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Ethical issues in labour care in Sri Lanka

Vithana Pelpita Koralalage Krishani Jayasinghe

A dissertation submitted to the University of Bristol in accordance with the requirements for the award of the degree of Master of Science by Research in Population Health Sciences in the Faculty of Health Sciences.

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Abstract

The overall aim of this project was to identify ethical issues in health care provision during childbirth in Sri Lankan context.

The project was originally planned as a descriptive empirical bioethics project. I expected to interview in-depth postpartum women to capture their views, perceptions, and experiences of childbirth. The aim was to produce contextualized ethical analysis, which is sensitive to lived experiences but still critically normative. However, due to Covid-19 restrictions, data collection became impossible, and I changed the methodology of the project. I performed a theoretical analysis instead, based on the three vignettes developed to facilitate interviews with women.

In this dissertation, chapter 1 describes the Sri Lankan healthcare context, in which the ethical issues were identified. I provide a brief account of the empirical project in chapter 2, to give a flavor of work that I would have carried out, and to lay a foundation for the later chapters. In chapter 3, I provide a descriptive account of ethical principles, which will be utilized in theoretical analysis. In chapter 4-6, I engage with ethical issues which can be identified in vignettes. In chapter 7 I discuss common themes emerging from the analysis and the way forward.

Addressing ethical aspects of care provision is the way forward for Sri Lanka to improving quality of obstetric care. The normative analysis identified the nature of Sri Lankan medical context (- paternalistic), patient doctor relationship (-trust based), patients (- extra vulnerable, less autonomous) and underlying ethical issues of care provision (- lack of respect for autonomy of patients, neglect of best interest of patients). It is also important to understand how Sri Lankan women perceive and experience ethical issues in labour care, before taking steps to address them.

Dedication and Acknowledgements

I dedicate this thesis to my mentor, Prof Athula Sumathipala, who was there for and with me guiding and supporting during the hardest times in my academic life.

I owe thanks to many people who were there for me guiding, supporting, and encouraging throughout this endeavour.

First, I would like to thank my primary supervisor, Dr Jonathan Ives, without whom, this thesis would have not been possible. He was always ready to go the extra mile to support. He was a true inspiration, a source of encouragement and the greatest support for me throughout the MSc journey.

I would like to thank my supervisor, Dr. Zuzana Deans for her guidance on thesis writing, and Prof Athula Sumathipala, for his valuable insights.

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My special thanks go to Dr. Buddhika Fernando, who supported me enormously throughout this journey. She is a mother and a sister to me. She is one of my role models, whose footsteps I followed ever since I met her.

I would like to thank the staff at the Institute for Research & Development, Sri Lanka for their kind support in numerous ways. Thank you Dr. Nihal Abeysinghe for trust placed in me, Dr. Kaushalya Jayaweera, Dr. Kalpani Abhayasinghe, Mr. Lasith Dissanayake, for being sources of support.

I owe a big thank to the Welcome Trust. Without their support studying at the University of Bristol may have become a dream never achieved.

At last, but not least, I would like to extend my sincere thanks to my mother, Mrs. Rathanseeli Vithana and my husband, Mr. Buddhika Atthanayake, for their support and encouragement throughout this journey.

Covid-19 Statement

Due to Covid-19 restrictions, data collection of the planned research project was disrupted, and I had to change the methodology of the research project as a result.

The project was originally planned as a descriptive empirical bioethics study. I expected to interview in depth 13-15 postpartum women who had recent childbirth to capture their views, perceptions, and experiences of childbirth to identify ethical issues in labour care in Sri Lanka. The idea was to produce contextualized empirical ethical analysis, which is sensitive to the lived experiences of stakeholders.

Gathering qualitative data was an integral part of the planned study, and I had secured ethical approval to begin. However, due to full lockdown in Sri Lanka, data collection became impossible and, as advised by the supervisors, I decided to perform a purely theoretical analysis instead.

I applied for, and was accepted into, this programme to conduct a qualitative study to uncover and describe ethical issues arising in Sri Lankan maternity care, and not to conduct a purely theoretical ethical analysis. In fact, I would not have applied to do the project I have done, and my academic background is such that I would not have been accepted to carry out the project I ended up having to carry out. As such, this has been a particularly challenging project, as I had to develop deeper skills in ethical analysis, and knowledge of ethical theory, from scratch, which I should have been coming into the programme with to carry out the project I ended up having to. This was made particularly challenging because my English language skills had developed specifically the vocabulary needed for empirical research, but not the in-depth theoretical analysis that I now had to carry out. So, as well as learning new concepts and theories from scratch, I also had to develop my English language skills to cope with this.

I have included, in my thesis details of the planned empirical project, in order demonstrate my competencies in that area, and I have based my ethical analysis around the vignettes that I developed for my empirical work. As such, I have attempted to meet something close to the original aim of my study by identifying ethical issues arising in Sri Lankan maternity care, drawing on some existing (though, necessarily, less directly relevant) empirical literature to show the vignettes are realistic, and then examining the nature of the ethical problems they present.

Author's Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's *Regulations and Code of Practice for Research Degree Programmes* and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

DATE: 22-07-2021

Table of Contents

List of Abbreviations	xiii
CHAPTER 1: INTRODUCTION	1
1.1 Childbirth	1
1.2 Maternity care in Sri Lanka	2
1.2.1 The Sri Lankan context	2
1.2.2 The Sri Lankan Maternity care model	5
1.2.3 Quality of maternity care in Sri Lanka	9
1.3 Childbirth, Quality care and Ethics	11
1.3.1 Impacts of a (traumatized) childbirth	11
1.3.2 Quality care & Ethics in childbirth	12
1.4 Aims & Objectives of the research	17
1.4.1 Research Questions	17
1.4.2 Aims	17
1.4.3 Objectives	17
CHAPTER 2: EMPIRICAL RESEARCH PROJECT	18
2.1 The Empirical Bioethics approach	18
2.2 The Empirical Research Project	24
2.2.1 Research Design	24
2.2.2 Study Setting and the Study Population	24
2.3 Sampling	24
2.4 Recruitment of participants	25
2.5 Data Collection	26
2.6 Data Analysis	28
2.7 Data management and storage	29
2.8 Ethical clearance for the study	30
2.9 The way forward for the project in the Covid-19 restrictions	30
CHAPTER 3: ETHICAL PRINCIPLES	32
3.1 Introduction	32

3.2	Non maleficence	36
3.3	Beneficence	39
3.4	(Respect for) Autonomy	41
3.5	Paternalism	55
3.6	Vulnerability	60
3.7	Trust	66
CHAPTER 4: PATIENT AUTONOMY, TRUST AND BEST INTEREST OF THE PATIENT; THE CASE OF CHATHURI		70
4.1	Introduction	70
4.2	Patient autonomy in decision making	72
4.3	Best interest of the patient	75
4.4	Trustworthiness of a doctor	81
CHAPTER 5: EPISIOTOMY, PAIN MANAGEMENT AND PATIENT AUTONOMY; THE CASE OF WASANA		83
5.1	Introduction	83
5.2	Episiotomy and its practice in Sri Lanka	84
5.3	Was (routine) episiotomy needed for Wasana?	87
5.4	Doctor's motivation behind performance of an episiotomy	88
5.5	Clinical interventions without informed consent	89
5.6	Pain management during labour	90
5.7	Trustworthiness of a doctor	91
CHAPTER 6: PATIENT'S DIGNITY AND OBSTETRIC VIOLENCE; THE CASE OF UDANI		93
6.1	Introduction	93
6.2	Obstetric violence	94
6.3	Vulnerability and obstetric violence	97
CHAPTER 7: CONCLUSIONS		101
7.1	Revisit findings- Ethical issues in childbirth care provision in Sri Lanka	101
7.2	Findings of the normative analysis	102

7.3	Recommendations	104
7.4	Summary and further work	106
BIBLIOGRAPHY		107
APENDICES		122
Appendix 01: Information sheet for Potential Participants		122
Appendix 02: Topic Guide with Vignettes		125
Appendix 03: Ethical clearance from University of Bristol		127
Appendix 03: Ethical clearance from Sri Lanka Medical Association		128

List of Abbreviations

ATH	Anuradhapura Teaching Hospital
CSHW	Castle Street Hospital for Women
C-section	Cesarean section
FHB	Family Health Bureau
HCP	Health care professional
HU	Health Unit
MOH	Medical Officer of Health
MoH	Ministry of Health
MOMCH	Medical Officer of Maternal & Child Health
MMR	Maternal Mortality Ratio
PHM	Public Health Midwife
PDHS	Provincial Director of Health Services
RDHS	Regional Director of Health Services
SLCOG	Sri Lanka College of Obstetricians and Gynecologists
UOB	University of Bristol
UK	United Kingdom
WHO	World Health Organization

Chapter 1: Introduction

Firstly, I aim to critically analyze how childbirth is understood in a Sri Lankan context, in reference to two widely accepted health care models- the medical model and the social model of health. Secondly, I describe the Sri Lankan maternity and childbirth health care system. Thirdly, I explore global literature on ethical issues of childbirth. I will also present the aims and objectives of the research project at the end of this chapter.

1.1 Childbirth

Childbirth is the act of giving birth to a child.

This definition is, however, deceptively simplistic. One way of thinking about childbirth is as an act that person does. The other way of thinking about it is as a ‘process’ that happens to somebody. This linguistic point reflects two theoretical models in which childbirth is described differently. These two models - the medical model & the social model - theorize how childbirth is understood and operationalized in different social contexts (Alistair, 1993; Van Teijlingen 2017).

The Medical Model describes childbirth as a mechanical process that needs to be managed and monitored. Childbirth is identified as ‘pathological’, and the pregnant women is considered a ‘patient’ who needs to be kept under the medical professional’s observation (Alistair, 1993; Van Teijlingen 2017). Currently, the medical model seems to be dominant and widely practiced throughout the world due to its rational basis and easiness in finding solutions to emergencies occurring during childbirth.

The social model of health is multidimensional, complex, and non-individualized compared to the medical model. It focuses on wider socio economic, cultural, and environmental aspects of health, and understands health and illness as an interaction between multiple factors in a larger context. According to the social model, childbirth is understood as a natural event in a woman's life, and reproduction is understood as a cultural act, rather than a medical process (Oakley, 1980). The social model is largely supported by a feminist approach, which challenges and criticizes the medical model. This feminist perspective argues that medical interventions, hospitalization are not normally necessary in childbirth. It argues against routine medicalization of childbirth driven by the medical model (Van Teijlingen, 2017).

I argue that maternity care models adopted in many social contexts (including Sri Lanka) in the modern world can be combinations of both the medical and social models with different compositions, although one model could be dominant in a particular social setting. Given that, before exploring the Sri Lankan maternity care model I will provide brief account of the Sri Lankan social context, which arguably contributes to shaping the maternity care model it adopted.

1.2. Maternity care in Sri Lanka

1.2.1 The Sri Lankan context

Health care is provided free to all its citizens in Sri Lanka, even though health is not considered a fundamental right by its constitution. Sri Lanka is a signatory to the Universal Declaration of Human Rights and has accepted that every Sri Lankan has the right to a standard of living adequate

for health and wellbeing of himself and of his family, including medical care and necessary social services.

Sri Lanka is an egalitarian society. The social value system in Sri Lanka is committed to valuing the welfare of others. Accordingly, Sri Lankan society expects the government to provide a welfare state, and welfare programs are given high political priority. There is strong political commitment to maternal (& child) health care programs in Sri Lanka, arguably influenced by the welfare ideology of Sri Lankan society (Pathmanathan & Liljestrand, 2003; Seneviratne & Rajapaksa, 2000). The current Sri Lankan health care system was developed in the post-colonial period, based on the Western medical model, integrating egalitarian principles and the welfare ideology of the Sri Lankan society (Banik 2017; Pathmanathan & Liljestrand, 2003, World Health Organization (WHO), 2015). It takes a holistic approach which incorporates both medical advancement and societal development together (Banik 2017; Pathmanathan & Liljestrand, 2003; Seneviratne & Rajapaksa, 2000; WHO, 2015). Free health care is distributed on egalitarian principle, even though ideal egalitarian distribution is yet to be achieved. Wide variation in regional maternal mortality rates indicate such disparities in health care distribution. Available free health care for the public is not up to their expectation. As a result, increasing utilization of private sector for health care needs (including maternity care), can be observed, especially among the urban population (Jayasinghe et al, 1998).

Although still broadly egalitarian, Sri Lankan society is transitioning from collectivism to individualism, arguably as a result of industrialization, urban development, open economy reforms and largely westernized education system (Freeman, 1997). The Sri Lankan ruling elite is also

highly westernized and tend to approach the problems of the country from a Western perspective (Oberst, 1985). This shift in one of the moral foundations of Sri Lankan society has an influence on how the health care system is operationalised. It is evident that the Sri Lankan health care system is hugely westernized. Western medicine was introduced to Sri Lanka during the colonial period and, although it did not replace the existing indigenous health care system, it became prominent and spread widely. As a result, maternal & child health care is largely provided through well-established health care institutions in which only Western medicine is practiced.

Sri Lanka has experienced a demographic transition in terms of health during past few decades, occurring simultaneously with the societal shift towards individualism and establishment of Western care model. One good example of such changes is the reduction in maternal mortality and fertility rates (Caldwell, 1996; Haththotuwa et al, 2012; Seneviratne et al, 2000). In Sri Lanka, free education is available for everyone, and education is highly valued in Sri Lankan society. The age of marriage of women has raised significantly over the years – mostly due to female education - and fertility rates are reduced as a result of this (as people start families later). This has an impact on reproductive and maternity health care needs in Sri Lanka such as demand for caesarian sections (c-sections) at childbirth. These changes are generally seen as positive, and female education and high literacy rate are claimed to have made a significant contribution to improvements in maternal health indicators (Caldwell, 1996; Haththotuwa et al, 2012; Seneviratne et al, 2000).

The Sri Lankan health care system is considered an exemplar for other non-industrialized countries when it comes to maternal and child health care. The Sri Lankan model of maternity care is considered one of the best in South Asia, referencing its significant reduction in maternal mortality

(Banik, 2017; Senanayake, 2011). The Maternal Mortality Ratio (MMR) was reduced from 2000 deaths per 100 000 live births in 1930 to 33 deaths per 100 000 in 2015 in Sri Lanka, which is considered a remarkable achievement, with relatively low expenditure (Banik, 2017; Haththotuwa et al 2012; Pathmanathan & Liljestrand, 2003). However, it is important to note that measurement of this single medical indicator alone is not sufficient to judge the overall quality of maternity care provision in a country. Now, let us move to discuss the maternity care model adopted in Sri Lanka.

1.2.2 The Sri Lankan Maternity care model

The Sri Lankan maternity care model can be best understood as a combination of the medical & the social model, even though the medical model is dominant. Childbirth is, for the most part, managed by Health Care Professionals (HCPs) at health care institutions in which only Western medical care is available. Women at childbirth are treated as patients, and HCPs are obliged to provide care for birthing women. In addition, various efforts were taken in Sri Lanka to address larger socio-economic determinants of maternal health such as nutrition, aiming to improve childbirth outcomes. Such efforts can be explained in reference to the social model of health.

There is a comprehensive network of health care facilities to deliver maternity care throughout the country. There are 77 hospitals with comprehensive emergency obstetric care services, 517 hospitals with basic emergency obstetric care services and 474 primary health care units (small hospitals and central dispensaries) for maternity care throughout the country. In these institutions maternity care is provided free of charge. Nearly 100% of births take place in a healthcare institution and home deliveries are not encouraged. This commitment to medical management of childbirth is considered a significant contributing factor to achievements in childbirth outcomes in

Sri Lanka (Fernando et al, 2003; WHO, 2015). Women tend to admit to hospitals for childbirth a few days before their due date (WHO, 2015), and 99% of women receive post-natal care at hospitals in the first two days after delivery (Department of Census and Statistics, 2017).

The Sri Lankan maternity care model is based on a life cycle approach, referred to as a “Continuum of care” (Hemachandra, 2011). It is a full package of services that targets all stages of life cycle of women. It includes pre-pregnancy care, antenatal, intrapartum, and postpartum care. Health care infrastructure is well organized to provide this continuum of care throughout the country (Hemachandra, 2011; Senanayake et al, 2011). The administration of maternal healthcare is decentralized and operated at provincial level, as depicted in figure 1 below.

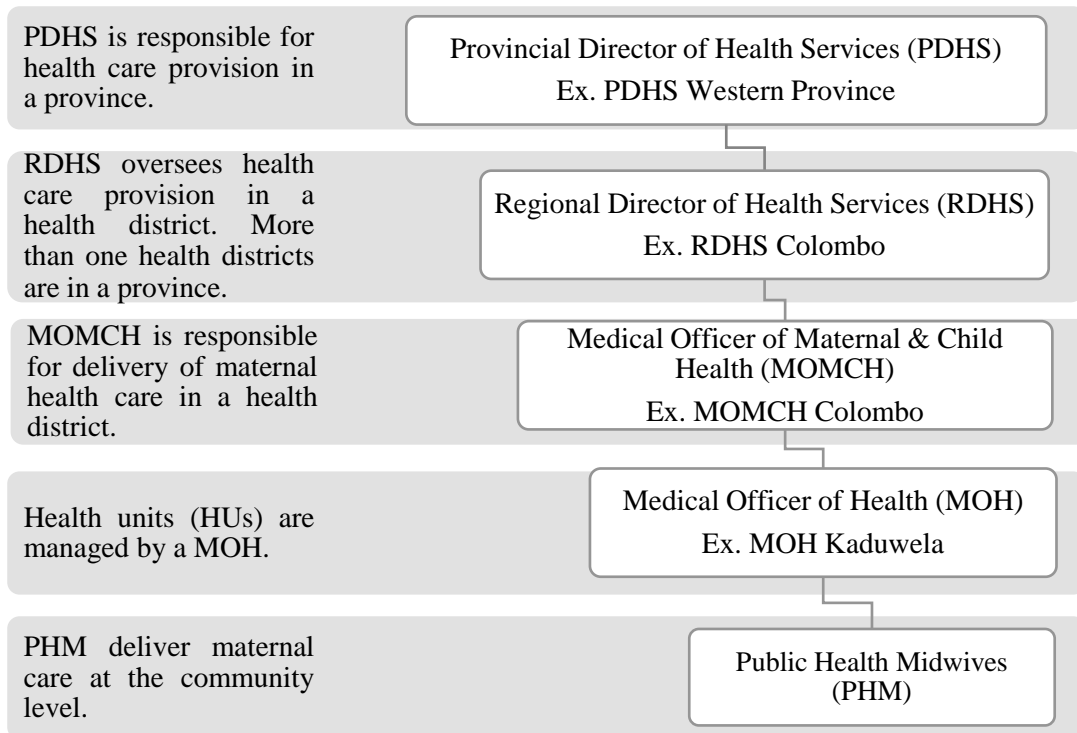


Figure 1. Maternal Health care administration system

Each health district is divided into Health Units (HUs) for delivery of preventive health care services. HUs are managed by a Medical Officer of Health (MOH). The MoH is supported by Public Health Midwives (PHMs) in delivery of maternal care. The PHM area is the smallest health administrative area in the health care system, and a PHM is responsible for a population of 3000-5000.

PHMs provide continuum of care at a community level. All pregnant women in the area are registered at the PHM. Provision of regular antenatal care (coverage is 100% throughout the country (Senanayake et al, 2011)), educating women on childbirth and maternal care, providing nutritional and food supplements, planning for a safe childbirth, linking women to advanced health care services and provision of postnatal care at domiciliary are responsibilities of a PHM. PHMs regularly visit women to deliver maternal health care. This practice is largely adopted from the social model of health.

Maternal care is not only provided by PHMs but also women have access to antenatal, postnatal, infant and child clinics conducted by MOH. Women who are at 'high risk' are identified by the MOH, and these women will be then referred to a high facility hospital (hospital with specialized obstetric care) (Fernando, 2003; Hemachandra, 2011; Pathmanathan & Liljestrang, 2003; Senanayake, 2011; WHO 2015). The establishment of maternal health services at community level contributed a lot to improving maternal health indicators (Fernando, 2003; Haththotuwa et al, 2012), and that was achieved in large part by addressing wider socio-economic determinants emphasized by the social care model.

In addition to the structured services described above, establishing Sri Lanka College of Obstetricians and Gynecologists (SLCOG) and Family Health Bureau (FHB), to work closely with Ministry of Health (MoH), were also important steps in improving maternity care in Sri Lanka. The Sri Lankan Maternal death review was undertaken by SLCOG and FHB to find out root causes for maternal deaths, aiming to prevent future occurrence of similar incidents. Maternal deaths are reviewed according to the 3 delays model: 1) delay in decision to seek care, 2) delay in reaching care, 3) delay in receiving adequate and necessary care at health care institutions (Thaddeus & Maine 1994; Haththotuwa et al 2012). Maternal death review ensures that lessons are learned to prevent such delays in future.

In addition, several other collaborative efforts have been taken to improve maternal health outcomes. For example, access to maternal health services has been improved by establishing health care centres in remote areas, training doctors, nurses and PHMs to facilitate childbirth at community level in emergency situations, increasing ambulance services, and encouraging women to admit to the hospital before due date (Department of Census and Statistics, 2017; Haththotuwa et al, 2012; Thaddeus & Maine, 1994; WHO, 2014). The SLCOG's 'safe motherhood' training program was an initiative that targets training HCPs (such as MOHs) in rural areas (Seneviratne & Rajapaksa 2000). In addition, the SLCOG developed guidelines to set minimum standards of care for birthing women in Sri Lanka (Haththotuwa et al, 2012, SLCOG, 2010). Such capacity building programs and initiatives targeting infrastructure development in Sri Lanka are financially supported by international non-government organizations (Haththotuwa et al, 2012). I have described the maternity care model in Sri Lanka and its achievements so far. Now, let us discuss to what extent quality care has been achieved.

1.2. 3 Quality of maternity care in Sri Lanka

The maternal death review report states that “in spite of impressive decline in maternal mortality (in Sri Lanka), majority of deaths remained preventable” (WHO, 2014). Among all maternal deaths, 78% occur in hospitals and 59% of them are preventable (Gunawardena, 2018). Deficiencies in quality care were identified as one of the major issues for this occurrence (WHO, 2014). There are number of ways in which Sri Lankan maternity services are failing to provide (sufficient) quality care. It is plausible to argue that, although Sri Lanka is considered a success story in the South Asian region, it still has lot more to achieve in terms of quality of maternity care provision. Sri Lanka targets single digit MMR by 2030 and improving quality of childbirth care is the key to achieve the success (WHO, 2015).

It is questionable whether good health outcomes are achieved at the cost of provision of quality care. Although limited, available literature provides reasons to think that Sri Lankan women do not receive quality care during childbirth (Gunawardena, 2018; Perera et al, 2018; Perera et al, 2013) Arguably, this could be a result of prioritization of few medical indicators such as MMR to assess achievements in maternity care provision. Quality of care provided during childbirth is not used as an indicator in Sri Lanka to measure success in health care delivery. Let us look at some evidence to suggest quality care provision during childbirth has been neglected in Sri Lanka.

One survey revealed that adherence to WHO recommendations for safe deliveries and SLCOG guidelines is poor in managing childbirths at Sri Lankan institutions (Gunawardena, 2018). Gunawardena revealed that availability of pain relief medications is lacking in hospitals, as a result of health care providers’ insensitivity to birthing women’s pain. Pain relief during labour is not

considered a priority by HCPs in Sri Lanka (Gunawardena, 2018). Another study, designed to estimate episiotomy rates in two tertiary care hospitals with higher rates of attendance for deliveries, reported that episiotomy rates are extremely high compared to the WHO estimated rate of 10% for normal deliveries. For example, the Castle Street Hospital in Colombo is reported to have a 96.5% episiotomy rate. Despite the WHO recommendation to abandon routine episiotomy, routine episiotomy is practiced in Sri Lanka, ignoring evidence-based guidelines. Further, the norm is to perform episiotomy without anesthesia and not to give an effective analgesia for pain relief (Perera et al, 2013). This is a clear indication that HCP are only targeting improvements to a few specific maternal health indicators (e.g., lowering the MMR) rather than providing overall *quality care*.

Poor quality of care received by birthing women is further evidenced by the findings of a study conducted on obstetric violence¹ in Colombo (Perera et al, 2018). The study revealed that some women were physically assaulted, emotionally and verbally abused, and sexually harassed inside the labour room. Women in more disadvantaged situations (for example, low socioeconomic status, cannot speak in Sinhala², teenage) were mistreated more frequently. Women who experienced obstetric violence reported that they felt loss of dignity, humiliated, and were scared. Women expressed that they have trust issues around HCPs. Based on this kind of evidence, although great strides have been made in lowering MMR, it is plausible to claim that provision of *quality care* during childbirth is neglected in the Sri Lankan system.

¹ Obstetric violence is defined as mistreatment that occurs in care provision during childbirth, immediate postpartum and in pregnancy. Bullying, coercion, and gender-based violence during childbirth comes under obstetric violence (Perera et al, 2018).

² Sinhala is the language majority of Sri Lankan people speaks.

Sri Lanka clearly has much to improve on in maternity care provision in terms of quality. Arguably, it is essential to address quality care aspects if further improvement in maternity care is expected. Now let us consider why quality care matters, specifically during childbirth. First, I will briefly outline impacts of negatively experienced childbirth to give an idea how absence of quality care may have an effect on lives of women and their family.

1.3 Childbirth, Quality care and Ethics

1.3.1 Impacts of a (traumatized) childbirth

Childbirth can be perceived by women either positively or negatively depending on her birthing experience. A considerable proportion of women (for example, 14.3% (Boorman et al, 2014), 34% (Soet et al, 2003) and 45.5% (Alcorn et al, 2010) throughout the world find their childbirth experience traumatic. Some women develop post-traumatic stress disorder as a consequence (Olde et al, 2006) and it has significant negative impacts on women's physical, mental, and social wellbeing (Ayers et al, 2006). For example, depression, poor self-esteem, relationship issues with the partner and the extended family or friends, sexual health issues (such as avoidance of sex, sexual dysfunction in later life), poor mother-baby bond, hesitation to have another child, were reported (Areskog et al, 1983; Ayers et al, 2006; Nicholls and Ayers, 2007). I have outlined the possible negative impacts of traumatized childbirth, now I shall move to discuss why women find a certain birthing experience negative.

Evidence suggests that the most significant factor for women in a negative birthing experience is the HCP's interactions with them (Fenwick et al, 2003; Nicholls and Ayers, 2007). Studies worldwide indicate that women can be traumatized due to HCP's actions or inactions (Beck, 2004;

Birthright, 2013; Fenwick et al, 2003; Rönnerhag et al, 2018). For example, lack of support of HCP during childbirth, acting against women's expectations, professionals' unfavorable language & unfriendly communication style, their unfavorable attitudes & care practices, unnecessary medical interventions during labour, unnecessary separation of the baby from the mother, professionals' not taking enough measures for pain relief, not getting women involved in decision making, unnecessary restriction of movement by professionals, etc. were identified as negative experiences by women (Fenwick et al, 2003; Nicholls, 2007). As a result, women felt negative emotions such as helplessness, fear, shock, feeling violated, confusion, feeling humiliated, feeling dehumanized (Nicholls, 2007). Arguably, then, a very significant factor contributing to a negative childbirth experience is poor quality care. I shall now move to discuss, in more detail, what quality care means, and how this is related to ethical care.

1.3.2 Quality care & ethics in childbirth

Quality of care received by a woman during childbirth can be a matter of life and death and has a large impact on women's health (Callister et al, 2011). Providing good quality care during and after childbirth is identified as the single most effective way to reduce maternal deaths. In such context, quality care means providing skilled care in a setting with adequate facilities for childbirth (Uford et al, 2008). However, quality care in childbirth is multidimensional, and is not limited to clinical quality and reduced mortality requires the competency of HCP and good facilities (Creel et al, 2002). Providing quality care is the key not only to reducing negative impacts of childbirth in terms of morbidity and mortality, but also to maximizing positive birth experiences. Women tend to believe that good quality care will ensure positive outcomes (including good psychological outcomes) for the women and the baby (Bohren et al, 2017).

The WHO defines quality care as “the extent to which health care services provided to individual and patient populations improve desired health outcomes. In order to achieve this, health care needs to be safe, effective, timely, efficient, equitable, and people centered” (Tuncalp et al, 2015; WHO, 2006). The WHO framework categorizes a birthing women’s experience of care into five key domains: 1) effective communication that is responsive to her needs and preferences, 2) care provided with respect and dignity for privacy, confidentiality, and informed choices, 3) emotional support to strengthen her own capabilities, 4) consistent availability of competent and motivated human resources, and 5) availability of physical resources for essential care and management of complications (Tuncalp et al 2015; WHO 2006). The provision and experience of care are both important, however, how women actually *experience* care is the key concern. Now, I will move to outline what postpartum women understand as quality care during childbirth, based on available literature.

In one study comprising 132 in depth interviews and 21 focus group discussions, which aimed to explore what quality care means to childbearing women in Nigeria and Uganda, women described quality care as when “you are treated the way you like”. Women mentioned the importance of good communication in quality care provision. HCPs building a good rapport with the birthing women using easily understood, positive language, and informing women what is happening around, and the rationale behind, professionals’ decisions regarding delivery were mentioned. Women also reported they desire to be treated with respect and dignity during a stay at hospital. Any form of mistreatment (for example, physical harassment) was – unsurprisingly - described as highly undesirable. Women preferred to be treated empathetically. Women expect HCPs to be

non-judgmental and non-discriminatory. It is important here to note that the characteristics of quality care reported by women are very closely linked to ethical principles, such as respect for patient autonomy, beneficence, non-maleficence, the principle of informed consent, patient rights, etc. In these terms, quality care tracks 'ethical care', and as such the HCPs moral character will likely play a significant role in quality care provision. For women, quality of care extends further than simply medical care and clinical outcomes, and women expect HCPs to be emotionally present and provide necessary guidance and support during childbirth (Bohren et al, 2017), and as such 'quality care' can be constructed in terms of 'ethical care' which encompasses good clinical care but also extend far beyond that. As such, provision of ethical care at childbirth should not be sacrificed or ignored in order to achieve good medical outcomes. It follows that understanding women's perspectives and experiences of childbirth and understanding the ethical underpinning of quality care from their perspective is an important first step in achieving meaningful improvement in care provision in childbirth (Rönnerhag et al, 2018).

The discussion above confirm that those factors highlighted as characteristic of quality care also reflect ethical aspects of childbirth care. I will now move onto look at the global literature specifically on ethical issues in maternity care.

In the global literature, multiple ethical issues have been identified around maternity care. Primary among these are concerns related to autonomy and dignity of the laboring women, decision making & informed consent during labor, privacy, experiences of obstetric violence, issues related to appropriate care and management during delivery and fair distribution of facilities and care (Aderemi, 2016; Birthrights, 2013; Chalmers, 2017; Grant, 2017; Hollowell et al, 2016; Laslie,

1982; Torres & De Vries, 2009). As I do not have enough space to discuss the outlined issues in detail, I will elaborate a little bit about respect for autonomy in childbirth care provision, to demonstrate how such ethical aspects come into play in quality care provision.

Not respecting patient autonomy has been identified as being central to many ethical issues in childbirth (Brook & Sullivan, 2002; Birthrights, 2013). Woman's autonomy ought to be central in maternity care. Autonomous women should be supported to make informed decisions about her labour, and the HCP ought to play the role of an advisor and an information provider (Brook & Sullivan, 2002; Beauchamp & Childress, 2009). However, research shows that HCPs are not aware enough about respecting autonomy of birthing women. In a study carried out in Australia with the participation of 336 PHMs and doctors to explore HCPs' attitudes and beliefs regarding women's right to make decisions during pregnancy and childbirth, it was revealed that professionals have poor understanding about women's right to autonomy. The data showed HCPs believed that it is essential to override women's choices for the safety of the fetus, even when they believe that the final decision should be with the women (Kruske et al, 2013). A review conducted drawing on global literature to identify ethical issues and challenges in maternal and child health nursing revealed that nurses throughout the world face problems of decision making in practice and that they needed to be familiarized with professional ethics (Aderemi, 2016).

The importance of identifying and addressing ethical issues experienced by women in labour has received considerable attention recently. WHO has recognised 'respectful maternity care' as central to quality care provision for laboring women (WHO, 2018a; WHO, 2018b; Patabendige et al, 2021). According to WHO, respectful maternity care means "care organized for and provided

to all women in a manner that maintains their dignity, privacy, and confidentiality, while ensuring freedom from harm and mistreatment, and enables informed choice and continuous support during labor and childbirth” (WHO, 2018a; WHO, 2018b; Patabendige et al, 2021). Although provision of respectful maternity care received significant attention in developed countries over the past few decades, this is not true of developing countries, including Sri Lanka (Aderemi, 2016; Birthrights, 2013; Callister, 2011; Declercq et al, 2014; Hollowell et al, 2016; Perera et al, 2018; Perera et al, 2013). One notable exception is a study aiming to identify ways to overcome challenges in obstetric care in low income settings, which suggested a lack of staff and equipment, and wider health system and governance issues, contribute the challenges in providing ethical care during labour (Hofmeyr et al, 2009). There are significant differences in birth practices across the globe that track differences in cultural and social norms, and which may mark differences in what is acceptable and unacceptable (Chalmers, 2017). It cannot, however, be assumed that ethical issues identified in one part of the world will be uniform the world over, and it is important when starting to theorize about ethical care during (and post) labour in Low- & Middle-Income Country settings that we have good understanding of the context of care in that country, including the views and experience of the women affected. As such, I designed a descriptive ethics study, aiming to explore empirically what ethical issues arise in Sri Lankan maternity care, specifically the period of labour and post-labour care. For reason outline above, I was not able to undertake this empirical study, but as it was nonetheless a central component of this project, I outline below the study design.

1.5 Aims & Objectives of the research

1.4.1 Research Questions

1. What do Sri Lankan women consider to be ethically important in their care during labour and post labour care?
 - a. What experiences of labour do Sri Lankan women describe as being positive or negative?
 - b. What experiences of labour and post labour care, described by Sri Lankan women, have an ethical dimension, and why?
 - c. How do women understand, negotiate, and reconcile areas of ethical concern during labour care?

1.4.2 Aims

1. Describe ethical issues in labour and post labour care in Sri Lanka as perceived by women with recent childbirth experience.
2. Identify and explore the beliefs that support women's perceptions about what is ethically acceptable and not acceptable in labour and post labour care in the Sri Lankan context.

1.4.3 Objectives

1. To gather data that capture the views, perceptions, and experiences of women regarding ethical concerns related to labour and post-labour care in the Sri Lankan context.
2. To use ethical theory as a lens through which to analyse data collected in meeting objective 1.
3. To identify, describe and explain ethical issues related to care provision during labour and post-labour care in Sri Lanka, as understood by women in the sample.

Chapter 2: Empirical research project

At the end of chapter 1, I outlined the research questions, aims and objectives of the planned research project. The overall aim was to explore ethical issues in health care provision during childbirth. Given that the answers sought required a combination of ethical analysis informed by empirical fact, I designed the project employing a descriptive empirical bioethics approach. The idea was to produce contextualized ethical analysis that described ethical issues in Sri Lankan maternity care, which is both sensitive to lived experiences but still critically normative (Ives; 2008, 2014).

Chapter 2 is dedicated to describing the methodology of the empirical project. In this chapter, firstly, I give an account of the empirical bioethics approach and justify its use in this study. Secondly, I present methods for the empirical research project, and the challenges posed to that project by the Covid-19 pandemic.

2.1 The Empirical Bioethics approach

Research endeavors in which both philosophical and empirical analysis are integrated in order to draw normative conclusions are described as ‘Empirical bioethics’ (Davies et al, 2015; Ives et al, 2018). This is commonly understood as a sort of interdisciplinary activity in bioethics with an empirical element, and to some extent the researcher is expected to work out a marriage between the empirical and theoretical (Ives, 2008; Ives et al, 2018).

The rise of empirical bioethics as a field is widely described in literature as a response to the social science critique of traditional philosophical bioethics as being too abstract and insensitive to social

realities and contexts (Davies et al, 2015; Hedgecoe, 2004; Ives, 2008). This demanded that bioethicists become more sensitive to the lived experiences of people and the realities of the social contexts in which ethical problems arise. This marks the ‘empirical turn’ of bioethics (Borry et al, 2005; Davies et al, 2015). However, it is important to note that this does not mean that purely philosophical approaches are of no value in bioethics, but, rather, to acknowledge that it lacks something crucial when the problems under scrutiny are experienced in a particular context, and the aims of the research are to offer practical solutions to ethical issues of interest (Ives & Draper, 2009).

Early criticism of empirical bioethics can be used to better understand what empirical bioethics is, which I shall now outline.

Some argued that ‘empirical bioethics’ is merely a new term given to the field of bioethics giving (unnecessary) emphasis to its interdisciplinary activities (including empirical), pointing out that bioethics has always been (and itself emerged as an interdisciplinary field (Herrera, 2008). Philosophical bioethicists may reasonably claim that good Applied ethics must pay, and has always had paid, attention to the empirical world and used empirical data to reach normative conclusions. In support of this claim, Haimes argued that philosophical bioethics has tended to use empirical research the way a queen uses handmaiden - (only) when something is needed (Haimes 2002). However, proponents of empirical bioethics have pointed out that the nature of the ‘empirical – philosophical’ relationship can and should be upgraded. As Ives argued, empirical bioethics goes beyond bioethicists merely being interested in and answering normative questions to act as premises in an argument, and empirical bioethics, rather, should be understood as an endeavor to

describe how different disciplinary approaches can be integrated to effectively answer normative questions in bioethics (Ives, 2014; Ives et al, 2017). The need for empirical and interdisciplinary approaches to bioethics is highly emphasized in recent literature, and according to Ives, this is based on the premise that “an empirically informed ethical analysis is more grounded, contextually sensitive and therefore more relevant to clinical practice than an abstract philosophical analysis” (Ives, 2014).

Those who engage in empirical bioethics should seek to utilize empirical methods to gather data that are required to inform a particular bioethical analysis. However, how data are used and how data are collected (and integrated to inform normative question) may vary. I will briefly describe how these two aspects add variety to the field of empirical bioethics now.

In empirical bioethics, data may be used in variety of ways. According to DeVries, empirical data can be used in four ways in empirical bioethics: – use of empirical data to describe attitudes toward an issue, use of empirical data to explore the likely or actual consequences of bioethical policies and decisions, use empirical data to explore the implicit normativity in scientific/clinical practice, and use empirical data to understand the institution of bioethics (DeVries, 2004). According to Ives (2018), data can also be used, “to identify ethical problems in a certain area of medical science and technology, to provide empirical data demonstrating that some of our ethical concepts require re-examination and to inform how ethics education is incorporated into practice”. As Ives (2008) mentioned, one simple ways data can be used is to identify ethical issues in medical context, and in this study, my intention is the same - to use empirical (qualitative) data to identify ethical issues

in childbirth care in Sri Lankan medical context and to frame them in the terms in which they are experienced, rather than theorised.

Researchers engaged in empirical bioethics acknowledge the heterogeneity in methods and methodologies used in empirical bioethics. Some believe that these differences add richness to the field, and being a field in infancy, empirical bioethics will actually benefit from experimentation and variety. However, they acknowledge that there is a challenge for researchers involved in empirical bioethics - how to connect normative bioethical analysis to the realities of lived moral experiences (Davies et al, 2015). Researchers in bioethics need to work out robust methodologies to successfully engineer a marriage between disciplines of two entities with divergent epistemological and metaethical perspectives (Ives, 2013). Regardless of how data are used and what methodologies are integrated, empirical bioethics studies should have a common goal of looking at the world as it is to inform how the world should be - if one accepts the premise that bioethics is a fundamentally normative enterprise, and it involves identifying and exploring an ethical problem to offer a normative solution and provide a coherent argument for why (Ives, 2008).

Given that, now I shall move to describe a widely accepted approach, which could be utilized if one wishes to take the empirical and the contextual seriously in normative theorizing, i.e., “having encounters with experience”. As Ives describes, in doing so, “philosophers [get] their hands dirty, [get] out of their platonic ivory tower, and [acknowledge] that ethics is about people, not just good arguments” (Ives, 2007). This is all about having encounters with experience to achieve a good contextual understanding. As Ives and Draper defined, having encounters with experience simply

means “positioning oneself so that one can understand, as far as possible, how an ethical problem affects people’s lives, how the problem is constructed and negotiated, and how different resolutions might affect stakeholders in different ways” (Ives and Draper, 2009). One of the advantages of this is that it sensitizes the philosopher to the needs and experiences of people most affected by ethical issue considered. For example, in the planned project, I expected to consult postpartum women, who are the people most affected by ethical issues I was interested in. Especially, in a context such as Sri Lanka where health care providers approach patients with paternalism (Ministry of Health, Nutrition, and Indigenous Medicine, 2017), it is essential to let these unheard voices to be heard. Otherwise, I will be far removed from the reality and the lived experiences of stakeholders of the research topic. As Ives points out, “the value of this kind of empirical work is, it brings philosophical ethical analysis to the ground, rooting it in real people and real problems” (Ives, 2007).

It is worth discussing another criticism of empirical bioethics to further understand what kind of work it actually is. Empirical bioethics is criticized as it describes the world as it is (as it does in descriptive ethics), where normative ethics expects to describe the world as it ought to be. However, Ives argues that this claim is based on incomplete understanding of what empirical bioethics might be able to do, and how might it do it. According to him, it is not descriptive ethics although it does include descriptions, and it is not purely normative ethics, although it does engage in normative theorizing. As he explained, it is some kind of a ‘chimerical hybrid’, combining both elements – normative and empirical (Ives, 2007).

Empirical bioethics is not simply documenting people's experiences and describing beliefs as it does in social sciences, which is exactly why I chose empirical bioethics approach in this study. In an empirical bioethics approach, data are gathered (in this study I planned interview women in depth to collect data on their views, perceptions, and experiences), but along the way they are challenged and evaluated (I was planned to interrogate and gently challenge their ethical opinions in order to understand them better). As Ives notes, in empirical bioethics, "the beliefs of one's research populations are not to be accepted at face value but are to be challenged and tested in order to examine not only what people think, but also why they think it, which is then itself subject to critical analysis" (Ives, 2007), which is exactly what I intended to do in my research.

Another strength in empirical bioethics approach is that it allows the researcher to mold the social scientific standard data collection methods for its own purpose (Ives, 2008). As Ives & Draper (2009) mentioned, this modifies the long-established social-scientific tradition of allowing only mild interventions in qualitative data gathering. In an empirical bioethics approach, researchers need to take more interventionist approach in interviewing participants (Ives & Draper, 2009).

I have presented the reasoning behind, and the strengths of, the planned research project so far.

Now, I shall move to outline methods of the planned research project.

2.2. The Empirical Research Project

2.2.1 Research Design

This was intended to be a descriptive ethics study which employs an empirical bioethics approach, and would comprise the first stage of a full empirical bioethics project. Qualitative in-depth interviews were planned to be conducted to meet the objectives described in chapter 1.

2.2.2 Study Setting and the Study Population

The study would have been carried out in Kaduwela Medical Officer of Health (MOH) area. Kaduwela MOH area is one of the 15 health units in Colombo district. Kaduwela is an urban area with multiethnic composition of residents. The vast majority is Sinhalese, while Tamils, Muslims, Burghers, and Malays live (Department of Census and Statistics Sri Lanka, 2012).

The target population would have been 3- 6 months postpartum women in the Colombo district.

2.3 Sampling

Purposive sampling would have been used, with the aim of achieving the maximum demographic diversity possible (e.g., a diverse mix of age, socio-economic status, education, and ethnicity) and differences in childbirth experience (including delivery with and without complications).

Data saturation would have been used, ideally, to determine the final sample size. The analysis of data would have begun in parallel with the data collection, and data saturation would have judged when no additional themes are emerging from data. However, my plan was to conduct maximum of 15 interviews, as it is the maximum allowed by the timeframe and budget of the project. This is an acceptable sample size for an in-depth qualitative study.

I aimed for fresh perspectives of women who had recent childbirth. However, due to practical reasons – women are being busy with the newly born, women might experience some kind of physical discomfort following the childbirth and Sri Lankan societal norms not to visit newborns until it reaches at least 3 months, I decided to include women 3-6 months postpartum. Inclusion & exclusion criteria are as follows.

Inclusion & Exclusion Criteria

Inclusion criteria for women (all criteria should be met):

- i. A postpartum woman (3-6 months) who delivered a baby in a state or private hospital in Colombo.
- ii. Decided to participate willingly.

Exclusion criteria women:

- i. Women more than 6 months postpartum will be excluded to avoid recall bias.
- ii. Unable to communicate in either Sinhalese or English.
- iii. Lack of capacity to consent.

2.4 Recruitment of participants

Contact details of potential participants would have been obtained from the PHMs at the MOH office, as they are the only official source to obtain information about postpartum women.

After getting contact details from the PHMs, the researcher would have then contacted women by phone and ask whether they are interested in participating in the study, after clearly explaining

about the research. An information sheet (see appendix- 01) would be mailed by post to participants who expressed their interest. After one week (enough time to take a decision) the researcher would have then again contacted the participants to ask for their decision. The researcher would have then sought basic information from willing participants in order to develop a sampling frame, describing basic characteristics such as age, education, ethnicity, differences in childbirth experience. The researcher would have then purposively selected participants for the study in order to achieve maximum demographic variation. Any contact details and personal information passed onto the researcher (KJ) for ineligible women would have been immediately destroyed.

Interviews would have been arranged for a time and a place convenient to the participant. The researcher would have asked for written informed consent before conducting interviews. The information sheet would have been explained again, and the participant would have been given opportunity to ask questions. The consent form would have been countersigned by myself and a copy would have been given to the participant. Participants would have been informed that they can withdraw from the study up to one week after the interview date.

2.5 Data Collection

In-depth interviews would have been carried out over a period of two months. Among other qualitative data collection methods, in depth interviews were chosen because it is the best method for collecting data on personal views, experiences and perspectives of participants, it has the ability to generate in-depth data, and it is the most appropriate for collecting data on sensitive personal experiences (Gill et al, 2008).

A topic guide had been developed (see appendix - 02) comprising guide questions and vignettes to facilitate and focus the discussions. A vignette is a short story about a fictional incident, which a participant can relate to her personal experiences of the topic. Vignettes are useful in helping participants to feel comfortable and encouraging the initially vicarious sharing of personal experiences on sensitive topics (Gourlay et al, 2014). Given the developing nature of qualitative research using empirical bioethics approach, the topic guide may have subject to change as the research progressed. Accordingly, interviews would have not been limited to the topic guide and vignettes, and participants' views and perceptions would have been explored through in-depth questioning and probing. The researcher would have been attempted to extricate the reasoning and the fundamental values that lead women to identify an experience as an ethical concern. Data collection would have been conducted until theoretical data saturation occurs (Saunders et al, 2015) or (if not) until the maximum number of interviews have been conducted.

Interviews would have been audio-recorded using a digital audio recorder, which would have been transcribed verbatim. The recordings would have been transferred onto a password protected computer and to the secure University of Bristol (UOB) OneDrive as soon as possible after the interview.

All the interviews would have been conducted at the participant's convenience at participant's own home, and at a convenient time. A comfortable private space would have been sought to maintain privacy and confidentiality and to minimize interference during the interview process. If

participants would have wished to conduct the interview outside of their home, an appropriate location would have been found.

University of Bristol lone worker guidance would have been followed to ensure the researcher's safety and security.

2.6 Data Analysis

Data analysis would have been carried out by me under the guidance of the lead supervisor.

A thematic analysis method would have been employed for the qualitative analysis, allowing the researcher to generate a rich and detailed account of participant's experiences and beliefs (Vaismoradi et al, 2013). In the pre-analytic phase, the researcher would have read and become familiarized with the transcripts by re-reading transcripts several times (data immersion). The analysis would then follow three steps of thematic analysis described by Miles and Huberman (1984, cited in Silverman, 2000).

Step 1: Data Reduction- Select chunks which provides the initial focus for analysis.

Step 2: Data Display - Assemble the data into networks and charts to clarify the main directions of the analysis.

Step 3: Conclusion drawing/ verification- finally deciding on meanings and identifying patterns and explanations.

The data would have been analyzed through the lens of ethical theory, with a view to identifying ethical issues arising in women's narratives.

To improve credibility of the analysis, the primary supervisor would have gone through the first few transcripts (translated into English) and check the coding and analysis of the primary researcher.

2.7 Data management and storage

All personal information and data would have been stored electronically in an encrypted folder in University of Bristol OneDrive. Hard copies of the contact details would have been destroyed after ensuring the availability of soft copies in the OneDrive.

The transcriptions would have been anonymized by changing or removing any information that could identify the participant. Participants' names and the names of other people or places mentioned in the data would have been changed by giving them a pseudonym. Any information that may potentially make the participant identifiable would have been changed or removed.

Anonymized transcripts would have been allocated a code number, which would enable the linking of the data to personal information of participants (via a separately stored key), which would allow data to be deleted if consent were withdrawn.

In any email communication with the supervisors, any document including data would have sent as password protected Word files through secured email addresses. However, transcripts would have been uploaded to the shared folder in UOB OneDrive permitting access only to the research team. All the electronic data would have been stored for five years. Data protection would have been ensured by following principles in the General Data Protection Regulation.

In publications, pseudonyms would have been used and any information that could potentially make the participants identifiable would have been removed.

2.8 Ethical clearance for the study

Ethical approval for the study was sought from the Ethics Review Committees of the UOB, United Kingdom (UK) and the Sri Lanka Medical Association, from which we received ethical clearance respectively in December 2019 and March 2020.

2.9 The way forward for the project in the Covid-19 restrictions

I have outlined the planned empirical bioethics project and its methods above. I also described the empirical bioethics approach to provide the rationale behind the selection of that methodology for this project. However, due to Covid-19 restrictions in Sri Lanka, field data collection became impossible. I also considered conducting remote interviews with women via phone calls or arranging virtual meetings, however, there were significant difficulties in arranging virtual meetings given that a considerable proportion of women do not have such facilities, etc. It also became clear early on that recruitment would have been impossible during the early days of the pandemic due to PHM workload and pauses in research support activity. Getting relevant data from secondary sources was also not possible given the lack of such data sources – which was the very reason my project was needed in the first place. Given that, I decided to progress the thesis without empirical data collection. I decided to explore ethical issues in theory using the vignettes that were designed for data collection. Use of vignettes was justified given that they were developed based on (although limited) available local literature and lived experiences of women whom I consulted in designing them.

Outlining key ethical theories and principles will be useful to lay the foundation for later theoretical analysis of the vignettes. The next chapter will describe the key ethical principles that will be employed in this thesis.

Chapter 3: Ethical principles

3.1 Introduction

In the next three chapters, I discuss ethical issues in childbirth care provision in Sri Lanka based on three vignettes. The vignettes depict three different incidents a Sri Lankan birthing woman could experience. It is important to note that, although the cases presented are not true stories, it is reasonable to consider them realistic as they were developed based on experiences of postpartum women that I consulted in developing vignettes and evidence from the available local literature.

To serve my purpose of theoretical analysis, I should look at the cases through an ethical lens. The content of this ethical lens should not distort the reality of the context and should be enough to achieve the purpose. Given that, I chose a set of ethical principles which fall under the category of ‘mid- level ethical principles’ (Schröder-Bäck et al, 2014). Mid-level principles are principles which may stem from many ethical theories and can be connected back to several theories. They are positioned in the middle of a hierarchy in which the top comprises overarching normative theories such as deontology and consequentialism, and the bottom comprises rules to follow such as codes of conduct. Mid-level principles are connected to many theories (which are of interest of philosophers in making normative judgements), codes of conduct and cultural norms (based on which health care staff take decisions in a medical context) (Schröder-Bäck et al, 2014), which will help to make my analysis balanced and relevant to the context. Now I shall move to introduce the ethical principles I will use.

The ethical principles chosen are a) respect for autonomy, b) beneficence, c) non-maleficence, d) paternalism, e) vulnerability, and f) trust.

It is important to note that I considered a wider range of ethical principles mentioned in literature (for example, justice, solidarity etc.) which I did not end up focusing on. I decided to take a pragmatic approach in the selection of principles – selecting based on their relevancy and usefulness in making moral judgements in Sri Lankan medical context, and also their relevancy, usefulness, and applicability for the analysis of the three vignettes. The reader might be curious why I did not include the principle of justice in my list, for example, as it is a very dominant principle in common morality and is also relevant to health contexts such as Sri Lanka, however, I decided not to include it given that its less useful in the analysis of the particular cases presented in the vignettes because none of them consider resource allocation or other issues central to questions of justice. Now, let us discuss the rationale behind the selection of these ethical principles further.

The first three principles - (respect for) autonomy, beneficence, non-maleficence - are three of the four principles presented in the framework of ethical principles by Beauchamp & Childress (Beauchamp & Childress, 2009). These principles (referred to as ‘Principlism’) received a huge recognition and following in medical ethics. The principles were considered to be derived from common morality, and the authors argue for their universalizability as common norms in a medical context (Beauchamp & Childress, 2009). Proponents of Principlism argue that these principles are comprehensive enough to guide decision making in (all) medical contexts (Gillon, 2003). However, the four principles framework has been discussed extensively and critically. For example, Huxtable found it to be “imperialist, inapplicable, inconsistent, and inadequate” (Huxtable, 2013) and Callahan found its approach is too individualistic (Callahan, 2003).

However, critics still value its practical usefulness in clinical settings, as a starting point for moral deliberation (Huxtable, 2013). In my opinion, the framework of four principles is more relevant and less inadequate in more individualistic Western social context compared to Eastern societies which are inclined towards collectivism and communitarian approaches. That does not mean that the four principles are not relevant and not applicable in Eastern cultures, rather they are not comprehensive enough to capture the entirety of eastern ethical cultures. However, it is important to note that in the Sri Lankan medical context, which is hugely influenced by the Western medical system (British) and Western ideologies (please refer chapter 1 for further details), the four principles are very relevant. Nevertheless, differences in cultural contexts still play a role in applying these principles. For example, the relative weight given to different principles in Sri Lankan culture is somewhat different from the Western world. In Western culture, it could be observed that autonomy is given priority over the other moral principles (Dawson, 2010), which is arguably not the case in Eastern cultures. Autonomy (in my opinion) is understood and expressed differently in Sri Lankan context and is (arguably) more akin to relational autonomy³ (Dove et al, 2017; Ells et al, 2011; Milligan & Jones, 2017). Arguably, the principle of atomistic autonomy⁴ is not as dominant in Sri Lanka as in a Western context.

³ Relational autonomy acknowledges an individual's social context as an important aspect in his/her decision making. Aspects such as values on mutual responsibility, cooperation, care towards others are considered in decision making. Whilst an individual is free to choose, that choice reflect the interconnectedness of people and the interests of others, and so respecting autonomy' becomes less about allowing people to make any choice so long as it furthers their interests as an individual, and more about allowing people to make choices that further their interests as part of network on interconnected autonomous beings.

⁴ Individualistic autonomy. An individual's personal autonomy is the focus. It does not consider aspects such as social values as it does in relational autonomy.

The three principles described above are not comprehensive enough to conduct a thorough ethical analysis, and so I have selected few other principles to complement them. It will help to produce more culturally appropriate and more justifiable and balanced theoretical analysis. Now, I shall give a brief overview of these additional principles, and how they operate in a Sri Lankan context.

In general, paternalism still plays a huge role in decision making in Asian countries (Tor, 2001), even though many people, mainly the new generation, are no longer ready to accept paternalistic behaviors without questioning (Chin, 2002). Although it is observed that autonomy is increasingly valued by people in Sri Lanka, the Sri Lankan health care system is still paternalistic (Ministry of Health, Nutrition, and Indigenous Medicine, 2017). I take paternalism as another relevant principle in my theoretical analysis. In a Sri Lankan paternalistic medical context, HCPs do take decisions on behalf of patients, believed to be for their own good. Results of an empirical study shows that Sri Lankan people welcome and mostly desire doctors to be paternalistic and, compared to the UK, acceptance of paternalism was very high (Kumarasiri et al, 2008). I argue that Sri Lankan patients accept paternalistic behaviors of HCPs based on trust. Sri Lankan people trust HCPs and their expertise as a result of the high value placed in the medical profession in Sri Lankan culture (Ministry of Health, Nutrition, and Indigenous Medicine, 2017). As (arguably) trust plays a critical role in understanding paternalism in Sri Lankan medicine, trust is included in my list as a relevant principle. However, it is also important to note that although HCPs are treated as trustworthy in Sri Lankan context, there is a growing understanding that patients' trust cannot be taken for granted, and an increasing number of cases of malpractice have been reported (Liyanage, 2011). Patients are generally considered vulnerable due to their impaired health status. I argue that

birthing women, who are my focus in this thesis, are extra vulnerable due to several context specific reasons which I will discuss later. Given that, vulnerability is also a key principle in my analysis.

I shall now outline the chosen ethical principles in the rest of this chapter. I will present the content of, and critically examine, each principle, providing examples from the medical context where and when it is needed.

3.2 Non maleficence

The principle of non-maleficence simply means ‘do no harm’ (Al-Bar & Chamsi-Pasha 2015; Beauchamp & Childress, 2009; Gillon, 1985). In a medical context, the doctor has a (negative) obligation not to harm patients (Beauchamp & Childress, 2009). A person inflicts harm on another when their actions have an adverse effect on the other person’s interest. In a medical context, adverse effects on patient’s physical and psychological health, wellbeing and survival are commonly considered harms. However, as a person’s interest is subjective, harms could be anything that impacts negatively on a person’s interest. One can certainly consider discomfort, humiliation, offense, intrusion into privacy, etc. as harms (Beauchamp & Childress, 2009; Callahan, 2003).

The principle of non-maleficence is considered a fundamental ethical principle in medical ethics (Beauchamp and Childress, 2009; Gillon, 1985). It is often identified with the famous maxim of the Hippocratic oath ‘Primum non nocere’- ‘first (above all), do no harm’. However, the English translation is a bit of a distortion of the original idea, which mentions nothing about ‘above all’ or ‘first of all’ which gives supremacy to the principle. What the Hippocratic oath requires doctors to

do is to do what they consider beneficial for their patients and to abstain from whatever is injurious and harmful (Beauchamp and Childress, 2009; Gillon, 1985). In a nutshell, the principle of non-maleficence does not necessarily claim priority over the other ethical principles (which will become further clearer later).

An important question one could raise is, is it always wrong to do harm to others? The answer is, although acts of harming are *prima facie* wrong, not all acts of harm are necessarily wrongful. Harmful acts that involve justifiable setbacks to another's interest should not be considered as wrong (Beauchamp and Childress, 2009). For example, in a case where a doctor performs a minor injury to the patient (for example, inserts a needle stick which may cause a swelling) providing a major benefit (for example, patient's life saved because of the intervention), this is justifiable even though it causes harm in the first place. Rightness or wrongness, therefore, cannot be decided solely on the principle of non-maleficence. In medical ethics, it goes hand in hand with the principle of beneficence (which is the next in line to discuss). In the above-mentioned case, the principle of beneficence overrides the principle of non-maleficence. However, that does not imply that it is the case always. Each individual incident should be appraised separately, which essentially treats beneficence/non-maleficence as the two sides of a utilitarian cost/benefit analysis. For example, one could argue that killing a patient who is going to die soon anyway due to a serious illness to save lives of two other patients who are going to die waiting in the list for organ transplantation is justifiable on utilitarian grounds as it produces maximum benefit to maximum number of people (more good than harm). In this case – in which it seems obvious such an act is morally wrong - the principle of non-maleficence should override the principle of beneficence.

The principle of non-maleficence includes not only obligation not to inflict harms on others, but also obligation not to impose risk of harm. A person can inflict harm on another with an intention to harm or not. ‘Standard of due care’ has been recognized in morality (and law) to determine whether a person is morally responsible for the negative consequences of actions. This standard provides specification to the principle of non-maleficence. Due care means taking sufficient and appropriate actions to avoid causing harm as a reasonable person would do, taking demands of the circumstances into consideration. Given that, in a medical context, a doctor is obliged only to impose risks on the patient if they are justifiable and reasonable in the given circumstances. A doctor who takes due care (even though risks are imposed on a patient’s health) is not necessarily morally wrong under the principle of non-maleficence.

Negligence is committed when a standard neglects their duty of care or fails to live up to the expected standard. Imposing unreasonable risks of harm intentionally, or unintentionally but carelessly, may both be negligent acts. Negligence is morally wrong, however, in my opinion, intentionally negligent acts are more unacceptable than unintended acts. In a medical context, professional malpractice occurs when negligence involves nonadherence to professional standard of care (Beauchamp and Childress, 2009). If a doctor performs below the expected standards of care, (s)he is to be considered negligent (and morally wrong under the principle of non-maleficence). One can point out that there are reasonable questions around this operationalized definition of negligence. While acknowledging them, I will stick to this definition for the purposes of this thesis.

I have already mentioned the principle of beneficence in connection with the principle of non-maleficence. Let us move to discuss it further.

3.3 Beneficence

Avoidance of inflicting (unjustifiable) harm (and risks of harms) on others is not enough for moral action; we must also take positive actions to help others. The principle of beneficence captures one's positive moral obligation to promote the interests of others (Beauchamp & Childress, 2009; Schröder-Bäck et al 2014).

Some philosophers, such as Frankena (1973), suggest combining the principle of non-maleficence and the principle of beneficence together. Gillon (1985) and Beauchamp & Childress (2009) showed that this is problematic, and I agree. Exploring these will be helpful to understand the distinction between these two principles clearly. According to Frankena (when the two are principles considered together), four moral obligations come under the principle of beneficence - not inflicting harm, preventing harm, removing harm, and promoting good. However, this is problematic because it obscures an important distinction between positive and negative obligations. The first, which is just non-maleficence, is a negative obligation while the other three come under beneficence and are positive obligations (Beauchamp & Childress, 2009). Combining the two principles - non-maleficence and beneficence in to one general principle will obscure this important distinction. The importance of maintaining this distinction can be found in the Kantian ideas of perfect and imperfect duty. We have a duty to not to harm anybody (a perfect duty), while we have a duty only to benefit some other people (imperfect duty). In other words, the obligation to nonmaleficence is for everyone i.e., general, while the obligation to beneficence is specific -

only to some people (Gillon, 1985). The principle of maleficence must be followed impartially, and certain acts can be prohibited, while the principle of beneficence does not require someone to be impartial, and in general not a reason to punish legally in inaction (Beauchamp & Childress, 2009).

Beneficence does not require us to promote interest of everyone, all the time, i.e., it does not require us to become what Susan Wolf called 'moral saints' (Susan Wolf, 1982). However, one is obliged to do so when they are in a special moral relationship (such as family or friends), or when they are in a special commitment such as in an agreement or contract. For example, in a doctor-patient relationship, a doctor is obliged to act to benefit the patient (Beauchamp & Childress, 2009). However, the principle of beneficence is not simply doing good in generic sense. A decision should be taken about what is good for that particular patient, consistent with their self-determined interest (which links with autonomy – discussed below). Sometimes, doctors do make decisions about what is the 'best interest' of the patient, which are presumed (Macciocchi, 2009). In the past doctors did widely use their own judgements about what is best for patients. However, with the growing emphasis on patient autonomy in the Western world, this kind of medical paternalism started to be questioned (Beauchamp & Childress, 2009; Birthrights 2013; Brook & Sullivan 2002). Whether the principle of beneficence or the principle of autonomy should be given priority in medical context is one of the central problems discussed in medical ethics, although of course it may be considered beneficent to respect autonomy (Idrees & Qarani, 2015; Macciocchi, 2009; Schor, 2014; Wancata and Hinshaw, 2016). Before discussing paternalism, then, it would be a good idea to outline the principle of autonomy.

3.4 (Respect for) Autonomy

Autonomy is a central notion in applied moral philosophy, particularly in biomedical context. It has roots in ancient times. The word ‘autonomy’ was derived from the Greek words – autos (Self) and nomos (governance or rule), together meaning self–government or self–rule. In ancient times, this term was used in reference to city states that those had an own ruling system and not obliged to be obedient to orders of an outsider such as a king. This term then extended to express the individual’s desire to self-rule (Beauchamp & Childress 2009). Since then, autonomy has been illustrated in different ways by different philosophers, in different contexts such as political, social, moral, and in relation to different notions such as self-rule, sovereignty, freedom of will, liberty, etc. Autonomy is, as such, a concept of conceptions (Dworkin, 1988). Given the diversity of the concept, it is necessary to clarify how I will use it in this thesis.

There are two conceptions of autonomy in the literature: procedural and non-procedural (substantive). According to procedural theories of autonomy, an action (of an individual) is autonomous if it fulfills certain procedural criteria. Such a procedural conception of autonomy is presented by Beauchamp & Childress (2009), in which an action of an individual is autonomous if it is voluntary (and free from controlling interferences) and informed. In contrast, substantive theories of autonomy (such as Kant’s) require the action of an individual to be consistent with some substantive views or abstract principles, for example, for Kant, the principle of universalizability. The Kantian conception of autonomy requires the individual to be impartial. In other words, an autonomous person’s choice(s) should not be contaminated by their personal opinions, views, expectations, or dispositions (Beauchamp & Childress 2009). In my opinion, this demands too much from a (self-regarding) individual and it is far removed from decision making

in the real world. In contrast, procedural views of autonomy do not set limits on what kinds of choices an individual makes and allows a person to have a wide range of options (Vereluis, 2006). Procedural notions of autonomy employ value neutral criteria to assess the process of choice making, rather than prescribing what kind of action an autonomous person should take – by providing substantive views on content of a good choice and the character of a good agent (Walsh, 2017). In my opinion, procedural notions of autonomy respect a person’s autonomy by not limiting the choices one can make. Considering what the procedural notion of autonomy has to offer specifically in deciding rightness and wrongness of choices made in medical context, in pragmatic grounds, I choose procedural autonomy – specifically the conception presented by Beauchamp & Childress.

According to Beauchamp & Childress (2009), personal autonomy is defined as follows.

“Personal autonomy encompasses, at minimum, self-rule that is free from both controlling interferences by others and from certain limitations such as an inadequate understanding that prevents meaningful choices. The autonomous individual acts freely in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and establishes its policies. A person of diminished autonomy, by contrast, is in some respect controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans. For example, cognitively challenged individuals and prisoners often have diminished autonomy. Mental incapacitation limits autonomy of severely retarded person, whereas coercive institutionalization constrains the autonomy of prisoners.” (Beauchamp & Childress, 2009, p 99,100).

According to Beauchamp & Childress, an action can be considered autonomous if it fulfills three criteria: it is intentional, the action was taken with understanding, and it was taken without interferences that may have a determining impact on the decision. The first criterion, intentionality (which simply means acts which are thought of or planned), is considered dichotomous by Beauchamp & Childress; either an action is intentional, or it is not. Criteria two and three allow for many possibilities from no understanding at all to complete understanding, and no interference at all to high level of interferences. All three criterion, together, can accommodate a wide range of more or less autonomous actions – from not autonomous at all to fully autonomous. According to Beauchamp & Childress, for an action to be considered autonomous (and in addition to being intentional), it only needs a *substantial degree* of understanding and freedom from interference, determined by the context in which the decision is to be taken.

The criterion of intentionality means that only intended actions can be considered autonomous. In general terms, intended means to have a plan or purpose (and unintended acts are accidental acts which are not planned or have not had a purpose). It is possible for a person to have more than one plan/ purpose for an action, albeit with a preference for one. Given that, if ‘intended’ means what is preferred to achieve or what is desired to get by making a choice, it is reasonable to ask whether one could have only one intention (preference) to achieve or a person’s intentions could be in a range, from which he decides one over the other? Beauchamp & Childress did not give much attention to this aspect in their account of personal autonomy.

Given that, Dworkin’s account of autonomy is a helpful addition. According to Dworkin (1988), an individual has first and second order preferences (although in my opinion, a person can have

many layers of preferences, not limited to two). First order preferences are mostly a person's desires which are more intrinsic or primary such as desires due to personal dispositions and may be considered simply and immediate preferences to satisfy immediate personal need. Second order preferences express, conversely, a person's higher-level commitments and are more rational. For example, a person may have first order preference to get something he desires by stealing. He may have a second order preference not to steal as he believes stealing is morally wrong. In making choices, an (autonomous) individual reflects upon his first order preference compared to the second order preference and decides what to do. It is important to note that second order and first order desires are not necessarily divergent; rather second order preference is more rational compared to the first order desire. In my opinion, whether the person goes with the first order preference or the second order preference, this has no impact on the dichotomous nature of Beauchamp & Childress' intentionality criterion. However, it does make a difference to the level of intention based on the level of reflection and preference. In my opinion, Dworkin's conception of autonomy is a good addition to Beauchamp & Childress's personal autonomy. It points out another important aspect of decision making - rational reflection about preferences. In this thesis, I will employ Beauchamp and Childress account of autonomy and Dworkin's when and where necessary.

I have discussed, so far, accounts of personal autonomy. Now, I shall focus on the principle of respecting autonomy of a person, especially in medical context.

According to Beauchamp & Childress's account of autonomy, respect for autonomy of a person means accepting and allowing an autonomous person's right to make their own decisions. Respect

for autonomy includes both a negative obligation - to avoid controlling interference over others, and a positive obligation – creating a supportive environment to facilitate autonomous decision making. For example, in a medical context a doctor is expected to respect the autonomy of her patient by providing necessary information regarding medical procedures and helping them overcome conditions which disrupt autonomous choices (such as fear). The doctor also has a negative obligation to avoid coercion of the patient to accept certain treatments that the doctor favours. In my opinion, Kant's conception of autonomy offers something useful here, in understanding the meaning and purpose of both negative and positive obligations to respect the autonomy of patients. According to Kant, people should be treated as ends in themselves, not as mere means to achieve someone else's ends (Beauchamp & Childress, 2009). By avoiding interferences and creating a supportive environment for decision making (as per the Beauchamp & Childress account), the ultimate aim is to ensure we treat patients as ends in themselves, not mere means to achieve someone else's agenda. Arguably, in Beauchamp & Childress's account of autonomy, the aforementioned Kantian view of autonomy is operationalized. The Kantian view can be considered a guiding statement for HCPs to treat patients in a way that ensures autonomy is respected. In this thesis, although I will use Beauchamp & Childress's account to assess whether a patient's autonomy is respected in clinical setting, I will combine it with Kantian view to see whether the intention of the HCP is to treat the patient as an end or as a means.

Kant's view is built up on the belief that human life has an intrinsic value, as humans have capacity for rational thinking, and so autonomous choices of human beings should be valued (Beauchamp & Childress, 2009). Following Kant's argument, one can argue that when a person loses rationality (for any reason), one's obligation to respect that person's autonomy becomes meaningless. On that

ground, arguably, obligation to respect autonomy is not applicable to people (patients) who are not sufficiently autonomous in a given situation such as the immature or incapacitated (I will discuss). For example, small children and persons with cognitive impairment may not be sufficiently autonomous to make certain decisions. However, it is important to note that there are some patients who cannot be included in this category (and are autonomous), but do not want to receive information or do not want to make decisions regarding their treatments (Beauchamp & Childress, 2009; Schneider & Schneider 1998). A patient's decision not to participate in decision making accords with Dworkin's higher order preferences if the patient decided to do so after careful consideration on what they want. In this situation medical paternalism – where doctors take decisions on for a patient in their interests - is acceptable: but only because the patient has autonomously chosen it. I will discuss medical paternalism later in this chapter.

An empirical study carried out with the participation of different ethnic groups in America showed that different ethnic groups accept different level of information disclosure to patients about serious illnesses and whether the patient should take decisions regarding treatment (Beauchamp & Childress, 2009; Schneider & Schneider 1998). In a study carried out in Sri Lanka, such differences are observable between rural and urban populations (Kumarasiri et al, 2008). Given that, it is plausible to conclude that this phenomenon is associated with the cultural and social contexts of people. I agree with Beauchamp & Childress's position, where they note that an autonomous person has right to make their own decisions, but not a duty to do so. So, in this thesis, I take the position that autonomous patients should not be forced to make decisions if they choose not to do so.

Now that we have discussed the HCP's obligation to respect the autonomy of patients, we shall move on to discuss practical aspects of respecting patient autonomy in a medical context.

The primary way respect for autonomy is practiced in a medical context is through the process of informed consent. A patient may express consent by giving verbal approval (for example, asking a doctor to perform a medical procedure or saying 'yes' when asked), signing a consent form, or by non-verbal actions (for example, giving a hand to draw blood). The general consensus is that both implied and expressed consent are ethically valid in medical context (Brazier & Cave 2016). However, this consent must be appropriately informed, and it is morally wrong to assume consent based on presumptions about the choices a patient would make. A valid consent can be achieved only if the patient's actual choices are expressed.

Another aspect of valid consent is whether the patient has the capacity to make a decision. In usual medical practice, HCPs assess patient's decision-making capacity (or competence) to decide whether the patient can make their own decision. It is obvious that capacity will lie in a scale from none to complete. However, the question is how to determine whether the patient's capacity is enough. A patient is considered competent if they can understand a medical procedure, can assess its major risks and benefits, and can take a decision based on that assessment. According to widely accepted standards of incompetence (Berg et al, 2001; Beauchamp & Childress 2009), the inability to express or communicate choices, to understand their own situation and its consequences, to understand relevant information, or to give rational or risk/benefit related reasons to reach a reasonable decision, are considered characteristic of a patient who is unable to make their own decision.

Where the patient is not competent to decide for herself, another person has to decide for them – often referred to as surrogate decision making. Surrogate decision-making is when, someone else (for example, HCP or a family member) makes decisions for or on behalf of an incapacitated patient. There is no consensus on the standard of surrogate decision making, with many different approaches worldwide, and the exact mechanism, and who had decision making authority, depends on the social context (DeMartino et al, 2017). However, there are three widely accepted standards currently in practice: a) the substituted judgement standard – where the surrogate decision maker is expected to make the decision the patient would have made if she was competent; b) the pure autonomy standard – where the decision is taken based on patient’s previously expressed competent preferences (sometimes via an advanced directive); c) The best interest standard – where a decision is made that aims to benefit the patient (by matching treatment to their interests) after assessing the risks and benefits of all relevant options (Beauchamp & Childress, 2009). There are pros and cons with each standard. In Sri Lanka, there is no formal mechanism for surrogate decision making or advance directives for medical matters, including for childbirth (Samarasekara, 2016). Anecdotal evidence and my discussions with HCPs suggest that patients' best interests are the main method of decision making, usually carried out by the most senior HCP available, with consideration of the wishes of the relatives.

When a patient does have capacity, ‘informed consent’ is the standard way to obtain legally or institutionally valid consent from a patient for a medical intervention. It is widely considered an expression of respect for autonomy of patients because it allows patient to self-determine, according to their own values and preference. As such, informed consent is an individual’s

autonomous authorization of a medical intervention (Beauchamp & Childress, 2009). However, O'Neill argues that informed consent is, rather, a practice to prevent coercion and deception in medical practice and cannot be justified in terms of respect for autonomy (Manson & O'Neill, 2007; O'Neill 2003). I argue that the prevention of coercion and deception is part of respecting autonomy, and so Beauchamp & Childress's wider point still stands and encompasses the more specific O'Neil view. In this thesis, I will use Beauchamp & Childress's explanation of informed consent considering its usefulness in critical appraisal of cases.

According to Beauchamp & Childress, there are seven elements of informed consent which are categorized as: preconditions, information elements, and consent (or refusal) elements. Preconditions are a) competence of the patient to understand and decide and b) voluntariness in decision making. The information elements are c) disclosure of information, d) recommendation of a plan, e) understanding of information and plan. The consent elements are f) decision and authorization of the recommended plan. I have already discussed elements of competence and consent above, and so now I discuss the information element and then about voluntariness in decision making.

HCPs have an obligation to provide adequate information to patients to enable them to make autonomous decisions. There are three general standards of disclosure of information: a) the professional practice standard, b) the reasonable person standard and c) the subjective standard (Beauchamp & Childress 2009). The professional practice standard requires the HCP to disclose the same information that other health professionals would customarily disclose (the UK's Bolam judgement, for example, is an example of this standard (Welsby 2017; Lee 2017)). The reasonable

person standard requires health professional to disclose the information that a (hypothetical) reasonable person would want and need in the circumstances. The subjective standard requires disclosure of information tailored to the patient's need (the latter two, combined, seem to me captured in the UK's Montgomery judgement (Welsby 2017; Lee 2017)). Although the subjective standard demands an HCP makes extra effort to understand the patient's needs and circumstances before disclosing information, arguably, it is the most appropriate method specifically in a Sri Lankan context, in which a considerable proportion of patients are less autonomous (compared to Western context) and extra vulnerable (please see 3.6 Vulnerability). Vulnerabilities may hinder the patients' autonomous decision making by having negative impacts on one or more elements of informed consent. For example, a woman who is vulnerable because of her poor literacy level may find it difficult to understand if the information is not provided in simple lay language. For another example, a woman from poor socio-economic background may find it difficult to refuse a free treatment offered to her even if it is substandard and she would not ordinarily want it.

The other element that comes under information is understanding, which is an essential component in autonomous decision making and closely linked to capacity and information. Providing information is not helpful unless the patient is able to understand it. Empirical evidence shows that patients understand differently in clinical settings (Falagas et al, 2009; Joffe et al, 2001). Given this, it should not be assumed that a patient's lack of understanding is a result of a lack of capacity: rather, it may be due to the environment and/or deficits in communication. As such, barriers to (sufficient level of) understanding such as poor communication styles should be avoided as much as possible.

There are exceptions (legally accepted) to informed consent in a clinical setting. A HCP can proceed without informed consent, for example, in an emergency situation, when the patient is incompetent or autonomously waives her right to decide. However, therapeutic privilege – withholding information based on a judgement that disclosure of information would do more harm than good (for example when the patient is not emotionally stable, depressed, etc., in my opinion) should be acceptable only in cases where the professional has a strong and demonstrable justification (Edwin 2008).

Moving on now to look at voluntariness, a person acts voluntarily when she acts according to her will without being the control of another's influence (Beauchamp & Childress, 2009). In other words, a person acts voluntarily when she is free from controlling interference in decision making. However, there is some disagreement about the scope and content of the concept of voluntariness. For example, some authors define voluntariness in a very broad sense - including the presence of adequate knowledge, absence of psychological compulsions and external restrictions (Feinberg, 1971, 1973). Beauchamp & Childress argue that such definitions are too broad; they overlap with the principle of autonomy and conflate voluntariness with autonomous action, to which I agree. Therefore, I adopt Beauchamp & Childress's narrower account of voluntariness. According to this definition, a person's voluntariness is undermined by controlling interferences of others. Importantly, not all interferences of others should be considered controlling. For example, a doctor trying to persuade a patient, to undergo a low risk but medically necessary procedure that she has avoiding for some time, despite clearly wanting the relief the procedure would give, may not be considered a controlling influence. However, it depends on how it is perceived by the patient. What feels like gentle persuasion to the doctor might be experienced as coercion by a patient. It is worth

noting that whilst some persuasion is likely to be acceptable, it is unclear in the abstract where it crosses the line into unacceptable pressure – and it will be different for all patients. However, in general, influences such as coercion, manipulation and undue inducement can be identified as controlling. I will extend the discussion on controlling influences after introducing another factor that I consider undermining voluntariness (which does not come under Beauchamp & Childress’s account). That is, freedom, which I now explore.

There is a tendency in literature to identify voluntariness in relation to freedom. However, Olsaretti (1998) argues that freedom and voluntariness are not necessarily related, and freedom is about the options available to a person whereas voluntariness is about the way in which the nature of those options affects the person’s will. She explains that claims of freedom are descriptive while claims of voluntariness are explanatory. Freedom is ‘*being free to act*’ while voluntariness is ‘*acting freely*’ (Olsaretti, 1998). It is clear that freedom and voluntariness are two distinct notions, in my opinion ‘being free to act’ and there being ‘options available to the person’ are both important sub-features of the wider concept of ‘acting freely’. With that understanding, I would consider having limited or no options as one factor that undermines voluntariness, which mean that voluntariness is undermined when options are limited unreasonably. Keeping that in mind, I now move to discuss four specific factors that might undermine voluntariness in a medical context.

No (good) choice situations: Lack of options (alternatives) may lead a person to accept a bad offer. In such situations, the person may be forced to choose the only available option (Eyal, 2019). For example, a woman who has to go for a c-section that she really does not want, because the expert (HCP’s) opinion is that it is required to save the baby’s life, may feel she has no choice other than

agreeing to the suggestion. In this situation, although technically there is a choice to refuse a c-section, there is no 'good choice'.

Coercion: Coercion occurs when a person is forced (or threatened) to act in a certain way, and the coercer controls the other person by exerting pressure on her (Beauchamp & Childress, 2009; Nelson & Merz, 2002). To classify an act of influence as coercion, the intention of the coercer and the subjective response of the victim must be considered. It may be that the same pressure/threat of harm may have coercive influence on some, but not for the others. Coercion occurs only when a person's decision is controlled in response to pressure/threat. (However, coercive behavior may still be considered wrong even if it does not ultimately lead to actual coercion (Nelson & Merz, 2002)) Conversely, a person's decision may be influenced by perceived pressure or threat, which is not intended. On my account, this would not be a 'coercive act' by definition. Whilst I agree with Nelson & Merz (2002) that an act cannot be considered coercion in absence of coercive intent (see the following paragraph on persuasion below), a threat or pressure perceived by the person should not be neglected, especially when the person is justifiably vulnerable to the perceived pressure/threat. Due to their vulnerabilities, people may be coerced by non-coercive acts, which are not in credible (or actual) threats. For example, fear of loss of healthcare benefits may be a perceived threat to an illiterate poor woman receiving free labour care in a government hospital who is asked to choose a certain labour plan, even if the HCPs had not intended her to have real choice. HCPs should be careful to avoid such perceived threats as much as possible in care provision. (I will discuss vulnerability specifically later in this chapter).

Persuasion: In general, persuasion is not considered a controlling influence, however there are times that persuasion might become a controlling influence. According to Beauchamp & Childress (2009), “in persuasion, a person must come to believe in something through the merit of reason another person advances”. According to Nelson and Merz (2002), persuasion means “the provision of truthful information and appeal to reason performed to convince a potential subject to act or decide in a particular way”. It is important to note that persuasion appeals to reasons, rather than emotions. However, the problem is that in health care, although truthful information is revealed, and rational argument provided about medical interventions, sometimes patients do not receive information as it is intended, and they become panicked or fearful (Nelson & Merz, 2002), and thus do not respond with reason. There are other problems with persuasion in a medical context. For example, we can question whether, in attempting to persuade, the values of the HCP are being unreasonably imposed on the patient, and an HCP is rarely completely objective and driven by reason alone (Nelson & Merz, 2002). In addition, given that the HCP is in a position of trust and (perceived) authority, the act of persuasion may be experienced as coercive (see above) just because of the power differential.

Manipulation: Manipulation is another form of influence exerted on a person aiming to alter her decision in a direction desired by the manipulator, using means other than coercion and persuasion (Beauchamp & Childress, 2009; Nelson & Merz, 2002). Some of the possible means used by the manipulator are manipulation of options, manipulation of information, and psychological manipulation. In health care, this might most often come in the form of informational manipulation, in which the manipulator manages information in a manner that alters the patients’ understanding regarding the matter of concern, to make the patient do what the manipulator wants.

For example, lying, withholding information, exaggeration, misleading, and misinterpreting data can be done. Sometimes, the way the information is presented to the patient, such as the tone of the voice, facial expressions, and the way the information is framed can be used to manipulate. Another form of manipulation is manipulation of options. Such acts of manipulation could be providing incentives, such free/reduce cost medical care. Such offers, which can cloud autonomous decisions, are referred to as ‘undue inducements’ in literature (Nelson & Merz, 2002). Psychological manipulation occurs when the manipulator works to change the psychological processes of the person, not his understanding. For example, the ‘bait and switch’ technique; creating an initial agreement that may be psychologically difficult to reverse later when unavailability of the promised product is revealed. Another form is manipulation of trust. Sometimes, displaying symbols of professional authority (such as a stethoscope and white coat) may be used to manipulate the trust of patients. In a Sri Lankan medical context, trust-based manipulation may easily occur, as the health care system is very paternalistic and there is generally a high level of trust in the medical profession.

In this section I have introduced the principle of respect for autonomy, and I showed how it is linked with other key principles. Now, I shall move on to discuss paternalism, the next principle in my list.

3.5 Paternalism

The obligation to act for the benefit of patients has been a guiding principle for HCPs from ancient times. Paternalism has been born out of this obligation and has been practiced in health care as a means to ensure that the patients are benefited in the best possible way. However, with increased

attention to the notion of personal autonomy in the Western world, the practice of medical paternalism has been increasingly questioned. Paternalism has become a central point of discussion in medical ethics as a conflict between the principle of beneficence and the principle of autonomy (Idrees & Quarani, 2015; Macciocchi, 2009; Schor, 2014; Wancata & Hinshaw, 2016). First, let us look at what paternalism is.

Paternalism can be easily understood through an analogy of a parent's role towards their children. A parent makes decisions for their children with the intention to benefit them. Similarly, in medical paternalism, an HCP, as an expert, makes decisions for the patient. The patient is viewed similarly to a child who is dependent, fearful, and not in a position to make their own decisions. According to Beauchamp & Childress, paternalism is defined as "the intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefitting or of preventing or mitigating harm to the person whose preferences or actions are overridden" (Beauchamp & Childress, 2009). According to this definition (which I adopt in this thesis), paternalistic acts either can be over patient's autonomous or non-autonomous decisions. A wide range of actions in medical practice can achieve paternalistic goals, such as persuasion, deception, limiting choice, coercion, manipulation, etc. These are all generally accepted to be *prima facie* wrong when directed toward a person with autonomy (Beauchamp & Childress, 2009). However, by definition, paternalism is normatively neutral, and paternalism is not always problematic. (For example, it is unproblematic when directed to a child who lacks autonomy.) Now, let us move to discuss the ideas of soft and hard paternalism and weak and strong paternalism to understand when paternalism goes wrong and when it might be appropriate.

Soft paternalism occurs when a person intervenes in someone else's decision, choice, or preference with an aim of preventing substantially non-voluntary conduct. Soft paternalism is justifiably practiced in a medical context when patients take decisions which are not informed, or when they are in a temporary or permanent condition with impaired rational decision-making capacity, such as having depression or having an addiction which have a direct influence on the matter of concern (Beauchamp & Childress, 2009). In contrast, hard paternalism involves interventions in situations where the person's choice is autonomous. Soft paternalism does not interfere with the principle of respect for autonomy, because the person is not autonomous - by virtue of lacking vital information of being unable to process or understand the information. However, in my opinion, there may be practical difficulties even in practicing soft paternalism, such as judging the patient's decision-making capacity. The other problem I find is, if unchecked, it seems too easy for professionals to choose this easy path - adopting a soft-paternalism approach where understanding is lacking rather than ensuring that patient is fully informed (in cases where poor understanding undermines voluntary decision making). However, in poor resource settings, with limited scientific literacy, such as a Sri Lankan medical context, in which HCPs are overloaded with patients (for example, a doctor is responsible for 10,000 population in Sri Lanka), it may not be easy to allocate the time required to ensure that patients are fully informed to make decisions by themselves. In this case, some soft paternalism might be excusable as a way of ensuring that people can benefit as much as possible when it is not practical or possible for them to fully understand what is going on, which is in keeping with their autonomously chosen ends of becoming healthy. However, I believe that still there is a room for improvement – where the aim should be a shared decision, with as full as possible patient understanding.

People who advocate for weak paternalism believe that it is acceptable to interfere with the means that a person selects to achieve her desired ends if those means are incompatible with the chosen ends (Beauchamp & Childress, 2009). For example, in public health, forcing people to wear safety belts when they drive may be justified on the presumption that people desire safety and value their lives and this is not compatible with not wearing seat belts. In weak paternalism, interference is justified on the ground of factual misunderstanding, but does not interfere with the values of the person. If the person's decision is autonomous enough and not clouded by any kind of controlling interferences, and their actions are consistent with their goals, we must accept whatever decision s(he) makes (for example, even if a person wants to commit suicide). Conversely, if a strong paternalist finds that a person may be mistaken, confused or irrational in deciding the ends, (s)he would feel it is acceptable to interfere, aiming to prevent the person from achieving those 'wrong' ends. Strong paternalists may not allow a person to commit suicide with a belief that what was chosen is mistaken. I do not see a problem with accepting weak paternalism, as it does not interfere with personal autonomy. However, I would advocate for supporting persons such as by providing necessary information to choose means to achieve the desired ends, as this then becomes autonomy enhancing. In contrast, (for me) it is difficult to accept strong paternalism, as it is a direct insult to personal autonomy.

As I mentioned earlier, the main problem for determining whether paternalism is appropriate is deciding which principle should override – respect for autonomy or beneficence. Although some feel that autonomy should always override the other principles (as discussed above) I agree with Beauchamp & Childress (2009) that it is not implied in Principlism that the principle of autonomy

should be given priority. Rather the problem is, as the framework is described referring to examples from the Western world (which is individualistic) autonomy tends to be valued over the other principles. In my opinion, a judgement on morally right or wrong acts of paternalism is largely context dependent. Arguably, paternalistic acts are perceived as more unjustifiable in individualistic societies compared to less individualistic Asian cultures such as Sri Lanka. Given that, in judging paternalistic acts in a medical context morally right or wrong, cultural aspects and value systems of the particular society must be considered. In my analysis of cases in coming chapters, I will ensure I do this.

As mentioned previously, Sri Lankan patients often accept and welcome HCP's paternalistic behaviors (Ministry of Health, Nutrition, and Indigenous Medicine, 2017). This could be explained in reference to the burden of responsibility that comes with personal autonomy. Some patients prefer to transfer this decision-making burden to an HCP they trust. Patients may believe that professionals can make better decisions on their behalf, and in their interests, as they are experts in medicine and health care. I argue that, in cases where patients are willing, and want to transfer decision making burden to HCPs, and this is in keeping with their higher order preference, paternalism is acceptable and should be accepted. Not only with regard to paternalism, but also in general, patients need to feel able to trust HCPs and the health care system (refer to 3.8 for further discussion). However, one of the important factors that interferes with the idea of accepting paternalism when it is wanted, is the question of how vulnerable a patient is, and whether a vulnerable patient can autonomously choose to place trust in a HCP and choose paternalism. Before moving to discuss trust, let us discuss vulnerability, especially in relation to Sri Lankan context – which will also link into the discussion above around persuasion and autonomy.

3.6 Vulnerability

Vulnerability is the “increased susceptibility of a person to harm or exploitation”. “Individuals are considered vulnerable if they are susceptible to be harmed, wronged, exploited, mistreated, discriminated against or taken advantage of in the context of health care or research” (Ganguli-Mitra & Biller-Andorno, 2011).

In my opinion, exploring how vulnerability interact with voluntariness is useful in understanding how vulnerability operates in medical care.

I discussed voluntariness under the section about respect for autonomy (please refer section 3.4). Threats to voluntariness increase with an increase in the vulnerability of a person. Given below is a graph that shows how vulnerability impacts on voluntary participation in research. Empirical evidence shows that, with increased vulnerability, participants are more prone to make less voluntary decisions due to controlling interferences such as coercion and manipulation (see Figure 1 presented by Nelson & Merz (2002)).

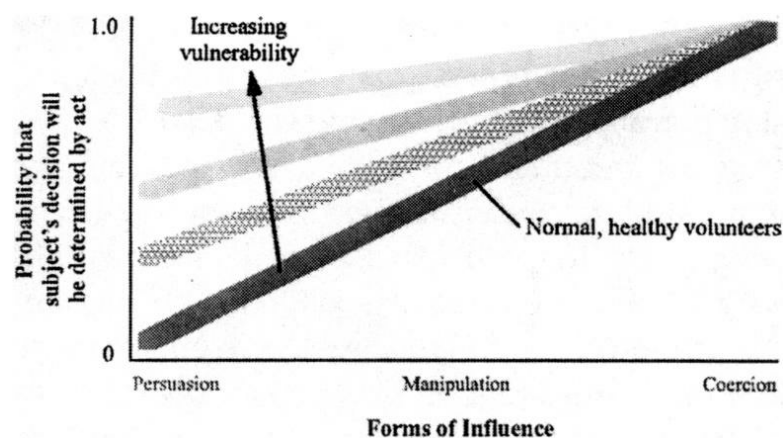


Figure 1: Probability of participants deciding to comply with controlling influences with increased vulnerability.

Vulnerability of patients in health care settings has not been discussed as widely as it has regarding vulnerability of participants in research (Martin et al, 2014). However, it is plausible to assume that patients' behaviors in a health care setting would follow the pattern shown in figure 1. With increasing vulnerability patients may be more prone to coercion, manipulation and controlling interferences in a health care setting. In addition, vulnerabilities can also lead patients to experience exploitation, receive un-chosen treatments, and receive a lower standard of care.

The question 'who are the vulnerable?' can be answered in different ways; however, definitions can be divided into – definitions in a) a broad sense and b) a narrow sense. Vulnerability in a very broad sense identifies all human beings as vulnerable. According to this idea, vulnerability is understood as a human condition which we all have (Callahan, 2000; Gert, 2004). This idea is linked with us having a human body which is fragile, mortal, and prone to be harmed (Harrosh, 2012; Kemp, 2000; Kemp & Rendtorff, 2000). However, in contemporary bioethics, vulnerability tends to be defined in a narrower sense, i.e., “the vulnerable are those who should be afforded special protection and additional attention in medical research and health care” (Martin et al, 2014). According to this definition, people who are more likely to be exploited or unable to protect or safeguard their own interests are considered vulnerable (Council for International Organizations of Medical Sciences & WHO, 2002; Macklin, 2003; Martin et al, 2014). The two streams of definitions are *prima facie* incompatible. However, I agree with Martin et al (2014) that these two views are not contradictory or competitive, rather they depend on each other. In my opinion, the difference between the two kinds of account lies in the level of manifestation. I find both definitions are useful in a medical context. In a broad sense, any patient receiving medical care

can be considered vulnerable, in general due to her illness or medical condition. However, not all patients are *equally* vulnerable, thus special protection and additional attention should be offered to the patients who are extra vulnerable (beyond the general level), as stressed by the narrow definition of vulnerability. This understanding – vulnerability with different levels of manifestation - justifies tailoring health care to the individual patient needs, considering their individual vulnerabilities. In my opinion, understanding vulnerability as a single concept (with different levels of manifestation) is advantageous. It helps to avoid categorizing patients into binary ‘vulnerable groups’ (for example, the elderly, children, prisoners, mentally ill people, people with disabilities, pregnant women, the uneducated, etc.) Labeling patients as ‘vulnerable’ is counterproductive sometimes - it sometimes leads to stigma and discrimination of patients. Sometimes, when HCPs are preoccupied with the ideas of vulnerable groups, there is a chance of them not recognizing vulnerabilities outside the standard categories, which will lead to failure to recognize some patients who are truly vulnerable and wrongly assuming vulnerability in others. In addition, as a result of identifying patients as belonging to vulnerable groups, HCPs may be more likely to treat patients in a paternalistic way, which may often be unnecessary and overprotective. Given that, I advocate for an account of vulnerability which is both broad and context specific. Anyone can become more vulnerable in certain situations, however, the level of manifestation of vulnerability depends on the context. Given that, I advocate for case-based evaluation of each patient for vulnerability in health care settings.

Now I have outlined my position regarding vulnerability in health care and its context dependent nature, I will discuss the underlying factors that contribute to a person becoming particularly vulnerable in a health care context. Arguably, vulnerability is a result of internal or external factors

and differences in level of vulnerability is created by how these factors are accumulated and combined (Beauchamp & Childress, 2009; Gopaldas, 2013). Now I list out some of these factors, providing a small description for each (this list is prepared considering health and health care in general.) It is important to note that, some of the factors in the list are modifiable where others are not.

- **Diminished cognitive capacity:** People may experience diminished capacity in understanding, rational decision making, in communication, permanently or temporary due to mental and cognitive disorders (Nelson & Merz, 2002).
- **Socio-economic status:** People with lower socio-economic status, such as prisoners or people in poverty may be vulnerable to inappropriate treatments (Nelson & Merz 2002).
- **Disease condition:** People become vulnerable due to their disease conditions, especially in serious disease or disability (Nelson & Merz, 2002).
- **Age:** Children and elderly may be considered vulnerable as they depend on others for care. Children are also considered lacking capacity to understand and express themselves properly. The elderly may be vulnerable due to general physical weakness or deteriorating cognition (Rogers, 1997).
- **Gender:** Gender is another factor for vulnerability. In patriarchal societies (such as Sri Lanka) women are considered more vulnerable than men in general, which is also linked to treating women and men differently in some cultures and societies (Rogers, 1997).
- **Race and Ethnicity:** Empirical evidence shows that people coming from minority ethnic groups are more vulnerable in some contexts, for example Black and Hispanic people in the

United States (Rogers, 1997). In Sri Lanka, Tamil only speaking people may be more vulnerable in some health care settings (Perera et al, 2018).

- **Social support:** A person's social support is an indicator of degree of vulnerability. Having good relationships positively correlates with good health in general. A social network is a source of emotional support for a person (Rogers, 1997). Women having strong social support are less vulnerable during childbirth in Sri Lankan context (Perera et al, 2018).
- **Education:** People who are illiterate, or with poor education, are more vulnerable in health care settings. Having good education links with better health in general. Educated people may be more able to take preventive measures and access health care facilities. Women who are well educated tend to engage with perinatal care, and experience better birthing outcomes than women with poor education (Rogers, 1997).
- **Income:** Income is a major determinant of health. People who are poor experience high risk for death, disease, and disability. People coming from poor backgrounds are more prone to abuse (Rogers, 1997).
- **Life changes:** People who are diagnosed with life threatening disease, who lost their loved one/ end a close relationship, lost jobs, who are undergoing a significant change in life (for example, childbirth), or facing a crisis can be considered vulnerable, as such experiences are detrimental to health and wellbeing (Rogers, 1997).

The National Health Strategic Master Plan 2016 -2025 of Sri Lanka has identified that people coming from low socio-economic backgrounds and the uneducated are vulnerable in the Sri Lankan health care context (Ministry of Health, 2014). There have been similar findings in a

Canadian study – suggesting that no matter where you live, you are made more vulnerable by relative poverty, low education, rural living, and immigration status (Clark, 2018).

The concept of ‘intersectionality’ coined by Kimberle Crenshaw can be used to describe how vulnerability operates in a Sri Lankan health context. Intersectionality is a framework which helps to understand how different identities of a person in combination creates discrimination and disadvantage in different ways. An individual can often fall into more than one discriminating categories in a social system (Zazzaron, 2018). According to Crenshaw, for example, an African American woman in the United States can be a victim of both sexism (as a woman) and racism (as an African American). Although she is a victim of discrimination as a woman and as an African American, she is just one person who is victimized in two ways (Zazzaron, 2018). Similarly, some Sri Lankan women in labour may be more vulnerable (to coercion, manipulation, exploitation, different treatments, for example) than others, depending on her (disadvantaged) social identities. For example, an uneducated woman coming from low socio-economic status is vulnerable in two ways due to her education level and her social status. Similarly, women in Sri Lanka can be identified with multiple vulnerabilities, when underlying factors are considered in different combinations. This creates many possible layers of vulnerability within the limits of context specific possibilities. Such accounts of vulnerability can be employed to identify and address vulnerabilities in a medical context. In my opinion, rather than grouping birthing women as vulnerable (or not), it is important to understand their true (intersectional) vulnerabilities. For example, if we consider a woman who is a teenage, poor, unmarried, gives birth in a government hospital, her vulnerabilities should be understood as having four intersections. Even under one considered factor, for example – being teenaged - there are multiple associated factors – high risk

to stigmatization, fear of childbirth due to un-maturity, self-criticism and shame linked to cultural values, psychological risks, etc. Understanding different layers of vulnerability is important in provision of quality care. It has been argued that, in human relations, the one who is stronger has a moral obligation to protect the vulnerable, and not to exploit the disadvantaged (Clark, 2018), and this need to protect the vulnerable is recognised by the Universal Declaration of Human Rights (Assembly, U. G. 1948). Accordingly, health care interventions should be to be justifiable in terms of mitigating the vulnerabilities of patients.

Now, let us move to discuss the next principle in my list, the principle of Trust, which plays a critical role especially in a context in which patients are extra vulnerable.

3.7 Trust

Trust is an integral part of patient - HCP relationship (Gilson, 2006). Empirical evidence shows that lack of trust in HCPs is a barrier to health service use (Whetten et al., 2006). Trustworthiness of healthcare professionals, and HCPs having strong trusting relationships with patients, were identified as the most important factors to improve patient engagement with healthcare services (Davy et al, 2016). Before moving to discuss how trust operates in health care, I shall first describe what trust is.

There are many definitions of trust in the literature. Hall et al (2001) define trust as “the optimistic acceptance of a vulnerable situation in which the trustor (the patient in our case) believes the trustee (the HCPs) will care for the trustor’s interests”. Here, the trustee is expected to act in a way the trustor approves of (Iltis, 2007). According to Hall’s definition, trust is inseparable from

vulnerability. Vulnerability occurs in a healthcare setting when a patient is more likely to be exploited or unable to protect or safeguard their own interests. Given that, trust is unavoidably necessary in medical care. This definition alone, however, does not help us to understand how trust operates. People have different views about trust and some of them are, arguably, misconceived. Critically analysing such views is a good way to understand trust. I will refer to O’Neill’s works to understand three widespread views that have become widely held (O’neill, 2017).

According to O’Neill, the first misconceived view about trust is the claim that there is a great decline in trust in our societies. O’Neill pointed out that this view has been generated by an unscientific source – opinion polls – which are just opinions of people, carried out and spread mostly by journalists and politicians, with an aim of generating sensational information that over-generalises and over-simplifies by turning complex questions of trust into binary options for trusted and non-trusted groups. In everyday life, however, we do not assume that all people who belong to a particular group (for example, doctors) behave in the same manner, so we can trust them all in the same level. Rather we trust some of them, but not the others. In addition, we trust some people to do some activities, but not others. For example, we trust a teacher to teach the alphabet, but not to drive children safely to school. I agree with O’Neill, trust is, and should be, something that intelligently placed in someone for a specific reason for a particular thing. Presuming that all healthcare professionals are not trustworthy or that patients’ trust on HCPs has declined in general, is inappropriate.

The second misconceived view about trust is that having more trust is, and should be, an aim in itself. O’Neill argues that this aim is irrational. Should we trust the untrustworthy? Rather, she

points out that one should aim to place more trust in the trustworthy, but not in the untrustworthy. O'Neill argues that our aim should be intelligently placed (or refused) trust. Given that, the matter in first place is not trust, but the trustworthiness of the putative trustee. In real life, what we need to do is judge the trustworthiness of a person in the relevant matter. For example, a patient, in choosing a doctor to perform a surgery, should look for relevant signs of trustworthiness in the doctor. O'Neill proposes three questions to judge a person's trustworthiness – 1. Is s(he) competent? 2. Is s(he) honest? 3. Is s(he) is reliable? (O'Neill; 2016, 2018). If a person is competent in doing the relevant task, is honest and reliable, s(he) deserves to be treated as trustworthy. If (s)he lacks in one aspect, for example is not reliable, it is unintelligent to place trust in them. In a medical setting, if a doctor is competent in doing what he is required to do, and is honest and reliable, it is reasonable for a patient to trust the doctor. A birthing woman (who may also be vulnerable due to her medical condition and other contextual factors - see 3.7 above) may need to place her trust in HCP. In such context, the HCPs should aim to be trustworthy – (s)he should be competent enough to provide necessary care for the woman and should be reliable and honest. In theoretical analysis of cases in next four chapters, I will look for these three aspects in judging trustworthiness of HCPs.

Before moving on, it will be useful here to discuss a strategy employed by many institutions and professions throughout the world that aims to demonstrate trustworthiness and therefore show that trust in them is intelligently placed – accountability. During the last few decades, efforts have been made to construct systems of accountability at institutions to demonstrate trustworthiness. According to O'Neill, if accountability is intelligently organised, it could be useful for the trustor to judge whether to place (or refuse) trust (O'Neill; 2006, 2014). However, some systems of

accountability fail to produce what is intended, and some are even counterproductive (O'Neill; 2006, 2014). According to O'Neill, systems of accountability often distract professionals from their actual duties – by requiring them to produce evidence of their trustworthiness rather doing the actual work. For example, doing paperwork to prove accountability is an additional burden to a PHM who provides care for a woman in labour. While producing evidence for accountability, she may have missed her opportunities to prove her trustworthiness by action, which is unfortunate (O'Neill, 2006). In this thesis, I advocate for trustworthiness in action, not by written documents.

The third widely spread misconceived view about trust is to understand trust as a task, constructed in terms of the task to rebuild trust. This view, according to O'Neill, has mistaken what trust is. Trust is something to be given, and it is questionable how someone can rebuild something that others have to give. Rather, one can provide a basis for others to trust. In this case, we need to provide usable evidence that we are trustworthy. In healthcare settings, HCPs can provide such evidence for patients by fulfilling the three criteria described above.

In summary, in a medical context, a HCP's role is to ensure that they are worthy of trust being placed in them and to provide the needed evidence and relevant information to allow patients to assess their trustworthiness.

Chapter 4: Patient autonomy, trust, and best interest of the patient; the case of Chathuri

4.1 Introduction

In chapter 2, I presented the methods for the empirical bioethics project I planned to carry out before having to conduct a purely theoretical analysis. To facilitate discussions with women, I developed three vignettes based on both available local literature on ethical issues in maternity care, and the lived experiences of several postpartum women I had spoken to. In this chapter, and those that follow, I theoretically analyse these vignettes, drawing on the ethical principles I outlined in chapter 3, and other relevant literature.

Before moving to analysis of the vignettes, it is important to note that some readers coming from developed Western countries may be intrigued as to why the vignettes chosen are so extreme that, from their perspective, there is no question that the behaviour presented in the vignettes are highly ethically inappropriate. However, I arrived at these vignettes (after consulting the literature and informally consulting post-partum women) and it was clear that the ethical issues presented needed to be extreme, otherwise women coming from Sri Lankan culture may not recognize the problems as ethical issues and thus discussion would not be facilitated by these vignettes.

I shall now start from the first vignette.

Vignette 01

Chathuri is a 32-year-old woman. She privately hired a Consultant Obstetrician & Gynecologist who has a reputation as the best in the area for labour care. She was very healthy and expected to have a normal delivery at a government hospital in two months time. Her doctor informed her that he planned to go abroad in a month, for 2 months, and so would not be around when her child was due. He advised her to have an early c-section, just before he went away, so that he could be present for the birth. Chathuri was not happy about this, but did not feel she could say no, because she feared if she does, she would not get the good care at childbirth she wanted.

Do you think there anything right or wrong about Chathuri's story? Why?

This vignette is about a woman who agreed to have an early c-section as per the suggestion of her doctor, although it is not medically indicated. *Prima facie*, the decision was made by her, but I argue that she was coerced into make that decision because she was not provided with enough options. Going for an early c-section was not her first choice and she was unhappy about it. For her, the best choice was for the doctor to be present at her (normal) delivery on the due date, which had seemingly been previously agreed with him⁵. Chathuri was in theory provided with two options: (1) to go for an early c-section or (2) deliver in the absence of the (hired) doctor. This, however, actually offered her only one 'good' option – as delivering with a doctor present was something she clearly felt was essential. However, she could deliver the baby with another doctor – but this option was not offered to her. The doctor could have referred Chathuri to another doctor

⁵ (I will use the pronouns 'he/him/his for the doctor from now on throughout the theoretical chapters. In Sri Lanka, the majority of Consultant Obstetricians and Gynecologists are males.)

who could provide the care she wanted. One could argue that she could have dispensed with this doctor's services and hired a different doctor. However, given that the nature of doctor- patient relationship in a Sri Lankan context – in which patients readily accept the paternalistic advice of doctors, trusting that they act in best interest of patients - Chathuri may have believed that the doctor's suggestion of c-section was for her best interest, especially given that she would likely have assumed he would know that delivering without a doctor was not an option for her. Given that, the doctor has arguably breached her trust and has exploited her in order to keep her custom. With the limited information presented in the vignette, it is not clear about the doctor's motivation – which is an integral part of his trustworthiness. If his motivation were to get personal benefits, for example, to get extra amount of money by performing a c-section, or to not lose Chathuri's custom, he was not honest and trustworthy. In addition, it is not clear whether a risk/benefit assessment was performed, but it looks like the necessary information about risks and benefits of an early c-section was not provided to Chathuri to support autonomous decision making. It is questionable whether the interests of the women (and the child) were adequately considered by the doctor.

4.2 Patient autonomy in decision making

One of the key questions one could raise about Chathuri's case is whether she was able – and also permitted - to make her own decision. Let us now consider that, referring to the procedural account of autonomy I adopted in chapter 3 (see 3. 4 above). A person can be considered sufficiently autonomous if she is free from controlling interference and have adequate understanding to deliberate on her own choices. Given that, I aim to answer two questions: (a)

Was her ability to make a decision interfered? and (b) Did she have adequate understanding to take a decision?

There are two types of interference one could have – external (i.e., influences or coercion by others) and internal (i.e., disturbance of mind or insufficient reasons). I argue that Chathuri was interfered with in both ways.

Although Chathuri did not want a c-section, she felt like she should oblige to the doctor's suggestion. In my opinion, the doctor's advice was manipulative in two ways - the way the doctor expressed his message, and its content. Seemingly, the doctor had already decided for her and then informed her what she should do. He excluded some important information from his advice such, including other possible options (for example, being referred to another doctor who could assist her childbirth on the due date) and this is information manipulation (see 3.8 above). He also conveyed the message in a way that implied it was in her best interest to have a c-section. As he claimed to be the best doctor in the area, Chathuri believed what was suggested was the best option. It was clear that she wanted him to preside over the birth, believing him to be the best doctor in the area, but she may well not have realized that other doctors might be equally competent, or release the addition risks of unnecessary c-section might outweigh risks of a slightly less experience doctor. The way the doctor offered her a c-section did not give her space to think, especially in a Sri Lankan context, in which a doctor's decision will be taken as the final word without questioning – with a belief that it is the best. In a Sri Lankan context, as discussed above, patients trust doctors, and tend to believe that they (always) act in benefit of patients. They will thus tend to accept (paternalistic) advice without questioning (see section 3.5 and 3.7 above), and

this potentially makes them vulnerable. It is plausible to think that the doctor took advantage of the trust placed in him, using it to manipulate her – which is clearly a moral wrong. Now, let us consider whether Chathuri was free of internal interference.

As presented in the vignette, Chathuri believed that if she refused the doctor's offer, she would 'not receive the good care she wanted'. Making assumptions about her thinking and motivation, and exploring what the outcome would be is a useful way to consider under what circumstances she might have had some kind of internal interference. One possibility is that she was in fear of childbirth, as many women are (Areskog, 1983; Nilsson, 2018; Storksens et al, 2012), which may be the reason she privately hired the doctor (even when government hospitals provide free care) to ensure that she will be given extra support during her labour – which may be the best possible strategy that she could think of for overcoming her fears. If she were in fear, it might interfere with her autonomy. In such a case, the doctor then has a responsibility to explore that and reassure her about the alternative care she would receive. Another possibility is that she may be worried about getting substandard care if she had to rely completely on government funded care. In my opinion, this would indicate a deficit in her understanding, and again the responsibility lies with the doctor to support her to develop better understanding of the care she would receive at a government hospital.

In both these cases, either fear or misunderstanding could well have been impaired Chathuri's ability to make an autonomous decision, but rather than acting paternalistically the correct thing to do would be to correct her misunderstandings and to provide necessary information to support her to overcome unjustified fears. If, after that, she wanted private healthcare at any cost, knowing

full well that public maternity care will be good enough, and was not being motivated by unjustified fear. Then there does seem to be acting autonomously.

Moving away now from hypotheticals, based on the information in the vignette I argue that Chathuri had not have adequate understanding to make an autonomous decision, but she could have been supported to make an autonomous decision. She was (a) not informed about possible options and (b) was unaware about risk & benefits of a c-section compared to a normal delivery. Chathuri, knowing what she did, had little choice but to accept the offer of c-section.

Consequently, she was not in a position to give informed consent for the c-section. Informed consent is the expression of respect for autonomy. As discussed above, there are three components to informed consent: a) the patient makes a voluntary decision, b) the patient has capacity to make a decision, and c) the patient was sufficiently informed to make a decision. According to the account I adopted, a person acts voluntarily when his action is a result of his will and not under the control of another's influence (see section 3.4 above). As I argued earlier, Chathuri was manipulated, and it is therefore reasonable to conclude that her voluntariness was impacted. If Chathuri was afraid of childbirth as I discussed earlier, it may have clouded her decision-making capacity. She was not sufficiently informed, as I argued earlier. Given that, it is plausible to conclude that the doctor failed to respect for her autonomy. He should have assessed her capacity, concluded that she has no cognitive deficit that would impair her ability to make a decision, and then facilitated autonomous decision making by providing her with necessary information.

Now I shall move to discuss whether the doctor's decision could have been in Chathuri's best interest.

4.3 Best interest of the patient

I argued earlier that the doctor was manipulative, however his advice may have been genuinely paternalistic if his doctor's intention was to act in her best interests. If the doctor was paternalistic, he may have manipulated Chathuri believing that an early c-section with him is the best option. Given that, let us evaluate whether the decision was for the best interest of Chathuri.

It is important to note that the term 'best interests' is used in different ways. It has strict legal usage in the UK law (Mental Capacity Act, 2005). However, in ethics, it is generally used in a much broader sense, and I am working here with Beauchamp & Childress's (2009) definition of best interest standards (which I outline later). I will assume, for the sake of argument, that the doctor intentionally presented Chathuri with 'no good choice' in an attempt to essentially make the decision for her. The question then becomes, 'could his action be justified on the grounds of it being in Chathuri's best interests? It is important to note that in making a decision in the patient's best interest, the doctor is doing something that is very difficult (if not impossible) to justify if the patient has capacity (Beauchamp & Childress 2009). Let us assume, then, to give the doctor the absolute benefit of the doubt, that he had good reason to believe Chathuri lacked capacity and he could not do anything to support her in making her own decision. According to Beauchamp & Childress (2009), "[u]nder the best interests standard, a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs". The surrogate

has to do a comparative assessment of risks, benefits, and costs, and in doing so, the patient's preferences, values, and perspectives should be considered. Now, let us move to decide whether Chathuri's best interest would have been served by the choice that was effectively made for her. First, I outline her preferences, values, and perspective as indicated in the vignette. Then I perform a risk-benefit assessment to see which delivery method (normal delivery or c-section) is (medically) more beneficial and has lower risk. I also compare costs of the two methods, before reaching a conclusion about what would be best for Chathuri.

It is mentioned in the vignette that Chathuri wanted to have a vaginal delivery at a government hospital. She was unhappy about going for an early c-section, implying she valued vaginal delivery over a c-section and wanted to deliver the baby on due date. She hired the doctor to ensure that she will be supported during her labour. She accepted the offer of early c-section just because she was afraid that she would not get the good care at childbirth she expected, which suggest that receiving good care is a high priority for her. In my opinion, so long as she would receive good care at hospital, even in the absences of hired doctor, her interests would be best served by waiting and not having an early c-section. I argue that Chathuri's expressed and implied preferences are to receive good care for a vaginal delivery – and she is more concerned with receiving good care than getting care from particular person. It was not mentioned in the vignette whether she would have to go to a private hospital for the c-section, however, if that was the case, it would be a deviation from her expressed preferences. In summary, Chathuri's higher preferences (see 3.4 above) does not match with what she was offered. Having considered what would be most consistent with Chathuri's preferences, I shall move to the risk/benefit assessments.

C-sections have both benefits and risks, however, there is a general consensus that risks, and possible complications outweigh the benefits for women who are eligible for vaginal deliveries (Keag et al, 2018; Mylonas & Friese, 2015). A review conducted specifically about risks and benefits of elective c-sections recommended that c-sections should be only performed when it is medically indicated and clearly advantageous, and elective c-sections should be avoided (Mylonas & Friese, 2015). The possible benefits for women engaged in elective c-sections (compared to a vaginal delivery) are very limited: less vaginal injury, reduced pain after the birth, reduced rate of urinary incontinence and pelvic organ prolapse (Keag et al, 2018; Mylonas & Friese, 2015). However, the number of possible complications is high. Some examples for intraoperative complications are infections, organ injuries to bladder, intestine and ureter, risks associated with anesthesia, need for blood transfusion, hysterectomy as a treatment for severe bleeding. Some examples for post-operative complications are adhesions, persistent pain, thromboembolic complications. Some examples for risks women have for subsequent pregnancies following c-section are intrauterine growth retardation, preterm delivery, spontaneous abortions, ectopic pregnancy, still births, uterine rupture, infertility, placenta previa, increta, or accreta and associated risks e.g., need for blood transfusion or hysterectomy (Weiss 2020; Martin 2012). Not only are women at risk, but also the babies. In neonates, risks are significantly associated with gestational age. The lowest complication rates are seen when c-section is performed after 39 gestational weeks. Cesarean deliveries before then have higher risk of respiratory complications (for example respiratory distress syndrome) in the newborn and requiring intensive medical care. Long term medical effects of c-sections to babies include bronchial asthma, type 1 diabetes mellitus, various food allergies and allergic rhinitis (Keag et al, 2018; Mylonas & Friese, 2015). The general consensus is that c-sections cannot be considered on a par with normal vaginal delivery (Keag et

al, 2018; Mylonas & Friese, 2015; Wiklund et al, 2007). I have summarized the advantages and disadvantages of both vaginal delivery and c-sections in table 1 below.

Table 1: Advantages and disadvantages of vaginal delivery and c-section

	Advantages	Disadvantages
Vaginal delivery	To the mother <ul style="list-style-type: none"> • Speedy recovery (<i>Recovery after a cesarean</i>, 2019; Weiss 2021). • Shorter hospital stays (Childbirth Connection, 2006; Weiss, 2021). • the mother is usually able to start nursing the baby sooner after delivery (Martin, 2017). 	To the mother <ul style="list-style-type: none"> • May have tears in vulva/ perineum (Childbirth Connection, 2006) and may need stiches to repair (Kettle, 2007). • May have pain in the perineum and vaginal area (Childbirth Connection, 2006).
	To the baby <ul style="list-style-type: none"> • Skin to skin contact and breastfeeding can be initiated sooner (Martin, 2017) • reduce the incidence of breathing problems for baby (Martin, 2017) • During delivery, baby receives a helpful dose of good bacteria which boost baby’s immune system (Martin, 2017) 	To the baby <ul style="list-style-type: none"> • Risk for birth injuries such as temporary bruising to the head, if the baby is large (<i>Birth Injury</i>, 2019).
C-section	To the mother <ul style="list-style-type: none"> • The birth can be scheduled in advance allowing for time to be controlled and predictable (Martin, 2017) 	To the mother <ul style="list-style-type: none"> • High likelihood of a repeated c-section in consequent childbirths (Weiss, 2020). • Longer stay in hospital (Childbirth Connection 2006). • Longer recovery time after a c-section (<i>Recovery after a cesarean</i>, 2019). • Risk for continued discomfort for months after the birth due to surgical pain (Martin, 2017).

		<ul style="list-style-type: none"> • Increased risk of placenta previa, placenta accreta, and placental abruption in future pregnancies (Weiss, 2021). • Higher risk for infections (Childbirth Connection, 2006). • Risk of injury to the bowels or bladder (Weiss, 2021) • Increased risk of the death of the mother due to blood clots, infections and complications from anesthesia (Martin, 2017). • Delayed initial contact with the baby (Childbirth Connection, 2006). • Infertility Childbirth Connection, 2006) • Increased blood loss (compared to vaginal delivery) (Weiss, 2020).
	<p>To the baby</p> <ul style="list-style-type: none"> • lower risk of head bruises during delivery (<i>Birth Injury</i>, 2019). 	<p>To the baby</p> <ul style="list-style-type: none"> • Accidental surgical cuts (Childbirth Connection, 2006) • Increased risk for postnatal respiratory complications (Buhimschi & Buhimschi, 2006) • Increased risk for asthma in later life (Buhimschi & Buhimschi, 2006) • Increased risk of stillbirth (Buhimschi & Buhimschi, 2006; Childbirth Connection, 2006) • High risk for childhood and adult obesity (Masukume et al, 2018).

Given that the risks and benefits of both delivery methods, I conclude that an early c-section is far less medically advantageous for Chathuri and her baby. Now, let us consider the costs of both delivery methods.

In Sri Lanka, compared to a vaginal delivery, c-section is costlier. The average price of a c-section in Sri Lanka is reported to be \$ 1967 in private sector (price range \$ 1639-2295) whereas a normal delivery priced less than one third of a c-section (123.clinic n.d.). As I mentioned earlier, it was not stated in the vignette where Chathuri's c-section would be performed, but, if it had to be performed in a private hospital it would have cost significantly more, which is arguably not in her interest, but may certainly be in the interest of the doctor.

Considering Chathuri's higher order preferences or vaginal delivery and good quality medical care, and higher risks associated with c-section for negligible (if any) benefit, I conclude that, and early c-section could not be in Chathuri's best interests – whether she had capacity or not. Given that, it is reasonable to question the doctor's motivation behind his offer to Chathuri.

4.4 Trustworthiness of a doctor

Trust is unavoidably necessary in medical care (see section 3.7 above). Especially when a person is vulnerable due to her medical condition, she expects the doctors to care for her interests, and trust accordingly (Hall et al, 2001). Chathuri (who was vulnerable due to the health condition and related fears) trusted the doctor that he will act in her interests. Let us assess, first, whether the doctor was in fact trustworthy. For this, I refer to the three questions posed by O'Neill (see section

3.7 above) to judge a person's trustworthiness – 1. Is s(he) competent? 2. Is s(he) honest? 3. Is s(he) is reliable? (O'Neill; 2016, 2018).

The doctor in Chathuri's case has his reputation as the best in the area for labour care and taking this at face value, it is clear that he was competent to provide labour care. It is plausible to assume that he is also reliable, given his reputation. However, I argue that the doctor was not honest with Chathuri. As I argued earlier, it is clear that an early c-section was not in Chathuri's best interests – and if he thought it was, then he was certainly not competent. One possible explanation, then, is that the doctor was motivated by a desire not to lose his fee. he could also have been further motivated by the large sum of money that is usually paid to a doctor when a c-section is performed at a private hospital (if Chathuri delivered in such place). In addition, the doctor was not honest with Chathuri about possible harms to Chathuri and her baby due to medically not indicated early c-section. Given that, it is plausible to conclude that the doctor was not trustworthy. *Prima facie*, Chathuri was wrong to place trust in him. The problem, however, is that she could not reasonably have known he was not trustworthy, given his reputation for providing the best labour care in the area, and so she cannot be blamed for placing trust in him wrongly. Rather, the doctor is at fault for not living up to the requirements of his profession to be trustworthy.

Chapter 5: Episiotomy, Pain Management and Patient Autonomy; the case of Wasana

5.1 Introduction

In this chapter, I theoretically analyse the case presented in vignette 02.

Vignette 02

Wasana is 26 years old and was admitted to a hospital for a normal delivery and she had a baby. Before the delivery, she told the doctor that she did not want to have an episiotomy, but if it was absolutely necessary then she wanted local anesthesia. During the delivery, the doctor performed an episiotomy without informing her and without giving local anesthesia. Later, he told her that episiotomy is routine in the hospital, and that local anesthesia is not necessary. However, Wasana found it very difficult and painful.

Do you think there anything right or wrong about Wasana's story? Why?

This vignette is about routine episiotomy, which is still in practice in Sri Lanka despite its recognition internationally and locally as a clinical practice that is not recommended (SLCOG, 2013; WHO 2018a; WHO 2018b). In this chapter, firstly I provide a brief account of episiotomy and its use in Sri Lanka. Secondly, I move to theoretically analyse the case of Wasana.

In theoretical analysis, firstly, I evaluate the doctor's decision to go for an episiotomy from a clinical point of view, to decide whether the benefits outweigh the risks. Secondly, I will discuss informed consent, which was not achieved in this case. Seemingly, Wasana trusted the doctor to act according to her request. I will discuss how trust is misplaced in this case. At the end of the

chapter, I will look into ethical aspects of pain management during labour, which is not prioritized in Sri Lankan settings.

5.2 Episiotomy and its practice in Sri Lanka

An episiotomy is a surgical cut performed into the perineum to further enlarge the dilated vaginal opening of a woman who is in the second stage of labour (Thacker & Banta, 1983; Serati et al, 2019). It is one of the most commonly performed obstetric procedures throughout the world, and has a long history (Huy, 2019; Serati et al, 2019). Establishment of routine episiotomy was identified as a milestone achievement in the history of obstetric care (Serati et al, 2019). However, it is important to note that episiotomy was introduced into obstetric practice without strong scientific evidence of its effectiveness (Lede, 1996) and with anticipation of some ‘hypothetical’ benefits - such as to prevent harm due to spontaneous perineal tears during vaginal delivery and to prevent postpartum complications (Thacker & Banta, 1983; Serati et al, 2019). However, obstetricians and women later started to question its predicted benefits, with increased observation of postpartum complications such as pelvic pain and associated morbidities such as postpartum pelvic floor disorders (for example, urinary incontinence, urinary retention, flatus incontinence) and sexual dysfunction (Huy, 2019; Serati et al, 2019). The first meta-analysis published in the Cochrane library in 2005 warned against the routine use of episiotomy, mentioning its association with high risk of postpartum complications (Hartmann et al, 2005). A Cochrane review in 2017 concluded that only selective use of episiotomy is beneficial in women in normal deliveries and showed that conducting routine episiotomies to prevent severe perineal tears cannot be justified. The systematic review failed to identify any benefit of routine episiotomy to the mother or baby

(Jian et al, 2017). As a result, episiotomy has started to be regarded as a harmful and sometimes unethical clinical practice (Serati et al, 2019).

Informed by scientific evidence, guidelines were developed (and revised) about use of episiotomy in clinical settings. The National Institute for Health and Care Excellence (NICE) recommends that episiotomy might be used in cases where foetal distress is present and the baby should be born quickly, an instrumental delivery (forceps or vacuums) is indicated, or risk of a tear to the anus is identified (Guideline, n.d.; Gurol-Urganci, 2013; Jangö et al, 2014). However, the American College of Obstetricians and Gynaecologists does not recommend the use of episiotomy for instrumental deliveries due to increased risk of perinatal pain and dyspareunia (Guideline n.d.; Sartore et al, 2004; Verghese et al, 2016). Although there are disagreements over use of episiotomy in emergencies, all currently available guidelines are against its routine use. For example, the WHO episiotomy policy 2018 does not recommend routine episiotomy for women undergoing spontaneous vaginal birth. It states that “[..], the lack of evidence on the effectiveness of episiotomy in general, and the need to discourage the excessive use of routine episiotomy across all settings, the Guideline Development Group felt that it was important to emphasize that routine use of episiotomy is “not recommended”, rather than recommending the selective/restrictive use of episiotomy” (WHO, 2018). The Sri Lanka national guideline on management of labour, which was developed by SLCOG, echo the recommendations of international guidelines. According to the national guideline, routine episiotomy is prohibited for spontaneous vaginal birth in Sri Lanka (SLCOG, 2013).

In addition, it is important to note that national and international guidelines outlined the ethical obligations of a doctor in performing an episiotomy (SLCOG, 2013; WHO, 2018). For example, WHO policy states that, “If an episiotomy is performed, effective local anaesthesia and the woman’s informed consent is essential” (WHO, 2018). The SLCOG guideline emphasise that doctors are required to respect the patient choice whether to perform an episiotomy or not (SLCOG, 2013). I have outlined what episiotomy is, and clinical guidelines on it that doctors are expected to follow. Now, I explore empirical evidence on practice of episiotomy in Sri Lanka.

A study was carried out with the participation of 799 and 283 women respectively from two highly populated tertiary care hospitals - Anuradhapura Teaching Hospital (ATH) and Castle Street Hospital for Women (CSHW) - aiming to compare episiotomy rates, practice of analgesia in episiotomy and maternal postpartum complications within 24 hours of episiotomy. The study found that, in both hospitals, the episiotomy rates are higher than WHO recommended rates of 10% (Melo et al, 2014). Episiotomy rate in ATH was 59% (463 out of 977 participants) while it was 96.5% (273 out of 283 participants) in CSHW. Aside from two women (out of 1082) who had epidural analgesia in labour, none of the other women had effective analgesia before performing episiotomy at both hospitals. In both hospitals, complications such as hematomas, re-suturing, vaginal pack insertion and anaemia were documented within 24 hours. From ATH, 12 episiotomy complications cases were reported while 8 cases were reported from CSHW (Perera & Fernando, 2013). Another study, carried out in Colombo Teaching Hospital with the participation of 876 women, reported an episiotomy rate of 51.4%. Prevention of perineal tears was the most reported indication for episiotomy (87%). Eighty percent of women complained of moderate to severe pain while performing the incision, while 73% complained of moderate to severe pain during suturing. In 8% of women, suturing was done later than half an hour after performing the episiotomy. 1%

Lignocaine was infiltrated for pain management, which seemed to be insufficient (Weerasekera & Udugama, 2002). It is plausible to think that the situation in Sri Lanka may have improved to some extent, and these studies may not reflect today's situation. However, when I inquired from several doctors and few postpartum women who had recent childbirth, they mentioned that the issues remain the same even today. Now, let us move to theoretical analysis of Wasana's case.

5.3 Was (routine) episiotomy needed for Wasana?

When Wasana inquired, the doctor mentioned that an episiotomy was performed on her as a routine practice. Other than that, he failed to provide any (acceptable) reason such as a medical indication which requires an episiotomy. As outlined above (see section 5.1), episiotomy is beneficial only in limited situations such as in some instrumental deliveries. Other than that, scientific evidence shows episiotomy has no benefits to the birthing women or to the baby. Even the situations which are considered medical indications generally are questioned by recent empirical evidence. For example, although there is a general consensus that episiotomy is beneficial in instrumental deliveries, scientific evidence is controversial, and there is evidence that it is not always the case (Youssef et al, 2005). For another example, episiotomy is considered a good way to prevent harm due to natural perineal tears, but empirical evidence shows that natural tears are actually less harmful and heal faster compared to laceration due to episiotomy (Munro & Jokinen, 2008). Empirical evidence shows that episiotomy is not effective in producing the intended benefits (Hewage et al, 2018; Youssef et al, 2005). Given that, it is questionable whether an episiotomy has anything to offer Wasana. Rather it is more likely it was actively harmful to her, as she had to suffer from pain and discomfort due to the surgical incision as depicted in the vignette. It is worth

looking at what motivated the doctor to perform an episiotomy, which was not medically beneficial, to consider whether there could be any justification.

5.4 Doctor's motivation behind performance of an episiotomy

Routine episiotomy is a practice which is not recommended by international and national guidelines, and so doctor's decision to do it could be considered professional misconduct. What could be the possible reasons for his nonadherence?

Hartmann et al. found that the doctors who used episiotomy routinely viewed it favorably with beliefs that— a) episiotomy should be used to prevent perineal trauma, and its future sequelae and b) it is easier to repair lacerations by an episiotomy compared to natural tears (Hartmann et al, 2005). It is plausible to think that Wasana's doctor believed the same. However, the first – to prevent perineal trauma, is in conflict with available scientific evidence as I mentioned earlier, and thus cannot be justified. If that was the reason in Wasana's case, it calls into question the competency, and professionalism, of the doctor. It is a duty of a doctor to update oneself with the current scientific evidence related to one's practice. If the doctor genuinely believed that it is beneficial and intended benefit his seems to be in agreement with the principles of beneficence and nonmaleficence *prima facie*. However, it is also in conflict with the principle of respect for autonomy (which I will discuss below), and it would also suggest he is either incompetent or failing stay up to date. If Wasana's doctor's motivation was the second – to make it easier for him in repairing the laceration - the decision was made (only) for his own benefit (against Wasana's wishes), and so would be an entirely selfish act. It goes against the principles of beneficence and nonmaleficence. It could be argued that the doctor is justified in doing this, because a faster repair

would mean he was able to care for more patients. However, the benefits of time saved would be negligible and does not justify the harm to Wasana. Given that his actions cannot be justified on consequentialist grounds, his action represents a clear breach of the trust placed in him by Wasana that he will act in best interest of her (I will discuss this later in this chapter). Now, I will discuss another ethical aspect of Wasana's case – informed consent.

5.5 Clinical interventions without informed consent

Informed consent is the expression of respect for autonomy of patients. It is the standard practice to achieve consent of patients in a medical setting (see 3.4 above). Professional codes and institutional policies require HCPs to obtain informed consent of a women prior performing an episiotomy (if the patient has capacity to consent) (SLCOG 2013; WHO 2018). To achieve informed consent – a) the patient makes a voluntary decision, b) the patient has capacity to make a decision, and c) the patient was sufficiently informed to make a decision.

In Wasana's case, she was capacious. Her decision was to only have episiotomy if it was absolutely necessary and then only under anesthetic. She informed the doctor under which conditions she would consent to an episiotomy. Those conditions were not met, and so her consent was not given for the procedure that was performed. It was not mentioned in the vignette whether Wasana was informed as it was happening, however it is clear that the doctor did not ensure that she was or, if she was, she is unlikely to have been in a position to object. Arguably, the first failure of the doctor was not revealing truthful information about how episiotomy is practiced in the hospital when Wasana explained what she wanted, and his second was then performing the procedure without consent. It is plausible to think that the doctor failed to provide relevant information (for example,

risks, benefits, medical indications, alternatives, etc.) to Wasana to decide whether she wants an episiotomy or not. He failed to communicate his opinion, and also, he decided to disregard hers. He could have informed her that he performs episiotomy routinely, and with this knowledge she could have chosen a different doctor or healthcare institution. Not revealing the truth prevented her getting the care of her choice. The doctor clearly failed to respect the autonomy of Wasana by failing to obtain informed consent for the procedure.

One could argue that the doctor's behavior was justifiably paternalistic, and the Wasana was not informed because the doctor did not want to make it difficult for her – he did not want to make her afraid by informing her he did it routinely and felt it would be kinder to just do it when she was not in a position to know what was going on or be concerned about it. However, it is clear that this episiotomy was not performed for Wasana's benefit, and this kind of manipulation cannot be justified in paternalistic terms. In addition, if the doctor's true concern was the best interest of Wasana, he could have given her analgesia to prevent her suffering from pain (assuming it was available). Now, let us consider further aspects of pain management in this case.

5.6 Pain management during labour

Wasana requested to have local anesthesia if it became necessary to perform an episiotomy. As described above, the procedure was not necessary, and that wrong is further compounded by the fact that it was also performed without giving local anesthesia. When questioned, the doctor mentioned that he did it as a routine procedure, and it does not require local anesthesia. However, Wasana found it very difficult and painful. Weerasekera & Udugama (2002) found out that, Sri

Lankan women experience moderate to severe pain during the performance of episiotomy and suturing, when measures were not taken for pain management.

It is certainly true that a doctor cannot be under an obligation to provide something for patient that is unnecessary or futile – especially where resources are scarce – but that cannot apply here. Sri Lankan national guideline on pain relief in labour requires doctors to take enough measures for pain management if episiotomy performed (SLCOG, 2013). It states that, “Adequate relief of pain is a basic right of every mother in labour. It is the duty of every member of the obstetric team to endeavour to achieve this”. Clearer instructions on pain management could not be given. However, local available literature, and anecdotal evidence, suggest that pain management during labour is very poor in many hospitals in Sri Lanka (Perera & Fernando, 2013; Weerasekera & Udugama, 2002), and so Wasana's case is very unlikely to be unique. Now, let us move to assess whether the doctor acted in a trustworthy manner in Wasana's case.

5.7 Trustworthiness of a doctor

It is obvious that Wasana trusted the doctor. Placing her trust in the doctor, she made several requests: not to perform an episiotomy unless it is absolutely necessary, and if it is necessary - to have local anesthesia. However, the doctor was apparently not worthy of this trust. One could argue that Wasana was at fault for trusting the doctor, however, given that Wasana delivered the baby in a government hospital, she had no say in choosing doctors, rather she had to deliver the baby with who is available. Furthermore, it is reasonable to assume that doctors are trustworthy, given the professional standards to which they are held. Given that, the doctor had a responsibility to be worthy of the trust placed in him.

According to the definition of trust by Hall et al (2001), the trustee is expected to act in a way that the trustor approves of (see section 3.7 above). In Wasana's case, the doctor failed to honor the trust placed in him when she was most vulnerable and failed to act in a way that Wasana had requested. As I have already argued, trust is inseparable from vulnerability. It is the duty of the HCP to protect and act in the best interest of the patient (who is necessarily vulnerable – but some more so than others) (see section 3.7 above). Wasana was certainly vulnerable due to health risks associated with childbirth, and the generally stress, anxiety, pain, and dependence that comes with childbirth and the doctor had an ethical obligation to keep the trust she placed in him by honouring her autonomous wishes.

Chapter 6: Patient's dignity and obstetric violence; The case of Udani

6.1 Introduction

In this chapter, I will theoretically analyse the case presented in vignette 03.

Vignette 03

Udani is 16 years of old. She is unmarried and pregnant, and attended hospital for a normal delivery. However, in the labour room, she could not tolerate the pain and screamed. A nurse came to her and shouted at her, telling her to stop making such a fuss and that she should have thought about this before having sex. Udani felt so ashamed at that moment. However, a doctor and another nurse who overheard this conversation came to her and cheered her up. Udani believed that the bad incident occurred for her good as it helped bring in other staff who were empathetic and supportive.

Do you think there is anything right or wrong about Udani's story? Why?

In this chapter, I will characterize Udani's treatment as an incidence of obstetric violence. In doing so I will present some data on obstetric violence in Sri Lanka using (limited) available literature. I will argue that obstetric violence, of any kind, is morally wrong, drawing primarily on the principle of nonmaleficence.

It is not uncommon for women in labour to express their pain in different ways, such as screaming, but women would rarely be scolded for it. It is important, therefore, to understand why (only) Udani was scolded (rather than being comforted) by the nurse. I argue that, in this vignette, Udani was in relatively vulnerable position – a confluence her age, labouring status and likely low social

status, which made her (more) vulnerable to being ill-treated by the nurse. The nurse who scolded her exploited Udani's vulnerability (for what reason, we can only speculate), and felt *able* to shout at Udani – perhaps because she made the assumption that Udani was not in a position to complain or fight back. In the following analysis, I will discuss how Udani is extra vulnerable in this case and how it relates to obstetric violence. I will further discuss what makes women vulnerable to obstetric violence during childbirth in a Sri Lankan context using available literature.

6.2 Obstetric violence

Women experience mistreatment, violence, abuse, disrespect, etc. during childbirth in health care institutions throughout the world (Bohren et al, 2015; Perera et al, 2018). Such negative treatment can be described as 'obstetric violence'. Obstetric violence is a legal term introduced in Venezuela in 2007 (D'Gregorio 2010), which captured certain acts of violence directed at women by HCPs in care provision during childbirth. For example, using instruments and medications without clear medical indications, disturbing natural birthing process, has been identified as an act of obstetric violence according to its original definition conceptualised. In this thesis, I will use a definition adopted to the Sri Lankan context by Perera et al (2018), who characterise obstetric violence as “mistreatment of women that occurs in the care provided during pregnancy, childbirth, and the immediate postpartum period. It includes bullying and coercion of pregnant women during birth by health care personnel, [and]...a systemic problem of institutionalised gender-based violence” (Perera et al, 2018).

Now, let us consider Udani's case.

Udani was scolded by the nurse when she screamed out of labour pain, who also used Udani's deprived social status, i.e., being a teenager who got pregnant out of wedlock, to castigate her. Udani was not exposed to any physical harm, but she was made to feel ashamed, unwelcome, undeserving, and less than human. In scolding her in this way, the nurse clearly failed to respect Udani's dignity and to treat her humanely. It is clear that Udani was psychologically harmed by the nurse's act of bullying. In reference to the principle of nonmaleficence (see section 3. 2 above), the nurse's behaviour is clearly morally wrong. According to the principle of nonmaleficence, a HCP has a (negative) obligation not to inflict harm on patients. Such harm could be any negative effect on the physical or psychological health or wellbeing of the patient, and this principle is clearly breached here.

Although limited, available literature suggests that Udani's experience of obstetric violence is not uncommon in the Sri Lankan setting. According to the study carried out by Perera et al in 2018, it was reported that obstetric violence is prevalent in health care institutions in Sri Lanka (Perera et al, 2018). Breaking 'the traditional culture of silence'⁶, PHMs who participated in the study agreed that obstetric violence is common in Sri Lanka and it needs to be addressed. A PHM quoted in Perera et al's study said the following:

"I will not try to safeguard my colleagues. Yes, it is happening...and not only in the hospital...Also, some of us in the field are responsible for certain occurrences of abuse."

(Perera et al, 2018, p.05).

⁶ In Sri Lanka, people, although experienced, heard, or witnessed obstetric violence, tend not to talk about it or act against. It seems, due to patriarchic, paternalistic culture, speaking up against HCPs has been considered not suitable and acceptable (Perera et al, 2018)

Women also expressed how common obstetric violence is in health care institutions. For example:

“I have seen enough staff blame mothers...[..] but I am not afraid to say that some of them [health care providers] are very rude to their patients.” (Perera et al, 2018, p.06).

It was reported that women felt ‘very upset’, ‘insulted’, ‘embarrassed’, ‘stupid’, ‘shocked’, and/or ‘bewildered’ while in labour due to experiences of obstetric violence. For example, a woman recalled:

“All the time, she [the nurse] was blaming me, telling me that I was a headache to her. As I understand, I didn’t do anything wrong.” (Perera et al, 2018, p.06).

Obstetric violence not only impacts women’s psychological health, but also on decision making related to reproductive health, as one PHM recalls:

“I asked the woman for the reason why she wanted a permanent method (of sterilization) ...At last she came out with the true story...A terrible story to tell...[She] had been hit in the hospital...She was suffering a lot from the incident. She didn’t want any more children because of what had happened.” (Perera et al, 2018, p.05).

Although women experience obstetric violence, they do not tend to disclose such incidents to anyone, even to the close informal network of people. Some women expressed themselves as follows:

“We very rarely say anything about these things to others, or we do not complain about these things to anyone [at all]” (Perera et al, 2018, p.06).

“Although we experience things, we keep quiet. We do not argue back” (Perera et al, 2018, p.06).

“I bore it [the violence]. It was my fate.” (Perera et al, 2018, p.06).

It is important to ask why (some) Sri Lankan women experience obstetric violence and bear it in silence. I argue that it is likely connected to their increased vulnerability - not simply because they are pregnant and/or labouring, but a confluence of factors. Further, this vulnerability makes the violence they are exposed to even more morally wrong.

6.3 Vulnerability and obstetric violence

Vulnerability makes patients more prone to coercion, manipulation, and exploitation (see section 3.6 above). I argued above that birthing women can be considered vulnerable because of childbirth related health risks, and due to fear and anxiety associated with it. I also argued that vulnerability also arises from other non-pregnancy related factors such as poor socio-economic status, ethnicity, education level, which combined creates extra layers of vulnerability for birthing women. I used the concept of intersectionality to understand how vulnerability operates (see section 3.6 above). If a woman is uneducated and coming from a low socio-economic class, she is doubly vulnerable, where if a woman comes from a marginalized social group, is uneducated and coming from a low socio-economic class, she is triply vulnerable. The concept of intersectionality allows us to understand how a labouring woman can be vulnerable in many different ways and combined may make her particularly vulnerable to abuse. It is important to identify what factors make birthing women extra vulnerable in a Sri Lankan context, and why that might so readily invite and/or allow obstetric violence. For that, I shall look at findings of the study carried out by Perera et al (2018), which aimed at exploring how age, social position or class, and linguistic and cultural background intersect and place women in varying positions of control and vulnerability to obstetric violence

in healthcare institutions in Sri Lanka. Then I will return to the case of Udani to see how she was vulnerable.

Perera's study found that disadvantaged social status, poor financial ability, linguistic and cultural background (inability to communicate in a language HCP speaks), and young age (teenage pregnancy) make women extra vulnerable to obstetric violence (Perera et al, 2018). Perera et al mention a (true) story of a woman, who had limited formal education and poor socio-economic status, to show how women coming from poor socio-economic backgrounds are treated differently during childbirth in health care institutions.

The woman, while in labour, passed a stool on the bed and when she requested another bed cloth the midwife threw a bed sheet at her and telling her that she was 'like a toilet'. The nurse who attended blamed the woman for 'messing up' the labour room. She explained "The nurse cursed me, telling me that even though I had not a cent to buy a cloth I had got 'the other things' [that is, becoming pregnant] done 'in good time'". When the woman was in severe pain at the last stage of childbirth, she accidentally touched a midwife who was standing near her. The midwife's response was to turn and slap the woman over her hands, yelling at her not to touch her (Perera et al, 2018).

Another research participant – a woman who got married in young age and went for her childbirth in a government hospital, explained how she was treated badly during childbirth:

"I still feel so upset to be reminded about what happened. That second 'Sir' [doctor] came to me and from the very first moment stared at me and asked me in a rude way to keep my legs in 'the correct position' [for him] to check [the progress of the labour]. I did as he

asked. Oh god! How terrible! That was the moment I felt the most severe pain during the entire labour – when he was checking me. I had no control and screamed loudly.” (Perera et al, 2018, p.07).

When she was crying with pain the doctor scolded her. Later in the labour, when she was exhausted and unable to push the baby out, the doctor slapped her. She explains:

“Then that doctor came close to me and pinched me on my shoulder, asking [me] to push, but I was weak. Then he slapped me on my thighs vigorously. Other staff around him kept silent.” (Perera et al, 2018, p.07).

What the women in Perera’s study tended to have in common was poor socio-economic background, young age, ethnicity and speaking language. Regarding the latter, Tamil and Muslim women sometimes experience obstetric violence, particularly verbal and emotional violence during childbirth due to their lack of ability to speak in Sinhala.

Whatever the motivation (whether an inherent racism, misogyny, classism, or simply misplaced moralising), these combined vulnerabilities appear to signal to the HCP who might have tendency towards ill treatment that ‘this is a woman who will not, and cannot, fight back’ and is therefore an easy target.

Now, let us consider to what extent Udani was extra vulnerable during childbirth, referring to the concept of intersectionality. I argue that Udani was doubly vulnerable during her childbirth. Getting pregnant before getting married is not socially acceptable in Sri Lankan culture. The young

are expected to abstain from sex before marriage, and if they engage in sex, it is considered morally wrong (Jordal et al, 2013). Given that, Udani becomes someone who is morally suspect. This can lead to Udani being discriminated against in society in general, but also by HCPs. Ultimately, the perception that Udani is somehow tainted by her own behaviour suggests she is not deserving, and furthermore deserves to be treated poorly. The nurse's scold reflects how she (and society in general) treat people in Udani's position.

I argue that her vulnerability makes the obstetric violence even more wrong. It is more than simply transgressing non-maleficence; it is also an abuse of trust and an abuse of power. When patients come with vulnerabilities, HCPs have an extra responsibility to protect them from mistreatments in a health care setting (see section 3.6 above). Whatever their life circumstances, patients have a right, in that space, to be treated with dignity and respect, which is equally applicable to Udani, and so the way she was treated in the labor room is not acceptable.

It is likely that, in Udani's case, the nurse was not seeking an 'easy victim', but felt she was justly and appropriately castigating someone who deserved it. This makes it no less wrong, or any less abusive, but it seems important to differentiate between cases of obstetric violence that are rooted in violence *per se* (and labouring women are an easy target on which to vent a tendency for violence) and cases where the violence is viewed by the perpetrator as form of justice - each of which will require a different sort of response. In my opinion, immediate legal measures should be enforced to protect the vulnerable to protect from the first – which are rooted in violence and abuse. For the second, it is possible that educating HCPs might be sufficient to correct the misbehavior – assuming that the motivation to seek 'justice' comes, ultimately, from a place of caring.

Chapter 7: Conclusions

In this chapter, firstly I will summarise the findings of the theoretical analysis conducted over the last three chapters. Secondly, I aim to generate some broad conclusions from the work, which will lead to the recommendations of the study. At the end of this chapter, I will discuss, to what extent I was able to achieve aims of the original research project, albeit via a different route.

7.1 Summarising findings - Ethical issues in childbirth care provision in Sri Lanka

Vignette 01- The case of Chathuri:

This case was about performing a c-section which is not medically indicated. The patient's choice was not to go for an early c-section, but she accepted when it was offered. Ethical issues identified: The patient's autonomy was not respected by the doctor in decision making. She was manipulated to consent. The decision was not for the patient's benefit, but for the doctor. The doctor breached Chathuri's trust that he would act in her interests. Reflection: In a paternalistic Sri Lankan medical context, patients can be manipulated easily as they trust HCPs and are ready to acquiesce to what HCPs suggest.

Vignette 02- the case of Wasana:

This case was about a woman who had to undergo a routine episiotomy, which is not medically indicated. Ethical issues identified: Episiotomy was performed without obtaining the patient's informed consent. The performed episiotomy was not beneficial to the patient. The doctor failed to act in the best interest of the patient. The doctor breached patient trust. Reflection: Routine episiotomy is still in practice in Sri Lanka despite it not being recommended. Such practice is not to serve the patient, but to make life easier for the doctors in repairing the incision. In trust based,

paternalistic Sri Lankan context, the doctors have an extra obligation to act in benefit of patients. Patient autonomy should be respected, and informed consent should be obtained for episiotomy.

Vignette 03- the case of Udani

This case was about obstetric violence. Udani, an unmarried teenager who was admitted to the hospital for childbirth was abused verbally and physically by a nurse during her childbirth. Ethical issues identified: The patient experienced obstetric violence, which is unambiguously morally wrong. The patient's vulnerability makes the obstetric violence even more wrong as it is more than simply transgressing non-maleficence; it is also an abuse of trust and an abuse of power.

7.2 Findings of the normative analysis

Ethical issues identified in the theoretical analysis are summarised above. In this analysis, a few key common themes are emerging on ethical aspects that need to be addressed in improving quality of care provision during childbirth in Sri Lankan context.

The Sri Lankan medical context is **paternalistic**, and there is a power imbalance present in doctor-patient relationship. Medical paternalism is often welcomed and accepted by patients in general. Patients trust HCPs that they will act for their benefit, and this trust is the basis for their acceptance of paternalism. In a such context, the possibility to misusing and abuse patient trust is significant. Patients, especially the uninformed, may accept and tolerate behaviors of HCPs which are not actually going to serve them, due to readiness to accept paternalistic behaviors. In such a context HCPs have a clear ethical obligation to keep the trust placed in them, and to always act in patients'

interest – however easy it may be to act in their own. It is morally wrong to abuse trust placed in them and to use patients' acceptance of paternalism for personal gain.

The other key issue emerging from the analysis is that HCPs not **respecting autonomy of patients**. In decision making, patients are sometimes not involved, and HCPs may fail to achieve true **informed consent** of patients. Patients are not always informed enough about the medical procedures that they undergo. Patients are not always asked for, or may not readily offer, their opinion or choices in decision making. In many cases, doctors will decide what is best for the patient, which may (or may not) be actually beneficial. In a context of relatively low scientific literacy, in which paternalism is accepted without a question, patients are particularly vulnerable, and HCPs have a correspondingly extra strong ethical obligation to provide enough information about medical procedures to the patients, and to communicate their medical opinion to the patient, so that the patient can decide for themselves. Arriving at a shared decision will always be a more appropriate way to make decisions in a Sri Lankan context – through it may be difficult to achieve. HCPs have a moral obligation to support and empower patients to take (autonomous) decisions for themselves.

As I argued above in chapter 3, Sri Lankan women are extra **vulnerable** during childbirth. Women coming from low socio-economic status, with poor education, ethnic minority groups, etc. are more vulnerable to be treated differently in a Sri Lankan health context. But there is also an additional vulnerability created by the tendency to accept paternalism without question. Given that, there is a positive obligation for HCP to identify and mitigate such vulnerabilities.

Two key themes emerge from the combined ethical analysis and consideration of the literature. which explain, to some extent, why certain ethical problems are significant in the Sri Lankan medical context. They are a) **paternalism** – the Sri Lankan medical context is paternalistic in its nature, and this is accepted by patients and b) **trust** – patients trust HCP that they will act in benefit of them, which is why they accept paternalism. Two broad ethical problems seem important, which seem to be related – almost enabled – by trust and acceptance of paternalism: c) **Lack of respect for patient autonomy** & not achieving informed consent for medical procedures and d) **Neglecting of best interest of patients in decision making**. Issues such as obstetric violence, coerced c-sections, routine episiotomy are some expressions of these two broad ethical issues. Women who are vulnerable are likely to be more prone to experience ethical issues in care provision during childbirth. As I argued, women are generally vulnerable during childbirth due to their health condition and associated risk of it. In addition, Sri Lankan women are extra vulnerable, especially in health care settings, due to some context dependent intersecting individual factors. The last theme emerging from the analysis is then, e) **vulnerability** of Sri Lankan women.

Having concluded the findings of the theoretical analysis, I shall move to briefly outline some recommendations.

7.3 Recommendations

The normative analysis of this project helps to understand Sri Lankan medical context and its implications on ethical care provision during childbirth. The analysis highlights the need for HCPs to understand the nature of Sri Lankan medical context, and what patients expect and need from them. They also need to understand how vulnerability comes into play, and how extra

vulnerabilities exist that they not immediately recognise. HCPs should aim to adhere to professional codes and guidelines in care provision, as a way to ensure that the patients are benefited. HCPs must also pay attention to ensure that they make decisions in the best interest of patient, but not or their own interests. They have an ethical obligation to support patients to take autonomous decisions by providing adequate information and by making sure that patients are not unnecessarily interfered and should be careful not to breach the trust placed in them. The way forward to improve the treatment of women in childbirth in Sri Lanka may require challenging the culture of paternalism and enabling women's autonomy, choices, safety, and interests to be respected.

The quality of obstetric care in Sri Lanka needs to be improved (Perera et al, 2018; Perera et al, 2013). As I argued elsewhere, addressing ethical aspects of care provision is one of the best ways to achieve this. Educating HCPs about existing ethical issues in care provision during childbirth will be a good way to begin this, and the education of HCPs around respect for autonomy, and around the clinical evidence e.g., the appropriate use of episiotomy, would certainly help. Perera et al (2018) also recommended that it is necessary to sensitize HCPs to obstetric violence for its prevention. A project piloted in Sri Lanka to see whether increasing knowledge and awareness of HCPs about obstetric violence & its consequences help to reduce obstetric violence, showed that it actually helps (Swahnberg et al, 2019). Ethics in obstetric care is not routinely taught to HCPs in Sri Lanka, but it should be included in professional trainings for HCPs, especially those involved in maternity care and delivery.

In addition, empowering women might also help. One of the issues identified is that women may accept and tolerate unethical behaviors of HCPs. Sri Lankan women tend not to complain or inform other people when something unethical happens (Perera et al, 2018). Improving awareness of

women, from where they can get help or to whom they can report/complain when they face such issue during care provision is possible through antenatal classes. Also, it might be possible to teach women that whilst trusting HCPs is necessary and important, they can and should be discriminating in whom they place their trust and empower them with the tools to do that.

7.4 Summary and further work

The overall aim of this project was to identify ethical issues in childbirth health care provision in a Sri Lankan context, and to produce a critically normative account of identified ethical issues. The project was originally planned as a descriptive ethics study in which an empirical bioethics approach would be employed.

However, due to Covid-19 (as I mentioned in the Covid 19 impact statement), I had to perform a theoretical analysis of ethical issues in childbirth in Sri Lanka, based on three vignettes that I developed to facilitate in-depth interviews with postpartum women. These vignettes were not mere stories, rather they are close to the ground realities of the Sri Lankan maternity care; they were developed based on available literature on current health care practices in Sri Lankan health care institutions and women's lived experiences of childbirth care in Sri Lanka. In addition, I consulted three postpartum women in developing and finalizing vignettes, as vignettes needed to reflect common experiences of childbirth in Sri Lanka. Based on available literature and using the ethical principles that I adopted in chapter 3, I theoretically analyzed the cases presented in vignettes, and was able to (normatively) identify several ethical issues in the Sri Lankan context. I was able to provide a critically normative account on ethical issues in childbirth in Sri Lanka. However, there remains a need to generate empirical evidence to clearly identify the ethical challenges faced by women during childbirth in Sri Lanka, which was my original aim in this project.

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Appendix 01: Information sheet for potential participants

A qualitative empirical ethics study to understand ethical aspects of labour and post labour care: Views and experiences of Sinhala speaking postpartum women in Kaduwela, Sri Lanka

Participant Information Sheet

My name is Krishani Jayasinghe. I live in Gampaha, and I am a post graduate research student at the University of Bristol UK. I would like to invite you to take part in the study “A qualitative empirical ethics study to understand ethical aspects of labour and post labour care: Views and experiences of Sinhala speaking postpartum women in Kaduwela, Sri Lanka”.

Before you decide whether to take part, it is important for you to understand why this research is being conducted and what it will involve. Please take time to read this information sheet carefully and feel free to ask if there is anything that is not clear or if you would like more information.

About this study

Childbirth is an important and life changing event for a woman. Childbirth has some risks and can be as a stressful time for women and health care providers. Receiving quality care during childbirth improves positive outcomes for women and children. However, quality care is not always consistently provided, and even when care is mostly good there is often room to improve. Studies conducted in other countries had said that that ‘quality care’ involves more than just looking after a woman’s health, but also involves providing good ‘ethical’ care. Several studies conducted in Sri Lanka suggest that ‘ethical’ care is not always provided, but it is not clear what having ‘ethical care’ means to Sri Lankan women. In this study, we aim to understand both positive and negative birth experiences of women and to identify ethical issues in labour and post labour care in Sri Lanka. We hope that findings of this study will help develop understanding of how to provide better labour and post labour care in Sri Lanka and will facilitate discussions about how to improve quality care provision for birthing women in Sri Lanka.

Why have you been invited?

You have been invited to take part in this study because we believe you have had recent experience of childbirth (in the last 3- 6 months), and you are living in Kaduwela MOH area.

What does taking part involve?

- If you are interested in participating, some basic information about you (age, ethnicity, education level) and whether your labour was with or without complications will be asked from you by me (Krishani). If you are eligible, I will contact you and ask to schedule a meeting to conduct an in-depth interview, to discuss your experience of childbirth.
- This interview will be conducted at a convenient date, time and place chosen by you. It will take approximately 40-60 minutes.

- This interview will be audio recorded and later transcribed. After transcribing is completed the audio recording will be destroyed and the information you give will be analyzed.

Do you have to take part?

No, taking part in this study is entirely voluntary. If you wish to take part you will be asked to sign a consent form at the beginning of the interview. This is to show that you have read this information sheet and agree to take part in the study. Whether you choose to take part or not, your current or future health care will not be affected at all in any way.

What if you want to leave the study at any point?

You do not have to give any reasons for leaving the study and are entitled to leave and have all your information deleted at any time before, during or up until one week after your interview date. Once a week has passed after your interview, the data will have already been analysed, and it will not be possible to withdraw your data from the study. However, you may still ask us not to include your quotes in the write-up and in any publications.

If you wish to leave the study, please contact me (Krishani Jayasinghe) using the contact details on page 3 below.

What are the benefits/risks of taking part?

There are no direct personal benefits to you from participating in the study, but some people enjoy, or find it helpful, to discuss their experiences. Your participation is more likely to benefit women who give birth in the future.

Given the nature of the interview, it is possible that you may recall, and talk about, experiences that you find upsetting – and this may be the case if you had any negative experiences.

You do not have to discuss anything you do not want to during the interview, but if you do find it to be distressing, we will either stop or postpone the interview or we will make arrangements to refer you to the necessary support service, with your permission.

Will your information kept confidentially?

Your participation will be kept confidential and your information and data will be anonymised through the use of a unique study code. Only members of the research team will have access to the data and the link to identify the data. All data will be deleted 5 years after the study completion (approximately January 31st 2021).

Your personal information and data will be kept securely, and only used for the purposes set out in this information sheet and detailed in the consent form.

In some rare circumstances it may be necessary to break confidentiality. If anything you say gives me (Krishani) cause to have serious and significant concerns about your safety or wellbeing (or the safety and wellbeing of others), or suggests that you suffered abuse during labour care, it may be necessary for me to alert relevant authorities. If this did happen, I would discuss it with you before taking any action.

What will happen to the results?

Analysis of the interview will help us understand ethical aspects of labour and post labour care in Sri Lanka, from the perspective of women. We will publish the results in scientific journals, present our work at conferences, and if you would like us to, we will send you a copy of the findings.

Who is funding the research?

This research project is funded by the Wellcome Trust MScR Bioethics programme at the University of Bristol, United Kingdom.

Who has reviewed the study?

This study has been approved by the University of Bristol Ethics Review Committee (ERC No: 96842) and Sri Lanka Medical Association Ethics Review Committee (ERC 19 - 021).

What if I have a complaint?

If you have any complaints regarding the conduct of the study, you can inform either of the ethical review committees listed below, or Dr Jonathan Ives (the UK project supervisor).

Details of Ethics Review Committees:

Chairperson, Ethics Review Committee, Sri Lanka Medical Association, Wijerama Mawatha, Colombo 07, Sri Lanka. Tel : +94(11)2693324 E- mail: office@slma.lk	General enquiries, Research and Enterprise Development, One Cathedral Square, Bristol, BS1 5DD Tel: +44 (0)117 42 83065 Email: red-office@bristol.ac.uk
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For more information please contact:

Krishani Jayasinghe: Tel- 0767465367 | 0112 763065, E- mail - krishanijayasinghe@gmail.com, oi19363@bristol.ac.uk

Dr. Jonathan Ives: E- mail- j.ives@bristol.ac.uk

Dr. Zuzana Deans: E- mail - Zuzana.Deans@bristol.ac.uk

Prof. Athula Sumathipala: Tel - 0112 863084 | 0115 662895, E- mail - a.sumathipala@keele.ac.uk

Appendix 02: Topic Guide

A qualitative empirical ethics study to understand ethical aspects of labour and post labour care: Views and experiences of Sinhala speaking postpartum women in Kaduwela, Sri Lanka

Topic Guide

- Please tell me about your experience of childbirth.
Probing Qs
 - When and where it happened? / How did you get to the hospital? / Who was with you? / How were the facilities? / How much time it took you to deliver the baby? / how do you feel about it?
- What do you think good quality care in childbirth looks like?
Probing Qs
 - What sort of things are essential for care to be good? / How do you think you *should* be treated during and after childbirth? / What do you think are signs of poor quality care?
- How would describe the care that you received during and after childbirth?
Probing Qs
 - Do you think you received good enough care (and why?) / Was there anything that did or did not happen that concerned you?
- Can you tell me about any positive experiences you had during and immediately after the birth?
Probing Qs
 - Why did you find that experience positive? / Do you think everybody should have that kind of experience (and why)?
- Can you tell me about any negative experiences you had during and immediately after the birth?
Probing Qs
 - Why did you find that experience negative / Why do you think this negative thing happened? / How do you feel about it? / What do you think should have happened instead?

If participants struggle to think about and discuss their own experiences, or if they are only able to recall and discuss only a little, the following vignettes will be used to stimulate discussion.

Vignette 01

Chathuri is 32 years old woman. She privately hired a Consultant Obstetrician and Gynecologist who has a reputation as the best in the area for labour care. She was very healthy and expected to have a normal delivery at a government hospital in two months time. Her doctor informed her that he planned to go abroad in a months time, for 2 months, and so would not be around when her child was due. , He advised her to have an early C-Section just before he went away, if she expect him to be present during the childbirth. Chathuri was not happy about this, but did not feel she could say no, because she feared if she does, she would not get good care during childbirth as she expect. .

- Do you think there anything right or wrong about Chathuri’s story? Why?

Vignette 02

Wasana is 26 years old and was admitted to a hospital for a normal delivery she had a baby. Before the delivery, she told the doctor that she did not want to have an episiotomy, but if it was absolutely necessary then she wanted local anesthesia. During the delivery, the doctor performed an episiotomy without informing her and without giving local anesthesia. Later, he told her that episiotomy is routine in the hospital, and that local anesthesia is not necessary. However, Wasana found it very difficult and painful.

- Do you think there anything right or wrong about Wasana’s story? Why?

Vignette 03

Udani is 16 years of old. She is unmarried and pregnant, and attended hospital for a normal delivery. However, in the labour room, she couldn’t tolerate the pain and screamed. A nurse came to her and shouted at her, telling her to stop making such a fuss and that she should have thought about this before having sex. Udani felt so ashamed at that moment. However, a doctor and another nurse who overheard this conversation came to her and cheer her up. Udani believed that the bad incident occurred for her good as it helped other staff turned to be more empathetic and supportive.

- Do you think there anything right or wrong about Udani’s story? Why?

Appendix 03: Ethical Clearance from University of Bristol

Letter date	18-12-2019
Sender	Gayle Hanbury (gayle.hanbury@bristol.ac.uk)
Recipients	Krishani Vithana Pelpita Koralalage (oi19363@bristol.ac.uk)
Record title	Re: 96842 - Ethics Application
Identification number	401577
Version number	1
Responsible	Christine Bennett
Attached documents	Re 96842 - Ethics Application
Documents without PDF-version (not attached)	
Printed	19-12-2019

To: Krishani Vithana Pelpita Koralalage (oi19363@bristol.ac.uk)
Cc: Liam McKervey (Liam.McKervey@bristol.ac.uk), Christine Bennett (Chris.Bennett@bristol.ac.uk)
From: Gayle Hanbury (gayle.hanbury@bristol.ac.uk)
Title: Re: 96842 - Ethics Application
Sent: 18-12-2019 12:00

Dear Krishani.

Ref: 96842

Title: Ethical issues in labour and post labour care in Sri Lanka: Views and experiences of postpartum women in Colombo district

The chair of the Faculty of Health Science Student Research Ethics Committee (HSSREC) has reviewed your amendments to the ethics application for the above named study. I am pleased to confirm that the chair has granted a favourable ethical opinion for your research and you can now proceed.

You should receive a confirmation e-mail from the online ethics tool shortly that a favourable opinion has been granted and you can begin your research.

Good luck with your research.

Best Wishes.

Gayle.

Gayle Hanbury
Senior Faculty Assistant

Faculty of Health Sciences
University of Bristol
5 Tyndall Avenue
Bristol, BS8 1UD
Direct dial: 0117 42 82784

Appendix 04: Ethical Clearance from Sri Lanka Medical Association

Ethics Review Committee, Sri Lanka Medical Association



10 April 2020

Ms. V P K Krishani Jayasinghe,
Post graduate student,
Centre for Ethics in Medicine,
Bristol Medical School, University of Bristol

ERC 19 - 021

Ethical issues in labour and post labour care in Sri Lanka: Views and experiences of postpartum women in Colombo district

PI: Ms. V P K Krishani Jayasinghe, Post graduate student, Centre for Ethics in Medicine, Bristol Medical School, University of Bristol

Details of Supervisors:

Dr. Jonathan Ives, Bristol Medical School, University of Bristol

Dr. Zuzana Deans, Bristol Medical School, University of Bristol

Prof. Athula Sumathipala, School of Primary, Community and Social Care, Faculty of Medicine & Health Sciences, Keele University

We are pleased to inform you that the SLMA ERC has granted ethical approval for the above proposal **effective from 20th March 2020** as per details given below.

Approval granted for

1. Protocol submission 2 version 1.8 dated 18 February 2020
2. ICF and IS submission 2 version 1.3 in English dated 18 February 2020
3. ICF and IS submission 2 version 1.2 in Sinhala dated 18 February 2020

We affirm that none of the study team members were present during the decision-making process of the ERC.

This approval is valid for **one year** from the date of sanction.

As PI, you are responsible for the submission of the following documents using the appropriate forms of the SLMA ERC, which will be emailed to you.

1. 6 monthly progress reports on the study
2. A final report at the completion of the study

Please note that if an extension for the period of study is required the **request should be submitted 3 months before the expiry of this approval** and that it will depend on the progress report submitted and the reason for extension.

Please note that ethical approval will be revoked if any alteration is made to the research proposal without obtaining prior written consent from the ERC.

As the Principal Investigator, you are expected to ensure that procedures performed under the project will be conducted in accordance with all relevant national and international regulations and guidelines that govern research involving human participants.

You are also responsible for negotiating individual arrangements with the heads of service departments in those situations where the use of their resources is involved. Copies of the approval letters should be submitted to SLMA ERC once obtained.

Yours sincerely,

Professor Chandanie Wanigatunge
Chairperson,
Ethics Review Committee