

**Termination of pregnancy for non-lethal fetal anomaly:
Professional perspectives.**

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Thesis Abstract

The topic of termination of pregnancy continues to attract extensive debate in both the public arena and in the academy. Debates about termination of pregnancy for fetal anomaly (TOPFA) in particular take place against this backdrop. Social science analyses of the views of medical professional providers of TOPFA are underdeveloped, and social care professionals (who care for those living with disability) are an under represented group in research more generally. In this contentious area of public policy, the insights could make an important contribution to the on-going policy debates.

Using a mixed methods approach, this thesis explores the views about the acceptability of TOPFA from the perspective of two professional groups: medical professionals and social care professionals. Four case studies were used to form a basis for the exploration, and these were selected for intrinsic exploratory value. An epidemiological overview of TOPFA acceptance rates from six areas of the UK was used to help inform the case study selection process. Data collection from professionals by questionnaires and semi-structured interviews followed. The questionnaire data suggest that the views between the professional groups were not radically different. The thematic analysis of the interview data generated two themes: theme one conceptualises the imagined child; theme two conceptualises the predicted experiences of the imagined child. When comparing the accounts given by the two professional groups, the data suggest that social care professionals also look at the wider social context of a person with an impairment when discussing their views regarding TOPFA. Medical professionals focus more on the individual impairment when discussing their views on TOPFA.

Whether an anomaly can be 'fixed', what pain is associated with the particular anomaly, whether a normal life experience will be had were all considered against what professionals deemed a 'morally acceptable' outcome. Acceptable TOPFA was based on what was morally acceptable to professionals both in their professional roles, and within a personal capacity. These findings show professionals are able to negotiate acceptable TOPFA in at least some instances while maintaining a sense of moral self. This research adds support to existing arguments on the extent to which the personal views of medical professionals influence their practices. It also offers insight into a previously under researched group, social care professionals. The mixed methods and interdisciplinary approach has been crucial in providing a productive framework within which to explore the concept of acceptable TOPFA from the perspectives of professionals.

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List of abbreviations

TOP: Termination of pregnancy

TOPFA: Termination of pregnancy for fetal anomaly

RCOG: Royal College of Obstetricians and Gynaecologists

WHO: World Health Organisation

ICF: International Classification of Functioning Disability and Health

BINOCAR: British Isles Network of Congenital Anomaly Registers

ONS: Office for National Statistics

HLH: Hypoplastic left heart

AVSD: Atrioventricular septal defect

CI: Confidence interval

Chapter 1: Introduction

1.1 Introduction

Termination of pregnancy (TOP) continues to be a topic of intense discussion within the UK. Key topics often debated include removing the two doctor clause, reducing the upper limit for TOP, and issues surrounding counselling. The Republic of Ireland has also made UK national news regarding the issue of TOP with the death of Savita Halappanavar. Savita Halappanavar requested, on numerous occasions, a TOP on an unviable pregnancy. She was denied her request, despite her deteriorating health, and died shortly after (BBC News, 2013). This case has resulted in a number of recommendations, including clarification of the legislation, in the Republic of Ireland. Clearly TOP remains a headline attracting issue in contemporary society.

Termination of pregnancy for fetal anomaly (TOPFA) attracts particular attention in the contentious area of TOP in general. One aspect of this attention is due to the late gestational age that these terminations can occur at. The legitimacy of TOPFA has also been questioned by a strengthening disability rights movement, which has successfully campaigned for increased social status for people with impairments. The social model of disability as a political tool has been successfully adopted by groups linked to the disability rights movement, and has resulted in the wider recognition of an alternative to biomedical understandings of disability. Many of the arguments from disability rights movements regarding TOPFA centre on the belief that TOPFA is discriminatory against living people with impairment and echoes eugenic regimes of the past. In 2002, Rev Joanna Jepson, who was born with a cleft lip, attempted to have two doctors prosecuted for authorising a TOPFA on a fetus for cleft lip. This brought the issue of TOPFA and the wording of the Human Fertilisation and Embryology Act 1990, 2008 into the headlines of the UK national press (Bates, 2011; BBC News, 2003a; BBC News, 2003b).

These recent examples highlight the continued importance of TOPFA as a socially contentious issue. This status, coupled with the continuing progression of medical advancements that have made detection of fetal anomalies increasingly accurate, puts TOPFA into an even more prominent position. Many prospective parents (hereafter referred to as 'parents') will be unprepared for a diagnosis of fetal anomaly, and so the medical profession are often the first point of contact in terms of delivering difficult, unexpected news to parents. This places them in a unique moral position. The

vulnerability that parents may experience at this distressing time may make them more susceptible to suggestions made by the medical professionals. Therefore, it is important to understand their personal views on such matters, given their potential to both consciously and unconsciously have a significant impact on parental decision making. In contrast, professionals working to help support people with impairments also have a unique insight, into the day-to-day experience of living with impairment. This is an insight that differs from affected individuals themselves and their parents. It is also a perspective that has had very little representation within health research on TOP to date. Their views and experiences on living with impairment may offer an important alternative perspective to the dominant medical perspective and may help to broaden our understandings of the relevant issues.

My research has adopted an interdisciplinary approach to explore the views and experiences of social care and medical professionals, in relation to TOPFA and living with impairment. Individually, different methods and perspectives of study have their own strengths and weaknesses as well as their own focus of study (Rubington and Weinberg, 2003). This study combined a number of different approaches in order to best address the research questions that have been presented. The study has the advantage of appreciating the values of multiple methods and approaches which allows the study to draw on epidemiological approaches, quantitative approaches, qualitative approaches, and medical sociology. This multiplicity of approaches within one study allows for an analysis that reflects a wider range of disciplinary and methodological approaches. Whilst the depth associated with the study of a topic from one disciplinary perspective is to some extent surrendered, the corresponding breadth of analytic scope is something that would be difficult to achieve in a study located in a single discipline.

1.2 Outline of thesis

This thesis starts with a review of relevant policy debates relating to TOPFA in chapter 2, providing an overview of the media attention that TOP and TOPFA have generated in recent years. The chapter then goes on to discuss policy developments and the legislation surrounding TOPFA. The medical guidance that medical professionals use as a guide and technological developments are also summarised. The account given of these debates provides the political and policy context to a discussion of TOPFA as a socially located phenomenon.

Chapter 3 provides a more conventional literature review, where current debates relevant to social science perspectives on TOPFA are discussed. This review begins with scholarly debate on the campaign to legalise TOP and then explores social science opinion on the disability rights movement. The chapter finishes with an overview of the social science literature on the two professional groups to be studied, and a detailed summary of how this study contributes to the development of knowledge by exploring and comparing the views of these two important professional groups.

Following on from the literature review, the more specific theoretical concepts that have influenced the development of the analysis in this thesis are discussed in chapter 4. The main theoretical tools used in the analysis are; social constructionism; key concepts from two of Erving Goffman's key works; *the Presentation of self in everyday life*, and *Stigma: notes on the management of a spoilt identity*; and consideration of interactionism and ethnomethodology traditions. Together, these influences form the theoretical framework that guided the analytic processes.

The methodological underpinnings of this thesis are described and discussed in chapter 5. The research question, and the research aims objectives open this chapter. Next, the added value of a mixed methods approach is outlined. In particular, I argue that the mixed methods approach was crucial in generating a broader insight into the under researched issue of professionals' perspectives on TOPFA. Each phase of the research design is then discussed, with details about each method of research provided, including the relevant approvals for research that involves the NHS.

Chapters 6-10 present the results for the study. Chapter 6 outlines the results from the case study selection process which included an epidemiological aspect. The chapter ends with the rationale for the four case study examples that were selected for phases two and three of my research. In Chapter 7, the findings of the questionnaire data are detailed. The results of the questionnaire are described, and a summary of the data concludes this chapter. Chapter 8 is the first of two interview data results chapters. This chapter draws on phase three of the research and describes social care professionals' and medical professionals' conceptualisations of the imagined child. Both descriptions have three sub-themes. The chapter concludes with a comparison of these themes between both professional groups. Chapter 9 is the second results chapter that draws on phase three of the research. This chapter describes social care professionals' and medical professionals' conceptualisations of the predicted experiences of the imagined child.

Both descriptions have three sub-themes. The chapter finishes with a comparison between the two professional groups.

In Chapter 10, I draw together the key findings from the research results, using the theoretical tools outlined in Chapter 4. I argue that acceptable TOPFA is best conceptualised as a result of the interplay between three key factors; whether an anomaly or impairment can be ‘fixed’; to what extent pain will be experienced; and whether a normal outcome can be achieved. These three factors are considered against what a professional deems a ‘morally acceptable’ outcome; i.e. they ‘perform’ a ‘moral self’ based on these three factors. Essentially, professionals base their arguments for acceptable TOPFA on what is morally acceptable to them in both professional and personal terms. In many cases, these personal and professional opinions may differ.

Chapter 11 presents the final conclusions of my PhD research. Ultimately, I argue that professionals present their position on TOPFA in a manner they deem morally acceptable in both personal and professional terms. Their personal values on ‘fixing’, pain and ‘normality’ impacted what was given priority in terms of their moral standpoint and thus acceptable TOPFA. Overall, this research suggests that members of these professional groups tend toward support for TOPFA as an available option, for those who deem it is the right option for ‘them’. Despite the difficulties and the contentiousness of the TOPFA debates in the public domain, the data suggest that these professionals are able to negotiate their way through the issues with their sense of moral self intact.

Chapter 2: Legal framework surrounding termination of pregnancy

2.1 Introduction

Termination of pregnancy generates much critical interest, in the public and policy domains, and the role of the medical profession in the process of providing TOP has also attracted attention. It is difficult to discuss the meanings and conceptualisations of TOPFA as a social phenomenon without reference to the legal and policy framework in which it exists, and so this chapter provides a brief overview of these issues. This chapter will detail the major components of the legal framework supporting the provision of TOP and of TOPFA. This framework governs clinical practice, and provides reference points for debates that emerge into the media spotlight.

2.2 Media spotlight and the public domain

The wording of Clause E of the Human Embryology and Fertilisation Act (1990) was brought into question in 2002. This occurred when Rev Johanna Jepson attempted to have criminal charges brought against two doctors who had authorised a TOP for cleft lip under Clause E (Bates, 2011; BBC News, 2003a; BBC News, 2003b). Clause E states that the provision of TOPFA is legal if, “there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped”. Jepson argued that cleft lip is a condition that does not satisfy the law as it is not a serious anomaly that would result in a ‘serious handicap’ for the individual involved (Bates, 2011; BBC News 2003a; BBC News, 2003b). Adding weight to her argument, she herself has had successful reconstructive surgery on a cleft lip (BBC News, 2003a; BBC News 2003b). The complaint was referred to the Crown Prosecution Service (CPS), but no prosecution was brought to the two doctors in question. It was concluded that they had not broken the law because the two doctors had authorised the TOP ‘in good faith’, as per the legislation (CPS, 2005).

In 2007 service delivery was also a topic for debate with the approval of two doctors argued to be causing delays (Coates, 2007). The debate on TOP provision was the subject of a House of Commons Select Committee review (HoC, 2007). MPs rejected calls to lower the 24 week upper limit due to their being no increases in the outcome for live births prior to this period (BBC News, 2007). Throughout 2011 and 2012, the issue of service delivery for TOP before 12 weeks was, again, a regular headline topic with conservative MP Nadine Dorries putting forward a Health Reform Bill (2011). This bill sought an

amendment which would state that women seeking a TOP would receive counselling and advice that was from a body separate from the providers of the TOP (Archer, 2011; Watt, 2011). Nadine Dorries' arguments centre on the idea that those who provide TOP have a financial gain from women having terminations. They are therefore not in an appropriate position to provide non-directive counselling to women seeking TOP (Saner, 2011). She claims that her proposal for reform can reduce the number of terminations of pregnancy by up to 60,000 (Saner, 2011). There are growing concerns over her proposals mostly voiced by those who believe TOP is a care option that should be openly available to women. These concerns are that Dorries' proposals will pave the way for those ideologically opposed to TOP to give counselling to women which will be biased, coercive and treat women as passive and unable to make the decisions best for them (Archer, 2011; Saner, 2011). It has been well documented within the press that the anti-choice lobby liken TOP to murder and have allegedly approached women on their way into TOP clinics with such claims (Ball, 2012).

The pro-choice lobby has been in active action again from 22nd February 2012 – 1st April 2012 under the slogan '40 days of choice' (FPA, 2012). This campaign was in response to the pro-life lobby campaigning outside a London clinic under the slogan '40 days of life'. This campaign has particularly targeted a London site run by the British Pregnancy Advisory Service (BPAS), where the staff have complained about bullying, aggressive and intimidating behaviour by the protesters. Protesters have even been accused of filming staff and patients (Ball, 2012). Such visible campaigning shows the continued interest and importance of TOP within contemporary UK society.

TOP has also been a regular headline topic in January and February 2013. The issue of the upper limit, TOPFA, questions about the need to update the law, the liberal interpretation of the law and the heavily restricted access in Ireland have all been headline topics in recent months. One article published in the guardian quoted a YouGov poll which suggests that public support for a ban on TOP is declining; down from 12% in 2005 (Quinn, 2013) to 6% in 2012 (Globyte, 2012). The poll also found 47% of the UK population are supportive of the current 24 week limit (Globyte, 2012). This is in contrast to 33% who would support a reduction of the upper limit to before 24 weeks (Globyte, 2012). A cross party commission will be undertaken to establish a potential review of the current legislation (the Human Fertilisation and Embryology Act, 1990, 2008). This will take into consideration medical advancements and improved attitudes towards impairment. The conservative MP

Fiona Bruce will be chairing the inquiry, which will also be assessing whether TOPFA is discriminatory to people with disabilities in light of the Equality Act 2010 (Dominiczak, 2013).

The liberal approach to the interpretation of the law and the restricted information of TOP in Ireland has also been a regular headline topic. Ann Fuerdi argues that the interpretation of the law is liberal in the sense that patients and doctors ‘pretend’ that women have mental health issues to enable them to sign off a TOP under Clause C (Bingham, 2013). According to the same article, the chairman of the Royal College of General Practitioners was reported as claiming that women stating they did not want their pregnancy to continue is now enough evidence to justify provision of a TOP (Bingham, 2013). Some argue this will lead to wide spread perjury, particularly by those in the pro-life lobby. However, the pro-choice lobby have argued that it is simply a reflection of how out of date the legislation on TOP is (Bingham, 2013).

This question of whether the legal framework needs revising remains prominent in the public domain in the UK. The BBC has recently aired a Panorama investigation titled ‘the Abortion Divide’ which questioned whether the TOP legislation needs updating. The programme provided an overview of the new measures taken by anti-abortion protesters, including protesting outside TOP clinics, showing extreme images of fetuses, approaching women going into the clinic and attempting to prevent them from going through with the TOP (Panorama, 2013). However, it also provided counter arguments, such as Ann Fuerdi, chief executive of BPAS, claiming that we live in a society where we believe that women should have the right to decide what we can do with our bodies (Panorama, 2013). This latter view would seem to be supported by the figures that suggest 1 in 3 women will have a TOP in their lifetime (BPAS, 2010).

The programme goes on to discuss the current predicament Irish women find themselves in. The opening of a Marie Stopes clinic caused renewed protests from both sides of the argument (Panorama, 2013). Many of the politicians in Northern Ireland are openly against TOP and an extension of the Abortion Act to include Ireland (Panorama, 2013). The recent death of Savita Halappanavar in the Republic of Ireland, a woman who requested a TOP on medical grounds and who was denied, has also renewed debates on reducing some of the restrictions in the legislation (Panorama, 2013). Doctors are said to be too scared to abort even if it is legal due to medical necessity (Panorama, 2013). According to the documentary, major medical bodies do not support a reduction in the upper limit. While

this occurred in the Republic of Ireland, the event received much media attention within the UK. This resulted in the issue of TOP remaining in the headlines for much of 2013. The coverage given to TOP in both newspaper and TV reporting suggests that the key issues remain prominent in the public domain. Such coverage has a tendency to be balanced in that the coverage acknowledges that there are two key perspectives to consider.

2.3 Timeline of policy developments

TOP and TOPFA are clearly issues that take place in a complex social context. Expressed views proliferate, contradictory views are apparent, and the legal framework is important as a benchmark for service providers. Making sense of the current context of in which TOPFA is conceptualised and legislated, it is important to discuss the policy chronology and the policy debates that led to the current position.

2.3.1 Legislation governing termination of pregnancy

In England and Wales, there are four key pieces of legislation that govern TOP; the Offences Against the Persons Act 1861; the Infant Life (Preservation) Act 1929; the Abortion Act 1967 and the Human Fertilisation and Embryology Act 1990 (Amended 2008). There are also a set of guidelines published by the Royal College of Obstetrics and Gynaecology (RCOG) which offer guidance for medical professionals working in the field (RCOG, 2010). The Offences Against the Persons Act was passed by parliament in 1861. This legislation makes it illegal to abort a pregnancy (RCOG, 2010). It is important to consider the development of the legal framework surrounding TOP to understand it in its current form. The significance of the development of the legislation is of particular interest when researching TOPFA as the risk of being born with impairment was a key argument that led to the Abortion Act 1967 (Francome, 2004).

The earliest legislation that governed TOP was The Offences Against the Persons Act 1861. This Act had two sections relevant to TOP: one section relevant to the woman herself, the other for those who aid the woman. Section 58 implicates the woman; any woman who attempts to “procure a miscarriage” either to “herself or another woman, through any known means are breaking the law and can serve up to life in prison” (The Offences Against the Persons Act, 1861). Section 59 refers to providers of tools or poisons that were known to cause a miscarriage; this offence was punishable by arrest for a misdemeanour, with a prison sentence. Despite this legislation stipulating life imprisonment for women who are guilty of instigating their own TOP or helping other

women to miscarry, it did not stop the practice. The offences against the Persons Act 1861 states:

Section 58

“Every woman, being with child, who, with intent to procure her own miscarriage, shall unlawfully administer herself any poison or other noxious thing, or shall unlawfully use any instrument or other means whatsoever with the like intent, and whosoever, with intent to procure the miscarriage of any woman, whether she be or be not with child, shall unlawfully administer to her or cause to be taken by her any poison or other noxious thing, or shall unlawfully use any instrument or other means whatsoever with the like intent, shall be guilty of felony, and being convicted thereof shall be liable... F82 to be kept in penal servitude for life... F83”

Section 59

“Whosoever shall unlawfully supply or procure any poison or other noxious thing, or any instrument or thing whatsoever, knowing that the same is intended to be unlawfully used or employed with intent to procure the miscarriage of any woman, whether she be or be not with child, shall be guilty of a misdemeanour, and being convicted thereof shall be liable... F84 to be kept in penal servitude... F84”

The next legislation that aided the governing of TOP was the Infant Life (Preservation) Act 1929. This legislation was significant in that it was the first legal recognition of TOP to save the life of the pregnant woman. This legislation made it illegal to ‘destroy’ the life of a child that has the potential of being a live birth. However, this Act also states that it recognises good faith in that if a mothers’ life was in danger, then destroying the life of a child to save the life of the mother was deemed to be an acceptable and legal act. The sanction for guilty parties was still stated as life imprisonment. The Infant Life (Preservation) Act 1929 states:

Section 1

“ (1) Subject as hereinafter in this subsection provided, any person who, with intent to destroy the life of a child capable of being born alive, by any wilful act causes a child to die before it has an existence independent of its mother, shall be guilty of felony, to wit, of child destruction, and shall be liable on conviction thereof on indictment to penal servitude for life:

Provided that no person shall be found guilty of an offence under this section unless it is provided that the act which caused the death of the child was not done in good faith for the purpose only of preserving the life of the mother”.

It has been well documented that the ‘backstreet abortion’ was common practice (Gleeson, 2007) particularly among the working class (Greenwood, 2001). This would be at a time where TOP was governed by the Offences Against the Persons Act (1861) and the Infant Life (Preservation) Act (1929). Whilst middle and upper class families spoke highly against the practice, with their small family sizes, illegal TOP was also widespread though all classes (Knight, 1977). Those who could afford it could seek a safer TOP from a private clinic (de Costa, 2009). The ‘backstreet abortion’ is still a problem in many developing countries that: a) have legislation in place that prohibits TOP, or b) access to such services is difficult. In 2003, the World Health Organisation reported that a woman dies every eight minutes due to unsafe TOP (WHO, 2007). Although the figure declined in a subsequent edition of the WHO unsafe abortion report, approximately 13% of all maternal deaths are due to unsafe TOP (WHO, 2011). The film *Vera Drake* attempted to highlight the circumstances in which the ‘backstreet abortion’ was sought in the UK prior to the Abortion Act 1967. This was mainly in desperate circumstances of poverty and undesirable social circumstances (Ali, 2004). It also showed upper class women having the ability to access safer TOP services through having money and the right contacts (Ali, 2004). This is something which is also documented within the literature (Knight, 1977). The film makes reference to the widespread demand for TOP at that time despite the illegality of the practice. This would suggest that the law was outdated and out of touch with the demands of society. It also suggests the ‘private’ and ‘public’ face of such matters were in stark contrast to each other.

The Abortion Act 1967 is the legislation that was the watershed in legalised TOP in the UK, and it was the end result of years of intense campaigning. The legislation does not allow TOP on demand but stipulates conditions that must be met in order for a legal termination to occur (Clauses A – D). These conditions must be authorised by two medical doctors. There is also a conscientious objection clause; this allows medical doctors who do not wish to participate in TOP to not do so legally. The Abortion Act 1967 states:

Section 1 – (1) “Subject to the provisions of this section, a person shall not be guilty of an offence under the law relating to abortion when a pregnancy is

terminated by a registered medical practitioner if two registered medical practitioners are of the opinions, formed in good faith –

F1 (a) “that the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family; or

(b) that the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or

(c) that the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or

(d) that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped”.

When filling in the paperwork for a TOP procedure, medical professionals fill in the HSA1 form. This form and the Office of National Statistics that publishes TOP statistics differ in the clauses used to categorise terminations performed. For the purposes of this thesis, the clauses as shown on the medical and government statistics reports are used, as this terminology is what medical professionals are most familiar with. As per section 4.2 of the statistical bulletin (with links to the original Abortion Act clauses), TOP is legal when certified by two registered medical practitioners as justified by one of these following grounds:

A: “the continuance of the pregnancy would involve risk to the life of the pregnant woman greater than if the pregnancy were terminated (Abortion Act, 1967 as amended, section 1(1)(c))”.

B: the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman (section 1(1)(b))”.

C: the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman (section 1(1)(a))”.

D: the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated,

of injury to the physical or mental health of any existing children of the family of the pregnant woman (section 1(1)(a))”.

E: there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped (section 1(1)(d)).

or in an emergency, certified by the operating practitioner as immediately necessary”:

F: to save the life of the pregnant woman (section 1(4))”.

G: to prevent grave permanent injury to the physical or mental health of the pregnant woman (section 1(4))”.

The Human Fertilisation and Embryology Act 1990 (amended 2008) amended the 1967 Abortion Act and took into consideration medical advancements. The main consideration relating to medical advancements was the threshold of viability. The upper limit as set by the 1967 Abortion Act, was 28 weeks. Lowering this limit seemed appropriate as medicine had since developed the ability to support babies born as young as 24 weeks gestation. The legislation also removed the upper limit for Clause E (previously restricted by the Infant Life (Preservation) Act) as the diagnosis and counselling process may mean parents with a diagnosis of fetal anomaly may miss the 24 week upper limit. There are also anomalies that may not present before 24 weeks. The Human Fertilisation and Embryology Act 1990 (amended 2008) made no changes to the wording in the 1967 Abortion act other than to stipulate 24 weeks for Clauses A – D and remove an upper limit for Clauses E – G.

2.4 National Institute of Clinical Excellence antenatal guidelines on screening

In a context where many aspects of pregnancy involve monitoring, measurement and explanations of medical terms, guidelines enable medical professionals to ensure all women receive the appropriate information, at the appropriate time to make the necessary informed decisions. These decisions in cases of TOPFA usually begin at the stage of prenatal screening. The National Institute for Health and Clinical Excellence (NICE) have published guidelines for the routine care of healthy pregnant women (NICE, 2008). Fetal anomaly screening is explained within these guidelines with explanations of the purpose of each screening occasion. The first screening test that is offered is for Downs syndrome, which should be completed between 11+0 and 13+6 (NICE, 2008: 9). This test is known as the ‘combined test’ (“nuchal translucency, beta-human chorionic gonadotrophin,

pregnancy-associated plasma protein-A”) (NICE, 2008: 9). A serum screening test is offered to women who present past 13+6. This test can be completed between 15 weeks and 0 days and 20 weeks and 0 days (NICE, 2008:9). Women are also offered screening for gestational diabetes providing the relevant risk factors (such as; BMI 30+, previous gestational diabetes, family origin) are met. This test is offered between 24 and 28 weeks of pregnancy.

Within the NICE guidelines there is evident a heavy emphasis on ‘informed decision-making’ and how women should make their decisions upon receiving sufficient information about that particular aspect of their care. Sufficient information about antenatal screening is recommended by the guidelines to be given to mothers on the first contact with a healthcare professional (NICE, 2008: 10). The guidelines also state clearly that the purpose of screening should be explained and fully understood before it is performed. Women should also be ensured of enough time to make an informed choice about their care. All decisions should be respected with women clearly told they have a right to decline any tests if they so wish (NICE, 2008: 12). An early ultrasound scan should be offered which will take place between 10 weeks and 0 days and 13 weeks and 6 days. This test is to determine the gestational age of the fetus and whether the pregnancy is a multiple pregnancy (NICE, 2008: 14). The guidelines also state that women should be informed of dietary supplements. The most notable supplement is taking folic acid preconception and up to 12 weeks post-conception (NICE, 2008), as research has concluded this reduces the risk of neural tube defects in the fetus.

2.5 Medical Professional Guidance

The legal framework supporting TOP and TOPFA provides a useful benchmark for providers of these services, but there are aspects of the law that are more ambiguous. Clinical guidelines on provision of TOP and of TOPFA form a useful adjunct to the legal framework in these cases. These guidelines provide an insight into the reality of the practices and dilemmas in the clinical setting. For example, there is no upper limit for TOPFA which may suggest that terminations at late gestations happen as a rule. By looking at the guidelines, more clarity into the reality of the TOPFA practice is revealed. The RCOG Guidance for TOP is the reference point for medical professionals in the field (RCOG, 2010).

The RCOG published guidelines for TOPFA in 2010, “Termination of pregnancy for fetal abnormality in England, Scotland and Wales”, an update from the original guidelines that were published in 1996 (RCOG, 2010). The 1996 RCOG Guidelines were published to set out the legal status of TOPFA in England, Scotland and Wales, and provide recommendations for the relevant medical professionals who are practicing in this area (RCOG, 1996). The 1996 guidelines acknowledge the current climate surrounding TOPFA, recognising that some professionals do not routinely provide TOPFA procedures, and also acknowledging some areas of potential confusion. The original guidelines sought to eradicate such confusions (RCOG, 1996). Key summary points include some criteria for assessing the seriousness of a fetal anomaly. Such points include; the ability to use Clause C if the gestational age is prior to 24 weeks (RCOG, 1996). Also, that the woman with the affected fetus should be helped to gain a full understanding of the anomaly(ies) in question (RCOG, 1996). There have been numerous changes since the 1996 RCOG guidelines. Advances in medical technology have resulted in improved diagnostic techniques, with diagnosis being earlier and with increased accuracy of the prognosis of the particular anomaly. These developments have occurred alongside the extension of screening as part of routine antenatal care (RCOG, 2010). Evidence relating to gestational diabetes, haemoglobinopathy and ultrasound has also contributed to the change in guidelines (RCOG, 2010).

A fetus becomes a legal child with rights when it is registered as a live birth. It is important to note that there are key differences between signs of life and signs of sustainable life, which may not be distinguishable to parents. This means specific measures should be taken to ensure fetal death in utero whenever there is a possibility of a fetus being able to breathe. Feticide is recommended for TOP from 21 weeks and 6 days. The detection rates for ultrasound screening are; 83% for lethal anomalies; 50% of serious anomalies with possible survival; and 16% for anomalies where immediate care is required after birth (RCOG, 2010: 12). Statistics are released annually regarding TOP rates but it is difficult to get accurate information on TOP rates after 24 weeks due to the small numbers recorded (RCOG, 2010: 12). Any raw numbers of less than 10 per category are not made publically available, due to confidentiality and anonymity concerns regarding the patient and the medical professionals involved (RCOG, 2010). A list of TOPFA at 24 weeks and above is provided in the RCOG guidelines; gestational age is a key issue when deciding whether to offer a TOPFA as dilemmas may arise over the legality of a TOPFA depending on the fetal anomaly in question (RCOG, 2010). It has been argued that assisted or dependent

performance as an adult should be classified as ‘seriously handicapped’. Upon diagnosis, or suspected diagnosis, a woman would be referred to a fetal anomaly specialist for further counselling regarding the diagnosis and prognosis for the fetus. It is important to be aware of medical guidance to gain more insight into the frameworks medical professionals work within when involved in TOP and TOPFA decision making.

2.6 The offer of termination of pregnancy

How TOP came to be legalised, and how this has influenced current practices surrounding the offer of TOP and TOPFA is an important consideration. One key influence in the implementation of the Abortion Act was the thalidomide tragedy (Francome, 2004). The ability to collect data on fetal anomalies and pregnancy outcome has been facilitated through the routine use of fetal ultrasound screening, which has become a routine part of pregnancy in the UK (Chaoui et al., 2009). Ultrasound examinations have received extensive uptake with recommendations that the scan should be offered to all pregnant women (Chaoui et al., 2009); it is inevitable therefore that more anomalies are detected and TOPFA offered as an available option.

The decision making process as to whether to have a TOPFA or to continue a pregnancy is a difficult one. Many factors are at play (such as existing children), and the experience of grief that is argued to be similar to that of a loss of an already born person (Seller et al., 2005). The anomaly in question may also play an important role in this decision process. For example, it has been reported that prospective parents would appreciate more insight into the lives of people with Downs syndrome during the decision making process (Skirton and Barr, 2010). This indicates that the decision whether to accept the offer of TOPFA or to carry on with the pregnancy is not clear cut. Although specific to feticide, Graham et al., found that decisions about accepting feticide were related to perceptions of suffering during birth and dying afterwards (Graham et al., 2009). Locock et al., (2005) also reported that the decision of two parents to decline TOPFA for Patau syndrome was based on their belief that they wanted to give their child a chance at surviving, however slim that chance was. They also revealed they wanted to be “able to live with themselves in the years to come” (Locock et al., 2005: 1188) indicating feelings of guilt associated with the decision. Despite the negative feelings felt by those affected by TOPFA, this does not mean it is not the right decision for many who have taken that option.

2.6.1 An anomaly record system

The Thalidomide tragedy highlighted the vulnerability of the developing fetus to environmental exposures (McBride, 1961; Lenz, 1962 cited in Rankin, 2007). Pregnant women who were prescribed the drug for morning sickness gave birth to children with congenital anomalies, (namely congenital limb defects) (Lenz, 1962 cited in Rankin, 2007). The National Congenital Anomaly System (NCAS) was established in 1964 for England and Wales in the wake of thalidomide (Rankin, 2007; Misra et al., 2006; Boyd et al., 2005). NCAS was a voluntary system run by the Office for National Statistics (ONS) collecting information on fetal anomalies in live and stillbirths (Rankin, 2007). A live birth is defined as a baby showing signs of life after delivery regardless of the gestational age (Nguyen and Wilcox, 2005). Such signs are breathing independently, beating of the heart or pulsation of the umbilical cord (WHO, 2013a). A stillbirth is defined as a baby that is born dead after 24 weeks gestation. TOPFA was not legal when NCAS was established therefore no information relating to TOP was collected. It was based on a system where information provided on birth notification forms was used to gain the necessary information for the ONS (Misra et al., 2006). The disadvantages of the system are well recognised, such as incompleteness, but NCAS did provide coverage of data on congenital anomalies (Rankin, 2007; Misra et al., 2005). NCAS ceased to exist in 2009, but data on congenital anomalies continues to be collected via regional congenital anomaly registers in some regional areas. The six regional areas selected for this study have coverage of 36% of all births in England and Wales (BINOCAR, 2013).

2.7 Definition of a fetal anomaly

The terms fetal anomaly and congenital anomaly have slightly different meanings. Fetal anomaly is an anomaly present during pregnancy. EUROCAT defines a congenital anomaly as “an anomaly that is present at the birth of the child that is not necessarily hereditary” (UK Screening Portal, 2012 cited in EUROCAT, 2012). BINOCAR offers a slightly more detailed definition of a congenital anomaly; “...any defect, probably originating before birth, and includes structural, chromosomal, genetic and biochemical defects and malformations” (BINOCAR, 2010). The WHO, and BINOCAR use the term congenital anomaly. These organisations are used within this thesis which is why it is important to be aware of both definitions. This thesis will focus on fetal anomalies. Fetal anomalies play a significant part in fetal mortality, neonatal mortality, stillbirth and infant mortality (Ritz, 2010; Rankin et al., 2009; Stothard et al., 2009; Rankin, 2007; Rankin et al., 2005; Boyd et al., 2005; Dastgiri et

al., 2002), with approximately 2-3% of newborn babies affected by a major congenital anomaly annually in the UK (Boyd et al., 2005).

Fetal anomalies are recorded and monitored in the UK by congenital anomaly registers. In 2010 there were a total of 5,818 notifications of fetal anomalies in England and Wales from a total of 260,085 births. Of the 5,818 notifications, 4,372 resulted in live births; 120 in stillbirths; 38 were late miscarriages (fetal death from 20-23 weeks gestation); and 1,288 had an outcome of TOPFA (BINOCAR, 2012: 18). Assuming the prevalence rate is consistent across England and Wales, the estimated total figure of congenital anomalies in England and Wales for 2010 is 16,260 (BINOCAR, 2012: 22). The overall TOPFA rate for the six registers was 50 per 10,000 (BINOCAR, 2012: 27). The TOPFA rate before 20 weeks gestation was 30 per 10,000 total births and the TOPFA rate for anomalies detected after 20 weeks was 19 per 10,000 total births (BINOCAR, 2012: 27). Chromosomal anomalies were associated with the highest rates of TOPFA at 24 per 10,000 total births (BINOCAR, 2012: 27).

2.7.1 Diagnosis and management of fetal anomalies

A pregnant woman is offered fetal anomaly screening during appointments with the midwife (Kirwan and NHS FASP, 2010). If an anomaly is suspected or identified, the pregnant woman is informed. She is then referred to either a second sonographer or consultant. At this referral, the pregnant woman is re-scanned. If an anomaly is still suspected, the pregnant woman will be referred to a fetal medicine unit (Kirwan and NHS FASP, 2010). The pregnant woman will be offered prenatal investigation for the suspected anomaly. If this investigation concludes the presence of a fetal anomaly, parents will have the option to continue the pregnancy or have a TOP (Kirwan and NHS FASP, 2010). Of the eight case study examples that have been selected for this study, all can be detected at the fetal anomaly scan. When an anomaly is detected, checks for other anomalies will also be conducted. For example, cleft lip may also be associated with other anomalies which are checked for after a cleft lip diagnosis (Slator et al., 2011).

2.7.2 Technological Developments

Developments in fetal ultrasound and fetal monitoring have resulted in more accurate diagnosis of fetal anomalies more frequently (Nettleton, 2006). This is an important consideration in any research considering TOPFA as increased developments mean more anomalies being diagnosed and potentially more TOPFA. The RCOG guideline has

detailed the benefits for earlier diagnosis as simply TOP being safer the earlier it is performed (RCOG, 2010: 17), but concedes that the majority of fetal anomalies will not be detected until the fetal anomaly scan. 3D imaging is now available, but due to limited research that has detected no additional benefits to that of 2D imaging, it is unlikely to be adopted on a wider scale (RCOG, 2010: 17). Imaging can be helpful for some anomalies during counselling of parents. This has been particularly helpful for external structural anomalies (particularly of the face) as parents can better understand a 3D image (RCOG, 2010: 17). Magnetic Resonance Imaging (MRI) is the ability to obtain a detailed image of the fetus through gaining an image taking out any problems that movement creates to the image. MRI has been researched by a number of cohort studies which have concluded that it may prove useful in diagnosing fetal central nervous system anomalies (RCOG, 2010). MRI has said to be particularly useful in providing information “about gyral patterning, the structure of the corpus callosum and cortical thickness that is not provided so well by 2D ultrasound” (RGOC, 2010: 17-18). This would suggest that MRI would be useful when used in conjunction with ultrasound as it has the ability to change up to 30% of diagnoses where central nervous system anomalies are suspected (RGOC, 2010: 17-18). The guidelines conclude that the real impact of this scanning device has yet to be established (RGOC, 2010).

2.7.3 Techniques for Prenatal Diagnosis

A pregnant woman has the option of a number of prenatal tests throughout her pregnancy to diagnose fetal anomalies. A number of techniques exist that allow for the likelihood and/or diagnosis of a fetal anomaly. For recessive gene carrier anomalies, such as cystic fibrosis, parents who are both carriers have a 1 in 4 chance of an affected pregnancy. Prospective parents with a family history of certain anomalies can undergo testing to determine the likelihood of the condition being passed on to their offspring.

Amniocentesis is an invasive test that has been successful in the diagnosis of chromosomal and genetic anomalies. This involves obtaining fetal cells through a needle from the amniotic fluid, placenta, or fetal blood (RCOG, 2010). Amniocentesis carries a risk of miscarriage, so if a woman has tested high risk as a result of the Biochemical Serum Screening, she may choose not to have the diagnosis investigated further by the invasive amniocentesis test. This may result in the loss of a potentially ‘normal’ fetus. Non-invasive tests include testing the pregnant women’s blood for higher than expected levels of chromosomes. This is done by using gene-sequencing to amplify the sample. This is known

as ffDNA. This test has not replaced other methods, but it is possible that, in the future, ffDNA could be analysed and used in prenatal diagnosis for certain gene anomalies (RCOG, 2010: 18).

2.7.4 Techniques used to Terminate a Pregnancy

Women not being made fully aware or fully understanding the purpose and potential outcome of the fetal anomaly scan has been raised as a concern (RCOG, 2010). Guidelines have been published to ensure information is now available to all women about the screening process (see NHS Fetal Anomaly Screening Programme, 2012). If women are well aware of the implications of the fetal anomaly scan, this does not discount the emotional distress suffered upon diagnosis (RCOG, 2010). Upon diagnosis of fetal anomaly, choices tend to be limited. These are; continue the pregnancy with a suitable care plan in place; continue the pregnancy with palliative care and TOPFA (RCOG, 2010). After the diagnosis of a fetal anomaly, parents may wish to TOPFA. A termination of a wanted pregnancy is a very distressing situation for the parents (RCOG, 2010), with studies showing long term grief is suffered by parents after TOPFA (Kersting et al., 2005). All medical professionals are advised to act in a non-judgmental manner with counselling delivered in a non-directional manner; however research questions whether this is possible in reality (Williams, 2006; Statham et al., 2002). Even if the suspected anomaly is fatal, medical professionals are advised not to make assumptions about the course of treatment a women should follow (RCOG, 2010). The importance of a quick decision may arise if the pregnancy is nearing the 24th week as there may be potential legal ramifications depending on the fetal anomaly in question (RCOG, 2010). A medical TOP induces labour through drugs and is offered after 14 weeks gestation. Inducing labour of the dead fetus can be very stressful and distressing for many women. Some women welcome giving birth and the opportunity to see and hold their baby (RCOG, 2010: 24) as many wanted to be a parent to their baby and valued any time spent with their child (Graham et al., 2009). A surgical TOP is the process by which gentle suction is used to empty the uterus. Feticide is offered after 21 weeks and 6 days as the TOP should be that the fetus does not survive. If the anomaly is so severe that death is inevitable then feticide is not a necessary requirement (RCOG, 2010).

Situations may arise where a fetal anomaly is diagnosed, but a TOPFA has been deemed an inappropriate care option due to strictures of the law; an example may be a missing limb. The medical professional in question may feel that a missing limb is not an anomaly that

has a risk of the affected person suffering “from such physical or mental abnormalities as to be seriously handicapped”. Women may still request a TOP and if the gestational age of the fetus is prior to 24 weeks they may still be entitled to a TOP under a different clause as per the Human Fertilisation and Embryology Act (1990, 2008). Women can also seek a second opinion (RCOG, 1996). If TOPFA is still deemed to be an inappropriate care option then further counselling should be offered (RCOG, 2010). Medical definitions of what ‘serious’ means has been subject to debate (for example Lee, 2000). Much of this surrounds the ambiguity over ‘substantial risk’ and ‘serious handicap’ with questions raised about the appropriateness of the medical profession making such judgments (Savulescu, 2001). There is also said to be a lack of consensus about what anomalies justify TOPFA and the gestational age this should take place. There is a need for further research into the views of the professionals involved. This project provides insight in this area by providing detailed and crucial information on professionals’ thoughts and views on the issue.

2.8 Summary

This chapter has demonstrated the continued importance of TOPFA. This chapter has shown how TOP and TOPFA is conceptualised in the public and policy domains. It is an important issue with a relatively prominent public profile. This is alongside the quite complex nature of the issue, which has a convoluted pattern of policy development in terms of legal regulation. More critical sociological perspectives on TOPFA as a social issue need to be considered to establish the current context of TOPFA as an issue for sociological enquiry.

Chapter 3: Literature Review

3.1 Introduction

In this chapter, an overview of the key social science discussions on the topic of TOPFA is provided. Debates both past and present, significant to the issue of TOPFA are discussed. These debates include; legalised killing, legal challenge to the legislation, campaign to legalise TOP, the concept of choice, the professional groups that have been studied in this research, the disability movement, eugenics and the arguments that TOPFA represents 'modern day eugenics'. Ultimately, it is argued that an ethical dilemma continues to be present as to issues surrounding TOPFA. Understanding professionals' views on this procedure, which are underrepresented, sought to unpack and understand this dilemma. This will enable more thorough policy debates with more knowledge as to professionals' feelings on these issues, and the inclusion of a neglected professional group will broaden current understandings.

3.2 The scale of termination of pregnancy: Epidemiology

Epidemiology allows for the scale of TOPFA to be measured, as well as a comparison of different measurements across different areas within the UK. Epidemiology has been defined as: "The study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems" (Last, 2001: 62). Epidemiology focuses on areas of research such as the burden of disease, death rates, birth rates, and anomaly screening and detection rates. The study of epidemiology is important within society as it informs policy decisions and informs preventative health policies by identifying disease risk factors. The distribution of disease, the factors which determine disease and the frequency of diseases are key to any epidemiological investigation (Rothman, 2002; Hennekens and Buring, 1987).

Patterns of disease have been recorded for centuries; the first known report was published in 1662 by John Graunt who analysed reports of births and deaths in London (Hennekens and Buring, 1987). Another key example of early epidemiology can be found in 1883, when a system for recording the number and causes of death was set up by physician William Farr. This system allowed the epidemiologist John Snow to create and test his theory on the cholera epidemic which occurred in London in the 1850's (Hennekens and Buring, 1987). John Snow wanted to test his hypothesis on the origins of cholera, which he argued was being transmitted through water. Using the data available, he noted that cholera death

rates were higher in areas of London where the water originated from the Thames River (Hennekens and Buring, 1987). There were three companies supplying water, one of which changed its water supply. This resulted in a decline of cholera rates in the areas supplied by that company (Hennekens and Buring, 1987). Epidemiology allows the quantification of risks in human settings adding to research that discusses human risk behaviour; this then allows the opportunity for risk to be reduced as humans can choose to alter their behaviour, or accept an intervention (if one is available) (Hennekens and Buring, 1987).

3.2.1 Aetiology of fetal anomalies

The aetiology of many anomalies is not fully understood with both environmental factors and genetic factors (WHO, 2012) playing a role. The BINOCAR is a system of congenital anomaly data registers. BINOCAR aims to provide the continued monitoring of anomalies in England, Scotland and Wales through national, regional and disease specified registers of congenital anomalies (Boyd et al., 2011; BINOCAR, 2010). With technological advances in ultrasonography and prenatal testing, more anomalies are detectable antenatally with increased accuracy (Statham et al., 2006). There are many well-known factors that are known to increase the risk of a pregnancy being affected by a congenital anomaly. For example, it is well established that increased maternal age increases the risk of a pregnancy being affected by Down's syndrome (National Down's syndrome Cytogenetic Register, 2011; Rankin et al., 2005; Hobbs et al., 2000); and other chromosomal anomalies (Irving et al., 2011). Maternal age is increasing (Office of National Statistics, 2010). In 2011, the mean age of mothers was 29.7 in England and Wales; this was 26.4 in 1973 (Office of National Statistics, 2013). The average age for a first birth in 2011 was 27.9, up from 26.6 in 2001 (Office of National Statistics, 2013). Associations have also been found between maternal obesity and increased risk of congenital anomalies (Stothard et al., 2009). Increased risk of fetal anomalies such as neural tube defects, cardiovascular anomalies, cleft lip with and without cleft palate, hydrocephaly and limb reductions have been found (Stothard et al., 2009: 646). Along with maternal obesity, maternal underweight is also linked to increased risk of fetal anomalies such as gastroschisis (Rankin et al., 2010).

There is a well-established link between taking folic acid supplements and reducing the risk of a pregnancy being affected by a neural tube defect (Werler et al., 1999; Medical Research Council Vitamin Study Group, 1991). Other research has linked a number of factors to increasing the risk of fetal anomaly. However research has found to be inconsistent. For example, studies have reported spina bifida and other neural tube defects to be associated

with younger paternal age (Materna-Kirluk et al., 2009) as well as older paternal age (McIntosh et al., 1995). Another has concluded that advanced paternal age has no impact on increased risk of neural tube defects (Yang et al., 2007). Behavioural factors have also been found to increase the risk of fetal anomaly. Examples include drug use, diet and smoking. Behavioural factors combined with young maternal age and being underweight can increase the risk of congenital anomalies (Green et al., 2010).

Tobacco smoking has been reported to have a number of adverse effects in pregnancy, including an increased risk of fetal anomaly (Nolan et al., 2010). Grewal et al., (2008) reported that smoking during the preconceptional period does not have a significant impact on the aetiology of a number of congenital anomalies. This finding has been however both supported and contradicted by several other studies (Grewal et al., 2008: 524). Despite this, smoking continues to pose a risk for disease development (Saracci, 2010). Current advice recommends stopping while trying to conceive, and avoiding nicotine replacement therapies as this still allows nicotine (although a significantly lesser dosage) into the system (NHS Choices, 2010). Examples of maternal smoking and the risk of congenital anomalies has been reported in research to include; heart anomalies, musculoskeletal anomalies, limb reduction anomalies, orofacial clefts (Hackshaw et al., 2011; Mossey et al., 2009).

Increases in air pollution occurred as a result of industrialisation in the 19th and 20th centuries. Studies into the effects of pollution started as early as the 1950's in response to the effects of rapidly increasing pollution levels in London during this time (Glinianaia et al., 2004). Areas with exposure to ambient air pollution indicate some evidence for an increase in fetal anomalies risk (Vrijheid et al., 2011). However not many studies have identified a conclusive causal link (Dolk and Vrijheid, 2003). Despite this, studies have found some links between pollutants and anomalies. For example, a weak positive association was found between nervous system anomalies and black smoke (Rankin et al., 2009). Exposure to pollution during pregnancy has been found to be associated with an increased risk of cardiac septa defects, ventricular septal defect, congenital pulmonary valve stenosis (Dadvand et al., 2011: 438; Maisonet et al., 2004).

The summary of the aetiology of fetal anomalies shows how different factors can impact on the presence of fetal anomaly. Different risk factors, such as increasing maternal age, have become more prominent within society. This means that there is a higher risk of fetal anomalies, resulting in more fetal anomalies being detected. An increase in fetal anomalies could lead to an increase in TOPFA.

3.3 Sociological debates on termination of pregnancy

Chapter one looked at current debates that have been surfacing in the media, the legislation governing TOP and the guidelines used by medical professionals which deals with offering TOP and the procedure of TOP. With this context set out, the further discussion presented here builds on that platform by exploring relevant sociological debates that also influence the debate surrounding TOP, TOPFA and the acceptability of the procedures. Sociological perspectives on killing as a general concept will first be introduced to further contextualise how TOP and TOPFA are understood. This is then followed by discussion of the more specific issues related to TOP: the backstreet abortion; medical professionals; and the disability movement. These issues are important to consider as they will aid in the understanding of how the TOPFA legislation came to be in its current form.

3.3.1 Killing

A key argument of the anti-abortion lobby is that TOP is the ‘murder’ of an innocent child. In the UK, a murder has been committed if a person;

- “is of sound mind and discretion;
- unlawfully kills;
- any reasonable creature (human being);
- in being (born alive and breathing through its own lungs)
- under the Queen’s Peace;
- with intent to kill or cause grievous bodily harm” (CPS, 2012).

The fetus is not recognised as a human being and thus does not have any legal rights in the UK. This, in addition to the fact that TOP is a legal procedure, means that TOP is not classified as murder. The moral status of the fetus has been a consistent feature in discussions of TOP since the initial campaigning for legal TOP (Gillon, 2001). It remains important because how a fetus is perceived will inevitably frame how someone conceptualises the bringing about of a fetal demise via the process of TOP. The idea of TOP ‘killing’ an innocent life is the focus of many anti-abortion campaigns. Arguments focused on the fetus see the fetus as a person who has the same ‘right to life’ as a person who is already born (Cannold, 2002).

The point at which a fetus becomes a legal person is when it has been born alive and breathing through their own lungs (CPS, 2012). Legislation in England and Wales also allows the procedure of TOP to occur without legal ramifications against the professionals who provide the TOP as per the Human Fertilisation and Embryology Act (1990, 2008). This means different things depending on the context in which it is being analysed. Some may argue that the current legislation of TOP allows for the institutionalisation of the killing of fetuses with fetal anomalies (Savulescu, 2001). Others may suggest that the legislation takes autonomy over women's bodies away from the woman and into the hands of professional men (Hadley, 1996). Arguments that public opinion on TOP supports the availability of the procedure due to its status as a 'necessary evil' have also been made (Furedi, 1998: 159). This idea is supported by Harman (2000: 322) who found that women regretted the TOP itself, but not the choice available to them. Regret about the TOP centred on the feelings of sadness felt after the procedure. Feelings of sadness, anger, anguish and guilt have been echoed in other research in the area of TOP (Graham et al., 2009).

Looking into the social phenomenon of legitimate 'killing' is important when discussing TOP and TOPFA as many of the arguments against TOP centre around the issue of killing an innocent life. For example, TOPFA has been conceptualised by some in the disability rights community to be an example of 'modern day eugenics', with eugenic programmes in the past seen as a legitimate form of 'killing'. This community range from people who are writing, researching, campaigning on issues related to disability rights, and/or comment from the position of being an affected person. The idea of 'killing' has been subjected to much scrutiny within the research realm as different societal events have legitimised the killing of another human being without legal ramification. Such examples include war soldiers killing fellow soldiers. Extensive research into the Holocaust has resulted in many questions focusing on the thousands of soldiers and civilians involved in the mass gassing of innocent Jewish civilians.

One focal question was how the perpetrators were able to complete the task of sending the Jews to the gas chambers knowing they were going to their deaths. Much was written about the Nazis being insane or inherently evil (Waller, 2007). However Waller has concluded that the majority of the Nazi were just normal people (Waller, 2007). Among those who were involved in mass killing were people from every background; educated people, church goers, people from loving families, people from broken families, young people, old people;

in essence, just normal people (Waller, 2007). The use of propaganda to establish Jews as the 'enemy' took advantage of the resentment present in Germany to influence the masses and reconstruct the Jewish identity as something to be feared (Kohl, 2011). The authority of which many of the Nazi soldiers were working on has also been concluded to be a reason for the actions of those soldiers, as killing in a systemised format has been argued to be more comfortable for people (Bauman, 1989). Bauman argues that modern civilisation has produced the efficiency of mass killing through social norms and social rules of the time (Bauman, 1989). In situations of war, Bauman argues those who 'enjoyed' killing were weeded out, but those who resisted the killing were deviant. This made the 'killers' the conformers to social norms of the time (Bauman, 1989). However, Bauman's approach has been scrutinised by other theorists within the research realm. For example, Stone (2010) argues that Bauman does not adequately answer why only some modernity's result in genocide.

How such widespread killing could have occurred has been studied extensively. The effects of authority being significant in such studies as the order to inflict harm on others would have had to have been given in the first instance. The most famous studies on authority have been conducted by Milgram (1963) and Zimbardo (1973). Milgram concluded that the presence of an authority figure was enough to make average everyday people administer electric shocks, steadily increasing in voltage, to another person as punishment (Milgram, 1963). Milgram sought to investigate what the maximum shock the participants would be willing to administer before refusing to continue. The 'order' to administer the shocks was given by an experimenter (Milgram, 1963). The dilemma faced by participants is to either continue following orders or listen to the pleas to stop from the learner (the recipient of the 'electric shocks') (Milgram, 1963). Twenty-six of the participants administered the highest electric shock with fourteen participants refusing to administer any more shocks at varying points prior to the maximum shock available (Milgram, 1963). Zimbardo (1973) wanted to investigate the impact of a situation on human behaviour by studying the effects of assigned roles in a prison; the effects being those in positions of power, the prison guards, and the effects of those assigned the role of prisoners (Haney et al., 1973). The participants adapted to their roles beyond the expectation of the researchers with the officers pushing the boundaries of their authority even to the extent of torture (Haney et al., 1973). The experiment was terminated after six days with the researchers arguing the experiment had showed the power of authority and obedience when a legitimate social role was assigned; essentially good people can commit acts of evil (Haney et al., 1973). This was

argued to be compatible with Milgram's findings (Milgram, 1963). Both these studies show the impact of power on the average person suggesting with the influence of authority and the social situation one finds them in may result in acts being committed that they would not have thought possible.

3.3.2 Social construction of murder

It is easy to see how even the term 'murder' is subject to social construction by simple definitions. For example, in the USA, 38 states have fetal homicide laws, which mean that a violent act against a pregnant woman can result in a double murder trial (National Conference of State Legislation, 2010). There has recently been public outcry in the USA as women are increasingly facing murder charges when they lose their babies; Rennie Gibbs was arrested for murder after her unborn child was still born at 36 weeks (Pilkington, 2011). Gibbs was found to have a cocaine habit and thus arrested, despite the fact that this habit had not been linked to the child's death (Pilkington, 2011). The situation in the USA is complicated though, because of the variation in state law. For example, a fetus can be considered a person from any gestation (e.g. Alabama), from 12 weeks gestation, or viability (e.g. Indiana) depending on the state in question (National Conference of State Legislation, 2010; Albert, 2001). This means that charges of wrongful death can be brought if injury or death occurs without the consent of the mother (Albert, 2001). This changes the definition of what a TOP is as the fetus is defined as a person at an earlier stage. The variation in the USA makes it very clear that the concept of murder or killing in relation to the fetus is highly dependent on other definitions, such as where life begins. This is very different to the legislation in England and Wales, where views on the fetus are less polarised (Gross, 2002). However, the notion of variation in legislation highlights the possible consequences of changing the legal definitions of procedures such as TOP, and how these frame the ways in which providers and recipients of TOPFA make sense of their experiences.

Despite the legal constraints medical professionals have to work within in the UK, and however hard it is for staff to provide health care services related to TOP, the difficult decision making processes parents go through must also not be neglected. The current legislation in England and Wales allows legal TOP with medical professionals having a very minimal chance of being tried for murder. Autonomy over their work has been a present feature throughout the history of medicine and remains an important factor while making difficult decisions surrounding TOP and TOPFA. Conserving professional discretion is

important for medical professionals as it is a safeguard against losing their medical autonomy.

3.3.3 Backstreet Abortions and the Bourne challenge

There is very little research that can clearly document the practice of the backstreet abortion as it was something that was only documented if a woman suffered complications or death. However, what is clear is that the practice was rife. Many felt a real need for TOP as a method of birth control for the working class, who were denied other means of birth control by the middle classes (Knight, 1977). Towards the end of the 1800s, the working class sought a more comfortable lifestyle, with smaller family sizes seen as a way to achieve this (Knight, 1977). Numerous methods of ‘procuring a miscarriage’ were adopted. Examples reported include using knitting needles or hairpins to scrape out or puncture the fetus, drinking mixtures of herbs and/or drugs boiling coins and drinking the water and taking lead in numerous formats (Knight, 1977). Herbs and drugs that were consumed included; colocynth, hiera picra, tansy, pennyroyal, apiol, gin and gunpowder, gin and salts, iron and aloes, caraway seeds, turpentine, washing soda and quinine (Knight, 1977: 60). Adverts also appeared in magazines and newspapers claiming to aid in women’s’ menstrual cycle; it was commonly known these pills were drugs to procure a miscarriage (Knight, 1977). This commonplace occurrence of illicit TOP is the backdrop against which individual cases began to challenge the definition of TOP as illegal.

A legal challenge to the legislation banning TOP was made in 1939 by a doctor who had performed a TOP. This event was significant in the development of the current legal framework. It recognised a circumstance where a doctor acted in good will to support the health of the pregnant woman over that of the unborn fetus. On the 14th June 1938, Mr Aleck Bourne, a consultant gynaecologist practicing in London’s St Mary’s hospital, performed a TOP on a 14 year old. The girl had been raped by an officer and had requested a TOP at St Thomas’s Hospital, London, but had been refused due to biases that were common at the time. These biases included; class biases and female stereotypes (de Costa, 2009: 230; The Lancet, 1938a). Bourne was said to not be influenced by the class system and other such biases and therefore considered the TOP request. He examined the girl and deemed that the girl was not a prostitute and did not have mental problems; her life was not in danger (as per the legislation). However, he questioned whether her health was in danger and based on his assertion that her health was at risk if the pregnancy continued, he performed the TOP (de Costa, 2009). Bourne wanted to challenge the

current law as he felt danger to health was just as, if not more, important than danger to life (de Costa, 2009). Bourne also sought clarification of the law as there were many instances where he had performed the TOP procedure as he felt it was beneficial to the health of the woman. Many professionals who spoke in his defence supporting his decision, suggesting that the practice of TOP should be supported in certain circumstances (The Lancet, 1938a; The Lancet, 1938c). The judge in the case, Justice MacNaghten, conceded that for unlawful TOP to exist, there must also be lawful TOP and therefore extended the meaning of the current legislation to include risk to the women's health (de Costa, 2009: 230). Justice MacNaghten also acknowledged that the practice of TOP was not uncommon (The Lancet, 1938a). It was also felt that public opinion was supportive of the fact that a girl of 14 should not be forced to bear the remainder of a horrific ordeal by carrying the fetus to term (The Lancet 1938b). This case proved to be significant for the implementation of the Abortion Act 1967, as one of the key defence arguments was the right for medical professionals to work in the interests of health in good faith (The Lancet, 1938c). It was clear for all to see that Mr Bourne had broken the law, yet he was acquitted despite this. The ruling also paved the way for the 'two doctor' clause in the 1967 Abortion Act as the registered medical practitioner should be prepared to seek, or be sought, for a second opinion in such cases (The Lancet, 1938c).

Looking at the sociological literature of killing, the social construction of killing and the backstreet abortion, provides a backdrop to how current understandings of TOP have come to be formed and understood. Looking at the campaigns which led to the legalisation of TOP will further cement the background of current perspectives.

3.4 The campaign to legalise termination of pregnancy

This section will describe the campaign to legalise TOP, as it appears in the social science literature. This is significant to how TOP and TOPFA is governed in its current form, and how it is conceptualised within the social science agenda. TOP in its illegal form was governed by law enforcers. The change in TOP governance to medical professionals paved the way for the legal TOP now available in England and Wales (Simms, 1998). This medical governance is still evident in current practice with the 'two doctor' clause still present and with medical opinion recognised within the legislation (Statham et al., 2006; Lee, 2000). In England and Wales, the most prominent campaigning for the legalisation of TOP was witnessed during the 1960's (Francome, 2004; Simms, 1998; Boyle, 1997). Illegal TOP had been practiced for years prior to this campaign and was in huge demand (Boyle, 1997).

Public and professional opinion was out of sync with the legislation that governed TOP. The stigma attached to pregnant unwed women (Paintin, 1998), as well as a desire to reduce family size, maintained the demand for illegal TOP (Knight, 1977). The major arguments presented for the legalisation of TOP included issues of social justice: for women through access to a legal safe TOP; and for women to have autonomy over their own body (Sims, 1998). But also, prevention of impairment featured in the argument for legislation (Simms, 1998). The drug Thalidomide, prescribed for morning sickness and later found to cause disabilities in the fetus (Gleeson, 2007), added more prominence to the arguments already presented (Francome, 2004; Cossey, 1998).

During the 1960's, a change was being seen among feminists; that of radicalisation which resulted in campaigning and debating all issues of which women were felt to be significantly affected by (Hoggart, 2010). It is important to note that not all women who fought in the campaign to legalise TOP affiliated to feminism, but feminist activism played a key role. Prominent feminist and women's groups, for example the Abortion Law Reform Association (ALRA), fought for access to TOP that women wanted, and not just what was deemed medically necessary by the medical profession (Paintin, 1998). Alongside women, and other supporters of TOP, medical professionals were also significant in this debate as they would become the providers of legal TOP services. The demands of medical professionals differed from the demands of women, with protection from prosecution and clinical freedom central for them. Recognising women's rights to a TOP in situations other than those medically necessary was not supported on the whole by medical professionals or members of parliament (Paintin, 1998). The enactment of the Abortion Act 1967 recognised the medical autonomy of doctors by enacting the two doctor clause in the act. It also set out the clauses of the Abortion Act to centre on satisfying medical requirements for a TOP. Medical autonomy and medical advancements continue to be prominent in the legislation. The Human Fertilisation and Embryology Act 1990, amended the Abortion Act 1967, with medical developments and medical reasoning again being at the forefront (Boyle, 1997). Medical developments were a key factor in this legislative change with the age of viability reduced from 28 weeks to 24 weeks in light of medical advancements (Boyle, 1997).

The concept of choice featured prominently in these debates; reproductive rights had been a strong point of campaigning for many feminists who sought control for women's own bodies (Tilley et al., 2012). The idea that women should have full autonomy over their

bodies ('A women's right to choose') was a strong slogan for many protests. It became widely adopted in the 1970's during a time where campaigns to restrict the newly legalised TOP legislation came into prominence (Bridgeman, 1998). Many questioned what choice actually really means in reproductive health. A woman having full choice and decisional autonomy in reproductive decisions have been argued to be problematic. This is due to the elimination of men and society from the decision which then eliminates them from blame (Petchesky, 1986 cited in Smyth, 2002: 336). There has also been research that suggested that women who continue a pregnancy after a diagnosis of fetal anomaly cannot expect help with their child as they knowingly brought that child into the world when it could have been prevented (Himmelweit, 1988). The legislation governing TOP does not recognise women's demands for a TOP as a justifiable reason. Medical criteria must be satisfied in order to gain access to a TOP. Despite this, the legislation can be interpreted in such a way that, as long as a TOP is deemed to be more ethical than forcing a woman to continue with the pregnancy, then TOP can be provided in the majority of cases (Paintin, 1998: 17).

It is important to remember that legal TOP remains at the discretion of two medical doctors. This requirement, and the fact that the legislation also includes a conscientious objection clause, can present a different challenge to the idea of 'choice'. Some writers argue the legislation is not 'women's choice' at all, arguing that the legislation in its current form is discriminatory against women (Savulescu, 2001) due to the differing services different women receive/have access to. Some women will have the knowledge and the means to enable them to access a late TOP if their current health practitioners are not prepared to offer one (Graham et al., 2008b; Savulescu, 2001). It could also be possible that women will be offered a TOPFA at 24 weeks for a condition (e.g. Down's syndrome), while others with a diagnosis of the same condition, will not be offered TOPFA past 20 weeks of pregnancy. This can occur depending on where maternal health services are (although a second opinion could be offered). This would suggest that the services an individual has access to in their locality are dependent on the subjective values of the medical professionals providing the service (Savulescu, 2001) adding weight to the importance of understanding medical professionals' opinions.

There are questions to raise about the concept of 'choice' and whether it is simply no more than ideology; i.e. the reality of choice is less flexible than the rhetoric suggests. Regardless of this, the choice for women to have a TOP is subject to medical criteria and medical

agreement. Reproductive choice is seen as a positive thing for women, with the RCOG guidelines outlining this reason as a justification of prenatal screening (RCOG, 2010). While TOP was legalised, the law does not recognise women's right to a TOP on demand. A number of medical criteria authorised by two doctors must be met in order to have the TOP procedure. This results in the decision making of doctors to be central in TOP and TOPFA discussions as the authorisation rests with them. It is therefore important to understand their views on these matters given their central role in authorisation.

3.5 The sociology of professions

The term 'profession', and the meaning that surrounded this, was neglected by the study of sociology until the 1960's, where the study of professionals started to become of sociological interest (Abbott and Meerabeau, 1998). This interest centred on what a professional is and who can claim professional status (Abbott and Meerabeau, 1998). There are a number of key aspects that are said are necessary to claiming professional status. There include: autonomy or control over their work; a clearly defined monopoly over an area of work; and a knowledge base (Abbott and Meerabeau, 1998). The medical profession can claim such professional status, but other occupational groups have more difficulty. In this study, the term 'social care professionals' has been adopted, however, there are doubts over whether the term professional can be claimed for the occupational groups included under this umbrella term. Abbott and Meerabeau (1998: 7) cite work which refers to the shorter training, less specified body of knowledge requirement and less autonomy over supervision or control from 'professionals', as reasons to categorise the caring profession as 'semi-professional' (Etzioni, 1967). However, research in the sociology of professions has adapted, and those involved in the field have not been restricting themselves to the strict boundaries of the concept of 'profession' (Gorman and Sanderfur, 2011). This has resulted in occupations that do not meet the criteria of a 'profession' no longer being neglected (Gorman and Sandefur, 2011). While Gorman and Sandefur's perspective has been criticised as inaccurate (Adams, 2014), what we can see is a continued interest in the sociology of professions.

Functionalism formed the dominant explanation for the sociology of professions until the 1970's (Muzio et al., 2013). Here, the issues that functionalism largely ignored were brought to light, namely the lack of acknowledgement of power and privilege, and for having a vested interest in the claims and interests of those groups deemed professionals (Muzio et al., 2013). The study of professionals has expanded since this time, with a number of

themes most popular within the study of professionals noted by Adams (2014) to include; inequalities in professional practice, professionalisation and professional development, de-professionalisation, declining autonomy, professional regulation, and the characteristics and experiences of professional workers (Adams, 2014: 3). Adams noted the most studies professions are those within health care, with particular attention to medicine and nursing (Adams, 2014).

3.5.1 The medical profession

The medical profession has been met with new challenges in recent years regarding issues linked to professionalism and their professional status. One such example is the creation of new roles within the institution. The NHS has seen an increase of management systems, in place to govern the professional practices in light of changes within the health system (Numerato et al., 2012). Such changes are mainly increased demands from more knowledgeable consumers, and exposed failures that have received mass attention (Numerato et al., 2012). Another notable change is the increased focus on market reforms. Such changes encourage consumer values, but also combined with cuts to welfare funding, increases notions of individual responsibility for health (Sturgeon, 2014). The Health and Social Care Act, 2012, adopts a pro market agenda, allowing health care to be commissioned to any provider who is qualified to provide the necessary care (Sturgeon, 2014). Such changes (among others) have argued to be contributing to a loss of the privileged position medicine holds in society, namely a loss or renegotiation of power (Lipworth et al., 2013). Lipworth et al., argue that the literature surrounding the issues of professionalism within medicine suggest that doctors are aware of such changes and are not adjusting to them smoothly (Lipworth et al., 2013). Maintaining professional autonomy over their work was visible during the campaigning to legalise TOP through the medical professionals' refusal to support abortion on demand by women.

The demand for the women's 'right to choose' and make decisions about her own body was popular during intense campaigning for legal TOP, but has never been supported by a majority within the medical profession. TOP on demand was never granted, with medical professionals able to maintain autonomy over their work by dictating the medical situations whereby they would be satisfied providing TOP. All attempts that have been made to make the legislation more liberal, or liberal to the extent that TOP will be performed on demand have all had limited impact. This is essentially due to the medical profession; medical

professionals wanted to maintain autonomy over their own work and were unsupportive of TOP on demand (Paintin, 1998).

The medical profession, since its early establishment, has generally attempted to maintain control over its practices. Alongside this, the institution of medicine is associated with attempts to gain more control over other practices, and ‘medicalising’ aspects of social life. Medicalisation is the process where an aspect of social life is discussed, explained and ‘treated’ in medical terms, even if they have previously not been seen as medical ‘problems’. Such examples include age, and pregnancy (Nettleton, 2006). The concept of ‘de-medicalisation’ is the opposite; things that were explained in medical terms which are no longer. Such examples of ‘de-medicalisation’ include homosexuality (Conrad, 1992), which in the past had been viewed as an illness (Szasz, 1970). The most commonly referred to example of medicalisation is childbirth (Annandale, 2009; Nettleton, 2006; Annandale 1998; Conrad, 1992). This has been witnessed from the 19th Century when doctors and surgeons attempted to take control of childbirth from midwives. Their claims were based on professional knowledge and the use of medical equipment such as forceps (Nettleton, 2006). Doctors sought to take control of ‘difficult’ or ‘problematic’ births. They were argued to need more ‘expert’ knowledge and care that the ‘under-qualified’ midwives were unable to provide. The medical professionals who sought control over childbirth took credit for the huge reduction in maternal mortality that was witnessed. This legitimated their control over such medical practices and enabled them to increase their control. It has since been concluded that increased hygiene was the major contributor to the reduction of maternal mortality (Woods et al., 1989). Midwives have sought recognition over their claim over childbirth. This claim was legitimately recognised in 1902 with the establishment of the Midwives Registration Act, meaning midwives would be subjected to regulation (NMC, 2010). Doctors and surgeons still maintain control over ‘difficult’ births. This process has seen childbirth become increasingly a matter of medical concern, something which has previously not been the case. Now, pregnant women are subjected to medical monitoring, during and after birth (Nettleton, 2006); this is especially the case if the pregnancy, or a past pregnancy, has been defined as a high risk pregnancy. Medical knowledge and technological equipment is continually improving. Pregnant women are subjected to numerous tests and antenatal classes to continually monitor the pregnancy (Annandale, 2009; Nettleton, 2006).

Medicalisation of reproductive health issues is often presented as a negative, but it is important to also acknowledge the weaknesses in such arguments. Medical sociology as a

whole can put the medical profession in a no win situation. For example, if the medical gaze remains focused on the physical body, doctors can be criticised for ignoring the social context of health and illness (or in this case, pregnancy). But on the other hand, if the medical gaze extends to relevant social factors, then a different critique is made, that of medicalisation (Nettleton, 2013). Similarly, it is important to remember the medical profession is a human group subjected to feelings and emotions like other groups. Therefore, the medical autonomy over TOP is not just about power. TOP is unpleasant work (Bolton, 2005), therefore we need to understand the complex reasons why they continue to perform it (Graham, 2006). The views of medical professionals in the context of TOP have been neglected with a focus on the mother and fetus (Graham et al., 2008). Assuming medical professionals are not affected by such emotionally charged situations would be somewhat hasty. It is important to understand these perspectives given the central role medical professionals have in authorising TOP.

3.6 The disability movement

Western society has witnessed a strengthening disability movement since the 1970's. In the UK the main time frame of campaigning for people with disabilities to have rights started in the 1980's (culminating in the 1995 Disability Discrimination Act). This was after the 1967 Abortion Act was legalised. The disability movement enabled people with disabilities to become more vocal and more prominent in the political scene, organising campaigns and fighting for legal recognition as a legitimate person in society (Barnes et al., 1999). Campaigning for anti-discrimination legislation for people with disabilities began in the UK in the mid 1970's (Barnes et al., 1999). Numerous organisations existed, all with senior level leadership by people with disabilities. All of them were part of a fight for equal rights and the removal of negative discrimination (Barnes et al., 1999). The Committee on Restrictions Against Disabled People (CORAD) took the initial steps to getting anti-discrimination legislation debated in parliament. The committee made recommendations on numerous issues related to everyday living (e.g. transport) as well as recommending legislation to secure rights for people with impairments (Howard and Fox, 2000: 43; Barnes et al., 1999: 162). There were 14 attempts from 1982 to get anti-discrimination legislation put in place; all were rejected until the 1995 Disability Discrimination Act (Barnes et al., 1999). It was 1991 before the government admitted there was a serious discrimination problem towards people with impairments (Barnes et al., 1999).

In the mid-1990s, legislation was finally approved. The Disability Discrimination Act 1995 (amended 2005) made it illegal for employers to treat a person negatively for reasons pertaining to a past or present disability (Howard and Fox, 2000). The 1995 Disability Discrimination Act also indicates action employers can take to ensure they follow the law. The 1995 Disability Discrimination Act was a significant move as it recognised people with disabilities in legislative terms and ensures discrimination is illegal. Since 2010, the Equality Act has replaced most of the Disability Discrimination Act, although aspects of the latter are still applicable (for example, the Disability Equality Duty) (Direct Gov, 2012).

Many writers have argued that despite campaigning and legal recognition, discrimination still exists. One such form has been argued to be TOPFA (Kerr and Shakespeare, 2002; Davis, 1999). While campaigning for disability rights was becoming increasingly more vocal and supported, alongside this, medical knowledge and technology was becoming, and continues, to become more advanced. This means detecting fetal anomalies has become more accurate. The relationship between medical technology and the definition of fetal anomalies is a significant concern for disability activists due to Clause E of the Human Fertilisation and Embryology Act, 1990 (amended 2008) which removes the upper limit for TOP for 'serious fetal abnormality'. This has been referred to as 'modern day eugenics' and 'discrimination' by many disability writers (Saxton, 2013).

“While it is not legitimate to abort a fetus because of its sex or ‘race’, termination because of anticipated impairment is permissible. Indeed, women come under considerable professional and family pressure to have an abortion where an impairment is identified (C. Thomas, 1997). The justification offered is that a disabled child places an excessive burden on the woman/family/society – both in terms of additional time needed to support the child as well as the financial and emotional resources that must be devoted to its well-being – with a consequent deterioration in the quality of family life and relationships. Yet to many disabled people this confirms a general public hostility towards those with impairments... It is hard to justify equal rights to those alive while denying such rights to the new generation of disabled people”. (Barnes et al., 1999: 222).

Despite this, approval for TOPFA has been shown in available statistical form since 1980 (Lee, 2000: 397). Overall research in the area of the acceptability of TOPFA remains scarce (Lee, 2000), even among medical students (Gleeson et al., 2008: 783).

The right to life of the fetus (Gillon, 2001) or the status of the fetus (Hopkins et al., 2005) maintains its prominence as a key issue in the debates surrounding TOP. The removal of an upper limit for TOPFA as per the Human Fertilisation and Embryology Act 1990, 2008 suggests the status or right to life of a fetus may be given more or less weight depending on the presence of a fetal anomaly. This would suggest that fetal anomaly is a valid reason for TOP (Green et al., 1993). Consideration of the circumstances around such instances of TOP is key. Many instances of TOPFA involve the termination of pregnancies of wanted babies (Furedi, 1998) with the grief suffered likened to that of loss of a live born. TOPFA has been met with less public approval in recent times, despite acting as a key component for the original legalisation of TOP (Furedi, 1998). This shows a changing attitude towards impairment and subsequent disability itself rather than TOPFA (Furedi, 1998), with discrimination now illegal (Office of Public Sector Information, 2005). Despite such changes, discrimination against people with a disability is still argued to exist in many forms within society. Such examples presented include the education system, the employment system, and within general society in terms of access (Hyde, 2006; Kerr and Shakespeare, 2002). Within the context of the broader debate about contemporary professional practice against a backdrop of societal discrimination, the specific issues of eugenics, non-directive counselling, and provision of social care, are of particular importance.

3.6.1 Eugenics

Eugenics is the idea that the genetic pool of a population can be improved through gene manipulation. Eugenics is often associated with the Nazi regime where eugenics was promoted by Hitler, who advocated for a pure German race (Proctor, 1988). The term 'racial hygiene' was used for the practice of destroying the lives of those not worth living; essentially adults and children with disabilities (Proctor, 1988). This 'cleaning' provided the model for further 'racial cleansing' which eventually led to the 'Final Solution', the name given to the mass execution of Jews (Proctor, 1988). Legislation was also implemented that those believed to "suffer from hereditary, mostly psychiatric, disorders" were subject to compulsory sterilisation to prevent them from being able to reproduce (Meyer, 1988: 575). A huge propaganda agenda was implemented in attempt to make the law popular, but this was unsuccessful (Meyer, 1988). In 1939, two parents requested the killing of their child due to severe disabilities; this request is argued to have acted as a stimulant to Hitler to commence extending eugenic programmes to children (Meyer, 1988). It became a requirement for all 'deformed' children to be registered with the decision to kill children

with disabilities decided by three experts without examination. Parents who resisted were threatened with withdrawal of the child from their legal custody (Meyer, 1988). Money was also credited to 'biologically sound' couples to reproduce (Kevles, 1995: 117).

The Nazi regime is perhaps the most well-known example of extreme eugenic programmes, however, there were other examples. For example, the USA, of whom 26 states in 1935, had compulsory sterilisation policies in place with an additional 10 states finalising such policies (Kerr and Shakespeare, 2002). Some states used impairments as an explanation for undesirable social behaviour. For example, Indiana implemented their compulsory sterilisation legislation in 1907 for "criminals, idiots, rapists and imbeciles" (Kerr and Shakespeare, 2002: 19; Kevles, 1995). The UK did not advocate such extreme practices but did opt for voluntary sterilisation, which was never implemented. It has been argued that the UK did carry out such methods through coercion (Barnes, 1991). Overt eugenic programmes became politically unpopular after the Second World War (King, 1999).

The practice of TOPFA has been argued to echo some of the eugenic principles of the past (Priestley, 2003; Kerr and Shakespeare, 2002). The removal of the upper limit for TOPFA has also been suggested as evidence that the practice of TOPFA is discriminatory. This is because TOP is allowed past the 24 week threshold which restricts TOP for other reasons. A distinction has been made within some research when discussing TOPFA between Active and Passive eugenics (Savulescu, 2001). Active eugenics refers to the practice where a person may be offered an incentive to practice a particular behaviour which directly promotes some eugenic outcome. For example, parents being offered financial inducements to reproduce as they have been deemed to be 'fit' to do so (Savulescu, 2001: 167). Passive eugenics refers to the restriction of options with the result that a eugenic outcome is more likely (Savulescu, 2001). Such examples include, not offering child support to people who choose to have a disabled child (Savulescu, 2001: 167). The absence of social care is not something that is present in UK policy. The presence of the NHS in its current form also enables access to health care services that people with impairments may not have in different countries. Despite the availability of services, this does not necessarily mean that other social pressures do not exist (King, 1999) with the attitudes held by the medical profession argued to lead to eugenic outcomes (King, 1999). Other philosophical positions have also been argued to impact on this debate. For example, the feminist position of 'women's right to choose' has been argued to be at odds with the disability

movements standpoint (Sharp and Earle, 2002). This is due to having a right to choose overrides other reasons a TOP is sought.

3.6.2 Non-directive counselling

“Determining which human characteristics are socially desirable or undesirable, and where we ‘draw the line’ between them, is therefore central to decision making about who should or should not be born” (Wolbring, 2001, cited in Priestley, 2003: 37; Buchanan et al., 2000).

Much of the interdisciplinary writing discussing TOPFA as ‘modern day eugenics’ or as ‘discriminatory’, frame TOPFA as a means of actively reducing the ‘burden of disability’ in society. It can be seen from the medical professional perspective, and the perspective of the women campaigning for legal TOP, that there is a lot more to the debate and the decision to TOP than simply to avoid a ‘burdensome’ child. It could in fact be argued that all children are a burden on their parents. It is, however, important to consider all relevant perspectives when considering TOPFA. In the crudest sense, what is being determined is what constitutes an acceptable future life, or what characteristics are deemed socially desirable. This, by extension, also means what characteristics are undesirable are also being determined. This in turn determines what an acceptable TOPFA is and what is not.

There is research that suggests women are not giving their fully informed consent as to whether they wish to undergo prenatal screening and testing due to not fully understanding the implications and reasons for the test (Dahl et al., 2011; Marteau and Dormandy, 2001; Santalahti et al., 1998). Most western countries adopt non-directive genetic counselling, which places the onus of the final decision on the parents (King, 1999). However, some research findings suggest that the medical profession holds attitudes that may lead to eugenic outcomes from parental decisions. Researchers within disability studies argue that if a pregnant woman is found to be carrying a fetus with an anomaly, she is strongly advised to have a TOP (Oliver and Barnes, 1998), and in many cases is expected to have one (Davis, 1999). Research conducted by Wertz and Fletcher (1997) showed 13% of UK geneticists agreed with the statement “An important goal of genetic counselling is to reduce the number of deleterious genes in the population” (Wertz and Fletcher, 1997: cited in King, 1999: 177). This figure would also suggest however that 87% do not agree with this statement. They also report that an average of 20% of English speaking countries and Northern Europe “...feel that, given the availability of prenatal testing, it is not fair to

society knowingly to have a child with a serious genetic disorder” (cited in King, 1999:177). Negative aspects of a condition were also reportedly emphasised by 15% of geneticists, thus providing biased prenatal counselling (cited in King, 1999: 177). King (1999) cites research using video recordings which not only support the findings from Wertz and Fletcher (1997), but indicates that geneticists and genetic counsellors underestimated the level of bias they present during counselling (King, 1999: 177). There is evidence to suggest that these issues extend beyond geneticists and genetic counselling. Green (1995) also found medical professionals agreed with statements of this nature. 13% of obstetricians agreed with the following statement “The state should not be expected to pay for the specialised care of a child with a severe handicap where the parents had declined the offer of prenatal testing” (Green, 1995: 11). Green also found in her study that obstetricians refused amniocentesis to pregnant women unless they agreed in advance to TOPFA if an anomaly is found to be present (Green, 1995). This supports the claims that women may feel they ‘should’ undergo a TOP if an anomaly is found due to them agreeing to testing. Green (1995) does point to the drastic drop in obstetrician support for such views from 1980 (75%) to 1993 (34%), and it could be assumed that it may have continued to decline since 1993.

Social contexts are often a strong indicator of people’s attitudes, not just personal feelings and values (King, 1999). A key social pressure is discrimination against people with disabilities. It is safe to say the explicitly eugenic regimes of the past are not acceptable in today’s societal climate in the UK. But this does not discount the arguments presented by some disability perspective writers who argue current TOPFA legislation promotes eugenic beliefs. However, it can also be argued that such principles are unlikely to be the motivating factor for the majority of medical professionals, who simply seek to increase patient choice.

3.7 Social care professionals

As part of the welfare state set up in the 1940s, social care services (or the personal social services) were never set up to cover all needs in the same way as other institutions were, such as the NHS (Hill, 2003). As a result, coverage has always been an issue. The other key issue is that some individuals (for example, the elderly) are in a vulnerable position in terms of falling between the responsibilities of the health system and social care system. Overall, what this means is that whilst care and support are provided in principle, the practical reality may be rather different and very reliant on third sector organisations. This research has used the umbrella term ‘social care professionals’ to refer to anyone who works with

people with impairments in a non-medical role. This professional group is therefore a very fragmented, ill-defined group, which has proved to be difficult in terms of recruitment (see Chapter 5: Methodology).

For the purpose of this research, 'social care professionals' is an umbrella term used to define multiple different types of employment. This is a strategy employed in this research, due to the fact that no existing sampling frames were available to recruit from. This is due to social care professionals being an underrepresented group in research in the area of TOPFA. This umbrella term encompassed a range of different employees. This research aimed to recruit those who were not involved in any medical aspect of the care of those with impairments, but more specifically those who had a perspective of people with impairments in their social context. Those recruited to this study were; workers involved in disability care support, teachers, and people who worked in facilitating access both at home and in the community. These particular samples all had experience working with people with impairments in a more social context (as opposed to the medical context that medical professionals see parents within). Such examples include the day to day living (disability care support workers), at school (teachers) and those who facilitated access into the community (both enabling independent living, and involvement in everyday activities).

The experience of this research has shown much resistance from managers of schools, charities and other employers to engage with research of a sensitive nature (such as TOP). Reasons given included fear of how it may affect perceptions of the school or charity (See Chapter 5, Methodology for more discussion on this issue). At the time of writing, I was not able to find research that has been able to shed any light on the opinions of this specific professional group on TOPFA. This is interesting in itself, given that the group members are significant to the care and support of many people living with impairment, and are likely to have important insights into understandings of life with impairment. This study aimed to bridge some of the gap in knowledge about social care professionals on the issue of TOPFA. It is important to understand perspectives of professionals involved in the support and care of those living with impairments. This is to ensure the appropriate care and support is being delivered to those making reproductive decisions, and to gain a different picture (to that of parents) of what life with an impairment is like in reality. Understanding these views will also gain insight into the ethos of those directly involved in provision of care for people with impairments with regards to TOPFA. Including a professional group with a professional insight into living with impairment will add a new

dimension to our understandings of professionals' opinions on TOPFA. This will occur by offering an alternative perspective alongside the traditionally narrower medical model understanding.

Social care professionals have a limited voice in debates on TOPFA, despite the importance of their perspective to understanding a future life with impairment; they remain a fragmented and less well understood professional body. Their professional insight can provide our understanding with a perspective to the roots to independent living (something not well understood) as well as providing the opinions of important stakeholders. The contribution of social care professionals could have considerable implications for policy discussions. This is as well as providing an alternative insight into life with impairment to be considered in open debates within society.

3.8 Professional views as an influential factor

It is vitally important to understand better how professional care providers conceptualise and make sense of the idea of living with an impairment. Medical professionals working in the field of fetal diagnosis and provision of TOPFA have the clear potential to influence decisions being made during an affected pregnancy, and social care professionals have the potential to influence quality of life after birth. Whilst the notion of professionalism is theoretically associated with assumptions of neutrality, social scientists have demonstrated that such neutrality may not be readily apparent in everyday practice (Williams et al., 2002). For example, there is a body of research that has documented extensive evidence of the medical profession treating different social groups differently based on a whole range of factors, such as health status and socioeconomic status, ethnicity, gender and other social divisions.

Studying ethnic differences in relation to health status is a good example, and is something that has been of interest in sociology and has steadily increased since the 1970's (Karlsen and Nazroo, 2000). Research has concluded that individuals in England who have the poorest health have been found to be from ethnic minorities (Nazroo, 1997). Differences in mortality and morbidity in different ethnic groups has also been found in other developed countries (Kelly and Nazroo, 2008). Ethnicity alone may not be the sole influencing variable; measuring multiple factors is important when studying inequalities as confounding factors may impact health experiences (Davey Smith et al., 2000). What factors affect a person's health is hugely complex with genetic influence as well as

environmental and lifestyle exposure all playing a role (Bartley et al., 2000). For example, between and within different ethnic groups can experience different income levels with the same educational achievement (Davey Smith et al., 2000). South Asian groups are often banded together as one group within UK policy discussion. Yet there are reports of wide variations visible between different South Asian groups (Indian, Pakistani and Bangladeshi) in reported fair or bad general health (Kelly and Nazroo, 2008). Wealth disparities have also been found at the same income level between ethnic groups (Davey Smith et al., 2000). Understandings of the issues that prevent equal health or obstacles that act as barriers to participation in health promoting activities are said to be important before implementing policies to improve health equality (Campbell and McLean, 2002).

Western society has witnessed a huge change in the lives of women with aspects of society once closed now open. This has had an impact on the health of women. Even within the discipline of sociology, women were largely ignored until the 1970's (Abbott, 2006). In the past, where women's roles in society were more passive, inequalities in health existed in terms of diagnosis of illnesses. Women were prone to be diagnosed with 'mental' illnesses such as stress, which 'did not affect men'. Women still remain more likely to be treated for mental illnesses (Payne et al., 2006). In today's society, what it means to be a woman has changed from simply being that of a child bearer and wife to someone that also contributes financially to the household and can be independent in their own right. This is as opposed to being dependent on their husband. However, while typical gender roles have changed, a more complex power is at play which means that women do significantly lag behind their male counterparts in terms of equality (Scambler, 2008). Other writers argue the societal structure continues to limit women's societal opportunities to the benefit of the males in power (Abbott, 2006). Although it is said the same structure imposes constraints on males also (Abbott, 2006). The changing role has also been said to increase the burden of roles that women are expected to take on as opposed to the relatively unchanging male role (Abbott, 2006). This changing role has had an impact on the health of women in multiple ways. For example; high status employment positions are available to women, but with that comes high stress (Bartley et al., 2000). High stress jobs have been linked to increased risk of depression (Stansfeld et al., 2012). Women have also witnessed a slower change in attitudes towards their 'proper role' in society (Bartley et al., 2000). Reproductive health is something that extensive research has found has become increasingly more medicalised in recent years. Developments in fetal monitoring, testing and continued guidelines ensuring the health of women during pregnancy (Nettleton, 2006). This also adds to the continuing

monitoring of women. It is important to acknowledge different forms and different combinations inequality can take. This is said to be of particular importance when studying women and health inequalities (Bartley et al., 2000). Studies in inequalities in health and gender reveal that women have a longer life expectancy yet report more ill-health during life (Bambra et al., 2009).

The examples of ethnicity and gender above are just a small selection from a vast area of research. However, they demonstrate that there are discernable differences in health status, and the experience of health care services, due to the influence of social divisions. The continued research into medical professionals remains a significant area of research given the impact they can have on health services, and the differences in health services that are experienced depending on who the patient is. Such examples include class, gender, ethnicity and sexuality. It is important to consider this potential for variation in how health care is delivered to patients, as these studies that have found differences that highlight there are some medical professionals who are delivering healthcare in a biased manner. This bias may not necessarily be conscious, but the fact remains that TOP services may not be exempt from such biases and judgments. Research has also questioned the reality of 'value free' counselling in healthcare and whether, in fact, it is a possibility (Statham et al., 2006; Williams et al., 2002). Evidence on such issues in the field of social care is underdeveloped in relation to the body of work on health care providers, and so is also an important area for further research.

3.8.1 The value of studying medical professionals specific to termination of pregnancy

There is an extensive knowledge base that has documented evidence of doctors treating different patients differently, or that they are not as objective as they claim to be. This means there is the potential for variation in practices in relation to other aspects of patient care. Information during pregnancy starts during the first trimester. Much of this is gained through midwives, who may also be biased in the information they provide. The Royal College of Obstetrics and Gynaecologists (RCOG) offer recommendations on screening for all relevant professionals. Research has suggested that antenatal units were unaware of such recommendations set out by the RCOG in screening especially for women at risk of Downs syndrome, neural tube defect, thalassemia and cystic fibrosis (Lane et al., 2001). There is evidence that many parents do not perceive the second trimester ultrasound scan as a method of screening (Skirton and Barr, 2010). This is indicative of a disparity between

information giving and understanding of this information. Other research has shown midwives have differing views on whose responsibility it is to discuss rather than just provide information and to check whether women understood (Ahmed et al., 2012). This gives us an insight into the personal opinions that affect the professional roles of medical and health care professionals who are involved in the care of pregnant women.

In relation to TOP, there is existing evidence that the medical profession do provide a service in which patients may be treated differently on the basis of a professional's personal opinions. Even if this is in a small number of cases, it remains important to study these differences in sensitive topics such as TOP and TOPFA to ensure women are getting the services required in the most sensitive manner. This is especially relevant given that figures suggest 1 in 3 women aged between 16 and 45 will have a TOP (BPAS, 2010). Mason (2005) surveyed women who had undergone a TOP. While most of the women reported positive experiences, those who did respond negatively to questions indicated that they were patronised, faced judgmental doctors, were lectured on contraception, or simply not referred (Mason, 2005). Voices for Choice found, of nearly half the women they studied, they had received a private TOP because they had been met with an NHS doctor who refused to help or they were told that help was unavailable (Voices for Choice, 1999 cited in Mason, 2005: 119). Kumar et al., (2004) found some women were met with requests to go away and think about their decision to TOP before returning at a later date and then being referred on. Overall, both Kumar et al., (2004) and Harden and Ogden (1999) conclude that referral can be unnecessarily delayed; much of this appears to be the gatekeeper (general practitioner) rather than the providers of TOP. What these studies highlight is the blocks to TOP that exist as a result of the personal views of the medical profession. While this may not be consciously done, or done on a large scale, it does however highlight the importance of studying professionals' views on TOP as their views can act as a barrier to TOP services. This is somewhat more pressing when TOPFA is concerned as the pregnancy is a higher gestational age.

Non-directive counselling is argued to be a desirable aspect of counselling within a health care setting. However, in the area of TOPFA, it is questioned whether this is desirable and even possible in practice (Statham et al., 2006; Bernhardt, 1997; Marteau et al., 1994; Pencarinha et al., 1992). Evidence in Michie et al 1997 (cited in Bernhardt, 1997: 17) suggests that, when researching directive counselling in genetic counselling settings, counsellors make assessments about their patients, and adjust their counselling accordingly.

For example the lower the socioeconomic status, the more directive the counselling indicating class differences result in differing counselling techniques. While Michie et al (1997) did conclude that only a minority felt directed towards a particular decision, this adds to evidence that professionals are influenced by personal values and this can come through during counselling. Marteau et al., (1994) concluded that the guidelines regarding non-directive counselling failed to acknowledge the difficulty of this in practice, and the wants of the patients. Pencarinha et al., (1992) also questioned the possibility of non-directive counselling in general, but also added that this became an even more impossible feat when the counsellor had a particular bias. Pencarinha et al., (1992) also found a difference in counselling techniques between sub professional groups. Genetic counsellors who have more training in counselling and spend more time with patients had stronger opinions about patient autonomy and the patients' right to choose. Marteau et al (1994) studied the difference in non-directive counselling between clinical geneticists, genetic nurses and obstetricians. None of the groups were found to be non-directive in all fetal anomaly cases that were studied. Obstetricians were found, when counselling directly, to be more likely to counsel towards TOP. Clinical geneticists and genetic nurses counselled for continuing pregnancy and for TOP depending on the condition being discussed (Marteau et al., 1994).

3.9 Why is my research important?

As reproductive technologies continue to advance, along with medical knowledge on issues regarding reproductive health, an ethical dilemma continues to emerge. This ethical dilemma ultimately retains key issues that have always been present (right to life of the fetus and the rights of the pregnant woman), but new characteristics have emerged as a result of developments in technology and changes in social attitudes towards impairment. This is said to be something that needs a resolution from those professionals who provide these services, those that receive these services, and the general mood in society as a whole (Pencarinha et al., 1992). This is important as medical professionals are placed in a position where, in many instances, they are the first port of information for prospective parents affected by a diagnosis of fetal anomaly. How this information is provided can play a role in the understanding of the issues raised, and the decisions parents subsequently make (Pencarinha et al., 1992). This is a clear indicator of the influence the medical professional can have at a time of considerable distress for parents. Pencarinha et al., also argues that "... professionals are in an ideal position to understand and influence the ethical impact of

new technology on the individual and society” (1992: 29). This again highlights the importance of knowing and understanding the views of the professionals directly involved when a diagnosis of fetal anomaly is made given the influence they can have on society as a whole. This relates to both medical and social care professionals. As social care professionals are in an ideal position to provide an alternative viewpoint to the parents and person with impairment of what life with impairment is like in reality. This can impact the ethical decisions of many who would otherwise be ignorant of this.

Within this context of concern about the gestational age at which TOP can take place, TOPFA attracts particular attention; TOPFA beyond the usual 24 week gestational threshold became legal in 1990 under Clause E of the Human Fertilisation and Embryology Act (which amended the 1967 Abortion Act). However, the legitimacy of TOPFA has been challenged by a strengthening disability rights movement in the West. Many have questioned the availability of Clause E within the 1967 Abortion Act with accusations of it being of ‘eugenic’ nature. This is particularly significant given the recent decision to have a Parliamentary enquiry deciding whether the TOP legislation needs to be debated (Dominiczak, 2013). This is taking into consideration improved attitudes towards impairments (Dominiczak, 2013). Over the same period, technological advances, particularly in fetal ultrasound, have increased the accuracy of both identifying some fetal anomalies and detecting an increased risk of others. Some anomalies are considered incompatible with life (e.g. Edwards Syndrome) and TOPFA for these conditions is generally less contentious. The option of TOPFA may be presented to a woman during counselling after a diagnosis of fetal anomaly if two doctors agree; the definition of how to determine which fetal anomalies fulfil the criteria for TOPFA is not specified. The decision to have the TOPFA rests with the parents. However, evidence documented above indicated that medical professionals are not always as objective as they claim to be. This makes it important to understand the views of professionals given the unique position they hold in being a first point of contact in many instances for counselling after a diagnosis of fetal anomaly. How information is delivered and understood can be indicative of what decisions parents make; personal biases and directive counselling may therefore influence parents’ decision making process. It is seen as broadly accepted that a TOP service should be available and the relevant NHS organisations have a duty to provide such TOP services. Other anomalies are not lethal but are seen as sufficiently severe for TOP to be an appropriate care option. In such cases, many women accept this offer. The latest data shows TOPFA representing 1% of all TOP provided in 2011 (DoH, 2012) which has

remained consistent with other statistical reports (DoH, 2012, 2011, 2010, 2009, 2008, 2007, 2006).

Academic and philosophical debates on TOP tend to focus on the relative rights of the mother and the fetus, and the personal (rather than professional) views of those providing TOP have been neglected (Graham et al., 2008). It is recognised in the literature that medical professionals providing TOPFA deal with complex information when deciding whether to offer TOP following the diagnosis of a fetal anomaly (Statham et al., 2006; Garel et al., 2002). However, medical professionals tend to have little experience of the day to day living with a non-lethal impairment. Similarly, those working in the social care sector who provide day to day care for people who live with impairment, have less insight into the counselling process and decision making process leading up to TOPFA. These different professional experiences might be expected to produce quite different understandings and conceptualisations of TOP for non-lethal anomaly. It is important to explore the views of these groups of professionals to establish whether this is the case, or whether there is more common ground between the two perspectives than might be anticipated. There is a lack of research that aims to compare different conceptualisations between professional groups. However, it is important to understand the views of medical and social care professionals in this field to inform on going policy debates about how decisions for TOPFA are made. This is to ensure that the views of professionals who provide care as part of their work are considered alongside those of the mother and the fetus. This is especially significant when we consider the impact of personal views on professional behaviour, and the impact professional views can have on the patient and general society. Having a broader understanding about what impacts on judgments on what constitutes a good life is also important in informing policy debates and general societal debates. Including a professional body as well as the medical profession ensures this broader perspective will be found.

Chapter 4: Theory

4.1 Introduction

This chapter provides an overview of the theoretical framework, and the specific conceptual tools adopted, that have influenced the analysis of the data in this research. The project draws on three main theoretical influences; social constructionism, and Goffman's concepts discussed in *The presentation of self in everyday life* and *Stigma: the notes on a spoiled identity*. Interactionism, ethnomethodology and the social and medical model of disability are outlined in some detail as they are particularly relevant to how the analysis progressed.

4.2 Social constructionism

Social constructionism is a theoretical perspective that takes into consideration the social context of which knowledge is produced and supports a critical stance on ways of thinking (Burr, 2003). Social constructionism is a perspective that does not take for granted any perspective that claims to explain society, including our own perspective on ourselves (Burr, 2003). How something or someone is defined is argued to be socially constructed. Thus social construction can define the action (if any) that is necessary. For example, Cohen showed that residents worried about the 'Mods' and 'Rockers' not upholding the values expected of that particular area (Cohen, 1972). As a result, the residents felt threatened and successfully started a moral panic (Cohen, 1972). How certain people or groups in society are perceived can be shown in the language used to describe them. In the past, language used to describe people with impairments is indicative of the societal perception (Spector and Kitsuse, 2001). Changing perceptions have resulted in the language used to describe people with impairments being dictated more by those affected. For example, many disability groups rejected the International Classification of Impairments, Disabilities and Handicaps definition of disability (Barnes and Mercer, 1997).

There is evidence of the influence of social constructionism in many areas of society. Social constructionism has been influential within the study of social problems. For example, Miller and Holstein (1993) provide a definition of social problems based on some societal groups making complaints about aspects of society that are claimed to be immoral. This would show that interpretation is a significant factor that represents actions such as crime (Miller and Holstein, 1993). Most recently the constructionist camp finds itself divided, some arguing for the 'strict' constitutive reading of constructing social problems while others argue for a 'contextual constructionism that focuses on the claims making process

but acknowledges assumptions about objective conditions (Best, 1989). Within the study of medicine, doctors claimed credit for reduced rates of maternal deaths when in-fact much of the reduction was attributed to improved hygiene. How individuals construct their own reality is a theme within interactionism.

The social constructionist perspective is also a significant school of thought within medical sociology (Nettleton, 2013; Bury, 1986). The social constructionist perspective was shown to be an influential perspective during a time where sociology was studying health and illness through a more critical standpoint (Nettleton, 2013). The conclusions of many of these critical studies was simple; medical knowledge was socially constructed, with diseases as currently understood being nothing more than constructions by those in the authoritative position to define it (Bury, 1986). A critique of the biomedicine practice was becoming more defined throughout the 20th Century, with the critique of psychiatry of particular focus (Nettleton, 2013). Key studies, such as Goffman's *Asylums*, and Rosenhan's *On Being Sane in Insane Places* highlighted how 'normal' behaviours are used to cement an 'insanity' diagnosis due to the social construction of those in control, namely psychiatrists. In Rosenhan's study, other patients often voiced their belief that the pseudopatients were in fact sane, but no member of staff ever voiced this concern (Rosenhan, 1973). Once the label of being 'insane' has been applied to the pseudopatient, there was nothing they could do to remove this label. Their every behaviour was explained as a result of this label, which overpowered every other aspect of the individual (Rosenhan, 1973). This would mean that someone who was deemed 'sane' cannot be distinguished from the 'insane' within a mental institution (Rosenhan, 1973). Goffman wanted to show the gap between what psychiatrists actually do and what they say they do (Goffman, 1961).

Research into different cultures has revealed a completely different understanding of health, illness and medicine. This adds weight to the argument of the social constructed nature of knowledge as medical practice and beliefs are culturally specific and have origins in the social understandings of the wider social context (Nettleton, 2013). Foucault has been influential in the field of medical sociology and the construction of knowledge. During the nineteenth century, the body became the location of illness and thus the focus of medical inquiry (Foucault, 1963). This created the 'clinical gaze'; the means of which trainee doctors are trained to 'see' (Foucault, 1963). This gaze "...is a way of seeing and understanding that becomes identical with the thing itself" (Higgs, 2008: 197). The development of medicine in the nineteenth century as a result of research, training and

teaching that became located within a hospital setting aided in the creation of our current knowledge about disease (Nettleton, 2013).

Freidson has done extensive work in the field of medicine through research on professionals. While he acknowledges a difficulty in defining a 'profession', (Freidson, 1988), he does suggest "In the most elementary sense, professionalism is a set of institutions which permit the members of an occupation to make a living while controlling their own work" (Freidson, 2001: 17). One defining quality of modern medicine is the superiority of expert knowledge and authority (Freidson, 1988). This superiority cements the privileged position medicine has come to possess within society (Freidson, 1988). The medical profession have, according to Freidson (1988) been given free rein to develop its own professional approach to illness, and the authority to define a set of symptoms as illness. A lay person presents with symptoms and the medical professional imposes a definition of these symptoms using their superior knowledge. This enables a re-definition of the problem from the lay persons' original definition and the problem becoming managed within the medical paradigm. It is worth noting that while alternative therapies do exist, there is no real direct competition to medicine and its official approval to define health and treat illness (Freidson, 1988). While Freidson has been hugely influential within the field of medical sociology, illness is the focus of his work (not disease). It also remains important to understand how the lay public are influenced and understand medical knowledge (Higgs, 2008) and how this can impact on health. For example, the news conference by Andrew Wakefield when discussing his paper in the Lancet had a major impact on the uptake of the combined MMR jab.

The perspective of social constructionism however, has not been without criticisms. Bury (1986) questions the idea of knowledge as all part of discourses; does that mean social constructionism itself is a discursive knowledge? Bury also asks whether social constructionism is any more critical or valid than other perspectives that look to criticise the social world (Bury, 1986). Realist approaches within sociology argue that the objective reality should be the focus of studies; this is an aspect of social problems that social constructionism denies the existence of (Miller and Holstein, 1993). However, despite such problems, the usefulness of social constructionism within the study of medical sociology cannot be denied or ignored. In this instance social constructionism cannot be ignored due to its influence within the study of medical sociology and its use in explaining how medicine has come to exist in its current form in society.

4.3 Theoretical perspectives on termination of pregnancy

Given the prominent position that TOP holds in the public and policy domains, and the complexity of the issues in scholarly debate in TOP (see Chapter 2), it is no surprise that the topic has also stimulated a significant amount of theoretical discussion and debate.

These more abstract debates have focused on teasing out the understandings of, and further implications of, key concepts to help clarify meaning. Feminist theorists in particular, alongside those affiliated with liberal groups, have discussed TOP as a legitimate option for women. Such reasons include reproductive choice, women having autonomous control over their own bodies, access to legal safe TOP procedures, to name a few.

Feminism encompasses a whole branch of different researchers. For the purpose of this discussion, the term feminism will refer to a theoretical perspective which has women's rights and equality for women at the forefront of their agenda. TOP has been theorised by feminists extensively, given the biological implications of women being child bearers.

During the campaigning that was witnessed in England, feminism was particularly prominent (see Chapter 3). These arguments were centred on women having the right to control and make decisions about her body.

TOP has been the subject of much sociological research in the UK since its legalisation in 1967. Much of this research has focused on the delivery and access by TOP services (Harden and Ogden, 1999). The background context of these studies has mainly been from that of feminist or political positions (Harden and Ogden, 1999). Another focus for much of the research surrounding TOP is that of reproductive technologies with two contrasting viewpoints emerging from the data. Firstly that these technologies and TOP is empowering for women and acts as a facilitator for autonomy over women's own bodies (McNeill et al., 1990, cited in Harden and Ogden, 1999: 427). Secondly, that these technologies are another means of which men control reproductive power (Corea, 1985 cited in Harden and Ogden, 1999: 427). Sociological research in the area of TOP has also looked into, and emphasised the importance of women's experience of having a TOP (Harden and Ogden, 1999). There are several authors who have concluded that women experience moral judgment when accessing such services (Hadley, 1996; Stacey, 1988; Doyal, 1985; Simms, 1985 cited in Harden and Ogden, 1999: 427).

Pregnancy adds a confusing dimension to Western notions of the autonomous body due to the biological makeup that makes a woman a child bearer (Wolf, 2001). Wolf argues that second wave feminism dehumanised the unwanted fetus as valueless. It has been suggested

that feminism would be better placed to argue that a woman has a life within her during a pregnancy, but sometimes she must place a higher value on her own life than that of the fetus (Wolf, 2001).

4.3.1 Philosophical perspectives

Many philosophical debates have focused on the moral status of the fetus and at what point does/should the fetus have a right to life. A woman having a right to control her own body also features in philosophical debates, though not as prominently. Feminists have argued that such positions defending a woman's right to choose a TOP from non-feminists do not offer the same conclusions, or path to similar conclusions as feminist ethical discussions lead to (Sherwin, 1991). At what point a fetus is a person with its own moral status is the crux of the matter. If the fetus is a person, then TOP is likened to the killing of another human being. Some would go so far as to describe this as murder. This is central to the pro-life campaign argument. Whether a fetus has a moral status is also linked to arguments about women having control over their own body. This is discussed in relation to whose moral status carried more weight. Much of the debate centres on whether a TOP is justified even if a fetus does have a moral status and a right to life through a woman having the right to control her own body.

4.3.2 Judith Jarvis Thomson – A defence of abortion

Many of those opposed to TOP argue that a fetus is a human life from the moment of conception. While Thomson does not deny the ideas behind this argument, she argues it is not actually well thought out (Thompson, 1971). This therefore makes the pro-life/anti-choice/anti-abortion lobby's arguments appear very weak due to the reliance on this central argument (Thomson, 1971). One example Thomson draws on is an acorn. An acorn is not an oak tree, it will develop into one, but that does not mean it is referred to as an oak tree while it is an acorn (Thomson, 1971). Thomson takes her argument further by supposing that a fetus is a person from conception. She argues that there are circumstances where TOP is a permissible act even if the fetus is defined as having a right to life. This centres on her argument that a right to life does not automatically entitle the right to use another person's body. Thus a fetus does not automatically gain the right to use their mother's body. The example she draws on involves a person being kidnapped and their circulatory system being plugged into a violinist. This is because the person would be the only person that could help the violinist live. In this scenario, the hospital director informs the

kidnapped person that they would not have permitted the kidnapping and circulatory system conjoining (Thomson, 1971). However, to unplug the kidnapped person from the violinist would kill the violinist. But if the kidnapped person remained plugged to the violinist for nine months it would save their life. Thomson questions whether the kidnapped person has a moral obligation to remain plugged to the violinist with the argument 'all persons have a right to life' (Thomson, 1971: 50). So to remain plugged to the violinist, the kidnapped person's right to decide what to do with their body has been outweighed by the violinist's right to life. Thomson suggests that many would find this a ridiculous scenario, but compares it to that of a fetus in a woman's body. Though many with unwanted pregnancies chose to have intercourse, she raises the question of rape; many who oppose TOP do not make a distinction for rape (Thomson, 1971). Thomson also states that the unproblematic nature of the notion of the right to life is the central problem with that argument (Thomson, 1971). Using the violinist example, just because the violinist needs the use of the kidnapped person's body, does not mean a right to do so has been established. The right to use of the kidnapped person's body must be given by that person. Thomson argues that just because someone has a right to life, does not mean they have a right to the use of someone else's body to sustain that life (Thomson, 1971). Her discussion leads to arguments concerning the right not to be killed. She also raises problems with the unproblematic nature of this, which leads to the right not to be killed unjustly (Thomson, 1971). Thus, for TOP to be a denial of moral justice would be if the TOP was unjustified. So while Thomson argues that TOP is justifiable, she does not say it is so in all circumstances (Thomson, 1971). She also questions whether a very early TOP can ever be defined as a killing of a person, thus not really a moral issue that her discussion applies to (Thomson, 1971).

These perspectives within the sociological literature highlight many of the main considerations that centre on TOP debates. The main argument is the right to life of the fetus verses the rights of the pregnant woman.

4.4 Interactionism

Interactionism is not a perspective that seeks to make macro-level grand theories about social phenomena (O'Byrne, 2011). It seeks to study the meanings a social actor attributes to a given situation at the micro-level focusing on understanding the world from the perspective of the participants (O'Byrne, 2011). For example, Becker (1963) argues that social groups have rules and will at times make attempts to enforce them. These social rules

define a situation and define the 'correct' way of behaving; this by virtue, also defines the 'incorrect' way of behaving (Becker, 1963). Therefore to understand a situation, one would need an understanding of the rules, or to gain an understanding of the social actors' interpretation of the rules. Such rules may be at societal level or more group specific. Interactionists make no claims to scientific neutrality or to any generalisable 'truths' (O'Byrne, 2011). They argue it is not possible to know an objective truth (O'Byrne, 2011). There are a number of theorists who have emerged from the interactionist tradition with different variations on their perspective on social research. However Plummer, (2004: cited in O'Byrne, 2011: 194) argues that a number of themes are common within the various forms of interactionism. For example, that:

- Society as symbolic with these symbols understood through interpreting the meaning derived from social actors.
- Or that; individual actions or consciousness is not the main focus of interactionism., because the shared experience of these individuals and their interactions is the focus.

Social interaction produces a situation from which social actors derive a meaning from. Social actors act according to this meaning thus 'truth' comes from meaning (O'Byrne, 2011). Blumer summarises this process with three 'premises of social action'; (i) peoples' actions are informed by meanings; (ii) these meanings are the product of social interaction between people; (iii) these meanings are developed through a process of interpretation and negotiation in the situations individuals find themselves in (Blumer, 1986). From this perspective, meaning is a social product that is created through interaction (Blumer, 1986).

The interactionism perspective is probably most well known for its contribution to social theory in terms of the theory of labelling. Becker's *Outsiders* is often cited by criminologists due to its application of labelling theory to deviance. Going back to Becker's ideas of social rules, someone who acts outside of the rules, thus behaving 'incorrectly' is labelled an 'outsider' (Becker, 1963). In essence, a person in a position of power asserts the label of 'deviant' on a particular individual. However, the individual who has been labelled an 'outsider' may not accept that their behaviour was 'incorrect' thus label the labellers 'outsiders'. This creates a situation of rule-breaking and rule-enforcing, which in turn creates the rule breakers and rule enforcers (Becker, 1963). Similar to Becker's idea of deviancy and Goffman's concept of stigma, the label ascribed to a discredited person is not

an inherent characteristic within that particular individual, but constructed within the relationship these ‘outsiders’ have with others in ‘mainstream’ society (O’Byrne, 2011: 152).

What is ‘the self’ is an important consideration within interactionism. The study of sociology based on this theoretical perspective relies upon the study of social interactions. The self has been dissected and defined slightly differently dependent on the researcher, however, there are common similarities. First that it is not something that is determined by biology and is constantly changing. Secondly, it is something determined by social interactions. For example, a person becomes what other see them as by internalising the perceptions they have of us and thus act accordingly (O’Byrne, 2011).

Mead discusses the self as in a permanent state of transition and uses the terms “I” and “me” to describe this (O’Byrne, 2011). “I” refers to the subjective self that is inside a social actor; “me” refers to the objective self, the self that is on the surface and used for interaction with others in the social world. Cooley, with his concept ‘the looking glass self’, argues the self is a social construction made through interaction with others (Cooley, 1983). Goffman takes Mead’s ideas of the self further through his work in *The Presentation of Self in Everyday Life*; the self is depended upon the audience of which a social actor is ‘performing’ to (O’Byrne, 2011). Becker develops his idea of the self by arguing that the self is not a permanent concept. A social actor is not born something. For example, you are not born a criminal, you become one through social interaction with others. Becker studied marihuana use to study how people learnt to interpret their own experience through interaction with other users (Becker, 1963: 181).

While symbolic interactionism has been influential in many areas of sociology, it is not without its critics. Early interactionism was met with criticisms surrounding the lack of a solid theory of symbolic interactionism (Benzies and Allen, 2001). Concepts and ideas were not given accurate definitions and were adopted in a multitude of different ways (Benzies and Allen, 2001). Some have argued that coming from the US, interactionism is too culturally specific to be successfully applied in other places (Plummer, 2012). The lack of acknowledgement of the social structure has also been levelled as a criticism of interactionism (Benzies and Allen, 2001). However, despite such criticisms, symbolic interactionism has been hugely influential in the social sciences and continues to be so. It is of particular use for informing this project because of the interactions professionals involved in this study have with either parents after a diagnosis of fetal anomaly, or people affected by an impairment. This interaction is an important consideration when unpacking

the meanings and understandings professionals have when considering an acceptable TOPFA. To understand this point, it is useful to consider both ethnomethodology, and Goffman's work, in more detail.

4.5 Ethnomethodology

Ethnomethodology is said to be an extension of interactionism. The key difference is going beyond how the social world is seen by the individual and looking to see the production of meaning (O'Byrne, 2011). While interactionists are interested in the meanings individual social actors attribute the social world, ethnomethodologists take this one step further by asking how these meanings come to be constructed (O'Byrne, 2011). One such example includes the research Garfinkel undertook on Durkheim's study of suicide. Garfinkel argues that "ethnomethodology is respectifying Durkheim's lived immortal, ordinary society, evidently, doing so by working out a schedule of preposterous problems" (Garfinkel, 2002: 91). It was argued the suicide statistics were not a social fact; they were an outcome of social processes surrounding the characterising of death. Questions, such as how do some deaths become characterised as suicides and others do not? And, what are the social processes and circumstances at play in producing the social 'facts' that Durkheim is said to have taken for granted? It is also argued that official statistics do not represent actual events. Thus labelling theory is used to show how prejudicial assumptions about 'causes' are used to provide the justification. This is demonstrated by those involved with defining a death as a suicide. They start with a preconception about what a typical suicide is, then this preconception becomes a fact that is used to explain a death as suicide (O'Byrne, 2011).

Ethnomethodology offers a perspective on the social order we have come to take for granted in society. Everything we do, even the smallest things we take for granted is a product of social order that is constantly being negotiated (O'Byrne, 2011). The system is fragile and is socially constructed through interaction and negotiation (O'Byrne, 2011).

In a similar way, Berger and Luckmann argue that understanding everyday knowledge is significant to our understanding if we wish to understand 'knowledge' as everyday knowledge is significant to what social reality is to individuals. Our knowledge about a given situation is based on our assumptions from the context rather than the information itself (O'Byrne, 2011; Berger and Luckmann 1966). Berger and Luckmann break down this reality construction into three processes; externalism, objectivation and internalism

(O’Byrne, 2011). Externalism refers to the positions individuals feel they are in to make sense of the social world based on their past experiences. This ‘reality’ is sustained based on these experiences through reproduction of their ‘knowledge’ (O’Byrne, 2011).

Objectivation refers to the ‘reality’ that is being presented being given some sort of order by the individual as if it is a reality in itself (O’Byrne, 2011). Internalism refers to the process that an individual goes through to reproduce the objective reality and act accordingly (O’Byrne, 2011). This would therefore suggest that social individuals are the producers and products of social reality and their own social world (O’Byrne, 2011). This would also give weight to the ethnomethodology argument that there is no ‘true’ reality just as there is no ‘true’ self, but a self based on negotiations through interactions within the social world, and a reality that is socially constructed (O’Byrne, 2011).

Ethnomethodology was met with mixed responses, many of which centred on confusion in Garfinkel’s work (Heritage, 1987). Much of Garfinkel’s work became trivialised and ethnomethodology deemed “a method without a substance” (Coser, 1975; cited in Heritage, 1987: 225). Such criticisms in mind, the production of meaning through interaction was useful in deconstructing the meanings professionals’ attributed to TOPFA decisions. The notion that the self in the context of everyday life is therefore crucial to the understanding of professionals’ conceptualisations of an acceptable TOPFA in this project. Whilst this is not an ethnomethodological study, the influence of ethnomethodological ideas is evident in the theoretical framework used to interpret the data.

4.6 Goffman

Within this framework informed by social constructionism, interactionism and ethnomethodology, Goffman’s concepts are of specific relevance to the analysis presented in this thesis. Goffman does not affiliate to either interactionism or ethnomethodology, yet his work has proved to be influential in both fields. Goffman’s work centres on the meaning of social action and preferred to see his work through ‘Frame Analysis’ (Williams, 2008). Goffman was interested in providing a sociological account of the social actor, with three versions of the self discussed by Goffman in his various works:

- Self in two forms ‘the performer’ and ‘the character’ and the combination of the two ‘performed character’. (an example of this version of the self can be found in *The presentation of self in everyday life*).

- Self as evolved from the organisational arrangements; the self is produced from the social and organisational circumstances they find themselves in. This definition is somewhat deterministic. However Goffman does discuss instances where resistance and challenges occur within these organisational set ups. (An example of this version of the self can be found in *Asylums*).
- Third version of the self is more fluid. The self changes to manage within different situations based on the motives of the individual, and the expectations that are scripted depending on the role being played. (Williams, 2008).

Metaphors are used within Goffman's writing to explain his ideas (Williams, 2008; Crow, 2005). The most famous metaphor within his many works has been argued to be from *The presentation of self in everyday life*. In this book, Goffman likens society to a theatre with the self being the performer. The production is society with the self, or social actors, performing who they are pretending to be (Rigney, 2001: 151 cited in Crow, 2005: 109). The performance a social actor will perform will differ depending on what the social situation is and who you are with (Williams, 2008). A differing performance occurs depending on the rules of the context a social actor is in. What is appropriate in one situation may not be in another. Linked to the society as a theatre metaphor are Goffman's concepts of 'front stage' and 'back stage'. The performance does not reflect the true self of the social actor with the performance being for the benefit of the audience, this is known as 'front stage'. The 'backstage' performance could be completely different showing the self in a different way. Goffman affiliates with the pragmatic idea that it is impossible to know the true self as he argues the audience can never know the 'real' truth of the social actor who is performing (Williams, 2008). He argues the audience can give an account of what they think a performer is thinking. Yet given that rules and obligations exist in all areas of social interaction, it can be said they we are always putting on a show with all forms of social interaction a performance for the benefit of the audience, i.e. all those around us in any given situation.

In *Asylums*, the self is discussed within the process of institutionalisation. In this text, the self is shown to be affected by the institution (Goffman, 1961). The patients had a role to play as did the guards and these social roles were performed according to the rules set out by the institution (implicit and explicit) (Crow, 2005). Goffman asks how we maintain our sense of self within such constraints and within social interaction (Crow, 2005). Within the confines of the asylum, social actors will witness strict rules and de-personification

(‘mortification of the self’) of which leads to a number of responses from inmates (Williams, 2008; Goffman, 1961). One such observation was that everything inmates did was interpreted as insanity (Goffman, 1961). One of the behaviours that Goffman draws on is the inmates tendency to carry a large number of items on their person. This action, according to staff, was a sure sign of mental illness. However Goffman draws our attention to the lack of individual lockers for inmates to store their stuff as an obvious explanation (Crow, 2005; Goffman, 1961). This is one of numerous examples that Goffman draws of which he offers an alternative explanation for the so called irrational behaviour. This examples shows how important it is to understand a social context when trying to interpret behaviour (Crow, 2005).

4.6.1 The Presentation of self in everyday life

One of Goffman’s most useful metaphors is the theatre and the performer; the social actor being the performer and society being the theatre. In *The presentation of self in everyday life*, Goffman argues that upon entering a social situation, the information about the individual aids in the definition of the situation and allows others present to know what to expect from him/her (Goffman, 1959). The individual has a role to play and requests the audience to accept this role. This means the individual performance is for the benefit of those present in order to present him/herself as what he/she claims to be (Goffman, 1959). The individual has a ‘self’ that they wish to portray; it is impossible to know the ‘real’ self.

Goffman states that there will be instances where only sociologists and the socially disgruntled will alone see through the act. In this instance the performer is fully convinced by themselves that the staged reality is in fact real (Goffman, 1959). The individual or performer may also not be taken in by his/her own act and have no care for the audiences belief of the act, Goffman refers to this as ‘cynical’ (Goffman, 1959). The cynical performer may be unprofessional in respect of gaining pleasures from his/her fake performance, may in fact be acting fake for the benefit of others, or may be cynical due to the audience preventing them from being ‘sincere’. Goffman draws on numerous examples of the forced cynicism. One such example includes shop assistants deluding their customers due to the demand of the customer. Goffman refers to a performer being ‘sincere’ when they believe in the impression they are giving from their audience but the audience are not convinced (Goffman, 1959).

Goffman discusses how the self comes from the act we put on. He cites Robert Park who draws on the meaning of person being 'mask' and how through acting out roles that we use in society we come to know ourselves and others (Park, 1950 cited in Goffman, 1959: 30). It is through these roles that we show through social situations and social interactions, the conceptions we have formed for ourselves. The 'front' acts as part of the performance to define the situation for those who are observing (Goffman, 1959). This front will reveal some claims to the audience that will (or not in some cases) be revealed in more detail during the performance. The performer will go through a process of 'idealisation'. The performer will present him/herself as committed to accredited values of the society, more so than the behaviour of the individual as a whole (Goffman, 1959). Goffman cites social mobility as an example of the idealisation process. The presentation of values accepted in middle class communities will aid in the performers goal of achieving middle class status.

Goffman's *The presentation of self in everyday life* is the first piece of research to study face to face social interaction as a matter for sociological study. Goffman's perspective has been criticised for being too focused on the surface presentation without considering a more emotive stance (Hochschild, 1983). Much of Goffman's focus is with the interaction without much commentary on the personal reflections of the individual. Despite such weaknesses it remains relevant to contemporary social theory. This is due to continued application of the concepts to relevant research, highlighting its continued relevance in society.

4.6.2 Stigma: Notes on the management of spoiled identity

The term stigma originated in Greece and referred to bodily signs that exposed something undesirable about the affected person (Goffman, 1963). These signs may have been cut or burned onto the body of the affected person and indicates that they are a criminal, slave or traitor (Goffman, 1963). The sign acts as a warning to other social actors as a person to be avoided (Goffman, 1963). The modern day use of the term stigma, still has some similarities to its original use however it refers more to the 'disgrace' itself as opposed to any cuts or burns that have been etched onto the affected person's body (Goffman, 1963). Goffman also notes a shift in what 'disgraces' attract concern among others. Such examples include; physical abnormalities; people with behaviours felt to be 'problematic' and what Goffman terms 'tribal stigma' of race, religion and nation (Goffman, 1963: 14). Examples of 'problematic' behaviour include; having a weak will, mental impairment, imprisonment and addiction.

Those with a 'stigma' may go through a number of processes in order to gain acceptance from wider society. One such method is to 'correct' or attempt to correct the 'stigma'. Goffman argues this may not necessarily accord the bearer with a full 'normal' status in society, but awards the bearer with a record of having tried or successfully corrected the 'stigma'. Another method of gaining acceptance is by devoting a huge amount of time gaining a high achievement in an activity that would normally be closed to those of a particular stigma. Such examples given include a blind person becoming an expert at skiing or rock climbing (Goffman, 1963). Gaining acceptance into society and being a high achiever in a field usually restricted to affected people can add an additional obligation to the affected person. Representing all others affected by a particular stigma may automatically be thrust upon them (Goffman, 1963). Despite the lengths an affected person may go to gain acceptance, the acceptance of the person with a 'stigma' by so called 'normal' people is conditional (Goffman, 1963). Goffman argues the stigmatised are asked not to 'push their luck' and not test the limits of the acceptance they have already been granted, nor use it to gain additional benefits (1963: 146). Goffman also refers to his concept 'good adjustment' whereby the stigmatised shields the 'normals' from revealing the constraints of their acceptance of them (1963: 146).

Many people with a 'stigma' decide to interpret their identity in a different way to the conventional approach. Thus giving themselves a new social identity which may or may not be accepted by the majority (Goffman, 1963). This is not an option that all those affected with a stigma feel they can do, as the rewards of normality are such that most of those that can do so, will attempt to 'pass' as normal to enable them to gain the benefits of being normal (Goffman, 1963). Goffman also notes that those with a 'stigma' who are allied with 'normal' people, or those with a 'less' stigmatising attribute may adopt the attitudes of 'normal' people.

The concept of stigma is influential in the social sciences, but has also attracted significant critique. Such criticisms include a lack of adequate definitions, and a focus which zooms in on the individual with the stigma (Crow, 2005; Link and Phelan, 2001). Nevertheless, the theory has been reworked and adapted in numerous formats, and has particular relevance in the field of health care and disability.

4.6.3 Use and developments of Goffman's concepts

Stigma in relation to disability and impairment has been well documented. It is widely acknowledged that Goffman's research on stigma is one of the earliest studies of the phenomenon. It offered one of the first definitions of the concept in terms of its sociological significance. The concept has been adopted in research, re-worked and further developed since Goffman's original publication (Werner et al., 2012). For individuals who suffer cognitive impairments, feelings of low self-esteem have been found in those who are more aware of being subjected to stigma (Paterson et al., 2012). Such stigmas include explicit and implicit forms of stigma. For example, open name calling, and the restricted opportunities preventing individuals participating fully in society (Paterson et al., 2012). Such examples, as well as others, has been said to be as a result of the negative perceptions of affected individuals being internalised into a sense of self (Crocker and Major, 1989 cited in Paterson et al., 2012: 167).

Negative perceptions of those with an impairment may be as a result of negative stereotypes that exist in wider society. Stereotypes that exist in society about people with a cognitive impairment include associations with being "unpredictable, irrational, dangerous, bizarre, incompetent and unkempt" (Thoits, 2011: 8). Such beliefs have been argued to have strengthened over time with people continuing to not associate with those affected by such impairments (Thoits, 2011). There is evidence to suggest that those suffering from a cognitive impairment are aware of being stigmatised (Jahoda et al., 2010). Those who attend mainstream school have also been found to be subjected to ridicule and stigma from their peers who are not affected by any impairment (Cooney et al., 2006). Parents of affected children are also subjected to stigma. Feelings of shame and embarrassment about actions that are deemed socially inappropriate are often experienced by parents whose children suffer from autism spectrum disorder, due to their behaviours associated with the condition (Farrugia, 2009). Parents with children with this condition often find themselves excluded from social activities (Farrugia, 2009).

The concepts of stigma and presentation of self have been studied, reworked and conceptualised with regards to impairment. In addition, Goffman's ideas have also been influential in other areas of sociological research, in both the original form or re-worked forms. For example, in class research, the concepts are used in explanations of how the working class are often subject to stigma. One such example is the use of the term 'chav' which Tyler describes as "ubiquitous term of abuse for white working-class subjects"

(Tyler, 2008: 17). Working class women in particular have been shown on popular TV as being incapable of being acceptable 'good' people. One programme depicting this example is *you are what you eat*, featured on Channel 4 (Skeggs, 2005). Another example of working class depiction on TV is working classness as a social evil through their undesirable behaviour (such as drinking, smoking) (Skeggs, 2005). Similarly, teenage mothers have been subject to much ridicule in recent years. It is noteworthy that a 'female chav' is often also assumed to also be a teenage mother. Teenage mothers are often spoken as interchangeable with lazy, benefit scrounging, unfit parents, single, and irresponsible (Yardley, 2008). The status of teenage mother is something that is felt not to be the ideal family form and ideal circumstances for motherhood thus open for stigmatisation (Yardley, 2008). Responses include disassociation and association with the stigmatised group as well as adaption of coping mechanisms (Yardley, 2008). Single mothers have also been singled out as constituting a deviant and unacceptable family form. As with the class connection, teenage motherhood and being single is also a common assumption. The assumption, as with teenage mothers, that all single mothers are the same also raises problems for stereotypes and thus opens the door for stigma (Hamilton, 2012).

The original use of the concepts of stigma, and the variety of ways in which the original concepts have been adapted (and continue to be adapted) in the social science community, demonstrate the potential value of adapting them for use in this study. In particular, the concept of stigma is useful for unpacking some aspects of acceptable TOPFA for some case study examples, whereas *the presentation of self* is useful for making sense of why these perceptions are presented.

4.7 Stigma and models of disability

As noted above (section 4.2) medical sociologists are heavily influenced by social constructionist perspectives. This is probably most apparent in the contrast made between the medical model and the social model of health (for further discussion of this contrast, see Nettleton 2013 for an overview). This general contrast between biomedicine and more socially informed ways of looking at phenomena related to health and illness can be played out in terms of many of the specific issues that arise in the field. Disability is perhaps one of the more commonly known examples, with the contrast being drawn between the medical model of disability and the social model of disability.

The medical model of disability is a model that uses medical knowledge and ‘facts’ to explain disability. The focus is on the individual impairment. This is seen to be the factor responsible for the disadvantage that many people who experience disability are exposed to (Locker, 2008). From this perspective, people in society who are disabled are such because of an impairment and this is the root cause of disadvantage experienced by the affected individual. Curing or managing disability involves identifying the impairment and ‘fixing’ it through medical means. Within the medical paradigm of biomedicine which likens the body to a machine that can be fixed (Nettleton, 2013). The person with an impairment is remedied by providing the opportunity of a more ‘normal’ body that can participate in a more ‘normal’ life.

The medical model has been subjected to major criticisms. These have mainly been voiced by those in support of the social model of disability, which in many respects is the opposite of the medical model (see below). The medical model has been criticised for focusing on the impairment of the individual. This is seen as problematic because the ‘blame’ is placed on those affected by a disability for disadvantage they experience as a result of their impairment. The medical model also places responses to disability firmly within the biomedical sphere by focusing on medical intervention on the impairment as the solution, by seeking to reduce the level of disability to reduced disability. This intervention aims to adapt the individual to wider society, in contrast to the alternative, which would be to adapt to wider society to accommodate people with impairments. The resources available are also directed towards medical intervention at the level of the impaired individual. Such intervention includes pre-natal diagnosis as well as investment in prosthetics, drugs and other ‘cures’. Ultimately, the medical model is argued to promote a disempowered image of disability.

Challenges to the oppressive social disadvantage that many people with impairment have suffered have been challenged over the past 30 years (Shakespeare, 2013). A significant aspect to these challenges has been the critique of over medicalised and over individualistic definitions of impairment (Shakespeare, 2013; Barnes and Mercer, 2010). The social model of disability offers an alternative account of the experience of impairment which focuses on the barriers that make a person with an impairment disabled (Barnes and Mercer, 2010; Locker, 2008; Oliver and Barnes, 1997). This model was used as a political tool to enable people with disabilities to be re-defined, and to bring to light the barriers suffered to enable them to be removed (Shakespeare, 2013). Exclusion and limited social participation are not

the fault of the individual with the impairment, but on society for restricting access to public places (Shakespeare, 2013; Thomas, 2007). Thus it is the responsibility of society to remove such barriers to enable full participation (Shakespeare, 2013). The social model offers a different approach to what it means to be disabled (which is defined as social exclusion due to societal barriers) and what impairment is (defined as physical limitation) (Shakespeare, 2013; Barnes and Mercer, 2010). Disabled people are defined by the social model as an oppressed group due to society limiting their participation, not as a result of the impairment (Shakespeare, 2013).

The social model was developed as a result of the principles set out by the Union of the Physically Impaired Against Segregation, who united to improve the fortunes of those suffering impairments (Shakespeare, 2013; Barnes and Mercer, 1997). Their policy statement identified areas within society that needed improvement or overhauling, to help change the attitudes towards people with impairment from an out of date prejudice understanding, to one which allows for the recognition as a legitimate person within their own right, despite the presence of an impairment (UPIAS, 1976). The removal of segregated institutions, using resources to support people within their own homes (as opposed to in institutions), and appropriate working environments were all stated within the policy statement as a means to allow people with impairments to have control over their own lives (UPIAS, 1976). UPIAS argue that it is inappropriate for the medical profession to define what disability is and what is best for those with impairments (UPIAS, 1976). This is not to say that medical assistance would be rejected should it be desired by the affected person, but the decision making process should be taken away from the medical profession (UPIAS, 1976). Overall the policy statement by UPIAS detailed the oppressive state people with impairments were subjected to, and the need for political action to change this status.

The social model as a political tool was successful in legislative terms after the Disability Discrimination Act was introduced into law in 1995. This legislation was legalised after Britain saw campaigners use the philosophy drawn out from the social model to identify the various forms of discrimination that were experienced by disabled people (Barnes, 1991). As a result, evidence of this legislation can be seen in various forms in society. For example, buildings and public transport have to be accessible to people with disabilities (Shakespeare, 2013). This adoption of the social model as a political tool is one of the many benefits. Other positives include; liberation of people with impairment; a collective identity

and improved self-esteem of people with impairments (Shakespeare, 2012). One of the major barriers of participation in society of people with impairment is a lack of self-esteem and self-confidence (Shakespeare, 2013). The social model has successfully highlighted the barriers of society that acts to disable people, thus removing the blame from the individual and placing it onto society. This acts to change perceptions of people with impairments (Shakespeare, 2013).

The criticisms of the social model of disability mainly focus on the way the role of the impairment itself is significantly reduced when discussing the social oppression many people with impairment feel. An impairment has been argued to have an impact on every detail of life. Therefore to render it irrelevant and place blame on society simply cannot be done in the ways detailed in the social model (Crow, 1992). Other criticisms centre on the demands set out in the social model. For example, it would be very difficult in practice to create a society where every social barrier was removed (Shakespeare, 2013). There is also the problem of different impairments requiring different adaptations to society. Some impairments require steps and defined indentations in paths to make clear where they should be standing (for example a person with blindness). A different impairment may require smooth surfaces (for example a wheelchair user) (Shakespeare, 2013). When considering cognitive impairments, removing all societal barriers becomes more difficult when reading and writing are significant skills required for social participation in many aspects of society (Shakespeare, 2013). It has also been noted within disability writings that reducing barriers will not fully remove disability (Bury, 1997) as having certain impairments will always be a disadvantage (Shakespeare, 2013). This is not to say that adaptations should not be made when it is possible to do so, however, there will always be impairments where no amount of adaptations will entirely remove all social barriers (Shakespeare, 2013). Shakespeare suggests dealing with specific special needs may be more appropriate than providing a barrier free society (Shakespeare, 2013).

Acknowledging these important limitations of the social model of disability approach, Shakespeare argues that the continued adoption of the social model is barrier to continued success in improving disability rights. This is due to it being limited in the understanding of the relationship between an individual with an impairment and their societal context and “More sophisticated and complex approaches are needed” to theorise disability (Shakespeare, 2013: 221). Issues have been raised regarding the origins of the social models political campaign. This original group composed of a small number of activists who were

mainly white men with either spinal injuries or other physical impairments (Shakespeare, 2013). As a result, a narrow understanding of impairment and disability was produced. This may have proved very different had people with learning impairments, mental health problems, complex physical impairments as well as women and homosexual disabled people been included (Shakespeare, 2013).

The World Health Organisation (WHO) has created the International Classification of Functioning Disability and Health (ICF) to define both functioning and disability (WHO, 2013c). This was to replace the earlier model, which it was argued adopted many of the principles of the medical model (Locker, 2008). The ICF has recognised that disability is an experience that many individuals within society will experience in some form throughout their lives (Shakespeare, 2013; WHO, 2013c). The focus is on what constitutes health as opposed to the impact of the impairment itself (Locker, 2008). This creates a definition that impacts all in society, not just those who have the defined disability label attached to them (Shakespeare, 2013). The ICF considers the impact of a health condition accounting for the social aspects of disability, not simply reducing it to a medical or a biological definition of anomaly (WHO, 2013c). Using such a classification system may be more appropriate as it is felt to be important to recognise both the role of the biological and the social dimensions of disability (Anastasiou and Kauffman, 2013) to gain a fuller understanding of the implications of a particular impairment.

Clearly the debates about how best to define and theorise the relationships between disability, impairment and social life are ongoing. Despite the weakness of the specific forms that the social model of disability has taken in these debates to date, there is much value in seeking an alternative to the biomedical approach. Given this, the social model of disability remains an important theoretical influence on the analysis in this project.

4.8 Summary of the concepts that inform this thesis

Key aspects are drawn out from the theoretical perspectives highlighted above to inform the research findings. The social construction of medical knowledge is an important consideration within this thesis. The right to define health, illness and impairment falls within a medical paradigm, as well as the treatment and care offered in attempts to 'fix' the impairment. The medical profession as a body have cemented their powerful position in society, which in turn has facilitated process of medicalisation. As a result, pregnancy, fetal anomalies and subsequent impairment are unquestioningly treated and discussed in medical

terms. The 'normal' functioning body is what is strived for. Under the biomedicine paradigm, medical intervention for many anomalies appears unquestioned. For example, after a diagnosis of cleft lip, the decision to undergo re-constructive surgery appears automatic.

Themes found within the interactionism tradition are also relevant to this the analysis presented in this thesis. The understandings and that meanings social care and medical professionals ascribed to perspectives about TOPFA were based on the interactions they had experienced in their professional lives and personal lives. Social interactions provide a situation from which social actives derive meaning from. Medical professionals can gain meaning from interactions with parents. How an anomaly can be defined as 'serious' can be affected by such interactions. Social care professionals' interactions with people with impairments enable meaning to be gained. These meanings are internalised and influence both professional groups' opinions regarding TOPFA.

Themes found within the ethnomethodology tradition have also provided insight for the analysis presented in this thesis. According to ethnomethodologists, all aspects of reality that we know are socially constructed, with a central theme being how meanings come to be constructed. These ideas link with the social constructionist perspective in terms of the medical profession being in a position of power thus enabling pregnancy, fetal anomaly and impairment to be defined under the biomedical paradigm. Ethnomethodology also point to the 'fixing' of 'problems'. It is deemed not possible to 'fix' a problem at structural level, a process of negotiation and interaction needs to take place in order for a change to come about. This may offer an explanation as to why despite some professionals being personally against certain anomalies being a justification for TOPFA, it is not always professionally appropriate not to intervene should the parents request a TOP. An example of this can be seen with Downs syndrome. For some professionals, while the chorionic villus test is conducted as part of a normal procedure, then it is inappropriate not to act should Downs syndrome be discovered.

Two of Goffman's works are important in the analysis of this thesis. *The presentation of self in everyday life* discusses how the information an individual allows their audience to have impacts on the desired response they are trying to achieve. Regarding impairment, some people will provide some information or none at all regarding their impairment. The individual performance is for the benefit of those present in order to present him/herself as what he/she claims to be; if the individual is playing the role of 'being normal' then they

will attempt to act as such. The act a person with impairment may put on may involve extra measures being taken to maintain the 'normal' status and 'hide' the impairment. Such examples may include researching bathroom facilities to ensure a space is available where the individual can drop their act and do anything necessary regarding their impairment.

For the professionals, they want to appear as 'morally sound', so their discussions regarding TOPFA will reflect this particular self that they wish to portray. For medical professionals, during counselling they may present 'a front' (front stage) which allows them to act in a professional manor within the legal parameters the legislation dictates. This means their *back stage* self, or self in other front stage performances, may be to perform the 'moral self' who does not condone the TOPFA of certain anomalies. This does not mean they will reject a TOPFA request so long as the legislation dictates that it may proceed. For both professional groups, should they perform as a moral, ethically considerate citizen, then they feel they are one. The majority do not support unquestioningly the TOPFA for certain fetal anomalies. However, if presented in the situation themselves, a different role may prevail.

Some social care professionals have discussed making decisions based on the best interests of the child. This means the presentation of being moral may be in direct conflict with what is best for the child. If a person does not want to be 'one of those people who terminates' then they may choose to continue the pregnancy to uphold their moral performance. But as a result, they may be subjecting their child to a life of pain. What is acceptable pain to decide on behalf of someone else? What is an acceptable amount of pain to put a child through? What is acceptable to put a child through to support a personal moral performance?

Goffman's work on stigma was also a key perspective within the analysis. Within this study both professional groups discuss medical intervention that can act to 'correct' an impairment. For example, for isolated cleft lip, reconstructive surgery appears unquestioned. Goffman discusses those with a stigma will attempt to 'fix' it to gain the benefits of 'being normal'. Goffman also discussed the rejection of the conventional approach to a stigma; this is those with a stigma who to interpret their identity in a different way. This new identity may or may not be accepted by the majority. The Deaf community have attempted to create a new identity. This has been successful in respect of establishing a Deaf community. However some areas of society do not recognise this as an alternative identity.

The social model of disability has been successful as a political tool to create awareness of the plight of people with impairment. Some within the movement have embraced their impairment and rejected attempts to normalise. Improvements in the area have been witnessed. For example, a children TV presenter with a missing limb successfully gained employment where she would be visible. This appointment did result in complaints from parents, indicating work is still needed. All of these factors, and more, act to redefine impairment and disability creating new meanings. This may impact on perceptions of TOPFA. A person with an impairment may decide to ensure they will be perceived as normal and do all possible to gain that status. Using a missing limb example, prosthetics are available for those and a person may accept this option to avoid reactions such as described above. Painful surgery is also available that will increase height by a couple of inches is also available with many people suffering from achondroplasia may accept in attempt to improve their social status.

This chapter highlights a number of theoretical perspectives, as well as the continued importance of TOPFA within the society and the research realm. This research draws on a number of theoretical influences that have been adopted to pull the PhD findings together, and draw out how professionals negotiate acceptable TOPFA while maintaining a self of moral integrity.

Chapter 5: Methodology

5.1 Introduction

This chapter gives an overview of the main methods used in the study, and a rationale for why the mixed-method approach was most helpful. Four phases were identified and the study divided accordingly. The research question asks: is termination of pregnancy an acceptable pregnancy outcome after the diagnosis of non-lethal fetal anomaly?

5.2 Study aims and objectives

This research has one key aim: To explore, describe and understand medical and social care professionals' perspectives on the meanings and implications of non-lethal impairment from birth, and to evaluate the relationship between these meanings with perceptions of TOPFA. This is followed by three objectives:

- (1) To explore how medical and social care professionals understand the meaning of non-lethal impairment from birth, in the context of their work;
- (2) To identify key factors that influence professionals' understandings of TOPFA;
- (3) To compare understandings of TOPFA within and between these two professional communities.

5.3 Qualitative and quantitative research designs

Qualitative and quantitative methodologies are terms which have a multitude of different meanings. As a result, it may be more appropriate to say that qualitative research and quantitative research are 'umbrella' terms, which consists of many methods, and many uses of these methods (Punch, 2005: 134). Both of these approaches have resulted in much debate centring on which approach is the best way of generating knowledge about social phenomena (Punch, 2005). Quantitative methodology was dominant within the social sciences and, for a long time, went somewhat unquestioned (Teddlie and Tashakkori, 2009). The debate started when the 'founding fathers' were attempting to get sociology recognised as a legitimate form of academic activity. The methods of the natural sciences were seen as the key to studying society and thus improving the stature of sociology. Theorists such as Comte supported rational argument and evidence about the world to be produced by the methods of the natural sciences. Durkheim (1964) sought to get sociology recognised as a legitimate subject through use of quantitative approaches. He studied the

‘social fact’ with approaches used in the natural sciences thereby attempting to eliminate bias (Durkheim, 1964). This epistemological approach is known as positivism (Matthews and Ross, 2010).

A positivistic view was usually adopted when quantitative methodologies were used (Teddlie and Tashakkori, 2009). Key characteristics included quantitative data, value neutrality and the focus of study being something that can be measured (through methods such as observation and recording) (Matthews and Ross, 2010). Quantitative approaches include methods of data collection associated with bigger samples, categorical or numerical data and results in numerical form which can be used to analyse trends and correlations (Bryman, 2008). Such methods include surveys, structured interviews and questionnaires. Quantitative approaches are used to produce factual data about the social world.

Qualitative methodology has been portrayed as the opposite to quantitative approaches due to its in-depth nature, enabling the analysis of ‘why’, as opposed to just using numbers to report ‘what’ (Punch, 2005). A stripped down definition of qualitative methodology is offered by Teddlie and Tashakkori (2009: 6) as “...the techniques associated with the gathering, analysis, interpretation, and presentation of narrative information”. The epistemological approach more commonly associated with qualitative methods is known as interpretivism, and is based on questioning the usefulness of the positivist position in studying social phenomena. One major aspect of the debate focuses on the relative importance of subjective meaning, understanding and explanations of the social world; in comparison to the collection of objective measurable data, favoured within the positivist approach (Matthews and Ross, 2010). Methods used within a qualitative research perspective have a tendency to adopt a small sample due to the in-depth nature of the research with other common features including working with data to generate theory and subjective meaning (Punch, 2005). Methodologies used in qualitative research include interviews, semi-structured interviews, participant observation and discourse analysis. The boundaries between these two distinct approaches are not as separate as they have been portrayed in the past. More recently, debate has shifted toward ensuring the research questions dictate the methodological approach. As a result, it is unusual for individual researchers to identify with one of these approaches throughout their research career (Bryman, 1984). A trend has emerged whereby for some research projects, both positivist and interpretivist approaches are utilised (Matthews and Ross; Alexander et al., 2008; Bryman, 2008). As the research question tends to dictate the methodological choice in

modern research (Bryman, 2008), using mixed methods does not create a superior research project over those that use either or. Rather, it offers a third route by which to map project activities to the needs of the project objectives.

5.3.1 Mixed methods

Johnson et al., (2007) collected 19 different definitions from leading mixed methods researchers and came up with a general definition of;

“Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration” (Johnson et al., 2007: 123).

Mixed methods as a term has been subjected to numerous definitions with a consensus on one firm definition yet to be reached (Cresswell and Clark, 2003). Some definitions focus on a simple definition of mixing both qualitative and quantitative methods of data collection and analysis in one study (Johnson et al., 2007; Cresswell and Clark, 2003). Other definitions specify the order of data collection methods and the relative weight of the data (Johnson et al., 2007; Cresswell and Clark, 2003). Mixed methods research can take different forms. For example, the research question might be addressed with mixed methods (Matthew and Ross, 2010). A specific question may also require specific data while another question or aim may require a different data (Matthew and Ross, 2010). While mixed methods research is not new, its popularity has grown (O’Cathain et al., 2007; Johnson et al., 2007). The ability to apply mixed methods to research has also been helped by technological advances. For example, different types of data analysis packages are more readily available to researchers, making analysis and coding easier (e.g. statistical packages) (Cresswell and Clark, 2003). This opens up new research opportunities and allows the utilisation of approaches that may otherwise have not been adopted. The use of mixed methods has been said to counterbalance some of the limitations of just using one method alone (Cresswell and Clark, 2003). For example, doing a social survey combined with focus groups has the statistical advantages of the survey as well as gaining some in-depth data from the focus groups. From this perspective, there is support for the idea that mixing methods can act to strengthen the findings of a study (Cresswell and Clark, 2003) allowing a broader understanding of the issues being researched (Johnson et al., 2007). Social

phenomena are complex and ever changing, and it is argued by some that repeatedly using the same methods of research will not yield the best understanding of society or of a particular phenomenon (Morgan et al., 2004; Cresswell and Clark, 2003). Despite these arguments however, ultimately, it must be the research question(s) that dictates the methodology (O’Cathain et al., 2007; Teddlie and Tashakkori, 2009; Wilson, 1996).

Despite the views supporting the idea of ‘mixing’ qualitative and quantitative methods, there are some strong views against this approach (Bryman, 2008). This stems from the idea that research methods are intertwined with a particular epistemological position, and that different epistemological positions have conflicting ideas as to how social phenomena should be studied (Matthews and Ross, 2010; Bryman, 2008). Epistemology is the idea of what knowledge is and what should be regarded as knowledge (Bryman, 2008). For example, because positivism is an epistemological position that states the social world should be studied akin to the natural sciences (Matthews and Ross, 2010; Bryman, 2008), it therefore only accepts research findings that have been gathered using the methods associated with the positivist position as knowledge. A separate but related argument features the idea that paradigms cannot be combined, qualitative and quantitative being seen as separate paradigms (Bryman, 2008). Paradigm is a term coined by Kuhn and refers to ideas and principles within a discipline that dictate how research should be conducted and analysed (Bryman, 2008). Whether or not qualitative and quantitative methodologies are actually viewed as paradigms remains to be seen as within these methodologies, there is much overlap (Bryman, 2008). Denscombe (2008) argues that the mixed methods approach can be viewed as a third research paradigm. Its use is therefore not driven by philosophical allegiance to a particular paradigm. Research methods are a tool used by researchers to find something out; the presupposition that they are rigorously tied to epistemological and ontological perspectives is something that is less thought of in modern research (Bryman, 2008). While there remains strong debates on the usefulness of mixed methods, adoption in research has increased over recent years (Matthews and Ross, 2010; Bryman, 2008). Widespread use may act to dispel the problems that have been raised about combining methodologies. But equally, others have argued that these positions have become so blurred that researchers do not believe or consider the differences and mixed methods are thus adopted uncritically (Sale et al., 2002).

5.3.2 Mixed methods in medical sociology

Research consisting of mixed methods is common practice in health research (O’Cathain et al., 2008; Sale et al., 2002). This has resulted in a number of journal articles dedicated to assessing key issues like; (i) mixed methods study quality; (ii) why mixed methods are adopted; (iii) a clearer definition of mixed methods (O’Cathain et al., 2008; O’Cathain et al., 2007; Johnson et al., 2007). Adopting this methodological approach has allowed health service research to address greater variety of questions (O’Cathain et al., 2007), where the more traditional method of enquiry (quantitative) in this area have been limited. The diverse nature of phenomena means that a more diverse range of perspectives are needed to gain a fuller understanding of the issues being studied; this is the case within the study of health and medicine as well as other areas (Sale et al., 2002).

This study has adopted a mixed methods approach due to the complex and sensitive nature of the issues involved when studying TOPFA. These require a broader range of perspectives to gain a fuller understanding of the issues involved. Focusing on the rationale for this mixed methods research, this research had three data collection phases. Each phase utilised a different methodology, and all of these have an informative value in their own right. Selecting relevant fetal anomalies in terms of type of impairment, potential implications of this impairment, diagnosis and TOP acceptance rates, means an analysis of the intrinsic value of different types of case studies and a quantitative analysis of epidemiology data was required. The epidemiology study tested for regional variation of TOPFA acceptance rates for the selected fetal anomalies. Phase one achieved its aim by providing information to enable case study examples to be selected through discussion of the different types of anomaly, and a comparison of TOP acceptance rates for eight fetal anomalies. This informed the selection of relevant case study examples for use in phase two and three of the research. Phase two involved the design and distribution of a self-completion questionnaire to a range of social and medical care professionals within the North East of England. The questionnaire was designed to collect data on professional and personal views and understandings of non-lethal impairment in general, and in relation to the four case studies. Data included whether professionals had opinions on women’s access to TOP in the UK, and what gestational age they think a TOPFA is acceptable for each case study. Phase three utilised semi and unstructured interviews. This was to enable the collection of in-depth data with exploration of the meanings of specific issues raised within this research. Phase three of this research involved a sub-sample of participants

from phase two to explore reasons and meanings behind professionals views on TOPFA, some in-depth discussion on the questions raised in the questionnaire and to explore further any particularly complex issues identified in the survey phase.

The three fieldwork phases have a clear place in the research process and the knowledge generated, and so adopting a mixed methods approach was the most conducive to the research aims. Phase one added intrinsic value to the case study selection, which was a significant part of the data collection for phases two and three. Phase two allowed for information of views about TOPFA in general, and in particular views of TOPFA in relation to the specific case study examples to be collected. The use of the questionnaire allowed for a bigger sample selection than would have been possible had the research moved straight onto phase three. Phase two also highlighted areas of interest and value that were raised during phase three. Phase three allowed for in-depth discussions about issues of particular interest from phase two, as well as allowing professionals to discuss openly any issues that they thought of as having particular importance when considering TOPFA. A mixed methods approach was therefore appropriate for this study to enable the gathering of data to all these aspects, and to build a phased design to support the study of an under researched phenomenon. For example, the data from phases one and two were necessary to conduct a good qualitative study. These data were not however available in the public domain because the area of professional views on TOPFA is under researched.

As a result of adopting these methods, three separate types of data have been collected, and analysed separately; following this, the analyses were synthesised. This involves the bringing together of different types of findings that have been gained from multiple data sets. The results chapters represent the methodological approach adopted for data collection. Phase three has produced two results chapters. This is a reflection of the depth of the data collection and analysis in that phase of the project. A synthesis of the key findings from all three phases is presented in Chapter 10. This discussion adopts a number of theoretical tools which are used to interpret key themes generated from the primary data. The case study examples are used to demonstrate some of these themes. Unlike many mixed methods approaches where there is a qualitative pilot section which is followed with a more extensive quantitative research design (Morgan 1998, cited in Sale et al., 2002: 49), this research has two quantitative phases followed with a qualitative phase. This has allowed each phase to explore and inform the following phase, culminating with semi-

structured interviews. This allowed for issues raised in earlier phases to be explored and discussed at length.

5.4 Fieldwork phases

5.4.1 Fieldwork phase one

Phase one involved a process of selecting case study examples for use in the design of phases two and three of the research. This first phase included an analysis of the intrinsic value of a number of different characteristics of impairment and an analysis of selected epidemiological data on detected fetal anomalies. This epidemiology study, provided data on pregnancy outcome after a diagnosis of fetal anomaly and regional differences in TOPFA acceptance rates. The sample was six BINOCAR registers. Access to relevant national level epidemiological data was enabled by Professor Rankin via the BINOCAR national network (Rankin, 2007).

Data were collected on pregnancy outcomes for eight anomalies that were selected as potential case studies. The epidemiological investigation examined whether there was any evidence of regional variation in TOPFA acceptance rates, and to use the findings to help inform case study selection for phases two and three. Sociology then seeks to investigate the origins of such patterns by challenging assumptions and looking to what the social basis of an illness is (for example, cultural behaviours) (Germov, 2009).

Six BINOCAR registers were invited to participate in this study (table 1). Data relating to eight different fetal anomalies were extracted. Each register covers a defined geographical area (see figure 1). Information on congenital anomalies occurring in live births, stillbirths, late miscarriage and TOPFA at any gestation is recorded by the congenital anomaly registers. The registers are population-based and cover all births that occur to residents of the geographically defined populations of each register (BINOCAR, 2010). Some inconsistencies were noted within some of the registers. There were three key inconsistencies between the registers that related to this study. SWCAR and WANDA provided data for spina bifida without hydrocephalus. The other four registers provided data for spina bifida with and without hydrocephalus. For the registers where these data were provided separately (NorCAS and CAROBB), the data were simply added together. SWCAR provided a variable 'fetal loss' which combined the TOPFA figures and the late miscarriage figures. SWCAR also did not provide data for ventriculomegaly.

The remaining two registers in England and Wales were not included in this study. YHCAR did not exist at the time of data collection. WMCAR was unable to contribute at the time of data collection. All of the registers are part of BINOCAR and five also belong to EUROCAT. The study period for the data request was 1st January 1998-31st December 2007. All registers were established between 1985 and 2002 (BINOCAR, 2001) with YHCAR being established later. Denominator data were obtained from the ONS, to allow for the calculation of prevalence rates for each anomaly. All the registers can record more than one anomaly per case. Only the first anomaly was selected for analysis as this should represent the primary anomaly and reason for TOPFA.

BINOCAR Register	Population Covered
CARIS	Welsh Congenital Anomaly Register
CAROBB	Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire
EMSYCAR	East Midlands and South Yorkshire Congenital Anomaly Register
NorCAS	Northern Congenital Abnormality Survey
SWCAR	South West Congenital Anomaly Register
WANDA	Wessex Antenatally Detected Anomalies Register

Table 1: BINOCAR registers approached

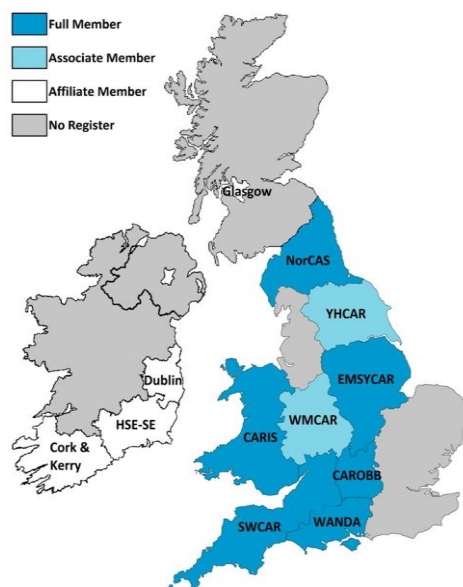


Figure 1: BINOCAR Map

5.4.2 Analysis of epidemiology data

Prevalence is the proportion of people within which a specific population who have a ‘disease at a specific instant’ and enables an estimation of the probability (risk) that someone will be affected (Hennekens and Buring, 1987: 57). Incidence and prevalence are often confused. Incidence is not used because it refers to the number of new cases in a given time period within a population (BINOCAR, 2013). Prevalence is reported in congenital anomaly registers. This is due to it being impossible to know all ‘new’ cases due to some pregnancy outcomes being affected by spontaneous miscarriage due to an anomaly before diagnosis can be made (BINOCAR, 2013). Population estimates of the total number of pregnancies at risk of being affected by an anomaly due to miscarriages or TOPFA are also not available (BINOCAR, 2013).

$$\text{Prevalence (at a given point in time)} = \text{Number of cases} / \text{total population} \times 10,000$$

A confidence interval (CI) is the range within which the true value is expected to lie. A confidence interval takes into consideration a number of factors such as the variability of the sample and the sample size (Diamond and Jefferies, 2001). A narrow CI indicates a more accurate estimate of the population mean and can be achieved through larger sample sizes or less variable sample sizes (Diamond and Jefferies, 2001). Data provided by the BINOCAR registers were analysed using the Statistical Package for the Social Sciences (v17) (SPSS). The descriptive statistics option was used to describe the available variables which mainly involved running frequencies. Prevalence rate and 95% CIs were calculated for congenital anomaly for each register using the Binomial distribution.

These analyses combined with the discussion of the intrinsic value of the eight case study examples, provided information on factors that might be anticipated to impact on professional perspectives on non-lethal impairment from birth. This information was used to identify which non-lethal anomalies had the greatest intrinsic value as case studies (Strake, 1994), for the four case study exemplars that would feature in phases two and three. The aim was to identify four anomalies for use as ‘case study’ examples in the survey phase. The key criteria for selection of the case study anomalies related to: (i) type of anomaly (e.g. chromosomal vs structural); (ii) type of impairment (physical vs intellectual); (iii) perceived seriousness (e.g. self-evidently serious vs contentious); and (iv) regional variation in TOP acceptance rates. During this phase, the ethics application for phases two and three was submitted via IRAS. Approval was granted by Newcastle & North Tyneside

2 REC (10/H0907/50) and relevant Research and Development departments of the NHS Trusts.

5.4.3 Fieldwork phase two

Phase two of this research involved the design and distribution of a short self-completion questionnaire to a range of social care and medical professionals within the North East of England (See appendix D and E). Drawing on the findings from phase one, the questionnaires were designed to collect data on social care and medical professionals' views and understandings of non-lethal impairment in general, and in relation to the selected group of case study examples. The design also allowed for the collection of some preliminary data on professionals' personal feelings and opinions about the place of non-lethal impairment in its social context. The questionnaire also asked whether participants were willing to take part in a fact-to-face interview. For medical professionals, recruitment was at two of four of the NHS sites. These two sites were selected for the practical reasons of location and cost.

5.4.4 Questionnaires

Self-completion questionnaires can be defined as a series of questions that are filled in by the respondent, that gather information from respondents (Bryman, 2008). Questionnaires are a popular method of data collection when the views of a bigger sample are required (Simmons, 2008); the practicalities of time and cost make questionnaires a useful tool in gaining access to lots of views in comparison to other methods, for example in-depth interviews (Wilson, 1996). Improved analysis software have also made this process more accessible and even more time efficient (Simmons, 2008). Questionnaires are said to collect data that fall into four main categories; attributes; behaviour; attitudes and beliefs (Simmons, 2008: 189). The current research focuses on participants' attitudes. Attitudes can be defined as how people feel about a particular issue. Information is usually gained through the use of a statement and a scale (Simmons, 2008: 190). Due to the self-completion aspect of a questionnaire, ambiguous questions must be avoided, as a result, questions are often fixed due to the ease in answering them (Bryman, 2008; Simmons, 2008). Questions must also be understandable to all respondents (Payne and Payne, 2004); as a result of this, two different questionnaires were used to reflect the language used by each professional group and the context of their work. For example, it was deemed likely that social care professionals may not understand medical terms.

The sampling strategy selected for this phase of the study was snowball sampling. This is a non-probability sampling strategy, selected due to the connections needed to access the professional groups selected for study. There is no defined regional or national organisational frame to recruit social care professionals. This meant an opportunistic sampling strategy had to be employed to gain the required number of respondents. Existing organisational structures in the NHS were adopted for the recruitment of medical professionals. Some of the questions were worded differently in the questionnaire to reflect the language anticipated to be more familiar for the particular professional group. For the social care professionals, the survey was distributed through personal and professional contacts which in-turn created more contacts. For the medical professionals, each research site had a primary investigator affiliated to this study. These primary investigators acted as a gatekeeper to the medical professional community, distributing the research packs to the relevant professionals at that particular research site.

When a potential participant had been identified, the research pack was sent to them. The pack included a participant invitation letter, a participant information sheet, an information sheet (social care professionals only), the questionnaire and a stamped addressed return envelope (See appendices A-G). An additional information sheet, with further details about the case study examples was given to social care professionals only. This reflected an anticipated difference in types of professional experiences, as it was anticipated that the social care professionals may be less familiar with some of the case study examples.

The questionnaire incorporated fixed choice questions. A number of these questions allowed for comments if participants wished to expand their answers. The issues covered in the questionnaire centred on whether TOPFA was an acceptable pregnancy outcome; whether they felt it was part of their professional duty to provide TOPFA services (medical professionals only); and what gestational age TOPFA is acceptable for each of the four conditions. The final section of the questionnaire included a section asking for consent for the researcher to contact the participant again to participate in an interview. In this section, participants left their name and contact information should they wish to participate in phase three of the research. This information is not included in any analysis, and will be stored in a secure location on Newcastle University premises as per the Data Protection Act.

The types of variables that have been used in the questionnaire are nominal and ordinal. Each variable represents a different type of data and some statistical techniques are

different depending on the variable, which is why they need to be distinguished from each other. The data were analysed using the 'Statistical Package for the Social Sciences' v17 (SPSS Inc, 2008). Written text was analysed narratively outside of the SPSS package. The results are presented descriptively.

5.4.5 Fieldwork phase three

Phase three involved a sub-sample of participants selected to take part in an in-depth interview; the total number of interviews completed was 23. This was to explore further any complex issues identified in the survey phase and to gain some in-depth discussion on the questions raised in the questionnaire. The sample was selected using a purposive sampling strategy, to ensure diversity on the basis of categories identified in phase two. The qualitative data from these in-depth interviews were analysed using a basic generative thematic type approach (Glaser & Strauss, 1967). The themed data were subjected to in-depth analysis using a number of theoretical tools; for example, key concepts from two of Ervin Goffman's major works, *The presentation of self in everyday life* and *Stigma: notes on the management of a spoiled identity*. This analysis sought to identify conceptualisations of the impact of non-lethal impairment on those most closely involved and on society, from the relevant social care and medical care professionals. Once identified, these conceptualisations were then compared, contrasted and deconstructed (Young, 1990). This analysis provided a more detailed, in-depth and critically reflexive layer to the findings of the project overall, which aimed to highlight similarities and discrepancies in the meanings attributed to non-lethal impairment across the two professional communities.

5.4.6 Interviews

Qualitative interviews are a good way of discovering and exploring participants' understandings, beliefs and preferences (Fielding and Thomas, 2008; Green and Britten, 1998). There are three different types of interviewing technique; the structured interview (more associated with quantitative approaches), the semi-structured interview and the unstructured interview (Bryman, 2008; Arksey and Knight, 1999). The structured interview is used to find descriptive information over a relatively quick time period. This type of interview is often used before a more in-depth technique is adopted (Arksey and Knight, 1999). Semi-structured interviews have an element of structure attached to them but allow the respondent to talk freely despite having already a topic/question agenda in mind (Arksey and Knight, 1999). The interviewer will follow the interview guide but is free to

probe or ask other questions that may arise from responses. This interview style is used to encourage the respondent to talk about the research issue in their own words (i.e. not being fixed by categories in a structured interview). In an unstructured interview, the interviewer has a general idea of the topics they wish to cover but will be flexible in their exploration of these topics, allowing the interviewee to be spontaneous about the research topic (Arksey and Knight, 1999). The fully unstructured interview can be described as a guided conversation, guided by the researcher who has a topic(s) or question(s) they wish to cover, but the respondent is free to do so in their own time and pace, with no fixed categories in which their answers are to fit (Bryman, 2008; Fielding and Thomas, 2008).

It is argued that perception, memory emotion and understanding are socially constructed by people; they are therefore not objective 'things' (Arksey and Knight, 1999). This takes place within a given culture which enables meanings to be made from such constructions (Arksey and Knight, 1999: 3). Communication in interviews is a key consideration to ensure responses are as spontaneous as possible and not dictated by the researcher through leading or closed questions (Fielding and Thomas, 2008). The researcher should ask questions that result in a frank discussion including the respondents' personal values and beliefs, as opposed to easy one word answers, logical answers or responding in a way that the responder thinks the researcher wants them to (Fielding and Thomas, 2008). The interviewer should be relaxed, unselfconscious, pleasant and interested but not intrusive (Fielding and Thomas, 2008; Singer et al., 1983). The unstructured interview allows for the interviewer to probe; it is important to do this without putting words into the respondents' mouth, with expectant silences and 'um hm' named as a few ways to probe (Fielding and Thomas, 2008: 251).

Phase three on the whole, adopted a semi-structured interview approach. During the planning of the research, it was anticipated that some social care professionals may not be as aware of the legislation regarding TOP. To combat this, more control over the discussion than a full unstructured interview would normally allow was deemed more appropriate. Questions or specific topics to be covered are listed on an interview schedule, and are used to guide and stimulate the discussion, but the researcher is not restricted by question ordering or fixed response answers (Bryman, 2008; Silverman, 2006). This was done in this project by using information sheets that gave details of the legal status of TOP with its own set of specific questions, in addition to those already planned. A semi-structured interview was also chosen in case the respondent did not have a definitive view

or opinion on the research topic and needed some guidance to frame their ideas. Time commitments of the professionals involved meant that it could not be assumed that participants would have time for long interviews. The interview schedule was also focused so that if participants could only spare 30 minutes then this would still be of intrinsic value to the research. This occurred on two occasions within the medical professional sample; the rest of the sample allowed for one hour or more. The use of the case study examples also provided an element of structure for participants to frame their ideas around. The sensitive nature of the research also means that the ability to talk freely and further explore the meanings and complex issues this research raised was necessary.

The participants who left their contact information on the questionnaire were contacted and an interview arranged at a place of their choosing. The data for the 23 interviews were collected via recording of the interview for 21 interviews and note taking for 2 interviews. The interviews that were recorded were transcribed; the remaining 2 interviews had the notes written up after the interview.

The data transcripts went through a preliminary analysis process where they were read and some general themes drawn out. These preliminary themes included value of life, value of pregnancy, informed consent, narratives as coping strategies, understanding potential, difference, equality (getting the same/special treatment) and tolerance. After drawing out these preliminary themes, the interview transcripts were consulted again with some preliminary themes eliminated if they did not emerge in more than five transcripts. Those that remained were then grouped with similar themes and given a sub-heading; a 'ethical/morality' theme included preliminary themes relating to the value of life, acceptable death, informed consent; a 'narrative' theme included preliminary themes relating to personal and professional insights, narrative coping strategies, and understanding potential; and the last theme was 'stigma' which included preliminary themes relating to tolerance, challenging assumptions, understanding difference, correctable and hidden difference and acceptable parenthood. These themes were further developed with additional analysis of the transcripts.

5.5 Sample

The sample was selected using a combination of snowball and purposive sampling strategies. Both these strategies featured within recruitment of both social care and medical professionals, but the prominence of each differed. There was more choice available from

the medical professional sample, so a purposive sample was featured more in the recruitment. Accessing social care professionals was much more challenging and so the snowball element was more prominent as a result. The medical professional sample included medical professionals from the specialities of obstetrics, gynaecology, neonatology, paediatrics and fetal medicine. Four NHS sites were selected for research; these were selected based on accessibility. Practical constraints of travelling to sites for phase three eliminated the possibility of a country wide sample selection. All NHS sites are based within the North East of England. At each NHS site, a Primary Investigator (PI) identified to take responsibility for the research. At each site a 'point of contact' was selected who could identify possible participants. At Site A and Site C, the PI assigned a research midwife as the point of contact; Site B and Site D the point of contact was mainly the PI, but some contact was made via a research midwife at Site D also. Site A, C and D required me to send the research packs directly to one specific person (either the PI or research midwife), who then distributed them to the relevant NHS staff.

For the social care professionals, a database was created listing all relevant contacts. This database included personal contacts, charity networks and disability support worker employees. From this database, contact was made. A 'cold contact' was defined as a contact not gained from someone known to the research team. These cold contacts proved very difficult to reach. As a result, a snowball strategy was introduced utilising personal contacts of the research team. The social care professional sample included social care professionals who have involvement in supporting people living with non-lethal disabilities. This sample includes professionals with a range of experience and roles. Those providing day to day support for people with impairment were included, as well as school teachers, and professionals providing support or advice. This professional group lacked a clear definition or professional community. The inclusion criteria essentially were anyone who had a role in the care or support of people with impairments in a non-medical capacity.

The total number of medical professionals that expressed an interest was 17 with 14 interviews were conducted. One medical professional declined to participate upon contact. One medical professional did not get back in touch upon contact, and the third person presented after the final completion date for medical professional interviews. The total number of social care professionals that expressed an interest in being considered for an interview was 11 with 9 interviews being completed. The other 2 did not respond when contact was made.

5.5.1 Snowball sampling

A convenience sample is simply a sample that is readily available to the researcher. Snowball sampling is a form of convenience sampling (Bryman, 2008). The researcher makes contact with a person or group relevant to the research topic. These contacts are then used to establish further contacts who meet the research criteria (Bryman, 2008; Vervaeke et al., 2007). Becker's well established study on marijuana users is a commonly cited example of snowball sampling (Bryman, 2008). He used his personal contacts through his past career as a musician to establish further links with other marijuana users known to his contacts (Becker, 1963). Becker uses the snowball sampling method as there was no other means to identify a sample of marijuana users (Bryman, 2008). Snowball sampling has proved to be a fruitful sampling method when studying hard to reach or hidden populations where such sampling frames are not available (Faugier and Sargeant, 1997). It is also a key sampling strategy when difficulties arise accessing the relevant sample groups (as experienced within this study). This is due to the study being vouched for by those who recommend the research (Foster, 1996). This sampling method is however unlikely to provide a representative sample (Bryman, 2008; Stoltz et al., 2007; Faugier and Sargeant, 1997; Foster, 1996). This does not however discount the value of the accounts that have been gathered through this sampling method.

The nature of snowball sampling is also biased as it relies on the subjective decisions and choices that contacts and respondents choose to disclose (Black and Champion, 1976). However, within qualitative research, this is a minimal concern due to sample selection being dictated by theoretical concerns, not statistical representation (Bryman, 2008). A snowball sampling approach was adopted for this research study. There is no appropriate sampling frame of people who are involved in the care and support of people with impairments. As a result, a snowball approach was adopted with respondents gained through two main avenues. All personal connections were contacted and informed of the study. They were asked if they could recommend any potential respondents. The second avenue of contact was with a cold contact. This was via disability support networks. They too were informed of the study and asked if they could recommend any potential respondents. There were no participants gleaned from cold contacts for this study. This therefore resulted in snowball contacts being an invaluable source of participants for this research.

5.5.2 Recruitment of medical professionals

This study recruited medical professionals through established NHS networks. Phase two involved 4 NHS sites, phase three involved 2 NHS sites. This selection was based on the practical constraints of time and cost. The study received 41 questionnaire responses and 14 completed interviews. The total number of research packs sent out to medical professionals was 114 indicating a 35.96% response rate. Of those responses, 17 indicated they would be interested in being approached for an interview.

5.5.3 Recruitment of social care professionals

Recruitment of social care professionals was particularly difficult. The database created of contacts proved to be unsuccessful in recruiting participants. 30 cold contacts were emailed in February 2011, with a follow up email sent after approximately two weeks. Four responses were received from these emails. Only one cold contact, a public service employer, showed a willingness to participate in the research. This particular cold contact wanted the research to be subjected to their own ethical procedures. Given that the research had already undergone ethical review, this response (and the inherent further delays) led to a decision not to involve this potential participant. Of the other three that responded, they simply stated they were not interested, with no detail given as to any reasons for this. From this point the focus was placed on personal contacts, which proved significantly more successful. These personal contacts were established through those I knew personally and from the supervisory team. This enabled links to those working with people with impairments in a non-medical capacity to be established. This in turn snowballed to further contacts.

After approximately 10 months of using snowball contacts, the volume of data obtained was still low; six interviews and 19 questionnaire responses. These numbers were particularly low, and while the data provided was still of value to the research, I felt it would be of more intrinsic value to the needs of the research to spend some time working on gaining a few more participants. A number of strategies were adopted. Firstly, I wanted to establish if there were any reasons why people were choosing not to take part. This was of particular importance as an impact on the findings. There is no doubt that the data provided some interesting perspectives, and added to the existing knowledge in this area by providing an alternative, under researched perspective. However, understanding why people are choosing to take part is important for both the results of this particular study,

and the impact of future research relating to TOPFA and other sensitive topics. In terms of the results of this study, the recruitment issues highlighted there is still significant stigma attached to TOP and TOPFA that those approached were unable to negotiate past in terms of allowing recruitment and being associated with a study of this nature. It is likely, that such issues will continue to be present in studies of such nature, with research needed in establishing links and negotiating access in such instances. Secondly, to negotiate access to organisations through a known person within that organisation. My belief was, that if access was negotiated through a known person, then those conscious of the sensitive nature of the topic may be more inclined to listen to someone they know and have an established relationship with. This was opposed to me as a researcher with whom they have had no previous interactions. This proved successful in respect that it enabled me to get to speak to someone directly about my research; this is something I had not been given the opportunity to do previously. In total I spoke to three head/deputy head teachers of three different schools that specialise in teaching children with impairments and one manager of an organisation that is also involved in supporting children with impairments. At the end of this process, the total number of research packs sent out was 89 with 31 returns. This was a response rate of 34.83%. To understand the meaning of this response rate, it is useful to consider some (anonymised) examples from the process of obtaining access.

Access to School A was negotiated through an employee who was a personal contact of mine. Response from the deputy head was favourable towards that particular person and the deputy head recommended I rang her directly. To her employee, she suggested the ideal scenario would be for me to come into one of their staff meeting and introduce my research. If people were interested in participating, then they could take a research pack and ask me questions directly. Upon speaking to the deputy head directly, the response was less than favourable. She was very negative towards me and claimed she *did not want anyone advocating termination of pregnancy to her staff*. I questioned this motive explaining that is not the point of the research and she rephrased the statement to *discussing termination for whatever reason*. I framed my discussion around conceptualisations of impairment and how such conceptualisations affected views in other areas in society. TOP was the particular area being focused on. She went on to explain that she did not want anyone coming into the workplace and discussing termination at all, as it is a highly emotive issue. She also claimed to have five members of staff pregnant and felt that research on this topic was not appropriate. The deputy head stated she maintains a *happy workforce*. She felt that discussions about TOP would cause upset and tension and she did not want that. I

questioned whether she felt that it was important for people in professions such as herself to be heard in policy debates about conceptualisations of impairment and how this influences TOP. She simply stated; *people do not want to talk about termination of pregnancy*. This deputy's response offered insight into the difficulties encountered inferring that managers may have prevented research of a sensitive nature from happening.

Access to the School B was negotiated through a previous participant in the research. This was a head teacher of a school who spoke very favourably about the importance of the research. Unfortunately, she would not allow access to the staff to distribute research packs within work time. She did consent to participating herself in a personal capacity and agreed to take a research pack.

In addition through a personal contact, a manager of an organisation that works with children with impairments expressed interest in the research. This person is a manager for an organisation that had already declined to participate in the research. This particular manager did not agree with the organisation policy on staff participation in research. She discussed some of the organisational policies regarding research and expressed concerns over how certain topics *look* to the wider public. Regarding this study, the organisation was concerned about being perceived to *support* TOP, which may not be viewed favourably. She felt the staff were perfectly capable of being able to decide for themselves if they wished to participate. Therefore, in her opinion, not even being given this opportunity does not fall favourably on worker moral. As a result, she was willing to take some research packs and pass them on in a personal capacity.

An additional Head Teacher of School C was also spoken to by RG as this contact was negotiated through a family friend. This head teacher recognised the importance of the research however could not give permission to recruit from his staff until he had sought advice from his superiors. This was due to the funding the school relies on. It was felt that the nature of the research could be interpreted as advocating TOP. It was a concern that if the school was *supporting research of this nature* it may affect its funding. He recommended that I create a detailed letter discussing the research for him to show to his superiors. A response was never received from this school; however repeated prompts were not made due to time constraints.

In addition to attempts to gain access to organisations, everyone who had previously been involved in the research were contacted and asked if they knew anyone else to whom they could recommend the research. No one recommended additional participants.

Two employees from organisations who rejected access to their employees still nevertheless participated in the research. One of these participants went to great lengths to seek me out. She gained my contact details from someone else who had participated in the research. This participant telephoned me and said she was in the local area for the morning and was interested in participating in my research. I immediately went to meet her in a local cafe. She expressed real anger towards those at management level who made decisions on her (and other members of staff) behalf about research participation. She would have liked to have been given the opportunity to participate in my research and genuinely felt that there would have been others who felt the same. She also explained that there are people in management roles who are very defensive about impairment and anything remotely in conflict with this immediately raises their self-protective and aggressive side. TOPFA is a subject that could be in conflict with people's feelings about impairment. However, this participant did not feel that this justified declining of take part on other people's behalf as it is important for employees, such as her, at such organisations to be heard in such debates. As a result she felt it was important to make the attempt to participate. The second employee I interviewed in a gatekeeper role. This participant felt that the decision to allow staff the opportunity to participate in my research should not have been a sole, snap decision by one person. She also raises concerns about those in management roles denying staff the opportunity to participate in such research on contentious topics. She felt many staff would have happily participated in their own time due to the importance of the topic.

While on the surface, some of these responses seemed negative, it satisfied both strategies of gaining information as to why people were not participating, and establishing access through someone known to the establishment. The response suggested to me that the nature of the research still holds significant stigma within society, such that such employers wish to distance themselves as much as possible from any association from it. It also suggested that negotiating access through someone known to the establishment was not necessarily going to result in extra participants. However, it did allow me to speak directly to someone who acted to prevent the research recruitment occurring with their staff. This is a finding in itself worthy of further exploration through further research within recruitment of sensitive topics (see Chapter 11). The image of many charities and

organisations are held in high regard by those who manage them; TOP is still too much of a sensitive topic in the current societal climate to allow open discussion about the issues involved without the fear of repercussions on image. This proved to be a key factor in recommendations for participating (or not participating as the case was here) as many felt that seeing the term 'termination of pregnancy' may be deemed to be 'advocating' the procedure. This was opposed to the aim of this study of discussing professionals' views and conceptualisations of impairment and how this perception affects views on TOPFA. Related to this point, those who have participated in the research were also asked why they think other people were not participating. Many of them said that they disagreed with those at the top of the organisation making decisions about participation on their behalf. They felt many had simply not been given the opportunity. Another major factor affecting participation is time; work and personal. Many of the organisations approached had experienced funding cuts. Allowing people to participate in research on work time was deemed very costly when budgets are so constrained. Public sector workers seemed to have less autonomy over their own work time and were unable to negotiate participation in research in the same way as other professions were able to do. This meant that people would have to participate in their own time.

Ultimately this means that the participants that took part in this study represent only a partial insight into professionals' experiences and views of TOPFA. This inevitably means the findings are a very narrow view of the vast potential sample that could be included under the umbrella term of social care professional. While both groups of professionals were affected by the bias associated with the possible difference between those that respond and those that do not, it is important to acknowledge that the bias is likely to be more pronounced in the social care professional sample. In addition to the variation in response from individuals approached, there was an additional layer of bias in terms of acceding groups of workers to give information about the study in the first instance. However, in such an under researched area, even this more partial view is of value in further understandings of professionals' views of TOPFA. The findings gained from establishing some reasons why participation in research of a sensitive nature will also pave the way for future research within this field, which will hopefully aid in future projects.

5.6 Approvals

Ethical approval was granted by the National Research Ethics Service, Newcastle and North Tyneside 2 Research Ethics Committee after the submission of the ethics form via

IRAS (10/H0907/50 24th December 2010). Minor amendments were requested after this meeting. Site Specific Forms were completed for each NHS site and authorised by the respective Research and Development office. This process took over 8 months due administrative issues (for example, one research site was being audited at the time of SSI submission). No specific issue was raised regarding during Research and Development approval other than 3 of the 4 site preferred that the research packs were sent to one individual in the unit to hand out. At the remaining site, the research packs were sent directly to identified individuals. This was following an email from the gatekeeper (the site PI) making them aware that they had been put forward and a pack was en route to them.

5.7 Research contribution

The subject of TOPFA is something that continues to be of public health interest. Recently, a commons debate surrounding TOP was heard in the House of Commons (Parliament UK, 2012). This is a result of a long campaign by conservative MP Nadine Dorris. While on the surface, this will not affect TOPFA, there are instances whereby a TOP will be offered after diagnosis of a fetal anomaly but under Clause C (social reasons). These situations arise when a parent requests a TOPFA but the medical profession feels the anomaly in question is not serious enough to meet the criteria in Clause E for TOPFA. Because TOP for social reasons has an upper limit of 24 weeks, this is felt to be a legitimate option that some medical professionals within this research have discussed. Research surrounding the area of TOPFA has found that the views of professionals in the area are relatively under researched (Graham et al., 2008) with much of the research focusing on the pregnant woman and the unborn fetus. Research specifically on children/people with disabilities again tend to focus on those living with an impairment or families of children with disabilities; professionals offering care and support are under researched. This research brings both medical professional and social care professionals views to the forefront, with the relationship between the two professional groups deconstructed and analysed.

Chapter 6: Results 1: Selection of case studies

6.1 Introduction

This chapter describes the selection of the case studies examples. The intrinsic values of eight selected fetal anomalies were first assessed; these were then reduced to four for subsequent phases of the research. This selection process was done using the features of each anomaly with the aim of getting examples with a range of impacts, as well as epidemiological data relating to variations in acceptance rates of TOP within England and Wales. Six regional congenital anomaly registers were invited to participate in the study. The data were analysed using SPSS.

6.2 Introducing the case studies

BINOCAR register data were used to determine anomaly detection and termination rates. The collection of registry data relies on multiple sources, including; antenatal ultrasound, obstetrics, cytogenetics, neonatology, paediatric surgery, neonatal screening, clinical genetics and pathology (Budd, 2007: 333). These sources of information allow the registers to record information about the mother and her pregnancy, and the anomalies suspected or positively diagnosed (Budd, 2007).

Eight anomaly subtypes were selected for inclusion in the analysis; hypoplastic left heart (HLH), isolated cleft lip, spina bifida, achondroplasia, ventriculomegaly, atrioventricular septal defect (AVSD), Edwards syndrome and Down's syndrome. The anomalies chosen for this study were selected based on the type of anomaly (structural versus chromosomal); the type of impairment i.e. mainly physical or cognitive; and the perceived severity. For example, it may be the perceived suffering is on a continuum with one end of the scale a very positive outcome with minimal suffering. As a result, TOPFA may not be an acceptable outcome, despite the more negative end of the spectrum being a possibility. The prognoses are wide-ranging from being lethal (Edwards syndrome) to a normal life experience with one or two interventions. This provides an aspect of consideration to frame ideas and perceptions on when making decisions about the choice of TOPFA as an outcome after diagnosis, which is relevant for phases 2 and 3 of the thesis. The lay knowledge about these conditions also gives a different dimension to the decision making

process, that may influence perceptions of TOPFA as a pregnancy outcome. For example, public discussions regarding TOPFA for Down's syndrome have been subject to public outcry despite evidence to suggest that the majority of antenatal diagnoses result in TOPFA (Morris and Alberman 2009). Conditions resulting in risk of physical or cognitive disability were purposefully selected to investigate whether there are any differences in TOPFA acceptability rates. This provided information to identify which non-lethal anomalies will be of most intrinsic value as case studies.

6.2.1 Description of the congenital anomaly subtypes

6.2.2 Hypoplastic left heart

HLH occurs when the left side of the heart fails to develop (Barron et al., 2009). As the left ventricle pumps blood around the body, children with HLH do not get sufficient blood to their vital organs like the brain. Without major heart surgery, HLH is fatal. Babies usually require multiple operations during childhood but in many cases survival is limited (Tennant et al., 2010; Barron et al., 2009); 65% survive to age 5 years and 55% to the age of 10 years (Barron et al., 2009: 551). In addition to surgery, management entails repeated hospitalisations and lifelong medical attention (Barron et al., 2009). There is also a risk of cognitive impairment after the heart surgery.

6.2.3 Cleft lip

Cleft lip arises when the upper lip fails to develop normally. This occurs when parts of the face that develop at different times during pregnancy do not fuse together correctly (CLAPA, 2009). The cleft can be unilateral (on one side), bilateral (on both sides) or in the midline (CLAPPA, 2009; Mossey et al., 2009). Cleft lip may also be associated with a cleft palate (a gap in the roof of the mouth) (CLAPPA, 2009; Mossey et al., 2009). Apart from the pre-surgery disfigurement, a baby with a cleft lip, especially if it associated with a cleft palate, may experience problems eating, speaking and hearing (Mossey et al., 2009). Appearance and psychosocial health problems may also be experienced by those affected (CRANE, 2012). Clefts can be successfully repaired with surgery, usually during the first year of life. Scarring is often evident. More extensive clefts also need on-going input from dental and speech therapists (Slator et al., 2011). The antenatal diagnosis for cleft lip and/or pallet is continually increasing; 42% of clefts were diagnosed during the antenatal

period in 2011. This is the highest proportion since this data started being collected in 2000 by the Cleft Register Craniofacial Anomalies Network (CRANE, 2012).

6.2.4 Spina bifida

Spina bifida is a neural tube defect (Barf et al., 2009) resulting from the incomplete closure of the embryonic neural tube. It is said to be the most complex fetal anomaly compatible with survival (Liptak and El Samra, 2010). Spina bifida can be categorised into spina bifida occulta, spina bifida cystica, meningocele and lipomeningocele. Spina bifida cystica is also known as myelomeningocele, which is the most common and most serious form. In this type of spina bifida, there is a sac on the back containing the membranes and spinal cord; this is often open leaving the nervous system exposed and vulnerable to infection (Fulton and Yeates, 2011; NHS Choice, 2011). Long term care is usually required from a range of specialists (Fletcher and Brei, 2010; Liptak and El Samra, 2010). Potential medical intervention includes neurosurgical intervention to close the spina bifida, bowel and bladder interventions and in many instances, devices to assist ambulation (e.g. braces) as well as psychosocial intervention (Fulton and Yeates, 2011). Hydrocephalus is a condition which is often associated with spina bifida; it is a build-up of cerebrospinal fluid inside the skull which may increase intracranial pressure (Pit-ten Cate et al., 2002). The effect of hydrocephalus varies depending on which part of the brain is affected. The impact can include impaired learning, attention and behaviours as well as impaired motor skills (Pit-ten Cate et al., 2002). People with spina bifida can lead relatively active lives with the prognosis dependent on the number of associated anomalies and complications (NHS Choice, 2011); although research has concluded that those with spina bifida suffer many restrictions in social participation (Barf et al., 2009).

6.2.5 Achondroplasia

Achondroplasia is a bone growth disorder and the most common form of skeletal dysplasia (Horton et al., 2007; Su et al., 2004; Vajo et al., 2000). The main physical feature is disproportionate short stature (the legs and arms are short compared to the body) (Vajo et al., 2000). The average adult height is approximately 127 cm. Other physical features include a prominent forehead, a protruding jaw, short and stumpy hands, and short flat and broad feet (Vajo et al., 2000). The condition is an autosomal dominant condition (Su et al., 2004; Spahis, 2002; Vajo et al., 2000) caused by a genetic mutation (Horton et al., 2007). Middle-ear infections are common in children with achondroplasia (Horton et al., 2007), as

well as respiratory problems as a result of a narrow nasal passage. Surgery can lengthen the legs by up to 30 cm but is painful and lasts over a number of years (BBC Health, 2011). Despite the health issues associated with achondroplasia, the survival prospects of those with achondroplasia are very good (Tennant et al., 2010).

6.2.6 Ventriculomegaly

Ventriculomegaly involves an excess of cerebrospinal fluid in the lateral ventricles of the developing brain (Gaglioti et al., 2009: 381). Ventriculomegaly can be mild (atrium width of 10-12mm), moderate (atrium width of 13-15mm) or severe (atrium width >15mm), with severe cases and those with associated anomalies having a poor prognosis (Hannon et al., 2012; Sethna et al., 2011). There is little research into the long term outcomes of mild to moderate ventriculomegaly (Sethna et al., 2011; Gaglioti et al., 2005) though research has concluded a more positive outcome when compared to severe ventriculomegaly (Gaglioti et al., 2005). Gaglioti et al., (2005) found only 16% of infants diagnosed antenatally with severe ventriculomegaly, were alive and normally developed at the age of at least 2 years. Breeze et al., (2007) studied twenty cases of severe ventriculomegaly; ten of these had a pregnancy outcome of TOPFA, the remaining ten were all live births. Of these 10, two babies died within four months, and seven out of eight had severely abnormal neurodevelopment (Breeze et al., 2007).

6.2.7 Atrioventricular septal defect

AVSD occurs when the septum in the heart fails to develop normally (CHD-UK, 2011) or is absent (Meisner and Guenther, 1998). Complete AVSD means that there is only one common AV valve. This results in blood mixing in all four chambers leading to an increased amount of blood going to the lungs. This results in high blood pressure in the lungs (CHD-UK, 2011). Heart failure and poor growth are common with complete AVSD. Partial or incomplete AVSD is when a hole is present between the upper chambers of the heart and the valve between the left chambers does not close as it should. This usually results in the valve in the heart leaking blood. Surgical correction is required with a diagnosis of AVSD, preferably within the first six months of life (Lange et al., 2007; Craig, 2006). There have been improved outcomes for children and adults with partial AVSD, with the management remaining relatively static over the past 15 years (Chowdhury et al., 2009). AVSD causes growth problems; medical intervention is essential to avoid further complications (including congestive heart failure, pneumonia, high blood pressure, bacterial

endocarditis and cardiomegaly). AVSD is commonly associated with Downs syndrome (Rankin et al., 2012; Lange et al., 2007).

6.2.8 Edwards syndrome

Edwards syndrome (also known as trisomy 18) is a chromosomal anomaly where there is an extra copy of chromosome 18. Edwards syndrome produces a number of minor and major anomalies (Cereda and Carey, 2012) and the overall prognosis is very poor with the typical life expectancy for live born infants being two weeks, although some studies indicating females surviving longer (Irving et al., 2011). There are some isolated examples of infants who survive into childhood but significant physical and cognitive impairment is present (Irving et al., 2011). Typical physical features include small head, small jaw and mouth, upturned nose, widely spaced small eyes, low-set ears (Cereda and Carey, 2012; Hicks, 2008). Anomalies of major organ systems are common in Edwards syndrome; malformations of the heart, kidneys, brain and digestive tract which cause the child many difficulties with feeding and breathing (Hicks, 2008).

6.2.9 Downs syndrome

Downs syndrome (also known as trisomy 21) is a chromosomal anomaly where there is an extra copy of chromosome 21. The physical features of Downs syndrome include a flat facial profile, small ears, protruding tongue, short broad hands and poor muscle tone. Many of those affected by Downs syndrome have heart defects (Rankin et al., 2012). All have varying degrees of learning disability (Macnair and Hicks, 2011). Improvements in management have resulted in an increase in the survival of affected individuals (Rankin et al., 2012; Glasson et al., 2002; Leonard et al., 2000). This includes those with other associated anomalies (Rankin et al., 2012). The total prevalence of Downs syndrome has increased in recent years with increased maternal age (a known risk factor). More effective screening during early pregnancy has meant that more cases are detected prenatally; although some of these cases in the past would have been undiagnosed fetal losses (Rankin et al., 2012). Whether medical intervention is necessary for long term survival for those affected with Downs syndrome is dependent on the presence of any associated anomalies. Table 2 summarises the eight fetal anomalies selected for study within this research.

Condition	Physical impairment	Cognitive impairment	Comments	Structural or Chromosomal
Hypoplastic left heart	X	X	Surgery a requirement for long term survival. Survival not guaranteed.	Structural
Cleft lip	X		Surgery required to 'repair' the cleft. Long term prognosis is positive.	Structural
Spina bifida	X	X	Surgery required. Hydrocephalus often associated with spina bifida Can lead to cognitive impairment as well as physical.	Structural
Achondroplasia	X		Surgery not necessary for long term survival.	Structural
Ventriculomegaly		X	Surgery rarely a requirement for long term survival in mild and moderate cases. Severe ventriculomegaly has poorer long term prognosis.	Structural
Atrioventricular Septal Defect	X		Surgery is required for long term survival. The type of surgery is dependent on the degree of AVSD.	Structural
Edwards syndrome		X	This is a lethal anomaly. There is no surgical cure.	Chromosomal
Downs syndrome	X	X	There is no surgical cure. There are surgeries and/or therapies available depending on the needs of the child/person.	Chromosomal

Table 2: Summary of fetal anomaly subtypes selected for study

6.3 Statistics

A Cochran chi square test for heterogeneity was conducted on the TOPFA outcome data. If $p < 0.05$ then there is significant heterogeneity in TOPFA rates between the six registers. If $p > 0.05$ then there is no significant heterogeneity in TOPFA rates between the six registers. The test included all six registers despite a number of inconsistencies between the registers (See Chapter 5). A further Cochran chi square analysis for heterogeneity was conducted on the four registers that provided data for spina bifida with and without hydrocephalus. Finally, a Cochran chi square test for heterogeneity was conducted omitting SWCAR data, which included data on fetal loss (late miscarriage and TOPFA combined).

6.4 Results

The total prevalence rates, 95% confidence intervals (CI) and the proportion of pregnancies resulting in a TOPFA for the eight anomaly subtypes are presented in tables 3-10.

Register	Prevalence Rate (per 10,000 births)	Lower CI	Upper CI	Proportion resulting in TOPFA
NorCAS	2.2	1.7	2.8	53.6% (n = 37/69)
WANDA	3.7	3.1	4.5	35.5% (n=39/110)
SWCAR	3.1	2.5	3.9	49.4% (n = 42/ 85)
CAROB	2.0	1.4	2.8	44.1% (n = 15/34)
CARIS	3.2	2.6	3.8	51.3% (n = 58/113)
EMSYCAR	5.7	5.2	6.3	49.9% (n = 199/ 399)

Table 3: Hypoplastic left heart prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

Register	Prevalence Rate (per 10,000 births)	Lower CI	Upper CI	Proportion resulting in TOP (These are not necessarily isolated cases).
NorCAS	3.5	2.9	4.3	10% (n = 11/110)
WANDA	4.3	3.6	5.1	0%
SWCAR	3.8	3.1	4.6	7.9% (n = 8/102)
CAROB	2.7	2.0	3.7	17.4% (n = 9/46)
CARIS	3.3	2.8	4.0	10.8% (n = 13/120)
EMSYCAR	4.5	4.0	5.1	25.1% (n = 79/315)

Table 4: Cleft lip prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

Register	Prevalence Rate (per 10,000 births)	Lower CI	Upper CI	Proportion resulting in TOP
NorCAS	6.8	5.9	5.9	78% (n = 165/211)
WANDA	6.4	5.0	6.9	76.8% (n = 146/190)
SWCAR	5.9	5.0	6.9	74.4% (n = 119/160)
CAROB	3.8	3.1	5.1	77.6% (n = 52/67)
CARIS	7.1	6.3	8.1	78.9% (n = 202/ 256)
EMSYCAR	10.6	9.9	11.4	69.3% (n = 512/739)

Table 5: Spina bifida prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

Register	Prevalence Rate (per 10,000 births)	Lower CI	Upper CI	Proportion resulting in TOP
NorCAS	0.4	0.2	0.6	0%
WANDA	0.6	0.4	1.0	0%
SWCAR	0.5	0.1	0.9	0%
CAROB	0.1	0.0	0.0	0%
CARIS	0.6	0.3	0.9	5% (n = 1/20)
EMSYCAR	0.6	0.4	0.8	20.5% (n = 8/39)

Table 6: Achondroplasia prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

Register	Prevalence Rate (per 10,000 births)	Lower CI	Upper CI	Proportion resulting in TOP
NorCAS	6.0	5.2	6.9	52.2% (n = 97/186)
WANDA	3.7	3.0	4.4	58.3% (n = 63/108)
SWCAR ¹				
CAROB	3.3	2.5	4.3	42.9% (n = 24/56)
CARIS	6.1	5.3	7.0	44.3% (n = 97/219)
EMSYCAR	7.4	6.8	8.1	49.4% (n = 256/ 518)

Table 7: Ventriculomegaly prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

¹ SWCAR did not provide data on ventriculomegaly.

Register	Prevalence Rate (per 10,000 births)	Lower CI	Upper CI	Proportion resulting in TOP
NorCAS	6.2	5.4	7.2	24.9% (n = 48/193)
WANDA	1.4	1.0	1.8	27.5% (n = 11/40)
SWCAR	0.9	0.6	1.4	32% (8/25)
CAROB	1.1	0.6	1.7	27.8% (n = 5/18)
CARIS	5.5	4.7	6.3	34.5% (n = 68/197)
EMSYCAR	9.2	8.5	9.9	21.9% (n = 140/640)

Table 8: AVSD prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

Register	Prevalence Rate (per 10,000 births)	Lower CI	Upper CI	Proportion resulting in TOP
NorCAS	5.5	4.7	6.4	74.7% (n = 127/170)
WANDA	7.6	6.7	8.7	69.9% (n = 159/ 226)
SWCAR	6.5	5.6	7.6	80.2% (n = 142/177)
CAROB	5.9	4.8	7.1	77.6% (n = 76/ 98)
CARIS	5.2	4.5	6.0	66.5% (n = 125/188)
EMSYCAR	10.4	9.6	11.1	66.4% (n = 479/721)

Table 9: Edwards syndrome prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

Register	Prevalence Rate (per 10,000 births)	Lower CI 95%	Upper CI 95%	Proportion resulting in TOP
NorCAS	20.5	18.9	22.1	40.6% (n =258/635)
WANDA	31.6	29.6	33.7	52.1% (n = 488/ 935)
SWCAR	22.0	20.3	23.9	53.6% (n = 320/597)
CARobb	21.6	19.1	23.6	54.2% (n= 193/ 356)
CARIS	20.0	18.6	21.5	48.5% (n= 348/718)
EMSYCAR	28.1	26.8	29.3	41.1% (n = 803/1955)

Table 10: Down's syndrome prevalence rate and proportion of pregnancies resulting in a termination of pregnancy for fetal anomaly

6.4.1 Chi square test

Significant heterogeneity was found for TOPFA rates between the six registers for AVSD ($p= 0.042$), cleft lip ($p= <0.001$), spina bifida ($p= 0.014$), Edwards syndrome ($p= 0.001$) and Down's syndrome ($p= <0.001$). No significant heterogeneity was found for TOPFA rates for achondroplasia ($p= 0.201$), HLH ($p= 0.106$) and ventriculomegaly ($p= 0.141$). Significant heterogeneity was found for spina bifida with and without hydrocephalus (Table 12) which was higher than inclusion of all six registers ($p= 0.004$) (Table 11). SWCAR and WANDA provided data for spina bifida without hydrocephalus only (see Chapter 5). This additional test omitting SWCAR resulted in no significant heterogeneity being recorded for Edwards syndrome ($p= 0.057$); this is in contrast to the heterogeneity test that included SWCAR.

Anomaly	All Registers p value	SWCAR omitted P-value
HLH	0.106	0.061
Cleft lip	<0.001	<0.001
Spina bifida	0.014	0.007
Achondroplasia	0.201	0.15
Ventriculomegaly	0.141	0.141
AVSD	0.042	0.027
Edwards syndrome	0.001	0.057
Downs syndrome	<0.001	<0.001

Table 11: Chi square test for heterogeneity

Anomaly	P-value
Spina Bifida with and without HC	0.004

Table 12: Chi square test for heterogeneity for spina bifida with and without hydrocephalus

6.5 Summary of results

Table 13 shows the condition with the highest regional variation in TOPFA was cleft lip (0% in WANDA to 25.1% in EMSYCAR). There is significant heterogeneity in termination rates between registers for cleft lip, with no cases of TOPFA in the WANDA region and 25.1% of cases resulting in a TOPFA in the EMSYCAR region. Edwards syndrome is the case study that has the highest number of TOPFA in all of the regions. There is significant heterogeneity in termination rates between registers for Edwards syndrome if SWCAR is included in the chi square test (fetal loss). When SWCAR is removed, there is no significant heterogeneity in TOPFA rates between registers for Edwards syndrome. Achondroplasia has the lowest number of TOPFA compared to all of the other conditions. There is no significant heterogeneity in TOPFA rates between registers for achondroplasia. This next lowest number of TOPFA is cleft lip. There is

significant heterogeneity in TOPFA rates between resisters for cleft lip. The two conditions with the highest number of TOPFA are Edwards syndrome and spina bifida.

Condition	Lowest TOPFA acceptance	Highest TOPFA acceptance
Hypoplastic left heart	35.5% (WANDA)	53.6% (NorCAS)
Cleft lip	0% (WANDA)	25.1% (EMSYCAR)
Spina bifida	69.3% (EMSYCAR)	78.9% (CARIS)
Achnondroplasia	0% (Norcas, WANDA, SWCAR, CAROBB)	20.5% (EMSYCAR)
Ventriculomegaly	42.9% (CAROBB)	58.3% (WANDA)
AVSD	21.9% (EMSYCAR)	34.5% (CARIS)
Edwards syndrome	66.4% (EMSYCAR)	80.2% (SWCAR)
Downs syndrome	40.6% (NorCAS)	54.2% (CAROBB)

Table 13: The lowest and highest regional variation per condition

6.6 Discussion of the results

This study has compared TOPFA rates for eight congenital anomaly subtypes to investigate whether there is regional variation. This information was used to inform the final case study selection for phases 2 and 3 of the study. The usefulness of adopting an epidemiological approach within this study's broad sociological framework of studying health issues allowed for trends and patterns to be identified. These data provide robust prevalence figures and TOPFA acceptance rates across six different regional areas within England and Wales using data from high quality congenital anomaly resisters.

Ascertainment found some differences in regional variation between TOPFA acceptance rates.

Possible reasons for these variations can be speculated, but more variables, for example, maternal age, may offer more conclusive explanations for such variations. For example; areas where maternal age is higher are likely to see an increase in anomalies where maternal age is a risk factor (e.g. Downs syndrome). Other variables, such as ethnicity, may also explain some differences in TOPFA acceptance rates. For example, studies have found inequalities in knowledge about conditions such as Downs syndrome between women from different ethnic groups (Hewison et al., 2007). Hewison et al., also found Pakistani women in the UK held less favourable attitudes to TOPFA when compared to white

women in the UK, yet wanted prenatal screening for many conditions that they would not consider a termination for. It is worth noting that the study by Hewison et al., (2007), was conducted using hypothetical questions; research is available showing more people opt for TOPFA in reality (Bryant et al., 2001) than hypothetical studies suggest. It is likely that a number of factors play a role in TOPFA acceptance rate variations.

6.7 Final case selection

The fetal anomalies selected as case studies were; isolated cleft lip, HLH, spina bifida and Down's syndrome. All these anomalies can be detected at routine screening.

Isolated cleft lip is a physical condition and surgical intervention is deemed relatively successful. The data above show the range of TOPFA for cleft lip ranged from 0%-25.1%. This would seem to suggest that TOPFA is a requested and acceptable pregnancy outcome for some. The data above includes non-isolated cases, but the focus for phases two and three of this research will be isolated. This case study is an interesting selection for this research as it is an anomaly which is physical with corrective surgery available. It has also been the subject of an attempted prosecution. Rev Joanna Jepson attempted to have two doctors prosecuted for authorising a TOPFA for cleft lip. This case brought cleft lip into the media spotlight. Given this research is concerned with professionals' opinions, it is important to include a condition that may be deemed 'correctable' and thus TOPFA may not be offered as an option. Including such a case study will aim to study how (i) medical professionals define the 'seriousness' as per the legislation of such anomalies within their professional sphere; and (ii) how much medical professionals use their own personal opinion to influence their counselling practices. This would add to arguments suggesting professionals are not as objective as they claim to be. In terms of the intrinsic value of this case study for social care professionals, including cleft lip, a condition not associated with major impairment, is important to broaden our understanding by offering an alternative perspective to that of the medical professionals.

HLH has been selected as it is a physical anomaly that can be detected at routine screening, and the long term prognosis can be uncertain. The range in the proportions of pregnancies that result in a TOPFA, as found in this study, was 35.5%-53.6%. This case study has value for this research as it is an anomaly where surgical intervention is a necessity in order to prolong life. Surgery is necessary but does not necessarily mean life will be guaranteed long term. The importance of including a case study that requires surgical intervention for any

chance of survival aims to show us how much both sets of professionals place value on medical intervention. For example, it may offer insight into how much medical intervention professionals feel it is acceptable to put a child through. This anomaly may also offer insight into whether embarking on a life of medical intervention is something both professional groups will place focus on when defining a particular anomaly as 'serious'. This anomaly may also indicate whether embarking on a life of medical intervention is something both professional groups feel is something that can be compatible with a 'good' or 'acceptable' life.

Spina bifida is a structural anomaly that can also be detected at routine screening. The data presented above indicates the TOPFA percentages between areas are relatively consistent (69.3%-77.6%). This case study is an important case study example because there is more uncertainty and diversity about the prognosis that cannot always be predicted until after birth. The importance of including a case study such as spina bifida was; (i) it is an anomaly that is compatible with life, (though support is often required in varying degrees); (ii) the physical presence of a wheelchair is something that is a visual sign of impairment. This will have analytic value during the discussion of the findings from phases two and three due to the fact it is an impairment that cannot be hidden.

Downs syndrome is primarily an intellectual impairment that may also result in other associated anomalies. The data presented above suggests the percentage of pregnancies affected by Downs syndrome that result in TOPFA ranges from 40.6%-54.2%. This study has intrinsic value as a case study due to: (i) the significant improvements in the long term outcomes for those affected with Downs syndrome; (ii) Downs syndrome has a wide ranging prognosis which may also involve a range of different physical problems, the most common being problems associated with the heart and (iii) Downs syndrome, like spina bifida, is something that is visual. It is an impairment that cannot be hidden and most people within society recognise when someone has Downs syndrome. Downs syndrome can also provoke strong reactions among the lay public. For example, the journalist Samantha Brick who said on national TV that she would have a TOPFA after a diagnosis of Downs syndrome. She was subject to a number of threats and name calling on internet forums.

Chapter 7: Results 2: Questionnaire data

7.1 Introduction

The questionnaire asked both medical professionals and social care professionals questions relating to their views on TOPFA in general and in relation to four case study examples selected based on findings from phase one (see Chapter 5).

7.2 Results

The following section describes the results for each question featured on the questionnaire. The majority are fixed questions so the results are displayed in numerical form in tables, but some qualitative data was also collected through ‘comments’ sections. The response rate and sex and age distribution are detailed in tables 14 and 15.

Professional group	Questionnaire response rate	Interview response rate
Social care professionals	34.8%	81.8% (11 indicated, 9 conducted)
Medical professionals	36.0%	82.4% (17 indicated, 14 conducted)

Table 14: Questionnaire response rate per professional group

Variable	Social Care Professional	Medical Professional
AGE		
<35 years	35.5% (n=11)	17.1% (n=7)
36-40 years	12.9% (n=4)	12.2% (n=5)
41-45 years	9.7% (n=3)	17.1% (n=7)
46-50 years	12.9% (n=4)	17.1% (n=7)
51-55 years	16.1% (n=5)	19.5% (n=8)
56-60 years	9.7% (n=3)	12.2% (n=5)
61>	3.2% (n=1)	2.4% (n=1)
SEX		
Male	25.8% (n=8)	46.3% (n=19)
Female	74.2% (n=23)	53.7% (n=22)

Table 15: Age and sex distribution for each professional group

7.2.1 General questions regarding termination of pregnancy for fetal anomaly

Tables 16-20 describe data on referring to general questions regarding TOPFA. Some qualitative data relating to table 20 is also described. This qualitative data refers to the option ‘other please specify’ option that was available on the questionnaire.

Response	Social care professionals	Medical professionals
Yes	45.2% (n=14)	85.4% (n=35)
No	35.5% (n=11)	14.6% (n=6)
I don't know	6.5% (n=2)	
Missing data	12.9% (n=4)	

Table 16: “Do you have any person opinions about women’s access to TOP in the UK?”

Question	Yes	No	I don't know	Missing data
“Do you feel you have a professional duty to provide TOP?”	68.3% (n=28)	24.4% (n=10)	2.4% (n=1)	4.9% (n=2)
“If you have personal views on access to TOP, are these personal views related to a sense of professional obligation?”	41.5% (n=17)	13.7% (n=13)	17.1% (n=7)	9.8% (n=4)
“Do you have any personal views on women’s current access to TOP on the grounds of fetal anomaly?”	85.4% (n=35)	9.8% (n=4)	2.4% (n=1)	2.4% (n=1)

Table 17: General questions regarding TOP and TOPFA, medical professionals

Response	Social care professional
Yes	45.2% (n=14)
No	32.3% (n=10)
I don't know	19.4% (n=6)
Missing data	3.2% (n=1)

Table 18: “Do you have any personal views on women’s current access to TOP on the grounds of fetal anomaly that are associated with disabilities after birth?” Social care professionals

Variable	Social Care Professionals		Medical Professionals	
	Personal view	Professional View	Personal View	Professional View
1. 100% against TOP for any circumstance	0	0	0	0
2. Against TOP with the exception of certain extreme circumstance	12.9% (n=2)	9.7% (n=3)	19.5% (n=8)	9.8% (n=4)
3. I don't mind what is available but wouldn't consider it for myself/partner	19.4% (n=6)	3.2% (n=1)	14.6% (n=6)	12.2% (n=5)
4. 100% agree the availability of TOP	38.7% (n=12)	25.8% (n=8)	53.7% (n=22)	53.7% (n=22)
5. TOP should be freely available on demand	9.7% (n=3)	9.7% (n=3)	4.9% (n=2)	7.3% (n=3)
	Missing data: 19.4% (n=6)			

Table 19: “Which statement best sums up your opinion on whether TOP should be available to pregnant women in the UK (Personally and Professionally)”

Variable	Social Care Professionals	Medical Professionals
1. 100% against TOP for any type of FA	0	0
2. I accept TOP when disability incompatible with life	12.9% (n=4)	9.8% (n=4)
3. I accept availability of TOP deemed serious that the potential child would need substantial extra support	12.9% (n=4)	26.8% (n=11)
4. I accept availability of TOP deemed serious that the potential child would need some additional support	3.2% (n=1)	12.2% (n=5)
5. I accept availability of TOP for any fetal anomaly but would not for me/partner.	3.2% (n=1)	5.0
6. I accept TOP if parents feel it is right for them.	54.8% (n=17)	39.0 % (n=16)
7. I don't know.	0	0
8. Other (please specify).	0	9.8% (n=4)
	Missing data: 12.9% (n=4)	Missing data: 2.4% (n=1)

Table 20: “Which statement best sums up your personal opinion on whether current availability of TOP for fetal anomaly is acceptable”.

Four medical professionals opted for ‘other’ and gave a written response.

Gestation specific threshold variation.

The law as it stands sums up my personal opinion.

I am personally against TOP for fetal abnormality but respect other parents choices. Although I would agree with 3 above {see table 22}, I do not think it is logical to limit to severe group when so many healthy fetuses are aborted.

I accept the availability of TOP for fetal anomaly that a group of peers would agree is ‘serious enough’ to warrant TOP for that reason. If the patient was still requesting TOP for a less ‘serious’ anomaly, I would offer it under Clause B or C.

7.2.2 Isolated cleft lip

Tables 21 and 22 describe social care and medical professionals’ responses to questions specifically related to the case study example of isolated cleft lip. Figure 2 shows social care

and medical professional responses to gestational age and acceptable TOPFA in the form of a chart.

Question	Yes	No	I don't know	Missing data
“Have you had personal experience in working with parents after a diagnosis of isolated cleft lip?”	9.7% (n=3)	87.1% (n=27)		3.2% (n=1)
“Do you have personal experiences that give you an insight into the quality of life for someone living with cleft lip?” Personal experiences	32.3% (n=10)	58.1% (n=18)		9.7% (n=3)
“Do you have personal experiences that give you an insight into the quality of life for someone living with cleft lip?” Professional experiences	12.9% (n=4)	61.3% (n=19)		25.8% (n=8)
“Do you feel parents get an adequately informed perspective of what living with a child with cleft lip would be like?”	9.7% (n=3)	9.7 (n=3)	77.4% (n=24)	3.2% (n=1)
“Do you think assumptions are made about an individual’s abilities when cleft lip is discussed by non-professionals?” Intellectual disability	48.4% (n=15)	25.8% (n=8)	22.6% (n=7)	3.2% (n=1)
“Do you think assumptions are made about an individual’s abilities when cleft lip is discussed by non-professionals?” Physical disability	54.8% (n=17)	16.1% (n=5)	16.1% (n=5)	12.9% (n=4)
“Has you experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to cleft lip?”	35.5% (n=11)	58.1% (n=18)		6.5% (n=2)

Table 21: Social care professionals’ responses to case study cleft lip

Question	Yes	No	I don't know	Missing data
“Have you had personal experience in working with parents after a diagnosis of isolated cleft lip in your line of work?”	78% (n=32)	19.5% (n=8)		2.4% (n=1)
“Do you have experiences that given you insight into the quality of life for someone living with cleft lip?” Personal experiences	70.7% (n=29)	26.8% (n=11)		2.4% (n=1)
“Do you have experiences that given you insight into the quality of life for someone living with cleft lip?” Professional experiences	70.7% (n=29)	26.8% (n=11)		2.4% (n=1)
“Do you feel parents get an adequately informed perspective of what living with a child with cleft lip would be like?” Parents I see at work.	48.8% (n=20)	9.8% (n=4)	34.1% (n=14)	7.3% (n=3)
“Do you feel parents get an adequately informed perspective of what living with a child with cleft lip would be like?” Parents seen in my unit	61% (n=25)	9.8% (n=4)	22% (n=9)	7.3% (n=3)
“Do you feel parents get an adequately informed perspective of what living with a child with cleft lip would be like?” Parents seen in the NHS across the UK	14.6% (n=6)	12.2% (n=5)	68.3% (n=28)	4.9% (n=2)
“Do you think assumptions are made about an individual’s abilities when cleft lip is discussed by non-professionals?” Intellectual disability	41.5% (n=17)	26.8% (n=11)	31.7% (n=13)	
“Do you think assumptions are made about an individual’s abilities when cleft lip is discussed by non-professionals?” Physical disability	63.4% (n=26)	9.8% (n=4)	26.8% (n=11)	
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Medical facts	100% (n=41)			
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Social facts	70.7% (n=29)	17.1% (n=7)	9.8% (n=4)	2.4% (n=1)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Personal views	22% (n=9)	68.3% (n=28)	4.9% (n=2)	4.9% (n=2)

Table 22: Medical professionals’ responses to case study isolated cleft lip

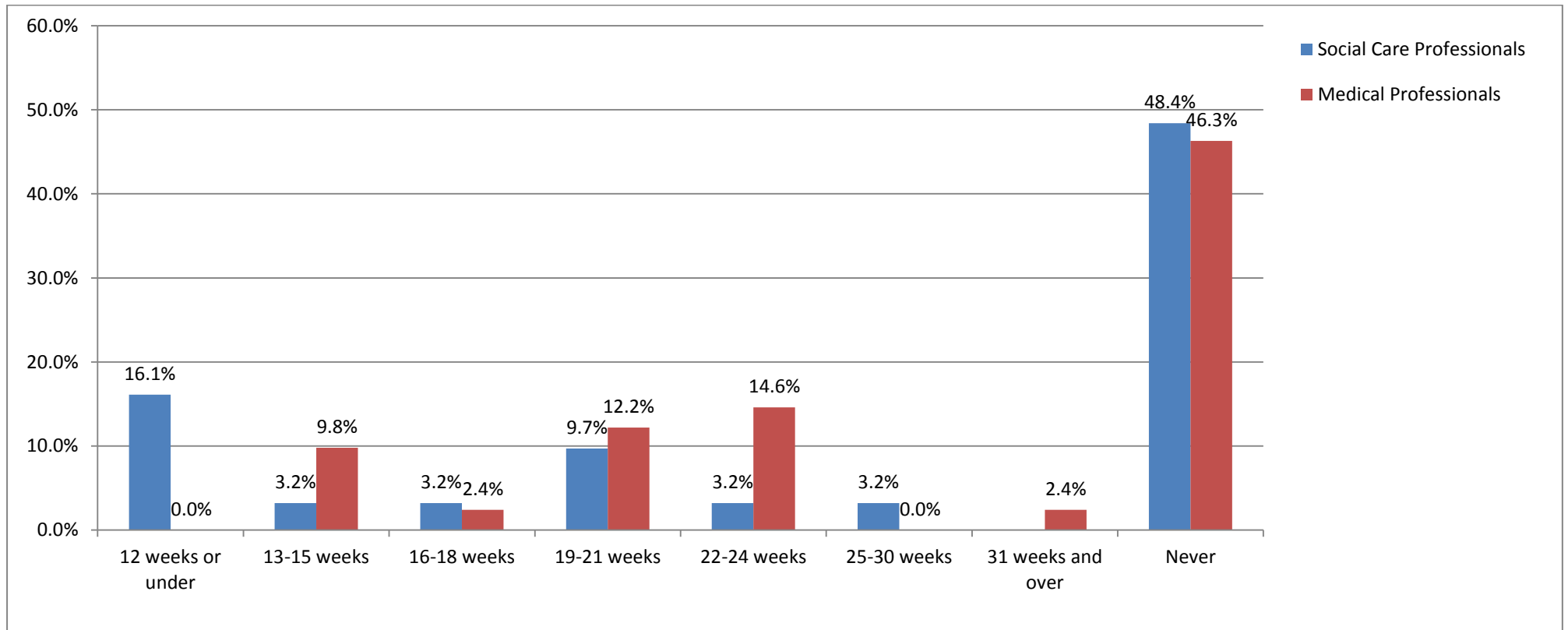


Figure 2: Chart showing gestational age and acceptable TOPFA for cleft lip for each professional group

7.2.3 Qualitative data

The question “what gestational age do you think it is acceptable to TOPFA for isolated cleft lip” also resulted in a number of comments from both professional groups. Some of the social care professionals commented that, personally, they do not agree but accept that parents may feel different when they have an affected child.

The choice should be the parents, with advice from doctors.

Because of ignorance. Some people find facial disfigurement a real hardship and unable to cope.

One social care professional commented that they do not agree with TOPFA for isolated cleft lip;

I don't whole heartedly agree with TOP for cleft lip.

Two social care professionals raised the positive aspects of having a child with an isolated cleft lip;

In theory, I support TOP before 12 weeks for any reason, but from personal experience of a friend at school, cleft lip is not incompatible with very good quality of life.

I feel that with medical treatments to face cleft lip is not the issue it once was. Dramatic changes in surgery work wonders.

Like some medical professionals, one social care professional indicated that, specifically for isolated cleft lip, TOPFA is not acceptable but acknowledged that the decision to have a TOPFA may be affected by certain circumstances (thus Clause C may be acceptable);

I think TOP specifically for cleft lip is morally wrong but accept that other reasons for TOP (e.g. lifestyle/ circumstances) are valid.

I would not support TOP for an isolated cleft lip. If it was associated with other anomalies then this is a potential decision.

Probably up to normal limits for non-medical termination.

when diagnosis is made.

One social care professional noted other reasons for TOP, that if we accept termination ‘healthy’ fetuses then why not for isolated cleft lip;

I don't agree but if you can abort for other reasons like 'not convenient in your life' then why not cleft lip?

For medical professionals, some of these comments relate directly to isolated cleft lip not being an acceptable reason for TOPFA.

I personally would not offer TOP for isolated cleft lip.

Cleft lip is very treatable, so I see no reason for TOP.

See my exclamation marks! I can't even imagine why someone would terminate a potentially healthy baby for a cleft lip and it certainly shouldn't even be offered as an option. EDUCATE THE PATIENTS!.

Some medical professionals distinguished between a personal and professional opinion in their comments;

This is a personal view, not an amendment/interpretation of the legal position.

Personally never, professionally <20 weeks.

Two medical professionals commented on TOP for isolated cleft lip being a possibility under Clause C.

Never: because you TOP for the maternal mental health Clause C not for Clause E.

As per item 6, both professionally and personally I wouldn't 'recommend/support' a TOP request for isolated cleft lip. However, if after counselling by appropriate professionals, the patient was still very distressed requesting TOP, I would proceed but under Clause B or C.

One medical professional commented on a personal experience of doing a TOPFA for cleft lip;

I have been coerced into TOP (mid trimester ~ 20/40) for isolated cleft lip many years ago. I regret it.

7.2.4 Hypoplastic left heart

Tables 23 and 24 describe social care and medical professionals' responses to questions specifically related to the case study example of HLH. Figure 3 shows social care and

medical professional responses to gestational age and acceptable TOPFA in the form of a chart.

Question	Yes	No	I don't know	Missing %
“Have you had personal experience in working with parents after a diagnosis of HLH?”	9.7% (n=3)	83.9% (n=26)	6.5% (n=2)	
“Do you have personal experiences that give you an insight into the quality of life for someone living with HLH?” Personal experiences	6.5% (n=2)	80.6% (n=25)	6.5% (n=2)	6.5% (n=2)
“Do you have personal experiences that give you an insight into the quality of life for someone living with HLH?” Professional experiences	16.1% (n=5)	61.3% (n=19)	3.2% (n=1)	19.4% (n=6)
“Do you feel parents get an adequately informed perspective of what living with a child with HLH would be like?”		19.4% (n=6)	80.6% (n=25)	
“Do you think assumptions are made about an individual’s abilities when HLH is discussed by non-professionals?” Intellectual disability	19.4% (n=6)	16.1% (n=5)	64.5% (n=20)	
“Do you think assumptions are made about an individual’s abilities when HLH is discussed by non-professionals?” Physical disability	32.3% (n=10)	3.2% (n=1)	58.1% (n=18)	6.5% (n=2)
“Has your experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to HLH?”	25.8% (n=8)	48.4% (n=15)	25.8% (n=8)	

Table 23: Social care professionals’ responses to the hypoplastic left heart case study

Question	Yes	No	I don't know	Missing data
“Have you had personal experience in working with parents after a diagnosis of HLH in your line of work?”	78% (n=32)	22% (n=9)		
“Do you have experiences that have given you insight into the quality of life for someone living with HLH?” Personal experiences	2.4% (n=1)	82.9% (n=34)	2.4% (n=1)	12.2% (n=5)
“Do you have experiences that have given you insight into the quality of life for someone living with HLH?” Professional experiences	63.4% (n=26)	34.1% (n=14)	2.4% (n=1)	
“Do you feel parents get an adequately informed perspective of what living with a child with HLH would be like?” Parents I see at work.	41.5% (n=17)	4.9% (n=2)	43.9% (n=18)	9.8% (n=4)
“Do you feel parents get an adequately informed perspective of what living with a child with HLH would be like?” Parents seen in my unit	51.2% (n=21)	4.9% (n=2)	39% (n=16)	4.9% (n=2)
“Do you feel parents get an adequately informed perspective of what living with a child with HLH would be like?” Parents seen in the NHS across the UK	17.1% (n=7)	2.4% (n=1)	75.6% (n=31)	4.9% (n=2)
“Do you think assumptions are made about an individual's abilities when HLH is discussed by non-professionals?” Intellectual disability	24.4% (n=10)	19.5% (n=8)	51.2% (n=21)	4.9% (n=2)
“Do you think assumptions are made about an individual's abilities when HLH is discussed by non-professionals?” Physical disability	56.1% (n=23)	7.3% (n=3)	36.6% (n=15)	
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Medical facts	95.1% (n=39)			4.9% (n=2)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Social facts	63.4% (n=26)	19.5% (n=8)	7.3% (n=3)	9.8% (n=4)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Personal views	17.1% (n=7)	65.9% (n=27)	2.4% (n=1)	14.6% (n=6)

Table 24: Medical professionals' responses to case study hypoplastic left heart

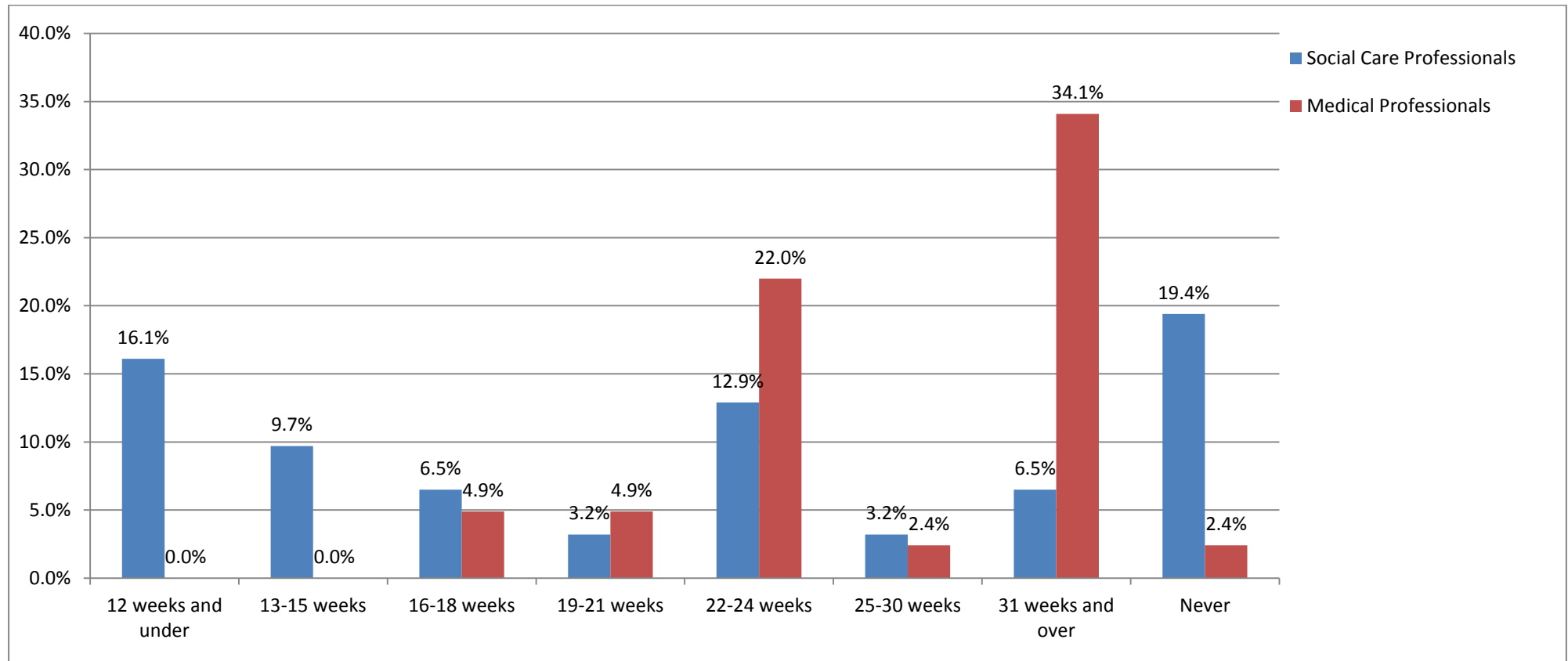


Figure 3: Chart showing gestational age and acceptable for TOPFA for hypoplastic left heart by professional group

7.2.5 Qualitative data

The question “what gestational age do you think it is acceptable to TOPFA for HLH” also resulted in a number of comments from both professional groups. Two of the social care professionals’ comments reflect an opinion that the choice is with the parents.

The choice should be the parents, with doctors’ advice.

It is up to the mother carrying the baby. If she does not want or cannot cope with a disabled child I think she should have the right to terminate the pregnancy.

Some comments reflect the limited knowledge that they felt they had on this condition.

I do not feel I know enough about this condition to comment. I would never support TOP past 24 weeks.

I don’t know – when can you detect it in a developing fetus? I don’t think it should be later than when termination by choice is allowed.

Not sure when it is identifiable – my response is based on rough estimation of typical gestational age limit.

The final comment from a social care professional questionnaire again refers to parental choice upon diagnosis;

I feel parents should be given the choice as soon as the HLHt is confirmed on the scan. As it states in the information, in many cases survival is limited.

For medical professionals, some of the comments referred to the gestational age of which a diagnosis can be made.

Difficult diagnosis before 20 week anomaly ultra sound.

I don’t think definitive diagnosis made locally prior to 19 weeks gestation.

One comment refers to the continuum of a diagnosis.

If prognosis is not bad, surgical correction often first should be offered.

Another comment refers to the long term prognosis.

HLH, though made require several surgeries, is treatable.

Many of the comments discuss the acceptability of TOPFA, some of which at any gestational age.

at any stage, when the diagnosis is certain.

HLH is a grim condition therefore TOP I believe would be acceptable. Children with HLH have a great deal of suffering.

I feel personally uncomfortable about late terminations and would accept as of if a serious medical condition e.g. HLH. Based on out of date experience of severe problems faced by such babies and children.

I do not really think there is any difference between terminations at different gestations.

One comment distinguishes between a personal and professional opinion.

Not an easy question, personally <24 weeks, professionally >31 weeks.

7.2.6 Spina bifida

Tables 25 and 26 describe social care and medical professionals' responses to questions specifically related to the case study example of spina bifida. Figure 4 shows social care and medical professional responses to gestational age and acceptable TOPFA in the form of a chart.

Question	Yes	No	I don't know	Missing data
“Have you had personal experience in working with parents after a diagnosis of spina bifida?”	45.2% (n=14)	54.8% (n=17)		
“Do you have personal experiences that give you an insight into the quality of life for someone living with spina bifida?” Personal experiences	41.9% (n=13)	48.4% (n=15)		9.7% (n=3)
“Do you have personal experiences that have given you an insight into the quality of life for someone living with spina bifida?” Professional experiences	54.8% (n=17)	35.5% (n=11)		9.7% (n=3)
“Do you feel parents get an adequately informed perspective of what living with a child with spina bifida would be like?”	19.4% (n=6)	25.8% (n=8)	54.8% (n=17)	
“Do you think assumptions are made about an individual's abilities when spina bifida is discussed by non-professionals?” Intellectual disability	64.5% (n=20)	22.6% (n=7)	12.9% (n=4)	
“Do you think assumptions are made about an individual's abilities when spina bifida is discussed by non-professionals?” Physical disability	74.2% (n=23)	6.5% (n=2)	16.1% (n=5)	3.2% (n=1)
“Has your experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to spina bifida?”	41.9% (n=13)	45.2% (n=14)	9.7% (n=3)	3.2% (n=1)

Table 25: Social care professionals' responses to case study spina bifida

Question	Yes	No	I don't know	Missing data
“Have you had personal experience in working with parents after a diagnosis of spina bifida in your line of work?”	80.5% (n=33)	14.6% (n=6)		4.9% (n=2)
“Do you have experiences that have given you insight into the quality of life for someone living with spina bifida?” Personal experiences	26.8% (n=11)	65.9% (n=27)	2.4% (n=1)	4.9% (n=2)
“Do you have experiences that have given you insight into the quality of life for someone living with spina bifida?” Professional experiences	78% (n=32)	17.1% (n=7)	2.4% (n=1)	2.4% (n=1)
“Do you feel parents get an adequately informed perspective of what living with a child with spina bifida would be like?” Parents I see at work.	48.8% (n=20)	9.8% (n=4)	31.7% (n=13)	9.8% (n=4)
“Do you feel parents get an adequately informed perspective of what living with a child with spina bifida would be like?” Parents seen in my unit	56.1% (n=23)	12.2% (n=5)	29.3% (n=12)	2.4% (n=1)
“Do you feel parents get an adequately informed perspective of what living with a child with spina bifida would be like?” Parents seen in the NHS across the UK	17.1% (n=7)	9.8% (n=4)	70.7% (n=29)	2.4% (n=1)
“Do you think assumptions are made about an individual's abilities when spina bifida is discussed by non-professionals?” Intellectual disability	63.4% (n=26)	9.8% (n=4)	26.8% (n=11)	
“Do you think assumptions are made about an individual's abilities when spina bifida is discussed by non-professionals?” Physical disability	73.2% (n=30)	9.8% (n=4)	14.6% (n=6)	2.4% (n=1)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Medical facts	95.1% (n=39)			4.9% (n=2)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Social facts	70.7% (n=29)	12.2% (n=5)	7.3% (n=3)	9.8% (n=4)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Personal views	31.7% (n=13)	48.8% (n=20)	7.3% (n=3)	12.2% (n=5)

Table 26: Medical professionals' responses to the spina bifida case study

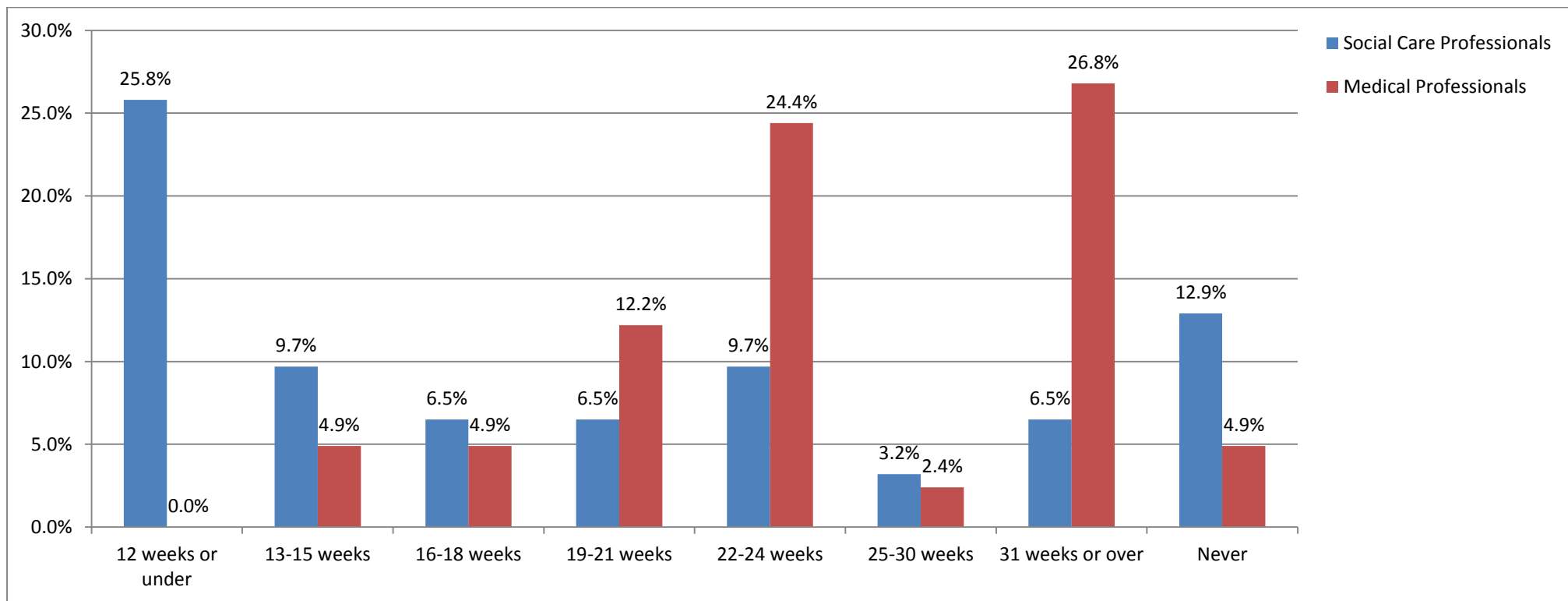


Figure 4: Graph showing gestational age and acceptable TOPFA for spina bifida by professional group

7.2.7 Qualitative data

The question “what gestational age do you think it is acceptable to TOPFA for spina bifida” also resulted in a number of comments from both professional groups. One social care professional referred to professional experience with spina bifida.

I have worked with some extreme cases of spina bifida and the quality of life for an older person is very poor

Two social care professional comments raised the point that it is a decision for the parents.

The choice should be with the parents with doctors' advice

Again parental choice

Another social care professional indicated lack of knowledge of identifying spina bifida.

Same as before – not sure when this condition would be identifiable.

Although spina bifida can lead to severe physical and cognitive impairment, the extent of this is not apparent until after birth (and cognitive impairment is caused by treatment, not the condition itself). People with spina bifida can lead very independent lives.

Medical professionals also left comments regarding this question. Six of these comments referred to the severity of the spina bifida.

If minor correctable defect. Before viability, if a minor defect.

Depends upon level of lesion.

Spina bifida – is a spectrum. Of occulta/isolated spina bifida – TOP not indicated if myelocele/myelomeningocele – TOP considered hydrocephalus.

Again, dependent on the degree of spina bifida and progression of associated issues (such as hydrocephalus), I would deem this to be a ‘serious’ anomaly. Would seek tertiary opinion > 24 weeks.

It should also depend on what kind of spina bifida. Some are asymptomatic and hence no need for TOP because they would live normal life.

but only if it looked ‘severe’ – not sure how much you can tell on ultrasound, but I assume some idea of extent of spina bifida is possible.

Three comments referred to the severity and gestational age for TOP.

I feel personally uncomfortable about late terminations unless serious medical condition spina bifida as a diagnosis covers a range of severities.

I doubt isolated spina bifida would be diagnosed prior to 15 weeks locally. I feel anxious about saying that TOP for isolated spina bifida beyond 30 weeks is acceptable especially if diagnosis made at 20 weeks.

Late diagnosis and 'likely' (up arrow) handicap could persuade me that later TOP would be acceptable.

One comment distinguished between their personal and professional opinions.

Same as for HLH - Not an easy question, personally <24 weeks, professionally >31 weeks.

One comment simply stated;

When diagnosis is made.

Professional stance regarding TOPFA services was also referred to by one medical professional.

Once again, I am not involved in offering TOP.

7.2.8 Downs syndrome

Tables 27 and 28 describe social care and medical professionals' responses to questions specifically related to the case study example of Downs syndrome. Figure 5 shows social care and medical professional responses to gestational age and acceptable TOPFA in the form of a chart.

Question	Yes	No	I don't know	Missing data
“Have you had personal experience in working with parents after a diagnosis of Downs syndrome?”	64.5% (n=20)	35.5% (n=11)		
“Do you have personal experiences that give you an insight into the quality of life for someone living with Downs syndrome?” Personal experiences	48.4% (n=15)	35.5% (n=11)		16.1% (n=5)
“Do you have personal experiences that give you an insight into the quality of life for someone living with Downs syndrome?” Professional experiences	74.2% (n=23)	16.1% (n=5)	3.2% (n=1)	6.5% (n=2)
“Do you feel parents get an adequately informed perspective of what living with a child with Downs syndrome would be like?”	32.3% (n=10)	32.3% (n=10)	35.5% (n=11)	
“Do you think assumptions are made about an individual's abilities when Downs syndrome is discussed by non-professionals?” Intellectual disability	96.8% (n=30)		3.2% (n=1)	
“Do you think assumptions are made about an individual's abilities when Downs syndrome is discussed by non-professionals?” Physical disability	87.1% (n=27)	6.5% (n=2)	6.5% (n=2)	
“Has your experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to Downs syndrome?”	48.4% (n=15)	32.3% (n=10)	12.9% (n=4)	6.5% (n=2)

Table 27: Social care professionals' responses to the Downs syndrome case study

Question	Yes	No	I don't know	Missing data
“Have you had personal experience in working with parents after a diagnosis of Downs syndrome in you line of work?”	95.1% (n=39)	4.9% (n=2)		
“Do you have experiences that given you insight into the quality of life for someone living with Downs syndrome?” Personal experiences	92.7% (n=38)	4.9% (n=2)		2.4% (n=1)
“Do you have experiences that given you insight into the quality of life for someone living with Downs syndrome?” Professional experiences	92.7% (n=38)	4.9% (n=2)		2.4% (n=1)
“Do you feel parents get an adequately informed perspective of what living with a child with Downs syndrome would be like?” Parents I see at work.	53.7% (n=22)	9.8% (n=4)	26.8% (n=11)	9.8% (n=4)
“Do you feel parents get an adequately informed perspective of what living with a child with Downs syndrome would be like?” Parents seen in my unit	58.5% (n=24)	7.3% (n=3)	26.8% (n=11)	7.3% (n=3)
“Do you feel parents get an adequately informed perspective of what living with a child with Downs syndrome would be like?” Parents seen in the NHS across the UK	34.1 (n=14)	12.2% (n=5)	51.2% (n=21)	2.4% (n=1)
“Do you think assumptions are made about an individual’s abilities when Downs syndrome is discussed by non-professionals?” Intellectual disability	85.4% (n=35)	2.4% (n=1)	12.2% (n=5)	
“Do you think assumptions are made about an individual’s abilities when Downs syndrome is discussed by non-professionals?” Physical disability	78% (n=32)	4.9% (n=2)	17.1% (n=7)	
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Medical facts	97.6% (n=40)			2.4% (n=1)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Social facts	80.5% (n=33)	12.2% (n=5)	2.4% (n=1)	4.9% (n=2)
Which of the following influence the advice you would give to a prospective parents regarding this condition?” Personal views	26.8% (n=11)	58.5% (n=24)	4.9% (n=2)	9.8% (n=4)

Table 28: Medical professionals’ responses to Downs syndrome case study

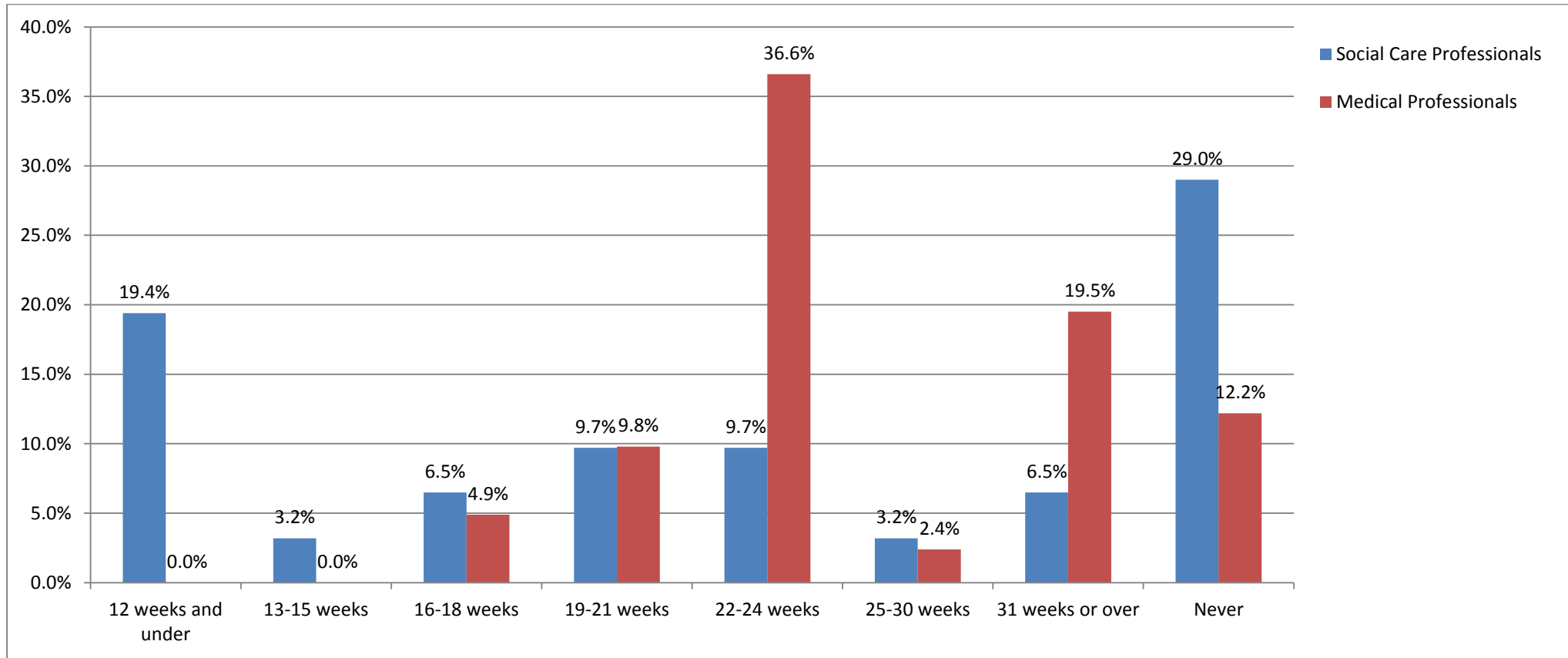


Figure 5: Graph showing gestational age and acceptable TOPFA for Down's syndrome by professional group

7.2.9 Qualitative data

The question “what gestational age do you think it is acceptable to TOPFA for Downs syndrome” also resulted in a number of comments from both professional groups. For social care professionals, some of these comments drew on being unable to know the spectrum of Downs syndrome before birth.

As with spina bifida, the extent of physical and cognitive impairment are not apparent until after birth and people with Downs syndrome can live quite independent lives.

One professional drew on professional experience of Downs syndrome where they indicated the experience may not have been positive for the affected person.

I have experienced 2 similar situations where the older client has no family through deaths and no quality of life. Not being able to communicate or move or feed themselves and personal hygiene.

Some comments refer back to parental choice.

Should be based on individual circumstances.

The choice should be given to parents with doctors’ advice.

One social care professional drew on personal experience.

Having grown up with a brother who has Downs I have first-hand experience of the problems of this condition. It has been hard for my parents but we would not change things for the world.

Gestational age was also raised with one social care professional indicating, ‘as before’ referring to being unsure of when such conditions can be detected.

One social care professional commented next to the gestation age options;

As soon as it is discovered”

As well as adding an alternative option;

If parents cannot cope and put baby up for adoption/fostering, will they get a loving home or be a burden and only fostered for the money.

Medical professionals also commented on this question. Many of these comments distinguished between Downs syndrome and Downs syndrome with associated anomalies.

TOP only if multiple defects associated with the chromosomal abnormality.

This is presuming that diagnosis made before 25 weeks and that the fetus does not have any known structural abnormality (e.g. AVSD etc).

Depends when diagnosed, but more difficult to justify in 'uncomplicated' cases > 24 weeks. Would ask for tertiary opinion.

♣ *gestation if other anomalies e.g. cardiac abnormalities.*

Many comments referred to being personally against TOP for Downs syndrome but could appreciate the request in a professional capacity.

See previous comments. Feel personally uncomfortable unless serious medical problems. Should Downs syndrome earlier but justifying of additional problems later may affect need for late termination.

Professional opinion. Not personal.

I wouldn't agree personally but professionally I understand why, for a lot of parents, continuing with a Downs pregnancy is not right for them.

I would not recommend this TOP for Downs syndrome but if it in parental choice I will understand and accept this.

I personally feel TOP for Downs is never acceptable/ However if current ethics allows TOP then it must be done <21/40.

Two medical professionals re-iterated they are not involved in offering TOP (conscientious objection) with another comment simply stating;

Tricky! <20 weeks?

7.3 Summary of results

The questionnaire data above shows a range of views regarding TOPFA for the four conditions under study. A number of responses to certain questions have raised issues which are of particular value.

Both professional groups were asked what gestational age they feel is acceptable to have a TOPFA for each case study condition. Social care professionals have selections in all

categories (see figures 2-5). This is in contrast to medical professionals who did not indicate selections in the first two options (<12 weeks and 13-15 weeks). Both social care professionals and medical professionals had indicated 'never' in almost half of the responses when asked about gestational age and acceptable TOPFA for isolated cleft lip. This may suggest that there is some degree of acceptability for TOPFA for isolated cleft lip but this is likely to be dependent on things such as the gestational age. For example, for social care professionals, the category most frequently selected for the gestational age for acceptable TOPFA was 12 weeks and under, followed by 19-21 weeks.

Figure 3 shows social care professionals had indicated answers in every category when asked "what gestational age do you think it is acceptable to TOPFA for HLH?". This is in contrast to the medical professionals for whom none answered '12 weeks and under' and '13-15 weeks' (see figure 3). For social care professionals, the range of selections was wider with the highest percentage of answers being in the 'never' category (19.4%). This is again in contrast to medical professionals; the most selected category was '31 weeks or over' (34.1%). Social care professionals were also asked whether they felt parents get an adequately informed perspective of what living with a child with HLH would be like. No one responded yes. It is possible that different support, outside of the remit of social care professional, is necessary after surgery has been completed. This would result in limited contact in a professional capacity meaning they may not have much knowledge on this condition.

However, social care professionals had indicated wider ranges in their selection for other case studies, which the data show they do have professional experience with. For example, both professional groups were asked what gestational age they thought it is acceptable to have a TOPFA for spina bifida (see figure 4). Social care professionals' responses were again spread across all the categories. This included some professionals that did not respond. The medical professionals had two categories that stood out; 22-24 weeks (24.4% of responses) and 31 weeks and over (26.8%). This may suggest other reasons other than different knowledge levels for this contrast.

Both professional groups were asked what gestational age they think it is acceptable to have a TOPFA for Downs syndrome (see figure 5). As with the previous case studies, social care professionals had selections in all categories. This is in contrast to the medical professionals, where no one had indicated an answer for '12 weeks or under' and '13-15 weeks'. The answer with the largest percentage for social care professionals was '12 weeks

or under' (19.4%). This again is in contrast to medical professionals for which the category most frequently selected was '22-24 weeks' (36.6%). This again may reflect knowledge about fetal diagnosis, counselling and other arrangements that surround a TOPFA decision. These responses regarding gestational age are of particular interest. They may reflect a general lack of awareness among everyone other than those knowledgeable in fetal monitoring about when anomalies are screened for and thus detected. It is also interesting to note many medical professionals still indicated the '16-18 weeks' category, despite the knowledge that the fetal anomaly scan is not conducted until 20 weeks. This again may reflect an idealised option. It may also reflect what they think medicine can actually achieve in the field of fetal monitoring. For example, detecting anomalies earlier than the 20 week ultrasound scan, though some comments left by professionals refute this as a possibility.

Similar percentages between both professional groups are reported when asked about assumptions about physical and intellectual abilities relating to spina bifida and Downs syndrome. For assumptions made about physical and intellectual abilities regarding spina bifida; Table 25 and 26 show 74.2% of social care professionals and 73.2% of medical professionals indicated yes for physical abilities; 64.5% (n=23) of social care professionals and 63.4% indicated yes for intellectual abilities. Regarding Downs syndrome, for intellectual abilities, 96.8% of social care professionals and 85.4% of medical professionals responded yes. For physical assumptions, 87.1% of social care professionals and 78.0% of medical professionals responded yes. These similarities in responses may reflect a greater knowledge and experience of social care professionals regarding these impairments when compared to isolated cleft lip and HLH.

Both professional groups were asked if they had personal opinions about women's access to TOP in the UK. More than half of the social care professionals have answered 'no' 'I don't know' or did not answer leaving 45.2% answering 'yes'. This is contrast to the medical professionals where 85.4% answered 'yes' and the remaining 14.6% answering 'no'. While there was no option for comments regarding this question, it may be that given TOP is not an aspect of social care professionals' roles, many people within this profession have never been in a situation where they have thought about it. Thus, as a result, they may have no personal opinion. This explanation may also be applied when looking at Table 16. While 'yes' is the most popular answer when asked whether they had any personal views on women's current access to TOP, there is a considerable contrast between the professional groups; 85.4% of medical professionals answered yes compared to 45.2% of social care

professionals. Again, this may be a reflection of TOP not being of particular prominence in the professional roles of social care professionals.

Recent debates within the media and parliament has included discussions on the legislation, and suggestions for the need to make amendments. Table 21 shows no respondent indicated that they were “100% against TOP for any circumstances” both personally and professionally. For both professional groups, both in their personal and professional opinion, the answer with the biggest percentage was “I am 100% in agreement for the availability of TOP”. Table 20 show none of the respondents, in either professional group, selected that they were 100% against TOP for any type of fetal anomaly. The statement “I accept the availability of TOP for any fetal anomaly if the parents feel it is the right choice for them” was the most selected option for both professional groups, although a higher percentage of social care professionals (54.8%) than medical professionals selected this option. This may indicate a wider support for women’s’ choices, even if the decision is something that a particular professional does not agree with personally. This may also suggest a general agreement with the current legislation.

Non-directive counselling is something supported within medical guidelines. The data show medical professionals indicated they use personal views in counselling for all four case study examples; these percentages were; for isolated cleft lip 22.0%, for HLH 17.1%, for spina bifida 31.7% and for Downs syndrome 26.8. While these percentages do not represent the majority, weight is added to the argument that medical professionals either knowingly or unknowingly bring personal views to their medical consultations. They also represent difference depending on the anomaly in question. Medical professionals bringing in personal views to the discussion could be argued to be undertaking directive counselling. It will also support arguments concerning value free counselling which is very difficult, if not impossible.

While the results show some differences, these are not radically different. Where there is the most variation in results could be the result of different understandings of the anomalies in question. The interview data will aid in clarifying whether or not there is a more profound difference between the professional groups.

Chapter 8: Results 3

Conceptualising the imagined child

8.1 Introduction

This chapter presents an overview of theme one where the data suggest, when discussing the acceptability of TOPFA, each professional conceptualised the imagined child or person. Such conceptualisations were drawn from the interview data and professionals discussed their personal and professional experience when forming their ideas. The perspectives of the two professional groups are similar in terms of the imagined child itself but these conceptualisations stem from quite different professional experiences, and with some reference to personal experience. Some background information about each professional is available on Table 29.

From the data, it was shown that the imagined child was an imagined concept of what a child with an impairment may be like, based on professional and personal interactions and knowledge. For social care professionals, this centres mainly on their professional interactions. This was often in a supportive role. This means that many social care professionals witness people with impairments in 'normal' social settings. This enables a construction in their minds of how similar or different impairments can fit within the social context, based on their own personal interactions. For medical professionals, the imagined child centres on their professional knowledge of the medical facts of an anomaly which may result in impairment. The 'abnormal' body was therefore imagined in a 'normal' social setting. Some impairments can allow the imagined child to 'work' within this 'normal' setting, for others potential difficulties as a result of the impairment are raised.

Theme one was made up of three sub-themes. Sub-theme one discusses conceptualisations of what a person with an impairment can contribute to society. The professional insight that social care professionals have enables them to discuss, based on real life interactions, how someone with an impairment can actively contribute to wider society. This was not only discussed in financial or cultural capital, but also in terms of the joy that a person with impairment brings to a family setting. Much of the aspect of contribution was discussed by comparison to a 'normal' person. Medical professionals focused on the medical facts that may act to restrict a societal contribution.

Sub-theme two centres on the spectrum of possibilities that are possible with an anomaly, and thus the outcome of a particular anomaly is not certain at the point of diagnosis.

There are numerous fetal anomalies where the outcome is not certain. Many fetal anomalies exist on a continuum of life quality and personal experience. At one end of the scale, a positive outcome can be seen with a good life outcome. On the other end of the scale, the outcome may result in a lifetime of medical intervention which does not 'fix' the problem. The final outcome may also still be death as a result of the anomaly. Medical intervention may be required which may result in pain. Certain anomalies that result in impairment may also restrict activities that an affected person can participate in, which can deviate dramatically from a 'normal' experience. Often, such restrictions may not be known until the child is approximately 2 years old, or possibly more.

Sub-theme three focuses on opinions of TOPFA when discussing anomalies where the outcome is relatively certain. The anomalies that were discussed in this context were those where the diagnosis is confident in the certainty of being affected by an anomaly (rather than a prediction about a possible affect), with the prognosis known and the likely medical pathway well mapped out. Such instances may also include a condition that will require medical intervention that may 'fix' the problem or just act to prolong the life of the affected individual. For example, isolated cleft lip, where medical intervention is necessary to repair the cleft, however, no further intervention would be necessary. It also includes conditions where the sufferer is likely to die as a result of the condition (for example, HLH).

Participant	Area of expertise	Comments
Social Care Professional 1 Male	Disability care support work	Provides support mainly for one person who has a range of impairments, but has extensive experience working with a range of impairments.
Social Care Professional 2 Female	Teacher	Special needs school. Range of children with various impairments in attendance. Also experience working in a supportive role one to one with Downs syndrome.
Medical Professional 3 Female	Obstetrics and gynaecology	Care of pregnant women, the fetus and management of diseases specific to women.
Social Care Professional 4 Male	Disability care support work	Provides support mainly for one person who has a range of impairments. Has experience working as a teacher. Also works with the autistic society.
Medical Professional 5 Female	Obstetrics and gynaecology	Care of pregnant women, the fetus and management of diseases specific to women. Female.
Social Care Professional 6 Female	Disability care support work	Provides support mainly for one person who had a major head injury. Has experience working with a range of different impairments. Manages a team.
Medical Professional 7 Male	Obstetrics and gynaecology	Care of pregnant women, the fetus and management of diseases specific to women.
Medical Professional 8 Male	Obstetrics and gynaecology	Care of pregnant women, the fetus and management of diseases specific to women.
Medical Professional 9 Male	Fetal Medicine	¹ Care of pregnant women and the fetus.
Medical Professional 10 Male	Obstetrics and gynaecology	Care of pregnant women, the fetus and management of diseases specific to women.

¹ Description of Medical Professional 9's specific professional role in this format may reveal potentially identifiable information, so has been omitted.

Medical Professional 11 Female	Obstetrics and gynaecology	Care of pregnant women, the fetus and management of diseases specific to women. Involved in autopsy after fetal loss.
Medical Professional 12 Female	Paediatrics	Specialises in care of physical, social and emotional health of children from birth until they are in their mid-teens.
Medical Professional 13 Male	Neonatology	Specialising in the providing care to newborn infants. This is typically for newborns that have been born prematurely and those suffering from congenital anomalies, injury, illness and life-threatening conditions.
Social Care Professional 14 Female	²	Involved in facilitating support and negotiating access to relevant services for people with impairments. Lots of experience with spina bifida. Personal experience with cystic fibrosis and cleft lip.
Medical Professional 15 Male	Paediatrics	Specialises in care of physical, social and emotional health of children from birth until they are in their mid-teens.
Medical Professional 16 Female	Obstetrics and gynaecology	Conscientious objection clause. Care of pregnant women, the fetus and management of diseases specific to women.
Medical Professional 17 Male	Obstetrics and gynaecology	Trainee consultant. Care of pregnant women, the fetus and management of diseases specific to women.
Social Care Professional 18 Female	Care support work	Works in a care home which offers respite for families with members with impairment. Experience with adults and young adults. Work place also offers end of life care.

² Inserting Social Care Professional 14's area of expertise is not possible for confidentiality reasons as it could reveal their employer.

Medical Professional 19 Female	Neonatology	Specialising in the providing care to newborn infants. This is typically for newborns that have been born prematurely and those suffering from congenital anomalies, injury, illness and life-threatening conditions.
Medical Professional 20 Female	Paediatrics	Specialises in care of physical, social and emotional health of children from birth until they are in their mid-teens.
Social Care Professional 21 Female	Teacher	Has experience as a disability care support worker. Currently employed in a special needs school.
Social Care Professional 22 Female	Teacher	Started her career in mainstream school. Has since moved to special needs school which accommodates children with a range of different impairments.
Social Care Professional 23 Female	Relief work	Involved in taking teenagers with a range of impairments into the community in a supportive role.

Table 29: Table with some basic information about the interview respondents

8.2 Social Care Professionals: Sub-theme 1: Conceptualisations of person(s) with impairment(s) contribution to society

The idea that a person living with a disability has the potential to make a significant contribution to society features heavily within the accounts by social care professionals. This was framed around the idea that a person with an impairment can have a ‘normal’ life. The data suggests the notion of a ‘normal’ life was conceptualised as the average life trajectory of expected behaviour and achievements of a person without impairment, in comparison to that of a person with impairment. Essentially doing ‘normal’ things included; having relationships, housework, working and having a home. This includes social care professionals encouraging individuals with impairment, and their parents to perform ‘normal’ tasks as part of their working lives as care professionals.

... the guy who I look after, this is his house. (Social Care Professional 1, Male).

... parents... they've rung up to see how they are, and we're like, oh yeah they're doing the hovering at the moment "they can Hoover?". (Social Care Professional 4, Male).

Also mentioned were the participation in conventional social activities, such as shopping; inclusion in social institutions, such as education and employment; and in general adhering to the life trajectory that a non-affected person would be expected to have.

...none of them have had a bad life, none of the ones I've looked after, and they all access the community, the erm.. have relationships, they have.. .. you know some of them have jobs, some of them work, some of them.. you know have their own house... they all have.. things to offer, even if it's just a small thing you know... a lot I have worked with... put more back into the system then... a lot of these younger people who are just draining the system... who have no disabilities but just can't be bothered to.. do anything with their lives. (Social Care Professional 1, Male).

... the guy who keeps popping in my head is the guy with Downs syndrome... he's one of the most independent Downs syndrome people that I've come across, he's almost like fiercely independent. (Social Care Professional 23, Female).

Some social care professionals felt that the medical profession give a distorted view of life with a child with impairment. This was framed as a lack of understanding on what a person with impairment can contribute, and a focus on the anomaly itself.

I've spoken to people erm with my other job that parents when they have a baby that's born with a disability, doctors basically make it out that like you're gonna look after this person for the rest of your life, it's gonna be a baby in a giants body basically, erm, and then they're not given any kind of idea that this person can have a full life whereas you, once you, start working with people like that you realise they can, erm, but, the doctors, kind of phrase it like, that's it, might as well just quit your job and become a carer cos you know that person is never gonna learn anything, they're gonna be dependent on you, which isn't true for a lot of disabilities. (Social Care Professional 4, Male).

It was explicitly acknowledged by some social care professionals that having an impairment will make life more difficult in some aspects. Many disabling aspects include reduced participation in society, limited access to places in society and restricted resources. Whilst some forms of impairment may have a limited or manageable impact on a person's life, others may have a huge impact on a life of the affected person, as well as the family more

broadly. Some social care professionals reported that variability in effect should not be ignored.

if it's gonna be something like Downs syndrome, even then the scale is sketchy... you get some coming into school with Downs syndrome that will go off and get jobs, but you can see some that are in wheelchairs and you need to help them with just about everything (Social Care Professional 2, female).

However, it was questioned whether having a major impact on the life of the person with impairment means they *should not have a life*. It was also pointed out that 'normal' people can have a difficult life.

That one seems quite severe, but again, like all of them, it's you know, you can still imagine them having a full life, so personally I wouldn't consider any of the case studies, I can see the other one is Downs syndrome, I've worked with lots of people with Downs syndrome and, they're great, you know, I prefer the people with Downs syndrome than half the other people that are normal, you know cos they're happy, and fun to be around stuff, so, no, erm.. obviously, it makes their life more difficult, but there are people that have difficult lives all the time, you know, it doesn't mean they shouldn't have a life. (Social Care Professional 4, Male).

This, however, was not a view held consistently across all social care professionals in the sample. Some examples of impairment that showed an alternative view were evident in the data. One such example was from Social Care Professional 21. Social Care Professional 21 chose not to be recorded. She discussed a boy whom she describes him as a *vegetable, he just exists*. She felt his life was not good and would personally terminate the day she was due to give birth if it would prevent the unnecessary suffering. The suffering, according to Social Care Professional 21, was not just isolated to the boy, but also his parents. She says they would euthanise him if it were legal to end his *life of pure existence*. Social Care Professional 21 said even if he did have a conscious awareness *it must be horrible for him* to be unable to convey anything to the people around. His parents' life revolves around care for their son, who was just an *empty shell, just existing*. She felt no one deserved such a life.

In this sub-theme 'contribution to society' the data suggest that social care professionals feel that a person with impairment does have a valuable contribution to make to society. This was in terms of what that person can personally give back. Examples include; employment, their engagement in 'normal' activities, such as shopping or having a relationship, or the joy they bring to their families regardless of the impairment. What the

data suggest was that opinions appear to differ between the balance between contribution and perceived suffering. While a person with an impairment may be a valued member of someone's family or wider society, some social care professionals feel this was not enough of a positive to outweigh the suffering involved. For example, if prolonged pain, prolonged suffering, long term medical intervention, or they are in a situation where 'everything' has to be done for them is apparent in their life, some social care professionals felt it would be very acceptable to undergo a TOPFA. This is not a lifestyle anyone would choose to have for themselves or a loved one, and it was perceived to be very difficult to anticipate watching a loved one in this position.

8.3 Social care professionals: Sub-theme 2: Conceptualising the imagined child when the outcome of the anomaly is not certain

For many social care professionals, the risk of the undesirable outcome, even if there are positive outcomes associated with the particular anomaly, was enough to support TOPFA. One example of this was Down's syndrome. Social Care Professional 2 discussed Down's syndrome being a condition that can have a limited impact, or result in the person with Down's syndrome needing support with everything they do. Social Care Professional 18 discussed people with Down's syndrome as having a good life, are *very caring and loving*, but also *very bad tempered* and can be *difficult* to manage. She also reiterated that she was *not against TOP in any circumstance*. She reported that it was very difficult looking after a person with an impairment, and very soul destroying watching a person with an impairment at the end of their life. This was something Social Care Professional 18 had seen often, as the home where she worked had a number of patients transferred there to die. Women's rights were very much at the forefront for Social Care Professional 18, and she made a statement that none of the other professionals in either group had referred to directly in any way;

I think the doctors should anyway, they should advise people to terminate. (Social Care Professional 18, Female).

This quote was interesting given her focus on women's rights. Being told to have a TOPFA of an affected pregnancy instead of allowing women to go through a process of decision making is a paternalistic approach, and still takes the control of a woman's body away from the woman. This is due to the doctor advising a TOPFA, not simply stating it as an option and allowing the decision to come from her. The participant's reasons were not definitive though she did discuss taking the onus off the mother, who may want to terminate but not

want to make the decision. This view may have resulted from experience of parents who had regretted having their children after a diagnosis of fetal anomaly. She also raised concerns with the medical professionals who counsel women after a diagnosis, as she feels the counselling should be done by people who have been in that position, not someone who does not understand what it is like.

The acceptability of TOPFA has been distinguished by some of the social care professionals as being influenced by differences between physical and cognitive anomalies. This would suggest differences in knowing the long term prognosis has a significant impact on the acceptability of TOPFA for some professionals.

Physical stuff isn't really a problem for me, it's the mental, I know it sounds awful but it's the mental side of it cos I think it affects them more, people can cope with someone looking a bit different (Social Care Professional 6, Female).

Others based the acceptability of TOPFA on perceived notions of pain and the likely outcome of the condition;

I think the difficult thing is when you get a condition that causes a lot of pain and you do get conditions where the child won't live more than maybe a couple of years and in that time.. erm.. you know to any objective measure would be suffering, and so it's whether preventing that kind of thing is ok... my own line would be somebody who's in pain that can't be alleviated (Social Care Professional 14, Female).

... with the heart condition and spina bifida, they are like serious physical conditions that that child's quality of life will not able to be the same as any other child, they're not gonna be able to fully enjoy aspects of life that other children do, and so I think on those grounds then yeah, like termination of pregnancy is acceptable (Social Care Professional 23, Female).

Many fetal anomalies have outcomes that are perceived by the participants to be positive and conceptualise the future affected person as having the potential to achieve a relatively positive life experience. There are also fetal anomalies where this outcome is not the case. However, some social care professionals describe feeling that this did not make life invaluable and thus TOPFA is not always an acceptable outcome. Downs syndrome was an example repeatedly referenced in the data, as well as anomalies where the affected individual has or seemingly has no awareness and needs everything done for them.

... it's just there's no reason why they shouldn't be able to live. (Social Care Professional 4, Male).

I suppose with a lot of conditions you don't know how bad it's gonna be until after the child is born... life is harder but it's.. not a life that isn't erm.. valuable or you know the person themselves values (Social Care Professional 14, Female).

I cannot get into my head what quality of life this boy must have cos there's just nothing, there's no movement, there's no- there's nothing, the only thing that moves is his eyes, that's it, so every single thing is done for him... but, the really really bizarre thing is, is that his mother... who absolutely will say, oh he's had a really good morning, he's been doing this, or he's been having a bit of a laugh, and I'm like looking and she'll drop him off, and I'm looking thinking, gosh, I actually can't believe what she's saying, but, that, that in turn makes me question my own assumption about, gosh, you know, I would think, I don't think there's any quality of life there, and yet she completely challenges my view of, cos she's saying that there is. (Social Care Professional 22, female).

From the data, this sub-theme shows that professionals distinguished between; (i) the lack of a certain outcome; (ii) distinctions between physical and cognitive anomalies; and (iii) perceived pain and likely long term outcomes. It is worth pointing out that the data also suggest that conceptualisations of physical anomaly centre around impairments such as cleft lip, a missing limb, spina bifida; anomalies with an outward sign of impairment. This excludes anomalies such as of the heart, renal, liver, etc., many of which could be defined as major structural anomalies. Looking at Social Care Professional 18's views also disregards the need to know a definitive outcome as she believes medical professionals should counsel for TOPFA. The implications of imagined life in the wider social context are also drawn on by participants. For anomalies that cause pain, is the affected person going to be able to engage and enjoy every aspect of life that other people would be expected to enjoy? For Social Care Professional 18, the social context surrounding her belief that medical professionals should counsel for TOPFA, may be due to her experience with parents who have regretted continuing with their pregnancy or wished they had not had children. In her opinion, the onus of the decision making should be taken away from the women who may want to have a TOPFA, but feel unable to express that view. This may be a wider reflection of the inequalities women still have within reproductive rights; TOP is legal but not on demand and only on the agreement of two medical doctors.

8.4 Social care professionals: Sub-theme 3: Conceptualising the imagined child when the outcome is relatively certain

The prognoses for many fetal anomalies are known with the likely medical pathway well mapped out. As reported by some social care professionals, TOPFA was still acceptable for some conditions when the outcome is relatively certain.

... if the.. fetus or whatever is gonna be so, so.. erm.. .. physically and mentally disabled that they aren't gonna get any quality of life... there's absolutely no doubt that the, that the child is... gonna get no quality of life at all.. you know what I mean.. and I'm talking.. you know absolute.. they wouldn't be able to move, walk, talk, do anything you know (Social Care Professional 1, Male).

{Cleft Lip} Yeab I suppose, there's still a lot of operations for a mother to go through... I think it should be a choice, and they should be given as much information as they possibly can, maybe even possibly going to meet parents who have these children, or meet adults who have gone through that and make an informed decision, they should have that option (Social Care Professional 2, Female).

There are fetal anomalies where professionals describe TOPFA as an unacceptable pregnancy outcome with conditions where the outcome is known. The most common condition, of the four case study examples used in this study, for unacceptable TOPFA with a relatively certain outcome was isolated cleft lip.

... with regards to cleft lip, I don't agree with termination, I don't agree with it at all because cleft lip isn't a life threatening thing. (Social Care Professional 6, Female).

I find that incredible that it's <cleft lip> even on the list, I genuinely found that when I did the survey I actually laughed cos I thought you are joking, that's obviously, obviously a reason why you put it on there cos it's obviously, you know, but it was so... ridiculous to me that I just was like... what!? Oh I've decided they've got brown eyes I'm not too keen, no, that's that's just absolutely outrageous. (Social Care Professional 22, Female).

... cleft lip, the very idea to me that somebody would terminate a pregnancy just because the, the lip's gonna look slightly different, it's like a cosmetic thing... I can't help feeling that's wrong. (Social Care Professional 23, Female).

Social Care Professional 21 had experience of someone in her personal life who had had a baby with cleft lip and cleft palate. The mother had said she had experienced some negative reactions specifically expressions of disgust, when people saw her baby, especially older people. Social Care Professional 21 felt strongly that just because she has different moral thresholds does not mean others should be denied access to the technological advances and the medical expertise that we have available. Social Care Professional 21 felt that TOPFA for cleft lip was not an acceptable outcome in isolation, however she argued that when you consider that it is acceptable to have a TOP because it is *not convenient in someone's life*, then why not for cleft lip? She added that even though she personally does not agree with it, she would *not be surprised if people do terminate* given the *level of disgust* that the mother she knew experienced for a 'simple' cleft lip that was *not unattractive or horrible to look at*. Social Care Professional 21 reported that she was more shocked at this attitude than for the idea of cleft lip as a reason for a TOP.

HLH was a condition that none of the social care professionals had heard of. Many of them did research on the internet between completion of the questionnaire and the interview taking place to gain more knowledge of the condition. HLH is a condition that many participants felt fell into the 'serious' category, with TOPFA considered an acceptable pregnancy outcome (2, 6, 18, 21, 23). However, the data showed other participants felt that it would not necessarily justify TOPFA (1, 4, 14, 22).

(re HLH) But people go for major surgery all the time, so again I wouldn't, I wouldn't, I mean in this country with the technology and the health care that we have that shouldn't be a consideration, I mean obviously it's gonna be traumatic for the parents having a baby that's going in and out of major operations for the first couple of years of their life and there's also the risk, obviously anyone who goes for a major operation there's always risks, but... you know, kids fall off their bikes and go into hospital and stuff like that, it doesn't mean you gonna stop them riding bikes, erm, so no I wouldn't consider it (Social Care Professional 4, Male).

From the social care professionals' perspective, isolated cleft lip and HLH were the conditions discussed in terms of a relatively certain outcome. Isolated cleft lip being a visible condition but with a surgical procedure. The cleft can be repaired and the affected person left with a small scar. With HLH, the outcome is different in each individual case. However, the data showed that certainty was defined by the necessity of medical intervention for survival. When discussing the outcome, the focus for social care professionals was on the impact on the imagined child. For example, pain, suffering, having

no life. An alternative perspective also suggested that the imagined child could still have a life, but does pain mean an affected person has no value, or would choose not to be alive? Social Care Professional 21 raised the question that if a TOP can be acceptable on a healthy fetus because *it's not convenient in someone's life* then *why not for cleft lip?* This may be a reflection of wider social opinions on the implications of a TOP and a TOPFA given TOPFA is still a widely taboo subject. There is also still debate on whether TOPFA is still acceptable for perceived serious conditions. HLH being of particular discussion regarding this within one medical professional interview. This is perhaps a reflection of wider societal opinions on the social value of children with illnesses. Should a 'healthy' child who at five gets cancer, not be offered treatment, even if the outcome is bleak? The data suggest that some professionals feel this should not be a given right; as this is a right denied to a fetus with a diagnosed anomaly if a TOPFA is selected as a pregnancy outcome.

The data suggest that social care professionals place high value on the social value of a person with an impairment, and on the potential social value of the imagined child, diagnosed during the antenatal period as a fetus. Despite this, TOPFA remains an acceptable pregnancy outcome in some circumstances; depending on the factors and the beliefs of the participants. These can be complex. For example, Social Care Professional 18 believes in women's rights to autonomous control over their bodies, and at the same time that the burden of such decisions should be removed from women and placed back to the doctor. This is somewhat contradictory for some as this as it would put control to the medical profession. But ultimately, for Social Care Professional 18, TOPFA was an acceptable option for any anomaly.

The data draw attention to the impaired person as similar to that of a non-impaired person that informs the understandings of the imagined child for social care professionals. A 'normal' life can be experienced for many individuals who suffer from a range of different impairments; therefore social value was about the expectation or likelihood of a normal life trajectory. The data also raise questions about assumptions placed on many anomalies that a difficult life will be experienced by the person with an impairment and their families. Some social care professionals question this arguing a 'normal' person can have a difficult life. Some also question whether a guaranteed difficult life meant that an individual with an impairment should not have a life, raising questions over acceptable of TOPFA. However, of these professionals, the data also suggest that many feel that if it was known that pain and suffering was guaranteed then TOPFA was an acceptable pregnancy outcome. This

would suggest that social value is placed on the contribution that many people with impairments provide. This can be financially, or the love and joy they bring to their families. This would also suggest value is placed on a pain free, or relatively pain free existence. The data also would appear to suggest that the opposite of this concept of social value was an existence that they; (i) would not choose for themselves or anyone else combined with; (ii) an existence of undue pain or suffering for limited rewards. For example, a lifetime of pain for a child to still die of that condition.

In summary, the social value social care professional place on an individual with an impairment was dependent on a number of factors; (i) their ability to contribute (e.g. economically, experiencing and providing pleasure); and (ii) the ability to experience life in general in a pain or suffering free/relatively pain or suffering free condition. These notions (i and ii) are also subject to personal values. These factors impact perceptions of acceptable TOPFA. For example, different social care professionals had different thresholds of acceptable pain and/or suffering. An anomaly such as isolated cleft lip, is an anomaly that is subjected to pain in the form of corrective surgery that is not long term and is unlikely to impact on the affected individuals societal contribution. It is therefore deemed to be an anomaly that was not an acceptable justification for a TOPFA by the majority of professionals. Though again this was reflective of different personal moral boundaries. For example, when compared to TOP for 'social reasons' up to 24 weeks, a TOPFA for isolated cleft lip can be deemed major by some professionals. An anomaly such as HLH was viewed by many social care professionals as a painful undesirable condition that may impact on their abilities to participate in 'normal' social activities. Thus the majority of professionals consider TOPFA to be an acceptable pregnancy option. Though again some felt that it was not reflective of the different suffering/pain boundaries that some professionals deem acceptable. Social Care Professionals 1, 4, 14, and 22 would not accept that a condition such as HLH should necessarily mean TOPFA. They drew on the availability of treatment programmes, and that many people have heart surgery so why should someone with the condition present from birth be denied surgery? The value of the imagined child was worth more than the pain the treatment programme would create meaning a TOPFA would be unacceptable. For the other social care professionals, they felt the pain associated with the treatment programme was such that it was a lot for the imagined child to go through. This meant that a TOPFA was an acceptable pregnancy option for HLH.

8.5 Medical Professionals: Sub-theme 1: Conceptualisations of person(s) with impairment(s) contribution to society

Unlike the social care professional sample, the medical professionals did not seem to explicitly conceptualise the imagined child/person(s) contribution to society in their accounts of the imagined child. However, the data show that some fetal anomalies will mean that the affected individuals will have limited societal contribution. As a result of this, a TOPFA was deemed an acceptable or even desirable pregnancy outcome. This would suggest that the conceptualisation of the imagined child was centred on the impairment itself with far less consideration relative to functional attributes.

... we're not talking about a baby that can't add to 10, we're talking about a baby that can't talk, speak and probably can't feed, can't move.. and she's 'what do you mean' so, but that's directive in some ways, the aim of it isn't to make them have a termination but it's based on the belief that the decision they're making is not an informed decision, it's, it's, their decision is based on all the nice things about having a baby, and not balanced, or our perception is that it's not balanced, erm, a balanced view of what the abnormality is (Medical Professional 7, Male).

...tend to find with good information that people's opinion, or people's interpretation of the law as well, it tends to agree with my own... In both ways some people have carried on a pregnancy that I think my goodness! Do you realise you're gonna bring a baby into the world that is definitely gonna be handicapped, that will not speak, that will not, erm, you think, 'how can you do this?'. (Medical Professional 9, Male).

These quotes suggest an element of directiveness in the counselling based on the belief that parents do not understand the full extent of a particular fetal anomaly. The data also suggest that personal values of family members are not as open minded as other data or discussion boards may suggest. Medical Professional 12 discussed attitudes that many family members had towards a child with an impairment. They reported that relatives of that patient had felt that if you had the chance to have a TOPFA then they should have done so.

... a relative had said to her.. what makes you think that you have the right to bring a disabled child into the world, which I was really shocked by, erm, cos we seem to have gone so far down the route of assuming that people won't go ahead with a pregnancy with a fetal abnormality, but that mother obviously felt that she had to justify going ahead... I've had mothers say to me.. that they felt they had to fight for their baby. (Medical Professional 12, Female).

The data also demonstrate that decision making is not necessarily primarily based on an individual basis. External influences were suggested to mainly come from medical professionals themselves, but also in terms of parents lacking an understanding of the full details of screening, and the potential for some difficult decisions.

... what would you do if this baby came out with a high risk, if your answer is 'I would do nothing' then I wouldn't go for the amniocentesis as it carries a risk of miscarriage then don't have the test. (Medical Professional 3, Female).

I do feel uncomfortable with the amount of screening that's offered, erm, across the board, because it causes a lot of anxiety, I know our false positives rate is a lot less than it used to be with the new first trimester screening, but it's, I think people are pushed into making decisions about Downs syndrome that they wouldn't necessarily entertain, erm, but I have no difficulty proceeding with termination. (Medical Professional 5, Female).

the young girl with spina bifida who hasn't delivered yet.. several of us have probably given, when I say directive counselling, I don't mean directive and we say 'you should have an abortion'... the social implications of 16 year old single girl in <place> looking after a baby that's gonna be severely handicapped your counselling is a little bit more forthright (Medical Professional 7, Male).

... doctors put pressure on patients to make decisions that they want them to make in a whole variety of different ways. (Medical Professional 10, Male).

I think very strongly think that we give people information, society decides what is appropriate erm, not individual clinicians and we try and give people as much information as we can so that they make the choice that's right for them, erm, and if society feels that that is inappropriate, thing.. erm, a termination to, to proceeded on then it's not really for me to say to somebody, no you can't. (Medical Professional 11, Female).

This aspect of influencing patient decisions also applied to medical professionals who wanted to portray a positive aspect of an anomaly. This shows personal views on particular fetal anomalies influencing counselling practices.

I don't think I would say I'm uncomfortable with that, but counselling would involve, the very.. positive view of.. of the outlook for.. erm, you know.. children, adults, who've had a cleft, so erm, so, in a way I'm trying to influence the people. (Medical Professional 8, Male).

Medical Professional 13, while having no issue with the legality of TOPFA, expressed concerns that decisions about TOPFA were being made without a fully informed perspective of what living with a disability is like.

... although I don't have any problem with people opting to terminate a pregnancy on the basis of Downs syndrome... but I do worry that people.. are making decisions because they have in their minds an image of what Downs syndrome is like, maybe an image of someone who looks clearly different, you having an image of care homes and you know needing support throughout life. (Medical Professional 13, Male).

Discussions around TOP for Downs syndrome raised some ethical dilemmas for some medical professionals. While it was felt Downs syndrome was a valid reason for TOPFA within a professional sphere by the majority of medical professionals, it was felt that parents should be aware of what a child with Downs syndrome can bring to a family. Downs syndrome itself being the reason for the TOPFA was also deemed unacceptable on a personal level for many professionals.

... you don't suffer with Downs syndrome, Downs syndrome is only a problem to the people around you, you know unkind to you, and go after you and whatever... fetal abnormality termination is actually such a small part of the number of terminations that we do, and if we're terminating healthy fetuses because it's not convenient to the family to have a child... why not for Downs syndrome really? But to me.. that isn't a reason for a termination of pregnancy. (Medical Professional 12, Female).

... the vast majority actually don't {have severe additional anomalies} and can survive pretty well and not all of them will live an independent life and some of them will have medical issues and it's a huge burden on the family perhaps, but I think also I've seen so many of them that they're just kids who contribute to their family hugely that I think it's probably wrong personally to terminate for Downs just cos it's a Downs kid but.. equally I'm very conscious and I feel quite- it's important that the power of the individual that they have to make their choice (Medical Professional 15, Male).

I would support parents that wanted to terminate a pregnancy for Downs syndrome, erm.. I sort of have a view that they should be aware of.. erm.. you know, what Downs syndrome is and erm, you know the fact that Downs kids are very loving kids and a lot of parents with Downs babies are erm.. you know very grateful for having them. (Medical Professional 17, Male).

While many professionals have raised objections regarding Down's syndrome, Medical Professional 8 raised the differences between gestational age. While expressing clearly how uncomfortable he was with late TOPFA for Down's syndrome, he also expressed no problem with the screening programme and routine TOPFA for pregnancies affected by Down's syndrome at an earlier gestational age. Medical Professional 8 also referred to acceptable TOPFA at earlier gestational ages for other fetal anomalies. This would suggest a moral value being placed on gestational age and TOPFA. This is of particular interest as Down's syndrome aside, prenatal screening does not occur until 20 weeks gestational age.

... very uncomfortable with late termination for Down's syndrome I have to say, you know, 24 weeks, beyond that point very very very uncomfortable, erm, before that, ok, partly depends on the detail of it you know, what's the heart like and all the rest of it, but erm.. generally speaking erm, yeah I think it's.. it, it's something that the later things get the more uncomfortable I get with the idea of termination.. I've no problem at all with screening and selecting out, erm... almost routinely terminating when you get a diagnosis of you know, 16 weeks, 17 weeks, I can kind of go with that, then you get beyond that point, and you're beyond 20 weeks, you're more uncomfortable with that (Medical Professional 8, Male).

Within this sub-theme, the data suggest that medical professionals did not have a concrete conceptualisation of the imagined child with impairments separate from the physical implications of the impairment. In other words, the imagined life was always already imagined as limited first, and anything else came after that. This may be due to lack of experience of the day-to-day life of living with an impairment that social care professionals have to draw on in their imagining. For some fetal anomalies, this focus on the implications of the impairment suggests a focus on the negative attributes of impairment, not on what a person can contribute socially. The presence of directive counselling was also reported both implicitly and explicitly in the data. This suggests that decisions are not made purely on an individual basis with the medical professionals influencing this process. The data also show that a particularly apparent moral dilemma exists over TOPFA for Down's syndrome. The data clearly show that most professionals feel this was a serious anomaly, but questions exist whether this automatically translates to an acceptable TOPFA. The professionals described their personal misgivings which made it an unacceptable option for themselves personally, but accepted it within their professional sphere as an option for others.

8.6 Medical professionals: Sub-theme 2: Conceptualising the imagined child when the outcome is not certain

For many medical professionals, risk of an adverse outcome was enough to justify a TOPFA as an acceptable option. This was despite acknowledgement of the positive outcomes for individuals with such conditions.

... Downs syndrome for instance is quite a debilitating condition and has a lot of implications for parents and for others and things, so you might say yes it's perfectly reasonable to expect a termination there, but on the other hand there are people with Downs syndrome who do have fruitful lives so it's a perception and you have no way of telling what type of baby it's gonna be until this child is grown (Medical Professional 3, Female).

Some professionals reported the parents' stance on TOPFA was an important consideration for anomalies where there is some grey area as to whether it meets the Clause E criteria. It is felt an affected person may fall into a Clause E scenario based on the perspective of the parents on the condition and TOPFA.

... what's messy about Downs syndrome is we don't really have a diagnosis in terms of severe handicap, we know they will all be handicapped but to the degree, we don't know... in the society we've got present, a persistent unrelenting form of handicap, which is severe often enough to be considered under Clause E, it's certainly not severe enough in all cases, and you will get it wrong in some cases, in that you'll have terminated a baby with Downs syndrome who might have done very very well... but if you've got parents who want to terminate you, that's not a good start to life... if you don't have the parents behind this baby, if you have them on the stance of wanting termination of pregnancy, I think it's much more likely that that baby's experience of life is gonna slip into a Clause E experience if you like, rather than anything else. (Medical Professional 9, Male).

The conditions that are on a continuum mean that decisions to offer a TOPFA are not clear cut.

... you'd have to be very cautious I think you've got conditions that if the baby was born then they'd live a relatively normal life as far as Downs babies are concerned, yep. (Medical Professional 7, Male).

For some medical professionals, their accounts of the imagined child suggest that they found it difficult to separate a positive life experience from a fetal anomaly. This then resulted in finding it difficult to support a TOPFA for that particular condition.

... it's very hard for me to stand there and look at someone with spina bifida who's, you know, wheelchair bound, and you know is kind of struggling with life, and say that their quality of life is poor. (Medical Professional 8, Male).

There are also a couple of professionals (10, 12) who feel if you can have a TOP because it is not convenient in your life why not for a fetal anomaly. This was even for anomalies that have generally positive outcomes, such as cleft lip.

... if you can terminate a healthy baby just because the mother wants to, I don't see why you can't terminate a baby with a minor abnormality if the mother wants to. (Medical Professional 10, Male).

This may raise questions as to why fetal anomaly may be discussed at all. A number of medical professionals (3, 9, 10, 13) discussed the legislation as nothing more than a means to satisfy our own personal consciences. That being said, their accounts suggest there was a perceived need for a discussion of fetal anomaly to provide the legal framework for a TOPFA, as well as fetal anomaly being a less problematic rationale for TOP than inconvenience. This was especially the case at later gestations, despite the legal upper limit being 24 weeks for Clause C.

Within this sub-theme, the data suggest that many medical professionals feel TOPFA was an acceptable pregnancy option if the risk of an undesirable life experience is high. This remains the case even if this means terminating fetuses that would have had a positive life experience. Some professionals stressed this was a professional opinion and would not be a personal decision. For example, many felt they would not personally have a TOPFA for Down's syndrome but felt it was an acceptable option for others. The data show that the definition of Clause E may be interpreted with reference to factors outside of the anomaly itself. For example, Medical Professional 9's discussion of parents' opinions placing a pregnancy into a potential Clause E situation by simple fact of requesting a TOPFA. This would suggest if parents do not want the baby, this would indicate a potential negative start in life. As a result, the imagined child therefore would *suffer handicap*. The data suggest an alternative agenda for the existence of the TOP legislation in general as a means to satisfy our own personal moral code as opposed to the necessity of it. The means and expertise to provide TOP exists but rules are imposed to avoid personal moral dilemmas.

8.7 Medical professionals: Sub-theme 3: Conceptualising the imagined child when the outcome is relatively certain

The data suggest the medical professionals participating in this study conceptualised a relatively certain outcome as one which that they are confident in the certainty of the prediction. For a condition such as HLH, TOPFA was felt to be an acceptable care option due to the seriousness of the condition. This being lifelong intervention that may not ultimately cure the condition and the sufferer is likely to die as a result.

... it's a diagnosis we tend to be certain about {HLH}... it's a diagnosis that people.. will understand it, I feel enough, that many people will consider it a severe handicap, and I would consider it a severe handicap, we're talking about long term, you're talking about palliation, so operations that do not.. that, that achieve a circulation but they do not fix the problem, a heart that operates on one pump, and eventually that will fail in some manor, that may be 20 or 30 years down the line, and we can all get knocked down by a bus in 20 or 30 years, it doesn't mean you don't look after your children for that long, but this is different, it's predictable, it will happen, erm, so I think it does constitute an abnormality that you can terminate at any gestation under Clause E in that it's a serious handicap (Medical Professional 9, Male).

... {HLH} it's very likely that either the baby won't survive or will need.. lots of surgery which may have a high chance of not being successful (Medical Professional 11, Female).

HLH is a very serious abnormality, many of the children will die.. and they will go through.. pretty major treatment to be treated... a very hard thing to have... it's a pretty grim thing to have. (Medical Professional 12, Female).

Medical Professional 15 discussed the importance of constant monitoring and researching of fetal anomalies. Researching the impact of living with such conditions and the medical advancements that are continually developing will impact the care given for those affected.

... we don't quite know how this cohort of kids that are surviving with HLH problems what they're gonna be like in 10, 20, 30 years time, erm but part of me thinks if they survive and even grow to get to school and be part of society and not be in and out of hospital all the time, then that's not a bad life and maybe it's worth preserving and erm.. but at the moment I still think it's legitimate to terminate. (Medical Professional 15, Male).

Medical Professional 3 expressed reluctance to support TOPFA for a minor condition that affected teeth and bone colouring. While she had the legitimacy to do the TOP under

Clause C instead, the problem she felt was the element of ‘playing god’ medical professionals have if they are selective over the conditions they will or will not offer TOPFA for.

... I can't remember exactly what it was but it seemed very minor at that time, and I remember thinking, oh my gosh the parents are asking for a termination on that basis seems a bit over the top, but I think the difficulty is if we're saying we are going to offer it, it then becomes very difficult to draw the lines when do you then say, no you can't offer it on the basis of the medical condition whereas you can for this one. It is playing god isn't it. (Medical Professional 3, Female).

For those medical professionals who are against TOPFA in a personal capacity, and in some cases also in a professional capacity, TOPFA can still be deemed an acceptable outcome. This was depending on the level of intervention, pain and suffering the child would have to go through as a result of the anomaly.

... if I was absolutely convinced there was an abnormality that was just gonna cause pain and distress and then death you know, to somebody, at an incredibly young age, whatever that abnormality might be, then, they're the kind of cases that you'd be more convinced that you were absolutely doing the right thing. (Medical Professional 8, Male).

... HLH... for babies to live long term they would have to go through serious operations, would be associated with major discomfort and you still might not have survival at the end... that is an example... where there's major worries about what you would have to put that child through for them to be a long term survivor. (Medical Professional 13, Male).

The middle ground option was something Medical Professional 19 feels is not widely explored. This is the option of having your baby, therefore not selecting a TOPFA, but opting for palliative care. This is opposed to lifelong commitment to medical intervention that can be very distressing and very painful for the child. The issue of why this is not widely explored as a legitimate care option could be due to the different moral thresholds different professionals hold. For example, many may feel it is their duty to do all they can to help the long term survival of a child. This is even if the parents feel this would be a lot of pain and suffering for the child to go through which may still result in death from that anomaly. The quote below may be suggestive of the different moral codes that exist among professionals, with three options essentially suggested. Firstly, TOPFA, which has its own moral dilemmas that some parents have difficulty dealing with. Secondly, a lifetime of medical intervention that is invasive and painful and has no guarantees of long term

success. A child may go through years of pain and suffering to die anyway. And thirdly, the option to offer palliative care allowing the child to be comfortable but ultimately die of natural causes. This is essentially removing the burden of the TOPFA decision, but also the pain of watching a loved one in pain.

... the outcome for the infants with HLH is.. is much more difficult to be hugely optimistic about... I'd have a live born baby, take it home, cuddle it, you know, wait for it to die quietly.. which is not the same thing as terminating it but also isn't the same thing as embarking on 35 years of, you know, horribly intensive, invasive medical involvement with the world... I don't think we are very good at saying, actually there is a middle ground, you could enjoy your pregnancy, be pregnant you know, enjoy the fact you're gonna have a baby, but knowing that that baby won't be with you until it's 15, and we expect that that baby will die within the first few days of life because we're not going to actively intervene... I think for some parents it's a very real option and.. one.. which gets you off both hooks. (Medical Professional 19, Female).

As with the social care professionals, isolated cleft lip featured heavily as a fetal anomaly not deemed acceptable for TOPFA for many professionals.

... they have a fantastic amount of resources service there to give these kids and the families, they have a pretty damn good life and erm so I'm quite clear in my view that isolated cleft lip should not be a good indication of termination, would I even say it should be taken out as an option? I don't know, maternal choice and whatever, but personally I would be uncomfortable seeing fetus's terminated for isolated cleft lip. (Medical Professional 15, Male).

I don't really think cleft lip is a reason to terminate pregnancy, erm, I think that surgery for cleft lip, cleft palate is erm, produces very acceptable results these days and these children are otherwise happy, erm, well functioning kids, so no I don't really agree with that (Medical Professional 17, Male).

I personally think that, cleft lip is a fairly minor erm.. anomaly or abnormality, that is treatable, and that has a good outcome (Medical Professional 20, Female).

Within this sub-theme, the data show that medical professionals conceptualised a relatively certain outcome as something that has a high level of confidence in the predicted outcome. This may be an anomaly that requires medical intervention which has no guarantees to 'fix' a problem. It may be likely that an individual affected with such a condition will die from it. The case study example of isolated cleft lip also features within this sub-theme. While

isolated cleft lip is a relatively certain outcome with respect to the requirement of surgery, it was conceptualised as an unacceptable reason to have a TOPFA due to the lack of long term impact and the lack of risk of dying as a result of that anomaly. HLH featured within this discussion due to the need for medical intervention for any chance of survival, and the negative life experiences of pain and suffering that is associated with this condition. Related to HLH however, Medical Professional 15 raised the importance of continued research. As medical procedures continue to improve, so do the life chances of individuals affected. This questioned at what point a current Clause E anomaly stops being classified as such. The data also raised questions over whether it was acceptable for medical professionals to be selective of the anomalies they deem to fall within Clause E and which do not. This adds weight to the continued argument that medical professional decisions are not objective. How much pain a child can be expected to experience to be a long term survivor was also raised within the data, suggesting a high social value being placed on a relatively pain free existence.

8.8 Comparison between social care professionals and medical professionals

This chapter presents the data relating to study theme one, the imagined child in the accounts given by the social care professional and medical professional participants. Understandings and conceptualisations of the potential an individual with a particular anomaly and expectations for their life are prominent, and influence decision about the perceived acceptability of TOPFA. Social care and medical professionals raise similar issues when discussing TOPFA and the potential of an individual with a particular anomaly but the interpretation of these issues were very different.

Social care professional participants tended to adopt a broader outlook that addressed the person with impairment and their fit with their social context. Whether a TOPFA was an acceptable pregnancy outcome was interpreted as dependent on the social value of the individual to society. This was conceptualised as the contribution an individual with an impairment can make to society and the element of pain and suffering they are likely to experience. The contribution encompassed a range of aspects that did not all need to be satisfied to make a life worthwhile. Such aspects included; contribution to family life and family experience, financial contribution, level of support, and the ability to be integrated into the community. The level of pain and suffering that an individual could be expected to knowingly experience differed depending on the moral values of the particular social care professional. Some felt any affected fetus should have the chance to survive. Others felt if

pain and suffering was inevitable then a TOPFA was acceptable. The medical professional participants focused on the anomaly itself, but also had a broader supportive view in general about the importance of maternal choices. While many spoke openly about being against TOPFA in many circumstances, no medical professional stated that the legislation needed to be amended in anyway or that TOPFA should not be an available option for those who decide it is right for them. The data also suggest that medical professionals had an impact on the decision making of parents, both implicitly and explicitly. Social care professionals had an insight into the real, tangible contribution a person with an impairment can have to society as a whole and to their own individual social context.

The socially constructed nature of society means we all have a perspective on what 'normal' life is. Many people will give a similar 'normal' life trajectory if asked. Such similar accounts may include; go to school, college/university/work, marriage, family, and travel. Much of these 'normal' aspects of life can still be achieved by a person with an impairment thus this was often used as a point of comparison by social care professionals. The data show that social care professionals openly discuss that having an impairment will make aspects of your life more difficult. Many stated that if their fetus were diagnosed with a fetal anomaly they would consider having a TOPFA. For other social care professionals, this did not mean someone should not have a life. However, having an impairment may have a limited or manageable impact on a person's life, it may also have a huge impact on the life of the affected person, as well as the family and that should also not be ignored. The idea of contribution to society was not explicitly discussed within the medical professional interviews in the same context as the social care professionals. However there are hints that some fetal anomalies will mean that the affected individuals will have limited societal contribution.

Where the outcome is not certain, a large proportion in both the professional groups felt the risk of an undesirable outcome was enough to support the availability of TOPFA. This remained the case even if they do not personally agree as they feel it should be an available option for others. For some professionals however, the positive outcome that can also be witnessed made them wary about their opinions. Downs syndrome for example, was an anomaly that was framed by professionals as not a 'normal' experience. It was also an anomaly deemed 'serious' as per the wording of Clause E by the majority of professionals. Yet, the positive outcome of many affected pregnancies was equally drawn on making decisions around an acceptable TOPFA more difficult for some professionals. The

perceived notions of pain and the likely outcome of the condition was shown in that data to be a factor when the outcome of an anomaly was not relatively certain or on a continuum. Some professionals noted that an 'undesirable' outcome does not mean that the affected person should not be able to live. This was mainly shown within the social care professional data, though some medical professionals, such as Medical Professional 8, had some sympathy with this perspective. There are also a number of professionals who felt if you opt for a TOP because it is not convenient in your life why not for a fetal anomaly. This was even the case for ones that have positive outcomes, such as isolated cleft lip.

The prognosis for many conditions are known with the likely medical or care pathway well mapped out. For some social care professionals, TOPFA was still an acceptable outcome for some conditions with a known outcome. What is 'normal' was something drawn heavily from both sets of professionals. Normal was conceptualised as being what a 'non-affected' person would be expected to experience in an 'average' life trajectory. When an anomaly can produce a 'normal' or relatively 'normal' outcome, TOPFA was deemed a less acceptable outcome. Isolated cleft lip was the case study that stood out given the success of reconstructive surgery. Social care professionals had insight into the 'non-normal' experience that can make life very difficult when a child with an impairment is factored in. This was particularly the case when other children are involved. The diagnosis of a fetal anomaly often leads to a discussion of two options. Firstly, continue the pregnancy and prepare for a life with the affected anomaly. Secondly, opt for a TOPFA. A third option of palliative care is acknowledged to be an option that is not widely explored. This would involve having the baby but not engaging with a lifelong commitment to medical intervention and allowing the baby to die 'naturally'. This was felt to be a real option that many parents would engage with. This chapter has highlighted the conceptualisation of the imagined child. With that, come the imagined experiences of the imagined child, which Chapter 9 will demonstrate.

Chapter 9: Results 4

Conceptualising the predicted experiences of the imagined child

9.1 Introduction

This chapter provides an overview of theme two of the qualitative study findings. Alongside the imagined child itself, professionals conceptualise the predicted life experience the imagined child may have as a result of living with a particular impairment. These two concepts are interlinked and combined give an insight into professionals' opinions into acceptable TOPFA. This chapter gives a descriptive overview of social care and medical professional views and understandings of the experience of an affected child, and assumptions they might have or make about this experience, or the TOPFA experience. This chapter is split into three sub-themes.

Sub-theme one centres on the imagined experiences of the person with an impairment. The idea of the alternative normal was a concept that was revealed in the social care professional data when discussing experiences of people with impairments. Throughout the interview process, the data showed a comparison between the normal life trajectories of a non-impaired person would be expected to have and that of a person with an impairment. These comparisons were used when making assessments and conceptualising thoughts about the acceptability of TOPFA. For social care professionals, this often resulted in what was described as an 'abnormal' experience for a 'normal' person becoming the normal and expected experience for a person with an impairment. For example, common examples given included having to attend regular hospital appointments, and being overlooked in social interactions. For the medical professionals, the comparison between the likely experiences of a normal and an affected person focused on the impact of the anomaly itself. For example, if the anomaly in question did not, or had very little impact on the expected 'normal' outcome, then the fetal anomaly was deemed to be questionable or unacceptable as a reason for a TOPFA.

Sub-theme two conceptualises assumptions that are made about people with impairments. Both positive and negative assumptions were reported within the social care professional data. The visible act was what social care professionals drew on as symbolic to the assumption. For example, recounting personal experiences of acts of physical disgust, such as crossing the road to avoid passing people with impairments. The assumptions medical

professionals made within this sub-theme were discussed in three categories based on what assumptions they were drawing on. Medical professionals referred to parents and society's assumptions, parents' decision making and assumptions about a fetal anomaly itself.

Sub-theme three discusses the family experience after a diagnosis of a fetal anomaly. How the family as a unit is impacted by an affected pregnancy and subsequent birth of a child with an impairment was discussed within this sub-theme. Social care professionals are in a position where they have first-hand experience or accounts of what this family experience is like. This means they are able to give an account of how they see the family experience with an affected child through their professional insight. How a particular family experience was discussed depended on how 'normal' the family life could realistically be, taking into consideration the person with an impairment. The idea of what was a 'normal life' was acknowledged as somewhat subjective. This acknowledgement was based on the participants' professional experiences within their work, their own personal experiences growing up and their own personal contact with 'normal' children. For medical professionals, the experience was discussed within the parameters of the options available after a diagnosis of fetal anomaly.

9.2 Social Care Professionals: Sub-Theme One: The alternative 'normal' experience of the imagined child

The experience of people with impairments has changed dramatically from the care provided in the past where institutionalisation was the norm. Deinstitutionalisation has been widespread since the 1950s with many such asylums permanently closing (Fakhoury and Priebe, 2007). Many impairments do not prevent the individual leading an independent life comparable to that of a 'non-impaired' person. Examples include the ability to go to school, to go to university, to work, to live independently. These are examples of life experiences that are expected that the average person will be able to do or achieve (Earle et al., 2007a). Other impairments may require the individual to have supported living or semi-independent living. In such cases individuals are positively encouraged to go *into the community* and supported accordingly. *Into the community* was a phrase used by social care professionals to describe a process whereby people with impairment are integrated into community settings doing 'normal' everyday things. However, it was acknowledged by participants that there are instances where this is not possible and thus the 'normal' experience for that individual is a typically 'abnormal' experience for a non-impaired person.

... he doesn't go out in the community, I know that sounds awful, but because of his behavioural issues we don't go out in the community as much so (Social Care Professional, 6, Female).

Social care professionals have had both positive and negative experiences when out in public with the people they support who have an impairment. The negative experiences of going into the community from the social care professionals differed from stares to open disgust;

... when I'm out shopping, I'll see people with learning disabilities, you'll see people staring at them (Social Care Professional 6, Female).

... you are very self-conscious because you are aware that people are looking at you (Social Care Professional 22, Female).

... it's the ones that actually moved away, there was a physical sign, actually I don't accept you. (Social Care Professional 6, Female).

And also assumptions about people's mental capabilities;

... the assumption is like 'oh you're thick, oh you're lazy or you're stupid' when it, it they just don't learn in the same way that other people do it's, it's basically if you don't fit into the mainstream then you're kind of looked at as other and as different. (Social Care Professional 23, Female).

Social care professionals argued that people make judgments and assumptions about others based on their impairment. This was something that was felt should continually be challenged, though there were mixed views on how to do this. Social Care Professional 2 described instances when 'normal' children were bullying the children with impairments. To help reduce the ignorance these children showed about impairment and disability, the children involved did some work experience at the school where Social Care Professional 2 worked. This was a school specifically for children with impairments. This resulted in a dramatic improvement in the attitudes these particular children displayed towards impairment and disability.

There were exceptions to the idea that those within this professional body have a high regard for people with disabilities. Some have witnessed or known of negative experiences within the care work setting;

... quite often go and pick the kids up or the young people up at their house and there's been a few incidents where, I mean there was one where, the person we were taking out was sat on the step waiting and the mum was talking to the other woman I was working with and the little toddler walked in and she slapped it round the head quite hard telling it to go away. (Social Care Professional, 4 Male).

... I have come across some really.. bloody horrible people that should not be working in social care at all.. just make kind of offhand like flippant remarks about people like 'oh he's thick as pigs shit' kind of thing, you're like he has actually got learning disability. (Social Care Professional, 23, Female).

Name calling was mentioned in some form in all the interviews. Three participants explicitly mentioned it, with two particularly derogatory names being mentioned.

When I was young and.. and our bus stand was right next to the bus stand for the people who went to the 'special school' and they used to get called 'window lickers'.. and that is so cruel, it's unbelievable. (Social Care Professional, 1, Male).

... I know how cruel people can be... like erm.. calling names and stuff like that. (Social Care Professional, 18, Female).

... they just call people names and point the finger and stuff like that you know.. spaka. (Social Care Professional, 23, Female).

What this sub-theme demonstrates is the alternative 'normal' experience that a person with an impairment was seen to experience by social care professionals. A 'normal' life experience is what a child or person without an impairment would be expected to experience within an average life trajectory. A life without stares, name calling and assumptions cast about their cognitive capabilities. This was the alternative 'normal'; an abnormal experience for a person without impairment that becomes a normal experience for those with impairment. Dependent on the specific characteristics of the impairment, some children or people are imagined to be unable to be integrated into the community. They therefore are imagined to potentially experience an existence that would be deemed abnormal to a non-impaired person. The issue of name calling, along with the other issues discussed, suggests that the social status of those with impairments is still below that of 'normal' people. The respect awarded to people with impairment is also less than that of 'normal' people.

9.3 Social care professionals: Sub-Theme Two: Conceptualising the assumptions made about people with impairments

This sub-theme discusses the assumptions, both positive and negative, that social care professionals raised in the interview data, based on their personal and professional experiences. Acts of physical disgust have been witnessed by some social care professionals when they have been in the community with the people they support.

... you go out with the people who I work with and you can see people look at them and they walk in another direction or cross the road, or grab hold of their kids' arm, their children's hands, to stop them going anywhere near, as if these people are some kind of monster, or erm freak show. (Social Care Professional 1, Male).

... we went into a cafe once, sat down, three tables around us full, full meal eating away happy as anything and then they sat down, took their plates away and sat at the other side of the restaurant... that really really upset me cos I just thought, he's no different to you or I, we're just having a meal... we have every right to have a meal. (Social Care Professional 6, Female).

I know a few people who are like confined to a wheelchair who have to deal with, like the assumption that there is something wrong with their ability to function mentally. (Social Care Professional, 23).

The idea that a person with an impairment is an individual in their own right and is a valued person comes through positively throughout all the social care professional interviews. A person with an impairment being defined by that impairment was something already hinted at in sub-theme one, through the acts of people within the community physically moving away from people with impairments. People with an impairment being overlooked in interactions in favour of speaking to the care support workers is a behaviour that was negatively received. The interpretation of the negativity differed between the particular individuals interviewed. Some understood the ignorance people have, others were disgusted by the ignorance. Judgments and assumptions made about a person based on their impairment were something that was despised by the social care professionals. It was also seemingly something that was the norm and almost expected.

I worked with one lady who had a very mild learning disability... had a terrible time with people, you know from name calling from.. not being.. being pushed out the way in queues because people think because she looks a bit different.. she would come back and she would absolutely cry her eyes

out and say 'why do people do this?'... it's hard for people like me... and say 'it's not because of you, it's other people', but they don't see that, they gonna look in the mirror and think it's because of the way they look. (Social Care Professional 1, Male).

The data show that people with a physical impairment often have assumptions cast about their cognitive abilities. In addition, those with cognitive impairments have their own set of assumptions to deal with. Downs syndrome was often used as an example of how people make assumptions about the condition. For example, Social Care Professional 4 discusses common assumptions of Downs syndrome such as; *they're cuddly, they're loving, they're like a child*. Downs syndrome exists on a continuum. The data show that many social care professionals felt that to treat all people affected by Downs syndrome with such assumptions was insulting, derogatory and small minded.

... there was a woman there who was on holiday with her daughter who had Downs and there was a couple sat and they were talking about her like she wasn't there going 'oh yeah, she's lovely, she loves to give you a cuddle' and stuff like that and she just sat there and the way she was talking about her, it was like she was a 3 year old little girl, and she was quite clearly a young woman... and then the one she was talking to said 'oh are you going to give me a cuddle before I go?' You know, like was a little kid and she just looked and then went 'no' and I just thought, you know, you know damn right no... and I'm like why are you treating them like that, talking down to them, talking about them like she's not there, treating her like a kid. (Social Care Professional 4, Male).

Undermining the physical and mental capabilities of people with Downs syndrome was an issue that Social Care Professional 4 felt particularly strong about. Within his interview he also cast doubts over other assumptions, such as *like a child in an adults body*.

... you still get people saying they're like a kid in an adults body and it's like how can a kids mind be in an adults body... cos even if they've got, even if their brains not erm, their understanding is less than the adult... how old their body is doesn't correlate to how old their brain is, there's still an adults body so it's not like it's a kid, it just, it just doesn't make sense, it's just stupid thing, it's just ignorance. (Social Care Professional 4, Male).

Social care professionals often accompany the people they support when they are out in the community. The significance of the presence of a 'normal' person when out in public was something that was problematic for many within this profession. While acknowledging the

levels of support needed for different individuals, those that do need less support are argued to have more value in society when in the presence of a 'normal' person.

... because she hasn't got a carer she is all of a sudden worth nothing. (Social Care Professional 1, Male).

Another social care professional (21) also raised this in her interview. *They are treated differently* depending on whether *they are with a carer* or not. Without a carer *they* are nobody and have no value in society. One experience that a number of the social care professionals interviewed have witnessed involved instances whereby the person they are supporting was overlooked. The participants, as the support workers, are spoken to on behalf of the person with an impairment.

...it's them who are waiting for a cup of tea don't ask me if they want milk (Social Care Professional, 4, Male).

It has been noted of particular commonality among medical professionals;

I've took some of the people I look after to, to a doctors appointment and they'll say to me, so erm does Joe Bloggs erm.. does he have incontinence or something and I'll say why don't you ask him? He's sat right next to me. He's quite capable of answering his own questions. (Social Care Professional 1, Male).

... GP's and dentists and people like that, they want to talk to me as a carer rather than them.. excuse me, I'm here with such and such, this isn't my appointment, talk to them please.. talk to them as an individual just cos he's got a disability doesn't mean they're not in the room. (Social Care Professional 6, Female).

The data within this sub-theme draws on the experiences that social care professionals have actually witnessed happen, and that therefore they can imagine happening to another impaired person in the future. The experiences of people with an impairment are such that they are conceptualised as having had, and continue to have, negative judgments made about them on a regular basis. The data suggest this negative view was shown in a multitude of ways. Examples include physical disgust, assumptions on their mental capacity, the value placed on people when they are in or out of the presence of a carer and their experiences of being overlooked in public places and medical appointments. The social care professional outlook goes beyond the impairment itself and provides an insight

into the some of the negative aspects of the social context of people with impairments and their experiences within it.

9.4 Social care professionals: Sub-Theme Three: Family experience with the imagined child

This sub-theme focuses on how the family as a unit was impacted by an affected pregnancy and subsequent birth of a child with an impairment. The perspective of social care professionals was based on their personal and professional experiences. Choosing to continue a pregnancy after a diagnosis of a fetal anomaly was an option some parents accept. Social care professionals are in a position where they have first-hand experience or accounts of what this family experience is like. This means they were able to give accounts of how they see the family experience with an affected child through their professional insight. How a particular family experience was discussed depends on how ‘normal’ the family life can realistically be, taking into consideration the person with an impairment. If an anomaly resulted in constant unbearable pain or *no life* then a TOPFA was thought to be acceptable. This is because it was felt this kind of family life is not fair or desirable. The idea of what is a ‘normal life’ was somewhat subjective. This is based on the professional experience within their work, their own personal experience growing up and their own personal contact with ‘normal’ children. This was either their own, other family members or friends’ children. One important difference was lack of pain. Even though a ‘normal’ child may experience something that inflicts pain, many fetal anomalies will guarantee pain. It is inevitable and unavoidable, whereas a ‘normal’ child may be in an accident, but they may not be. There is also the issue of *having no life*. A person who cannot *do* anything for themselves, cannot communicate and simply *exists*. In these instances, a TOPFA was considered an acceptable option among many professionals.

If they were told that their child was going to be so erm.. you know, have such a bad disability that it was gonna have no kind of life whatsoever, then I think that's the right thing to do... that's just causing a situation that's not fair on anyone... that's a drain on everybody's life, you know what I mean, including the child (Social Care Professional 1, Male).

The simplicity of participation in everyday activities that people without impairment take for granted, was conceptualised as being thrown up in the air when an affected child was included in the mix. This was demonstrated by Social Care Professional 2's summary. She

also draws on the improved outlook other family members have in terms of what they learn from such life considerations.

... a child with disabilities needs more attention, whether it's a physical disability you can't just hop to the supermarket, and all nip down, you have to plan things around, is it gonna be a long walk, are we gonna be able to park the car closer, just simple things too, have we got pee bags, have we got pads, are they gonna need that and.. holidays and all the rest of it are altered and changed ever so slightly... the case with Downs syndrome, the young lady I support, her sister has struggled and that's why they tried to put her into supported living because, well she's been pushed down the steps and mother would keep having to step in and to the point where she hated her sister for a short time, I mean yeah she loved her when she wasn't being thrown down the stairs and stuff (Social Care Professional 2, Female).

This quote highlights some aspects of everyday life that are taken for granted. Such examples include going shopping, and how it can become a very difficult process depending on the impairment in question. The life and social experiences that a person with an impairment can vary hugely depending on the support available. Social Care Professional 2 talked in detail about parents who cannot cope through no fault of their own, needing extra support and may simply not know where to get it. She also discussed the experience children may have through un-supporting or un-caring parents. While this may happen to any child, when a child has an impairment to cope with it, she saw this as additional and unnecessary stress.

... every time you get parents like that they're a bit upset anyway so whether it's just shouting in anger or they really mean it, I don't know, you're getting the impression that some parents would quite happily never really.. a snow day is a perfect example, you have a snow day and.. you know the parents that want to be there they come rushing over picking them up, you've got other ones that will still be there at 9 o'clock at night waiting for people to pick the kids up, I can't imagine leaving my child in the school till 9 o'clock especially in some of the conditions I'd be thinking god they need to be home... I don't think those parents are really interested in having their kids and would've definitely have changed their minds, at least the majority would. (Social Care Professional 2, Female).

Social Care Professional 4 has also heard rumours of bad experiences some people with impairment have had. There are services available that are there to allow people with impairments to develop in a way based on their needs and abilities.

I hear about the darker side of it, you know like how open they are to being abused, and I mean I've worked with some people with the Autistic Society where you meet them and you think, they should be in care where they would get structured days, and.. their progress would be tracked and.. they would be able to talk better and, communicate better and use makaton better, whereas at the moment they're living with their parents and they're just stuck in front of the tv and you just think, the only reason you're with the parents is so the parents are getting the benefit, you know, its money from it.. but then.. if they're all in care then it's more open to staff abuse, and things like that as well (Social Care Professional 4, Male).

The importance of thinking about the child and the impact on the parents' life was an important consideration for some social care professionals. Carrying on with a pregnancy affected by a fetal anomaly because you feel too guilty to have a TOPFA, was deemed a selfish act by some professionals. Even a minor impairment may result in an inability for parents to cope with that situation. Some social care professionals (2, 6, 18, 21) felt a TOPFA is more desirable for any anomaly, however minor, if the other option is being brought up in a home that does not want the child, or cannot deal with the child. Considering an aspect of 'normal life' is that it is normal for parents to want their children, it is also, perhaps somewhat naïvely, normal to assume parents can cope with this. For whatever reason, is not always the case with affected or unaffected children.

... you see them come in and they're dressed pretty, they smell nice, they look, they're looked after, they're loved... you can tell the difference between parents who can afford it and really really love doing it, and you can see the ones that were shocked, and don't really know... some of them just stick them in stick them out and 'oh I've got them again, let's stick them in <name of school>' but it's because they weren't really given enough information on how to deal with them, they're not gonna be nasty people, obviously there is nasty people who don't care less and would neglect any child, but they really do seem to struggle and that makes me think, if all these people, some of these lovely people, can't cope even with a child... how the hell would I cope? (Social Care Professional 2, Female).

... if the child was to suffer from physical or mental disabilities, you've gotta think about the child, you can't be thinking about yourself (Social Care Professional 6, Female).

Social Care Professional 2 was very open about supporting TOPFA even for relatively minor conditions. The inability for some parents to cope, and the guilt that many experience, she felt it was not fair on anyone, especially when there are other children

involved. Parents having the right to exercise choice was also supported, again even for relatively minor anomalies by Social Care Professionals 2, 6, 18 and 21.

... she wouldn't even have support to begin with, cos she had the test and knew that she was and thought well I've made that decision now I'm gonna have to lay on this bed, and she was struggling, it's made her very very depressed and she was struggling, most of the time she is on medication for depression because she feels guilty coz she can't cope, and she made the choice to keep the child <Downs syndrome>, so there's both sides and it swings in roundabouts.. she's a very strong lady and she's got another young girl, who again, quotation marks, is normal, and, she's 18 and she will try and push her sister down the stairs, and pull radiators off the wall, it's not something you expect in that scenario, everything else she's been lucky, she's got no heart conditions or nothing, but she is very challenging and attention seeking, like having a 6 year old in a 19 year olds body that's throwing tantrums and causing chaos, and even I can't help positively handling her to calm down, you can't she's too big, hard work. (Social Care Professional 2, Female).

Despite support some social care professionals had for TOPFA for some anomalies, including minor anomalies, concerns were raised about placing a value on life and making value judgments on what is an acceptable life. For example, Social Care Professional 14 discussed this, even if death is inevitable.

I think you need to ask what value people with those conditions put on their lives and, and I'm not sure you'd get many people saying.. it's that bad that they wish their parents hadn't continued with the pregnancy erm.. I mean my experience with cystic fibrosis... my sister had a friend with cystic fibrosis who died when she was about 25, erm.. but.. that young woman was very, she was a very active person and erm.. I think she was doing, she did her degree and she was erm, she got involved very much as an expert patient with the NHS so advising on, you know, things like physio and that kind of thing.. erm.. and so you know I think.. again it's a bit of an ethically dubious area but it's kind of.. almost putting a value on a the life a person has and I think 20, 30 years of.. a fulfilling life even if somebody does need a lot of medical treatment is still worthwhile... certainly I think it's a condition that people can live with, erm.. to a certain degree. (Social Care Professional 14, Female).

What constitutes a fulfilling family life was raised in a number of interviews. This was often intertwined with what was seen as 'normal'. Social Care Professional 1 summarised a

fulfilling life as having something to offer and doing ‘normal’ things¹. Social Care Professional 4 also draws on something that can be fixed, thus ‘normalised’, and therefore a normal fulfilling life can happen. Many parents face a tough decision if a diagnosis of a fetal anomaly is made. Decision making about TOPFA was framed as something that should not be an available option for some conditions by some social care professionals.

<Re HLH> Yeah I think we should make it not even a question really, to be honest, I think obviously the parents would need to know if it was identified during the pregnancy so they can prepare themselves, erm, you know, work related, thinks like that, things like I wouldn't think it would be a consideration for termination really (Social Care Professional 4, Male).

With regards to cleft lip, I don't agree with termination, I don't agree with it at all because cleft lip isn't a life threatening thing. (Social Care Professional 6, Female).

... it's very difficult to find where the line is and I think probably... my own line would be erm... would be somebody who's in pain that can't be alleviated (Social Care Professional 14, Female).

While the decision may not be something a social care professional agreed with or would support on a personal level, some felt that it was not their decision to make and therefore not for them to pass judgment.

... but I wouldn't judge anyone for doing it or anyone for not doing it, do you know what I mean, it's their choice, it's their child, it's their life as long as you stick by it, stick by your decision, but so you can see people who have it, and then to think, I can't cope with this, we'll just shove them in a home, do you know what I mean, when they don't need to be there (Social Care Professional 6, Female).

... my cousin has very severe cerebral palsy and.. erm my aunt had.. well very bad postnatal depression afterwards and erm.. it, occasionally now she will say, if they'd known she might not have continued with the pregnancy (Social Care Professional 14, Female).

The idea that women should be able to exercise choice regarding matters of their own body was a strongly held view for one Social Care Professional (18) in particular. Others felt that TOP should not be denied, but the fetal anomaly or potential impairment and subsequent impairment should not be the justification for the termination. Thus, they would be having TOP for Clause C, not TOPFA under Clause E.

¹ Examples of this include getting a job, having relationships and becoming independent of your parents (Earle et al., 2007a).

I think it shouldn't matter, you know it shouldn't matter what, what's wrong, if there's anything wrong with the child or not, it shouldn't make any difference, it should be the same standard... Downs syndrome... I don't see the difference, if you're gonna have a termination, have it because you can't cope with that, not because this person has an anomaly that you can't cope with. (Social Care Professional 22, Female).

Within this sub-theme, the data show a broader outlook of the life of the person with an impairment. The participants give an insight into the social context that they have witnessed through the people they support. There is a constant comparison to the 'normal' expectation of life and acceptable TOPFA is judged based on these subjective valuations of normality. The 'abnormal' life experience that a person without an impairment would not be expected to experience becomes the normal experience for a person with an impairment. This contributes to societal barriers that create disability. For some social care professionals, while they had had positive experiences with people with impairments and the positive life that can be experienced, they had also seen some negative experiences. While it may be deemed selfish, in the opinion of some social care professionals, to undergo a TOPFA, for others, carrying on a pregnancy because they do not want to be a person who has a TOPFA was also felt to be selfish. The general consensus within this professional group was to support what was in the best interests of the potential child, though opinions on how to achieve those best interests differed. The data show that for those who feel a TOPFA, even for minor anomalies, is an acceptable pregnancy option, in part because the alternative may be to grow up with a family who may have wanted to have you terminated, will struggle to cope and thus are unable to provide the 'best' possible life experience. The importance of considering the needs of the parents, especially when other children are involved, is something the data show is important for some social care professionals. For others, the social context based on the positive experience people with impairments have had and can have was important in TOPFA discussions. In those discussions, TOPFA was therefore not an acceptable option and it was seen as not fair to place a value on what is an acceptable life. But even in that context, there were examples given of where TOPFA was considered acceptable. No single social care professional objected to TOPFA in all circumstances. However, this acceptability tended to be based on subjective notions of pain and positive life experiences.

9.5 Medical Professionals: Sub-Theme One: Experiences of the affected fetus

The data show that the idea of what is a 'normal' life is likened to what a person without an impairment can be expected to experience. If the anomaly in question does not, or has very little impact on the expected 'normal' outcome, then the fetal anomaly is deemed to be questionable or unacceptable as a reason for a TOPFA.

<re cleft lip> there's an isolated problem given the fabulous things that can be done, erm for these things, erm, and the normal quality of life they can have (Medical Professional 8, Male).

You haven't chosen limb reduction... people can picture what it means... and they often terminate, where we're trying to say, you've got a completely normal baby it's just missing a foot or a hand... yet in a way cos people can visualise that child at school they can visualise that child growing up they will terminate the pregnancy and you feel uncomfortable with that (Medical Professional 9, Male).

Ideas reflecting arguments found within the social model of disability were also expressed within the medical profession through the idea that with certain anomalies, Downs syndrome in particular, the problem rests with other people, not the impairment.

You don't suffer with Downs syndrome, Downs syndrome is only a problem to the people around you (Medical Professional 12, Female).

This view of Downs syndrome was common among medical professionals when there were no associated anomalies. But there was no indication that all people with Downs syndrome, or their families and carers would necessarily agree with this generalisation. The NHS enables the affected fetus to have a chance at life without the cost burden² being placed on the parents. This is a consideration for some medical professionals. However it is worth noting that caution has been raised within media discussions about over emphasising the positive aspects of Downs syndrome and neglecting the negative experiences. These experiences may make life very difficult for some families who cannot cope. The value being placed on life and the fact that a 'normal' child may have an illness or accident which impacts on their health in the same way as a fetal anomaly would have done, has led to

² The NHS will provide cover for many of the direct costs associated with providing care, but does not provide compensation for the costs of living in a world ill-suited to the impaired individual. E.g. the opportunity costs missed (through attending appointments and having to make special arrangements to do things such as travel), or the inability to get a well-paid job with some conditions. So the 'cost burden' can be interpreted in different ways. It seems that the medical professionals are interpreting in the narrow sense of 'what does it cost me to get X' rather than, 'what would my life have been like if society was more enabling for people with my characteristics'.

some professionals feeling that certain fetal anomalies should not have a TOPFA available as a care option.

... at some point... society's gonna have to say we're not gonna give certain choices about some things because we as a society value these people and they can look after them and give them a fulfilled life and they can contribute to our society (Medical Professional 15, Male).

The data suggest that some medical professionals believe that as 'normal' an experience as possible should be experienced by those children affected by fetal anomaly, and was encouraged.

... places wrap children who have any kind of abnormality in cotton wool, and actually part of our job is to go out to the school and say well this kid is on dialysis but actually they should still be doing their homework and doing games and doing this and doing that and erm, and they shouldn't be ringing in sick all the time. (Medical Professional 20, Female).

There are many fetal anomalies of which the expected life trajectory would not be what the average 'normal' child would experience. For example, medium and long term medical interventions. In these instances, TOPFA was deemed acceptable. This was the case even if there was the potential for a positive outcome. This was because medical intervention is inevitable and a child may have to go through a significant level of treatment to get to that 'positive outcome' point. The end point may also be early death. The data show TOPFA was also deemed acceptable in these instances despite a 'normal' child having the potential to die as a young adult through an accident or illness. With an affected fetus it is definite, it will happen and a significant level of medical intervention may also be a requirement.

Anomalies with short term medical interventions (such as isolated cleft lip) were, in general, not deemed an acceptable justification for TOPFA due to the balance of minimal intervention and positive outcome tilting hugely in favour of the latter.

... they realise that the child would need help with the bowel or walking, you know may need a shunt and those things, then that is unacceptable. (Medical Professional 5, Female).

We don't quite know how this cohort of kids that are surviving with HLH problems what they're gonna be like in 10, 20, 30 years time, but part of me thinks if they survive and even grow to get to school and be part of society and not be in and out of hospital all the time, then that's not a bad life and maybe it's worth preserving... but at the moment I still think it's legitimate to terminate. (Medical Professional 15, Male).

I've looked after kids who, been on dialysis 5, 6, 7 months in hospital then die, so actually, that kids been back and forth to the theatre, they've had operation after operation... you name it, they've been through it, and therefore for those, although I can see that there can be a good outcome... that isn't how it always comes, turns out, and there's a lot to get through to get to that point (Medical Professional 20, Female).

Many medical professionals felt the problem with Downs syndrome was other people's views, not the condition itself. However many acknowledged that the life of someone with Downs syndrome will not be the same experience as that of a child without any anomalies. But many also countered this by expressing that this does not make it an undeserving life.

Downs syndrome kids are different and they come with a range of medical problems... but the vast majority actually don't and can survive pretty well, and not all of them will live an independent life and some of them will have medical issues and it's a huge burden on the family perhaps, but I think also I have seen so many of them that they're just kids who contribute to their family hugely (Medical Professional 15, Male).

This was an opinion that a number of medical professionals affiliated to, and can be said to go against the current rhetoric of individual responsibility. Individual responsibility is a culturally dominant value within current society. A child with an impairment was only conceptualised as a contributing family member if the family were able to facilitate that role. If independent living was not possible, then the family was the deciding factor on how the individual was imagined to live their life.

Within this sub-theme, we can see the focus on whether the experience will be, or as close to, 'normal', or that of an 'abnormal' experience. We can also see with the Downs syndrome case study that an 'abnormal' experience may also be a valued experience. However, how value was judged tended to be what was conceptualised to be a normal experience. For example, having a good life, being happy, being loved by your family. The data show that the focus in these accounts was firmly on the individual with the anomaly and how they will experience the process of fitting into normal society. Can they be 'normalised', can they have some 'normal' experiences, or will their experience be that of 'abnormal'? This 'normal' experience was also not necessarily dependent on the characteristics of the anomaly, but rather the characteristics of the family they have been born into.

9.6 Medical professionals: Sub-Theme Two: Conceptualising the assumptions made about people with impairment

This sub-theme focuses on the assumptions that medical professionals demonstrated in their accounts, and based on their personal and professional experiences. These assumptions have been sub-divided into three categories; (i) how medical professionals discuss parents and society's assumptions, (ii) parents' decision making, and (iii) assumptions about the fetal anomalies. It is important to consider that assumptions and values medical professionals hold regarding fetal anomaly and impairment, may have an influence on the counselling that is given to prospective parents after the diagnosis of a fetal anomaly. There is emphasis placed on non-directive counselling within medical guidance. There was a common theme within the data that showed medical professionals have a tendency to see disagreement between parents and professionals, or recognise societal disagreement with TOPFA decisions or availability, as stemming from ignorance on the part of parents and society.

Society as a whole was conceptualised by the medical professionals in this study as having an opinion on many of the decisions that are made after a diagnosis of a fetal anomaly. Parents were also conceptualised as having opinions about the decision making process. These opinions were contextualised in the medical professionals' accounts, in a number of different ways. Some were framed as incorrect or misinformed.

... HLH... I'm very surprised that they take, parents, do continue... you know, they, that erm... they feel that they, the child looks normal, therefore will be normal, but it's such a very very difficult course for them to follow (Medical Professional 5, Female).

... there may be a public perception that people ask for termination of pregnancy when there's a diagnosis of cleft lip, but that's... the exception rather than the rule. (Medical Professional 9, Male).

We can see from Medical Professional 5's surprise at the notion of continuing the pregnancy after a diagnosis of HLH, despite the very good explanations. Medical Professional 9 drew on what he deemed a typical public perception that did not seem to be based on any sound fact. The data show some rationales for a TOPFA are considered to be more socially acceptable than others. Some medical professionals raised concerns about parents justifying their decisions to have a TOPFA on what they (as professionals) perceived to be dubious grounds.

I would now say that although I don't have any problem with people opting to terminate a pregnancy on the basis of Downs syndrome... but I do worry that people.. are making decisions because they have in their minds an image of what Downs syndrome is like, maybe an image of someone who looks clearly different, you having an image of care homes and you know needing support throughout life... I wonder whether people.. use that to try and justify a decision that I think is largely a social decision. (Medical Professional 13, Male).

The data show that some of the medical professional participants felt that the decision making process is solely a parental decision and has nothing to do with wider 'society' or others. What a parent decides to do has nothing to do with anyone else as they are the ones directly involved by the decision. This was of particular relevance to medical professionals who drew on the case of Joanna Jepson who attempted to get two doctors prosecuted for authorising a TOPFA for a cleft lip (see Chapter 3).

Is a cleft lip a serious anomaly? The majority of society would say no, but to that person who has a section of their face missing may say it is a major anomaly (Medical Professional 7, Male).

(re Joanna Jepson) I found that upsetting because it was nothing to do with her in the first place, it wasn't her baby... we obviously have to be careful about imposing our own values on other people, and just because she happened to have a cleft lip doesn't mean that.. the risk wasn't serious enough (Medical Professional 10, Male).

The issue of hypocrisy was raised, although not specific to TOPFA. In this instance, decisions not to treat were seen as more contentious than decisions to treat.

I do struggle with why people sometimes have such an issue with us resuscitating very premature babies when they wouldn't have an issue with a kid they'd brought in with cancer... I can't see anybody even with a 1 in 5 chance, oh you know what don't give them all that chemotherapy. (Medical Professional 13, Male).

Biases among colleagues were also explicitly raised as a concern by one professional. Medical Professional 16 was uncomfortable with the assumptions that professionals make about parents and about what is considered to be a valuable life. She questioned why it is assumed that TOPFA needs to be discussed as a care option. Some medical professionals made the assumption that parents will choose to have a TOPFA for certain fetal anomalies. When considering instances that this did not occur, this deviation from the expected normal was often framed as a lack of understanding on the part of the parents in terms of

the implications of the fetal anomaly. For example, some instances may be those with lower amounts of social capital, such as being young and poor, or may have fewer resources to use to justify their decision to continue a pregnancy. They may have a positive view of life with an impairment, but that positive view was generally interpreted as somewhat irrational and incomprehensible to some professionals.

I don't try and dissuade people from their decision, I think, the young girl with spina bifida who hasn't delivered yet.. several of us have probably given, when I say directive counselling, I don't mean directive counselling, I don't mean directive and we say 'you should have an abortion', but when you've got a 16 year old saying 'oh yeah but it's my baby and it will be lovely and I'll look after it' and you know the social implications of 16 year old single girl... looking after a baby that can't add to 10, we're talking about having a baby that can't talk, speak and probably can't feed, can't move... the aim of it isn't to make them have a termination but it's based on the belief that the decision they're making is not an informed decision. (Medical Professional 7, Male).

... tend to find with good information that people's opinion, or people's interpretation of the law as well, it tends to agree with my own... in both ways some people have carried on a pregnancy that I think my goodness! Do you realise you're gonna bring a baby into the world that is definitely gonna be handicapped, that will not speak that will not, erm, you think, 'how can you do this?'... I think the problem is that you feel it's your duty to constantly bang on about it and tell them about it, because you think, surely you haven't understood. (Medical Professional 9, Male).

(Re lethal anomaly) there's just an assumption that people will have a termination of pregnancy on the background, that I understand it, that it's easier.. erm.. I think it gets the problem out of the way for the health professionals if we're honest... I've had people say they've felt pushed into it, (Medical Professional 12, Female).

Parent assumptions about not wanting to be a person who has a TOPFA were dismissed by Medical Professional 9 as due to the perceived lack of understanding parents have of other important issues.

(re lethal anomaly) it just takes a long time to get to the point where you're comfortable with that they've really understood it, cos you can't imagine why they would want to carry on... because the crux of the matter is, the thing that people often don't think about is it's, it can be more risky for the mum to carry on with the pregnancy than to terminate... suddenly it becomes more complex for people than just about the baby... oh I would never be someone who would terminate.. is the black and white view that a lot of people have. (Medical Professional 9, Male).

Concerns are raised by some medical professionals about ultrasound screening and the issue that many parents do not fully understand the purpose of the 20 week fetal anomaly scan, and thus have not given informed consent for this to be performed. This could be indicative of a number of factors. For example, there may also be an institutional paternalistic view of the fetal anomaly scanning. Medical Professional 10, however, felt that it was better that parents do not fully understand as it causes unnecessary worry, when so few pregnancies are affected.

... what worries me though actually about the testing is that I don't think it's done with proper informed consent. (Medical Professional 12, Female).

Regarding the case study Downs syndrome, some medical professionals expressed concern that parents do not understand Downs syndrome and how rewarding a child with the condition can be. But the screening programme that was offered also led some professionals to feel that TOPFA must be an option for parents as Downs syndrome was a particular focus for screening.

I think a lot of parents don't necessarily have a good appreciation of the vast spectrum of Downs syndrome and we can't normally tell how badly a child is gonna be affected... we offer screening and therefore they know that has to be with a view to doing something if you, or is offering the option of doing something if you have a positive screen so, if we decide as a professional body and as a society that we're gonna screen for this, then.. we have to follow that through. (Medical Professional 11, Female).

There was an acknowledgement among some within this professional group that while they may not agree with a particular decision that does not mean there was not a legitimate reason for it. This was indicative of experience of holding competing views as an individual on a personal and professional level. The interview data show that some of the medical professionals interviewed openly admitted they held their own biases about certain fetal anomalies and they did not agree with TOPFA for these anomalies. However, some felt that this should not take away from the fact that parents may feel differently about the same condition and feel TOPFA was an appropriate outcome.

Why should we impose our own social biases (Medical Professional 10, Male).

I think it's probably wrong personally to terminate for Downs just cos it's a Downs kid but equally I'm very conscious and I feel it's important that the power of the individual that they have to make their choice. (Medical Professional 15, Male).

This sub-theme indicates a focus on the details of assumptions made about societal and parents' beliefs and about fetal anomalies themselves. Many of these beliefs are felt to be incorrect or misinformed if the opinions do not tally with that of the medical professionals. This was based on the assumption that parents or society do not fully understand the implications of the anomaly in question. The data suggest that directive³ counselling is employed in such circumstances to ensure that the patient has a full understanding of the diagnosis and prognosis. The data also shows assumptions are made about different anomalies. This was shown through the fact that a different rationale was deemed acceptable depending on the anomaly being discussed. This was alongside the assumption that with some anomalies a TOPFA will be selected. If it was not, some medical professionals would employ directive counselling. Downs syndrome again raises moral dilemmas within this sub-theme. The data suggest that many medical professionals did not accept it as a reason for a TOPFA on a personal level, but appreciate why it is available on a professional level. Other anomalies are felt to raise conflicting professional and personal views but this does not mean that parents should not have the option of a TOPFA should they decide to make this choice.

9.7 Medical professionals: Sub-Theme Three: Family experience of an affected child and after a fetal anomaly diagnosis

This sub-theme discusses how the family as a unit is impacted upon by an affected pregnancy from the perspective of medical professionals. This was based on their personal and professional experiences.

Available options after a detection of a fetal anomaly are; having a TOPFA, or carrying on with the pregnancy and preparing for a life with an affected child. However, another option is available that was said by participants to be not often discussed as a 'real' option. This was carrying the pregnancy to term, but not intervening. Thus the parents are not entering into a life of medical intervention. As previously discussed in Chapter 8, Medical Professional 16 also discussed continuing a pregnancy after diagnosis of lethal anomalies

³ Regarding directive counselling, it is important to acknowledge that medical professionals are not encouraging people to TOP in an explicit manner. It would seem the concept of directive counselling assumes there is a dichotomy (yes/no), but actually it would appear to be more like a spectrum.

and how parents should not be made to feel this is not a legitimate care option. She felt this was a better way of coming to terms with the loss of a wanted baby. This perspective was shared by Medical Professional 12 who expressed a view that a TOPFA of a lethal anomaly was not necessarily the best option for parents. Medical professionals also have the option not to intervene after the live birth if this is what is deemed the best outcome for a child. A lifetime of invasive medical treatment, which may still not result in a *positive outcome*, was deemed to not be in the best interests of the child. This was conceptualised by Medical Professional 19 as a life of pain and hospital settings.

... can I not intervene for something where the treatment is still.. you know massively invasive and complex, yes we can...that's us acting what we believe is the best interests of the baby, which is not necessarily to commit them to a massively invasive series of things that might not work (Medical Professional 19, Female).

The data show many medical professionals discussed positive experiences in such cases of palliative care. Parents have been able to parent their child despite it being for a very short amount of time. Many of these experiences are discussed in relation to lethal anomalies, and enables a 'normal' family experience for the parents of being able to care for their baby in a 'normal' capacity. For example, cuddling their baby. This is reflecting a change in practice from a system where babies were taken away and hidden from grieving parents (Earle et al., 2007b).

I delivered a baby once with anencephaly, the diagnosis was antenatally and they decided not to terminate, she delivered and for the parents it was their first baby and was their beautiful baby and the baby breathed for about 3 or 4 hours and their experiences of parenthood was amazing for 3 or 4 hours. It's not just the babies that suffer, you have got to consider the parents' emotional needs as well. (Medical Professional 8, Male).

... a paediatrician did a study about getting babies home... the thing that's really striking about it is that if the parents cared for their child.. even if it was just changing them in hospital and things like that, but particularly if they got them home, when they were interviewed at a later stage, their perception of their child's life was better, so people who'd got their child home.. perceived that they had a happy life even if it was a short life... a life that's a day is as valid as any other life, and particularly of course for the people that love them. (Medical Professional 12, Female).

We have maybe one a year where we know the baby is not going to survive independently when its born and the parents have chosen palliative care and I have to say that my experience of every

single one of those is entirely positive always... It's about what is parenting and you know, how long do you have to parent before you're a parent? (Medical Professional 19, Female).

Medical Professional 16 also discussed alternative options to TOPFA after a recent experience with a parent with a diagnosis of a lethal anomaly. The baby survived the birth and the mother expressed a desire to be with her baby. Medical Professional 16 retold how the mother was *happy* because the *decision* she was being asked to make about TOPFA was *removed* from her and she had got to meet and care for her baby for a short time. Medical Professional 16 felt the *natural progression of life* enabled the mother to *better come to terms* with what had happened. The natural progression being that the baby died of the anomaly as opposed to being terminated.

Concern and references about different families' abilities to bring up an affected child fell into three categories; (i) the family set up being 'right'; (ii) any other children involved; and (iii) decisions affecting a family lifestyle that may not be an approved decision by a large proportion of people. This last category conceptualised choice for the woman independent of how others feel about it, as it was not other people who are going to have their life impacted by the fetal anomaly. The 'right' family set up was a subjective opinion. This however, did not discount its value in the decision making process given the negotiation between parents and the medical profession when it comes to TOPFA decisions. Many of the medical professionals felt that if a family simply contemplates TOPFA then the family set up, whatever that might be or mean, was not 'right' for those particular parent(s).

... for some families it isn't right to bring a Downs children, a Downs child into their family because it does impact on the rest of the family. (Medical Professional 5, Female).

We've got a... on-going pregnancy at the moment, a 16 year old whose got a spina bifida, she's now 35 weeks... this baby will be severely handicapped... if she turned round... and she's suddenly realised what it's all about, I would terminate. (Medical Professional 7, Male).

<HLH> it is one of those conditions that depends so much on the families set up... their support... you can give them the same information, one family can, can imagine... a child with that condition in their family and they can imagine how they'd cope... and another family can't, or they just see problems with it. (Medical Professional 9, Male).

A different consideration for the family experience has to be taken into account if other children are involved. How the other children will be affected by on-going medical

interventions, parent(s) being away from home while the affected child is in hospital, and lifestyle changes, such as going on holiday and employment implications are considered.

There is a difference between people who've already got a family and people who haven't got a family cos they tend to think more about the implications on the other children. (Medical Professional 11, Female).

<my training> has made me appreciate more the impact of severe fetal anomalies on parents, being a parent myself you know that children are demanding so children with fetal abnormalities so that would be incredibly demanding on a family so I can see that termination for fetal anomalies are an important issue. (Medical Professional 17, Male).

It was acknowledged by participants that there are anomalies where a child will go through a significant amount of medical intervention and may die at a relatively young age. Dealing with the death of a child was seen as something that adds a completely different but significant dimension to the decision process. This was especially the case if there are other siblings who may have to deal with this tragedy at a young age.

... we've had a lot of people who die as young adults, and you know maybe that's, that's perfectly reasonable if parents want to, take that risk and, you know, that's a worthwhile life, that's fine, and I'm not saying it's not a worthwhile life, but, I also can see the other side of it and what, what, what kids and their families go through... we've had families who, who have said to me... if I'd really known how bad it was I wouldn't have gone ahead with- I wouldn't have carried on with this pregnancy. (Medical Professional 20, Female).

Participants reported their view that within society, there are a range of opinions and perspectives that exist regarding TOP in general and specifically TOPFA. These are decisions that can affect a family lifestyle that may not be an approved decision by many, but some within the medical profession argue that it should remain an option for prospective parents. This view seemed to stem from the idea that it is not 'society' or the medical professional that is having this individually affected baby, it is the parent. However, if parents do not want to give up certain aspects of their life because their child has an impairment, this is not a good start for the life of the child. Ultimately, it was argued that it was the parents who have to live with the consequences of their decision. If the parents' definition of what was 'serious' differs from the medical professional, or the majority of society, why should that matter? Society or the medical professional should not be imposing its values on another person's decision. Professionals also reported that they felt

that the majority of society, who may disapprove of such decisions, are not affected with a diagnosis of fetal anomaly. People simply do not know what they would do until they are in the position of having to make that decision.

It's very easy for these people.. who write books, may have a kid themselves or a Downs kid themselves, I've got a Downs baby who's perfect why you trying to terminate? But they have an agenda, they may not admit to having an agenda... but sometimes you have to look at the wider implications of a handicapped child... with a teacher married to a barrister.. you're aware that.. in some ways it's maybe socially much more of an issue for them and their lovely little environment of skiing holidays.. or that the kids won't get 12 A's at GCSE, is it more of an issue for them socially than the deprived girl... you do end up talking to them differently because their issues are sometimes different. (Medical Professional 7, Male).*

If the woman thinks she wants to keep going to parties rather than go to hospital with a disabled baby and stuff like that, it's a serious change for her... it might be, not a pro-life view, but.. I think it's in my view it's an opinion that should be out there rather than lumbering a woman with a baby they don't want or lumbering a baby with a mother that doesn't want them... it's not right for everyone, but for those who think it's right for them should access it. (Medical Professional 10, Male).

Selecting the option of TOPFA *to continue a lifestyle of parties and so forth* was a view that was likely to not be supported by society. However, as Medical Professional 10 illustrates, firstly, it was seen as the choice of the parents involved, not wider society. Secondly, it was felt that the medical expertise are available why should she not access them. Thirdly, some professionals raised concerns about what kind of life would the child have if this was the parents' response? A number of medical professionals feel judgments are made about women who select a TOPFA which are unjustified and based on misinformation. Medical professionals in such situations of TOPFA, or delivering an affected fetus, or those involved in the after care of the baby, are involved with parents in a particularly distressing time in their life. The care options tend to be split between the TOPFA is an acceptable option; TOPFA is not an acceptable option; or it is up to the parents. Many medical professionals feel they give the reins back to the parents in terms of decision making. Medical Professional 9 goes as far as to say he does not feel he does TOP, the parents do, as he would not be doing it without the parents' permission.

Whatever decision they make is the right decision... People know what they want anyway (Medical Professional 5, Female).

... but ultimately people make their decisions.. in a way they can live with the decision, so whatever way.. kind of cynically, but whatever way they feel less guilty about is the way they'll go. (Medical Professional 9, Male).

At what point a woman becomes a mother is the subject of philosophical debate. At the point where a pregnant woman feels her baby move is arguably a significant moment within the pregnancy and may have implications for the decision making process. This notion was also evident in the data:

I've had more than one mother say to me she thinks she might have actually had a termination of pregnancy if she hadn't felt her baby move. (Medical Professional 12, Female).

The implication of the NHS brings another consideration to the argument regarding the decision to TOPFA. This was due to the cost burden of long term medical treatment being removed from the parents. Some medical professionals defined such instances as *social factors* as they are important considerations but removed from the family. Thus, bringing social factors into the decision making process was felt to be unhelpful as society has the resources to care for affected children, even if the family is not able to. This means social factors do not help in decisions about what is ethically best for the baby.

I actually think it's very difficult to feel you're making the right, in terms of an ethical sense, the right decision for a baby if you allow social family issues to cloud your judgment (Medical Professional 13, Male).

Having one affected pregnancy experience will impact on the decision making process of a second affected pregnancy.

I've had them <parents> say they couldn't do the process again and that they think they would terminate a second affected pregnancy (Medical Professional 19, Female).

Medical Professional 5 recalled an experience of being pressurised into providing TOPFA. The parents had elected not to go down the usual route of counselling and their decision making process was done without it. This made Medical Professional 5 very uncomfortable given the nature of the anomaly (cleft lip) in question. The decision was persuasively assured to her by the parents and she proceeded with authorising the TOPFA.

I.. have deep regrets about that because I felt I was being pressurised by a couple, erm... it was mid trimester termination at 20, well related to the 20 week scan, and it was a professional couple, erm, who, and it was cleft lip and palate, unilateral, and they wouldn't accept any counselling, wouldn't see the cleft lip and palate services... they were adamant that was not what they wanted, it was sub 24 weeks... but I felt very uncomfortable about it... I felt I'd been coerced into doing that by the couple without them having sought the advice of the specialist in the cleft lip and palate services... but, erm, had they.. sought advice, and had they taken everything into consideration, and had I had a second opinion that I respected, then I would have then.. have respected their decision and gone ahead with it, I just felt.. it wasn't... They wanted the perfect child, yes, really, deep down, but that's not what they said. (Medical Professional 5, Female).

This sub-theme has given the perspective of the family experience of an affected child after a diagnosis of fetal anomaly from the perspective of the medical professional sample. The data show slight references to the social setting a potentially affected child may be in. This was indicated through discussions of the 'right' family set up that is able to best deal with a child with an impairment. Despite this, the focus remains on the individual impairment and how that will impact on the family setting. This was opposed to an alternative view, such as how the setting can be changed to accommodate the impairment. A third legitimate option that is available to parents making decisions about TOPFA was indicated: palliative care. This option was seen as avoiding the TOPFA decision but also allowing parents to avoid entering into a life of medical intervention. This again focuses on the individual with the condition. Parents want the opportunity to meet their baby so do not want a TOPFA, but also do not want their child to have a life of hospital appointments and pain. They may also not want to raise the impaired child. The decision making process was again seen as being influenced by the condition. As with the social care professionals, for some anomalies, TOPFA was an acceptable option, for others it was not. Other medical professionals felt it was a decision that was not theirs to take or influence whatever they felt about it; this was suggestive of the importance of the option of TOPFA being available despite not personally agreeing with it.

9.8 Comparison Between Social Care Professionals and Medical Professionals

This chapter gives a descriptive overview of social care professional and medical professional views and understandings of how they perceive the experiences of the imagined child. These perceptions are shown in the data to be based on professional and personal experiences as well as personal moral values based on these experiences. The

views of the two professional groups are not radically different. This may be a reflection of wider social acceptability of issues surrounding TOPFA. When discussing 'normal' experiences, social care professionals drew on the abnormal experience that is the normal experience for people with impairment. In contrast, medical professionals draw on how to 'normalise' an impaired person. The more 'normal' a person can be presented then a TOPFA becomes questionable or unacceptable. Both professional groups have in some instances drawn on the fact that having an 'abnormal' life experience did not mean life was not worthy. For the medical professionals who raised this, this was often in relation to Down syndrome. This may be a reflection of a wider moral and ethical issue relating to that particular anomaly.

Both professional groups discuss assumptions, but how they are discussed raises contrasting issues again. Social care professionals discussed assumptions held about people with impairment and wider notions of disability, particularly assumptions placed on cognitive abilities. Medical professionals discussed the assumptions held by parents and society in general. The data also show that many medical professionals made assumptions about decisions about TOPFA upon certain diagnoses. When discussing the family experience of an affected child, the social care professionals were able to draw out the small aspects of life that become magnified into a process of ensuring all aspects of care are accounted for. Thus a simple trip to the shop to get milk has a multilayered decision making process associated with it, that must be considered and accounted for to ensure the adequate care of a child with impairment. Social care professionals were also able to draw on negative life experiences of children with impairment where their parents have been unable to cope with the demands that such a child brings to family life. Other social care professionals drew on the family experiences. While many of these experiences can be defined as 'abnormal' through not following the usual and expected life trajectory, this does not mean the life was not of value.

Concerns were raised about placing value on life and how a fulfilling life is defined. Some social care professionals felt TOPFA should not be a consideration for some anomalies. Medical professionals drew out their professional experience of dealing with palliative care. This allows parents to experience a life with their child for a short space of time, but not entering a life of hospital appointments and treatment. Medical professionals also raised issues with parents who contemplated TOPFA in the first instance, and whether the potential child's life experience would be a positive one as a result. The family experience

that resulted in TOPFA decisions that many in wider society would not approve of was also raised. This met with some professionals feeling that parents make their choices within the parameters of the law, thus it is not up to others to judge them, however morally wrong they think their decision is. The data show the similar issues that have been raised are conceptualised differently between the professional groups. Medical professionals tend to focus on an individual with a condition; social care professionals tend to adopt a broader outlook that addresses the personal within disability and their fit with their social context.

Chapter 10: Discussion

10.1 Introduction

In this discussion, I have adopted the theoretical tools outlined in Chapter 4 and applied them to the findings outlined within chapters 6-9 in this thesis. Figure 6 is a simple illustration of the overall argument made in this chapter. Based on my findings, I propose that an acceptable TOPFA is determined with reference to three key factors. These factors are: whether a particular anomaly can be ‘fixed’ under the paradigm of biomedicine; what pain this ‘fixing’ will inflict; and whether there will be a ‘normal’ life trajectory. These considerations are then balanced out against maintaining a ‘moral’ sense of self. These considerations, I argue, is at the heart of maintaining the ‘moral self’ performance, as it leads to a decision about an acceptable TOPFA. A difference between a personal and a professional acceptability is often expressed by professionals.

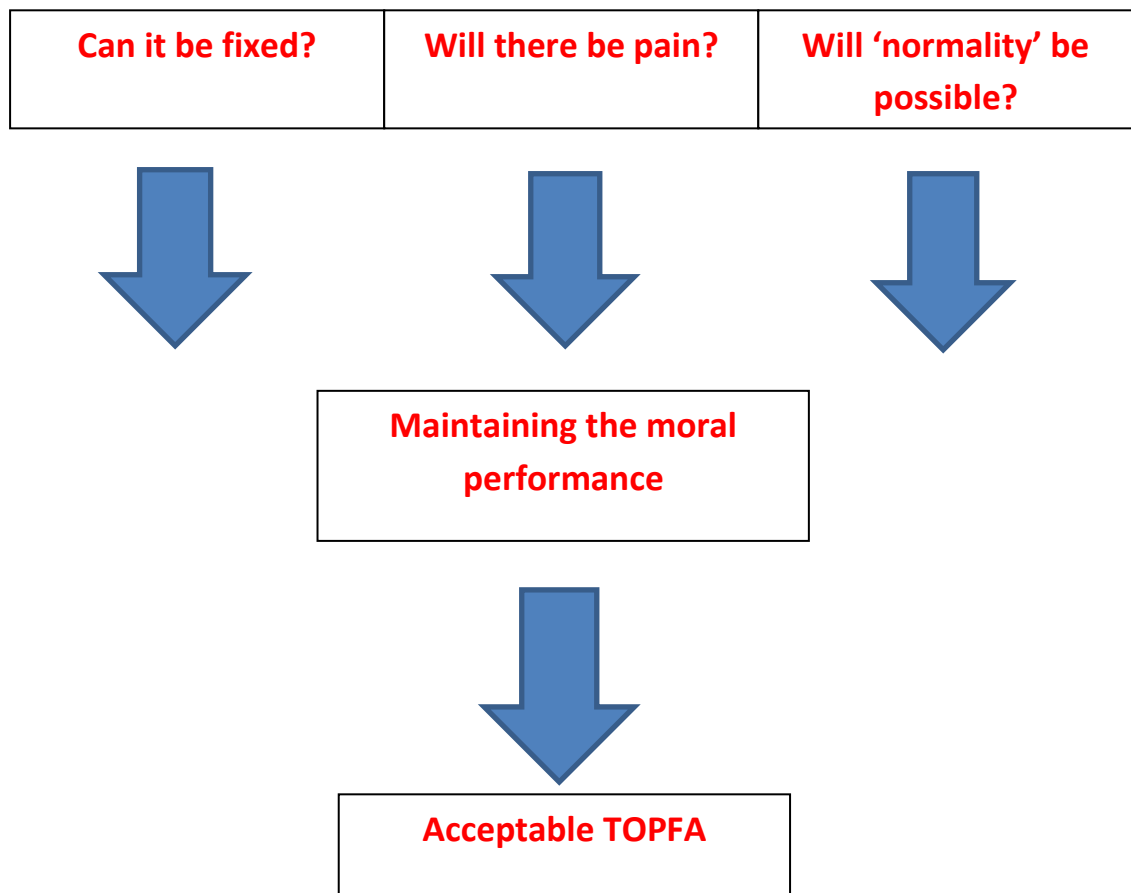


Figure 6: Diagram of discussion

10.2 'Can it be fixed?': The power of medical knowledge

Modern Western medicine remains under the dominant paradigm of biomedicine (Nettleton, 2013). Despite this, the medical profession can no longer claim sole ownership of knowledge about health and illness (Nettleton, 2013). The social model of disability for example, has presented an alternative definition of disability, placing the onus on society rather than the individual impairment (Shakespeare, 2013). Despite the recognition that the power base of medicine is not as secure as it has been in the past, it retains a position of dominance in many social spheres. Medical knowledge is still seen to be superior, with the social model of disability offering no real threat to the power of the biomedicine paradigm (Nettleton, 2013). Two assumptions about the characteristics of biomedicine are relevant to this discussion. Firstly, that the mind and body can be likened to a machine thus can be fixed (Nettleton, 2013). Secondly, that the advantages that medical technology can bring are sometimes overplayed resulting in a 'technological imperative' (Nettleton, 2013). These two aspects are of particular relevance to this study due to the seemingly automatic enrolment into medical intervention if a fetal anomaly is detected. This intervention includes further testing to establish the extent of the anomaly, and to determine if there are any additional anomalies and medical intervention to the baby with impairment, should the pregnancy result in a live birth¹. The data would suggest that, for professionals, after a birth of a baby with an impairment, assumed enrolment into medical intervention is unquestioned.

The technological imperative is an important consideration within this research as pregnancy has become a time where women are exposed to testing and monitoring during a time which is a natural life process. "...the prestige of physicians compared to other occupations is high in all industrial countries. Furthermore, the physician is the symbol of healing whose authority takes precedence over all others" (Freidson, 1970: 15). Patient information on prenatal screening is said to be biased in favour of screening (Seavilleklein, 2009). The data again suggest that for the majority of professionals in both professional groups, this screening is seemingly not questioned, with a high value placed on prenatal screening by those in the knowledgeable position. This means that women who may wish to decline screening are fearful of doing so as they perceive that they may be labelled 'irrational' or 'irresponsible' (Seavilleklein, 2009). The pregnancy and child birth period has become medicalised with many aspects of pregnancy becoming subjected to medical

¹ Some prenatal tests may come back with positive for an anomaly. This result may be anomalous, but not necessarily have a clinical significance. Thus there may be no impairment, or it is unknown if there will be one.

intervention; this has become the norm within Westernised nations such as the UK (Johanson et al., 2002). Pregnancy in the past was dominated by females, but medical men sought control over firstly difficult births, and then extended this to normal births (Johanson et al., 2002; Annandale, 1998). Some medical professionals interviewed questioned the extent of the testing that is done during pregnancy. For example, according to Medical Professional 5, women are felt to be forced or coerced into entering the prenatal diagnosis programme that they would not necessarily entertain had they understood the full extent of it. Many medical professionals question a TOPFA after a diagnosis of Downs syndrome, but Downs syndrome is the focus of the combined test offered to all women prior to 14 weeks gestation. The availability of the test leads to suggestions that this is with a view to doing something about it, should a diagnosis be made, namely TOPFA should be the parents wish. The case study examples help to demonstrate the expected nature of medical intervention; in many cases the options were discussed as TOPFA or medical intervention after birth. The exception to this was Medical Professional 19 who discussed palliative care as a real option that is not well explored by medical professionals, however the reliance on expert knowledge was still revealed to be part of this option.

10.2.1 Automatic enrolment to medical intervention: Isolated cleft lip

Including isolated cleft lip as a case study example enabled a moral threshold to be defined. This is because it is a condition that many of the participants had defined as minor, due to the success rate of surgery. It acts as a tool for defining 'serious' within the professional sphere, as per the wording of the Human Fertilisation and Embryology Act (2008). It also provided data that showed medical professionals using their own personal opinions to influence their counselling practices. The findings support arguments that professionals as individuals are not as objective as they claim to be as a professional group. Social care professionals offered an alternative perspective to the dominant medical views. This alternative perspective broadens our understanding of how a person with an impairment could fit within the social context. It is also worth noting that while the majority of professionals in this study defined isolated cleft lip as a minor anomaly, some internet forums do not. Given the wide access to the internet that is now available, parents may come across such forums. This may have an impact on the meaning they ascribe to the definition of isolated cleft lip, which may influence how the anomaly is defined in terms of seriousness. Use of the internet has been proven to be influential in patients researching and gaining support for health related issues, with the notion of the 'expert patient' being

something that has become increasingly recognised within health and healthcare (Fox et al., 2005).

Slightly less than half of both professional groups felt that TOPFA for isolated cleft lip is never an acceptable outcome. The comments made on the questionnaire by social care professionals showed a range of understanding. For example, one comment was suggestive of the rights to parental choice; another comment discussed the improvements in surgery, meaning that isolated cleft lip is not an issue that it might have been in the past. Another example referred to the other available clauses allowing for a TOP *if it is not convenient in your life then why not when there is a presence of an anomaly, even if it is minor*. What these comments have in common is that they are factors that are independent of the individual anomaly that, nevertheless, have an impact on the decision making process; ethics around parental choice; the medical interventions that are available; and the other clauses allowing for TOP up to 24 weeks gestation for comparably minor reasons than a 'minor' anomaly. This is perhaps professionals acknowledging a consideration of the wider context of the diagnosis of the anomaly, and recognition that it is possible to consider TOPFA without considering TOP in general, at least indirectly.

The comments made on the questionnaire by medical professionals covered a similar range of views to that of the smaller number of social care professional participants. A number rejected isolated cleft lip as a reason for TOPFA. Some comments drew on the interpretation of the law; for example, using Clause B or C instead if the gestational age is below 24 weeks. Others reported the use of the 24 week limit for other reasons as a measure of acceptability. The treatment available was also raised. All of the comments referred to common knowledge or interpretation within current medical knowledge frameworks. Many comments discussed professional actions they could do as individuals within the legal framework (and in the context of the NHS where organisations are obliged to provide TOP services), despite being personally against isolated cleft lip as a reason for TOPFA.

Just over half of both professionals within both groups reported varying degrees of acceptability for TOPFA for isolated cleft lip. Opinions may differ in professional and personal capacities. It is worth noting that whilst isolated cleft lip was the term used in the interviews, this often referred also to cleft palate. Professionals viewed isolated cleft lip as an anomaly that can be fixed with surgery, thus accepting treatment within the biomedicine paradigm. Other aspects of treatment may be required to aid with feeding and other

features relating to the mouth and nasal passages, but on the whole, this was not deemed to be a major impact on quality of life. Nor is it predicted to impact the affected persons' passage to a normal life trajectory. Thus, it is concluded that isolated cleft lip can be 'fixed', and a normal life ensured. For these reasons, this makes isolated cleft lip a questionable or unacceptable reason for most professionals for TOPFA. Some professionals drew on the issues outside of the individual anomaly itself. Upon considering these aspects, a TOP under Clause B or C could be justified in their opinion. Many professionals, however, reiterated that personally they still did not agree, but respected the legislation and decision of those directly involved. When looking at the social model of disability, many within the disability movement would question why society does not simply adapt to accept those with impairment into full, non-stigmatised participation into its fold. The focus on the 'treatment' available that is readily acceptable and takes place within a definitive time period, retains a focus on being 'normal' and 'fixing' any anomalies that are present in any way possible. According to Goffman, the rewards of appearing 'normal' far outstrip those of retaining a stigmatising quality (Goffman, 1963), thus it makes sense to fix an impairment if it is possible to do so. The focus on the ability to 'fix' a cleft lip, thus enabling the individual with the impairment to continue life in a normal trajectory, supports this interpretation. Without any attempt to fix the impairment, the affected individual will therefore be seen as a second class citizen, with acceptance by 'normal' people conditional in respect of this (Goffman, 1963). The stigmatised individual would be expected to withdraw without complaint from situations where their impairment may be a source of discomfort to other 'normal' people (Goffman, 1963). There are other issues associated with isolated cleft lip, such as potential eating and speaking issues. While these can be argued to be separate from being cosmetic, society recognises a 'correct' way of doing things such as eating and speaking. Thus, fixing the cleft to achieve 'normal' eating and speaking would also be necessary to 'fit in' and achieve normality.

Since Goffman's writing, a number of changes to the lives of people with disabilities have been witnessed. This is most notably the legislation of the Disability Discrimination Act (1995, 2008), which makes it illegal to discriminate against a person because of a disability. A person with an impairment, on the surface, would not be expected to remove themselves from a situation in the same way that Goffman has described above. This is not to say that felt or enacted stigma does not occur. However, the continued focus on the medicalised 'fixing' of impairment suggests that the need to present and appear as normal continues to be a primary concern for those impacted with a diagnosis. It is seemingly unquestionable

that a baby born with an isolated cleft lip will undergo reconstructive surgery. It may be questioned why this is necessary? The social construction of the importance of the 'normal' 'healthy' body, as well as medical control over diagnosing and treating impairment, ensures that the 'normal' course of action for a baby born with cleft lip is reconstructive surgery. The data show no indication that a baby with a cleft lip should not undergo surgery, nor does any participant question the necessity of surgery to 'repair' the cleft. The medical profession as a body have cemented their powerful position in society allowing for medicalisation. As a result, pregnancy, fetal anomalies and subsequent impairment are unquestioningly treated and discussed in medical terms. The 'normal' functioning body is what is strived for to achieve normal life passage in all areas associated with isolated cleft lip; appearance, eating and speaking.

This is despite the social model of disability having moderate success in re-defining certain impairments as an alternative identity. One example is Deafness. Deafness has been described as a minority linguistic community with up to 70,000 people in the UK who identify British Sign Language as "their first, preferred or only language" (McLaughlin et al., 2004: 155). However, this status is highly contested and is not always recognised within society (McLaughlin et al., 2004) highlighting a continued struggle within this Deaf community and so called 'normal' society. Despite this struggle, Deafness is something that is embraced as a cultural identity (Munoz-Baell and Ruiz, 2000). This is in contrast to the medical perspective which focuses on the failure of hearing which needs 'fixing' (Munoz-Baell and Ruiz, 2000). The extent of embracement was highlighted in 2002 when a Deaf lesbian couple actively sought to conceive a Deaf child (Spriggs, 2002). This was met with some sympathy, but also a lot of criticism. The couples' refusal to engage their son in medical intervention also received criticism. They did however state that should he wish to have a hearing aid when he was older, they would not stand in his way (Spriggs, 2002). This section highlights the value placed of 'fixing' and impairment where it is medically possible to do so. When this is the case, the enrolment into the biomedical paradigm is unquestioned and the 'fixing' process begins to ensure 'normality'. Isolated cleft lip, an anomaly that is argued to be easily fixable, is an example of how this process is seemingly unquestioned. Given the ease of fixing this anomaly, the pain that is associated with undergoing the procedure is deemed an acceptable amount to decide on behalf of the child.

10.3 ‘Will there be pain?’: Deciding on behalf of someone what is acceptable pain

While pain is something that is deemed an expected aspect of life (Aldrich and Eccleston, 2000), it is also argued to be something that encourages behaviour that seeks to reduce or avoid circumstances that would provide pain (Melzack and Wall, 1982). Perceptions of pain are also argued to be culturally specific, and meanings are drawn by factors influenced by the individual affected by pain (Ridson et al., 2003; Melzack and Wall, 1982). Pain is also said to have two key aspects; it is unpleasant in nature and can be long term after its “survival value is spent” (Ridson et al., 2003: 375). Engaging in ‘normal’ activities was found as a common theme for those suffering from and accepting of chronic pain (Ridson et al., 2003). This finding was argued to suggest that by accepting pain, many of those affected by pain have a central aim of not letting the pain dominate their life (Ridson et al., 2003). Pain as a feature of life, with the knowledge that it is unlikely to be overcome, was found as another feature in chronic illness patients; thus the acceptance that life had to change to accommodate pain was recognised (Ridson et al., 2003). Rejection of the notion that the presence of pain meant a reduction in a meaningful life was also rejected by participants (Ridson et al., 2003). Charmaz argues that chronic illness results in a ‘loss of self’; this results in a new self that does not maintain the same level of value as their previous self (Charmaz, 1983). From this perspective, it could be argued that an impairment from birth would suggest that the self is defined around the impairment from birth and the ‘usual’ or ‘normal’ level of value is not given to that person. However, the data from my study do not support the notion that a lesser value of personhood status is attributed to children or adults with impairments from birth.

Conceptualising pain was a consideration for many professionals from both groups when discussing an acceptable TOPFA. For social care professionals, one aspect of the social value of a particular individual was discussed in terms of the pain and suffering they potentially may experience. However, the acceptable pain thresholds differed between social care professionals. The different moral values of acceptable and unacceptable pain were conceptualised depending on the anomaly being discussed, personal views and personal experiences. From the case study examples, isolated cleft lip was an anomaly defined as relatively minor by social care professionals. Some professionals (2, 18, 21) however, still acknowledged the pain a baby would have to go through for corrective surgery, and the stress that this will place on parents. This, combined with options of

choice, meant that they felt that TOPFA should be an option for parents even if they did not agree personally with the decision.

10.3.1 Hypoplastic left heart: a case study of expected pain

HLH provided a valuable case study due to the necessity of surgical intervention to prolong life and the uncertain prognosis after this. HLH was deemed an anomaly that cannot be 'fixed', but life with HLH could be prolonged with medical intervention. The affected person is likely to die as a result of the anomaly despite medical intervention. HLH as a result, was defined to be a serious anomaly by all professionals. The epidemiological data indicated that TOPFA was the pregnancy outcome in approximately half the cases registered.

A range of answers were indicated for acceptable age and TOPFA for HLH by social care professionals, with the most common response being 'never'. This range of responses could reflect wider lay perspectives on both the fetal anomaly scan, and understandings of the implications of an anomaly such as HLH. While this sample is by no means representative, alternative answers may have been given had there been a greater understanding of HLH. The interview data suggested that there was wider support of TOPFA for HLH at later gestations than the responses indicated on the questionnaires. In contrast, the medical professional questionnaires recorded no responses for the lowest gestational ages with the most selected answer being '31 weeks and over'. This again may indicate a greater knowledge of the detection methods and the implications of HLH among medical professionals. It could also reflect a wider social acceptability of difference and living with impairment among social care professionals. There was a wider gap between professionals when asked about assumptions about physical and intellectual abilities relating to HLH again suggesting more of a discrepancy of knowledge between the professional groups.

On discussing HLH, one social care professional commented that people have heart surgery all the time thus why should a fetus be denied life because their heart problem will be present from birth? This would suggest the high pain threshold that a child with HLH would have to go through is acceptable. However many medical professionals discussed the pain that a child would have to go through to get them to a position where they could live reasonably well. This was such that a TOPFA was an acceptable option for the majority of medical professionals in a personal as well as professional capacity. Many social

care professionals when discussing HLH also drew on non-specific anomalies that would result in an affected child being in a lot of pain. This level of pain, in the majority of cases, was deemed an acceptable justification for a TOPFA. Living in constant pain is felt to be an unacceptable life experience. This, however, was not the case for all social care professionals, a couple of whom suggested that being in constant pain does not give others the right to deny that existence, however limited. This would suggest that those particular professionals felt that being in constant pain is an acceptable threshold for a child to live with.

The interview data showed that HLH was a condition that none of the social care professionals had ever come across within their professional careers. This does not discount their perspective on TOPFA for this condition, as its selection is based on the requirement of life long medical intervention and despite this, long term survival is not guaranteed. Many of the social care professionals have had experience working with people for which this level of medical intervention is a requirement. Much of their perspectives on HLH came from the information sheets provided in the research packs, and additional research many of them did on the internet after completing the questionnaire and prior to participating in the interview. Opinions seemed to be on the whole split between those who felt that HLH was an acceptable justification for TOPFA and those who do not, despite the group as a whole receiving very similar information on the condition via the study.

There were social care professionals who were in agreement that HLH was an acceptable reason for TOPFA. Much of this centred on the impact on the child, the intervention they would have to go through, and the pain they would have to endure for it never to be enough to guarantee long term survival without further intervention. Medical professionals on the whole were supportive of TOPFA for HLH within a professional capacity (many in a personal capacity also). One professional noted the importance of monitoring advances in healthcare. Improving healthcare and enabling a child to experience 'normal' aspects of life may act to change the perspective regarding TOPFA for this condition.

Thus HLH appeared to present a discussion on what was acceptable to put a child through, to get them to a reasonable standard of living. As with isolated cleft lip, the focus on a live birth with HLH is on surgical intervention. However, unlike isolated cleft lip, surgical intervention for HLH was conceptualised as a permanent fixture in an affected persons' life as HLH cannot be 'fixed', only temporarily alleviated. In time, more surgical intervention

will be required to sustain life. The palliative care option was mentioned. It may also place an ethical burden on the medical profession who may place the value of the child's life over the wishes of the parents and intervene.

HLH is an anomaly that on the surface can be hidden. The data suggested that the exposure to stigma associated with that of an obvious disfigurement is not present with HLH. It can be argued that repeated medical intervention and long stays in hospital can create suffering through pain, but also can create stigma in a different way to that of disfigurement. This is due to engagement with medical intervention both regularly and for extended periods of time, which is not indicative of a normal life trajectory for a child and young adult. The impact of the interventions may also result in the individual affected with the condition being unable to participate in some social activities. This again leaves them exposed to stigma. The data did not indicate much in terms of any stigmatising aspects of life associated with HLH. This would suggest that given this is a condition that on the surface can be hidden, potential stigma may not be an important consideration among professionals. Goffman argues that people with a stigma that can be hidden can go to great lengths to maintain a normal identity by performing as normal (Goffman, 1963; 1959). The performance could be exposed should the individual place themselves in a situation where their condition prevents them from full participation. However, the likely course of action would be to avoid such circumstances.

10.4 'Will normality be possible?' Stigma: The performance of 'being normal'

Normality is something very difficult to define and is culturally and time specific (Earle, 2003). In this research, normal was conceptualised as the experience that a non-impaired person would be expected to experience in a normal life trajectory. This can also be referred to as 'the life course', which highlights the expected path of individuals within their life (Earle, 2007a). According to Goffman's theory of stigma, people who have a 'stigma' may go through numerous processes to be accepted in society. Much of this centres on being or appearing 'normal'. This may also be to avoid the 'master status' that Goffman (1963) argues is the first point of defining a person with an impairment. Drawing on his work within *The presentation of self in everyday life* it can be theorised that people with an impairment may also 'perform' the role of 'being normal'. The act to present the 'self' they wish the audience (society) to believe, and that is being normal, thus accessing the benefits that this status provides. The means a person may go through a number of things to perform and maintain the 'normal self' (Goffman, 1963):

- (i) a person may go through means to ‘correct’ the stigma. This may be through surgical correction;
- (ii) a significant amount of time may be dedicated to gaining high achievement in an activity not usually deemed open to those with a particular ‘stigma’;
- (iii) some with a particular ‘stigma’ may act to interpret their identity differently to the usual conventional approach. This may or may not be accepted by the majority;

According to Goffman (1963), the rewards of being normal are so high that any person with a ‘stigma’ that can pass for being normal will do so in order to access these rewards. The medical interventions available within the UK can act to ‘correct’ a stigma. For example, when an isolated cleft lip is discovered reconstructive surgery is seemingly not questioned. When spina bifida is discovered, numerous medical interventions will be offered to allow the best possible opportunity for the affected person to walk. Walking is a key method of mobility, seen as a significant characteristic of modern day living. This significance, coupled with the fact that a wheelchair implies impairment, then it may be unsurprising that the first question many parents ask after a diagnosis of spina bifida is around mobility.

10.4.1 Spina bifida; an example of the ‘normal’ performance

The inclusion of spina bifida as a case study proved to be valuable as it is a condition in which there is a lot of uncertainty about prognosis. The lack of certainty means that the potential seriousness of the condition will not be known in many cases until after birth. This uncertainty may effectively place parents and professionals in a moral dilemma, given that they have the potential to offer (or accept) a TOPFA on a fetus that may have ‘done’ very well. Spina bifida is compatible with life. Varying degrees of support may be required, but again, this is something that is not assessed until after birth. Spina bifida may also lead to an inability to walk. The ability to be mobile is something society places high value on. The epidemiological data showed that most parents faced with a diagnosis of spina bifida opted for a TOPFA, although this did vary somewhat between regions. The questionnaire data suggested that TOPFA was deemed an acceptable pregnancy outcome by both professional groups.

The interview data shows that all social care professionals were able to draw on personal and /or professional experience of spina bifida. The group had mixed opinions as to the acceptability of TOPFA with ethical challenges being raised based on their personal and/or professional experiences. The data show this stemmed, from the perspective that it is a serious anomaly with serious consequences, yet if you asked a person affected by the condition if they would rather have not been born, the answer would likely be no. The data show a number of considerations are factored in to conceptualisations on the acceptability of TOPFA for spina bifida from both professional groups; where the lesion is located, the presence of hydrocephalus, and mobility issues. Another major consideration was how much information was gained from the scan. Many of the associated risks will not be known at the prenatal diagnosis stage. The social construction of society places high value on being able to walk and not having visible signs of impairment. Spina bifida is associated with mobility impairment and the presence of a wheelchair. This is a very obvious sign of disability that cannot be hidden in the same way other impairments associated with spina bifida can be; for example, bowel or bladder problems.

Goffman discusses the lengths people will go to hide an impairment (Goffman, 1963). When leaving the home, where the performance of being normal can be relaxed, the person with an impairment will try and ensure that, while exposed to an audience, they maintain the performance of the 'normal' self. This may be through simple steps, such as ensuring there are adequate toilet facilities. This would enable the performance to be relaxed while dealing with issues that their impairment presents (for example, for those with spina bifida related incontinence, changing an incontinence pad). Though the data showed that many professionals personally question TOPFA for spina bifida, in certain circumstances (low lesion in particular), the majority also indicate it is an acceptable reason for a TOPFA, or would not deny the parents the right to make that decision. Where a low lesion is discussed, questions were raised by some professionals. It was indicated in these circumstances, that a TOP could be consented under Clause C if the gestational age was sub 24 weeks. This is of particular interest given the positive outcome of spina bifida that many professionals raised. This may suggest a high value is being placed on parental choice. It may also suggest a high value on being able to present the 'self' as 'normal', thus the presence of a wheelchair would indicate an obvious impairment and sign of a body with an impairment.

Engagement with the medical profession after birth is not questioned when discussing spina bifida. Changes in access for physical impairment, particularly wheelchair access, are one area where changes in society are visible. For example, it is illegal for a building not to provide wheelchair access where it is structurally possible for them to do so (Disability Discrimination Act, 2005). This would suggest that changes in attitudes regarding access to places within society are changing. It would also suggest that as people who are in a wheelchair have more access in society, they may be more visible. This will act to re-enforce potentially changing attitudes. However, the emphasis placed on being able to walk in the discussions would suggest that a wheelchair is still a significant and obvious sign of impairment. It is suggested that it is acceptable to wish to avoid this stigma, and to engage in any means possible in order to 'perform' the 'normal' role within society. The political movement provided by social model of disability was biased towards people with physical impairments (Shakespeare, 2013). While the social model of disability has been influential for all people affected by impairments, ensuring those with intellectual impairments have access to social institutions (for example, mainstream schools) is more complicated to implement. Another aspect that is associated with being or performing being 'normal' is having a desirable life experience.

10.4.2 Stigma: The desirable life experience

Social care professional participants tended to adopt a broader outlook that addressed the person with impairment and their fit with their social context. Medical professionals tended to focus on the impairment itself. How an individual with an impairment can contribute to a given society was discussed in terms of the life experiences they could be predicted to have. This was compared to a 'normal' life experience of an average person. A number of aspects were discussed in relation to this, not all of which needed to be fulfilled to establish a worthy life. The most prominent examples were; contribution to family life and family experience, financial contribution, level of support, ability to be integrated into the community. Social care professionals were able to reflect on these aspects based on insight into the real, tangible contribution a person with an impairment can have. Medical professionals tended to speculate based on their medical knowledge of a particular impairment.

All members of a society have a perspective on what is 'normal'. Many people within a given society aspire to similar goals. For example, going to university and getting a good career, traveling, buying a house, and getting married. These are some examples of life

goals that society has constructed as desirable aspirations to achieve. When discussing a child with an impairment, these 'normal' life experiences are used by professionals as comparative factors when discussing whether TOPFA is acceptable. Many professionals within both groups argue that having an impairment will make your life more difficult to varying degrees, but this does not mean that a positive life experience cannot be achieved. Many of the normal and acceptable goals that society has deemed desirable can still be gained by people with impairments. Going to school was a point of reference for some medical professionals. This milestone made some question the acceptability of TOPFA.

For some professionals in both groups, it was important to think of those directly affected by a diagnosis of fetal anomaly other than the individual themselves. Many respondents reported feeling that the huge impact on the lives of family members should not be ignored. A diagnosis of fetal anomaly was seen as changing the life of the parents and any other siblings forever. For example, the level of thought that needs to go into simple aspects of everyday life were discussed by social care professionals, and the inconvenient times of unexpected hospital trips by medical professionals. The medical professional data showed limited impact on the wider social impact of an impairment. There are hints that some fetal anomalies will mean that the affected individuals will have limited societal contribution. Some medical professionals noted the different life experiences that parents expected from their child. These differing expectations impacted on how professionals felt that the parents perceived seriousness of a particular condition. For example, some professionals reported that parents placed a high value on educational achievement. This means that anomalies that could have a major impact on cognitive function (intelligence) may be deemed very serious. In contrast, other parents, whose life experience does not place the same value on educational achievement, may not define anomalies that may impact on this as serious.

The point of comparison for what was defined as 'normal' in the data was a useful tool, in terms of unpicking how professionals conceptualised notions of acceptable TOPFA. The findings from the social care professionals add a new dimension to the professional perspective on 'normal' experience, by highlighting that what is normal for many people with impairments is actually an 'abnormal' life experience, and the social impact of falling on the side of abnormality. Basic experiences of staring, name calling and physically distancing oneself from a person with an impairment were regularly discussed in social care professional accounts of their observations of encounters between the impaired person and

others. Medical professionals discussed ‘normalising’ a person with an impairment. Though social care professionals drew on such ‘normalising’ procedures also, more flexibility and consideration for the needs of a particular individual in a societal context were also discussed. Some within both professional groups have, in some instances, drawn on the fact that having an ‘abnormal’ life experience means your life is not worthy. For example, a life of constant pain is an ‘abnormal’ life experience for a child and deemed by many as undesirable. Equally, a life where a person does not suffer is also discussed as a desirable experience. This is where moral dilemmas surrounding the case study Downs syndrome emerge. For example, a number of medical professionals stated words to the effect that: *you do not suffer with Downs syndrome*. This would suggest, that despite the fact that it is defined as a serious anomaly by the majority of professionals, which has serious implications, it is not necessarily a justifiable reason for a TOPFA. This is because the notion of ‘suffering’, that is central for many to the case for legitimate TOPFA, is questioned. This is despite it also being a visual anomaly and may suggest that the meaning of suffering is being re-negotiated.

Acknowledging the social impact of disease and the fact that medical intervention has a key outcome of increasing the quality and length of survival time has an impact on health and health care perceptions (Carr, 2001). Health care is often evaluated considering the quality of life of the patient (Carr, 2001). There is no homogenous opinion on what defines quality of life. Those who are suffering from severe disease do not always report having a low quality of life (Carr, 2001). This would suggest experiences and expectations need to be considered. With regard to chronic illnesses, many patients are encouraged to adjust their expectations and maintain a normal life pattern factoring in such adjustments (Carr, 2001).

10.5 ‘Maintaining the moral self’: The performance of the moral self

According to Goffman in *The Presentation of Self in Everyday Life*, the individual will reveal information that they wish the audience to have, to provide the image of the self that the individual wants the audience to have (Goffman, 1959). Within his work, Goffman also discusses the front stage performance and the back stage performance. The front stage is the performance the audience sees and the self the individual wishes to portray to the audience. The back stage is where the audience has gone and the individual can step out of the character of the self they wish to portray to the front stage audience. With reference to these data, the assumption is that the discussion with parents is the front stage performance, while they reveal within the interview more personal insights, (the back stage

view, at least in part). Both professional groups had members that differentiated between what they would do and what they think should be an option for others. No professional said that TOPFA should be illegal in all circumstances; but there were professionals who said they would never select that option personally.

Within the counselling sessions with parents, medical professionals could be said to be performing their front stage performance. According to the interview data, this performance may have many influencing factors. The implications of the anomaly itself was said to be a key discussion point as these implications affected other aspects of the decision making process. Medical professionals have to work within the parameters of the legislation. The legislation is open to interpretation however, which is where personal opinions may come to influence the front stage and back stage performance. Medical professionals are in a unique position where they may be a very influential factor within the decision making process given the moral, ethical and vulnerable position parents find themselves in after a diagnosis of fetal anomaly. The data suggests some medical professionals do bring their personal opinions about anomalies, or TOPFA, into their counselling sessions. For example, Medical Professionals 8 and 13 discuss how it is possible to 'sell' a particular choice in the way that the medical facts about the condition are presented. For example, if 1 in 10 children suffer as a result of the anomaly, and a professional was being more cautious of the implications of the anomaly, they may focus on that 1 in 10 and heavily present all the potential implications of the anomaly. If the medical professional had a more positive outlook on a particular anomaly, they may focus on the 9 out of 10 figure, and spend more time discussing how many of the factors can be overcome.

For medical professionals, the front stage and back stage performance may also reveal them authorising a TOPFA in the front stage performance, which the back stage self may not agree with. This is due to the parameters within the law that they are able to work with. Many medical professionals revealed that a TOP can be performed up to 24 weeks. So while they may not agree with a TOPFA for a particular anomaly, if the pregnancy is before 24 weeks gestational age, they may authorise a TOP under Clause C. There are other instances where medical professionals do not personally agree with a TOPFA for a particular anomaly, but would authorise it within their professional capacity. It may be that they wish to appear moral by openly condemning the TOPFA to an audience, such as the interviewer, but may still be concealing their true self. It may be that as part of their

professional performance, they feel it is their professional duty to interpret the law that is available to them and work with it, which may involve authorising a TOPFA.

The interview data from the social care professionals did not reveal a clear distinction of differing perspectives in the same way as medical professionals. This may be due to the difference in the professional roles. Social care professionals do not offer counselling within their professional capacity unlike medical professionals. This means they do not need to have a separate objective perspective based within the parameters of the TOPFA legislation. None of the social care professionals had an extensive knowledge of the TOP and TOPFA legislation. Some social care professionals indicated that although they did not personally agree with TOPFA in certain circumstances, it was not up to them to judge other people. The case study Downs syndrome produced interesting results from both professional groups. Many professionals objected to TOPFA after a diagnosis of Downs syndrome, however, existing research suggests that the majority of pregnancies diagnosed with Downs syndrome result in a TOPFA (Morris and Alberman, 2009; Bryant et al., 2001). This may suggest that the findings from this project support other research, when participants are asked about Downs syndrome hypothetically. Professionals may feel morally obliged to not openly support TOPFA for Downs syndrome, but when faced with the reality of the diagnosis, may well choose otherwise. Over 90% of pregnancy outcomes after a diagnosis of Downs syndrome result in TOPFA (Morris and Alberman, 2009; Bryant et al., 2001), however the public image and reactions to people who openly admit to considering TOPFA for Downs syndrome, would suggest this would be much lower. This may suggest that people feel obliged to be openly against TOPFA for Downs syndrome, but when met with the reality of the diagnosis will select TOPFA over the life with impairment that a diagnosis of Downs syndrome would indicate.

10.5.1 Perspectives on Downs syndrome as a moral performance

A difference between the front stage and back stage performance may also be revealed depending on the anomaly in question. Downs syndrome provided an insightful case study. A diagnosis of Downs syndrome means a child will suffer cognitive impairment. They may also have other associated impairments. There is also uncertainty about the extent of cognitive impairment. Parents may not know, until their child is two years old or more, the extent of the impairment. Downs syndrome is also an anomaly that the majority of professionals class as a serious anomaly. Yet it is also an anomaly that places many professionals in a moral dilemma in respect of the public reaction surrounding having or

considering a TOPFA. Journalist Samantha Brick received a huge negative response in 2012 after admitting on live TV that she would consider TOPFA if Downs syndrome was detected. Prenatal diagnosis for Downs syndrome is increasing. However, the number of live births of babies with Downs syndrome is not increasing; births in 1989/90 was a similar number to that recorded in 2007/8. Yet the number of diagnosed cases rose from 1075 in 1989/90 to 1843 in 2007/8 (Morris and Alberman, 2009: 2795). Approximately 92% of Downs syndrome cases identified antenatally result in TOP; this is a figure that remained consistent throughout the study period (Morris and Alberman, 2009).

Social care professionals indicated the highest response regarding gestational age and acceptable TOPFA for Downs syndrome was 'never'. This is in contrast to the medical professionals who indicated '22-24 weeks'. For social care professionals, the data show that despite being an anomaly that many agree does not lead a normal life trajectory, many participants felt this abnormal trajectory is somewhat irrelevant given that people with Downs syndrome do not physically *suffer*. This is raised as a comparator to a 'normal' person that may also have a difficult life even with the absence of an impairment. The positive experiences had by those affected mean that TOPFA is questionable or unacceptable.

The public perception, which suggests that openly admitting to considering TOPFA for Downs syndrome is condemned in society, was also raised. Some professionals commented that the views suggested in society as a whole reflect the positive experiences of Downs syndrome and neglect the negative experiences. While many acknowledge Downs syndrome as a serious condition, it is felt that this in itself is not always a justification for a TOPFA. This is due to the positive life experiences that can be had despite being affected with Downs syndrome. The data also show agreement among the medical professionals that Downs syndrome is a serious condition that justifies TOPFA as per the wording of Clause E. Thus, many professionals did not personally agree with TOPFA, but professionally supported the availability of the option for others. And yet, despite these perspectives, and the public image that participants referred to, the vast majority of diagnoses result in a TOPFA.

Downs syndrome is not an impairment that can be hidden, unless the affected person is removed from society. The stigma that is associated with a condition such as Downs syndrome may be an influential factor in TOPFA decisions. However, the views of the professionals, though by no means representative, suggest that Downs syndrome is a

condition that TOPFA is not an acceptable option in a personal capacity. Yet, as a society, routine screening for Downs syndrome through combined ultrasound and biochemical testing is offered to all pregnant women. It is also noteworthy that despite a rise in diagnoses of Downs syndrome over a 20 year period, the live birth rate remained relatively unchanged (Morris and Alberman, 2009). The availability of this routine test may in itself be a factor. By merely being available, this may act to socially construct the opinion that something should be done if a positive result was returned. It may also be that both professional groups feel morally obliged to disagree with TOPFA for Downs syndrome, and are thus performing a moral self that, when faced with the decision themselves, they may not actually follow through.

The moral performance was also deemed a selfish performance by some social care professionals. They suggested that what is best for a child with an impairment is not necessarily being born, if a key reason for continuing the pregnancy is because the parents *do not want to be someone who has a TOPFA*. Social care professionals draw on examples where the parents would have made a different choice if they were able, with one example conceptualised as being based on the parents' selfishness as opposed to what was best for their child. A parent wanting to portray the self as moral and ethically sound by not having a TOPFA is therefore not an acceptable reason either for some professionals, as this in itself is not necessarily what is best for the imagined child. What was said to be best for the imagined child was parents who are 100% behind and in support of their child and willing to put in the necessary work to support that child. Not wanting to be a person who undergoes a TOPFA was not felt to be 100% behind a child; this was felt to be a selfish act on the parents. Some social care professionals (2, 6, 18, 21) were very supportive of TOPFA even for relatively minor conditions if this was the best option for the parents. Even if it is not an anomaly that they would necessarily accept as morally right for someone to have a TOPFA, neither is continuing a pregnancy in an attempt to maintain a sense of moral self. A TOPFA may be the best outcome for some parents, even for 'minor' anomalies.

It is important to acknowledge however, that according to Goffman, the interview itself was a performance. This would mean the 'self' the interviewees portrayed in the interview were done for the benefit of the interviewer and is not necessarily their 'true self'. Theoretical perspectives, such as those from the interactionist perspectives would argue that you can never know a person's 'true self'. This is why it is important to consider the

importance of the interactions professionals have in the meanings and understandings they have about TOPFA.

10.5.2 Choice: denying parental choice as immoral

There is much focus within the medical guidance around TOPFA on the issue of choice. While the legislation does not support women's choice on demand, the data suggest choice was a consideration. This choice was not at the forefront of TOPFA decisions for many professionals in both groups; the issues of pain, normality, and whether something can be fixed, had more prominence in this study. However, parental choice was not ignored or neglected in the data; it was simply not the focal point. Many professionals expressed that parents should make the decision that is right for them, even if this is in conflict with their own personal feelings. This may suggest that professionals feel it is immoral to deny parents an element of choice in a TOPFA decision.

It is argued that choice is restricted to two options; accepting or declining the medical options presented to them (Seavilleklein, 2009). "If prenatal screening is intended to represent something more than an additional consumer choice for women, then a broader conception of choice is required" (Seavilleklein, 2009: 72). Screening may reveal a fetal anomaly from which counselling follows. A number of medical professionals revealed within the interviews that they may employ methods to present a certain decision as more obvious/preferable. This would support evidence that medical professionals influence prenatal decision making. Seavilleklein (2009) also discussed other impacting factors on the 'choices' women have; the detail of the information, the choices that are made available and how they are presented. Additionally, other social pressures may also act to influence the decision (Seavilleklein, 2009). Examples were drawn from medical professionals where a parent who revealed a family member had expressed disgust at her knowingly bringing a baby with impairments into the world. Medical professionals also drew on conversations with women who felt they had to fight for their baby after a diagnosis of fetal anomaly. The medical professionals indicated that it is rare for prenatal testing to be declined; it is also common for women to not fully understand the implications of the testing. Testing has become so common that it is normal to accept it and harder to decline (Seavilleklein, 2009).

Non-directive counselling is promoted within medical guidance (RCOG, 2010). This is despite evidence to suggest it is not possible in practice (Statham et al., 2006). The data

from the medical professional questionnaire indicated they draw on personal views during counselling. Although only a limited sample, these data add weight to existing evidence that medical professionals continue to bring personal feelings into counselling. It can be argued that non-directive counselling in practice is difficult if not impossible (Williams et al., 2002). This combined with the fact that medical professionals are human beings with emotions, may even lead to questions as to whether non-directive counselling should be promoted in its current strict manner. Perhaps adopting a guideline that acknowledges different patient needs and the reality that personal opinions may be beneficial to some patients may better reflect current practices, and that being transparent about personal views may be better than pretending they do not exist. The interview data also show that medical professionals indicate they impact on the decision making of parents, both implicitly and explicitly.

Medical professionals are in a unique position in the counselling process by virtue of the fact that they are the people who deliver the news of a positive diagnosis. Understanding medical professionals' opinions on TOPFA decisions is of particular significance given this unique position. They may be in a position to influence, both consciously and unconsciously, the paths prospective parents may take. Knowingly or unknowingly attempting to influence a particular decision is dependent on the fetal anomaly that has been diagnosed, and the assumptions medical professionals make about the prospective parents. One example raised was directive counselling given to a 16 year old who was deemed to have undesirable personal circumstances meaning she may be unable to manage. While there is no doubt that many of these such assumptions are reflective of what is deemed the best interests of the mother, there is nothing to suggest that the mother in this particular instance would not have coped perfectly well.

Maternal choice has been given significant prominence within discussions about TOP. In particular, much of the campaign during the 1960's in the UK to legalise TOP was centred on women's' rights to make decisions about her own body. Social Care Professional 18 argued that women should be able to have a TOP should she so wish. The same professional also discussed that the burden of choice for a TOPFA should be removed from women. She argued that this would be achieved by medical professionals counselling for TOPFA upon diagnosis of a fetal anomaly. While Social Care Professional 18's intentions were clearly in support of women's rights, many women would argue this is not empowering to women. This perspective places the decision about a women's body in the

hands of the medical profession. This may also place too much power with the medical profession, who may be influenced by their own personal values.

The concept of choice raised another dimension to the decision process. Some medical professionals made assumptions about parental decisions with certain diagnoses. This was particularly the case regarding lethal anomalies, where some medical professionals did not understand the decision to continue a pregnancy. Medical Professional 9 discusses the unnecessary medical implications that a woman exposes herself to when continuing a pregnancy after a diagnosis of lethal anomaly. He discusses the risks of pregnancy and birth that he deems are unnecessary for an unviable fetus. On the other hand, Medical Professional 16 questions the right that medical professionals have to make such assumptions about women with a fetus diagnosed with a lethal anomaly. She discusses maternal choices and the choice to be a mother to a baby, despite it being for a short amount of time.

The medical professional participants focused on the anomaly itself, but also had a broader supportive view about the importance of maternal choices. There were also a number of medical professionals who felt if you opt for a TOP because it is not convenient in your life why not for a fetal anomaly. While many medical professionals spoke openly about being against TOPFA in many circumstances, no medical professional stated that the legislation needed to be amended in anyway, or that TOPFA should not be an available choice for those who decide it is right for them. Some raised the question of whether a child would have a positive experience if their parents were considering TOPFA in the first instance.

The issue of palliative care was discussed for parents, this could be viewed as getting them off both hooks in that the decision to have a TOPFA is removed, and they also do not have to engage in a lifetime of medical intervention. It also allows parents to care for their child for a short period of time. This perspective may also reflect the wider social context which places TOPFA as a problematic issue and social taboo. Palliative care would enable parents to not have to engage in difficult discussion about ending a pregnancy. Some professionals reflected that parents make their choices within the parameters of the law. This perspective questions anyone's right to judge a parent, however morally wrong they think the decision is.

10.6 How social contexts create meaning in termination of pregnancy for fetal anomaly discussions

Drawing on symbolic interactionism, a situation can be understood as being given meaning at a macro level based on the understandings of the world from the perspectives of the participants. Individual actions alone have no real meaning in the grand scheme of society; the interactions and shared experience is the focus. These social interactions provide a situation from which social actors derive meaning from. The understandings and meanings social care and medical professionals ascribe to perspectives about TOPFA are likely to be informed by the interactions they have in their professional and personal life. According to Blumer (1986: 6), interactionism seeks to investigate the nature of “human groups or societies, social interactions, objects, the human being as an actor, human action, and the interconnection of the lines of action”. The relevance to this PhD study lies in the social interaction described by participants, i.e. between the medical professional and the parents during the counselling stage after a diagnosis of fetal anomaly, and between the social care professionals with people with impairments (and sometimes family members of the impaired person).

Medical professionals generate meaning from interactions with parents. How an anomaly can be defined as ‘serious’ can be affected by such interactions. The meanings generated from the initial interaction after a diagnosis can define: (a) if an anomaly is deemed minor by the medical professional, whether the diagnosis fulfils the requirements for a TOPFA under Clause E and; (b) the understanding of the parents and whether they wish to carry on the pregnancy. The portrayal of an anomaly can influence the meaning constructed by the parents. “The actions of others enter to set what one plans to do, may oppose or prevent such plans, may require a revision of such plans, and may demand a very different set of such plans” (Blumer, 1986: 8). The medical professional may have no intention of offering a TOPFA, but the parents’ reactions may result in them revising their plans and may result in a different set of plans, i.e. to offer the option of TOPFA. The result may also prevent the offer of TOPFA, in which case, the medical professional may have to revise their counselling content to present the anomaly in question in a more positive light. The medical professional may also be set on providing a TOPFA and the parents request to carry on the pregnancy. This again may result in the medical professional revising their counselling techniques. It is important to understand the social context of those involved

and understand the world of the individual in order to understand the meaning derived from it (Benzies and Allen, 2001).

Social care professionals' interactions with people with impairments enable a meaning of life with impairment to be generated. This meaning is internalised and influences their opinions regarding TOPFA. Social care professionals are able to see people with impairments within their social context thus enabling them to derive meaning of their social context. One example raised was a boy who was describes as needing everything done for him, with questions raised over what kind of life this must be. During this discussion however, Social Care Professional 22 starts to question her own assumptions when she started to discuss the boy's mother. The mother will describe his day, he's had a really good morning, or he's been having a bit of a laugh. These descriptions question her initial assumptions about how he must have no quality of life, and yet his mother questions this assumption. This interaction with the boy with the impairments and his mother, have revealed the social context of which he lives. While initial interactions with the boy would result in an understanding of his quality of life being very minimal, this understanding is challenged and a new understanding is developed after interactions with the boy's mother. This in turn, creates an additional understanding during subsequent interactions with the boy.

According to theorists from the ethnomethodology tradition, all aspects of reality that we know are socially constructed. Ethnomethodologists are interested in how meanings come to be constructed. The social order can be challenged in the event of an unforeseen event or circumstance. This would suggest that even the powerful medical profession can have their position challenged. Ethnomethodologists also argue that it is not possible to 'fix' a problem at structural level, a process of negotiation and interaction needs to take place in order to bring about change.

The 'normal' functioning body is what is strived for; when an impairment is discovered, medical treatment is not even questioned. For medical professionals, their individual opinions on certain anomalies may not necessarily make much impact in the grand scheme. For example, there are lots of opinions for an anomaly such as Downs syndrome, where TOPFA is critically questioned or not deemed an acceptable reason for justification. However, the medical profession have advanced access to advanced technologies through medical research, to such a degree that individual screening for Downs syndrome is now offered as part of a national screening programme as routine, with most women accepting

the tests. This would suggest that screening is offered with a view to doing something about it, something medical professionals raised even if they did not personally agree with Downs syndrome as a justification for TOPFA. This would suggest that there are instances where it may be viewed as not always appropriate not to intervene should the parents request a TOPFA. While this study did not follow the traditional methodology of interactionism and ethnomethodology, given the importance of how meanings have been conceptualised in this study, it is important to acknowledge these perspectives as having an important contribution to these findings.

10.7 Acceptable termination of pregnancy for fetal anomaly: Concluding statements

The power of medical knowledge reveals that biomedicine continues to be the dominant paradigm within UK society. Fetal anomalies continue to be explained and treated with primary reference to this domain; with the focus of this paradigm on fixing and normalising the impaired body. This is opposed to improving societal perceptions of impairment, something which the social model of disability has tried to improve. It is also important to consider the power of medical knowledge, as it may be the case that the advancements may have gone to such lengths that may not be supported by medical professionals. An example of this may be Downs syndrome, a focus of the combined test, yet an anomaly that many professionals stated that they do not personally support TOPFA for.

Conceptualisations of pain provided a tangible means for consideration for many professionals when discussing acceptable TOPFA. However, different professionals had different acceptable pain thresholds. This leads to the question, what is an acceptable level of pain to firstly, put a child through, and secondly, decide on behalf of someone else? Some social care professionals who support TOPFA in most circumstances argue that parents will place their own feelings before that of their imagined child. It could be suggested that parents may balance what is an acceptable amount of pain to put a child through and wanting to maintain the 'moral' performance.

Many fetal anomalies result in an impairment which renders the sufferer subject to stigma. As a result, many people with impairments will go to great lengths to perform as 'normal'. This performance of 'being normal' occurs to enable sufferers to enjoy the benefits of being normal. Many of the routes to achieve a normal 'self' include entering into medical intervention. Much of this involves painful surgery which may include multiple visits.

Considering the 'normal' perspective is important within this research. What is a normal life trajectory for a non-impaired person was used as a comparative factor when determining the acceptability of TOPFA. Spina bifida provides an interesting insight based on professionals' perceptions of people living with the condition. Many professionals expressed that it seems ridiculous to suggest that those they know who have spina bifida could have been terminated given their legitimate life experiences. However, despite this, many professionals deem it a legitimate reason for TOPFA. This is suggestive of more deep rooted issues surrounding the visual aspects of the condition, most notably the wheelchair.

Consideration as to whether something can be fixed, the level of pain that may be experienced by the imagined child and whether the imagined child will have the ability to function as part of a normal life experience are all considered within TOPFA decisions. This in turn, leads to a consideration of what is the moral thing to do. Thus, professionals perform the 'the moral self' by debating between the above three factors to decide which will present their views on the accessibility of TOPFA in the most moral way. This offers an explanation as to why there may be a discrepancy between different opinions between personal opinions and what should be available in society. For medical professionals, the 'front stage' performance includes working within, and being seen to be working within, the parameters of the legislation. However, the legislation is open to interpretation, which is where their personal interpretation may influence the counselling process. Using the case study of Downs syndrome, many professionals within both professional groups express that they personally do not agree with TOPFA. This may be to perform a moral stance reflecting the current social mood condemns TOPFA for Downs syndrome, and not a reflection of their true feelings which may present them as 'immoral'. They may want to perform a self that would not consider a TOPFA for Downs syndrome.

Understanding the meaning applied in situations surrounding TOPFA decisions are important. The professionals involved in this research hold meanings and understandings about TOPFA which have been influenced by the interactions within their professional roles. Social care professionals' interactions with people with impairments allow them to develop an understanding of a person with an impairment within a social context. This enabled meaning to be created where an understanding of the kind of life a person with an impairment can expect to have, as well as the meaning that person can give to the lives of their family. These meanings and understandings have been found to have both positive

and negative experiences. The negative experience was often not assigned blame, mainly sympathy when parents were unable to cope with the impairment. Medical professionals' interactions with parents after a diagnosis of a fetal anomaly may be an influencing factor in the determination of a 'serious handicap'. Parents may not be 100% behind the child or may outright reject the child which may create a Clause E situation that the anomaly itself may not have justified.

When discussing meanings of a situation, it is important to consider how these meanings come to be constructed. The biomedicine approach within UK has come to dominate pregnancy. Thus medicalisation has continued to keep pregnancy under medical scrutiny. This has resulted in the meanings created from pregnancy and testing being understood from this biomedicine perspective. As a result, 'treatment' is not questioned. . The medical profession does not remain unchallenged and as such may explain why caution may be employed upon the diagnosis of certain anomalies. For example, a TOPFA request for isolated cleft lip may not be supported but TOP under Clause C may be authorised.

This research has explored the views of two groups of professionals on TOPFA, and these two groups of professionals have legitimate interests in the meanings ascribed to impairment and disability. The findings suggest that the views of social care professionals and medical professionals are not radically different, but that the journey to these perspectives are based on different professional experiences, which are then blended with personal views, to form opinions on the acceptability of TOPFA that present a moral self that they can accept.

Chapter 11: Conclusion

11.1 Introduction

This chapter summarises the concluding remarks of this thesis. Using a number of theoretical tools, this thesis has offered an interpretive explanation to the research data. Overall, I argue that TOPFA is deemed an acceptable pregnancy outcome upon consideration of the factors, with acceptable TOPFA negotiated through a performance of 'the moral self'. This 'self' is performed through conceptualisations of pain, normality and whether an anomaly can be 'fixed', and are used to justify an acceptable TOPFA. However, whilst this argument adds to existing research knowledge on this topic, it is by no means an exhaustive exploration of the issues. Much benefit would be gained from future research in this area.

11.2 Summary of arguments

TOPFA is an important issue for continued study, and there remain dilemmas in the ongoing discussion around the topic. The original argument about balancing the right to life of the fetus and the right of bodily autonomy for the pregnant woman is still present. However, against this backdrop, other aspects of the debate have changed. Disability rights have increased, meaning people with impairments have more of a voice in the debate. Improvements in fetal monitoring are resulting in a more detailed and accurate understanding of the developing fetus, and so the diagnosis (and prognosis) of fetal anomalies has become more complex. Within this context of both continuity and change, professional perspectives are important, but less well researched, and thus less well understood. Social care professionals are in a position where they have day-to-day experience with people with impairments in their social context. Providing an insight into their views represents an alternative explanation to the meaning of living with impairments, which can be added to the perspectives of parent carers, which is more dominant in the existing literature. Medical professionals are routinely involved in the domain of reproductive health. They are involved with the management and care of pregnant women and the advice and information they receive (Abbott et al., 2008). They are also involved with the counselling that parents receive after the diagnosis of a fetal anomaly. It is important to understand their perspectives because of the unique position they are in when parents are in a vulnerable place, and have some difficult decisions to make. Their personal opinions may influence the approach they take in their professional roles and therefore it is

important to understand these perspectives. Whilst insight produced from any one disciplinary perspective would have been useful, an interdisciplinary approach was adopted in this instance. This helped to produce a much needed breadth of understanding to an underexplored issue.

Three distinct methodologies were incorporated in this interdisciplinary PhD. Phase one included an analysis of relevant potential case studies and an epidemiological study on TOPFA acceptance rates. Although there was some variation in TOPFA acceptance rates in the eight selected fetal anomalies, the four with the most analytic value for this study were isolated cleft lip, HLH, spina bifida and Downs syndrome. Phase two utilised the questionnaire method, with the data suggesting some areas of professional perspectives on TOPFA were ripe for further discussion in the interview phase, as well as revealing some interesting findings as a standalone method. Phase three adopted the semi-structured interview, of which the data provided data in the form of two key themes: conceptualising the imagined child, and conceptualising the experiences of the imagined child.

The findings from the three phases of the research were combined to generate a simple model to provide insight into the relationship between personal values and professional views on the acceptability of TOPFA. The model generated reflected the key factors (list them briefly here) used by individuals within the sample, in their accounts of acceptability in relation to TOPFA. Using this model best demonstrated the similar points of view on TOPFA in relation to X, Y Z; and best demonstrated the different routes in which that view was reached by individuals in the two professional groups included in the study.

Both social care and medical professionals display a certain level of similarity in their acceptability of TOPFA but their journey to reach these conclusions come from different perspectives. These similarities include; consideration of medical intervention, considerations of pain, considerations for the impact on a 'normal' life experience, and whether an anomaly can be 'fixed' under the biomedical paradigm. These factors are used to maintain a sense of moral integrity when discussing acceptable TOPFA. "Is termination of pregnancy an acceptable pregnancy outcome after the diagnosis of non-lethal fetal anomaly?" is the research question, as detailed in Chapter 5. While it can be safely stated that analysis has shown TOPFA to be an acceptable pregnancy outcome in many instances to the study participants, a multi-layered series of considerations are evident within professionals' responses, which the simple model detailed in the discussion chapter demonstrated. It is clear that for each particular anomaly, a number of implications were

considered which influenced the perspective on the acceptability of TOPFA. Such implications include the pain experienced, engagement with medical treatment, and the potential for a 'normal' life trajectory. After the consideration of all such factors, a clear indication of acceptable TOPFA was not always revealed. Some social care professionals reflected on who's right it is to decide that a fetus has no right to life. This would indicate that even if a life of pain, medical intervention and limited 'normal' life participation were guaranteed, this is not necessarily a justification for TOPFA. The findings suggest that all participants were accepting of the need for TOPFA as a care pathway in at least some cases. This would suggest that all participants had instances in mind where a TOPFA would be an acceptable outcome.

The knowledge, meanings and interactions the different professional groups gain from their professional roles help shape their perspectives on TOPFA. The level of similarity may also be important in terms of assessing the extent to which knowledge about impairment, normality and suffering is constructed with reference to societal level factors. The research has provided data about social care professionals, a previously under-researched group. Data on the personal views of medical professionals has also been presented in this thesis, which has also been neglected. However, it is important to be mindful about what the distinction between personal and professional views actually means and whether it is in fact possible for such views to be distinguished.

In addition to the substantive argument of the thesis, there is also a methodological argument implicit in the interdisciplinary approach adopted. Numerous theoretical tools have been used to offer an explanation of these findings. The successful use of several methodologies, adds to existing discussions supporting mixed methods research where the research would benefit from such methodological choices. The research has also successfully crossed over multiple disciplines with each one bringing in its own perspective and highlighting the potential merits of interdisciplinary research.

11.3 The researchers perspective with regard to the research

The role of the researcher has been studied extensively within the social science paradigm. Numerous challenges are experienced by the researcher; this may be especially prominent when researching sensitive topics (Dickson-Swift et al., 2007). The process of coding, analysing and drawing conclusions may also be impacted by the researcher themselves, with different researchers potentially drawing out different ideas for analytic value, thus different

conclusions from the same data. What needs to be acknowledged is the impact the researcher's perspective has on any research. This research has been composed through numerous factors that have made an impression on me as the researcher.

Although a PhD thesis is necessarily a stand alone piece of work, at the same time this work is the culmination of many years interest in the topic and the wealth of interdisciplinary knowledge drawn on to explore that topic. The completion of this PhD has been the work of myself as a lone researcher, with the guidance of three supervisors, who each represented different a different disciplinary background. The development of the research proposal was the result of several aspects being brought together over a period of 18 months. This time period started during my undergraduate study through to the beginning of my first Masters degree. During my second year of my undergraduate degree (Sociology and Social Policy), I was introduced to the debates and ethical conflicts that surrounded the abortion debate. This was specifically in relation to the US, however, watching a video about the picket lines outside abortion clinics that saw intense campaigning on a daily basis, made an impression on me in terms of what motivated campaigners into such action. This module (social policy) ran alongside my first introduction to medical sociology, where the social construction of knowledge also made an impression on me. Bringing these two aspects together, I completed an undergraduate dissertation on how particular discourses act to impact on societal perceptions of abortion. This was being completed during my third year of my undergraduate study, where I was introduced to the sociology of disability. Having already thought about ideas surrounding TOPFA, this module furthered my ideas by introducing me to the eugenics debates surrounding TOPFA. This discussion and further reading I did on this issue came together in the formulation of the questions this raised for me about how medical professionals' personal values impacted on their views of acceptability in relation to TOPFA.

Having already expressed interest in further study, I decided, with advice, to move into the medical school setting to pursue a Masters degree in Health Sciences. During the summer between finishing my undergraduate degree and starting my Masters degree, I became interested in studying those who worked with people with impairments. This was through discussions I had within my part time employment, in which I had regular contact with people with impairments and their support workers. This was through gym classes; at the time, and throughout studying, I worked as a fitness instructor in a local gym. Through interactions I saw between gym members, who also had impairments, I found myself

drawn to their care support workers and being fascinated by the insight they must have. In turn, I thought their views on TOPFA would be fascinating. Given the lengthy ethics procedures in place for researching NHS staff and patients, researching medical professionals was not an option for a Masters dissertation. This led me to compose a proposal focusing on TOPFA from the perspective of disability care support workers. My supervisor (Dr Graham) felt that my proposal was significantly developed and with some additional work could easily be converted to a PhD proposal. This was when I included the medical profession in the proposal, as the time allowed for a PhD project would allow for the NHS ethical process to be included. The application was sent to the MRC ESRC interdisciplinary studentship open competition, which was successful. This award is of particular value in terms of explicitly supporting the interdisciplinary aspect of the research, given its importance in general in terms of understanding health and illness.

11.4 Study limitations

It is important to appreciate the limitations of a study to enable to appreciate fully the usefulness of the research findings. Whilst qualitative research provides a useful framework within which to do exploratory research in under-explored topic areas, participant samples are usually small scale and unsuited for generalising to a wider population. This research adopted a snowball sampling approach in the recruitment of participants. Snowball sampling is inherently biased as it is a sampling method based on the subjective decision making regarding suitability of participation (Black and Champion, 1976). This study encountered several problems recruiting social care professionals. Much of this surrounded management fear surrounding the subject matter, i.e. TOPFA. This resulted in more limited options in terms of recruitment. Such difficulties in recruitment would also lead to suggestions regarding difficulties in researching sensitive topics such as TOPFA. And so, whilst snowball sampling was invaluable as a recruitment source in this research, it creates other problems in terms of the wider applicability of the findings.

The case study selection phase provided an analysis of eight potential case studies using the predicted value of those selections and epidemiological data on TOP rates in six different regions within the UK. Some regional variation was found between TOPFA acceptance rates. It is important to be aware of the criticisms of epidemiological data used, while still acknowledging its usefulness to the thesis as a whole. Some questions have been raised about the validity of the methods adopted in epidemiological research. This in turn reflects the reliability of the results (Rothman et al., 2008). Rothman et al., (2008) cite an example

of a disparity between findings gained through observational epidemiology. This example highlights contrasting findings regarding research on postmenopausal hormone therapy, as discussed by Prentice et al., (2005). Other criticisms of the nature of epidemiological research can also be found in Chapter 5 of this thesis. Much of this focuses on the issues raised with quantitative research techniques.

The case study which had the most significant regional variation in TOPFA acceptance rates was cleft lip. Rates of TOPFA for cleft lip in the EMSYCAR region were as high as 25.1%. It is possible the epidemiological data collected by the register was flawed in terms of the question asked for this research. It is likely that additional associated anomalies were present in a high proportion of the cleft cases that opted for TOPFA, but the register data did not change the ICD code to indicate this. This may highlight problems with coding data. Also, no register can ever have 100% ascertainment.

The questionnaires provided data on social care and medical professionals feeling about TOP in general, in relation to TOPFA and specific questions relating to the four case study examples. The questionnaire data suggest social care professionals have a lack of general awareness of some conditions, as well as the screening process. A lack of knowledge has also been found among parents undergoing prenatal screening, despite having supposedly given informed consent (Marteau and Dormandy, 2001). A fuller understanding of the screening process may result in different moral thresholds for acceptable gestational age for a TOPFA. The questionnaire data also provides evidence of medical professionals' personal opinions in counselling. This supports existing findings that suggest directive counselling does occur in practice (Statham et al., 2006).

While adopting the questionnaire approach, it is important to be aware of the criticisms, as detailed in Chapter 5. A key criticism is that questionnaires are an inadequate tool to understand the issues being addressed in this thesis. With the benefit of hindsight, some aspects of the questionnaire would have been different. For example, on the medical professional questionnaire, I would have allowed alternative options for those who accept the conscientious objection clause in the TOP legislation to explain their answers. One medical professional expressed how she wanted to answer in a way that expressed her feelings without indicating that her patients do not get the necessary services; she felt my questionnaire did not allow for this. Despite the issues, the aim of the questionnaire to identify information has been satisfied. Phase three of this research, the interview data,

addressed the more complex issues around TOPFA that were identified at the questionnaire phase.

The interview data also provided an insight into social and medical professionals' views about TOP in general, TOPFA, and specific to the four case study examples. These data were more detailed and enabled a more in-depth discussion of some of the issues raised in the questionnaire data. Despite the interview method being the most utilised method of research within the social sciences REF??, it is not a perfect method of data collection. Some of the criticisms centre on practical constraints. The time it takes to plan, recruit, conduct and transcribe interviews can be costly. This often adds restrictions on recruitment location and sample size. However, if the data dictates the use of the interview method of data collection, a large sample size will not be a requirement to gain the information needed. The focus will be on the quality of the data, not the quantity. This was the case for the semi-structured interviews conducted in phase three of this research. It must also be acknowledged that this research does not provide information on actual observations of interactions, despite the use of Goffman's theoretical concepts as a framework for part of the analysis, and interactionism more generally, in the discussion. Further data on actual interactions would be an obvious avenue for useful future research. In a similar way, the theoretical tools used in my study were selected based on my interpretation of the data findings. The theoretical tools I have selected may not be the same as those chosen by a different researcher. This means that the research discussion is my interpretation of the findings, and may not be the same as what another researcher would conclude. This does not, however, discount the value of these research findings, but it is important to understand that the results may not be reproducible in the way that the results of other types of studies may be.

While this PhD research has a number of limitations, the study was conducted in the manner deemed most appropriate for the needs of the research. This study has demonstrated the need for this more localised form of knowledge generation to understand the complexity of the issues involved. The strengths of the approach taken are detailed in Chapter 5.

11.5 Implications for future research

This PhD thesis has demonstrated that TOPFA continues to be a topic of debate within society. This research adds to these existing debates by providing an exploratory insight

into the perspectives of two key professional groups involved in providing care related to either TOPFA, or to a baby born with impairment. The medical professionals are actively involved in diagnosis, counselling and interventions. Social care professionals are actively involved with the support of people living with impairment. Both of these perspectives offer insight into current debates, to supplement the well-established literatures on the rights of the fetus, and the rights of the pregnant woman. This research has provided insight into social care professional views that are underrepresented in this field of research, allowing this professional group to have a voice in research and enable their views to be represented.

This PhD has shown there are many dimensions that contribute to how professional conceptualise the acceptability of TOPFA decisions, and that these dimensions are not widely reported in either the academic, lay or public domains. This research also offers an alternative perspective to TOPFA discussions through the professionals' perspective, as opposed to that of the women or fetus. Including social care professionals also offers an alternative perspective to living with impairment. This is again adding to an existing knowledge which focuses on families with children with impairment. These findings also add to existing arguments that suggest stigma remains a reality for many people with impairments in society. Social care professionals highlighted aspects of life with impairment that continue to be stigmatised. The two most notable examples are visible signs of disgust, and speaking about a person as if they were not present as opposed to them directly as if they are a valid person.

In providing insight into an under-researched area, it is inevitable that this research would also highlight a number of potential areas for further study. One key area for further research is in the general area of researching morally and/or legally sensitive health care topics. This study looked into such issues during recruitment of social care professionals, with some interesting findings emerging. It is important for future projects for such issues with recruitment to be unpacked, discussed and published within articles to establish more effective ways of recruitment. Further research into this area should explore issues in participation, how to overcome these, and how to best present research to potential organisations who deal with the support of people living with impairment. Establishing reasons why people are not participating is important to any research findings as it may shed light onto the topic of study in general. For this particular research project, the lack of

participation highlighted continued stigma surrounding TOPFA, and attempts to distance from such research for fear of being seen to *support* such procedures through participation.

A second general avenue for further research would be to pursue similar questions but with an extended selection of relevant professional groups. Although both professional groups came to similar conclusions about TOPFA, I feel it would be beneficial to explore the views of other relevant professional groups; in particular midwives, paediatric nurses, genetic counsellors may provide an interesting perspective given their different roles and interaction with parents and people with impairment. It would also be informative to extend the research to people with impairments themselves. While researching people with cognitive impairments may be very challenging, those with physical or minor cognitive impairments may offer a similar level of insight in the acceptability of TOPFA, albeit from a different perspective. Lay perspectives more generally would also offer a new dynamic to this discussion. The issues surrounding the moral debates about TOPFA for conditions such as Down's syndrome may offer real insight into the lay views and feelings surrounding TOPFA for such conditions. Why such strong emotions are provoked would also contribute further depth to the findings and resulting explanatory insights.

A more topic specific area for further research would be around the issue of acceptable pain, and what level of pain to decide to put a child through. This is an area of research I feel may offer additional insight into TOPFA decisions, as a means to unpack the meaning of pain in terms of the decisions parents make regarding TOPFA or to continue with a pregnancy. This may also lead to discussions surrounding euthanasia and having a baby to save another child; two other morally contentious issues. Discussions around decisions whether or not to TOPFA for lethal anomalies may also emerge. Previous research has revealed decisions about understandings of pain/suffering to be influential in such decisions (Graham et al., 2008). Two more specific areas of potential further study are issues surrounding non-directive counselling, and the distinction between professional and personal views. These final issues are explored in more detail below.

11.5.1 Counselling

This research has added to existing knowledge regarding non-directive counselling. Non-directive counselling has been found, in previous research, to be very difficult if not impossible to achieve (Janvier et al., 2012; Jeon, 2012; Statham et al., 2006; Pencarinha et al., 1992), despite it being encouraged in medical guidelines (RCOG, 2010, 1996). Other

studies have reported that parents felt counselled to TOPFA (Guon et al., 2013; Walker et al., 2008), again suggesting a more directive approach to counselling is being adopted in practice. This research has revealed professionals admitting to consciously and possibly unconsciously drawing on personal views and experiences during counselling after a diagnosis of fetal anomaly, and adds weight to arguments that transparency may be a more meaningful goal than neutrality in such interactions. I propose that further research is needed in this area. The results of this study demonstrate that medical professionals, in many instances, have openly discussed being 'non, non-directive' in their counselling relating to fetal anomalies. I use the term 'non, non-directive' as the data suggest that not being 'non-directive' does not automatically equate to being directive. No medical professional stated they had ever said outright what pregnancy outcome parents should decide. This however, does not take away from the fact that the evidence in this study suggests both implicitly and explicitly a non-directive approach is not being adopted in many circumstances. At present, the documentation available to medical professionals would appear to suggest that if you are not counselling in a non-directive manner, you are thus being directive. The data clearly show that this is an over simplification of what is occurring in practice. This would suggest that there needs to be some form of definition of the 'grey area' that exists between being strongly directive and being strongly non-directive in the approach to patient/parent counselling. Evidence is available within the academic sphere that has concluded that non-directive counselling is very difficult if not impossible (for example Statham et al., 2006), however, no research has attempted to bridge the gap between directive and non-directive counselling.

This research supports the work of those like Statham et al (2006), by demonstrating that that non-directive counselling is very difficult. It is also important to acknowledge that as humans, medical professionals are subject to human emotion. This means that fully eliminating bias from all circumstances is likely to be impossible. The data also show that counselling was not either directive or, non-directive. When a 'non, non-directive' approach was adopted by medical professionals, this did not automatically equate to a directive approach. Thus, this approach was not done to openly push parents in a particular decision per say. In many cases, it was adopted based on the belief that the parents did not understand the implications of their decision, i.e. to ensure an appropriate level of informed consent. While this may reflect particular biases about certain fetal anomalies, the counselling technique was assumed in the best interests of the parents involved.

The legislation governing TOPFA leaves the decision, thus the interpretation of the law, with the medical professional (Lee, 2003). Medical professionals are in a position whereby they can refuse a TOPFA if they deem the request does not satisfy Clause E. Refusing to offer or to authorise a TOPFA for a particular anomaly may also be argued to reflect a personal opinion, and again is an issue worthy of further exploration. Being in a position to agree to a TOPFA for one condition and not another was raised as a concern for Medical Professional 3. She, in particular, felt if you were prepared to offer TOPFA then distinguishing between conditions was inappropriate, due to personal bias and *playing god*. The interviews have indicated many medical professionals using personal views and experiences to aid in their own definition of a serious anomaly. However, given the implications of human emotions, and the experiences of gaining meaning and understanding from personal and professional interactions, it is unsurprising that personal views and experiences shape professional opinions.

At present, the concept of directive counselling assumes there is a dichotomy of yes and no, but actually, there is in fact a spectrum, with 'pure' versions of non-directive in reality being a very difficult achievement. I recommend additional research focused on the issue of defining working definitions of directive and non-directive counselling that can be used to guide skill development, and to provide a structure for self reflection, in clinical practice. This research should address (a) what the medical professionals themselves deem a realistic approach to counselling, and (b) how to define the 'grey area' that exists between the realms of directive and non-directive, where it is likely the majority of counselling currently lies. Establishing a more realistic framework for counselling will maintain transparency within the guidelines, and create a more user-friendly approach for medical professionals, and allow individual clinicians to continue to reflect on and develop their skills as part of an ongoing dialogue in their professional communities.

11.5.2 The distinction between personal and professional views

This research has offered a distinction between personal and professional views. These distinctions were based on the professionals' own perceptions of what they felt were their personal and professional views. It is important to be aware of the distinction and to question the extent to which it is possible to differentiate between personal and professional views. A difference between social care and medical professionals is apparent in this consideration. For social care professionals, they are not involved in any TOPFA discussions with parents. They also work in a professional capacity with people with

impairments. They do not have to make decisions in their line of work regarding whether a particular impairment satisfies the legal criteria for TOPFA. It is therefore, important to acknowledge the extent to whether their professional opinion was their personal opinion and vice versa. There is less distinction between maintaining a professional demeanour in terms of personal and professional feelings towards TOPFA. It is also unlikely that discussions around TOPFA emerge as a basis of regular discussion within their professional role. Thus, as a result, it could be argued that there may be little difference between a professional and personal opinion with regard to TOPFA as there is no professional requirement to maintain a professional opinion on such issues.

For medical professionals, a typical example of the distinction between professional and personal opinions was; *professionally I agree with TOPFA for a particularly condition as it is deemed serious as per the wording of the legislation, thus Clause E would be applicable however personally it is not an anomaly I deem serious enough to have a TOPFA for, and is not something I would consider personally.* While there is an obvious distinction in this dialogue, it can be asked whether there is in fact a clear distinction between professional and personal views. For example, the counselling of the condition in question in this dialogue may reflect the personal opinions the medical professional has. Thus a focus on the positive aspects may inadvertently happen as a reflection of the personal opinion. Another example can be seen when discussing lethal anomalies. Some medical professionals could not personally comprehend why parents would continue a pregnancy after a diagnosis of a lethal anomaly. Thus, their counselling, as part of their professional role, reflected this personal opinion in that they felt *you have to constantly bang on about it because you think, surely you haven't understood.* Research shows there is a danger in making assumptions about what the 'correct' way to act during pregnancy loss (Earle et al., 2009). In this example, after a diagnosis of a lethal anomaly for this particular medical professional was a TOPFA. A more effective response from professionals has been said to be to find out the wishes and needs of the patient involved (Earle et al., 2009: 89).

The decision as to whether a TOPFA for a particular anomaly is legal as per Clause E is based on decisions by medical professionals made in good faith. Thus it could be argued that personal insight may act to influence the decision made in good faith. The data also suggest distinctions between what medical professionals felt was legally acceptable and what was personally acceptable. Thus a difference emerges between what a medical professional will authorise within the context of their work, and what they would

personally do if it were them. For example, Medical Professional 12 discussed anomalies in the context of the impact of the child; *it's a pretty grim thing to have, if you were going to offer TOPFA then that is the sort of condition I would feel should be available*. However, she made it very clear that during all three of her pregnancies, she did not have any fetal anomaly screening, and indicated clearly she personally did not agree with TOPFA for any condition. It could be argued a difference between what is acceptable in a professional opinion and her personal opinion is clear in terms of what she felt was acceptable legally, and what she felt was acceptable personally. In this instance, personally there were no exceptions to an acceptable TOPFA, which was demonstrated through her refusal of all fetal anomaly screening.

While this section is arguing there may be a smaller distinction between personal and professional opinions than what previous chapters, or professionals themselves have suggested. This is a distinction worthy of investigation in future research, given that part of the 'job' of being a professional is that you are expected to hold a 'professional' rather than a personal view of things. It is also important to acknowledge how professionals define their own opinions. While it may be that professional and personal opinions are close than professionals themselves realise and thus discuss during the interview, this research has used professionals' own distinctions between personal and professional opinions within the results, and subsequent discussion chapter.

11.6 Concluding remarks

To conclude, this study argues that a number of factors are considered when conceptualising acceptable TOPFA which were focused around portraying a 'moral self'. Overall, the data supports the availability of TOPFA, and suggests no strong desire to change the existing legislation. Both professional groups come to similar conclusions albeit through different personal and professional experiences. Recent debates regarding lowering the upper limit, or restricting access to TOP and TOPFA are not supported by my research findings. Parental choice was supported in many instances, though not a strong theme in isolation, even if those choices were in conflict with the professionals own views. Parental choice was discussed in keeping with maintaining the 'moral self' as some professionals indicated that it may be unethical to deny choice. The findings have also added support to existing arguments surrounding personal views of medical professionals influencing their practices. It has also provided the view of a previously under represented professional group. The value of a mixed methods and interdisciplinary approach has been invaluable to

answering the research question. This approach provided a fruitful avenue in the pursuit of researching perspectives of acceptable TOPFA for non-lethal fetal anomaly from the professionals' viewpoint, which has previously been given little research attention.

Appendices



Termination of Pregnancy for non lethal fetal anomaly: Professional perspectives.

Participant Information Sheet (version 2, 25.11.10)

You have received this participant information form because your work involves providing care for people who have a disability, or who have a pregnancy affected by fetal anomaly. In this research project, I am interested in finding out your views about women's access to termination of pregnancy for fetal anomaly. Before you decide whether or not to take part, it is important for you to understand why the research is being conducted and what will be involved in the study. Please take time to read the following information carefully, and discuss it with others if you wish.

What is the purpose of the study?

Termination of pregnancy generates much critical interest, with a current focus on the role of the medical professional within that process. In recent times, the issue of service delivery for TOP before 12 weeks has been a regular headline topic and has been the subject of recent House of Commons Select Committee reviews. Within this context of concern about the gestational age at which TOP can take place, TOP for fetal anomaly (TOPFA) attracts particular attention. The legitimacy of TOPFA has been challenged by a strengthening disability rights movement in the West, and some have questioned the availability of Clause E within Act. Over the same period, technological advances, particularly in fetal ultrasound, have increased the accuracy of both identifying some fetal anomalies (e.g. spina bifida) and detecting an increased risk of others (e.g. Down's Syndrome).

Debates on TOP tend to focus on the relative rights of the mother and the fetus, and the personal (rather than professional) views of those providing health and social care in related areas are less well understood. In this study, I am interested in finding out about your experiences and views on the accessibility of TOP for fetal anomaly. It is important to understand the views of health and social care professionals in this field to inform ongoing policy debates about how decisions for TOP FA are made, to ensure that the views of professionals who provide care as part of their work are considered alongside those of the mother and the fetus.

Do I have to Take Part?

No. Recruitment has not been random, as I would like to select for a diverse sample population. The decision to participate in the study however remains with you, you can withdraw from the research at any time without having to give a reason. If you decide to take part, you will be given this information sheet to keep.

Crowe (2010) TOP for non lethal fetal anomaly: professional perspectives (Participant information sheet, v2, 25.11.10)

What will happen to me if I take part?

If you agree to participate in the study, you will need to complete and return the enclosed questionnaire survey in the return envelope provided. If you do not wish to be considered for the in-depth interview stage of the study, then no further action is required.

I am recruiting participants from four sites. At two of these sites, some participants will be invited to take part in an in-depth interview. If you indicate that you are willing to be contacted for an in-depth interview on the survey return, you may be contacted by the researcher (Lisa Crowe) by telephone or email to see if you are still interested in undertaking an interview. If appropriate a convenient time to meet will be arranged. The interview can take place in your preferred location of 1) your place of work; 2) your home; 3) a quiet room at Newcastle University; or 4) a public location of your choice. The interview will normally last for approximately 45-90 minutes. At the beginning of the interview you will be asked to sign the study consent form. You will be given a copy of the consent form to keep. If you do not mind, the interview will be tape recorded. However, if you do not wish this, then notes can be taken instead.

The interview can be ended or postponed at any time you wish, and you do not have to give a reason for withdrawing from the study. If you would like a copy of the interview transcript, this can be made available if you so wish. You can withdraw from the study at any time. The results from the study will be available on request; please let me know by email if you wish to have your contact details stored for the purposes of dissemination of the results. Expenses for travel relating to your participation in an interview are also available on request.

Are there any disadvantages of taking part in the study?

With the research being of a sensitive nature, you may feel distressed as a result of the discussion.

What are the possible benefits of taking part?

The information received in this study may not be directly beneficial to you, but may help to provide insight to future discussions and debates on termination of pregnancy and termination of pregnancy for fetal anomalies.

Will my taking part in this study be kept confidential?

All information that is provided by you during the research will be kept strictly confidential. However, if you choose to reveal information regarding a serious breach of professional conduct, this information may need to be disclosed to individuals beyond the research team.

Contact Information

Should you require any further information about the study please contact:

Lisa Crowe: L.L.Crowe@ncl.ac.uk
School of Geography, Politics and Sociology
Newcastle University
Newcastle Upon Tyne
NE1 7RU
Tel: (0191) 222 7459

Supervisors

Dr. Ruth Graham R.H.Graham@ncl.ac.uk
Prof. Steve Robson S.C.Robson@ncl.ac.uk
Prof. Judith Rankin J.M.Rankin@ncl.ac.uk

Crowe (2010) TOP for non lethal fetal anomaly: professional perspectives (Participant information sheet, v2, 25.11.10)



Dear XXXXX

Research Project:

Termination of pregnancy for non lethal fetal anomalies: professional perspectives

Lisa Crowe (PhD student)

Supervisors: Dr R Graham, Prof S Robson & Prof J Rankin, Newcastle University

I am writing to invite you to take part in a research study which is exploring views and experiences of health and social care professionals, in relation to their work with people with disabilities or with pregnancies affected by fetal anomaly. This study is being organised as part of a doctoral programme by myself, Lisa Crowe, at Newcastle University. The project has received ethics approval from the XXXXX REC (MREC ref).

There is relatively little research on the views and experiences of health and social care professionals working in these areas. The aim of this research project is to explore the views of relevant professionals and to compare professionals' conceptualisations of disabilities in different fields of practice. The findings from the project will provide important insight into developing understandings of professionals' views about their work.

Participating in this study involves completing the attached short questionnaire, which I anticipate will take approximately 20 minutes. I also hope to conduct some in-depth interviews with some of those who return a completed survey, and this will take approximately one hour. If you would like to consider taking part in the in-depth interview aspect of the study, please provide your contact details as directed in the last section of the questionnaire.

I very much hope that you will agree to help us with this important study. If you would like to take part, please read the Participant Information Sheet attached. Completed questionnaires can be returned by post, using the stamped addressed return envelope enclosed. The study has been designed so that your response is anonymous; if you decide to give information so that I can contact you regarding the in-depth interview aspect of the study, these details will be detached from your survey response on receipt.

If you would like any further information, please get in touch with myself Lisa Crowe (l.l.crowe@ncl.ac.uk), or my doctoral supervisor Dr Ruth Graham (r.h.graham@ncl.ac.uk)

Yours sincerely

Lisa Crowe
Doctoral researcher, Newcastle University

Crowe (2010) TOP for non lethal fetal anomaly: professional perspectives. Invitation letter v1, 20.9.10

PARTICIPANT CONSENT FORM

Title of project:

Termination of pregnancy for non lethal fetal anomaly: professional perspectives

Name of Researcher (PhD student): Lisa Crowe

Name of Supervisors: Dr. R.H. Graham, Professor S.C. Robson, Professor J. Rankin.

Initials

- 1. I confirm I have read and understood the information sheet dated.....for the study titled above.
- 2. I understand and acknowledge I have had the opportunity to consider the information, ask questions and have had satisfactory answers.
- 3. I understand that my participation is voluntary and that I am free to withdraw from the research at any time, without giving any reason, without my legal rights being affected.
- 4. I confirm that I agree to the interview being audio recorded.
- 5. I am aware that the audio recording will be listened to and transcribed by the researcher (Lisa Crowe) and after completion of the research, the audio recordings will be destroyed, but the transcripts kept (in accordance with the Data Protection Act) in a secure location for 10 years.
- 6. The transcript will have no identifiable features included on it; pseudonyms (e.g. Participant 1) will be used to replace any names.
- 7. I understand that small sections of my written interview transcript ('quotes') may be used in the thesis write up and in any other published writing about the study, and I will not be identified at any time.
- 8. I agree that the transcripts (which will be anonymised with no way of the transcript being traced back to me) can be used in any future research of which they may be of value to.
- 9. I agree to take part in the above study.

Name of Participant
Date
Signature

Researcher
Date
Signature

Consent form version 1 20.9.10



Title of project:

Termination of pregnancy for non lethal fetal anomaly: professional perspectives

Name of Researcher (PhD student): Lisa Crowe

Name of Supervisors: Dr. R.H. Graham, Professor S.C. Robson, Professor J.M. Rankin.

University: School of Geography, Politics and Sociology

Newcastle University

5th Floor, Claremont Bridge Building

Claremont Road

Newcastle Upon Tyne

NE1 7RU

[REC reference here]

Social Professionals Questionnaire v1 20.9.10

Section 1

1. Do you have any personal opinions about women's access to TOP in the UK ?

Yes

No

I don't know

2. Which statement below best sums up your opinions on whether TOP should be available to pregnant women in the UK ?

	Personally	Professionally
I am 100% against TOP for any circumstances.	<input type="checkbox"/>	<input type="checkbox"/>
I am against TOP with the exception of certain extreme circumstances (for example risk to the life of the pregnant woman).	<input type="checkbox"/>	<input type="checkbox"/>
I don't mind what is available but wouldn't consider it for myself/my partner.	<input type="checkbox"/>	<input type="checkbox"/>
I am 100% in agreement for the availability of TOP.	<input type="checkbox"/>	<input type="checkbox"/>
I think TOP should be freely available on demand.	<input type="checkbox"/>	<input type="checkbox"/>

3. Do you have any personal views on women's current access to TOP on the grounds of fetal anomaly that are associated with disabilities after birth?

Yes

No

I don't know

4. Which statement below best sums up your personal opinions on whether current availability of TOP for fetal anomaly is acceptable?

I am 100% against TOP for any type of fetal anomaly.	<input type="checkbox"/>
I accept the availability of TOP for disabilities only when the fetal anomaly in question is deemed to be incompatible with life.	<input type="checkbox"/>
I accept the availability of TOP for disabilities only when the expected disability in question is deemed to be so serious that the potential child would need substantial extra support above that required of a child without a disability.	<input type="checkbox"/>
I accept the availability of TOP for disabilities when the expected disability in question is deemed to be so serious that the potential child would need some additional support above that required of a child without a disability.	<input type="checkbox"/>
I accept the availability of TOP for any fetal anomaly but would not accept it as an option for myself/my partner.	<input type="checkbox"/>
I accept the availability of TOP for any fetal anomaly if the parents feel it is the right choice for them.	<input type="checkbox"/>
I don't know	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>

Case Study 1: Isolated Cleft Lip

5. Have you had personal experience in working with parents after a diagnosis of isolated cleft lip in your line of work?

Yes

No

I don't know

6. Do you have experiences that give you insight into the quality of life for someone living with cleft lip?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

7. Do you feel parents get an adequately informed perspective of what living with a child with cleft lip would be like?

Yes

No

I don't know

8. Do you think assumptions are made about an individual's abilities when cleft lip is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

9. Has your experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to cleft lip ?

Yes No I don't know

10. What gestational age do you think it is acceptable to TOP for cleft lip? (Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Case Study Two: Hypoplastic Left Heart

11. Have you had personal experience in working with parents after a diagnosis of hypoplastic left heart in your line of work?

Yes

No

I don't know

12. Do you have experiences that give you insight into the quality of life for someone living with hypoplastic left heart?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

13. Do you feel parents get an adequately informed perspective of what living with a child with hypoplastic left heart would be like?

Yes

No

I don't know

14. Do you think assumptions are made about an individual's abilities when hypoplastic left heart is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

15. Has your experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to hypoplastic left heart ?

Yes No I don't know

16. What gestational age do you think it is acceptable to TOP for hypoplastic left heart ?
(Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Case Study Three: Spina bifida

17. Have you had personal experience in working with parents after a diagnosis of spina bifida in your line of work?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

18. Do you have experiences that give you insight into the quality of life for someone living with spina bifida?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

19. Do you feel parents get an adequately informed perspective of what living with a child with spina bifida would be like?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

20. Do you think assumptions are made about an individual's abilities when spina bifida is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

21. Has your experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to spina bifida ?

Yes	No	I don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22. What gestational age do you think it is acceptable to TOP for spina bifida? (Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Case Study 4: Downs Syndrome

23. Have you had personal experience in working with parents after a diagnosis of Downs Syndrome in your line of work?

Yes

No

I don't know

24. Do you have experiences that give you insight into the quality of life for someone living with Downs Syndrome?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

25. Do you feel parents get an adequately informed perspective of what living with a child with Downs Syndrome would be like?

Yes

No

I don't know

26. Do you think assumptions are made about an individual's abilities when Downs Syndrome is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

27. Has your experience of working with people with disabilities affected your views on whether termination of pregnancy should be available in relation to Downs Syndrome ?

Yes No I don't know

28. What gestational age do you think it is acceptable to TOP for Downs Syndrome? (Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Section 3: demographic details

30. How old are you?

< 35 yrs 36 - 40 yrs 41 – 45 yrs

46 – 50 yrs 51 – 55 yrs 56 – 60 yrs > 61 yrs

31. Are you: male female

32. How long have you been working professionally with issues related to disability care ?

1995 or prior 1996 – 2000

2001 - 2006 2007 - 2011

Section 4:

This section is voluntary and will not affect the participation in section 1 of this questionnaire. If you would be interested in participating in an in-depth interview to further explore and discuss some of the issues mentioned above then please leave your contact details below.

At this stage you are expressing an interest to participate; this is not binding and you can change your mind at any time, without having to give a reason.

Name:

Email:

Contact Number:

Preferred means of contact:

Thank you very much for taking the time to fill in this questionnaire.



Title of project:

Termination of pregnancy for non lethal fetal anomaly: professional perspectives

Name of Researcher (PhD student): Lisa Crowe

Name of Supervisors: Dr. R.H. Graham, Professor S.C. Robson, Professor J.M. Rankin.

University: School of Geography, Politics and Sociology

Newcastle University

5th Floor, Claremont Bridge Building

Claremont Road

Newcastle Upon Tyne

NE1 7RU

[REC reference here]

Medical Questionnaire v1 20.9.10

Section 1

1. Do you have any personal opinions about women's access to TOP in the UK ?

Yes

No

I don't know

2. Do you feel that you have a professional duty to provide TOP ?

Yes

No

I don't know

3. If you have personal views on access to TOP, are these personal views related to a sense of professional obligation?

Yes

No

I don't know

4. Which statement below best sums up your opinions on whether TOP should be available to pregnant women in the UK ?

	Personally	Professionally
I am 100% against TOP for any circumstances.	<input type="checkbox"/>	<input type="checkbox"/>
I am against TOP with the exception of certain extreme circumstances (for example risk to the life of the pregnant woman).	<input type="checkbox"/>	<input type="checkbox"/>
I don't mind what is available but wouldn't consider it for myself/my partner.	<input type="checkbox"/>	<input type="checkbox"/>
I am 100% in agreement for the availability of TOP.	<input type="checkbox"/>	<input type="checkbox"/>
I think TOP should be freely available on demand.	<input type="checkbox"/>	<input type="checkbox"/>

5. Do you have any personal views on women's current access to TOP on the grounds of fetal anomaly?

Yes

No

I don't know

6. Which statement below best sums up your personal opinions on whether current availability of TOP for fetal anomaly is acceptable?

I am 100% against TOP for any type of fetal anomaly.

I accept the availability of TOP for disabilities only when the fetal anomaly in question is deemed to be incompatible with life.

I accept the availability of TOP for disabilities only when the expected disability in question is deemed to be so serious that the potential child would need substantial extra support above that required of a child without a disability.

I accept the availability of TOP for disabilities when the expected disability in question is deemed to be so serious that the potential child would need some additional support above that required of a child without a disability.

I accept the availability of TOP for any fetal anomaly but would not accept it as an option for myself/my partner.

I accept the availability of TOP for any fetal anomaly if the parents feel it is the right choice for them.

I don't know

Other (please specify)

Case Study 1: Isolated Cleft Lip

7. Have you had personal experience in working with parents after a diagnosis of isolated cleft lip in your line of work?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

8. Do you have experiences that give you insight into the quality of life for someone living with cleft lip?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

9. Do you feel parents get an adequately informed perspective of what living with a child with cleft lip would be like?

	Parents I see at work	Parents seen in my unit	Parents seen in the NHS across the UK
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Do you think assumptions are made about an individual's abilities when cleft lip is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

11. Which of the following influence the advice you would give to a prospective parent regarding this condition?

	Yes	No	I don't know
Medical Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. What gestational age do you think it is acceptable to TOP for cleft lip? (Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Case Study Two: Hypoplastic Left Heart

13. Have you had personal experience in working with parents after a diagnosis of hypoplastic left heart in your line of work?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

13. Do you have experiences that give you insight into the quality of life for someone living with hypoplastic left heart?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

14. Do you feel parents get an adequately informed perspective of what living with a child with hypoplastic left heart would be like?

	Parents I see at work	Parents seen in my unit	Parents seen in the NHS across the UK
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15. Do you think assumptions are made about an individual's abilities when hypoplastic left heart is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

16. Which of the following influence the advice you would give to a prospective parent regarding this condition?

	Yes	No	I don't know
Medical Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. What gestational age do you think it is acceptable to TOP for hypoplastic left heart ?
(Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Case Study Three: Spina bifida

18. Have you had personal experience in working with parents after a diagnosis of spina bifida in your line of work?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

19. Do you have experiences that give you insight into the quality of life for someone living with spina bifida?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

20. Do you feel parents get an adequately informed perspective of what living with a child with spina bifida would be like?

	Parents I see at work	Parents seen in my unit	Parents seen in the NHS across the UK
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. Do you think assumptions are made about an individual's abilities when spina bifida is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

22. Which of the following influence the advice you would give to a prospective parent regarding this condition?

	Yes	No	I don't know
Medical Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. What gestational age do you think it is acceptable to TOP for spina bifida? (Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Case Study 4: Downs Syndrome

24. Have you had personal experience in working with parents after a diagnosis of Downs Syndrome in your line of work?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
I don't know	<input type="checkbox"/>

25. Do you have experiences that give you insight into the quality of life for someone living with Downs Syndrome?

	Personal experiences (e.g. family, friends)	professional experiences
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

26. Do you feel parents get an adequately informed perspective of what living with a child with Downs Syndrome would be like?

	Parents I see at work	Parents seen in my unit	Parents seen in the NHS across the UK
Yes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

27. Do you think assumptions are made about an individual's abilities when Downs Syndrome is discussed by non professionals ?

	Intellectual disability	Physical disability
Yes	<input type="checkbox"/>	<input type="checkbox"/>
No	<input type="checkbox"/>	<input type="checkbox"/>
I don't know	<input type="checkbox"/>	<input type="checkbox"/>

28. Which of the following influence the advice you would give to a prospective parent regarding this condition?

	Yes	No	I don't know
Medical Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Facts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal views	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. What gestational age do you think it is acceptable to TOP for Downs Syndrome? (Please tick all that apply)

12 weeks or under	<input type="checkbox"/>	22-24 weeks	<input type="checkbox"/>
13-15 weeks	<input type="checkbox"/>	25-30 weeks	<input type="checkbox"/>
16-18 weeks	<input type="checkbox"/>	31 weeks or over	<input type="checkbox"/>
19-21 weeks	<input type="checkbox"/>	Never	<input type="checkbox"/>

If you wish to clarify your response, please do so in the space below:

Section 3: demographic details

30. How old are you?

< 35 yrs 36 - 40 yrs 41 – 45 yrs
46 – 50 yrs 51 – 55 yrs 56 – 60 yrs > 61 yrs

31. Are you: male female

32. How long have you been working professionally with issues related to fetal anomaly ?

1995 or prior 1996 – 2000
2001 - 2006 2007 - 2011

Section 4:

This section is voluntary and will not affect the participation in section 1 of this questionnaire. If you would be interested in participating in an in-depth interview to further explore and discuss some of the issues mentioned above then please leave your contact details below.

At this stage you are expressing an interest to participate; this is not binding and you can change your mind at any time, without having to give a reason.

Name:

Email:

Contact Number:

Preferred means of contact:

Thank you very much for taking the time to fill in this questionnaire.

Research study: TOP for non lethal fetal anomaly: professional perspectives
Additional clinical information sheet A, version 1, 30.9.10

Case Study 1: Isolated Cleft Lip

A cleft lip arises when the upper lip fails to develop normally leaving a 'gap' in the lip which may extend into the nose. Cleft The cleft can be unilateral (on one side) or bilateral (on both sides) and may be associated with a cleft (gap) in the roof of the mouth (cleft palate). Apart from the disfigurement, a baby with a cleft lip, especially if it associated with a cleft palate, may experience problems eating and speaking. Clefts can be successfully repaired with surgery which is ideally done during the first year of life. More extensive clefts also need ongoing input from dental and speech therapists.

Case Study 2: Hypoplastic Left Heart

Hypoplastic left heart (HLH) occurs when the left side of the heart fails to develop normally such that the pumping chamber (the left ventricle) is very small. Since the left ventricle pumps blood around the body, children with HLH struggle to get enough blood to the vital organs like the brain. Without major heart surgery the condition is fatal. Babies usually require multiple operations during childhood but in many cases survival is limited.

Case Study 3: Spina Bifida

Spina bifida occurs when the spine fails to develop normally such that the nerves in the spinal cord are not protected by the bony spine and overlying skin. As a result the exposed nerves are damaged resulting in a range of problems including difficulties with walking and bowel / bladder control (incontinence). The severity of these problems varies with the level of the spina bifida. Spina bifida can be surgically closed after birth, but normal function is not restored to the damaged nerves. Also children with spina bifida often develop hydrocephalus (an increase in fluid within the brain) which requires a separate operation to insert a tube (shunt) to drain the fluid. Sometimes shunts can get infected and this may lead to learning difficulties

Case Study 4: Downs syndrome

Downs syndrome is a chromosomal disorder where children have an extra copy of the 21st chromosome. This results in the physical features of Downs syndrome which include a characteristic facial appearance (with a protruding tongue, small ears, flat nose). All children with Downs syndrome will have learning difficulties which can range from mild to moderate. Some children with Down syndrome also have other abnormalities (e.g. heart

problems). After the first year of life, the outlook improves dramatically with the current average life expectancy around 50.

TOP for non lethal fetal anomaly: professional perspectives (Information sheet B, v1, 30.9.10)
Summary of Clauses re: 1990 Human Fertilization and Embryology Act

Clause A: Continuing the pregnancy will be a risk to the life of the woman, a bigger risk than if the pregnancy were terminated.

Clause B: Termination is necessary to prevent serious permanent injury to the pregnant woman; this can be physical or mental health.

Clause C: The pregnancy is before 24 weeks gestation and to continue with the pregnancy would be a risk of injury to the physical or mental health of the pregnant woman, a risk greater than the termination of the pregnancy.

Clause D: The pregnancy is before 24 weeks gestation and to continue with the pregnancy would be a risk of injury to the physical or mental health of any existing children of the family of the pregnant woman, a risk greater than the termination of the pregnancy.

Clause E: There is substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be serious handicapped.

Clause F: to save the life of the pregnant woman.

Clause G: to prevent the serious permanent injury to the physical or mental health of the pregnant woman.

Source: Department of Health (2008), 'Statistical Bulletin: Abortion Statistics, England and Wales: 2007', *National Statistics* (available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_085508 accessed 3rd February, 2009).

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