into three sections. In the first section, I theoretically address the political economy of hope, as relatives' hope gives a substantial rise to the political economy and stratified biomedicalisation. The concept of the political economy of hope describes how personal and collective hope is associated with the political, economic structures (DelVecchio Good et al. 1990; Novas 2006; Brown 2007, 2005; Mrig and Spencer 2018). In the second section, I identify the trajectories of hope in life-prolonging treatments to illustrate relatives' accounts of hope. In the third section, I will address the quandaries of hope in continuing life-prolonging treatment to describe the uneven access to the life support

technologies that resulted in stratified biomedicalisation. In this section, I will also discuss how the differences in accessing life support technologies contribute to different 'expectations' of high-tech life-prolonging technologies. Drawing on my fieldwork, I will conclude this chapter with a discussion of the juxtapositions of mistrust and dependency that concurrently emerge in life-prolonging treatment.

The objective of the following section is thus to present the making of technologised hope and discuss its emergence as a political economy of hope in the life-prolonging treatment.

The political economy of hope and prolonging death

The public health researcher Atul Gawande⁶⁸ (2002, 2014) describes death as not a failure but a normal phenomenon in a book based on his experiences as a physician. He says that "*death may be the enemy, but it is also the natural order of things*" (2014: 8). Though it is natural, we mostly want to resist and delay death. As Kaufman said, "*when faced with a life-threatening disease, most of us want the miracles of medicine to extend our lives into a vaguely perceived open-ended future*" (Kaufman 2015: 2).

Brown's (1998) observation on hope precisely reflects this situation, as he said, "hope serves to designate a vocabulary of survival where survival itself is at stake." Franklin (1997)

⁶⁸ Atul Gawande is an American surgeon, writer, and public health researcher.

comments that the language of hope has the same expressions as that of scientific discovery, as it is directed to overcoming obstacles, exceeding boundaries, and discovering a new range of vision. Besides hope, anticipation also exists in the life-prolonging treatment by life support technologies. Adams et al. (2009) explicate that anticipation as a lived condition acts in the present in response to speculation about the future. They set out the future as living in the present. Adams et al. (2009) show how anticipation works in the context of death by reconfiguration. In this regard, it can be said that with biomedical anticipation death can be predicted, not only in time but also by one's ability to control the time of death through decision making (Adams, Murphy, and Clarke 2009; Kaufman and Morgan 2005; Kaufman 2005).

Following the discussion, it can be said that, in recent times, life support technologies often work as 'miracles of medicine' that can prolong life, or make the process of dying prolong, a matter of choice, visible, and complex (Kaufman 2005; 2015; Lock, Young, and Cambrosio 2000; Franklin and Lock 2003; Lock 2001). It is noted that life support technologies have been implemented following the curative philosophy of care, that is, an ICU (hospital) to save and extend the life and delay death (Kaufman, 2005). Some would argue that life support technologies stimulate the desire to delay death (Novas 2006).

The desire to live longer is found in Bangladeshi proverbs, and similar ones can be found across different cultures. There is a popular proverb in Bangla – '*jotokkhon shash, totokkhon ash*' [while there is life, there is hope]. There is a strong bond between being alive and hope. Generally, we could say that the core of human nature is active even when the time of death arrives, whether it is 'timely' or 'untimely.' Until a person breathes his/her last breath, their family generally tries to prevent the death. In Bangladesh, the hope and expectation of a

‘cure,’ and sometimes the sense of family responsibility and duty, compel relatives to choose ‘aggressive’ life support treatment options.

It is worthwhile to consider framing the hope in the context of a political economy to capture the sociocultural context and the complex factors involved around life-prolonging treatment and technologies. As Novas (2006) says, hope is situated in a broad range of socioeconomic situations and phenomena while Ehlers and Krupar (2014) identify socioeconomic factors as the guiding principle of biomedicine, suggesting hope drives biomedicine further.

Nevertheless, to materialise the hope requires a considerable amount of money in the marketised health care system, a consideration I bring up at the various point and discuss in detail later in this chapter. DelVecchio et al. (1990) and Novas (2006) first brought up the political economy of hope in discussing the meaning of ‘live-in’ hope as taking an active action towards the future by extracting possibilities and potentialities possessed in the present. They mention how personal endeavour and collective hope is associated with the broader political, economic, and social structures in the biomedical interventions (DelVecchio, et al. 1990; Novas 2006; Brown 2005). The stories of relatives in this chapter are analysed with this anthropological concept of the political economy of hope to comprehend the broader context in which hope is constituted and produced and identify stratified biomedicalisation. By deciding the life support treatment, relatives become medical technology consumers based on hope, like in many other places in the world⁶⁹. In contemporary Bangladesh, privatised health is considered as one of the most flourishing profitable economic sectors. Moreover, the private

⁶⁹ Becoming ‘consumer’ of organs by the virtue of organ transplantation is another popular example of this kind.

health care service has marketing techniques to motivate more users, which transforms patients into 'consumers,' as high financial stakes are involved in the operation of ICUs. Thereby, market expansion goals have a greater influence on hope motivation.

Beyond the universal desire to survive, hope for life depends on access to resources to pay for life-sustaining treatment, whether the family has enough financial capacity to support the treatment. In this point of discussion, the medical imaginary plays an important role. As life support technologies bring up the hope of death to be 'cured' or prevented or avoided, relatives choose the aggressive intervention of life support option despite knowing the slim chance of success, based on medical imaginary.

DelVecchio (2010) mentions that, in the context of life-prolonging treatment, hope interplays with a medical imaginary and a biotechnical embrace and is eventually influenced by them. DelVecchio (2010) defines medical imaginary as an idea of the capabilities and function of biomedicine taken up by a particular society. It is mainly a positive understanding, with individuals investing emotionally and financially in the hope of a cure. This specific point of discussion is explicated by DelVecchio by stating that "Enthusiasm for medicine's possibilities arises not necessarily from material products with therapeutic efficacy but through the production of ideas, with potential although not yet proven therapeutic efficacy (2010: p, 274)."

According to DelVecchio (2010), a medical imaginary circulates through professional and popular media. I argue here that medical imaginary is also a moral imaginary in that it has a strong normative imperative. While DelVecchio (2001) also mention 'biotechnical embrace,' by which she means the affective and imaginative dimension of biomedicine and biotechnology

that envelops physicians, patients, and the public, thus positioning the medical enterprise as something deeply entrenched in the hope and promises of biomedical/ biotechnological developments, and 'regimes of truth.' She argues that the hope surrounding biotechnological advances is often not based on evidence of therapeutic efficacy but a significant expectation.

My research finds that relatives, embedded within a complex situation of hope, are primarily motivated by advanced medical treatment options. Families who can pay higher treatment costs will usually try to reach the hospitals with the most advanced technological medical treatment, with the hope that only 'such hospitals can provide the best treatment.' As seen in this study, relatives invest in the medical imaginary influenced by the doctors, by someone who has prior experience of such treatment or *Dalal*. All of the cases discussed in this chapter show that patients were first taken to the independent international chain hospital or renowned private hospitals, because these are well known to be well equipped with sophisticated technology from abroad, and were suggested by either doctors, well-wishers, or *Dalal*. For relatives, advanced life support technologies become the vehicle for hope. However, many people in Bangladesh are not able even to bring their dying relatives to the hospital because they have absolutely no resources.

Hence in the context of life-prolonging treatment, hope cannot be reduced to patient families' 'own wishes,' as it is also influenced by the interests of the privatised health service market. The structural forces of the biomedicine combine with hope, familial responsibility, and affection to motivate relatives' decisions to seek or accept life-prolonging treatment. Thus, life support technology, sociocultural values (hope, familial responsibility, power,) and the economy get strongly tied together in the ICU. The hope and expectations, emotions and

responsibilities, and the life-prolonging technologies and finances become part of the political economy of hope (Brown 2005).

Trajectories of Hope

The following stories map the social life of life support technologies, which constitute how hope emerges from imagination, expectation, and sustains and creates new techno-subjectivities and becomes a marketised product. The biomedical embrace and medical imaginary can be identified in creating hope. The following stories of Rohan explain similar hope.

Harunur Rashid, father of Rohan (who was injured in a road traffic accident): Many people said to me, I am taking my dead son to Dhaka; I will not be able to reach even Sitakunda.⁷⁰ I did not listen to them. He is my elder son. We, his grandparents, never let him get even a scratch on his body (being very much protective).

[The patient was taken to Alpine⁷¹ hospital from Chittagong Medical College Hospital]

This observation can be analysed in terms of a 'moral role of imagination' (Fesmire 2003). Fesmire means that imagination involves testing potential futures in thought experiments and predicting outcomes in order to carry them out. While Rohan was taken to Dhaka for better treatment, Rohan's father had only 'hope' of imagining the potential future rooted in the moral decision. Coeckelbergh and Mesman (2007) similarly discuss their study on the role of moral imagination in decision making in neonatal intensive care. They want to relate

⁷⁰ *Sitakunda* is an *upazila*, or administrative unit, in the *Chittagong* District of Bangladesh. It is located on the way to Dhaka, 56 kilometers away from Chittagong while Dhaka is 260 kilometers from Chittagong.

⁷¹ Pseudonym

imagination to morality and explain that “Imagination is a crucial element in the decision-making process [...] and the moral reason involved in it”(Coeckelbergh and Mesman 2007). Coeckelbergh and Mesman show in their study that, in a critical situation of a patient, when the decision of ‘treatment or no treatment’ is needed to be taken, it is the imagination that helps to take the moral decision, despite the doubts, fear, and uncertainty. In the NICU, parents take a decision based on a complicated calculated estimation of chance provided by the doctors. When information is very limited, it is hard to project the estimate. According to Mesman and her colleague (2007), imagination is required to fill the gap. Imagination projects the implication of the decision.

Similarly, relatives also used imagination to decide the course of treatment. By imagining his son’s death, Harunur Rashid took him to the most sophisticated hospitals, which was beyond his financial capacity, to access the most advanced medicine. Primarily he thought of selling everything he had for the sake of his son’s life. That decision was taken not on the prediction by medical calculation but based on hope created by the biomedical technology’s promise.

I found in this research that it is relatives’ anticipation of relatives’ death that forces them to explore every possibility in the most advanced hospitals to ‘prevent’ the ‘premature’ ‘unexpected’ death. Thereby, relatives carry hope and also place their trust in high-end hospitals and advanced life-supporting technologies. Further, I argue that hope is an impulsive but enduring expression, located at the individual level, often grown from the convoluted conception of ‘assurance’ apparently given by the advancement of medical technology. Simultaneously, the collective and socio-cultural elements of care and responsibilities are also embedded in the ‘hope’ process, when familial responsibility enforces the hope. In this connection,

Kaufman et al. (2004) observe that “the increasing availability of medical interventions is re-shaping patient expectations and norms [...]” (Kaufman et al. 2004: 3). Again, relative’s expectations get inspired by the success stories from various sources, as happened in the case of Mithu. After the gunshot on the neck, Mithu was first taken to a local private clinic. After the first operation was done, relatives decided to take him to the Phoenix Private Hospital by a friend’s advice. Knowing Mithu’s brain injury, a friend suggested this hospital as his relative recovered from a serious brain injury by treating at Phoenix. As a result, relatives desperately place expectations in the advanced treatment of Phoenix.

The following sections show how hope and life support treatments go together hand in hand with other aspects of the hospitalisation process.

Hospital Emergency to ICU

When a critically ill patient is brought to the hospital, it is not always straightforward to get the treatment adequately done. Patients from different classes and backgrounds (urban, village, core-periphery) may have to go through many different processes to get a patient admitted to an ICU. Sudnow (1967a) has also mentioned a similar situation in his ethnography of Dead on Arrival (discussed in the introduction chapter). To get the right hospital is not always a matter of luck or ‘choice.’ The following discussion will establish this claim.

Coeckelbergh and Mesman (2006) note that treatment decision-making follows at least three stages: taking the decision of treatment, continuing the treatment, and; reflections on the

decision, such as doubt and uncertainty. I also found similar reflection in the following case of Shimul, which shows that the decision of treatment process involves doubts and uncertainty, with the probable outcome of the treatment and the economic condition of the patient. However, I also find that the 'indecision' was swept out by the anticipation embedded in the outcome of treatment. As Adams and his colleagues (2009) stress, 'anticipation is also always in part, about optimization as a 'condition of possibility (p.256).' The anticipation of life plays a pivotal role, allowing relatives to decide on further treatment of Shimul along with other factors that made the decision possible. In this case, the treatment was not started until a neurosurgeon came down to the emergency room and got to know about Shimul's maternal grandfather, a Member of Parliament, and a renowned politician. The neurosurgeon instantly instructed doctors to start treatment, suggesting the role of class and social power. This case suggests that biomedical therapeutic decisions can be changed for the privileged group, which also represents the example of stratified biomedicalisation.

Nahid, brother of Shimul (who was injured by a road traffic accident): My brother bled a lot. Even grey matters of the brain came out through his ear. When we took him to Alpine hospital, he was 'dead.' The Doctor said that my brother's pulse was 3. We told an emergency doctor, why won't you treat him since we already paid? [UTH]

When Shimul was taken to Alpine Hospital, an international five-star⁷² chain hospital in Dhaka, at 5.30 am from Char Fashion, the emergency doctor found his pulse to be three beats per minute. Shimul's relatives took him to this hospital by a family friend's suggestion as he

⁷² This hospital is considered to be the most expensive hospital in Bangladesh.

witnessed someone's recovery after a brain stroke. The doctor explained to them that Shimul needed a major brain operation for his injuries and would also need ICU, which would cost a lot. The doctor told them to take Shimul to the Government hospital, as his survival chance was also very slim. The doctor's advice to them was not to spend much money on such a case. Before the arrival of Shimul's ambulance at the hospital premises, at 2.30 am, one of the relatives had deposited 100,000 BDT (One lac taka)⁷³ to Alpine Hospital, as per their hospital admission rule. Shimul's accompanying relatives repeatedly requested doctors to get the treatment started as they had brought the patient from Char Fashion⁷⁴ Upazilla and already paid the deposit, and he was still alive. They said to the doctor, "we know our patient is dying, but still try whatever is possible."

Shimul's situation can be explained through the role of hope, the medical imaginary, and access to resources in different contexts. We can see several issues in the treatment process. The doctor was hesitant to proceed with the treatment for several reasons: Firstly, Shimul required the critical care treatment (which is expensive) for his severe head injuries, but his chances were very 'minimal.' The doctor might have wanted to avoid being blamed or wanted to save relative's money for initiating an expensive treatment when knowing a patient could die at any moment (this kind of allegation is commonly made against private hospitals by patient groups, which will be discussed in chapter 7), thereby doctor advised first to take him

⁷³ Approximately equivalent to £850 as per exchange rate of October 2015 (link <https://www.poundsterling-live.com/best-exchange-rates/british-pound-to-bangladesh-taka-exchange-rate-on-2015-10-15> last accessed 21/04/2018).

⁷⁴ Distance is approximately 250 kilometres from Dhaka, which is considered as a long distance in Bangladesh as there is no direct road route. Hence need to travel by water transport and road transport.

to the government hospital. Here, the possibility of surviving was determined based on scores and expert opinion, where decisions about interventions are taken based on a prognosis (Coeckelbergh and Mesman 2007). In Shimul's case, all parties were involved in the decision process. This also reveals that those who have social power and financial capacity to avail themselves of medical technologies are *probably* able to get better and immediate treatment. Those who do not have this access to social power would have a different experience.

Secondly, The doctor might think that the family is not able to pay the bill, as Alpine Hospital is one of the most expensive international chain hospitals in Bangladesh, and the patient came from a village that made the doctor assume that they would not be able to afford it.

Shimul Gani was given life support, received a CT scan, and other emergency treatments. After 45 minutes of emergency treatment, Shimul responded to it, and his pulse rate rose to 47 beats per minute. Both doctors and the family became more hopeful seeing this initial 'development.' After 22 days, he was transferred to intensive care in the University teaching hospital (UTH) as he needed long term life support. The doctor at Alpine advised them to shift to a government ICU that would be less expensive. After six months of continuing his treatment in UTH, his GCS⁷⁵ score raised from 3 to 7, which made the doctor and family again hopeful about his recovery. He stayed another 12 months, but his condition never improved. At UTH, doctors repeatedly advised the family to discharge Shimul from the hospital, as there was no more treatment for him. However, his family refused. Instead, they agreed to transfer him to

⁷⁵ The Glasgow coma scale is used to assess patients in a coma. The initial score correlates with the severity of brain injury and prognosis. The Glasgow Coma Scale provides a score in the range 3-15; patients with scores of 3-8 are usually said to be in a coma. Source: <https://www.glasgowcomascale.org> Last accessed on 28.09.2019

HDU.⁷⁶ Shimul's relatives often avoided meeting doctors in order to avoid their requests for Shimul's discharge. Eventually, Shimul was taken to his village home after one and a half years in the hospital.

An increasing number of technologised medical hospitals in Bangladesh offers a range of life-saving treatment options available to those who can afford it. For the relatives, it is hard to resist these options. Relatives often start life support therapies without knowing the burden of crossing the line of 'too much' hope. Those who have enough money can keep continuing the battle, but for those who do not have the resource, their journey becomes a difficult one. The experiences of ICU patients are diverse, and their relatives' narratives varied depending on differences of class, social status, and the condition of the patient.

Shimul's story illustrates that financial capacity is an essential factor in getting high-end treatment, but not all. Shimul was first taken to the (Government) Barisal Medical College Hospital, but doctors refused him after giving primary treatment because they could not treat this level of injury. The class, social status, and power, and above all, the relatives' hopes and effort made the high-tech treatment possible and accessible for Shimul Gani. His relatives believed that if they could not take Shimul to the most advanced hospital, he could not 'survive.' However, despite their relatively wealthy status, Shimul's family still had to sell their property to pay for his treatment. One of Shimul's relatives once expressed to me the frustration about spending a considerable amount of money for this treatment. He ended up his conversation

⁷⁶ High Dependency Unit. This unit is considered as one step down to ICU. The patients who do not need mechanical ventilation generally are taken to the HDU.

with me saying, “I will tell my family not to put me on life support ever. There is no point in being alive on life support by putting the family in deep crisis.

[Shumon, UTH]

Shumon’s opinion on expensive technologised life-support treatment reflects another side of familial responsibility and moral obligation of choice. Shumon is unable to take withdrawal decisions for his kin for the sake of familial responsibility and care. However, morally he cannot think himself on life support as it would put his family in the economic crisis. I also want to consider this as his familial responsibility.

Inevitably, not all critical patients receive the same care and treatment, particularly those from villages, whose kin furthermore had no proper knowledge of how the health service works in practice in Bangladesh: in particular, this involves harassment by *Dalal* or brokers. The story of Taufiq, involving these factors, tells us a different trajectory of life support treatment.

Taufiq reached Dhaka Medical Hospital⁷⁷ by a private ambulance from Laxmipur, almost 8-10 hours after his road accident. He was first taken to Laxmipur Sadar (Upazila or primary) Hospital as soon as a microbus hit him on 27th October 2015. Taufiq was left untreated in the emergency ward for hours at Sadar Hospital. After a couple of hours of waiting, he was only given primary treatment to his broken arm. He had a severe head injury. He had been unconscious since then.

⁷⁷ One of the largest government medical college hospital in Bangladesh, located in the capital city of Dhaka.

Nevertheless, Sadar hospital only could provide him with primary health care and advised family members to take him to the (Government) Dhaka Medical College Hospital (DMCH) immediately. This scenario is not very unusual in a government hospital, especially outside the major cities in Bangladesh. These hospitals are also not able to provide treatment for critical cases like brain injuries. Lack of resources, lack of workforce, lack of sufficient health professionals, and lack of political interest in strengthening the health system are reasons for weak government hospital care outside the major cities. When the patient and family reached Dhaka Medical College hospital, it was midnight. Faisal, Taufiq's brother, who was with him, said, "*there was no doctor at DMCH, Taufiq was left on the corridor as there was no bed available in the ward.*" (UTH)

The family was told about his brain injury and informed that Taufiq needed immediate treatment at the neuro ICU. However, there was no bed in the ICU. Taufiq's father works in the Middle East, and Faisal, who is 21 years old, is the eldest male member of the house and was facing this kind of crisis for the first time. He did not know Dhaka, the capital city, very well, or Dhaka Medical College Hospital, or any other private hospitals. He only could realize the urgency of his brother's treatment; the sooner it took place, the better, since Taufiq was not getting adequate treatment from DMCH. All medicines and medical tests need to be arranged by the patient's family (as discussed in chapter 4). Going here to there, from this building to that building requires the physical efforts of relatives too.

Meanwhile, Faisal was targeted by a *dalal* of a private clinic. The *Dalal* was able to convince him that the ICU bed would not be available immediately, and failing to provide him immediate ICU care would cost him his life. So, Faisal agreed to take his brother to a private hospital

the next day as per that man's suggestion. He found only another patient in the ICU when they reached there. Faisal realised his mistake of trusting the *Dalal* when he found out there is only one doctor for the ICU and no consultant or senior doctor to start the treatment. They managed to call a consultant to see his brother in the late evening after calling him several times.

With the help of his relatives, at last, he managed to leave that clinic by paying almost 50,000 BDT (approximately 420 GBP) and shifted him to another private hospital, named Anowara, which was relatively better as Taufiq received treatment at Anowara. Taufiq was treated there for 8 more days. He was on the ventilator, which cost them more than 4 lacs taka.⁷⁸They then managed to get an ICU bed at UTH by an ICU consultant's recommendation who saw Tuhin at Anowara Hospital. Relatives did not know how long Taufiq needed to be at the ICU, as his brain was not responding when I saw him for the last time. He could open his eyes, but still, there was no reflex. His GCS level was 8. Taufiq was transferred to HDU to reduce the cost. Faisal, repeatedly nodding his head, says,

We do not have any money left to continue the treatment. We cannot even take him out of the hospital as we owe the hospital and pharmacy money. We do not have any more property to sell. Taking loans and charities from relatives- all are exhausted. Nothing is left. [UTH]

On 27th March 2016, Taufiq was taken to his village home on a bond for hospital debts. He did not require mechanical support and regained some response, but was bedridden.

⁷⁸ One lac Bangladeshi taka is equivalent to almost 850 GBP.

The story of Taufiq provides a very typical journey of a critical care patient from outside Dhaka whose family have inadequate knowledge regarding life support options and also have financial constrain. However, even with limited resources, Taufiq's family brought him to the capital city because he did not get proper treatment for brain injury in their small town. Unlike in the Shimul case, like most people in Bangladesh, Taufiq's family first took treatment at a government sadar hospital⁷⁹ according to their financial ability. However, Taufiq's relatives had to choose private hospitals due to not getting necessary treatment even in the tertiary level government hospital DMCH in Dhaka. However, Taufiq did not get the proper critical care treatment even after his family spent a huge amount on private care for not having the necessary service. Taufiq's family had to spend their limited resources in vain for failing to access quality treatment. If Taufiq would have able to get treatment in the DMCH, and if the *Dalal* would not be able to trick them, their suffering would be lesser. They would not have to exhaust all their resources in this treatment process. This story reveals how adversity forces relatives to move further to get the advanced treatment options made possible by biomedical technology in a low and unregulated condition. Hence in the context of life-prolonging treatment, hope cannot be reduced to patient families' 'own wishes,' as it is also influenced by the interests of the privatised health service market. The structural forces of the biomedicine combine with hope, familial responsibility, and affection to motivate relatives' decisions to seek or accept life-prolonging treatment. Thus, life support technology, sociocultural values (hope, familial responsibility, power,) and the economy get strongly tied together in the ICU.

⁷⁹ Sub-district level secondary hospital

The hope and expectations, emotions and responsibilities, and the life-prolonging technologies and finances become part of the political economy of hope (Brown 2005).

Hope and the temporalities of death

Another salient aspect brought by life support technologies is to control the time of death as a new affordance of the technology. I argue in this section that the affordance of life support technologies creates temporality of death. Kaufman suggests that the transformations of death by controlling time are the consequence of biomedicalisation in *affluent* societies (2010). She points out that considering the time of death as a controllable event is a relatively new phenomenon. Kaufman (2010) further explains that the transformation of time by medical technologies in this area has two dimensions. One is the control over the timing of death, and another is controlling over death by the creation of time left.

The death of Mr. Mahmudul Huq stands as the first example of controlling the timing of death by technology, where his wife requested the doctor to push back the time of death with the help of medicine and machine for their children to come from abroad.

The use of the GCS scoring scale for the prognosis of the dying patients reveals the second type of controlling over death by the creation of time left by using biomedical knowledge and technology. Despite Mrs. Momota's vital life signs were 'almost' absent, she was not declared dead until the ECG machine (like any other death in ICU) confirmed her death. The technology has direct control over determining death. Including Shimul, Rohan, Tareen, Siam all are the second type of control of time.

However, based on the following stories of Mahmudul Huq, Shafayet Alam, Akram Ahmed (Father of Fahad Ahmed, stated in chapter 5) I can illustrate that life support technologies have *also* contributed to transforming the ‘times of death’ in both of these dimensions in Bangladesh. Each of the stories allows me to explore the relatives’ hope expressed through the affordability of life support technologies in Bangladesh.

Kaufman (2010) suggests that the emergence of a controllable timing of death also expresses the desire for individual clinical control, and the technology can be considered a reflexive tool for confronting or ignoring mortality (Kaufman, 2010). The life support technologies seemingly give some control over death and prolonging life.

Mahmudul Huq has had stomach cancer. Mr. Huq’s family (his wife) has given consent for “no resuscitation” (DNR – ‘do not resuscitate’) to the doctors. Mr. Huq has been treated in the Phoenix Hospital on and off sporadically since December 2015, after receiving treatment in Singapore. When Mahmudul Huq’s heartbeat started falling despite medicine given, the doctor explained the situation to Mrs. Huq. She asked the doctor, “My son is on his way from abroad. Can you please keep him alive with low dose medicine until my son reaches us?” The doctor says, “let us see what happens.” Mr. Mahmudul Huq died the next morning. The doctor could not keep him alive on the machine for his son to arrive. His son could not see him ‘alive.’ This shows that technology is not always capable of giving us what we expect from it, regardless of our hope as the control of biomedicine and biotechnology has limits. In this case, the promise of technology to control the time of death was not fulfilled, but hope was created.

Hoping for 'Quantity or Quality' of life

Whatever the actual likelihood, when a family decides to put their relative on life support, the ultimate hope is that the technology will save his/her life. Thus, life support machines are considered supremely important medical devices.

At the moment of relatives' hoping for life, they often only hope for a quantity rather than the quality of 'life.' As Priya, *wife of Mithu Chakrabarty, a gunshot victim, who has been on life support since then*, said,

Priya: *The doctor said that he might not be able to stand on his own feet. I do not care. I only want him to live and nothing else [emphasis]. He does not need to do anything. I will feed him my whole life. I will sell all my jewellery if necessary.*

[Phoenix hospital, second waiting room/counselling room]

Priya was in tears while she made the above statement and repeatedly said that she only wanted her husband to be alive regardless of the quality of such life, even he had to lay on the bed the whole of his life, being incapable of doing anything. She also stressed the will to bear the cost of sustaining her hope [At first, the patient was taken to a local private hospital, and on the same day, he was transferred to Phoenix hospital].

Sharifunnesa expressed similar thoughts regarding her husband's Shafayet Alam's condition. She is not concerned about the quality of her husband's life. That her husband is alive makes her happy, though bedridden and unconscious and despite the financial cost. Sharifunnesa said,

'He might be bedridden, but he is alive. The doctor said he was dead six months back. Nevertheless, he is alive till now, that is very important for me. Who knows, he might be fully recovered one day.'

[Chittagong, at their apartment, which was transformed to taking care of Mr. Alam with necessary medical devices].

The story of Shafayet Alam below reveals the controlling of death and prolonging of life, with the emergence of a new subjectivity of personhood during the attempts to control the time of death. It also highlights negotiations about the meaning, and the quality, as well as the cost and value of life. Both the cases of Mahmudul Huq (above) and Mohammed Shafayet Alam (below) reveal that resources make it possible to take control over death by machine – but only to some extent. Despite spending huge amounts of money, technology is ultimately not effective at controlling the timing of death. I want to argue that this type of futile attempt of life support treatment serves both the hope of affluent society and privatised health care service.

Technology and medical staff together created Mrs. Sharifunnesa's (wife of Shafayet Alam) hope to combat her husband's health condition. However, she had to spend millions of Bangladeshi Taka to materialise this hope. The total cost of the treatment for Mr. Alam is beyond the imagination of most people in Bangladesh. Often, financial resources are the primary factor in the decision or capacity to keep continuing with life support. This is how death-dying becomes a space of commodification through life-prolonging technology.

Mohammed Shafayet Alam was taken with acute appendicitis, from a private hospital in Chittagong to another in Dhaka by an air ambulance. By this time, the patient's appendix had burst, and his condition became very critical. Eventually, he had several consecutive cardiac arrests. Doctors put him on life support for three days and informed the family about his 'dying' condition. Relatives felt that doctors were keeping the patient at their hospital to make money, despite the patient's condition being out of their control. Following a tense discussion with the hospital management, family members took Mr. Alam to Singapore Hospital by air ambulance, where he had been treated for four months. Family members were satisfied with ICU care at Singapore hospital, despite high treatment costs, because they were allowed inside the ICU all the time, i.e., given constant access.

Mr. Shafayet Alam's wife recorded the physiotherapy sessions in Singapore hospital with her phone, bought a medical bed and other equipment, hired a nurse from the Singapore hospital, and returned to Bangladesh with her husband. They converted a flat and modified a room with mechanical devices to meet her husband's needs. The Singaporean nurse gave training to Mr. Alam's wife and two other nurses from a private hospital. Mrs. Sharifunnessa says that she does not have any confidence in Bangladeshi treatment. She thinks the medical facilities and care in the Singapore hospital have kept her husband alive. She is hopeful that her husband will recover one day. She firmly tells me: *"The Bangladeshi doctor declared him dead, they do not know anything. He is still alive. We did not let him die"*.

Six months after I interviewed his wife, Mr. Alam died at a local private hospital after developing respiratory distress. He survived almost a year after the appendectomy in Dhaka, Bangladesh.



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



**Picture 14 Mr. Shafayet's room with a few medical devices.
The continuation of life-prolonging treatment at home**

Similarly, Tarannum Jahan and her family transformed one of their rooms into a hospital-like private room with necessary medical devices for her mother. Her mother has been in a 'vegetative stage' following heart surgery on 21.08.2013 in India. After being in the hospital for 14 months, she has been transferred to the home. Tarannum Jahan narrates why she wants her mother to be alive. As she told me,

We were like friends. We used to talk about everything with each other. Regardless of the many opinions in the family, I want my mother to stay alive. I want her to stay alive for me.

[At her residence, Dhaka]

These quotes represent the views of the relatives I have spoken to, who have invested their hope into life support technologies when falling back on life-prolonging treatment. From the anticipation of the future, they act in the present to attempt to control the time of death within their social and financial position.

The quandaries of hope and unequal access to the resource

Given financial restrictions, technology has specific horizons of expectation (Koselleck, 1985; Lock 2001). It also makes it difficult to decide where to draw the line of intervention, as life support opens up life-prolonging possibilities (Kaufman, 2005). The cases of Rohan- (19 years boy; brain injury by a road accident and father is a small service holder who already sold his properties for Rohan's treatment), Tareen (12 years, girls; unconscious for a couple of months for a brain tumour; father is a migrant worker in the middle-east; relatives do not want to

withdraw life support despite doctor's advice; yet unable to continue treatment for a financial reason), Siam (11 years boy; cardiac arrest following GBS; unconscious for a couple of months; father is a small service-holder in a private company. Colleagues, friends, and relatives are financially helping in the treatment; relatives do not want to take withdrawal decision; despite struggling to continue treatment) (Discussed in chapter 4 and 5)- reveal the predicaments of life support treatment decisions brought about by financial constraints.

The parents of the three struggled but continued to provide life support to their children.

The basis of their hope is that life support technology can fight with death as Kaufman (2015) says, sometimes, we can buy time with the help of medical technology.

Rohan's father is unhappy with hospital care. He thinks if he could take Rohan home, he would give him better care, and eventually Rohan could improve. Because of hospital and pharmacy debts, he is unable to take Rohan out of the hospital. Being a 'third-grade' government officer, his salary is not enough to cover this expensive treatment. By this time, he has sold land property and a small garage he has. He is trying to arrange money for paying the hospital bill.

(UTH)

In the case of Siam, whose father is an accountant of a private firm. He supports his family with his small salary. Siam's treatment would never have been possible to continue without help from friends and family. Siam was first taken to a private hospital, where he was treated in ICU for a week. It was difficult for him to pay 35,000 BDT for a day, so then he has taken Siam to [cheaper] UTH with the help of an ICU consultant.

Though I have provided here, only two stories of relatives struggling with financial constraints, 20 out of 24 cases in my fieldwork involved financial problems. A public charity, financial help from friends and family, savings, and selling property were the primary sources of providing payment for treatments. This scenario of the financial burden of life support clearly demonstrates the stratified biomedicalisation of death mentioned throughout this chapter. I now turn to explore it in more detail about the paradox of death.

Choice of no-Choice

'Hope emerges as a paradoxical temporal practice' (Mattingly 2010, 5)

Life support treatment is costly⁸⁰ in terms of money and intensive medical care in the ICU provided by sophisticated medical devices. Despite strong urges to keep their next of kin alive, family members often had to accept the reality of their inability to continue the treatment, especially in the face of scarce resources and uneven access to them. Accepting this reality, and taking the withdrawal decision, is the central quandary or predicament of life support technologies.

Ratna was responsible for such a decision and her family, regarding her father Faruk Mia's life and death decision (67 years old; respiratory failure; conscious but intubated; family is unable to continue treatment). Faruk mia's daughters and sons were unable to continue the ICU

⁸⁰ Average annual per capita income of Bangladesh in 2016 was 1,466 USD. A family can pay up to 3 days' life support bills at a private hospital in Bangladesh with this amount of money. The first few days of treatment are even more expensive.

treatment cost. However, they cannot stop the treatment as their father was conscious. They all knew, to stop treatment means his father's inevitable death. Furthermore, the doctor could not give them an idea when their father can breathe by himself.

According to my fieldnotes, *"Apa, we have decided not to take off the ventilator in a family meeting on Friday"* [UTH]. Ratna seems very happy and relieved when telling me the family decision. Her father was conscious but could not speak as he was on a ventilator. The doctor has been trying to take him off the ventilator, but Faruk Mia is unable to breathe even with the BiPAP.⁸¹ Ratna says to me on another day,

My father does not want to stay in ICU. He is conscious, able to see everything around him in the ICU. He could not stay alone after my mother's death. He is afraid of being alone. But how can we take him? He wants to go to our village home. We couldn't take my mother to our village home when she was dying. She died here in Dhaka which she never wanted.

[UTH]

Ratna explained how she and her siblings find it difficult to arrange money for their father's treatment. Her two brothers have official jobs; one sister has recently joined a college, another is a school teacher, and herself is a housewife. They already have paid 3,50,000 TK at BIRDEM. At the time of the first interview, ICU cost 10,000 taka to 15,000 taka per day, sometimes less than that. She told me,

⁸¹ A non-invasive ventilator

We do not know how long we can continue it. My siblings are all small service holders; they do not earn a lot. But my father is conscious, how can we remove the ventilator? We cannot kill him by withdrawing life support.[UTH]

A few days later, Ratna and her family decided to take their father to the village home. They took him with the oxygen cylinder by ambulance. Her father was alive until he reached the village home, and then he expired. I came to know when I called her to know about her father's condition. Over the phone, Ratna says with a deep sadness: *"We are happy to think that at least we could take him to the village to fulfil his last wish, which we could not do with my mother's last wish."* [UTH]

While it seems that she is justifying their withdrawal decision in terms of 'fulfilling the desire of their father,' it can also be seen as a form of self-consolation; they reduce feelings of powerlessness by seeing a positive side.

Faruk Mia's story depicts two sides of life support. On the one hand, it reveals the hope created by life support technologies. The promises of the medical imaginary, along with familial responsibility, have encouraged relatives to opt for taking the treatment option. On the other hand, it sets up a paradox of life support technology as hope is destroyed when families cannot continue the treatment. Then the choices demanded by the creation of control over life and death become painful and hope-destroying. However, Faruk Mia's case stands in contrast to Shimul or Mr Alam, as Ratna and her siblings could not continue their father's treatment, though they pushed themselves a little further, but ended up with consoling their mind by fulfilling their father's end-of-life desire.

To summarise, it can be said that, with resources, technologies fulfil the promise of the medical imaginary and provide control over death. Without resources, this control is lost, and the family has to actively make choices that remove control over the time of death. In the case of Ratna and her family, they found a way to cope with this stressful choice, which was to assert that it was fulfilling their father's wish. In that way, they reasserted control.

The following story also shows life support withdrawal for financial reasons, despite doctors suggesting the 'possibilities' of a cure. This case reveals that this quandary and helplessness of a patient family are also possible in a *private* hospital, where patient and treatment can be considered as consumer and service products, rather than patient and care. It shows how ethics, morals, and life support withdrawal protocols get shaped and negotiated in a specific context.

My field notes state that:

The duty doctor was looking for a family member to sign the discharge papers. One man from the patient's family came inside to inform the doctor that the patient's elder son is delaying coming as he became ill. Shohag is a 22/23 years old young man who is still a student. His father, Monir Hossain, is only 57 years old and used to work in a newspaper office as a journalist before he fell sick. He has been suffering from TB and diabetes, which got critical over time. Dr. Tauhid told me that the patient had not been fully diagnosed yet at BIRDEM. He has been treated at the National Institute of Chest Disease and Hospital, Dhaka, for a month for Tuberculosis. The doctor adds, sometimes the medicine for TB damages the liver severely, which might have happened to the patient. He has Hepatitis as well. Since his father's

condition worsens at home (he became unconscious), Shohag has taken him to BIRDEM. Eventually, he has been admitted to the ICU on February 15, 2016, and was given life support. The next day, the family decides to release him from ICU on DORB (Discharge on Risk Bond). When I manage to talk to Shohag, he was with his cousin's brother. Shohag tells me, "I managed 60,000 taka for two days' treatment. But we cannot keep him here. My father is in great pain. We can't tolerate it anymore. Look, they (hospital management/doctor-nurse-caregivers) tied his hands with the bed rail. We can't tolerate it. So, we are taking him home."

After Sohag left, his cousin told me,

"He (Shohag) has been trying hard for his father's treatment. He brought his father here. However, the doctor said he would not recover. On top of that, they have other problems..." he speaks in whispers, *"they have financial problems. His father is sick for a long. They have finished all the resources they had."*

I observed the withdrawal of life support by removing the artificial respirators for the first time. After signing all the paperwork, Munir Hossain was taken to the ambulance on a stretcher with the oxygen. The intubating tube was removed when Shohag's father was shifted to the ambulance to ensure he does not die at hospital premises. The last step of removing oxygen was done to avoid the hospital's ethical and moral responsibilities. The patient's struggle for breathing was getting visible slowly; this time, the ambulance door gets closed, and it starts moving to the 'destination.'

[BIRDEM]

The withdrawal decision and the discharge process of Monir Hossain from ICU on the DORB (Discharge on risk bond) represents a localised form and practice of adopting life support

technologies in the context of financial hardship. Instead of the standard withdrawal procedure of life support (declaring brain-death followed by standard procedures by doctors- as described in chapter 1), the patient is discharged on DORB by saying relatives are transferring the patient to another hospital for better treatment, yet, they are taking him/her off the life support and taking him/her to home. These localised forms of action are taken and practised in the hospital to reduce the legal and bioethical disputes, perhaps as they know what is actually happening.

DORB is a form of coping strategy which allows patients' relatives to take a patient from the hospital without leaving the hospital at a legal, ethical, and moral risk. The hospital authority wants to avoid a patient's death at the hospital premises by providing patient oxygen while transferring from ICU to the ambulance. They provide the oxygen until the ambulance sets to start. The ethical and moral practices of life support treatment are thus negotiated and coped with in a DORB process. This negotiation and withdrawal process is shaped by local contexts, giving a very localised shape to the stratified biomedicalisation of death in Bangladesh.

***Your pocket is what cures you*⁸²**

The following case of Mrs Mansura Begum tells another story of an unregulated and lack monitored health care system, by the presence of *Dalal*, making patient and relatives endure another level of suffering and negotiation. This story also shows the vulnerability of people who come from major outside cities and how the *dalal* group deceives them.

⁸² I have chosen this from the title of the book written by Ellen E Foley (2009)

When treatment and health care is just a commodity, 'it is your pocket what cures you.'

Mrs. Hosna Begum took her mother, Mrs. Mansura Begum, to the Phoenix Hospital from Munshiganj⁸³ accompanied by her husband and brothers. Her appearance is a typical rural upper middle class with a decent but not expensive cotton *Saari*⁸⁴. This case illustrates another typical story of *Dalal's* deception to bring the patient to get a commission from the hospital. The emergency unit shifted the patient to the ICU as she was unconscious. Mrs. Hosna Begum told me that her mother had had Parkinson's disease and living with her elder son. She had collapsed at home. The doctor at Munshiganj Hospital had refused to give her treatment for lack of resources, and that resulted in her move to Phoenix Hospital by the deception of *Dalal*. Mrs. Hosne Ara told me that, "*the ambulance Driver [Part of Dalal group] took us to this hospital, by saying it is an excellent hospital*" without informing them how expensive this hospital was. Thereby, soon after admission to the ICU, Mrs. Mansura's family decided to take her from the Phoenix Hospital. Mrs. Hosna Begum looks very anxious and sad while she was standing beside her mother's bed. She tells me, "*We are taking her back to our home. We are not keeping her in the ICU. My brother is arranging an ambulance.*" I ask why, and she replies, "*the doctor says she is not going to be cured. They cannot say how long she needs to be in the ICU, so we take her back home. There is a very renowned hujur⁸⁵ in our village. I will bring holy water from him for my mother.*" After some silent moments, she adds, "*If we stay here any longer, the bill will raise to 50/60 thousand (nearly 450-500 pounds). We cannot afford that.*" A nurse advises her to take the release order as soon as possible to stop

⁸³ It is a district 55 km far from Dhaka city which takes more than two hours by road. Though it is a district, but not urbanized yet like major cities like Dhaka, Chittagong.

⁸⁴ Traditional Bangladeshi outfit usually wear by married women.

⁸⁵ A religious medicine man or woman, who usually gives holy water or holy amulets to 'heal' disease.

charging medical bills. I have observed Hosne Ara repeatedly calling someone and conveying the message given by the nurse and quickly arrange an ambulance. This is the only case I found in this study of relatives who decided on withdrawal for an alternative treatment given by religious *hujur*. This case also indicates that inability to avail the ICU treatment forces them to choose the alternative.

This is a story of a typical deception happening to people who have no prior knowledge and apparent control over the situation. I found in this study that such a feeling of deception renders the scepticism about doctors and health care management. Indeed, there is a group of people who make money from the helpless situation of marginal and disadvantaged people. Relatives also suggest that the overall health sector's effective monitoring could have stopped this situation. This type of incident negatively influences public perception about health care service, more specifically about life support treatment. I am going to address this issue in the next chapter.

Hope and stigma

Often, the imagined possibilities of cure offered by life support technology become an expected standard of 'taking care at the end-of-life.' Relatives fear stigma if they fail to accept the 'hope' provided by the 'modern' health care. Failing to provide treatment and care stands as negligence in caring for kin. Sometimes hope is a socio-cultural value deployed to justify aggressive life support treatment. It can also be understood as being indicative of biomedicalisation, which is usually dependent on individuals' willingness and agency. However, in the case of life support, individual willingness is impossible because the patient cannot consent,

and is therefore derived through familial responsibility, duty, and avoiding social stigma. Hope is therefore conditioned and shaped by sets of conventions. Hope also has to be socially endorsed. On the one hand, scepticism surrounds life support treatment; on the other hand, there is a growing public expectation, solidified through social practice, of the normality of taking advantage of life support. The following story illustrates this.

In the case of Anita Islam's parents-in-law (discussed in chapter 5- she had to take the mechanical support decision for her father in law, as her husband and brother in law were out of the city), I find not only responsibility that pushes relatives further to opt life support treatment; it is also the social stigma that obliges them to choose the futile treatment. She also mentioned about the so little time she was given to make the decision, which did not allow her to discuss this matter with other family members.

"Father was taken to ICU for suctioning his lungs as per doctor's advice. I was sitting outside the ICU. Father was staring at me from the trolley while he was taken to ICU as if he was seeing me for the last time. I cannot forget that look ever. After some time, suddenly, I saw the doctor was telling me something by holding a pipe in one hand. I could hear him asking, "tell me quickly should we give him the ventilator, he has already had a brain stroke." I quickly responded "yes". The doctor didn't give me time to think or consult with other family members. Only I was present there. I didn't have any other choice but give consent. [At her residence, Uttara, Dhaka]

This situation reveals the familial responsibility that leads to the decision to opt for invasive treatment. This situation also shows that, when a decision regarding life and death has to be taken for others, it becomes more complicated.

A stigmatised repercussion was also faced by Monobendro Sen, a dentist, who decided to withdraw his father's life support three days after he had a haemorrhagic brain stroke from which the doctor indicated that there was no hope of recovery. His mother and brother also gave consent to the decision to take him off the ventilator. His father was a famous singer and was quickly taken to a private hospital and kept on a ventilator. However, he was seriously criticised by his father's sister for not keeping him on life support for longer. She accused him of not taking responsibility for his father's treatment. She also thought that by doing this, Dr. Monobendro saved money. These two stories indicate the societal pressure and expected familial responsibilities towards close kin. 'Not hoping with the biomedical intervention' opens the possibility of stigmatisation. To 'get the best treatment,' by arranging the life support technologies, not only rooted in hope but the socio-economic context. It is often seen as a duty to avail the 'best' option within the financial capacity. Furthermore, in contrast, 'trying life support' offers the pleasure of fulfilling familial responsibility.

Conclusion

In this chapter, I have discussed the interplay between hope, affordability of technology, and its consequences, which is situated in the political-economic and cultural context of the society, which often takes the localised form in adopting advanced technology imported from the West. The localised form is also a form of negotiation which tends to fill the gap that is raised from practising life support treatment in an adopted condition. Life support technologies do not merely delay life or death – instead, they deal with life and death – which are the most crucial societal part. This chapter discussed further cultural dimensions of medical practice evident in the discourse of life-prolonging treatment that show the 'local variants of

international biomedical culture' (DelVecchio Good 2010; Novas 2006; DelVecchio Good et al. 1990; Brown 2007).

This chapter identifies the stratified biomedicalisation in this sector as manifesting as an unequal distribution of, and access to, technoscientific biomedicine. Hence, the discussion of a political economy of hope has highlighted the socio-cultural value of choosing life support but has also identified a *stratified* biomedicalisation which lies in the unequal access to the resources. This socioeconomic context has a localised form in Bangladesh, which makes this Bangladeshi context different from any other country where health care is mostly privatised. According to relatives, the unregulated nature of the privatised health service system and unequal access to health care services have substantially shaped the localised form of Bangladeshi health care and also life-prolonging treatment. I described in chapter 1 that the privatisation in health care has always been encouraged by the successive governments in Bangladesh by the influence of the neoliberal economy. Chapter 7 is addressing this issue. The hope for extending life has grown in this political-economic context where biomedical embrace and medical imaginary play an essential part in influencing the public choice and creating hope.

The different cases show how the process, timing, and nature of death are constructed and complex and open to dispute, and then how these are 'coped with' when they are operational decisions enforced by lack of control. The paradox is between the 'control' and 'choice' implied by the affordances of technology and the medical imaginary, and the lack of control and choice, which is the reality of not having money but having love, care, responsibilities, and

social norms, and then the ways of coping with this paradox through ideas of final wishes and reducing pain. As Bharadwaj and Inhorn (2016) say, “To live in a biotechnological mode is to negotiate with death continually – to define and interpret it” (p. 67). These stories also show the negotiation with the institutional rules as negotiations with death.

Medical interventions, to some extent, prolong life or prolong death. This chapter shows that eventually, they bring about quandaries and predicaments of how to live with, and in relation to, the world of modern medicine and its life-prolonging technologies and hope; when, where, and how to limit the boundary (Kaufman 2015). This chapter discusses how, in recent times, how the dilemmas of hope and responsibility have been drawn in the technological possibilities and control. On the one hand, patient’s relatives are embedded within a complex web of hope and familial responsibility. On the other hand, there is the attraction of advanced life support treatment and technologies, which may or may not be within practical reach of the relatives’ financial capabilities. In the context of critical care in ICUs, relatives express hope according to their emotions, which often does not reflect the exact capacity of existing medical technology. However, it is not only such hope and emotion that is responsible for the ‘over anticipation’ of life support technology, but also the ‘medical imaginary,’ the ambiguities that arise through existing communication systems in ICU care, and the alleged unethical misconduct by private hospitals engaged in making a profit. The next chapter will broadly focus on the governance of health care in Bangladesh.

CHAPTER SEVEN

Examining the “Bangladeshi Biomedical TechnoService Complex Inc.”

Public health policies, however, are shaped not only by science but also by ethical values, legal norms, and political oversight.

Gostin (2010 : XIX)

Introduction

Given the complexity of biomedicalisation processes in the health sector in Bangladesh, this chapter addresses the changes at the organisational and institutional levels caused by introducing and spreading life support technologies into health care. I discussed in chapter 1 that the privatised health sector plays a significant role in Bangladesh, which the Government has encouraged since the 1980s through grants, subsidies, tax reductions, and low-interest loans to help establish private hospitals and facilities in less advantaged, under-serviced, and rural areas (GOB 1998; Rahman 2019; Rahman 2000).

In this context, this chapter discusses how private hospitals and clinics operate in parallel to government health services and how their governance operates at both macro and micro levels. This discussion focuses on laws and policies, monitoring of the health service, and the regulatory framework for ICUs in the overall health care system of Bangladesh. In doing so, I aim to analyse elements of the ‘Biomedical TechnoService Complex Inc.’ BMTSCI as it is constituted and contested in Bangladesh. I have taken the BMTSCI concept from Adele Clarke and

colleagues' extensive research on biomedicalisation (2003, 2010) in the US health care system. This concept is rooted in the medical-industrial complex,⁸⁶ propounded by HealthPAC (Ehrenreich and Ehrenreich 1971), and the "New World Order" coined by Haraway (1997), and from President Eisenhower's naming in the 1950s of "the military-industrial complex" with reference to the Cold War.

I describe the elements of this 'complex' in Bangladesh regarding life support technologies and ICUs. I, therefore, define and analyse the BMTSCI as consisting of the medical-industrial complex, laws, and legislation, the professional regulatory bodies for health care services, and public discourse and the media.

This chapter is divided into three main sections: the first part covers the conceptualisation of the Biomedical TechnoService Complex Inc; the second covers medical-industrial relations (between the manufacturers of technology and health care providers), lawmakers, and the state; finally, the third part, covers the media and civil society groups.

In addressing biomedicalisation in Bangladesh, it is necessary to understand how the health service in general, and life support treatment specifically, has become commodified through the marketisation of this sector. The second part of the chapter focuses on this question by illustrating the medical-industrial relations, which are a constituent part of the BMTSCI in Bangladesh. The last two chapters raised questions about the political economy of hope in

⁸⁶ The 'medical-industrial complex' was used as a conceptual tool in the 1970s in the middle of the medicalisation era.

the context of unequal access to life support technologies. They addressed the relatives' 'mis-understanding' towards health service providers. Concerning this, the second part of this chapter also discusses lawmakers and the state, and the professional and regulatory bodies around ICUs. The question of why it is said that *'there is no [effective] law in health care'* is answered by analysing the laws and regulatory framework that currently exist to deal with cutting-edge, popular medical technologies in Bangladesh.

The third part of the discussion aims to understand how the BMTSCI is challenged and contested by analysing incidents occurred in private ICUs during my fieldwork. This line of inquiry is further developed by illustrating prevailing controversies surrounding both public and private health care treatments, where the issue of the 'effectiveness' of the law and regulations has been brought to the public's notice. This section is thus based on media reports on life support care and ICUs and supplemented by ethnographic data gathered from interviews and ethnographic study of patients' relatives' experiences. I also analyse health activists' interviews in this section.

I analyse both primary and secondary data in this chapter. The empirical data is used as primary source material, while secondary sources consist of health-related acts and regulations, various health research reports by the Health Ministry and non-government bodies, daily news from my fieldwork period in 2015-2016, and updates regarding the issue up to the time of writing.

The 'Biomedical TechnoService Complex Inc.'

Clarke and her colleagues developed this concept to understand processes of biomedicalisation, accelerated by corporatised and privatised research, and products and services made possible by technoscientific innovations. In the previous chapter, I discussed how biomedicalisation in Bangladesh is situated in an expanding politico-economic and sociocultural biomedical sector, which is one of the major points of this study, theoretically identified by biomedicalisation by Clarke et al. (2010: 48) in the context of the US health service sector. In *Biomedicalization* (2010), Clarke and her colleagues define the Biomedical TechnoService Complex Inc. thus:

[...] the incorporation of technoscientific innovations is at once so dense, dispersed (from local to global to local), heterogeneous (affecting many different domains simultaneously), and consequential for the very organization and practices of biomedicine broadly conceived, that they manifest a reincorporation—a reconstitution—of this historically situated sector. We term this new social form the “Biomedical TechnoService Complex Inc. (p, 49).

This statement suggests that the health sector requires reconstituting in order to incorporate new technoscientific innovations of biomedicalisation. This involves interactions between different people and institutions that employ social and legal authority: international technology corporations, state agencies, and doctors. This is because of the complex nature of the health care industry and the commercial relationships between technology and medicine (bearing in mind that establishing an ICU requires a considerable capital investment). It is to be noted that the private health sector in Bangladesh is mostly profit-driven. Given the above definition of the BMTSCI, the following questions arise: to incorporate life support technologies, has

such a complex been developed in Bangladesh? How is it constituted? What distinctive form does it take? This discussion will highlight how the BMTSCI is challenged, resisted, and contested in Bangladesh.

Medical-Industrial Relation

Ehrenreich and Ehrenreich (1971) mention the medical-industrial complex regarding American medicine in their influential study, *The American Health Empire*. In this book, they mainly argue that the health industry functions in the same way as other industries do to gain profit. This argument inspired me to look into the relationship between medicine and industry. Thus, this section illustrates medical-industrial relations in health care in Bangladesh. As I described in the first chapter, people generally rely on private health care. The public health care sector in Bangladesh is not entirely free, for it has limited resources. For instance, the government ICU provides consultation, some essential medicine, and facilities for free; but the patient must provide other medical supplies, medical tests, and food. In the medical-industrial complex, pharmaceuticals and pathological diagnostic centres are a vital component. Even government hospitals ask in-patients to get pathological tests and medicines from the private diagnostic centres and pharmacies, as government hospitals are often unable to provide them. Some of the big pharmaceutical companies in Bangladesh are also involved in private health care services. The following is an example of one of the leading pharmaceutical companies in Bangladesh.

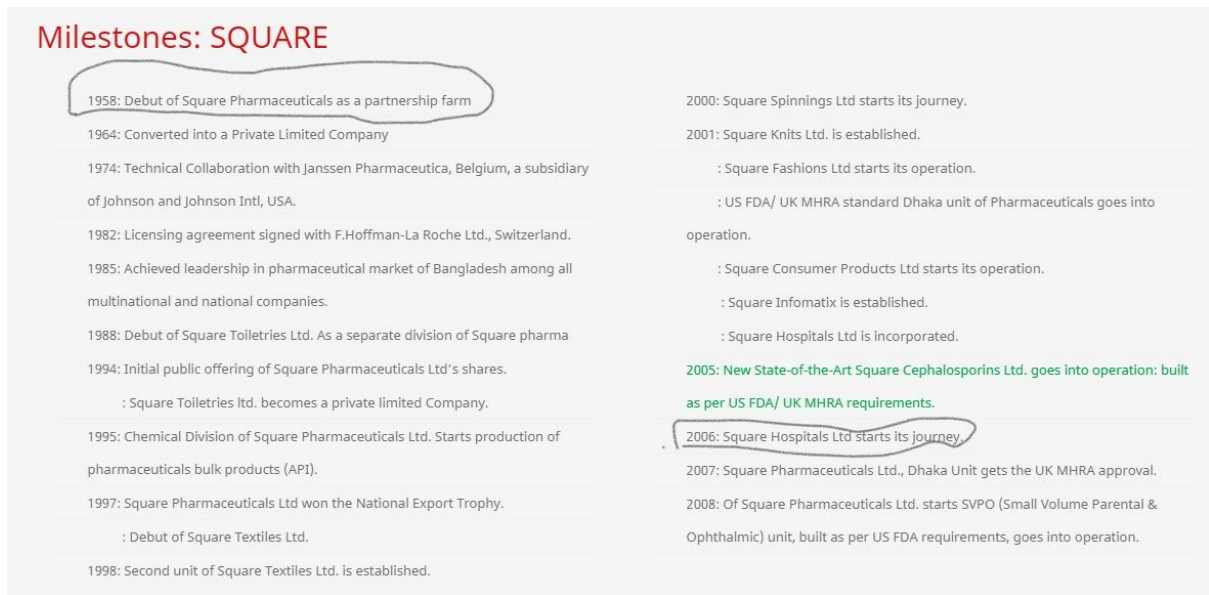


Figure 3 This is a screenshot taken from the home page of Square Group.

The two annotated entries are showing the start of a pharmaceutical and a hospital along with other businesses of this group. Source <https://www.squarehospital.com/aboutSquareGroup> Last accessed 29.09.2019

The figure shows that Square Pharmaceuticals started its journey as a partnership firm in 1958. Over the following 50 years, this company gradually expanded its business from drug manufacturing to toiletries, textiles, chemicals, spinning, garments, holdings, a private media channel, and informatics, which were individually considered the most successful industrial sector at the time. As a continuation of their business expansion, Square group started a high quality and highly expensive tertiary level hospital in 2006. I researched this company's history to show that starting a high-quality hospital is nothing more than a business venture for them, such as they have been doing for more than five decades. During that time, a few more 5-star, international, free-standing private hospitals started their journey in Bangladesh, established by companies that have similar business involvements. These tertiary-level private hospitals have brought advanced biomedical technologies and modernised treatments (see figure 3) to people who cannot go abroad for advanced level treatment. However, these

hospitals are costly, and ordinary people cannot afford to be treated in them, which I have discussed in this thesis.

Outside the major cities, few places have free-standing, highly equipped hospitals such as these. As I mentioned in chapter 1, people in Bangladesh mostly depend on privatised health care, as two-thirds of the health expenditure comes out of the patient's pocket. A similar scenario is found in the context of life support care, where people mostly depend on private ICUs (Faruq et al. 2010). The following picture shows an ICU bed at a free-standing international chain hospital in Dhaka.



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

This picture was taken from the hospital webpage on 29.09.2019 (<https://www.apollodhaka.com/critical-care-units/>). Any Bangladeshi could mistake this for a foreign hospital. Such hospitals claim that they provide the most advanced biomedical technologies and modern treatments, yet most of the population of this country cannot afford it.

Biomedical research and technoscientific therapeutic and enhancement treatments are one of the features that signal biomedicalisation. The present government has taken small model initiatives to develop informatics, computerisation, and health insurance very recently under the Universal Health Coverage project (Chaudhury, Z, and Ishtiaq 2019; Directorate General

of Health Services 2018). In Bangladesh, these developments, such as computerisation and health insurance, and new treatments, such as stem cell therapy and *in vitro* fertilisation (IVF), are all still at a very early stage⁸⁷. The first IVF baby was born in 2001 (Sultana 2014), and since then, it has been getting increasingly popular. Sultana (2014) mentioned in her unpublished thesis that embryonic research emerged in Bangladesh by establishing a National Biotechnology Institute in 1999. However, for instance, the Bangladeshi government adopted the National Medical Biotechnology Guidelines in 2010⁸⁸. According to Sultana, there were no national IVF guidelines (2014: 340). Despite the Bangladeshi government's interest in Bioinformatics in the health service and computerisation, this sector has not been established yet due to limited resources⁸⁹.

To look into the medical-industrial relation in Bangladesh, I examine the political, economic condition of privatisation in the health sector and a new emergent group of people who become consumers of life support technologies. In reference to this, my last chapter identified the emergence of hope in relatives while choosing life support technologies, and how their hope and expectations are created by life support in the political-economic context. In short, those who buy the service become health service consumers; as Mamo suggests,

⁸⁷ There is a lack of research to provide a comprehensive survey about the use and consequences of medical technology in Bangladesh.

⁸⁸ <http://www.dghs.gov.bd/index.php/en/medical-biotechnology/87-english-root/medical-biotechnology/126-national-guidelines-on-medical-biotechnology-2010> Last accessed 29/09/2019

⁸⁹ http://www.dghs.gov.bd/images/docs/Publicaations/2014_11_A_Quiet_Revolution-Strengthening_the_Routine_Health_Information_System_in_Bangladesh.pdf

‘biomedicine within a consumerised health care delivery system brings forward consumers and offers putative choice’(2010: 176).

In Bangladesh, biomedical technoscientific innovation and research are minimal; therefore, its technoscientific, biomedical health service care depends on mostly imported technology. Under the neoliberal global economic era, technologies can be circulated quickly from one place to another. Neoliberalism not only makes possible the transfer of technologies from the core to the periphery, but it also accelerates the transfer of technology globally. Consequently, despite a lack of biomedical research and innovation in Bangladesh, the penetration of technoscientific biomedical practice is increasingly occurring, though it is still concentrated in the main cities, as I mentioned earlier.

The business of privatised health care was flourishing In Bangladesh and targeted as a potentially profitable sector for foreign companies. For example, *Business Sweden*, a Swedish government-commissioned company that promotes the Swedish industry globally, published a report on the health care sector in Bangladesh with a profile on their website⁹⁰. Based on the information provided by the WHO, the Ministry of Health of Bangladesh, and the DGHS, they created a business country profile of Bangladesh. According to that report, the health care service and medical equipment industries are a growing market. The overall health care market in 2018 was worth US\$9.2 billion, rising from US\$3.9 billion in 2011. In 2014, the medical equipment and pharmaceuticals market was worth US\$2.2 billion.

⁹⁰ The Swedish Trade and Investment Council https://www.business-sweden.se/contentassets/885d15e5a480462d8d21101927d57956/151127-bangladesh-healthcare-study-pa13_online.pdf Last access on 27.09.2019

Undoubtedly the value of this growing market attracts foreign investors. It is not only the large population of the country which attracts foreign investment but the existence of government support, such as low customs tax and easy procurement policy for private health care. Moreover, the Bangladeshi government also buys medical devices from these suppliers. I talked to a medical technology installer during my fieldwork. Mr. Ikhlas told me that only a handful of ICU importers dominate the business in Bangladesh. He also informed me that the installer company provides training to ICU doctors and nurses. I have observed the queue of medical representatives outside the ICU at UTH who offered 'gifts' to doctors to promote their company's medicine. However, medical representatives are strictly prohibited in the other two hospitals I visited. In this context, I argue that this marketisation technique, which aims to expand the private health care service, follows neoliberalism, which 'as a discourse and ideology emphasizes its ideals of ownership, competitiveness, investment and individual responsibility' (Mamo 2010: 176).

The Government has been encouraging the expansion of the private sector through five-year plans since 1980. The state, therefore, is a crucial player in the BMTSCI by enabling the proliferation of life support technology in the private sector, as it is not able to expand government ICUs (Tazmim 2019; Rubaiyat 2015; Adhikary and Mollah 2015). Hence, the actions of the government contribute to an ever-expanding biomedical market. Privatisation and corporatisation, which are the salient features of the BMTSCI, have been taking place in Bangladesh since the 1980s, as also prescribed by the World Bank (Kikeri, Nellis, and Shirley 1992) as part of 'development' of 'under-developed' and 'developing' countries. These neoliberal development strategies have been followed in the health sector since then, systematically encouraging the size, scope, and reach of private health services. As a result, several private

organisations, grouped collectively under the general heading of civil society, have become a cornerstone to health development (Mamo 2010, Rahman 2019).

Despite government initiatives to strengthen the public health sector, which has always been an election promise in Bangladesh, the government encourages the expansion of private health care. Rahman and Caulley (2006) report in their research that the Prime Minister stated that there is enough scope for the development of health care in the private sector and urged private providers to develop services to supplement the public health sector. He also mentioned that, via the presence of the Prime Minister at the inaugural session of private health care, the government symbolically encourages private health care as well.

Though the Bangladeshi BMTSCI is different from that of the US and the West at large (as described by Clarke et al. (2003, 2010), changes at the institutional level to incorporate technoscientific, biomedical technologies are evident in contemporary Bangladesh. Previous chapters showed that the government-provided, technoscientific life support care is limited to tertiary level government hospitals in Bangladesh. According to the media and government reports, this may change as the government is now taking the initiative to set up ICUs even in secondary hospitals (Directorate General of Health Services 2015) by buying ICU machines and medical devices. However, government hospitals are still unable to open ICUs due to not having appropriately enough qualified staff (i.e., specialised doctors and nurses), and expensive life-support machines are becoming unusable through staying idle for too long (Rubaiyat 2015). In the private sector, hospital numbers are increasing rapidly, and they are also appearing on the outskirts of major cities and in small towns. From my observation and the

interview of DGHS personnel, the lack of specialised or skilled workforce does not seem to be a problem in setting up private ICUs; but this is probably only because they are not effectively monitored regarding a high standard of ICU management.

The business activities of the privatised health care services are not only limited to high-tech medical devices, hospitals and clinics. My study found that several small businesses have emerged around the major hospitals. Indeed, among them, the pharmacy is the most salient, as I mentioned in chapter 4. Besides, many guest houses, boarding, food stalls, and shops are seen around hospital areas. In recent times, privatised home care service providers and retail shops for used ICU medical devices (e.g., clinical beds, portable ventilators, suction machines) have also been emerging in Dhaka.

I find in this study that the interconnected aspects of the medical-industrial complex, limited resources, the political economy of the health service, and policy and governance lead to a distinctive and localised character of the BMTSCI in Bangladesh, where the specific nature of the health service has developed under 'weak' health governance. This 'weakness' is because the state is not sufficiently equipped to oversee health care. In the context of life support technologies and ICUs, there are no standard protocols and rules provided by DGHS or MOH in Bangladesh. Thereby, the emergence of life support technologies is also conditioned by the 'weak governance' of the health sector.

This study suggests that the processes and mechanisms of re-corporation and reconstitution of the legal, regulatory, and monitoring framework of the health sector have only begun to

incorporate life support (and other cutting-edge) technologies relatively recently; almost 30 years after their first introduction into Bangladesh. It is important to mention that the Ministry of Health and Family Welfare (MoHFW) and the Directorate General of Health Service (DGHS) are the central overseeing bodies who are also responsible for creating and updating the legal and regulatory framework. Furthermore, as life support involves huge costs and life and death decisions in very intense situations (as I have discussed in chapters 5 and 6), it requires close regulations to ensure that it is used correctly in the context of ‘mistrust’ in the popular discourse in Bangladesh: particularly the perception of life support machines being used unnecessarily due to profit motivations. Nevertheless, after many attempts, the MoHFW still has not passed any law to protect patient rights or any ICU-related law to date. I will discuss this point later in the chapter.

Regarding regulating such a sector, Gostin (2010) addresses the legal structures necessary for regulating public health and protecting individual rights. He observes that:

The field of public health is grounded in law and cannot function effectively without a robust legal infrastructure. Law establishes the foundations for public health governance — for example, funding mechanisms, administrative structures, and workforce. Law empowers public health agencies to act, sets limits on those powers in order to protect individual rights, and requires health authorities to follow defined procedures. At the same time, the law defines boundaries for acceptable behaviour, both individual and organizational, and permits the deprivation of liberty, autonomy, privacy, and property to safeguard the public’s health (Gostin 2010: XX).

According to Gostin, it is generally expected to be the responsibility of the government to monitor the health sector, with an efficient public-oriented regulatory framework. If the regulatory framework remains disconnected from the concerns of the public, eventually, the health care service will fail to meet patients' and their families' needs.

In the context of India, Peters and Muraleedharan (2008) say that even a robust regulatory framework is ineffective if it is not accountable to the public. They observe that, although India has a wide-ranging and robust legal and regulatory framework, the health sector is effectively ungoverned because of a lack of government monitoring, a market-based approach, bias against the poor, a lack of transparency of financing in the private health sector, and unassured public safety in the face of new medical technologies and pharmaceuticals. For these reasons, the law and the government have failed to protect the interests of vulnerable groups or to generate trust between health service providers and the public. Substantial regulation on its own is not sufficient without proper enforcement.

There is a similarity between India and Bangladesh. In both cases, there has been a failure to reform the health sector's legal and regulatory framework in accordance with the existing health care service system, and to monitor and regulate the health sector effectively. Even though the Indian health sector has a more robust legal, regulatory framework, it is mostly not being enforced. Similarly, the legal and regulatory framework of the health sector in Bangladesh is incompatible with the increased quantity of health care service; hence the legal and monitoring framework is not being implemented and effective. In some cases, there are no

required rules, regulations, and frameworks, particularly for the life support technologies and the ICU.

By contrast, the NHS in the United Kingdom has Guidelines for the Provision of Intensive Care Services⁹¹ (GPICS) and health care regulators such as Care Quality Control. There is also referral guidance and criteria for admitting patients to ICUs and HDUs in the NHS. ICUs and life support in Bangladesh operate without any such frameworks and guidelines. These ICUs follow the international ICU guidelines and protocols; however, there is no national regulation or oversight to monitor whether the service providers are maintaining an acceptable standard and if the 'right' patients are getting admission to ICUs.

The GPICS principles provide a list of essential factors that ICU inspectors could use to avoid possible 'mishaps' in the ICU.⁹² These guidelines also remind us of the gap in the existing practices of life support technologies in Bangladesh, for example, mandatory training for service providers; the presence of required skilled staff (such as pharmacists, nutritionists, physiotherapists) in the ICU group; the correct use of medicine, services, cleanliness and infection control; the right to information for the relatives; the provision of laws in the case of negligence or abuse; how negligence is to be addressed if it occurs; how lessons should be learned from incidents; how the skills, knowledge, and experiences of the staff are to be maintained;

⁹¹ <https://www.ficm.ac.uk/standards-research-revalidation/guidelines-provision-intensive-care-services-v2>
Last access on 17/09/2019

⁹² I am not discussing GPICS as an 'unquestionable' standard; rather I am using it to get an idea of a standard provision of ICU.

how to assess patient's risk, outcomes of treatment, care and support, and quality of life; understanding of and responsiveness to the patient's relatives; and decision-making processes.

The lack of legal, regulatory, and monitoring frameworks reflects the weak health governance in Bangladesh (BHW 2010). I, therefore, argue that the BMTSCI has taken a localised form in Bangladesh through the practice of deploying highly sophisticated medical technology within a limited legal, ethical, and economic framework in a specific socio-politico-economic context-

In summary, this process of BMTSCI is of the introduction of advanced medical technology (life support) and its associated practices within the health system and associated legal and monitoring domains where the latter have not been entirely restructured in such a way as to deal with such technologies competently. Chapters 5 and 6 claims that "biomedicalisation does not merely bring changes in health-related practices and knowledge; rather, it creates 'new hybrid socio-technical forms.'" Hence, this chapter mainly shows the emergence of a new social entity of BMTSCI at the advent of advanced medical technologies. At the institutional level, I argue that life support technologies require the reconfiguration of related institutional techniques. In the absence of reformed regulatory and monitoring techniques, their introduction has resulted in severe social consequences, including patients' and their relatives' suffering.

The context of the Bangladeshi health sector is one of the limited resources and limited monitoring: there is a need to look beyond the laws and more closely at governance as it is enacted

in practice. The effective governance of this sector has always been a primary public concern, as I will now illustrate.

The Bangladesh Health Watch⁹³ 2009: 'How healthy is health governance?' (BHW, 2010) showcases several positive examples that can be used as models for good governance in the health sector. However, it also reveals various problems: the ineffectiveness of statutory and regulatory bodies, deficits in ethics and standards; the politicisation of health policy and its lack of continuity; partisanship of the medical profession; and the absence of accountability. The Bangladesh Health Watch report (BHW, 2010) also raises the following issues: in public medical facilities, service providers (including doctors, nurses, and other service givers ('ward boys', *ayas*, cleaners) were often unfriendly and unresponsive to patients; service providers did not feel that they were accountable to the patient and their relatives, and were unaware of the patient's expectations and need for confidentiality, respect, and dignity. Absenteeism of doctors and medical staff is another complaint identified by numerous studies (WHO 2015; Transparency International Bangladesh (TIB) 2018; Chaudhury, Z, and Ishtiaq 2019; Ain o Salish Kendra (ASK) 2013), while lack of resources and skilled human resources are also shortcomings of public health care service: for example, despite the high demand for neonatal ICU (NICU) beds, Dhaka Medical College Hospital is unable to open a NICU due to lack of human resources. Nonetheless, specialised public hospitals always exceed capacity with patients because most people cannot afford to go to private hospitals for critical and intensive treatments, and thus depend on public hospitals. The shortage of resources, absenteeism,

⁹³ BHW, a multi organisation civil society network, was formed in 2006 to establish a tradition of holding the state as well as non-state sectors accountable for their performance in delivering quality health care to citizens. BHW decided to produce an annual report on the state of health in Bangladesh focusing on a theme that deserves priority attention.

negligence, and harassment by *Dalal* often cause the suffering of patients in government hospitals, revealing the weak governance of this sector.

The weak governance is also evident in the poor oversight of private-sector health care. Although private hospitals are the place where the majority of the people must receive treatment, complaints abound. Several studies (Ain o Salish Kendra (ASK) 2013; Transparency International Bangladesh (TIB) 2018; Barkat and Maksud 2003; Chaudhury, Z, and Ishtiaq 2019; Rahman 2007; WHO 2015; Rahman 2019) have expressed opinions that the health care sector at large, and more specifically, the private health care sector's monopolistic attitude, causes patient suffering and compels them to pay excessive amounts. Hence, it is necessary to analyse how and why the health sector is left 'unregulated' despite the reported problems and complaints.

Following Fukuyama's (2013) statement mentioned earlier, I want to explore relevant rules, regulations, and laws to uncover the possible factors behind the 'weak governance' in the Bangladeshi health sector. Therefore, in the following section, I discuss the regulatory bodies, framework, and laws in the health sector to explore the degree to which it is 'unregulated.' The discussion then analyses whether the existing regulatory, legal, ethical and monitoring framework is fit for facing the challenge of 'biomedicalisation.'

State, legislations and regulatory framework

As I have mentioned earlier, there are no specific laws and regulations for intensive care units and life support technologies. ICUs have instead been monitored under general law and regulations on health care. However, according to an interview I conducted with DGHS personnel, civil servants have been working on creating specific rules and regulations for the ICU. The following section thus examines the content of the legal and regulatory framework and investigates why it has been claimed that ‘there is no effective legal framework in Bangladesh.’

Several studies have been done to identify the shortcomings of health law and regulations in Bangladesh (Rahman 2007; Ain o Salish Kendra (ASK) 2013; Ain O Shalish 2008; Rahman 2019; Barkat et al. 2001). These reports are aimed to catalogue existing health legislation and identify its shortcomings and were prepared for DGHS, Ministry of Health and Family Welfare (MoHFW), and WHO, Bangladesh. According to their findings, 87% of existing health laws were created in the 20th century, and some laws are up to 150 years old, still in force in Bangladesh. Barkat and Maksud described the existence of health and health-related laws, acts, orders, and ordinances as a strength of the regulatory system, but they considered their insufficiency and lack of implementation as a weakness. The key findings of this study included:

- i) Lack of awareness and knowledge about rights and obligations on the part of the medical service providers and patients’ groups;
- ii) Lack of accountability of the medical service providers (patient groups’ unawareness regarding patient rights);

- iii) Existing laws cannot be adequately applied as the negligence cases are framed loosely and not under the requirement of the law;
- iv) Failure to take necessary steps against infringements by law enforcement agencies, including the police; and
- v) Complex and time-consuming procedures of legal action.

Negligence by health service providers is one of the significant allegations made by ASK (2008; 2013) after conducting research on medical services and negligence. This study examined existing laws and policies in order to assess the legal regime of Bangladesh regarding medical negligence. ASK (2008; 2013) analysed the Penal code of 1860, as this law is used when medical negligence or fraudulent medical practices take place. As well as medical negligence, they found a lack of accountability in health care administration. According to the report,

Medical negligence mainly concerns the negligent or rash act of medical professionals, causing any injury to the patient. Medical negligence is a kind of professional misconduct on the part of a medical practitioner. In a strict sense, the term, medical negligence, may not include professional misconduct or malpractice of other kinds such as fraudulent misrepresentation regarding eligibility or qualification, prescribing unnecessary drugs or tests for undue profit, taking undue advantage of the patient's situation, etc. (Ain o Salish Kendra (ASK) 2013: 10).

'Negligence' and 'in good faith' are the most controversial terms used in health law, as 'negligence' in treatment is hard to prove and often disguised under the doctor's intentions of 'good faith.' Action will not be considered a crime if a patient suffers from treatment aiming for their betterment 'in good faith.' This norm operates in many countries. Until and unless it

is proven a doctor has acted with ill motive, it cannot be considered as a crime. It is said by ASK that, due to not being defined and justified, these two terms cause significant problems in the regulation of the health sector, and the term 'in good faith' often works as a shield for doctors even if there is an incidence of negligence. Professional accountability and transparency between the two groups of people can improve this tension.

The legal, regulatory, and monitoring framework is only effective to the degree that it is enforced in practice (Ain o Salish Kendra (ASK), 2013). Despite the existence of regulations, hospitals and medical professionals can efficiently resolve allegations by paying a very nominal fine (ASK, 2013). More often, it is hard to prove a doctor wrong. ASK's research (2013) finds several obstacles to proper implementation of regulation such as ambiguities that fail to define 'negligence' or 'gross misconduct'; bureaucratic delays in getting viscera⁹⁴ and post-mortem reports, and other proceedings needed in lawsuits; the investigating force and public prosecutors lacking medical knowledge; and specific provisions of the Penal code protecting physicians through immunity for actions done 'in good faith.'⁹⁵ These are the legal and statutory inadequacies in dealing with medical fraudulence and negligence.

⁹⁴ A viscera and post-mortem report is needed to determine the cause of death. In the viscera test the internal organs of the body, specifically those within the chest (as the heart or lungs) or abdomen (as the liver, pancreas or intestines), are tested thoroughly.

⁹⁵ As Section 88 states: "Act not intended to cause death, done by consent in good faith for person's benefit."

Note that Bangladesh has one of the lowest ratios of nurses per capita in the world (Rashid, Savchenko, and Hossain 2005). According to a WHO country-specific report (2015)⁹⁶, there are an estimated 3.05 physicians and 1.07 nurses per 10,000 population (Ministry of Health, Family Planning Welfare HRD 2011⁹⁷). Regarding this situation, a DGHS official asked: *“how can we maintain or enforce the standard of ICU since we do not have enough trained and skilled doctors and nurses to ensure the requirement?”* (DGHS, Dhaka)

Dr. Liza from BIRDEM reflects a similar line of frustration regarding ICUs in general. She said, *“what we learn from the textbook from Europe and the US cannot apply fully in Bangladesh for the lack of resources and facilities.”*

Despite the shortage of resources, the government has been trying to create new legislation and update existing laws. The existing health-related laws and regulations applicable to private clinics and hospitals also need updating to incorporate the changing situations brought about by modernised and technology-centred medical practices. The Medical Practice Private Clinics and Laboratories (Regulation) Ordinance Act 1982⁹⁸ was first enacted in 1980 with amendments in 1984. In an interview, the DG (Directorate General) confirmed that they have been updating the acts and laws. However, at the time of writing this chapter, no specific law and monitoring framework regarding intensive care units or life support technologies has been enacted, despite being discussed in cabinet meetings in 2014 and 2016. The DGHS and

⁹⁶ <https://www.who.int/workforcealliance/countries/bgd/en/> [Last accessed 30/11/2020]

⁹⁷ http://www.mohfw.gov.bd/index.php?option=com_content&view=article&id=112%3Aperformance-report-2009-2010-and-hrd-data-sheet-2011-of-mohfw&catid=72%3Aperformance-report-2009-2010-of-mohfw&lang=en [Last accessed 5/07/2020]

⁹⁸ The Medical Practice and Private Clinics and Laboratories (Regulation) Ordinance 1982. [Document] [Online] Available at: http://bdlaws.minlaw.gov.bd/sections_detail.php?id=620§ions_id=11781 [Accessed 22 Jul. 2017]

the MoH have not been able to update the legal and monitoring framework of ICU despite its necessity, which perhaps reveals the conflicts of interest of the concerned stakeholders.

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| <p>8. License to establish private clinic: No person shall establish a private clinic without a license under this Ordinance.</p> <p>9. Conditions for license: No license for establishing a private clinic shall be issued unless the following conditions are fulfilled, namely:-</p> <ul style="list-style-type: none">(a) There is proper accommodation with hygienic environment for the patients;(b) There is at least eighty square feet of floor space for each patient;(c) There is an air-conditioned operation theatre;(d) There are such essential equipments as are specified in schedule B;(e) There are adequate supply of life-saving and essential medicines;(f) There are such number of full-time registered medical practitioners, nurses and other staff as are specified in Schedule C;(g) There are specialists for the operation, treatment and supervision of patients <p>10. Application for license:</p> <ul style="list-style-type: none">(1) Any person intending to establish a private clinic shall apply in the prescribed form to the Director-General for a license. |
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Figure 4 Excerpt from the Medical Practice and Private Clinics and Laboratories (Regulation) Ordinance 1982

Oversight and Monitoring: DGHS

DGHS has a monitoring framework to oversee private hospitals, clinics, and diagnostic centres. The monitoring groups are as follows:

There are two committees for the capital city Dhaka, consisting of:

1. Deputy director (leader)
2. Assistant Director (2)
3. Medical officers
4. Subject experts (in practice, not always go with the team, unless any specific issues arise).

For the divisional and district level, monitoring groups are as follows:

Divisional level

1. Assistant Director
2. Medical college consultant (2)
3. Civil Surgeon (a member of secretary)

District level and Upazilla

1. Civil Surgeon (Head)
2. District Consultant
3. Medical officer.

Usually, law enforcement members (police) are not included in monitoring teams as the existing legal framework does not have provisions for law enforcement. However, according to Dr. Priyo Raj, a DGHS official, ‘the proposed new law’⁹⁹ included members of a law enforcement body in the committees. However, interviews with the DG and a staff member of the DGHS revealed that “monitoring cannot be done as required because of the shortage of manpower.”

This statement explains a critical factor of the ‘ineffectiveness’ of the monitoring framework in practice. The staffing of government oversight bodies has not increased in line with the rapidly expanding private health care service. This reveals the inability or unpreparedness of government institutions to oversee the increasingly technology-driven health care service, mostly run by the privatised health sector, which characterises the Bangladeshi BMTSCI.

Furthermore, DGHS struggles to obtain useful information about private clinics and hospitals. For example, in order to prepare a complete list of private hospitals and clinics, the DGHS published a notice in popular newspapers inviting private hospitals with ICUs to provide

⁹⁹ The Patient and Health Service Provider’s Protection Law 2014 and 2016 were not approved by the cabinet. However, the draft copy was sent to stakeholders for review. The Patient and Health Service Providers’ Protection Law 2018 draft was not available for the public as it was not sent to stakeholders and journalists for review. There is no publicly available information regarding this draft law.

information regarding their facilities and human resources. After three months, only 44 hospitals responded to the notice, meaning that the DGHS still does not have actual data on private ICUs running in Bangladesh. Dr. Raj suggests that there are many more private ICU services than those who responded to the invitation:

Despite DGHS serving public notice several times to register private clinic and hospital with the information of human resources (number of doctors, nurses, care staff), specialities and facilities, and medical devices, very few private hospitals and clinics have registered themselves. Therefore, many private health care providers are out of reach from the health ministry, leaving them unmonitored.

[DGHS, Dhaka]



Picture 16 The ministry of Health, Dhaka

There is no well-defined standard for setting up an ICU in Bangladesh's existing regulation. Public and private ICUs are regulated by the 1982 Act and by other general hospital regulations. The effectiveness of the monitoring role of DGHS is questionable, given repeated incidents of reported 'malpractice' at private ICUs. In reference to this, the DGHS says that intensive care cannot be adequately monitored without specific ICU protocols and guidelines for monitoring and measuring the standard of treatment. Though according to my findings, ICUs have their adopted international standard, these are not regulated or monitored by the state overseeing body. This study also finds that there is no standard protocol of who is to be put on life support and in which situation clinicians should refrain from putting patients on life support; rather, this depends on relatives' consent or doctor's advice (chapter 5). The fact that protocols and regulations have not been created in the 30 years since life support treatment started in Bangladesh shows the low priority of regulating this sector.

Then there is the issue of licenses to operate. A flexible and inadequate monitoring system has meant that required standards for obtaining a license to operate are not all fulfilled by ICUs in private *or* public hospitals. These conditions include minimum allotted space for each patient, patient/health professional ratios, adequate lifesaving mechanical supports, number of full-time consultants, and so on. I observed from visits to ICUs at a state medical college hospital and a popular private hospital that standard space conditions (condition 9 (b) of the Medical Practice and Private Clinics and Laboratories Regulation Ordinance 1982) were not being met. However, the fines for violating such rules are nominal, only 5,000 BDT (approx. 50 GBP). This was decided in 1982 and has not been updated, providing an incentive for a hospital authority to maintain the standard. In a competitive privatised system, more focus

might be paid to aesthetics to attract patients, given that patients' families are unlikely to understand or focus on such technical standards of a treatment since the fines for non-compliance are so light.

In summary, the failure to oversee the health sector by relevant bodies is evident in the research and reports discussed above. The government of Bangladesh has established different professional regulatory and statutory bodies to develop a capable health workforce for its people (doctors, nurses, midwives as such.); ensuring standardised health services; protecting people's right to health; and ensuring access to health services (BHW 2010). However, recent research (BHW 2015; Chaudhury, Z, and Ishtiaq 2019) finds that these bodies do not or cannot perform their duties as expected.

The Bangladesh Medical and Dental Council (BMDC) emerged as a statutory body under the Medical Council Act in 1973, but its statutory power was abolished in 1980. Since then, the BMDC has been limited to regulating the registration of physicians and dentists and monitoring medical, educational institutions to establish uniform standards of primary and higher qualifications in medicine and dentistry. According to the 1973 Act, the BMDC was composed of several representatives from the Ministry of Health, medical education, nursing services, medical colleges (both public and private), professional associations, members of the Parliament, the Bar Council, and each administrative division in Bangladesh. The Council was a supreme body that could take all significant decisions and execute its functions through various committees. However, at present, there is widespread frustration about the functionality of BMDC; the TIB, ASK, and Bangladesh Health Watch (BHW) reports all allege that that BMDC is, in practice, an ineffective body except for its registration function. The BMDC is the body

with which patient groups can lodge complaints against doctors for taking improper action. However, according to the reports mentioned above, patient groups are unaware that the BMDC is the proper body to which complaints should be made. It is also claimed that the BMDC protects doctors' interests over the patient's interests (Ain o Salish Kendra (ASK), 2013). Reports find the BMDC to be a stakeholder responsible for not proposing or giving support for the approval of any laws, rules or acts that can be used against doctors' negligence (Ain o Salish Kendra (ASK), 2008; 2013; TIB, 2018; Barkat and Maksud, 2003; BHW, 2010; Health System Review, 2014). The ASK report points out that the BMDC, as the regulatory body of the medical and dental profession, has the power to take disciplinary actions against a registered physician or dentist if they are found guilty of any misconduct or violate any provisions of the Act. The BMDC could use this act to bring accountability to the medical and dental profession. According to ASK, it is apparent that the BMDC is reluctant to recognise negligence as misconduct (Ain o Salish Kendra (ASK), 2013: 41), as it has not taken any initiative to define negligence.

When interviewed, Dr. Zafar Ullah, who is a health activist, pioneer of 'Drug Policy of Bangladesh,' and founder member and trustee of Gonoshasthaya Kendra¹⁰⁰(GK-Center for Mass people), says,

¹⁰⁰ In 1971, while Dr. Zafar Ullah was studying in the UK, the Bangladesh Medical Association (BMA) was formed by 1000 Bangladeshi physicians in UK. In May 1971, Dr. Zafar Ullah and Mobin Khan were sent to India with the help of the BMA and the UK to organise the Bangladesh Field Hospital. The hospital was built by doctors, medical students, soldiers and volunteers, and established a 480-bed field hospital with the help of Mujibnagar Bangladesh Provisional Government to treat independence forces in Tripura State in India. After independence, the Bangladesh Field Hospital was registered as the Gonoshasthaya Kendra, a charitable public organisation with the motto of 'let us go to village to build village'. Since then, GK has expanded its activities to train men and women in primary health care and to demystify health medicine in villages in Bangladesh. GK is engaged with education, women's development, agriculture, disaster management and other activities beyond the delivery of primary health care, from house to house in Bangladeshi villages.

Have you ever seen any cancellation of doctor's license by BMDC in 45 years of Bangladesh independence? Never. They have never done it. They always uphold doctor's rights, not patients' rights. That is why doctors never care about anything. Therefore, the doctor's professional ethics have never grown.

(Dhanmondi, Dhaka)

Dr. Zafar Ullah's dissatisfaction with the role of BMDC has also been echoed in the *Medical Negligence and Fraudulent Practice of Private Clinics* research conducted by ASK (2013). This report lists problems other than staffing facing the health service. These include:

1. A very centralised health system: as shown in previous chapters, very critical patients were taken to Dhaka for treatment as they had been refused further treatment for lack of resources;
2. A weak governance structure and regulatory framework, and weak management and institutional capacity in the Ministry of Health and Family Welfare (MoHFW);
3. Fragmented public service delivery, and inefficient allocation of public resources;
4. A lack of regulation in the private sector, which employs 58% of all physicians;
5. Absenteeism of health workers, and;
6. The poor maintenance of health facilities and medical equipment.

This suggests that governance and lack of resources are major issues in this sector. Besides, profit being prioritised in the private sector health service is probably the most discussed issue that makes this sector controversial, especially considering that the majority of the

population depends on secondary and tertiary level private health services. These overall findings of the report point the finger at health governance for mismanagement and under-monitoring in health care.

ASK (2013) say that, despite gaps, existing laws *could* still be applied to control and monitor problems in the health sector. They suggest that, for the most part, it is not the lack of law, but the incompetence of the monitoring authorities that results in them not being enforced. Most complaints, regardless of their severity, do not result in legal action. This leads to a situation where public trust in the medical service is wholly lost, and doctors' negligence going unpunished has firmly established a culture of impunity in both the public and private health sectors (ASK 2013).

Some incidents have shaken even the health authorities. The media often plays a crucial role in making these incidents public beyond the hospital's boundary. Due to public attention or media pressure, the health authority and associated statutory bodies have to be seen to take action. The lack of a framework and regulation for ICU and life support causes mistrust and unwanted situations in the health sector. Several incidents, studies, and research articles seem to justify this 'mistrust', as will be discussed below. In the field, while I was talking with patients' relatives, health activists, and journalists, respondents mentioned 'malpractice and mismanagement' of hospitals and doctors from their own experiences. These were in many forms: a low standard of services provided; negligence in care and treatment; poor communication between health professionals and relatives (e.g., not explaining the patient's condition and treatment properly); hospitals and doctors prescribing unnecessary tests and

medications for profit-driven reasons; high hospital bills; falling under the influence of the *Dalals*, as such. The following section focuses on two incidents that occurred during the study period.

Media reports, public discourse, and governance

News coverage of health constitutes one of the most visible features of the contemporary world. The avalanche of recent news stories about Ebola provides just a small indication of the proliferation of health coverage. H1N1 (“swine flu”), avian flu, SARS, and other epidemics similarly became the biggest stories of their day (Briggs and Hallin 2016: 1).

In Bangladesh, the newsprint media is still¹⁰¹ essential. Health-related news also gets considerable public attention and is the topic of widespread debate. This news could cover many topics and incidents. As Briggs and Hallin (2016) mention:

health stories range across many genres, from consumer to business to political reporting, and they vary in tone from highly positive stories about miracles of biomedical technology to exposés of regulatory failure or physicians whose drug recommendations have been swayed by perks and gifts (p, 17).

However, Lupton and Mclean (1988) find that:

¹⁰¹ I used ‘still’ to indicate the changing nature of publishing and spreading news at the age of social media.

both media representations of the medical profession and doctors' responses to these portrayals take place in a broader socio-political context, in which there exist a number of debates concerning the relative social status and professional autonomy of the medical profession (p, 947-948).

These statements reveal two crucial points for the following discussion: one is that 'media reports both positive and negative news about health issues'; and another is that the context of media representation is situated in broader socio-political issues. In the context of media reporting on the Bangladeshi health service, the above points help to conceptualise the scenario. The media plays a role in the process of overseeing the health sector by reporting anomalies. Dr. Raj (DGHS) states that both ongoing media coverage of reported malpractice, accidents, and negligence, and legal interventions from the High Court have spurred DGHS reforms.

Within a few months of starting my fieldwork, two incidents occurred in ICUs in two different private hospitals. Both hospitals are situated in central Dhaka. According to newspaper reports¹⁰², one hospital kept a dead baby on life support, and in another hospital, three babies died in one night and two others in another week from not having adequate doctors and technical support available (Hassan 2016; Daily Star 2015; New Age 2016). In the first case of Japan-Bangladesh Hospital, where a baby was kept on life support after death, a 'mobile court'¹⁰³ fined the private hospital Tk 1.15 million on the grounds of three irregularities:

¹⁰² Please see Appendix

¹⁰³ The Mobile Court Ordinance 2007, Ordinance No. 31, was published in the Bangladesh Gazette, October 29, 2007. This is a unique feature of the judicial system in Bangladesh where executive magistrates are given limited judicial power to speed up the legal process. By their judicial power, an executive magistrate can decide the case

keeping unauthorised drugs; issuing a diagnostic report without any expert's authorisation, and the 'negligence'¹⁰⁴ that caused the baby's death. It is not beyond the realms of possibility that the doctor was at fault. Again, the description of the incident was only from the patient's family's perspective, which does not explain the doctor's side. However, the BMDC, the licensing authority, did not find the doctor guilty¹⁰⁵, according to news reportings (Morol 2017; BDNews 24 2016). As there is no publicly accessible document regarding this claim, I cannot verify the media report. On February 11th, 2016, the High Court summoned the authorities of the Japan-Bangladesh hospital to explain their position in this case.¹⁰⁶ The High Court also issued a rule asking the government to explain why a criminal case should not be filed against the hospital authorities for the allegations mentioned above.

on the spot and can establish the punishment impromptu, without proceeding to a full courtroom trial. (Source: <https://www.loc.gov/law/foreign-news/article/bangladesh-mobile-court-ordinance-2007/>)

¹⁰⁴ There is a difference between medical malpractice and medical negligence: medical malpractice is the breach of the duty of care by a medical provider or medical facility; medical negligence applies when a medical provider makes a "mistake" in treating a patient and that mistake results in harm. While the act or omission is definitely negligence, it does not rise to the point of medical malpractice because the medical provider did not commit the action either with the intent to cause harm or the knowledge that the patient might suffer harm. (Source: <http://wdpickett-law.com/faqs/what-is-the-difference-between-medical-malpractice-medical-negligence/>). According to US law, any negligence by an act or omission of a medical practitioner in performing his/her duty is known as medical negligence. Medical negligence happens when the medical practitioner fails to provide the care which is expected in each case thus resulting in injury or death of the patient.

¹⁰⁵ As there was no public record available at the time of fieldwork, I have failed to find out the reason why the BMDC did not find the doctor guilty.

¹⁰⁶ <https://www.thedailystar.net/city/hc-summons-md-japan-bangla-hospital-459619> [Last access 24/07/2020]
<http://www.dhakatribune.com/crime/2016/feb/12/hc-criminal-case-against-japan-bangladesh-hospital> [Last access 24/07/2020]

Explaining how such cases might happen, a health journalist Shoibal Mitra¹⁰⁷ from a popular daily newspaper told me in an interview about the persuasive power of the doctor:

Popular physicians are part of big hospitals as directors or similar. They are, most likely, personal physicians of the most influential persons as well. If any anomalies and incidents occur regarding 'wrong-treatment' or 'business-motivated' acts (such as 'keeping the dead patient on life support') in their hospital, they try to conceal it with 'powerful' personal patients and settle out of court. In the end, these incidents often go legally unattended and unchallenged. Influential people act as the safeguards of doctors and hospital management. Therefore, we do not see any doctors and hospitals being punished for their wrong-doings.

(Shoibal Mitra, Dhanmondi, Dhaka)

This remark can be interpreted in terms of classic anthropological, political theory on the patron-client relationship, where a hierarchical yet mutual obligation exists. Ideally, in a classical sense, a patron acts as a protector (under the patron's social and political power and wealth) of a client (who is inferior to the patron) in return for 'unconditional' support towards the patron. However, in contemporary times in such situations, patrons who have legally approved power (authoritarian) hold less 'power' than clients; hence they depend on clients' support (through social power and wealth, such as through donations to a political party, providing workforce in terms of voting) to gain their power. Despite the hierarchical relation,

¹⁰⁷ He was physically attacked by private hospital management while researching a report about a doctor using fake degree. (source: <https://www.dhakatribune.com/uncategorized/2014/05/13/prothom-alo-journalist-as-saulted-by-doctors-in-capital>)

it is more complementary. This study has no intention to justify or investigate the truth of Shoibal Mitra's statement; instead, this statement is considered as a widespread perception about the health care sector.

Nonetheless, the incidences of a dead child being kept on life support and the deaths of three new-borns¹⁰⁸ suggest that regulatory and monitoring bodies have failed in overseeing standards of intensive care in private hospitals. However, the existing monitoring and regulatory framework do not help DGHS to stop these kinds of incidents. According to the Medical Practice and Hospital Act 1982, getting a license to set up a private clinic or hospital is not very difficult and failing to meet given standards, or 'malpractice' and 'negligence' in treatment, are not treated as a significant 'misconduct.'

Updating Laws and their outcomes

According to Rahman, "both the immediate previous government of Sheikh Hasina of the Bangladesh Awami League, and the present government of Begum Zia of the Bangladesh Nationalist Party, have sought to revise the 1982 Ordinance. A new proposed Bill was prepared in 2000 (2007: 198)." Rahman finds both initiatives were unsuccessful as the BMA (Bangladesh Medical Association) deleted the part of the framework, which they found in conflict with their interests.

¹⁰⁸ As I summarise the news and incidents in appendix I

Again, according to the news media on the 3rd July 2014 (Uzzal 2014), a regulatory framework for private hospitals is in construction. I visited the DGHS to learn about such updates to the regulatory framework but was informed that the committee was still working at the time of my visit. Therefore, I could not manage to gather details of the draft as it was a 'work in progress.' When I interviewed the Directorate General (13/01/16), he expressed doubts about the draft proposals for a regulatory framework for private hospitals and ICUs getting approval from the cabinet and the parliament. He said that,

yes, we are working on the regulatory framework. But it is still in the working stage. We don't know yet whether we will be able to implement it. You have been sitting here so long, you already have seen, a journalist is pursuing a clinic which has been seized for not having proper papers. We are always getting pressure from everywhere. We even cannot take any legal action against hospitals for not following rules as the High Court gives us a stay order as there is no law to take action against such 'incidence'. We are trying to set up a framework, despite the fact that we have not enough doctors, nurses to follow the standard rules of the hospital.

[Dhaka, DGHS]

He repeated that the draft would be put forward to stakeholders and specialists in this field, consisting of five senior ICU specialists from state medical institutes, yet expressed scepticism about finalising the regulatory framework. He claimed that those who will work on the draft regulatory framework are also involved in hospitals either as business or working partners, and he suspects that they will never set any rules which go against their interests.

He stated that:

they are stakeholders [the members of the committee who will approve the draft to proceed it to the parliamentary committee meeting]. *They may collapse everything* [hospital/treatment] *if the new regulatory system goes against them. That is why we may have to take a middle road and negotiate something to get an effective mechanism.* [DGHS, Dhaka]

The DG's statement exemplifies the multi-layered conditions of private health care services in Bangladesh and suggests the dominance of stakeholders in the health sector who have the power to prevent the making of law if they find it against their 'interest.' In a further interview with Dr. Priyo Raj (who was working with the regulatory framework during my fieldwork), he expressed similar doubts to those of DGHS regarding the approval of The Patient and Health Service Provider's Protection Law 2016. However, Dr. Priyo Raj was optimistic about the prospects of law. He said that this reform is overdue. For instance, one hospital is running an ICU with only one permanent doctor, but the DGHS cannot stop this as there is no set rule for a minimum number of consultants. Although the DGHS had shut down the hospital (i.e., ordered to run the hospital), the hospital owner then acquired a six-month stay order from the High Court as there is no 'law' that can support DGHS in taking action against hospitals. Dr. Raj's review team is now creating new standards of care for ICU, informed by policies and practices of western countries such as the US and the UK, adapting them for the Bangladeshi context. Dr. Raj agreed that media reporting of the recent incidents at private hospital ICUs added pressure for a framework and monitoring processes to be developed and adopted. Therefore, media is arguably having some effect on the institutional reform of the Bangladeshi health care system.

However, the Patient and Health Service Providers' Protection Law 2016 was not approved by the cabinet, and the legal and regulatory framework that was mentioned by the DGHS has not been approved at the time of writing. It is noteworthy to mention that a platform of health activist groups explicitly showed their dissatisfaction against the Patient and Health Service Providers' Protection Law 2016 for being protective of the doctors rather than patients¹⁰⁹. Besides, in the proposed law, there was a provision of unbailable crime for any patient group that harasses health service providers. On the other hand, health service providers' punishment was less severe and bailable, even if the action is proved to be intentional and harmful.

Dr. Priyo Raj has since confirmed that

the draft law is now being forwarded to the Law ministry, waiting to be placed in parliament. The standard of ICU is not in the law; instead, it is going to be a part of the rules and regulations under the law. When the law would pass the regulations also will be formed.

[WhatsApp call, 31/05/2018]

However, the 2016 draft was not approved by the cabinet. Hence, the regulatory framework and standard of the ICU and CCU protocols could not be enacted either, as these were supposed to be made under the law.

¹⁰⁹ Source: <https://ubinig.org/index.php/network/printAerticle/44/English> Last retrieved on 16/08/2019

There was a day-long discussion organised by health activist groups on the draft law. They expressed their firm position against the proposed law, as will be discussed below. The following section focuses on the role and position of health activists in Bangladesh.

Patient rights and health activism

This section is about health activism in Bangladesh, which shows a particular pattern arising from a specific socio-political context. Popular perceptions were reflected in the health activists' statements while they talked to me in interviews. By analysing their interviews, I found that despite their deep concern about unregulated health care, no organised health movement and platform has yet been created, and little has been achieved.

In the context of Bangladesh, which is a relatively young country, health care activism has not yet emerged with its full capacity. It was initially centred on women's reproductive health, but the 1980 National Drug Policy was another significant issue raised by health movement activists led by Dr. Zafar Ullah Chowdhury. The national Drug policy played a significant role in listing and approving Drugs in the local market, creating restrictions for importing Drugs and encouraging local Drug production, which reduced the cost of medicine notably.

In recent times, groups of health activists have formed a collaborative platform to demand mass-oriented national health policy and the right to be consulted on health policy. UBINIG¹¹⁰

¹¹⁰ UBINIG (Policy Research for Development Alternative) is a non-governmental organisation formed in 1984 by a group of activists to support people's movement (what movement?) and search for alternatives to

and Shasthyo Andolon (Health Movement) jointly organised an opinion sharing meeting on 29th February 2016 to express their deep concern against the proposed Patient and Health Service Providers' Protection Act 2016. They claim that this proposed act is contradictory and not clearly clarified; hence, they feared it protects only health service providers rather than patient interests. Therefore, health activist groups opposed this act. In the opinion sharing meeting, Professor Dr. Rashid e Mahbub in his statement, called upon the government to stop malpractice and to stop advising unnecessary pathological investigations.¹¹¹

The following excerpts from interviews with health activists who are both health professionals and also independently run two hospitals in Dhaka city explain some existing anomalies in the health service. Both of them identify the 'unregulated' health care service and the profit-driven attitude of the service provider. Dr. Zafar points out some crucial issues, including the strengthening of the power of nurses, the implementation of professional ethics, and the death protocol, to ensure the accountability of the service provided; on the other hand, Dr. Qamruzzaman also identifies the profit-motivated health service as a persistent problem in the health sector, although he sees it as typical of a global system. Both of them emphasise human care rather than technoscientific treatment options. Ironically, the positions and voices of health activists are not yet apparent in the health rights movement in Bangladesh.

mainstream development. Among many activities, UBINIG has been involved in protesting against harmful population controlling schemes. Source: <http://ubinig.org/index.php/campaign/index/english>

¹¹¹ Source: <https://ubinig.org/index.php/network/printAerticle/44/english>

Dr. Zafar Ullah, the creator of the National Drug Policy, says the rule of thumb for private hospitals is to charge a minimum of 500,000 BDT (minimum total cost of the treatment) (appx. 5000 GBP) to care for a patient in the ICU. He claims that some private hospitals charge the patient family at least ten times more, which is possible as there is no monitoring and regulatory framework. Regarding management, patient admission protocols, and ICU treatment in general, Dr. Zafar also emphasizes the need for ‘intensive care’ instead of intensive machine dependency at the ICU. While critical care needs medical devices to monitor bodily functions, it also requires intensive human care that can be provided by a trained, skilled nurse. Dr. Zafar Ullah said in an interview that, *“the nurse should have the power to communicate with the doctor, what we do not have in our hospitals. Nurse [are] afraid of talking to a doctor.”* (Dhanmondi)

By this statement, Dr. Zafar Ullah indicates the existing professional hierarchy between doctor and nurse in the Bangladeshi health system. He thinks that treating a patient in a hospital, especially in an ICU, requires teamwork. The treatment process would become more effective and successful if the doctor and nurse were to work as a team to exchange their thoughts and experience. Dr. Zafar also mentioned that if any new doctor makes a mistake, a nurse who might be more experienced than the newcomer would not be able to ‘warn’ him because of the hierarchical relationship between them.

Dr. Qamruzzaman¹¹²told me in an interview (07/03/2016 and 08/03/2016 at his community hospital) that an intensive care unit means ‘where intensively care given,’ not ‘intensive technological care,’ so emphasising the role of nursing. Dr. Zaman, who also runs a community hospital, expresses his position against the popular concept of the ICU. He insists that critical patients need close monitoring and intensive care, which can be assured by giving intensive human care. Machines alone cannot do that. He says that, by decorating hospitals with tiles and lights, business-motivated authorities take money from people’s pockets without ensuring the proper treatment. Dr. Qamruzzaman says, “*the business-oriented attitude [has] become [a] major issue as a group of business-motivated people has captured the health sector for the last twenty years. They invested money in this health sector and to make a profit.*” (Community Hospital, Mogbazar, Dhaka)

He also expresses his concern about the enduring health care problem from the global perspective:

it is not only the problem of Bangladesh, but it is also a global problem created by the emergence of a new economic system one might call this neoliberalism. A country like Bangladesh is only a part of the whole system. We should remember that Bangladeshi people celebrate death. When someone dies, relatives organise a feast and invite people. We must consider the cultural context of society even when we deal with life support treatment. Without incorporating our cultural values, the treatment will not be treated well by relatives.

(Community hospital, Dhaka).

¹¹² Trustee member of Dhaka Community Hospital, a non-profit, self-financed, trust-owned hospital which provides health care for low-income, unprivileged people.

He thinks that the lack of effective regulation in the private health sector is somewhat understandable for a relatively new country, since the most powerful countries also have problems in their health sectors, though perhaps in a different manner.

Conclusions

In this chapter, I described the Biomedical TechnoService Complex Inc. (BMTSCI) in Bangladesh. By analysing the medical-industry complex, the state, legislation, overseeing bodies, the media, and health activists' statements, I showed that the BMTSCI had taken a local form in the Bangladeshi political, economic and social context with its dynamics.

This chapter discussed that the governance and regulation of life support treatments are inseparable from health care in general. Much attention must be explicitly given to such a highly specialised, high-cost life support treatment, which involves critical decisions regarding life and death. Furthermore, this chapter shows that legal and institutional (in the form of ICU protocol and standards) are entangled in life support treatment. This study finds that ICUs and life support treatment is not adequately regulated by the existing framework, as required by their complicated nature. Due to the lack of effective regulation and governance in the ICUs and health system at large, patients and their relatives suffer and eventually lose trust in the health system. In the context of life support treatment, there are different stages of death, such as coma and brain death. Failing to differentiate these forms of consciousness from death can lead to an immense misunderstanding. Again, not following and maintaining the standard guidelines opens the possibility of malpractice in the use of life support

technology. Furthermore, not being responsive to the dying patient's relatives can worsen the situation.

Already a controversial health care service, the emergence of life support treatment in the private sector makes the situation even more complicated. The scandals that have arisen in this sector indicate the same weak regulations are operating. On the one hand, private health services have become more accessible outside the major cities. However, it seems that people still go to the capital city to get critical care treatment as they believe that the most advanced and best treatment options are available there. On the other hand, the number of stories of malpractice and dissatisfaction with private hospitals spread out in daily conversation and are increasingly evidenced by newspaper and social media coverage of events in ICUs. The nature of the allegations centre on doctors' and hospitals' profit-motivated intentions and attitudes, from charging too much for intensive care and other treatment in general. However, this complex situation needs further attention, as the 'mistrust' lies in the very heart of the existing doctor-patient relationship, communication, and finally, marketisation of health care at large.

The BMTSCI in Bangladesh incorporates these multi-layered factors. This chapter has discussed the socio-political context of privatisation and corporatisation of health service in Bangladesh. Secondly, it has discussed how the recently emergent technoscientific treatment in Bangladesh has led to a disputed situation conditioned by a lack of effective and updated laws and regulations. Hence, the commodification of health service, coproduced with a lack of effective regulations and governance, means that malpractice is more likely, but those

involved are rarely held responsible or punished for their actions. When incidents emerge in the popular media, they generate significant public debate but little government action.

DISCUSSION AND CONCLUSION

Technological interventions have reached the capacity to modify both life and death.

Franklin and Lock (2003: 3)

The main inspiration for this study comes from some troubling experiences associated with death and dying on life support that my friends and family shared with me. Other factors, including public perceptions, experiences presented in the media, and everyday conversations, motivated me to conduct an in-depth study in this area, in which I have explored the biomedicalisation of death and dying in the ICU concerning life support technologies. Throughout this thesis, I have discussed my empirical evidence of how life support technologies and their associated practices have changed how people understand life and death and, in so doing, created a hybridised technologised form of life and death. I also have shown that, while life support treatment often ends with the death of the person involved, the trajectory towards that end moment involves a waiting among dying patients' relatives in the waiting room (chapter 4)- a space that I argue here is a hybrid-domestic-medical space. A new form of technologised hope and care (chapter 5) to which patients have unequal access, often resulting in life support being withdrawn (chapter 6). However, at the level of governance, this domain of technologized hope and care remains largely unregulated and unchecked, because of the lack of state guidelines or a robust policy framework, despite repeated media reports of malpractice and the market-driven logic of private ICU providers (chapter 7).

This final chapter serves a dual purpose. First, I intend to draw together the strands from the previous chapters to show how I identified the biomedicalisation of death and dying at ICUs in Bangladesh. Second, I discuss the key findings of the study, its limitations, and areas for further research.

This thesis is structured into three parts.

Part One- Introduction, theoretical discussion and research methods (Chapter 1,2 and 3)

Part Two-Empirical chapters (Chapters 4, 5,6 and 7)

Part Three- Discussion and Conclusion: In this section, I put shed light on the previous chapters, the major findings, limitations, and the possibility of future study.

Overview of the study

Part One

In chapters 1, 2, and 3, the background of the study, the theoretical background, research methods, ethics are discussed.

Chapter 2 describes the theoretical progression from the concept of medicalisation to biomedicalisation. At the inception of this study, I was looking at only the 'medicalisation' of death; however, after coming across the work *Biomedicalization* (2010) I became deeply fascinated by the theoretical concept proposed there by a group of North American

academics, and it became the central theoretical platform of this study. Biomedicalisation, as a theoretical and analytical concept, guided me to understand the recent development of the health care system in the context of Bangladesh. By the term biomedicalisation, Adele Clarke and her colleagues identify the increasingly complex, multi-sited, multidirectional processes of medicalisation that have emerged and are comprehended as '*the social forms and practices of highly and increasingly technoscientific biomedicine*' (Clarke et al. 2003: 162).

Chapter 3 discusses the research methods, ethics, and the field of this study. I found that ethnographic research methods give some flexibility to the researcher. As it is a relatively open mode of research, it has the scope to incorporate many relevant issues that come up. When I started my fieldwork at the ICU, I realised that this place (the waiting room) is not a place for asking questions of the relatives; rather, it is a place to listen to their stories. This openness of the research methods contributed to the study enormously. It also allowed me to sidestep the ethical and moral dilemma of asking subjects sensitive questions.

Relatives shared their thoughts and experiences with other patient relatives. They created a communal sharing space derived from individual experiences. Hence the integral cultural system is developed and revealed within the bounded subject matter. An ethnographer depicts this picture from the micro-level, which is a reflection of the systems playing out at the macro level as a background. To link the biomedicalisation of death and the broader political economy of hope, this study situates ethnography and addresses the relatives' experiences through their narratives.

I had started interviewing people outside the hospital using my contact, whose close relatives were on life support when I was delayed waiting for permission from the hospital (mentioned in chapter 3). I kept continuing to interview, even after I got permission from UTH. I found it was also an excellent opportunity to listen to their different stories. Besides, I found that these stories by no means conflict with the observations I made in the hospital as I wanted to present relatives' reactions to the situations they experience in this study. Through their narratives, I described the relatives' moral and emotional dilemma regarding the choice of life support, responsibility and care, and scepticism and deception. At the same time, I presented the health professionals' narratives and perspectives throughout the thesis. My observations also highlight the dependency on medical technologies in the ICU.

Part Two

Empirical chapters

The second part of the thesis consists of chapters 4, 5,6, and 7.

Chapter 4 is the first empirical chapter of the thesis, which discusses waiting and the transformation of the waiting spaces at ICU premises. Waiting is probably the best word to describe the ICU patients' relatives' reality. The waiting room was the place where I first encountered the relatives. I argued that this room is an extension of the ICU, representing a hybrid medical-domestic space.

With this thesis, I aimed to focus not only on the development of life support technologies, but also on what these technologies are doing to the way death and dying takes place, and how these transformations are affecting patients and families, associated institutions (biomedical practices, government overseeing bodies, legislations) more broadly. By shedding light on the new hybridised techno-social forms that are coproduced within the practice of life support technologies and its related domain, I wanted to show that, in addition to the prolongation of life, the advent of life support technology in Bangladesh has caused other and more complex phenomena. In chapters 5 and 6, the socio-technical hybrid forms that have been created through the biomedicalisation process are discussed. Both chapters primarily present biomedicalisation in action. In chapter 6, I discussed the political economy of hope that describes the hope that is blind to relatives' financial capacity, which characterised the localised form of biomedicalisation. However, I have explained hope as a practice that stems from technoscientific innovations, as well as being an emotion and a cultural attitude.

Nonetheless, relatives hope for the prolongation of life and typically opt for life support technology. Often, the financial incapacity to bear the treatment eventually results in a decision of withdrawal. I argued in this chapter that the stratified biomedicalisation of death had taken place in Bangladesh due to uneven access to resources, that have been revealed in the various forms of withdrawal decisions and treatment process taken in the ICU.

I explained the concept of a 'Biomedical TechnoService Complex Inc.' in the context of life support technologies in Bangladesh and the governance of the health care service, in chapter 7, which is the last empirical chapter of the thesis. I reported in this chapter that there is no

effective regulatory framework for ICU, not even any state-provided standard ICU protocols. The private health care service has been rapidly increasing over the last four decades, and it has been encouraged by the government since 1980. My research finds that the government's overseeing body is still not fully equipped to monitor ICUs because it lacks a legal and regulatory framework and the human resources needed to enforce it. The major ICUs are provided by private hospitals, which have often been accused of being overly profit-driven and conducting malpractice. Due to the absence of effective laws and a regulatory framework, the technologized critical care service remains unregulated, and this has given rise to a public perception that 'there is no law in the health sector.' Health activists note a similar perspective regarding the health care service at large. However, the health rights movement in Bangladesh is still in its infancy regarding its activities since the country gained independence. Chapter 7 also discusses secondary sources, such as health reports, media reports, government reports on health, and the laws and regulations of the health service, along with interviews of personnel of DGHS (Directorate General of Health Service), health activists, and journalists.

Part Three

Contribution of the study

Following Adele Clarke (2010) and her colleagues, I wish to point out that biomedicalisation is not intended inherently or only as a critique (of medicine), but instead as an analytic term

used to identify and describe a new set of phenomena, which are still taking shape in Bangladesh.

Through the empirical research, I have completed, my thesis makes a novel contribution that is highly relevant to health professionals' and policymakers' understandings of those who experience life support technologies in unequal, troubling but also hopeful ways. It is also my hope that by documenting the inequalities that characterise the Bangladeshi healthcare system with respect to intensive care, in particular, this research will provide evidence that can be used by health activist groups and policymakers to push for better regulation of biomedical technologies. Academically, my work also offers a contribution to future comparative studies on the biomedicalisation of death in Bangladesh and adds to the literature on science studies, medical sociology, medical anthropology, and to health policy debates more broadly. I spell out the principal contributions of this thesis below.

From relatives' and medical staff's (doctors-nurse-care givers) conversations, encounters, communications, in a given moment, I uncover the practice of life support treatment. I wanted to depict the reflection of health systems (the macro level) in the people's lives (the micro-level). I consider their experiences (suffering) not as an individual, but as social (Kleinman 1986). I showed in this study why relatives opt for an invasive yet expensive life support treatment, despite knowing there is a slim chance of patient's survival. While doing so, I also identify the embedded motives of this decision, which often lie in the broader context of life support technologies where it is located and practised. Hence, the personal accounts and narratives of experience ought to be seen as a response to the set of actions structured by the total health system, where the health system includes: legislation and monitoring

systems, ethics, doctor-patient relations, the treatment procedure (from admission to diagnosis, cost, care, withdrawing protocol, and counselling), hospital service, and family involvements (in providing financial and care support).

Technology of self and denial

Throughout the thesis, I have shown that patients' relatives' hopes and expectations result in the choice of life support treatment. I also found that relatives had to decide on life support in the emergency room when they only request doctors to 'do whatever you can.' However, in most cases, it was the health practitioner who suggests first life support. Lack of financial means is the main reason for the withdrawal of life support; otherwise, patients' families prefer a 'natural' death on life support. Sometimes, even when a family understands that death is inevitable, they still choose between death now or death later (Kaufman, 2005). I also found that sometimes patients' relatives repeatedly request to maintain life support because they consider it as the only option, not seeing the futility of it because the idea of switching off the machine is equivalent to 'killing' their relative. Of course, for those who cannot afford this option, they do not even have to face this dilemma.

Various positions regarding life support exist among the relatives in Bangladesh: on the one hand, it is believed that life support is the 'point of no return' because 'being on life support' is very painful; on the other hand, it is also thought that the ICU is the best place to get comprehensive treatment. Therefore, relatives often do not want to remove their patients from the ICU, even after doctors have told them to do so. This situation indicates the technologies

of self-described by Foucault(1988) as people using technologies to transform their kin's life/death according to their own choice and desires.

Some patients return from life support and manage to continue living, with or without mechanical support, but without mobility. In this study, I found that some relatives are in complete denial regarding taking further life support, even if the patient would need it in the future. For example, some relatives said, "my [...] would never want to live like that". Relatives sometimes place themselves in the patient's position and decide as if it was them.

As I mentioned, technology makes death contradictory. I have shown in this thesis that relatives did not consider withdrawal of life support to relieve suffering. I have noted two types of action/position: one, praying to God for 'natural' death to end the suffering, and two, as long as the patient is breathing, they consider the act of withdrawal as murder.

ICU and life support technologies reconstitute death in a particular way. Life support can 'turn the death clock off' for a while. The technologised conceptualisation of death occurs through a series of negotiations. Life support technologies offer control over life processes. When a person is on life support, death becomes juxtaposed with others' wishes or factors. As Kaufman correctly states in the *And time to die* (2005), it is a grey zone, between health, awareness, function, and viable life on the one hand, and 'no longer a person,' 'death in life' and 'death' on the other hand (2005: 63).

In my research, I have shown that through the increasing development of technoscientific biomedicine, death, and dying, along with our hopes, expectations, cares, and sense of responsibility, have been reconstituted.

The practices of life support are localised and globalised

I have discussed in chapter 7 that there are no standard guidelines or protocols for ICUs and life support treatments set by the state. Therefore, hospitals follow 'the international standard guidelines' for ICUs and protocols which differ from hospital to hospital; for instance, UTH follows both US and UK critical care standard provision of ICU while BIRDEM follows the EU standard provision.

Nonetheless, following an international standard protocol raises another problem. Life support technologies are not only a device (like a stethoscope or thermometer), but technology in a Foucauldian sense (1988), which involves life and death decisions, decisions to withhold or withdraw treatment, and the capacity to carry it out. This technology and treatment is surrounded by ethical and moral concerns and is also characterised by financial constraints for those who have limited access to these resources. I have shown in chapter 5 that life support technologies produce a new type of death and a new type of hybridised subjectivity. This technoscientific treatment is mixed with socio-cultural phenomena; I found in this study that, regardless of their position in the treatment process, the people involved, whether relatives or medical staff, are continually negotiating with the life support technologies. The negotiations take place when the demand for maintaining life support technologies cannot be

fulfilled. In chapters 5 and 6, I have illustrated the case of Faruk Mia, Monir Hossain, and Mrs Momota, where relatives negotiated the withdrawal of life support as they could not bear the high expense of life support treatment.

I find in this study that the practice of life support technologies is characterised by constant ambivalence and negotiation. Here, we see not only the negotiation between relatives and life support technology but also a negotiation between ethics, legality, and institutions. Concerning this latter point, the practice of life support technologies in Bangladesh has been negotiated with the standards and guidelines followed. I have described in chapter 6 the withdrawal decision and procedure in hospitals. When relatives are unable or decide not to continue the treatment, they discharge their patients on a risk bond. Those patients who fulfil the medical criteria of brain death can be declared as dead and taken off life support. However, for those who are not brain dead, the only 'legal' way to withdraw life support is to discharge the patient on a risk bond (DORB). Here, we can see the negotiations between law, institutions (hospital), medical technology, and relatives.

Making explicit their implications for the understanding of human health, illness, reproduction, and death is a major task facing contemporary social scientists. It is a task that requires constant innovation and revision, a critical scepticism toward overestimations of the significance of developments in the life sciences, and caution about the hype surrounding cloning genomics and many other new biotechnologies (Franklin and Lock 2003: 3).

This statement reveals the inspiration and responsibility for social scientists in mapping the changes brought by modern technologies in our life and society. With this in mind, I have used the ethnographic method to collect data.

Regardless of place and culture, life-prolonging treatment at the ICU is critical and sometimes controversial for both family and health professionals for various reasons. It involves decision-making and consent for the withdrawal of treatment, the justification and ethical issues of prolonging or withdrawing treatment, the issues of 'quality of life' versus 'quantity of life,' and the controversy regarding brain death. Social scientists from sociology, anthropology, ethics study, legal study, STS, and other social science disciplines have been engaged with these end-of-life issues in the last three decades. In the last 20 years, there have been a significant number of studies conducted concentrating on the ethical, moral, legal, cultural, and political economy of the end-of-life. I found that many of the debated and controversial issues that pervade the discussion of end-of-life are *not* evident in life-prolonging treatment in Bangladeshi hospitals. For example, brain death, living cadavers, ethical-legal issues in the withdrawal of life support, and 'euthanasia'¹¹³ are not clearly present here. Instead, these debates and controversies have taken a different shape in the form of 'mistrust' and 'scepticism' between relatives and health service providers regarding the life support decision.

This study suggests various issues regarding hope and deception. Firstly, families also go through intense pain while they are hoping to end their kin's suffering. This moral suffering often becomes a burden for the rest of their lives based on an inability to help. Because of

¹¹³ Euthanasia, and organ donation from living cadavers are not practised in Bangladesh, though organ donation from a brain-dead person is legal in Bangladesh.

that, relatives start blaming health service providers for their suffering. Secondly, I understand from this study that it is tough now to assess whether the family or the doctor made the right decision.

Nevertheless, two things are clear: first, that the doctors could have explained more about the patient's condition to the family. Isolation of the ICU patient from their relatives is one reason that relatives' doubts grow strong. They are usually allowed to see the patient only very briefly, once or twice a day. Second, relatives (according to themselves) do not get enough information to understand the condition of the patient clearly. In Bangladesh, life support, mechanical death, brain death, and coma are not very common words for laypeople. Family members know next to nothing about critical care medicine, intubation, mechanical support, or brain death if they have not been explained to them. They may expect a 'miracle,' so letting them decide may lead to futile treatment.

I showed in chapters 5 and 6 that relatives want to continue treatment until they reach the limits of their financial capacity. They request the doctor to "do whatever is needed." Kaufman finds a similar situation in her ethnographic study (2005), where she mentioned that, "[...] asking a family member if they 'wanted everything done' was a leading, loaded question – a trick question. Of course, they want everything done! But if you were to explain precisely what could happen[...] (p, 204)".

This statement clearly indicates the need for detailed advice. I have found doctors to take firm positions regarding futile treatment. However, in private hospitals, generally (an exception is the BIRDEM), I have not seen any firm position taken by a doctor.

Regulation and enforcement

The complexities of Bangladesh 'Biomedical TechnoService Complex Inc.' (Chapter 7) regarding life support technologies arise from the allegation of being overly profit-motivated, the absence of effective rules, regulations, and legislation, the lack of proper public understanding of life support, and the lack of effective interaction between relatives and health professionals in ICUs.

The media plays an important role in the health sector by reporting anomalies and the negligence of health care providers, as well as reporting the success stories of the health sector. However, 'negative' reports are more evident in the media. Often, we do not see the health provider's perspectives in the media. In relation to the two incidents discussed in chapter 6, we find very little from the doctors' or hospital management's perspective. Where they were presented, they were in the form of denial, hiding the 'incident'- by saying, 'no negligence happened' or 'no one could be found to comment on this issue.' This type of position does not improve the existing relations between health providers and patient groups. Lupton (2013; 1998) finds the language of the news representation in media very important as it represents two things: existing social relations between the actors represented in the news; and the popular perceptions and discourse about the news. In the context of Bangladesh,

both issues are evident. I found that there is a ‘misunderstanding’ and a lack of knowledge regarding the different types of death which happen on life support. Given the complexities arise from the definition of brain death, it is also evident that often death and brain death stand as synonyms. My interviews with doctors in this study noted that the Japan-Bangladesh Hospital incidents of ‘keeping dead bodies on life support’ mentioned in chapter 6, might have arisen from the misunderstanding of brain death. However, doctors also express their concern about the insufficient counselling that might take place in such situations. Some of the doctors also showed grave concern about the sinister motives of the ‘hospital management’ and *dushtu*¹¹⁴ doctors (‘naughty’ doctors) who could hide the brain-dead condition of the patient from the relative improperly. There is another issue revealed in this context, which is considering hospital management and doctors as a collective in opposition to the patient group. This reflects the popular perception and discourse of the existing social relations between doctors and patients. I found that in most cases, doctors keep their expression of seriousness while talking to relatives. When I asked doctors about the reason for keeping this serious attitude, they said that relatives would otherwise make them ‘mad’ by asking too many questions and would not let them work in the ICU. This statement denotes the workload of an ICU doctor. However, once I asked why there is no ‘social worker’ or someone separate from the ICU doctors to counsel relatives, I got a reply that it is nearly impossible to have a ‘non-biomedically’ trained person in the ICU for counselling, as relatives will never trust them. This statement clearly conveys the hegemonic authoritative voice of upholding biomedical pride, that carries the classical notion of science being ‘the only truth.’ However, other groups of doctors think that there should be someone trained in that category who can do

¹¹⁴ In Bangla, this word usually is used to describe children being naughty.

counselling, as it happens in the West. However, at the same time, they said that they practice critical medicine with limited resources in Bangladesh, for which reason it is not possible to meet the 'international' ICU standard. The main limitations are the lack of trained health service providers (doctors, nurses, physiotherapists) and insufficient medical devices. However, I have not seen any concern about not having any standard ICU protocols and regulations.

Despite the limited resources of skilled workforce and technologies, stratified biomedicalisation of death is in progress in Bangladesh, mostly through the commoditisation and marketisation rules introduced by the global neoliberal economy. This whole life support health sector depends on imported medical instruments, which require intensive capital investment, which mostly comes from the private sector. However, the state encourages this by providing flexible taxation and import benefits. The market of privatised ICU is expanding, but at the same time, public perceptions regarding life support and their experience are largely ignored and unattended.

Stratified Biomedicalisation of Death

Kaufman observes in her ethnography, *And a Time to Die* (2005), that dying as a process has changed dramatically between the 1960s and the 1980s with the presence of intensive care and life support machines. Similarly, I also found in this study (discussed in chapter 4 and 5) that death and dying have also changed over the last few decades in hospitals in Bangladeshi, after the introduction of life support technologies in the 1980s. The inception of the ICU in Bangladesh took place in 1978 at the National Institute of Cardiovascular Disease (NICVD),

and this can be regarded as the starting point of how death has become biomedicalised. I have shown that through the increasing development of technoscientific biomedicine, death, and dying, along with our hopes, expectations, cares, and sense of responsibility, have been reconstituted.

I have found at least five different forms and understandings of death and dying have emerged by the intervention of life support technologies that often contradict how relatives perceive death. These include *death controlled and determined by a machine, not yet dead-life* between life and death (coma, brain death, vegetative state), *decided death-* by the withdrawal of life support, prolonging death by life support-death, *familiar and unfamiliar death*. In this manner, death (or life) may become a matter of 'choice' which is unevenly available – to live or to die; to die now or to die later; a matter of scoring and numbers – that subjugates bodily response at the physiological level. For instance, 'there is no reflection,' 'comatose stage,' 'vegetative stage,' 'reversible/irreversible stage' etc.

I have shown that through the increasing development of technoscientific biomedicine, death, and dying, along with our hopes, expectations, cares, and sense of responsibility, have been reconstituted. As Lock and Franklin (2003) note in this context, technological interventions have reached the capacity to modify both life and death (2003). Paul Rabinow reminds us that 'the changes biomedicalisation brings, do not indicate an epochal shift with a totalizing coherence rather fragmented and sectional changes that pose problems' (Rabinow 2003:14). In this regard, the changes in death and dying brought by medical technological interventions are essential to understand, regardless of whether death is seen as systemic. Because the way

death and dying are presented in life is not merely something that affects individuals or society, but it provokes a response from all who are affected, including the dying person (Das and Han 2016).

In this context, I showed that stratified biomedicalisation occurred in Bangladesh regarding death and dying in ICU. I found the nature of the stratified biomedicalisation of death to be complex, multi-layered, and sometimes contradictory in the socio-economic and political context of Bangladesh. The entire process of biomedicalisation of death is conditioned by the socioeconomic context of the user (consumer) of life support technologies in Bangladesh. The standard of life support treatment and service (such as doctor-nurse-patient ration, medical procedures of the pathological test, amenities at the waiting room for relatives) is mostly followed by either in terms of money or social status. This study also found that, when a critical patient reaches the hospital emergency ward, s/he is transferred to ICU regardless of the prognosis. In this situation, often, the decision is made considering the patient's socio-economic background or business interest of the private hospital (a common allegation raised by relatives), not always by the logic of 'who will be benefited by the life-support.' Thereby, I find that the futility of life support treatment sometimes occurs from the ineffective intervention, which may be explained from the logic of market interest.

Decolonising knowledge: Biomedicalisation in the local context

Before moving to the discussion of the key findings of the study in the light of biomedicalisation theory, I will discuss the challenges I faced initially using a theory rooted in the North

American context to understand the empirical findings in a country situated in the Global South. Put another way, how can we conceptualise biomedicalisation and the use of life support technologies in non-Western Bangladesh?

In this regard, Wen-Yuan Lin and John Law (2019) reminds us of George Basalla's (1967) famous proposition that:

The modern science diffused from a 'Western core' to the 'non-Western periphery' in three overlapping stages in which colonies were first a resource for European scientific expeditions before adopting Western institutions and traditions, and finally creating local independent national science (Lin and Law 2019: 3).

I agree with the above statement, and I maintain that the biomedical practices in Bangladesh have been shaped by its colonial legacy, which is different from the Western core where the knowledge originated. As a part of the Indian subcontinent, advanced medical care was introduced in Bangladesh (former East Pakistan) by British colonial rule. As Zaheer Baber (Baber 2001) noted, scientific knowledge, institutions, and colonialism are mutually coproducing. He also explained that colonial rule not only brought modern science from core to periphery but also it enforced the development of new forms of scientific knowledge and institutions both in the periphery and the core. Baber's statement helped to theorize the colonial influences in biomedical practices that originated and expanded during the British rule in India (Biswamoy 2001; Arnold 1993; Bala 1991). Bala (2009) specifically explained the practice of biomedicine

in the colonial context, where they explicitly noted the existence of colonial discourse in medicine, which defines the power, inequality, hegemony in the colonial context.

The existing practice of visiting hours (influenced by germ theory¹¹⁵), the structure of waiting rooms (except for the five-star private hospital, the other two hospitals' waiting rooms have minimal facilities for the relatives, as described in chapter 4), and the segregation of relatives and health professionals (displayed in the conversational manner and body language of health professionals with patients' relatives) are rooted in the colonial practices which were imposed or imported by the British during their occupation. These practices mentioned above have been maintained in this geographical territory from the very beginning of the introduction of biomedical practice. Over this period, the uses and availability of technologies, treatment patterns, and health care services have not remained the same, but the legacy of colonial rule is still evident. In what follows, I explain that the first challenge that I faced in applying biomedicalisation theories in this study was to address the specific context of the Bangladeshi practice of life support technologies.

In the age of the neoliberal economy, many modern biomedical technologies and resources are available in Bangladesh, and they are utilised by both the private and public health care sectors. However, public health facilities equipped with modern technologies are limited mainly to the hospitals in the major cities of the country. However, as I have stated earlier, the sociocultural and economic context of the technology-receiving country (Bangladesh) is

¹¹⁵ Which states that microorganisms known as pathogens or "germs" can lead to disease

different from that of the technology-producing countries in Europe and North America. These modern biomedical technologies are practised and located in the specific socio-economic context of Bangladesh. In the case of life support technologies, I have shown in chapters 5,6 and 7 that in this particular context, partly due to weak governance, this life support care service has resulted in the suffering of relatives who face difficult and frustrating dilemmas entailing constant negotiation and uncertainty.

Returning to the point of decolonising biomedicalisation, I found that, in the context of this research, biomedicalisation theory and other relevant theories originating in the Global North do not provide me with the appropriate basis on which to describe the changes brought about by the recent advancements of life support technologies in Bangladesh. Clarke et al. argued that biomedicalisation “is co-constituted and manifested through five central (and overlapping) processes: (1) major political-economic shifts; (2) a new focus on health, risk and surveillance biomedicines; (3) the technoscientisation of biomedicine; (4) transformations of biomedical knowledge; and (5) transformations of bodies and identities” (2003: 166).

In daily practice, biomedicalisation processes are not fixed but conditional (Friedson 2001; Olesen 2002; Olesen and Bone 1998; Clarke et al. 2003) . This argument also suggests that the biomedicalisation process is not homogenous, as it further depends on the context of a society where it is taking place. I find in this research that in many places in the context of life support treatment in ICUs, people as patients and as provider/health system workers respond to and negotiate biomedicalisation processes and create a new kind of ‘practice’ of the scientific innovations (life support technologies) and organisational forms to meet their own needs (Strauss 1981; Wiener 2000; Clarke 2010). It also seems to suggest that the way

biomedicalisation occurs in the global West will not necessarily occur in the same way in Bangladesh. The forces of biomedicalisation are advanced, contested, mediated, and ignored in specific contexts and situations, for example, due to limited resources and local cultures of practice; hence 'users' of technologies make their negotiations within institutions to act according to the situation.

These five processes have occurred to different degrees in Bangladesh. The first process has indeed taken place. I mentioned in chapters 6 and 7 that the privatised health care sector is now considered as a major service providing the business sector in Bangladesh, as it has rapidly increased in size in the last two decades, making it possible to offer modern and high-tech medical care to those who can afford it. In the context of life support treatment, I found that the number of ICU beds in government hospitals is insufficient compared to demand. Besides, in most cases, after spending a large amount of money at a private ICU, families transfer their relative to government hospitals depending on the availability of beds. Again, relatives require an 'unofficial' channel to get a bed in a private hospital, where they often go despite the high cost. This excessive cost constitutes the main problem of this private sector. As the overseeing body is ineffectual in Bangladesh, the private health sector is reported to be unregulated in deciding its service fees. I have also shown in chapter 7 that the government encourages the development of private health care, as public health facilities are insufficient to meet the demand for health care for the majority of the public. Hence, we see a different form of biopower (Foucault 1976) exercised in Bangladesh. Indeed, the form of biopower exercised here takes a different shape to the Foucauldian explanation of biopower exercised by the state in the form of surveillance over the body, life, and death. Whereas the Bangladeshi government does not have full control over this medical practice, the private health sector

that provides the technologized care has complete control over life, death, and bodies. Instead of biopower being exercised by the state, the privatised health care service exercises control over bodies, life, and death in Bangladesh, compounded by weak state governance, and the situation where relatives have no alternative but to go to a private ICU. Thus, private health care providers have power over patients; for instance, they can charge excessive amounts of service fees, which is one of the major allegations against private ICUs. I found that relatives sometimes do not feel able to challenge the service providers, even if they find a 'mistake,' as the family member will be in their care.

The second and third processes of biomedicalisation, that of 'a new focus on health, risk and surveillance biomedicine' and the 'technoscientisation of biomedicine,' are two specific areas that appear in Bangladesh differently. The second process is a very much Western, specifically, the US phenomenon derives from commodity culture and the (re)engineered body considered a valuable possession (Clarke 2014). With the rise of privatised high-end hospitals, health has become a commodity; relatives withdraw life support, as they are unable to pay the cost of treatment, clearly following market logic. The third process of biomedicalisation is less evident in Bangladesh than in the US.

However, I suggest that it is still present in the former, which is evident in the technoscientific nature of life-prolonging treatment and the transformations of bodies and identities that are the fifth process of biomedicalisation. This research suggests life support technological interventions transform dying person personhood (a patient's identification often determined by bed number; relative sometimes cannot accept the patient's unconscious state, hands being tied with bed rail for the unstable patient), and creates various forms death and dying which

may be different from how it took place in the global north. In the context of death and dying, I argue that the meaning and nature of technoscientific biomedicine differ globally.

However, the fourth process occurs in Bangladesh contextually and partially. Private hospitals' advertisements for their ICU and life support technologies are on show in Bangladesh on the media, part of a self-campaigning marketing strategy in which they claim to be of an international standard. On the other hand, the government and NGOs use media for health awareness campaigns, such as vaccinations, tuberculosis inoculation, and family planning. This process also develops in Bangladesh very contextually. The experiences of uneven access to resources, which end up in withdrawal of life support, can be considered as a Bangladeshi contextual feature of the biomedicalisation of death. At the same time, biomedicalisation theorists remind us that biomedicalisation is highly historical and local. Its specificities vary across geographies and temporalities in ways that largely remain to be empirically explored. In this regard, Fischer argues, "it is increasingly artificial to speak of local perspectives in isolation from the global system[...] the world-historical political economy" and "transnational cultural processes" (Fischer 1991:526).

In this study, I want to suggest that biomedicalisation in Bangladesh is characterised by its local forms of biomedical practice, cultural understanding, localised ethics and moralities informed by the socio-economic context and the state's provided rules and regulation informed by the socio-political-economic condition.

Limitations of the Study and Opportunities for Future Research

I did not have any technical knowledge about life support technologies and other ICU devices before commencing my observation in ICUs. I visited one ICU at Chittagong Medical College Hospital (CMCH), a government facility, in 2014 before coming to Lancaster University, in order to gather some first-hand knowledge about ICUs. However, when I first entered the ICU at UTH, it was completely different from the CMCH: the CMCH was equipped with very few and (apparently) old machines at that time, whereas UTH was equipped with up to date medical devices. Even the knowledge I gathered from the internet to prepare myself did not help much. Given my lack of technical knowledge about the ICU medical technologies and unfamiliarity with frequently used medical terms, initially, it took time to understand the inside of the ICU. I did not substantially focus on the monitoring of machines that require more technical knowledge to understand than I possess. Somewhat, I limited my focus to ICU monitoring (machine-human, discussed in chapter 5) and gathered my understanding from a non-medically trained social scientist perspective. I consider this issue simultaneously as a shortcoming and a strength. If I were to have had proper training on this, I could have gathered more information on machine monitoring in ICU. However, the fact that I focused on the socio-technical part of the life support technology and tried to bridge the gap between the ICU and the outside world through an ethnographic study constitutes the strength of this study.

This study finds both healthcare and relatives go through immense mental stress. This study did not have a scope to engage with the mental wellbeing issues, which is a limitation of the study. Though I talked with doctors and nurses about their coping strategies, I could not

address this issue as a separate theme. The health professionals' perspective and their workloads should be another consecutive part of the research on the biomedicalisation of death.

I will not deny the 'uncomfortable feelings' I initially felt whenever I entered the ICU. These feelings come from the sad and depressing environment of the ICU, which always reminds visitors of the mortal condition of the patients. I was aware of such feelings and careful not to allow them to hamper my ongoing study. I became more concerned when I learned from a doctor¹¹⁶ from the Gynaecology department that she became depressed after her training at the ICU (I did not get to know whether she needed any psychiatric help). She was surprisingly asking another ICU doctor how they constantly work there in such a depressing environment. It is not only the stressful conditions posed by the patients' critical situation that doctors and nurses need to deal with continually; they work long hours in the ICU as well, for instance, at BIRDEM ICU, where doctors work 34 hours at a time. Apart from the ICU duty, most of the doctors have study loads and exam stress as well. This is an essential issue of the mental health condition of health professionals who always deal with critical patients, and it requires serious consideration and independent social research. This issue needs serious attention in the policymaking.

Similarly, attention to the comfort of relatives and health professionals are largely ignored. This study suggests taking this issue into consideration while making the ICU guidelines.

¹¹⁶ It was mandatory for all postgraduate trainee doctors at UTH to take a short training at ICU.

The cost of life-prolonging treatment is immensely high. The government should take steps to reduce the cost and reduce the unnecessary use of life-support treatment. At the same time, steps should be taken against *Dalal*.

These critical treatment procedures require a high level of medical expertise, failing to provide intensive care and monitoring at ICU may result in severe consequences. This study suggests strengthening state-level monitoring regarding this matter.

The choice and availability of research sites may be considered as a limitation of the study. Initially, I had intended to choose hospitals in two major cities in Bangladesh: Dhaka and Chittagong. Due to time constraints (as I mentioned in chapter 1, I could not acquire permission from UTH before I arrived in Bangladesh for the fieldwork), I could not do that. I only took relatives' interviews in Chittagong (I explained in chapter 1 why I decided to interview relatives who already have experiences of life support care for their close kin. Seven interviews were taken in Chittagong). As I could not get permission at private hospitals in Chittagong, I had to stop my observation at the ICU of government hospital because, without empirical data from private ICUs, I would not have been able to compare the private and government hospitals. Hence, the regional differences in life support practices in Bangladesh are absent from my thesis. Since there are no state-provided standard ICU provisions or a specific and effective regulatory framework for ICU and life support care, it requires much attention to explore how ICU and life support care operates across the country.

This is another area of interest in this field that I want to explore in the future. This future study would require not only an overview of life support technologies in Bangladesh, which could contribute to uncovering insufficiency and weakness and highlight the areas that need immediate development; but also this future study could contribute to comparative studies of life support technologies globally to assess how biomedical technologies from the Global North operate in and affect the Global South. This comparative study can be a first-hand source of knowledge for scholars from STS, medical anthropologists and sociologists, and policymakers. As Latour (1998) reminds us, '[..]to follow the transformation of society by science, we must look not in the home country but in the colonies.' Therefore, looking at the biomedicalisation of death in different parts of Bangladesh can also contribute to the understanding of the decolonisation of knowledge of biomedicalisation and life support technologies.

I find in this research that in many places in the context of life support treatment in ICUs, people as patients and as provider/health system workers respond to and negotiate biomedicalisation processes and create a new kind of 'practice' of the scientific innovations (life support technologies) and organisational forms to meet their own needs. This also seems to suggest that the way biomedicalisation occurs in the global West will not necessarily occur in the same way in Bangladesh. The forces of biomedicalisation are advanced, contested, mediated, and ignored in specific contexts and situations, for example, due to limited resources and local cultures of practice; hence 'users' of technologies make their negotiations within institutions to act according to the situation.

This research did not aim to decide on what is a good or a bad death or to make judgments about the morality and ethics of life support technologies. Instead, It is aimed to provide the realities in which the whole system of life support technologies in Bangladesh is situated.

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Appendix

News: 1

Three new-borns died within a few hours in a private hospital on October 2, 2015. Another newspaper mentioned another three-new-born died in the same hospital in the previous week. After the death of three new-borns, parents of the deceased and local people kept confined the only paediatric specialist till the next day at 7.30 am. The local police first came to the spot after being informed by the incident, found none of the physicians but only nurses. The rest of the patients were preparing to leave the hospital. Later, Directorate General Of Health Service officials had come and sealed the hospital. The hospital's signboard says (according to newspaper reporting), almost all kinds of intensive care treatments (general, neonatal, paediatric, coronary, dialysis) are done in this hospital. The news also reveals that the patients were taken to this hospital either by a broker or by the physician of Dhaka Medical College Hospital. One new-born's parents said that they had been brought to this hospital by the ambulance Driver, who recommends the hospital for their baby.

After closing for one and a half month, the hospital authority brought the writ petition from the High Court to start the hospital again.

News: 2 “Dead baby kept on life support.”

A 16 months child was admitted to a private hospital from an outskirts of the Dhaka city with respiratory distress. She has been treated in the intensive care unit and kept apart until her death on February 9, 2016. Even the hospital authority did not inform the parents of her demise yet kept her on life support. While the child’s mother had suspected something going ‘wrong,’ she informed the mobile court about the secretive role being played by the hospital staff. The mobile court forcefully entered the ICU and found the baby already dead. Later the hospital authority informed the court they did not realize when the baby died.

Screenshots of the news

Calls for government to regulate private hospitals in Bangladesh

bdnews24.com/bangladesh/2016/02/11/calls-for-government-to-regulate-private-hospitals-in-bangladesh

Senior Correspondent, bdnews24.com

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An appalling incident at the Japan-Bangladesh Friendship Hospital in Dhaka has underscored the need for a mechanism to regulate the private health sector.

A mobile court on Wednesday found the private hospital in Dhanmondi treating a child even a day after its **death** to present an inflated bill to its parents.

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3 babies dead in shady Dhaka hospital | The Daily Star

The Daily Star

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05:34 PM, October 03, 2015 / LAST MODIFIED: 06:57 PM, October 03, 2015

3 babies dead in shady Dhaka hospital



The four-storied Aslan Cardiac General Hospital, located in Block-B, in Dhaka's Lalmatia where three newborns died allegedly from negligence of the doctors. Photo: Shaheen Mofiah

Star Online Report

- 3 newborns dead
- Hospital found empty, illegal
- Newborn unit runs with only one 'doctor'
- Probe body to be formed