

WOMEN'S EXPERIENCES WITH MEDICAL, SOCIAL, AND MORAL ISSUES
OF OPEN-UTERINE SURGERY TO REPAIR SPINA BIFIDA

By

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For Shane and Sophia, with love
and thanks for all you have taught me

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INTRODUCTION: WOMEN’S EXPERIENCES WITH OPEN-UTERINE SURGERY TO REPAIR SPINA BIFIDA

When I first learned about open-uterine surgery to repair spina bifida, I responded with astonishment: “They can do that? That’s amazing!” The wonder at the technological and medical feat is the starting - and ending - point of the story for most people. But as I began learning about the development of this cutting edge procedure and about the women who chose to undergo it, my focus and attention shifted: my wonder was no longer directed towards the technological aspects of the surgery. Instead, I began thinking about the women and families: “They can do that? That’s amazing!” I started wondering about the different elements of such a morally and medically complex decision. How did women learn about spina bifida and the prenatal surgery? How did they make sense of the certain harms and probable risks with the uncertain possibility of benefit? What mattered to them in their decision-making, as they weighed risks and benefits, and considered the future for their child-to-be with spina bifida? How were ethical issues addressed in clinical encounters? These questions began orienting my research into women’s experiences with medical, social, and moral issues with open-uterine surgery to repair spina bifida.

The complexity and uncertainty of the clinical circumstances and the fervor of the ethical controversies surrounding this procedure made the challenges of moral inquiry apparent early in my research. First, it became apparent that except for the women and families considering open-uterine surgery, neither this innovative procedure, nor the

spina bifida it is designed to repair was well known. As such, the medical and ethical concerns emerged as the typical – and circumscribing – frames for the discourses about what mattered, even for women making decisions about these procedures. Further, and more troubling, it appeared that in trying to resolve the many controversies about this procedure, the medical and ethical discourses rarely took account of the experiences of women and their families. In the clinical setting, this often translated into a procedural model of informed consent that overlooked the social and moral experiences, values, and resources women brought to decision-making. Though many claimed to address the ethical issues that emerged, only a few ethicists considered whether women’s experiences could or should inform discussions of ethics for maternal-fetal surgeries. Thus, the challenge for my project of trying to learn about women’s experiences would require research beyond the dominant medical and ethical discourses.

My initial questions of method emerged as I began recognizing these challenges to moral inquiry about women’s experiences. The complexity of the issues, the limited discourses available to address those issues, and the absence of women’s voices meant that if I wanted to learn about and understand what mattered in open-uterine surgery to repair spina bifida, my research would need to be complex and multi-faceted as well. I would need to account for the complex constellation of medical and ethical issues, I would need to use and expand the available discourses, and I would need to identify and highlight the social and moral concerns being neglected by the discourses that overlooked women’s experiences.

To begin to understand the complex medical, social, and moral issues that emerge from this innovative procedure and influence’ women’s decision-making, I had to

become familiar with the circumstances surrounding the procedure. In Part I: the Circumstances at Hand, Chapter I focuses on the medical and surgical circumstances surrounding the procedure. In particular, the chapter emphasizes the clinical presentations of spina bifida and the history of its treatments. It also details the development of surgical procedures for maternal-fetal surgeries, including open-uterine surgery to repair spina bifida, and the design of the Management of Myelomeningocele Study (MOMS trial), a multi-center, randomized clinical trial evaluating the surgical outcomes of the procedure. Chapter II identifies and probes the “ethics of maternal-fetal surgeries,” including this procedure, through the medical and social discourses available in the professional literature. This chapter reviews and engages key issues such as the justifications for experimental procedures and the validation of research, the moral status of the fetus as patient and the relationship between the pregnant woman and the fetus, and finally, the ethics consultation process designed specifically for open-uterine surgery to repair spina bifida. However, even with the multiple perspectives available regarding what matters in open-uterine surgery to repair spina bifida, as Chapter III shows, some stories are overlooked or are otherwise missing from considerations of these procedures. There are very few stories available from the women who considered the surgery and made a decision about whether to pursue it or not, even though these women were most directly and dramatically affected by the procedure.

To address this lack, my project begins with the pursuit of the missing stories about the procedure and identifying the methodologies and methods necessary for learning about women’s experiences and decision-making. The methodologies and methods emerged through preliminary research: attention to and probing the

circumstances at hand in open-uterine surgery to repair spina bifida. The most promising approach, for my concerns for understanding what mattered in this procedure, was using qualitative interviews to learn about and learn from the experiences of women who were offered, who considered and who made decisions about the surgery.

Part II: Methodologies and Methods considers questions of how to investigate and probe moral experiences and ethical issues like decision-making. Chapter IV describes the methodological questions and processes of my preliminary research, which were shaped and influenced by Adele Clarke's *Situational Analysis*. It also identifies the limitations of methodology in conducting research in moral and social themes. Chapter V takes up the challenge of those limitations by considering questions of method for research, drawing from Pierre Bourdieu's work on sociological interviewing and understanding, and from Richard M. Zaner's deeply moral concerns about method and understanding in clinical ethics consultations. Chapter V also considers the question of method for analyzing and learning from women's experiences, using key categories from the sociological and phenomenological work of William James and Alfred Schutz.

Part III: Women's Experiences and Decision-Making identifies and reflects on themes from my research into women's accounts of open-uterine surgery to repair spina bifida. By framing women's accounts with categories from James and Schutz, Chapter VI identifies and engages key moral concerns women described in the interviews, such as the difficult experiences of diagnosis and learning about disability, the importance of prayer, faith, and community, the process of decision-making, and the challenges of living with their decisions. As ethics consultations figure largely in women's accounts, and in the ethical discourses discussed in Chapters II and III, the final chapter, reflects on

methods and activities of ethics consultation. In particular, Chapter VII identifies the potential benefits and harms of ethics consultation itself, offers suggestions for ethics consultations based on women's reflections, and identifies the reflective questioning of ethics consultation as a significant strength of this type of moral inquiry.

PART I: ATTENDING TO THE CIRCUMSTANCES AT HAND

CHAPTER I

SPINA BIFIDA AND OPEN-UTERINE SURGERY TO REPAIR SPINA BIFIDA

In my initial research, the story of the medical and technological development of open-uterine surgery for spina bifida emerged as one of the dominant stories about the procedure. Physicians and surgeons have argued the medical issues – can open-uterine surgery for spina bifida be done and is it beneficial? – with great attention to how the procedure is performed and what its clinical sequelae may be. In the medical and surgical literature, the focus of decision-making became the gathering and balancing of medical information. In my effort to understand how women experienced and made decisions regarding open-uterine surgery to repair spina bifida, I too became an information gatherer. And, in the process, I discovered that while the medical information is necessary for understanding spina bifida and this innovative procedure, the information is often uncertain and is seldom sufficient for making a decision that also includes ethical, social, and moral features. Most women begin their story trying to make sense of large amounts of unfamiliar medical information and new terminology, however, and so perhaps it is fitting that this chapter will do the same thing, providing an introduction to the key medical information about spina bifida and some brief background on the development of open-uterine surgery to repair spina bifida. I will close the chapter with a

description of the Management of Myelomeningocele Study or MOMS trial that is currently evaluating the procedure.

Spina Bifida

Descriptions of Spina Bifida

Spina bifida is the incomplete closure of the spinal column during embryologic development, occurring around 21 days after conception.¹ From the Latin for "split spine", a spina bifida lesion can occur anywhere along the spinal column. In some cases, a sac filled with fluid and spinal nerves, called a myelomeningocele, will protrude from the opening and through the skin of the back. In other cases, the opening is flat with limited nerve involvement, called meningocele, and in the mildest form, spina bifida occulta, the spinal lesion is not visible except by x-ray.² In cases of myelomeningocele, the spinal nerves are exposed and can become damaged through the open lesion, limiting or destroying the function of the associated organs and muscles (for example, affecting the nerves that control leg movement, the development of clubfeet (*talipes*), or bowel and bladder continence). Lesions can be detected by ultrasound around 18-20 weeks

¹Center for Disease Control (CDC), *Trends in Spina Bifida. United States, 1991-2005*. (Center for Disease Control, 2008, accessed 8/12/2008 2008); available from <http://www.cdc.gov/Features/dsSpinaBifida/index.html> (hereafter *Trends in Spina Bifida*); Spina Bifida Association (SBA), *Frequently Asked Questions About Spina Bifida* (Spina Bifida Association of America, 2009, accessed 12/22/2009); available from http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2642327/k.5899/FAQ_About_Spina_Bifida.htm. (Hereafter *Spina Bifida F.A.Q.s*).

² Most patients and families use the term spina bifida to refer to myelomeningocele, so for the remainder of the dissertation, I will do the same, unless directly quoting or referring to one of the milder forms in a particular instance. (SBA), *Spina Bifida F.A.Q.S* (accessed).

gestational age, and with a prenatal diagnosis, the lesions are described by their vertebral level. Other indications of spina bifida include malformations of brain structures such as the lemon sign³ and banana sign⁴. Further, spina bifida is often accompanied by hydrocephalus, or a build-up of cerebrospinal fluid in the ventricles of the brain, and the Arnold Chiari II malformation, or hindbrain herniation, where the base of the brain stem slips in to the top of the spinal column at the back of the neck. Both hydrocephalus and Arnold Chiari II malformation can cause physiological, cognitive, and developmental impairments. The multifactorial, wide-ranging disabilities associated with spina bifida make prenatal diagnosis and prediction of outcomes complicated and uncertain.⁵

Causes of Spina Bifida

Also known as a neural tube defect, spina bifida is the most common congenital birth defect compatible with life, occurring in roughly 1 of every 1,000 live births in the

³ National Institutes of Health (NIH), *Management of Myelomeningocele Study (Moms)* (2003, accessed 8/12/2008); available from <http://www.spinabifidamoms.com/english/index.html> (Hereafter *MOMS Website*). The lemon sign is a descriptor referring to the slightly flattened frontal skull bones. It is seen on ultrasound for some fetuses with spina bifida. The lemon sign is a secondary marker for prenatal diagnosis of spina bifida, but almost always disappears by the third trimester.

⁴ Marvin Bergsneider, "Hydrocephalus: New Theories and New Shunts?," *Clin Neurosurg* 52 (2004), 76-78. The banana sign is an abnormal curvature of the cerebellum, often associated with Arnold Chiari II malformation. It is also an indirect sign of spina bifida in prenatal diagnosis.

⁵ Julie Chaplin, Robert Schweitzer, and Shelley Perkoulidis, "Experiences of Prenatal Diagnosis of Spina Bifida or Hydrocephalus in Parents Who Decide to Continue with Their Pregnancy," *Journal of Genetic Counseling* 14, no. 2 (2005), 151-52; Staff Mayo Clinic, *Spina Bifida* (Mayo Foundation for Medical Education and Research (MFMER), 2009, accessed 12/22/2009); available from <http://www.mayoclinic.com/print/spina-bifida/DS00417/DSECTION=all&METHOD=print>. ;(SBA), *Spina Bifida F.A.Q.S* (accessed).

United States, according to the Centers for Disease Control.⁶ Scientists and physicians cannot identify a single cause of spina bifida, though several factors are thought to contribute, most notably, limited intake of folate during early pregnancy.⁷ Since 1992 when the CDC began recommending that women planning pregnancy take 400 mg of folic acid a day and 1996, when the USDA began fortifying grains and cereals with folic acid, the incidence of spina bifida has decreased by 65%-70%.⁸ Increased folic acid has reduced the incidence of spina bifida in the United States, but folic acid intake does not account for all spina bifida incidence: in about 30% of pregnancies diagnosed with spina bifida, the pregnant woman was taking a folic acid supplement.

Spina bifida may have a genetic component, as spina bifida tends to appear in family clusters and to have a higher incidence among different racial groups (Caucasians and Hispanics are more likely than African-Americans, for example).⁹ Though scientists have not isolated a particular gene or set of genes related to the condition, having a diagnosis of spina bifida in one pregnancy increases the likelihood of spina bifida occurring in future pregnancies, including pregnancies of close relatives. Similarly, there may be environmental influences, as spina bifida tends to have a higher incidence in different regions (for instance, Appalachian, Southeast, and Southwest United States, versus the Northeast or Northwest), but scientists have not yet determined what environmental factors may contribute to the condition. Spina bifida could also be caused

⁶ (CDC), *Trends in Spina Bifida* (accessed).

⁷ *Ibid.* (accessed).; Mayo Clinic, *Spina Bifida* (accessed).

⁸ (CDC), *Trends in Spina Bifida* (accessed).

⁹ *Ibid.* (accessed).

by some factor in embryologic development that is not yet understood, as the defect occurs between 20 and 22 days after conception, before most women even know they are pregnant.

Effects of Spina Bifida

Spina bifida is a complicated defect because it has multiple contributing factors and a spectrum of effects and outcomes. The effects can include physical, developmental, or cognitive impairments or any combination thereof. The level of the spinal lesion as well as the presence and severity of hydrocephalus and the Arnold Chiari II malformation can all influence where a person functions along the spectrum of possible disabilities.¹⁰

The first major factor in the type and extent of disability appears to be the level of the spinal lesion and the extent of damage to the spina cord and associated nerves.¹¹ Physical impairments caused by nerve damage roughly correspond to the highest vertebral level of the lesion and can include limits to mobility requiring braces, walkers, or wheelchairs, bowel and bladder incontinence, and limited sexual functioning. In general, the higher the lesion on the spine (for example, from the upper lumbar (L1-L3) to the thoracic (T1-12) vertebrae), the more extensive the physical disabilities because more nerves along the spinal cord are involved.¹² If spinal nerves are protruding out of

¹⁰ Hareesh M. Kirpalani and others, "Quality of Life in Spina Bifida: Importance of Parental Hope," *Archives of Disease in Childhood* 83, no. 4 (2000), 293; Mayo Clinic, *Spina Bifida*(accessed).;(NIH), *Moms Website* (accessed).

¹¹ Natalie E. Rintoul and others, "A New Look at Myelomeningoceles: Functional Level, Vertebral Level, Shunting, and the Implications for Fetal Intervention," *Pediatrics* 109, no. 3 (2002), 409-410.

¹² Ibid., 412-413. Ross Hetherington and others, "Functional Outcome in Young Adults with Spina Bifida and Hydrocephalus," *Child's Nervous System* 22, no. 2 (2006), 117-118.

the lesion, as with myelomeningocele, the disabilities associated with those nerves will often be more severe than if the lesions remain within the spinal column, as is the case with meningocele spina bifida. Lesions in the sacral vertebra (S1-S4), the lowest 4 vertebra on the spine, tend to involve ankle and toe movement, while lumbar vertebra (L1-L5) can also involve knee and hip movement, bowel and bladder continence, and sexual functioning. Lesions in the thoracic vertebrae (T1-T12) tend to have more severe effects, involving abdominal and chest muscles and organs.¹³ Even though the functions associated with vertebral levels of spinal nerves have been identified, knowing the highest vertebra of a spina bifida lesion only predicts the range of possible disabilities: it does not predict with certainty which disabilities a particular individual will have. Thus, one child with an L5 lesion may walk unassisted, while another may require braces to increase her mobility. Though the location of the spinal lesion is a key factor in the type and extent of physical disability for an affected person, people with spina bifida may face developmental delays and cognitive impairments as well.

The second major factor influencing disability is the presence of hydrocephalus with spina bifida, which occurs in up to 85% of all persons with spina bifida.¹⁴

¹³ Robin M. Bowman and others, "Spina Bifida Outcome: A 25-Year Prospective," *Pediatr Neurosurg* 34, no. 3 (2001), 114-20; J. P. Bruner and others, "Fetal Surgery for Myelomeningocele and the Incidence of Shunt-Dependent Hydrocephalus," *Jama* 282, no. 19 (1999), : 1819-20; Daniel Doherty and David B. Shurtleff, "Pediatric Perspective on Prenatal Counseling for Myelomeningocele," *Birth Defects Research Part A: Clinical & Molecular Teratology* 76, no. 9 (2006), 645-46; M. A. Fichter and others, "Fetal Spina Bifida Repair--Current Trends and Prospects of Intrauterine Neurosurgery," *Fetal Diagn Ther* 23, no. 4 (2008), 271-73; Paul M. Kanev and Jonas M. Sheehan, "Reflections on Shunt Infection," *Pediatric Neurosurgery* 39, no. 6 (2003), 285-86.

¹⁴Michael S. Dias and David G. McLone, "Hydrocephalus in the Child with Dysraphism," *Neurosurgery Clinics of North America* 4, no. 4 (1993), 715-718 ; Rintoul and others, "A New Look at Myelomeningocele," 409-410; Leslie N. Sutton, "Fetal Surgery for Neural Tube Defects," *Best Practices in Research & Clinical Obstetrics & Gynaecology* 22, no. 1 (2008), 176; Spina Bifida Association (SBA), *Symptomatic Chiari Malformation Fact*

Hydrocephalus is the build-up of cerebrospinal fluid (CSF) in the ventricles of the brain. The cerebrospinal fluid puts pressure on other structures of the brain and, in effect, squeezes brain tissue against the skull as the volume of fluid increases. Hydrocephalus is typically managed by the placement of a ventricoperitoneal shunt to drain excess cerebrospinal fluid from the ventricles into the abdominal cavity. Shunts have made a tremendous difference in both survival and cognitive / developmental function for children with spina bifida and hydrocephalus, but shunts can also become clogged or infected.¹⁵ Untreated or poorly managed hydrocephalus can lead to brain damage and mental retardation. Surgical shunt revisions are common, whether for the above problems or due to the individual's growth throughout life. However, while 25-50% of children with spina bifida demonstrate developmental and learning delays, and 15% will have severe cognitive impairment, most children with spina bifida (70%) have average IQ levels.¹⁶

Hydrocephalus can also be associated with a third factor influencing disability: the development of the Arnold Chiari II malformation, or hindbrain herniation.¹⁷ In hindbrain herniation, the base of the brain stem, which controls breathing, swallowing,

Sheet(Spina Bifida Association, 2009, accessed 12/22/2009); available from http://www.spinabifidaassociation.org/site/c.liKWL7PLLrF/b.2700293/k.4316/Symptomatic_Chiari_Malformation.htm. (Hereafter *Symptomatic Chiari Malformation*).

¹⁵ (SBA), *Spina Bifida F.A.Q.S* (accessed) ; Rintoul and others, "A New Look at Myelomeningocele," 409-410.

¹⁶ Sutton, "Fetal Surgery 2008," 126 ; David G. McLone and Michael S. Dias, "The Chiari I I Malformation: Cause and Impact," *Child's Nervous System* 19, no. 7-8 (2003), 548; Hetherington and others, "Functional Outcome," 633; Pippa Oakeshott and Gillian M. Hunt, "Long-Term Outcome in Open Spina Bifida," *British Journal of General Practice* 53, no. 493 (2003), 117-119.

¹⁷ McLone and Dias, "The Chiari I I Malformation: Cause and Impact," 548.

and other basic physiologic functions, slips in to the top of the spinal column. People with the Chiari II malformation can experience difficulty breathing, including apnea and stridor, as well as difficulty swallowing. Though only 1 in 3 persons with Chiari II malformation are symptomatic, this can be a particularly devastating complication for neonates learning to nurse or drink from a bottle, and breathing difficulties can continue into infancy and early childhood. The breathing difficulties associated with Chiari II malformation are the leading cause of death for people with spina bifida, especially early in life.¹⁸

The leading theory for the increased hydrocephalus and the development of the Arnold Chiari II malformation associated with spina bifida is the "unified theory." According to this description, in a typical brain, the brain and spinal column work as a closed system where the cerebrospinal fluid circulates around the brain and spinal cord. In the brain of a person with spina bifida, the spinal lesion creates a hole in the system, causing fluid to leak from the lesion, into the dural sac or myelomeningocele. This leakage creates negative pressure, which 'pulls' the hindbrain into the top of the spinal column at the base of the neck, creating a plug that prevents cerebrospinal fluid from escaping the ventricles. The ventricles of the brain continually produce cerebrospinal fluid, but without an open passage to the spinal column, fluid continues to build in the ventricles, increasing pressure on and causing damage to other structures in the brain.¹⁹

¹⁸ SBA, *Chiari Malformation*.

¹⁹ D. G. McLone and P. A. Knepper, "The Cause of Chiari I I Malformation: A Unified Theory," *Pediatr Neurosci* 15, no. 1 (1989), ; McLone and Dias, "The Chiari I I Malformation: Cause and Impact," 1-12; SBA, *Spina Bifida FAQs*.

The “unified theory” explains the interactions among the spinal lesion, the hydrocephalus, and the Arnold Chiari II malformation in many cases of spina bifida, but in other cases, hydrocephalus develops even without the Chiari II malformation, possibly from some disruption on a cellular level.²⁰ Others will develop the Arnold Chiari II malformation without hydrocephalus, and some individuals will have spina bifida uncomplicated by either hydrocephalus or the Chiari II malformation. The different structural malformations of spina bifida and the wide range of possible presentations of the condition make diagnosis, prediction of outcomes, and treatment a series of challenging exercises, complicated by layers of uncertainty.

Treatment of Spina Bifida:

Historical Treatments

Until the 20th century, there was no successful treatment for spina bifida and its associated disabilities. Children born with myelomeningocele often did not survive birth or for very many days after. Some children with severe hydrocephalus died during delivery because their enlarged skulls could not pass through the birth canal. Others died because the dural sac would rupture during vaginal delivery, leading to shock, hemorrhage, and infection of the open lesion.²¹ Even the early attempts at closing the

²⁰ Dias and McLone, "Hydrocephalus," 215-226.

²¹A. Aschoff and others, "The Scientific History of Hydrocephalus and Its Treatment," *Neurosurgery Review* 22, no. 2-3 (1999), 71-82; Max A. Fichter and others, "Fetal Spina Bifida Repair--Current Trends and Prospects of Intrauterine Neurosurgery," *Fetal Diagnosis & Therapy* 23, no. 4 (2008), 273; R. H. Gross and others, "Early Management and Decision Making for the Treatment of Myelomeningocele," *Pediatrics* 72, no. 4 (1983), 450-8.

lesion immediately after birth, starting in the 1930s, often failed because of infection, or because of uncontrolled hydrocephalus following the lesion closure.²²

Contemporary Treatments

With the development of antibiotics and sterile surgical procedures, and with better understandings of the brain's structures, surgeons were able to close the spinal lesion successfully and they attempted to control developing hydrocephalus by placing shunts from the ventricles in the brain to the peritoneal, or abdominal, cavity. The ventriculo-peritoneal shunts decreased the swelling in the brain from hydrocephalus, but could become clogged, leading to rapid redevelopment of hydrocephalus, and could become infected, leading to meningitis, both of which could cause significant brain damage and, often, death. Children born with spina bifida and hydrocephalus were often taken to special hospitals or nursing facilities to be cared for until they died. Yet, many children survived, whether they received aggressive treatment or no treatment at all, raising difficult questions of what treatment to pursue for which children.²³

John Lorber, a British physician, made the argument that lesion closure and shunt placement should not be attempted on every baby born with spina bifida, but only on those with the greatest chances of survival. He developed selection criteria to determine

²² Rosalyn B. Darling, "Parents, Physicians, and Spina Bifida," *Hastings Center Report* 7, no. 4 (1977), 10; Oakeshott and Hunt, "Long Term Outcome," 632; (NIH), *Moms Website* (accessed).

²³ John M. Freeman, "To Treat or Not to Treat?," in *Practical Management of Meningomyelocele* (Baltimore, MD: University Park Press, 1974), 13-22 ;John M. Freeman, "Early Management and Decision Making for the Treatment of Myelomeningocele: A Critique," *Pediatrics* 73, no. 4 (1984), 564-6 ; Gross and others, "Early Management and Decision Making for the Treatment of Myelomeningocele," 450-458.

appropriate treatment, but a follow-up study discredited the selection criteria, and treatment for all babies born with spina bifida resumed.²⁴ The argument caused a tremendous uproar in the medical and emerging bioethics communities about how decisions were made about spina bifida treatments.²⁵ In particular, the question raised by Lorber's non-treatment at birth was whether non-treatment could be ethically justified, given the uncertainty of prognosis at birth.

By the 1980s, standard of care was to avoid infection by closing the spinal lesion as soon after delivery as possible, and to place a ventriculo-peritoneal shunt within 48 hours. For those children who survived and for those who did not develop shunt-dependent hydrocephalus in the first place, physical disabilities were managed with available resources. Clinicians offered braces, walkers, and wheelchairs for varying levels of mobility impairment, including talipes, and offered medical and surgical options for bowel and bladder continence, including drug therapy, ostomy bags, and bladder catheterization, though the latter two also carry a risk for infection.²⁶

By the end of the 20th century, better monitoring of hydrocephalus, shunt malfunction, and antibiotics for infection led to better outcomes for children with spina bifida, but even with the most aggressive treatment, the range of outcomes is confounding in its width and severity, from little or no impairment to profound life-long

²⁴ John Lorber, "Results of Treatment of Myelomeningocele," *Developmental Medicine & Children's Neurology* 13 (1971), 279-303; John Lorber, "Early Results of Selection Treatment of Spina Bifida Cystica," *British Medical Journal* 4 (1973), 201-204 ; D. G. McLone, "Spinal Dysraphism," *Clin Neurosurg* 52 (2004), 160-162.

²⁵ Mark J. Bliton, "Ethics at the Forefront: Moral Decisions and Responsibility with Spina Bifida," in *Neural Tube Defects: From Origin to Treatment*, ed. Diego F Wyszynski (Oxford: Oxford University Press, 2006), 371-388. See for a detailed account of this debate in the ethics and spina bifida communities.

²⁶ D. G. McLone, "Spinal Dysraphism," *Clin Neurosurg* 52 (2004), 160-162.

disabilities to death. And the uncertainty of possible outcomes, including the question of appropriate treatment options, remains a challenge for clinicians and parents, though often in the antenatal period as much as in the neonatal period.

Outcomes of Spina Bifida Treatments

Even with standard therapy, spina bifida can profoundly affect physical development: 40% of children with spina bifida are wheelchair bound for life²⁷ and 30-60% will require surgical spine instrumentation. 75% of children achieve continence of urine and 85% of children are continent of stool,²⁸ but 85% require anticholinergic medicine or urinary diversion and 50% will require an aggressive bowel regimen including suppositories and enemas. Even with these physical challenges, however, 50% of children with spina bifida will grow up to live independently.

Hydrocephalus and the Arnold Chiari II malformation can also profoundly alter development. 80-90% of children with spina bifida develop hydrocephalus and with standard therapy, 80% have a VP shunt placed in first six weeks of life. As explained above, though shunts relieve the pressure of cerebrospinal fluid in the ventricles, shunts can also get clogged or otherwise malfunction and shunts carry a 10-20% lifelong risk of infection. As a result, 85% of children with a shunt will need at least one shunt revision,

²⁷ Bowman and others, "Spina Bifida Outcome: A 25-Year Prospective," 115-116 ; Hasan Mirzai and others, "Outcome of Patients with Meningomyelocele: The Ege University Xperience," *Child's Nervous System* 1 (1998), 120-123.

²⁸ Hetherington and others, "Functional Outcome," 122-123; Paul Steinbok and others, "Long-Term Outcome and Complications of Children Born with Myelomeningocele," *Child's Nervous System* 8, no. 2 (1992), 94-95.

and 50% will need a shunt revision in the first year after placement.²⁹ The danger of poorly controlled hydrocephalus and repeated shunt malfunction or infection is an increased risk of cognitive and developmental impairment or even mental retardation, which occur in 15% of children with spina bifida. Finally, though 25% - 50% of children with spina bifida have some learning disabilities, about 70% of children with spina bifida have normal cognition with an IQ greater than 80.³⁰ All of the statistics again emphasizes the wide range of possible outcomes.

The most startling statistic, perhaps, given that spina bifida is not considered a lethal congenital defect,³¹ is that even with the most aggressive treatment available, 10-15% of children with spina bifida will die by age six.³² With hydrocephalus and severe Chiari II malformation as well, the percentage may be up to 35% of children.³³ Thus, for families of children with spina bifida, and their care providers, the uncertainty that

²⁹ Steinbok and others, "Long-Term Outcomes," 92-93; Noel B. Tulipan and others, "The Effect of Intrauterine Myelomeningocele Repair on the Incidence of Shunt-Dependent Hydrocephalus," *Pediatric Neurosurgery* 38, no. 1 (2003), 28.

³⁰ Oakeshott and Hunt, "Long Term Outcome," 133; Hetherington and others, "Functional Outcome," 117.

³¹ See Tracy K. Koogler, Brian S. Wilfond, and Lanie F. Ross, "Lethal Language, Lethal Decisions," *Hastings Center Report* 33, no. 2 (2003), 37-41. Here I am contrasting spina bifida, where a live birth and post-natal treatment are typical, with structural or neurological anomalies likely to lead to in utero or neonatal death. The term "lethal" is problematic, as it becomes increasingly inaccurate for many conditions now treatable, and as it forecloses on possibilities for and discussions about quality of life for fetuses with particular conditions. Though I recognize that the terms "lethal" and "non-lethal" are problematic, they have also been central to the debate about the ethics of open-uterine surgery to repair spina bifida and on occasion, I use them for clarity's sake or in reference to the historical discourse around the ethics of this procedure.

³² Gordon Worley, James M. Schuster, and W. Jerry Oakes, "Survival at 5 Years of a Cohort of Newborn Infants with Myelomeningocele," *Developmental Medicine & Children's Neurology* 38, no. 9 (1996), 817-818.; Steinbok et al. "Long-Term Outcomes" 94-95.

³³ Oakeshott and Hunt, "Long Term Outcome," 632-633; Sutton, "Fetal Surgery 2008," 176.

accompanies the initial diagnosis and prognosis continues well past infancy into early childhood and beyond.

Prenatal Surgery for Spina Bifida

Given the range of outcomes for spina bifida, with its various disabilities and levels of severity, physicians, surgeons, and researchers have used a variety of approaches in the diagnosis and treatment of spina bifida, some of which have been described above. Most recently, beginning in the 1990s, researchers began investigating open-uterine repair of the spinal lesion as a treatment option. This “prenatal surgery for spina bifida,” or “PNS4SB” as it is known colloquially, is part of a longer history of prenatal interventions and their attendant controversies. A brief review of that history will help frame more recent investigations into and controversies surrounding prenatal interventions, including open-uterine surgery to repair spina bifida.

Rh Transfusions in the 1960s

The story of prenatal interventions in the late 20th century is a history complicated by the rapid increase in available technologies for accessing the fetus within the pregnant woman's uterus, by the variety of interventions attempted, and by the number and depth of the ethical concerns such interventions raised.³⁴ In the early 1960s,

³⁴ Deborah Blizzard, *Looking Within: A Sociocultural Examination of Fetoscopy* (Cambridge, MA: MIT Press, 2007) ; Monica J. Casper, *The Making of the Unborn Patient : A Social Anatomy of Fetal Surgery* (New Brunswick, N.J.: Rutgers University Press, 1998) ; Barbara Duden, *Disembodying Women: Perspectives on Pregnancy and the Unborn* (Cambridge, MA: Harvard University Press, 1993) ; Lynn Morgan, *Baby's First Picture: Ultrasound and the Politics of Fetal Subjects* (Toronto, CA: University of Toronto Press, 2001) ; Rayna Rapp, *Testing Women, Testing the Fetus : The Social Impact of Amniocentesis in America, Anthropology of Everyday Life ; 1* (New York: Routledge, 1999).

A. W. Liley, at the Women's Hospital of Auckland, New Zealand, developed the first successful fetal interventions with inter-uterine transfusions for Rh incompatibility.³⁵ Using blood-typing to determine whether an Rh factor incompatibility existed, and using ultrasound technology to deliver transfusions, Liley became an early champion and spokesperson for prenatal interventions.³⁶ Following Liley's successes, the increasing use of ultrasound technology and laboratory testing from the 1960s onward increased the number of conditions that could be diagnosed before birth, and increased efforts toward and demands for treatment, particularly for conditions likely to result in fetal or neonatal death.³⁷

Animal Studies in 1980s & 1990s

Various prenatal interventions were developed in the 1980's and 1990's that quickly moved from animal models to experimental series with pregnant women and their affected fetuses,³⁸ most notably at the University of California - San Francisco (UCSF) and, later, at the Children's Hospital of Philadelphia (CHOP). In the early history

³⁵ Andrew W. Liley, "Intrauterine Transfusion of the Foetus in Haemolytic Disease, ," *British Medical Journal* 2 (1963), 1107-1110.

³⁶ Casper, *Making the Unborn Patient* 42-46, 59-67.

³⁷ William O. Bell and others, "Prenatal Diagnosis and Pediatric Neurosurgery," *Pediatric Neurosurgery* 24, no. 3 (1996), 134-137; Diana L. Farmer, "Fetal Surgery: A Brief Review," *Pediatric Radiology* 28, no. 6 (1998), 409-410.

³⁸ N. Scott Adzick and others, "Successful Fetal Surgery for Spina Bifida," *Lancet* 352, no. 9141 (1998), 1675; Timothy Jancelewicz and Michael R. Harrison, "A History of Fetal Surgery," *Clinics in Perinatology* 36, no. 2 (2009), 228-229; Michael R. Harrison and others, "Fetal Treatment 1982," *New England Journal of Medicine* 307, no. 26 (1982), 1651-1652; Maria Michejda, "Intrauterine Treatment of Spina Bifida: Primate Model," *Experimental Pediatric Surgery* 39 (1984), 259-261.

of prenatal interventions, the two main interventions – entering the uterus (endoscopy) and opening the uterus (hysterotomy) – caused premature birth and, in some cases, fetal death. Despite the risks of prematurity and death, however, researchers justified the interventions in terms of rescue. The women who underwent the ‘rescue operations’ were carrying fetuses with a malformation or complication likely to result in fetal or neonatal death, such as fetal hydrocephalus, blocked urinary tract and fetal hydronephrosis, Congenital Diaphragmatic Hernia (CDH), and Twin-to-Twin Transfusion Syndrome (TTTS).³⁹ Women were initially offered maternal-fetal surgeries through research protocols designed to investigate whether in utero interventions were feasible and to identify what the risks and possible benefits from such interventions might be. The research protocols were offered for conditions that carried a significant likelihood of death, where even the best postnatal treatment often failed to sustain the affected neonate.⁴⁰ Research into in utero repair of spina bifida, however, raised a different set of questions about risks and benefits for surgery, specifically for a “non-lethal” condition.⁴¹ Research on prenatal repair of spina bifida, using animal studies, has been ongoing since

³⁹ Albert R. Jonsen, "The Ethics of Fetal Surgery," in *Genetics and the Law III*, ed. Aubrey Milunsky and George J. Annas, National Symposium on Genetics and the Law, 1984 (New York: Plenum Press, 1985), 365-267; John C. Fletcher and Albert R. Jonsen, "Ethical Considerations in Fetal Treatment," in *The Unborn Patient*, ed. Michael R. Harrison, Michael S. Golbus, and Roy A. Filly (Philadelphia, PA: W.B. Saunders Company, 1984, 1990), 15-17.

⁴⁰ Edmund G. Howe, "Ethical Issues in Fetal Surgery," *Seminars in Perinatology* 27, no. 6 (2003), 446; Anne D. Lyerly and others, "Toward the Ethical Evaluation and Use of Maternal-Fetal Surgery," *Obstetrics & Gynecology* 98, no. 4 (2001), 690-691.

⁴¹ Chapter II considers more fully the scientific discourse around the ethics of maternal-fetal surgeries, including justification and validation for lethal conditions and for non-lethal conditions like spina bifida. See pp 34-41 below.

the 1980s⁴² with the potential for lessening, though not eliminating, spina bifida related disabilities.

Researchers and ethicists asked whether a potential reduction in the disabling affects of spina bifida, with life-sustaining treatments available after birth, justified a risky and experimental procedure, previously offered only as research into preventing fetal or neonatal death.⁴³ The risks of fetal death during or after surgery and the risks of extreme prematurity, including neonatal death, were significant, even in the early phase of research for prenatal surgery for spina bifida. For example, researchers attempted lesion closure as an endoscopic procedure in this early phase, but abandoned the method because the benefits were limited and the risks were significant, especially for a non-lethal condition.⁴⁴ Four fetuses underwent endoscopic repair in the VUMC protocol, with mixed results. Two died, one was born extremely premature at 28 weeks gestational age, and one was delivered by planned caesarian section at 35 weeks.⁴⁵ Despite the significant risks, women and researchers were still willing to pursue prenatal interventions, possibly to avoid, as Bruner notes, “the large burden for affected persons, their families, and society in general.” Bruner continues his reflections on the endoscopic procedure, observing that “ the potential for decreasing the burden of disability resulting from

⁴² Michejda, "Intrauterine Treatment of Spina Bifida: Primate Model," 259-261.

⁴³ Mark J. Bliton and Richard M. Zaner, "Over the Cutting Edge: How Ethics Consultation Illuminates the Moral Complexity of Open-Uterine Fetal Repair of Spina Bifida and Patients' Decision Making," *Journal of Clinical Ethics* 12, no. 4 (2001), 347-348; Anne D. Lyerly and Mary B. Mahowald, "Maternal-Fetal Surgery for Treatment of Myelomeningocele," *Clinics in Perinatology* 30, no. 1 (2003), 160-161.

⁴⁴ Joseph P. Bruner and others, "Endoscopic Coverage of Fetal Myelomeningocele in Utero," *American Journal of Obstetrics & Gynecology* 180, no. 1 Pt 1 (1999), 153-158;

⁴⁵ Joseph P. Bruner and Noel B. Tulipan, "Intrauterine Repair of Spina Bifida," *Clinical Obstetrics & Gynecology* 48, no. 4 (2005), 947.

congenital myelomeningocele may well justify the risks of ante partum intervention to the extent that they are known.”⁴⁶ Even after the unsuccessful endoscopic protocol, researchers at Vanderbilt and other centers continued to investigate prenatal repair of spina bifida.

Surgeons and researchers continued to pursue the possibility of prenatal surgery for spina bifida based on the “two-hit hypothesis” of the condition. Briefly, the theory proposed that the damage of the “first hit” – the incomplete vertebral closure – was compounded by the “second hit” – the long-term exposure to amniotic fluid and the exposure of spinal nerves throughout gestation. If clinicians could limit damage to the nerves, researchers hypothesized, patients might have improvements in leg movement and mobility and / or continence of bowel and bladder. If the “two-hit” theory was correct, earlier treatment would be better treatment and repairing the lesion in utero might lessen the damage to the spinal nerves.⁴⁷ More critical, for my concerns, is that that in spite of the risks and the early failures in attempts to repair spina bifida in utero, women and their families still were willing to undergo prenatal procedures rather than wait for standard postnatal repair of the defect. For a condition like spina bifida, where the prenatal surgery risks the death of the fetus who is otherwise likely to be born at term, something beyond the medical facts, something other than risk-benefit calculation, appeared to be motivating women and their families to participate in these research

⁴⁶ Bruner and others, "Endoscopic Coverage of Fetal Myelomeningocele in Utero," 157-158.

⁴⁷ Bruner and others, "Fetal Surgery 1999," 1820; Leslie N. Sutton and others, "Improvement in Hindbrain Herniation Demonstrated by Serial Fetal Magnetic Resonance Imaging Following Fetal Surgery for Myelomeningocele," *JAMA* 282, no. 19 (1999), 1827; Noel B. Tulipan and others, "Effect of Intrauterine Myelomeningocele Repair on Central Nervous System Structure and Function," *Pediatric Neurosurgery* 31, no. 4 (1999), 28.

protocols. The nature of and the strength of these non-medical motivations became even clearer during the elective series of open-uterine procedures at Vanderbilt University Medical Center.

VUMC Elective Series in 1990s

Since endoscopic interventions were not considered successful enough to justify the risks, clinicians and researchers at Vanderbilt University Medical Center began researching and offering an open-uterine surgery to repair spina bifida. After a series of discussions with a sub-committee of the Ethics Committee, the first open-uterine surgeries for spina bifida were performed at Vanderbilt University Medical Center in 1997, as an elective surgery under a research protocol.⁴⁸ Between 1997 and 2002, almost three hundred (300) procedures were performed at VUMC, Children's Hospital of Philadelphia (CHOP), University of California at San Francisco (UCSF) and University of North Carolina at Chapel Hill (UNC).⁴⁹ The early series of elective procedures showed no clear improvement in leg movement or continence, as compared to historical controls, but did show two unexpected changes. First, children who had open-uterine surgery to repair spina bifida appeared to have a lower incidence of hydrocephalus requiring the placement of a VP shunt – a 59% shunt placement rate versus a 91% placement rate for the historical controls, or a risk reduction of 32%.⁵⁰ Second, researchers noted that

⁴⁸ Bruner and Tulipan, "Intrauterine Repair of Spina Bifida," 949-950.

⁴⁹ Joseph P. Bruner, "Intrauterine Surgery in Myelomeningocele," *Seminars in Fetal & Neonatal Medicine* 12, no. 6 (2007), 471; Jancelewicz and Harrison, "A History of Fetal Surgery," 232-233.

⁵⁰ Bruner and others, "Fetal Surgery 1999," 1822-1824.

“compared with babies treated postnatally, those treated in utero had a decreased incidence of hindbrain herniation,” though they also noted “it is not yet clear whether this [decrease] translates into improved survival or functional outcomes.”⁵¹

Though the changes documented in the elective, experimental protocols appear positive, several factors complicated their evaluation, as Sutton notes, in terms of survival or functional outcomes. First, while a reduced risk for a shunt presented an obvious improvement, it was unclear to researchers and clinicians what effect the changed appearance of hindbrain herniation had on neurological or physiological function.⁵² Second, in many cases the benefit of avoiding a VP shunt was complicated, if not countered, by the increased incidence of prematurity and, in some cases, fetal death. All of the surgeries from the combined elective series led to premature births, with 12% born extremely premature (<30 weeks), which included a 5% rate of fetal death.⁵³ By comparison, most fetuses with spina bifida were delivered by planned c-section at term, and from 1990-1994, the infant mortality rate for spina bifida in the United States was under 1% per 10,000.⁵⁴ Thus, while infant mortality was a significant risk for spina bifida, the risk of fetal or neonatal death from open-uterine surgery to repair spina bifida was higher. On the other hand, it was unclear whether the potential short-term and long-

⁵¹ Sutton, "Fetal Surgery 2008," 179.

⁵² Recent studies indicate that complications from Chiari are the leading cause of death for people with spina bifida, early in life, which raises questions about whether a change in hindbrain herniation might have the potential for significant neurological improvement. See McLone and Dias, "The Chiari I I Malformation: Cause and Impact," 548; Sutton, "Fetal Surgery 2008," 176.

⁵³ Bruner, "Intrauterine Surgery in Myelomeningocele," 472.

⁵⁴ Aldo Rosano and others, "Infant Mortality and Congenital Anomalies from 1950 to 1994: An International Perspective," *Journal of Epidemiology & Community Health* 54, no. 9 (2000), 664.

term benefits of avoiding a shunt outweigh those risks from prenatal surgery. Third, researchers found it difficult to compare the data from different institutions. Different surgical treatment centers had used different inclusion criteria (e.g. – CHOP would not offer surgery if the obstetric ultrasound showed fetal talipes, but VUMC would), making it difficult to compare results across the four centers.⁵⁵ Additionally, all of the results were compared against historical controls, which did not take into account improvements in the standard of care treatment for children born with spina bifida and so did not provide an accurate comparison group. Even after almost 300 surgeries at the four centers, researchers were unable to say whether open-uterine surgery or postnatal surgery produced better outcomes for children with spina bifida.

The MOMS Trial: 2003 – Present

The uncertainty that remained after the series of elective surgeries prompted demands from researchers and clinicians for a multi-center, randomized controlled trial (RCT) to compare the measurable risks, harms, and benefits of open-uterine and standard postnatal repair of spina bifida.⁵⁶ Researchers and clinicians often demand a clinical trial when they believe the researchers are “equally poised in our beliefs between the benefits and disadvantages of a certain treatment modality.”⁵⁷ This “clinical equipoise,” in the

⁵⁵ Bruner and others, "Fetal Surgery 1999," 1820; Sutton and others, "Improvement in Hindbrain Herniation," 1827.

⁵⁶ Bruner, "Intrauterine Surgery in Myelomeningocele," 471-474; Lyerly and others, "Toward the Ethical Evaluation," 692.

⁵⁷ Anne D. Lyerly and Mary B. Mahowald, "Maternal-Fetal Surgery: The Fallacy of Abstraction and the Problem of Equipoise," *Health Care Analysis* 9, no. 2 (2001), 156. See also Frank A. Chervenak and Lawrence B. McCullough, "A Comprehensive Ethical Framework for Fetal Research and Its Application to Fetal Surgery for Spina Bifida," *American Journal of*

language of medical and research ethics, traditionally justifies conducting a research protocol to determine which treatment option is most effective – which provides the greatest benefit with the least amount of harm.

Open-uterine surgery to repair spina bifida generated considerable controversy in the clinical and research communities over medical issues of risk, harm, and benefit described above, and over ethical issues, which will be discussed in the next chapter. A 2001 survey about the attitudes of maternal-fetal specialists towards maternal-fetal surgery found that 58% of respondents did not feel the procedure had been validated and 57% called for a moratorium on the procedure until a multi-center controlled trial was completed.⁵⁸ While some clinicians and ethicists argued that differences between the purely medical benefits of each type of intervention were unknown and required a clinical trial to study the procedure, others pointed out that the net benefit of the in utero procedure was at issue. In particular, some clinicians and ethicists argued that questions about the psychological, emotional, social, and financial costs of the surgery on pregnant women and their families needed to be addressed alongside questions about the physical risks, harms, and potential benefits. Only after these costs had been identified and evaluated could researchers “assure that equipoise is achievable in conducting research on MFS (maternal-fetal surgery) for repair of fetal MMC (myelomeningocele).”⁵⁹ Clinicians and ethicists were concerned with identifying the social and moral elements to include in discussions of equipoise as part of designing a clinical trial. For example, they

Obstetrics & Gynecology 187, no. 1 (2002), 10-11; Anne D. Lyerly, "Achieving Equipoise in Maternal-Fetal Surgery," *American Journal of Obstetrics & Gynecology* 188, no. 3 (2003), 855-856.

⁵⁸ Lyerly and others, "Toward the Ethical Evaluation," 689-97.

⁵⁹ Lyerly and Mahowald, "Maternal-Fetal Surgery," 162.

were concerned with what evaluations of psychological and emotional costs would look like in a net benefit calculation. These social and moral concerns, however, were overwhelmed by pressures from pregnant women and their families seeking prenatal interventions, and researchers eager to resolve the medical and surgical questions through a scientifically validated clinical trial. The urgent demands from the public and from some in the research community led to the design of a multi-center clinical trial for open-uterine surgery to repair spina bifida funded by the National Institutes of Health (NIH) and National Institute of Child Health and Human Development (NICHD).⁶⁰

The Management of Myelomeningocele Study, or MOMS trial, began in 2003 and was designed to enroll and randomize 200 pregnant women – 100 to the prenatal arm of open-uterine repair of their fetus’s spina bifida, and 100 to the control arm of postnatal repair.⁶¹ The MOMS trial was designed as a randomized controlled trial, meaning that random selection determines which intervention a participant receives: neither the participants nor the surgeons / physicians have any say over which trial arm the participants will enter. Women can choose to enroll in the trial, but unlike the elective series, they cannot directly choose open-uterine repair. The same surgeons at each center perform the open-uterine and postnatal surgeries, to minimize “operator differences,” and all of the study participants are asked to bring their children back to their trial center at 12 months and 30 months for evaluation by a separate, blinded team of evaluators. Until preliminary data from the trial is available (1 year from the birth of the 200th child), a

⁶⁰ (NIH), *Moms Website (accessed)*.

⁶¹ *Ibid. (accessed)*.

community wide moratorium means open-uterine surgery to repair spina bifida is only available through the trial.⁶²

Overlooked Stories: Ethics of Maternal-Fetal Surgery, MOMS, and Beyond

The MOMS trial is the most recent chapter in the medical story of open-uterine surgery to repair spina bifida, but it is not likely to be the last. The trial seeks to resolve several medical controversies about open-uterine surgery to repair spina bifida. In particular, the primary endpoints of the study are survival and shunt placement at one year, with specific criteria for shunt placement. The secondary endpoints are neurologic function, cognitive outcome, and maternal morbidity.⁶³ MOMS is supposed to identify the relationship between the risks and the potential benefits of the surgery and to discover any variations in the mortality and types of morbidity among children with spina bifida, based on whether they had open-uterine or postnatal repair. The controversies about the procedure are likely to continue, however, as maternal-fetal specialists, and pregnant women and their families, are likely to understand the data and its implications in different ways. As Bliton argues in 2005,

In the aftermath of the current randomized study, advocates for the interventions might want to say that they have established valid empirical indications that the surgery improves function by avoiding ventroperitoneal shunt placement... Skeptics might say that whether ventroperitoneal shunt placement for the child is delayed or avoided altogether, this still does not justify the surgery, given the significant risks to the woman and of prematurity for the infant and all the other multiple problems that spina bifida creates.⁶⁴

⁶² Ibid.(accessed) ; Nancy C. Chescheir and Mary D'Alton, "Evidence-Based Medicine and Fetal Treatment: How to Get Involved," *Obstetrics & Gynecology* 106, no. 3 (2005), 10-3.

⁶³ (NIH), *Moms Website* (accessed) ; Sutton, "Fetal Surgery 2008," 184-186.

Though it was designed to produce important medical data about open-uterine surgery to repair spina bifida, the MOMS trial and its results may not resolve the controversies about the procedure. The data from the MOMS trial may help clinicians more accurately predict shunting, neurologic, and cognitive outcomes for spina bifida, but as Bliton points out, controversies about the risks are likely to persist within the medical and surgical discourses. Further, as a surgical trial focused on clinical data, MOMS does not address how women learn about, interpret, act upon, or are affected by medical information about the risks, benefits, and outcomes of open-uterine surgery to repair spina bifida. It does not investigate or account for what women find relevant to their decision-making or how they actually make their decisions and live with them, which may, in the end, prove as important to long-term outcomes as whether the spina bifida lesion is repaired before or after birth.⁶⁵

The medical discourses – including the information generated in the MOMS trial – are crucial for understanding innovative procedure, but are inadequate in understanding what matters in open-uterine surgery to repair spina bifida. The social and moral concerns raised by maternal fetal surgery and shaped by the uncertainties and complexities of *this particular* procedure remain in need of attention.⁶⁶ As a way to illustrate this need, the next chapter will identify and probe themes in the ethical debates from the ethical discourses on maternal-fetal surgeries, including about open uterine surgery to repair

⁶⁴ Mark J. Bliton, "Parental Hope Confronting Scientific Uncertainty: A Test of Ethics in Maternal-Fetal Surgery for Spina Bifida," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 596.

⁶⁵ *Ibid.*, 596, 598-599. See also Kirpalani and others, "Quality of Life in Spina Bifida," 293-297.

⁶⁶ Bliton, "Parental Hope," 596.

spina bifida. After more than 30 years, the scientific discourses about justifying risks and validating research still remain, as do questions about the relationship between the pregnant woman and the fetus and questions about methods for addressing the ethical issues of maternal-fetal surgery. As the next chapter will show, open-uterine surgery for spina bifida has brought the theme of “ethics in maternal-fetal surgery” into sharp focus.

CHAPTER II

ETHICS OF MATERNAL FETAL SURGERIES: IDENTIFYING ISSUES FROM SCIENTIFIC, SOCIAL, AND MORAL DISCOURSES

In this chapter, I review and engage with the prominent ethical discourses surrounding open-uterine surgery to repair spina bifida, with two goals in mind. The first goal is to illustrate the depth and passion of the ethical debates surrounding maternal-fetal surgery in general and open-uterine surgery to repair spina bifida in particular. The second goal is to show that despite that depth and passion, the controversies over the “ethics of maternal-fetal surgeries,” including this particular procedure, are still unresolved by the medical and ethical discourses available. To those ends, I will review the medical and scientific presentations of the ethics of maternal-fetal surgery, which focus on justification and validation of experimental procedures, and review the social discourses that focus on the concept of the fetus as patient, potential maternal-fetal conflicts, and maternal-fetal surgery as a women’s health issue. I will conclude by examining the typical ethics discourse that emphasizes achieving informed consent, and critique that model by exploring the ethics consultation model developed for this procedure, which emphasizes learning about and understanding women’s experiences and values. This chapter demonstrates the need for clinicians and ethicists to learn more about women’s experiences in considering this procedure, beyond the “ethics” discussed in medical / scientific and social discourses. Women’s experiences, and the ethics

consultation model that elicited them, will be explored through published accounts in Chapter III and through my own qualitative interviews presented in Chapter VI.

Scientific Discourses: Justification and Validation of Maternal-Fetal Surgeries

Justification

The earliest articles to mention the ethical issues raised by maternal-fetal surgeries were reports by physicians and researchers of procedures designed to correct congenital anomalies before birth. These discussions focused on the technical feasibility and medical justification for maternal-fetal surgeries. In their 2009 “History of Fetal Surgery,” Timothy Jancelewicz and Michael R. Harrison explain that

the impetus provided by the neonate who had an uncorrectable disorder at birth considered with the fetus who had a birth defect detected before birth led to the realization that many fetal diseases may require medical management before birth. Although neither impetus was sufficient itself to justify fetal procedures, together they spurred the necessary clinical and experimental studies that would lead to successful fetal treatment.¹

Research into maternal-fetal surgeries was designed to learn whether *prenatal* interventions could change *neonatal* outcomes for lethal or life-limiting conditions to a degree that might justify the risk of fetal death or severe compromise from extreme prematurity. Thus, many, if not most, discussions of ethics emerged in the context of justifying experimental procedures: what procedures surgeons were attempting and the rationale for each procedure. For example, in his groundbreaking 1963 article about intrauterine transfusion, A. W. Liley focused on the justification for attempting the procedure, technical descriptions, and results of transfusing the fetus affected by Rh-

¹ Jancelewicz and Harrison, "A History of Fetal Surgery," 231.

incompatibility.² The report included only the briefest mention of ethical concerns like explaining risks and benefits to the pregnant woman. Similarly, in the early 1980s, when surgeons began attempting more invasive procedures in fetuses with lethal congenital anomalies, they presented their initial cases as questions of technical feasibility: can it be done and how do we measure success? Michael R. Harrison, Michael S. Golbus, and Roy A. Filly reported on the several in utero surgical procedures they had designed and attempted for “anatomic malformations...that interfere with fetal organ development and that, if eliminated, would allow normal fetal development to proceed.”³ They claimed

treatment of several fetal diseases have proved feasible, and treatment of more complicated lesions will undoubtedly expand as techniques for fetal intervention improve. It seems likely that the fetus with a treatable birth defect is on the threshold of becoming a patient.⁴

Because fetal demise was a likely outcome with these defects, researchers could attempt procedures to determine whether correcting the defect was possible. Once a procedure proved feasible, the justification was anchored in the ideas of technological ability and medical progress. The researchers at UCSF expressed confidence in both the improvement of techniques for maternal-fetal surgery, and in the acceptance of procedures on “the fetal patient.” Other early “fetal surgeons” shared that same confidence in technological progress and the technological rationale for maternal-fetal surgeries.⁵ For example, in 1982, Frederick D Frigoletto, Jr., Jason C. Birnholz, and

² Liley, "Intrauterine Transfusion," 1107-1110.

³ Michael R. Harrison, Michael S. Golbus, and Roy A. Filly, "Management of the Fetus with a Correctable Congenital Defect," *JAMA* 246, no. 7 (1981), 776.

⁴ *Ibid.*, 777.

⁵ Joseph P. Bruner, "In Their Footsteps: A Brief History of Maternal-Fetal Surgery," *Clinics in Perinatology* 30, no. 3 (2003), 439-440. Bruner's article describes how maternal-fetal

Michael F. Greene, at Harvard University and Brigham and Women's Hospital, Boston, presented a similar report on their first attempt at placing a shunt to correct hydrocephalus in a 26-week-old fetus.⁶ Although the surgery had to be repeated, and the neonate, delivered early, died after a five-week stay in the NICU, the surgery was considered a success because it demonstrated the capability of and progress in performing the procedure "when a clinical condition warrants intervention, when professional resources and equipment are available, and when parents are fully involved in the decision-making process."⁷ The authors even provide a list of guidelines or clinical indications for considering such an intervention. However, while they acknowledge the multiple questions these procedures raised, the justification remains technological: if we can do it, we should offer it.

As enthusiasm for maternal-fetal surgeries grew, questions about the rationale and justification for risks were published following or sometimes in conjunction with reports of feasibility. The concern was whether the "can" implied the "ought" for maternal-fetal surgeries on vulnerable pregnant women and fetuses with congenital anomalies.⁸ In addition to the significant risks to the otherwise healthy pregnant woman, the risks of maternal-fetal surgeries included premature delivery and death of the fetus. Researchers

medicine was created and sustained by the same ideas of progress and technological justification. Bruner's extols the vision and dedication of four clinicians / researchers among the "fathers of modern maternal-fetal medicine." He describes the vision, effort, challenges, and successes of developing procedures for obstructive urinary tract, congenital diaphragmatic hernia (CDH), hydrocephalus, Twin-to-Twin Transfusion Syndrome (TTTS), and the endoscope that made such procedures possible.

⁶ Frederick D. Frigoletto, Jason Birnholz, and Michael F. Greene, "Antenatal Treatment of Hydrocephalus by Ventriculoamniotic Shunting," *JAMA* 248, no. 19 (1982), 2496.

⁷ Frigoletto, et al, 2497.

⁸ Fletcher and Jonsen, "Ethical Considerations," 15.

justified these risks because the early procedures were only offered for conditions where the fetus likely would die in utero or shortly after delivery.⁹ In these cases, an experimental procedure that offered even the slightest improvement in neonatal outcome, the slightest chance of survival, seemed to justify the risk of fetal death because without any intervention the fetus was likely to die. The experimental fetal surgeries were seen as attempted rescues from almost certain neonatal death. Even with the justification that these procedures were “rescue” operations, however, others were concerned about the possibility of “half-correcting” the problem.¹⁰ As Harrison, Golbus, and Filly explained, a major concern was that doing the procedures because they were technically feasible might salvage some fetuses that would have died, but in the process might create significantly damaged or compromised survivors. The question was whether survival was always the best outcome for fetuses with extreme congenital anomalies, but early researchers were convinced that the risks could be minimized and that maternal-fetal surgeries would become progressively safer and more effective.¹¹

Many clinicians and researchers exploring maternal-fetal surgeries shared the idea that maternal-fetal surgeries were a part of medical progress. Echoes of that commitment can be heard even 20 years later, as research into in utero procedures continues and expands to include non-lethal conditions. Jancelewicz and Harrison, for example, argued that “as the number of professionals devoted to fetal treatment increases and the number and quality of fetal treatment centers around the world continues to grow, the banner for fetal surgery in the twenty-first century should read, “Proceed with Caution...and

⁹ William R. Barclay and others, "The Ethics of in Utero Surgery," *JAMA* 246, no. 14 (1981), 1552-1554.

¹⁰ Fletcher and Jonsen, "Ethical Considerations," 14.

¹¹ Barclay and others, "Ethics," 1555.

Enthusiasm.”¹² And yet, this story of steady progress has been challenged, even from within the medical profession.

Not all those exploring maternal-fetal medicine were as sanguine about the eventual technological success and others were even more concerned about the troubling implications of maternal-fetal surgeries beyond the questions of feasibility and progress. As early as 1970, Frank Ayd warned that experimenting on human fetuses without respect for the “inviolable rights of the fetus from conception” would contribute to the dehumanization of physicians and researchers and society as a whole. He saw maternal-fetal surgeries as perpetuating a medical / technological morality based on the idea of human perfectibility and the unlimited powers given to physicians and scientists.¹³ Ten years later, John Fletcher responded to Harrison, Golbus, and Filly’s report of maternal-fetal surgeries with questions about the potential conflicts of interest if the fetus is considered a patient in distinction from the pregnant woman, what regulations should guide fetal therapy research, and whether our society with limited medical resources should support such research.¹⁴ Around the same time, George Avery raised additional questions about accommodating parental wishes, what levels of treatment should be pursued and how to scientifically validate new maternal-fetal surgeries as therapeutic.¹⁵ In spite of these concerns published in leading journals, surgeries proceeded based on the

¹² Jancelewicz and Harrison, "A History of Fetal Surgery," 235.

¹³ Frank J. Ayd, Jr., "Fetology: Medical and Ethical Implications of Intervention in the Prenatal Period," *Annals of the New York Academy of Science* 169, no. 2 (1970), 376-377.

¹⁴ John C. Fletcher, "The Fetus as Patient: Ethical Issues," *JAMA* 246, no. 7 (1981), 772-773.

¹⁵ George B. Avery, "Fetal Surgery: Some Questions," *JAMA* 248, no. 19 (1982), 2498.

confidence that scientific and medical progress would continue and would improve the outcomes of surgeries while minimizing risks. The questions about maternal-fetal surgeries began to shift towards Avery's concern for validating the successes of innovative procedures: while some few asked the question of *ought*, most early practitioners focused on the questions of *how*, including how to validate experimental procedures scientifically and responsibly.

Validation

The process of scientific validation is one means of demonstrating the safety and effectiveness of a procedure to the satisfaction of one's peers and the broader community and ensuring patient and participant safety as a procedure moves from the category of innovation to research to standard of care.¹⁶ The first question in the process tends to be determining whether to designate an experimental procedure as an innovative therapy or as research; the second is whether and how to design a clinical trial to evaluate and verify the risks and benefits.

Researchers and clinicians pursuing maternal-fetal surgeries have tended to address at least the first and sometimes the second question as they designed their experimental procedures. Ethicists John C. Fletcher and Albert Jonsen, involved with maternal-fetal medicine from the beginning, explain that there is an important distinction between innovative research and treatment:

Innovative treatment involves a previously untried maneuver that is done in the reasonable but yet unproven expectation that it may provide medical benefit, usually in a desperate situation. Research consists of techniques designed to gather and analyze information about a procedure that may or

¹⁶ Fletcher and Jonsen, "Ethical Considerations," 14-15.

may not be intended to benefit the subject, so that generalizable conclusions can be drawn.¹⁷

Harrison, Golbus, and Filly, for example, designed procedures for anatomical malformations that would qualify as “desperate situations” for the fetus, but designed the procedures under research protocols – trying to learn if correction of such defects was at all possible, rather than attempting the corrections with the expectation that the procedures would be beneficial.¹⁸ The distinction between innovative therapy and research is important for clinicians and researchers in the design and evaluation of their procedures, but the distinction is also important – and difficult – for research participants to understand. Counteracting the idea that research will be beneficial to the participant – the “therapeutic misconception” – is often a significant challenge in the informed consent process,¹⁹ and a challenge that must be accounted for in trial design. The therapeutic misconception needs to be addressed in ethics consultation and informed consent processes as well, so that patients or potential research participants can understand the details of their clinical circumstances and can have realistic expectations regarding possible outcomes.²⁰

Fletcher and Jonsen also identify a further distinction: while research requires approval from an Institutional Review Board (IRB), innovative therapy does not. Fletcher and Jonsen observe that because many techniques for maternal-fetal surgeries were variations on techniques used to treat neonates and premature infants, maternal-fetal

¹⁷ Fletcher and Jonsen, 15.

¹⁸ Harrison, Golbus, and Filly, "Management," 776-777.

¹⁹ Gail E. Henderson and others, "Clinical Trials and Medical Care: Defining the Therapeutic Misconception," *PLoS Medicine* 4, no. 11 (2007), 1735.

²⁰ Bliton and Zaner, "Cutting Edge," 352.

surgeries could have been classified as innovative therapies and not subject to the stringent review processes required by formal research. However, researchers in the early 1980s were alert to the ethical issues created by their innovations and many framed their work as research rather than as innovation, and submitted their protocols for validation by IRB and peer review before proceeding.²¹

Early researchers in maternal-fetal medicine were confident that practice and rapidly advancing technologies would establish fetal therapy as a field of medicine with scientifically validated measures of success, finding precedents for both the critics' doubts and their own assumptions of success. Frigoletto, et al point to the concerns that emerged following Liley's first reports of intrauterine transfusion. They emphasize the steady progress since Liley "pioneered" the procedure: "during the interim, diagnostic evaluation, indications for use, utility, and safety have been refined. A comparable evolution may be anticipated for other percutaneous intrafetal procedures."²² Their confident expectation that concerns about validating maternal-fetal surgeries will be answered by further research raise the second question of how researchers validate claims of success for new procedures.

Validation of experimental procedures has been among the most prominent ethical concerns since Harrison, Golbus, and Filly began their research on maternal-fetal surgeries. Over 25 years after research – and ethical debate – began, validation is still a

²¹ Fletcher and Jonsen, "Ethical Considerations," 15. It is important to note, however, that while the decisions to pursue these procedures as research, rather than innovative therapy, were ethically justified, they did not sufficiently address the ethical concerns raised by the procedures, including, most prominently, the women's understandings of this distinction. See Rothschild et al for their investigation of ethics consultations and women's understandings of research and informed consent.

²² Frigoletto, Birnholz, and Greene, "Antenatal Treatment," 2497.

prominent theme in the medical and surgical discourse about the ethics of maternal-fetal surgery. Frank Chervenak and Laurence McCullough, in their contributions to the discourse, developed a framework intended to guide research through and in relation to clinical trials for maternal fetal surgery.²³ They began by challenging the medical story of the development of fetal surgery as guided by and grounded in ethical research. In contrast to Fletcher and Johnson, they describe the development of maternal-fetal surgical procedures as “unmanaged,” not unlike other surgical innovations, and they caution that ongoing developments need to be guided “in an ethically responsible fashion, for which there is widespread support in the professional community.”²⁴ Chervenak and McCullough describe ethical criteria for initiating and evaluating research on maternal-fetal surgical procedures, moving from the design of a procedure to animal studies, to a single case, a series of cases, and through a clinical trial. They argue for beneficence-based criteria for such research including the possibility for fetal benefit, minimization of harm to fetal patients, and evaluation of maternal harms.

Chervenak and McCullough argue that clinical trials should begin when there is clinical equipoise – disagreement in the professional community about the merits of a procedure – or when there is normative equipoise – the evidence based judgment of innovative and standard procedures that determines neither is better than the other.²⁵ They offer criteria for determining whether the innovative procedure evaluated by a clinical trial should become standard of care, including the probability of the innovation

²³ Chervenak and McCullough, "Comprehensive Ethical Framework," 10.

²⁴ Frank A. Chervenak and Lawrence B. McCullough, "Ethics of Maternal-Fetal Surgery," *Seminars in Fetal & Neonatal Medicine* 12, no. 6 (2007), 426.

²⁵ *Ibid.*, 428.

being life-saving or preventing serious disabilities, low or manageable risk to the fetus and low or manageable risk to the pregnant woman.²⁶

Published in 2002, Chervenak and McCullough's criteria for validating maternal-fetal surgeries closely mirrors the actual process by which early practitioners developed their procedures. For example, in a 1983 Council Report from the Council on Scientific Affairs, Division of Scientific Analysis and Technology, the American Medical Association passed a resolution calling for "a study of in utero surgical procedures intended to improve the health of the fetus, recommendations for the appropriate applications, and discussion of diverse issues of informed consent."²⁷ The council report reviews the types of procedures, while noting that too few procedures had been done to recommend anything but further investigations and optimism. And yet, years after initial efforts at validation, some physicians were calling for caution, rather than enthusiasm, in response to and in the use of in utero surgery²⁸ and, more recently, others have been calling for a reevaluation of designing clinical trials for in utero surgeries.²⁹ With the advent of in utero surgeries for non-lethal conditions like spina bifida, some researchers and clinicians started asking whether the risks of death or prematurity to the fetus, combined with the physical harms to the pregnant woman were outweighed by the

²⁶ *Ibid.*, 428.

²⁷ American Medical Association (AMA), "In Utero Fetal Surgery. Resolution 73 (I-81) Council on Scientific Affairs," *JAMA* 250, no. 11 (1983), 1443-1444.

²⁸ Charles Marwick, "Coming to Terms with Indications for Fetal Surgery," *JAMA* 270, no. 17 (1993), 2029.

²⁹ Anne D. Lyerly and others, "Attitudes of Maternal-Fetal Specialists Concerning Maternal-Fetal Surgery," *American Journal of Obstetrics & Gynecology* 185, no. 5 (2001), 1052-1058.

“prevention of serious disability” in Chervenak and McCullough’s framework.³⁰ They began asking how serious a congenital condition had to be to justify maternal-fetal surgeries, and how a clinical trial could balance between and evaluate the risks, harms, and potential, though uncertain, benefits to the fetus and the pregnant woman.

Even as late as 2003, at the beginning of the MOMS trial, the validation of in utero procedures continued to meet with such scrutiny and challenges from within the medical community. In particular, the introduction of in utero surgery to repair spina bifida, a non-lethal condition, raised the stakes of ethical research and scientific validation.³¹ Arguing from the significant moral distinction established by Mark J. Bliton and Richard M. Zaner, Anne Draper Lyerly and Mary Mahowald noted the unavoidable differences in operating to avoid almost certain fetal death (the initial rationale for risky procedures) and trying to improve quality of life conditions as with myelomeningocele repair.³² In particular, they reviewed the uncertain benefits and significant risks associated with in utero surgery to repair myelomeningocele, a condition, they emphasize, whose diagnosis is often heavy with clinical uncertainty. Lyerly and Mahowald focus on the significant risks to maternal health and explore the experimental nature of this procedure along with the mixed evaluations of its success from different maternal-fetal medicine specialists.³³ They ask whether a clinical trial of in utero surgery

³⁰ Chervenak and McCullough, "Comprehensive Ethical Framework," 11.

³¹ Mark J. Bliton, "Proposals for New Guidelines: Attending to Moral Matters in Fetal Surgery," in *Fetal Surgery and the Moral Presence of the Fetus Conference* (Vanderbilt University, Nashville, Tennessee: 2000), 1-2; Bliton and Zaner, "Cutting Edge," 348.

³² Lyerly and Mahowald, "Maternal-Fetal Surgery," 155-156.

³³ Lyerly and others, "Attitudes ", 1058; Lyerly and others, "Toward the Ethical Evaluation," 689-693.

to repair spina bifida could successfully identify and weigh risks and benefits of the procedure, or could even meet the criteria, described by Chervenak and McCullough, of avoiding disability with minimal fetal and maternal risks. Lysterly and Mahowald argue that to meet those criteria or the ethical requirement of equipoise, questions about the “psycho-social impact of maternal-fetal surgery on women” need to be addressed.³⁴ They explain,

maternal-fetal surgery has implications for women, the fetus, and their families beyond those that would be considered physical or medical. If the medical risks to the women could be counterbalanced by psychosocial gains to her, the ethical requirement for equipoise may be met in her regard.³⁵

For Lysterly and Mahowald, maternal-fetal surgery requires a reevaluation of the medical / scientific criteria for ethical clinical trials as described by Chervenak and McCullough which neglect the psycho-social and physical harms to healthy pregnant women. Following Bliton and Zaner,³⁶ Lysterly and Mahowald wanted researchers to address both the medical and non-medical questions before establishing ethically justified clinical trials for myelomeningocele repair or offering the surgery electively.

In the 15 years since it was first offered, open-uterine surgery to repair spina bifida has become the exemplar of the medical, social, and ethical complexities inherent in validating the safety and potential benefits of maternal-fetal surgeries. Although the MOMS trial was designed to determine and evaluate surgical outcomes for the procedure,

³⁴ Lysterly and Mahowald, "Fallacy of Abstraction," 160.

³⁵ *Ibid.*, 160.

³⁶ Bliton, "Parental Hope," 590. Bliton cautions that regardless of whether the advocates or skeptics prevail after the MOMS trial, unresolved ethical issues will need to be addressed, including “the need for identifying and establishing legitimate ways to handle the issues surrounding maternal and fetal vulnerability at previable gestational stages, which is when the defect is often diagnosed and likewise when fetal repair is likely to be performed.”

Lyerly and Mahowald's questions about how to evaluate non-surgical aspects of the procedures still challenge the maternal-fetal medicine community. Part of the difficulty stems from the inseparable relation of pregnant woman and fetus, which is not only framed medically, but also by the social and interpersonal issues that amplify benefits and burdens. The medical and moral ambiguities of harming the healthy pregnant woman for the possibility of benefiting the fetus have haunted maternal-fetal medicine since before it was a field. These ambiguities have led to impassioned debates about whether such procedures are better justified by considering the fetus a patient in its own right, or by considering the procedures a reproductive health choice and a women's health issue. In the following sections, I will explore how these debates have shaped the design of, justification for, and validation of maternal-fetal surgeries,³⁷ and have raised questions about how and where such procedures are performed and how clinicians, researchers, and pregnant women have understood the ethical issues these procedures raise.³⁸

Social Discourses: The Fetus as Patient and Maternal-Fetal Surgery as a Women's Health Issue

Understanding the complex relationship between the pregnant woman and the fetus has troubled maternal-fetal medicine since its beginnings. Understandings of the

³⁷ Fletcher and Jonsen, "Ethical Considerations," 14-18; Susan S. Mattingly, "The Maternal-Fetal Dyad. Exploring the Two-Patient Obstetric Model," *Hastings Center Report* 22, no. 1 (1992), 13-18; William Ruddick and William Wilcox, "Operating on the Fetus," *Hastings Center Report* 12, no. 5 (1982), 10-14.

³⁸ Blizzard, *Looking Within* 41-73; Stephen D. Brown and others, "Paediatrics-Based Fetal Care: Unanswered Ethical Questions," *Acta Paediatrica* (2008), 1617-1619; Casper, *Making the Unborn Patient*; Anne D. Lyerly, Margaret O. Little, and Ruth R. Faden, "A Critique of the 'Fetus as Patient'," *American Journal of Bioethics* 8, no. 7 (2008), 42-44; Lyerly and Mahowald, "Maternal-Fetal Surgery," 155-165.

fetus as patient and of maternal-fetal surgery as a women's health issue both have vocal proponents among clinicians, researchers, ethicists, sociologists, and lawyers trying to make sense of these procedures. The following sections will detail these prominent perspectives regarding the contested concept of the fetus as patient and the alternative focus on maternal-fetal surgeries as a women's health issue.

Establishing the Fetus as Patient and Maternal-Fetal Conflicts

The 'fetal focus'³⁹ that motivates many researchers and characterizes much of the discourse surrounding maternal-fetal surgeries is the product of technological advances, social pressures about abortion and disability, and competing professional interests. Monica Casper documented these complex developments and social dimensions of the fetal patient in her 1997 book, *The Making of the Unborn Patient: A Social Anatomy of Fetal Surgery*.⁴⁰ Deborah Blizzard conducted similar research in her work, *Looking Within: a Socio-cultural Examination of Fetoscopy*, focusing on the development of fetoscopy and the social implications of "looking within" for pregnant women and clinicians. While Casper focused on and "framed her work as a women's health issue," Blizzard sees her own work as "entrenched in a new ethnographic approach in which

³⁹ Ruddick and Wilcox, "Operating on the Fetus," 12-13.

⁴⁰ Casper explains the social implications of maternal-fetal surgery for pro-life activists and for activists who promote choice in all women's reproductive issues. [See 42-46 ('breaching the womb'); 59-67 (pro-life activities of early fetal surgeons); 81-89 (women's health focus)]. She also explores the social and institutional implications of devoting resources and personnel to the fetal patient (118), and to the cooperative and competitive elements of establishing a "new patient population" with its attendant turf wars between pediatrics and obstetrics / gynecology for predominance in the new field. [See 110-115 (emphasis on cooperative elements); 117-124 (emphasis on difference, women as work object vs. fetus as work object)]. Casper's work on the various social dimensions that intersect in maternal-fetal medicine is one of the primary texts in the field.

emotions and personalities must be made apparent.”⁴¹ Like Casper’s examination of social and political interactions, Blizzard’s research allows for a broader socio-cultural understanding of the procedures she is investigating and the socio-medical contexts in which they emerge. Rather than rehearsing the details of Casper’s and Blizzard’s work here, I will focus on the implications of a social and moral issue their work raises for my research: whether maternal-fetal medicine is the purview of pediatrics or obstetrics/gynecology. Underlying that question is the still unresolved set of issues regarding the different ways clinicians and researchers, and pregnant women themselves, understand the ‘patient’ – as the pregnant woman, as the fetus, or as a single, inseparable entity? Blizzard’s and Casper’s questions focus on how the different ways clinicians think about their patient – and who they recognize as their patient – influence how they respond to pregnant women who are considering maternal-fetal surgeries. My research explores the ways women who considered open-uterine surgery to repair spina bifida saw that relationship, and whether those perspectives influence their complex decision-making.

As noted above, a significant amount of work in the early literature considered the potential for and implications of maternal-fetal conflict created by maternal-fetal surgeries and the concept of the fetus as a patient. In a rash of court cases in the late

⁴¹ Blizzard, *Looking Within* 44-49, 67. In addition to her attention to methodological concerns, Blizzard works through the “Feminist Problem of the Fetus,” the problem created by the scholarly difficulties in examining the fetus as a subjective entity (e.g. something that may have cultural, human, or personal identity) without potentially supporting or entrenching arguments of fetal rights (44-48). Blizzard writes, “Though an in utero entity may exist as either fetus or baby, it is the rare case that a pregnant woman in western medical contexts is not a maternal entity” (48-49). The slipperiness of descriptive categories complicates examinations of the relationship between pregnant women and the fetus in fetoscopy, but also, as Blizzard shows, complicates how women and clinicians understand the relationship in their own experiences. Blizzard’s accounts focus on the patients’ and the professionals’ experiences, often in the midst of their interactions.

1970s and early 1980s, courts ordered women to undergo c-sections and other procedures in the interests of “the unborn child.”⁴² Many ethicists, clinicians, sociologists, and lawyers were concerned that maternal-fetal surgeries, if successful, might be forced on women as well, especially if the fetus was considered a patient distinct and separable from the pregnant woman with inviolable rights, as some claimed.⁴³

As researchers continued to develop and test maternal-fetal surgeries, the initial optimism about easily measurable successes waned, as did the polemical concerns about state enforced maternal-fetal surgeries. In an article published in 1984, George Annas and Sherman Elias noted that in spite of their earlier prediction that “experimentation with fetal surgery has come of age, and its routine clinical application seems inevitable,” by now it appeared to them as though “the road from experimentation to therapy will be longer than most observers originally predicted.”⁴⁴ In that same year, Fletcher and Jonsen observed that maternal-fetal surgeries could not be considered ethically mandatory at the time, given the risks and the limitations on success.⁴⁵ As the initial fervor of both enthusiasm and consternation faded, what became clear was the central issue and the actual questions about the ways clinicians, researchers, and pregnant women could

⁴² George J Annas and Sherman Elias, "Perspectives on Fetal Surgery: On the Road from Experimentation to Therapy (and What to Do When We Arrive)," in *Genetics and the Law III*, ed. George J Annas and Aubrey Milunsky (New York, NY: Plenum Press, 1984), 335-356; Fletcher and Jonsen, "Ethical Considerations," 15-16; Lyerly and Mahowald, "Maternal-Fetal Surgery," 157-159; J. Paul Phelan, "The Maternal Abdominal Wall: A Fortress against Fetal Health Care?," *South California Law Review* 65, no. 1 (1991), 467-470.

⁴³ Andrew W. Liley, "The Foetus as a Personality. By A.W. Liley, 1972," *Fetal Therapy* 1, no. 1 (1986), 8-17; Annas and Elias, "Perspectives," 352-353; Phelan, "Fortress," 467; Fletcher and Jonsen, "Ethical Considerations," 15-16.

⁴⁴ Annas and Elias, "Perspectives," 347.

⁴⁵ Fletcher and Jonsen, "Ethical Considerations," 16.

understand the relationship between the pregnant woman and the fetus in the context of maternal-fetal surgeries.

In that context, an important discussion by William Ruddick and William Wilcox will illustrate the complex set of overlapping relationships. Ruddick and Wilcox proposed three models for understanding the relationship between the pregnant woman and the fetus in the context of maternal-fetal surgeries: the gynecological model, the pediatric model, and the obstetric model.⁴⁶ They were concerned, along with their contemporaries, about how the concept of the fetus as a patient might affect understandings of the autonomy and bodily integrity of women.

The first model they proposed to establish a stable understanding of the physician's obligations was a gynecological model, which puts maternal-fetal surgeries in the context of women's reproductive choices. In this model, the focus of the health care provider's obligations is on the pregnant woman herself and to her interests. As an autonomous decision-maker, the pregnant woman resolves questions about abortion, treatment, or non-treatment of the fetus.⁴⁷

The second model is the pediatric model, which presumes the fetus is the primary patient who should receive the same treatments as the neonate would. In this model, both the pregnant woman and the health care providers are focused on and committed to the interests of and possible treatments for the fetus, even if these include risk or harm to the pregnant woman. This requires a kind of "balancing" of interests, and the question becomes the appropriate ways to measure these interests that need to be "balanced." Both of the first two models have had proponents over the years, though more pushed for the

⁴⁶ Ruddick and Wilcox, "Operating on the Fetus," 11-14.

⁴⁷ Barclay and others, "Ethics," 1551-1554.

pediatric model.⁴⁸ Ruddick and Wilcox pointed out the flaws in both, however, namely that focusing on the fetus or the pregnant woman as the patient to the exclusion of or at the expense of the other did not account for the physical, social, and often emotional connections between them.

Ruddick and Wilcox suggested a third alternative – which they called the obstetric model. They see the obstetric model as balancing the pregnant woman’s and the fetus’s interests by focusing on the overlap in those interests rather than presuming those interests conflict. They suggest that an obstetric model can account for most cases in the context of maternal-fetal surgeries, where the health care providers and the pregnant women are partners working for both the pregnant woman’s and the fetus’s interests, health, and well-being.

Susan S. Mattingly reaches a similar conclusion in her 1992 work on the maternal-fetal dyad.⁴⁹ Instead of a conflicting two-patient model of obstetric care, Mattingly suggests an environmental or family model that acknowledges the fetus as patient, but as a patient integral to and inseparable from the maternal patient. She argues that a model that emphasizes the interrelation and dependence of maternal-fetal dyad can “reinforce the physician’s customary ethical stance – working cooperatively with the pregnant woman for common, linked goals of infant, maternal, and family well-being.”⁵⁰ Such a perspective would contradict the tendency to focus on either maternal or fetal interests.⁵¹

⁴⁸ Casper, *Making the Unborn Patient* 117-121.

⁴⁹ Mattingly, "Maternal-Fetal Dyad," 17-18.

⁵⁰ *Ibid.*, 18.

In her analysis of the two-patient and one-patient models of the maternal-fetal dyad, Mattingly explains that in balancing benefits and burdens of treatment, a one-patient obstetric model allows physicians to weigh benefits and burdens for both the pregnant woman and the fetus. She argues, “When the maternal-fetal dyad is regarded as an organic whole, what matters is that *combined* maternal-fetal benefits outweigh *combined* maternal-fetal burdens”⁵² rather than attempts to distinguish which benefits belong to whom. On the other hand, the two-patient model that separates the fetus from the pregnant woman, creating a distinct patient, creates the possibility for conflicts in the *physicians’* obligations: the benefits and burdens must be weighed for each patient and benefits to one (the fetus) do not outweigh the burdens to the other (the pregnant woman). Physicians may recommend therapy that benefits the fetus but be unable to recommend a therapy that harms the pregnant woman with no direct benefit to her *even though the procedure is the same*. She argues that “on the two-patient model of the maternal-fetal dyad, a single treatment recommendation for both patients cannot be justified in terms of the beneficence principle alone, for it includes no provision for balancing burdens of one patient against benefits to another.”⁵³ Mattingly explains that it is not the pregnant woman’s refusal of intervention that causes conflict, but that the conflict stems from physicians’ beneficence duties preceding any question of maternal consent or refusal. She argues, instead,

Caring for one implicates the other and the family context. An environmental medical model would remove the specter of dueling

⁵¹ Casper, *Making the Unborn Patient*, 81-89.

⁵² Mattingly, "Maternal-Fetal Dyad," 14.

⁵³ *Ibid.*, 14.

specialists vying for medical control of a complicated pregnancy – the *reductio ad absurdum* of the two-patient thesis.⁵⁴

Mattingly observes, too, “maternal-fetal conflicts are interesting out of proportion to the incidence in part because they raise in a compelling way questions about the integration of medical and family ethics, an important and underdeveloped topic.”⁵⁵ Her environmental or family model is a more detailed version of the obstetric model suggested by Ruddick and Wilcox, and is designed to avoid the issues that emerge when clinicians and researchers understand the pregnant woman and fetus to have inherently conflicting interests.

Arguing the debate from a different perspective, Chervenak and McCullough have long promoted the concept of fetus as patient with dependent moral status, as a way of avoiding the “ethical and clinical gridlock” created by those conflicting interests. They argue that considering the fetus as a patient with dependent moral status supports the autonomy of the pregnant women and the interests of the fetus in clinical settings.⁵⁶ In an essay on “Ethical Considerations,” Chervenak and McCullough consider two prominent, competing understandings of the fetus as patient. In the first, the fetus is a patient because it has independent moral status based on inherent characteristics. In the second, the viable fetus is a patient when presented to the physician and the previable fetus is a patient when the pregnant woman has granted it dependent moral status and presented it to the

⁵⁴ *Ibid.*, 14; Casper, *Making the Unborn Patient* 81-89.

⁵⁵ Mattingly, "Maternal-Fetal Dyad," 17.

⁵⁶ Frank A. Chervenak and Lawrence B. McCullough, "Ethical Considerations," in *The Unborn Patient: The Art and Science of Fetal Therapy*, ed. M. R. Harrison et al. (Philadelphia: W.B. Saunders Company, 2001), 20-21.

physician.⁵⁷ Chervenak and McCullough argue that the first understanding of fetus as patient with independent moral status sets up the possibility of an untenable situation where a physician has beneficence-based duties to the pregnant woman and fetus that may conflict – especially, as they point out, given conflicting and apparently irresolvable views of whether the fetus has the moral status of a person or a patient.⁵⁸ As an alternative, they argue that the fetus as a patient based on the dependent moral status of the fetus, as granted by the pregnant woman who continues her pregnancy. As they explain in a later article, “the fetus is a patient when reliable links exist between it and its later achieving the moral status of a child and then a person,”⁵⁹ and when treatments exist that can be expected to benefit the fetus. This temporal frame allows the physician to honor beneficence-based duties to both the pregnant woman and the viable fetus and allows the physician *and* pregnant woman to honor beneficence-based duties to the fetus while the physician maintains his autonomy-based obligations to the pregnant woman.

Chervenak and McCullough claim that this understanding of the fetus as a patient is a “central concept of obstetric ethics,”⁶⁰ and use it to support their work on the scientific validation of experimental procedures, as discussed above.⁶¹ They also use this concept to challenge ethical frameworks that consider the life, health, and decision-making of pregnant woman as preeminent, what Ruddick and Wilcox called the

⁵⁷ Ibid., 21.

⁵⁸ Ibid., 20-21.

⁵⁹ Chervenak and McCullough, "Ethics 2007," 427.

⁶⁰ Ibid., 426.

⁶¹ See pages 37-42, above, on scientific validation.

gynecological model.⁶² Chervenak and McCullough argue “when the fetus is a patient, the physician has beneficence-based obligations to protect its life and health,”⁶³ and that any ethical framework which does not consider this obligation to the fetal patient along with obligations to the pregnant patient is inadequate. In part due to the clarity of their analysis and in part due to the frequency with which they have published it in one form or another,⁶⁴ Chervenak and McCullough’s view of the fetus as patient, which leans towards Ruddick and Wilcox’s pediatric model, apparently has become well received. Nevertheless, this dominant ethical concept has been challenged, over the years, sometimes with striking fervor.⁶⁵

Maternal-Fetal Surgery: Women’s Health, Relationships, and Autonomy

Some of the challenges to the concept of fetus as patient must be examined because they highlight a key ethical theme – how maternal-fetal surgeries affect women’s health and well-being – that is often overlooked by the medical discourse and, according

⁶² Lawrence B. McCullough and Frank A. Chervenak, "A Critical Analysis of the Concept and Discourse of 'Unborn Child'," *American Journal of Bioethics* 8, no. 7 (2008), 37-38; Ruddick and Wilcox, "Operating on the Fetus," 13.

⁶³ Chervenak and McCullough, "Ethics 2007," 428; Brown and others, "Paediatrics-Based Fetal Care," 1617-1619. This is part of the problem that Brown, Lyerly, et al, and Mattingly identify – that such a set up creates possible conflicts, even when Chervenak and McCullough claim maternal concerns are still involved. Brown, Lyerly, et al describe how different this is in pediatrics-based model vs. obstetric based model.

⁶⁴ Chervenak and McCullough, "Comprehensive Ethical Framework," 10-14; Chervenak and McCullough, "Ethics 2007," 426-431; Frank A. Chervenak and Lawrence B. McCullough, "Ethics of Fetal Surgery," *Clinics in Perinatology* 36, no. 2 (2009), 237-246; Frank A. Chervenak, Lawrence B. McCullough, and David J. Birnbach, "Ethical Issues in Fetal Surgery Research," *Best Practice Research in Clinical Anaesthesiology* 18, no. 2 (2004), 221-230; McCullough and Chervenak, "Critical Analysis," 34-39.

⁶⁵ Brown and others, "Paediatrics-Based Fetal Care," 1617-1619; Lyerly and Mahowald, "Maternal-Fetal Surgery," 155-165; Mattingly, "Maternal-Fetal Dyad," 13-18.

to these critiques, by the “fetal focus” of the ethical discourse as well. Anne Draper Lyerly and Mary B. Mahowald, for example, begin their article, "Maternal-Fetal Surgery for Treatment of Myelomeningocele," by noting that despite “prenatal testing and treatment [which] have fostered an inaccurate understanding of the fetus by treating them as separate or separable patients,” the relationship between the pregnant woman and the fetus is *defined by pregnancy*: the pregnant woman and fetus are inseparable.⁶⁶ Lyerly and Mahowald note that the emphasis on the fetus as an individuated, separated patient even emerges in the language of “fetal surgeon” or “fetal treatment center” that effectively “erase” pregnant women from consideration.⁶⁷ On the one hand, this consistent erasure manifests itself in a neglect of research on maternal outcomes of the maternal-fetal surgeries, despite researcher claims that the women’s health is paramount.⁶⁸ On the other hand, it makes the fetal focus clearly visible in the number of journals, books, conferences, and centers devoted to “this whole new patient population.”⁶⁹ Lyerly and Mahowald point out that “concepts of fetal patient-hood, however, are neither accurate nor helpful as they ignore the essential tie between fetuses

⁶⁶ Lyerly and Mahowald, "Maternal-Fetal Surgery," 162.

⁶⁷ Lyerly, Little, and Faden, "Critique," 42-44; Lyerly and Mahowald, "Maternal-Fetal Surgery," 156; Margarete Sandelowski, "Separate, but Less Equal: Fetal Ultrasonography and the Transformation of Expectant Mother/Father," *Gender and Society* 8, no. 2 (1994), 238. See also Casper, *Making the Unborn Patient* on actual erasure of the pregnant woman from the videography screen during open-uterine surgeries.

⁶⁸ Michael R. Harrison, "Fetal Surgery," *American Journal of Obstetrics & Gynecology* 174, no. 4 (1996), 1255.

⁶⁹ Yoshihiro Kitano and others, "Open Fetal Surgery for Life-Threatening Fetal Malformations," *Seminars in Perinatology* 23, no. 6 (1999), 448; Joe L Simpson, "Fetal Surgery for Myelomeningocele: Promise, Progress, and Problems," *JAMA* 282, no. 19 (1999), 1873; Jancelewicz and Harrison, "A History of Fetal Surgery," 777.

and the women in whom they develop.”⁷⁰ They challenge Chervenak and McCullough’s argument that the viable fetus and the previable fetus with conferred moral status are patients distinct and separable from the pregnant woman, noting that such a view creates the possibilities of an untenable conflict between beneficence to a fetal patient and respecting a pregnant woman’s autonomy, even up to and including her refusal of intervention. Lyerly and Mahowald argue, “Practitioners need to avoid the tendency to consider fetuses as distinct patients and instead need to emphasize the fact that there is one patient, the pregnant woman.”⁷¹ To counteract the fetal focus that overlooks women, at best, or coerces them, Lyerly and Mahowald argue that “any adequate understanding of the term ‘fetus’ necessarily entails recognition of the pregnant woman.”⁷² They conclude, along with Mattingly and with Ruddick and Wilcox, that as women often identify with the interests of the fetuses they carry, providing care to pregnant women and working with them to support fetal health should be the goal for health care providers.

In answer to such critiques, Chervenak and McCullough insist that their framework for ethical considerations does account for the pregnant woman,⁷³ but many clinicians and scholars remain unconvinced. Anne Draper Lyerly, Margaret Olivia Little, and Ruth R. Faden, for example, argue that a troubling implication of the “fetus as patient” is that the concept can subtly change the perceived relationship between the pregnant woman and fetus, despite Chervenak and McCullough insistence that ‘fetus as

⁷⁰ Lyerly and Mahowald, "Maternal-Fetal Surgery," 159.

⁷¹ *Ibid.*, 159.

⁷² *Ibid.*, 156.

⁷³ McCullough and Chervenak, "Critical Analysis," 38.

patient' does not require that the fetus be regarded as a *separate* patient."⁷⁴ Though Chervenak and McCullough argue that their framework accounts for the relationship between the pregnant woman and the fetus, Lyerly, Little, and Faden have argued that their framework and the concept of "fetus as patient" have the same practical effect of overlooking the pregnant woman on whom and through whom clinicians operate. As if to prove the point, an article by Stephen D Brown, Anne D Lyerly, Margaret O Little, John D Lantos documents the shift in perinatal medicine, over time, towards a pediatrics-based fetal care model. They identify significant problems in fetal care provided by pediatrics in children's hospitals rather than the traditional obstetrics-based care of women and fetuses, noting that

The location of fetal care centers at children's hospitals rather than in general or women's hospitals may carry different professional or ethical priorities into the domain of prenatal care. Traditionally, obstetrics has focused on the health and well being of women, while pediatrics has focused on the well being of the child.⁷⁵

They are concerned that ethical quandaries may emerge from the shift to a pediatric model that focuses on the concept of the fetus as patient, and that shifts focus away from the health and well being of the pregnant woman. Even while the authors acknowledge that "concerns for the well-being of pregnant women and fetuses overlap considerably," they point to the areas and cases where concerns diverge and where the obstetrics- or pediatrics-based model of prenatal care offer different views of maternal and fetal interests and status.⁷⁶ They find it quite clear that

⁷⁴ Lyerly, Little, and Faden, "Critique," 43.

⁷⁵ Brown and others, "Paediatrics-Based Fetal Care," 1617.

⁷⁶ *Ibid.*, 1617.

Champions of pediatrics-based fetal medicine have strongly emphasized the fetus as a distinct patient who resides in utero. A traditional pediatrics approach may elevate concern for the fetus or future child in ways that have the potential to overshadow concerns for maternal welfare.⁷⁷

Brown, Lyerly, et al point to the limited studies on maternal outcomes after intrauterine procedures as evidence that women's concerns are often overlooked in favor of fetal concerns, just as Lyerly and Mahowald saw the language of "fetal care center" and "fetal surgeon" as evidence of the harmful effects of a "fetal focus" that erases women even from the medical and surgical vocabulary. Revisiting the polemical concerns of the 1980s, Brown, Lyerly, et al reflect on the possibility that women's decisions to refuse intervention may be overridden by legal means or, alternatively, that pregnant women may demand fetal procedures that are not medically indicated.⁷⁸ They note significant differences among pediatricians and obstetricians about the "nature of maternal responsibilities to the fetus... and to what extent maternal autonomy might be overridden for fetal benefit."⁷⁹ The authors identify pediatrician-based fetal care centers as sites where these key ethical issues emerge and where they need to be addressed explicitly and transparently.

What we find then, is that for clinicians and scholars like Brown, Lyerly, Little, and Mahowald, and Chervenak and McCullough, these questions about whether the fetus is a patient and these questions about how to understand the relationship between the pregnant woman and fetus have practical, moral significance for decision-making in pregnant women's lives. These concepts also have the power to influence clinical

⁷⁷ Ibid., 1617.

⁷⁸ Ibid., 1618.

⁷⁹ Ibid., 1618.

practice in terms of the ways clinicians identify and think about their patients, what maternal-fetal surgeries are offered, and how the surgeries are presented to pregnant women and families who have received a prenatal diagnosis of some congenital anomaly in their pregnancy.⁸⁰ These questions and concepts have been considered throughout the discourses surrounding maternal-fetal surgeries since the beginning, but more significantly, their complexity only seems to have increased. There is no surprise that these questions continue to reemerge, revealing that some facets of maternal-fetal surgeries are deeply troubling to clinicians, researchers, ethicists, and pregnant women. What is surprising, and equally troubling, is the very limited focus in either the medical or social discourse on how these questions should be addressed in a clinical or research setting, where they influence the interactions among and decision-making by clinicians, ethicists, and pregnant women.

Moral Discourses: Informed Consent and Ethics Consultations for Maternal-Fetal Surgeries

Most of the work on the ethics of maternal-fetal surgeries has focused on two areas discussed above: the *medical* questions of risks and benefits and the *social* questions of fetal patienthood, women's autonomy, and informed consent for maternal-fetal surgery. In their 1981 article, "Operating on the Fetus," Ruddick and Wilcox recognized that maternal-fetal surgeries demanded new conceptual frameworks to account for the moral complexities raised by these procedures,⁸¹ and in 1983, the American Medical Association echoed this demand when it issued its Council Report

⁸⁰ Lachlan de Crespigny, "Words Matter: Nomenclature and Communication in Perinatal Medicine," *Clinics in Perinatology* 30 (2003), 18.

⁸¹ Ruddick and Wilcox, "Operating on the Fetus," 13-14.

calling for more research and significant work on the “diverse ethical issues” raised by maternal-fetal surgeries.⁸² Despite the recognition *that* understanding the “ethics of maternal-fetal surgery” is important for those involved with the procedures, including clinicians, ethicists, and pregnant women, there is still little agreement about *how* to understand what matters in the “ethics of maternal-fetal surgery.” Clinicians, sociologists, ethicists and lawyers have been trying to identify what matters, and disagreeing about what matters for decades, as illustrated above. The medical and social questions they raise are important, but these questions do not sufficiently account for the moral complexities and “diverse ethical issues” surrounding maternal-fetal surgeries. First, these discourses continue to overlook crucial accounts of the moral issues of maternal-fetal surgeries from the pregnant women and families who consider these procedures. Second, these discourses overlook the question of how clinicians, ethicists, and pregnant women talk about these issues in clinical encounters. For my research, the important question here is whether ethical issues can be identified in advance, such that a typical informed consent process sufficiently addresses those issues, or whether the “ethics of maternal-fetal surgery” must identify and address the moral issues that emerge in the actual circumstances and women’s experiences of decision-making. In the final sections of this chapter, I will briefly introduce typical features and limitations of informed consent procedures for maternal-fetal surgeries before exploring an ethics consultation model intentionally developed to address those limitations for open-uterine surgery to

⁸² (AMA), "Resolution 73," 1443.

repair spina bifida⁸³ and the questions still remaining about moral issues and ethics consultations for these procedures.

Informed Consent: Calculating Risks and Benefits

Until the advent of open-uterine surgery to repair spina bifida, addressing the ethical issues of maternal-fetal surgery was presumed, by most, to be a procedural matter of achieving informed consent, including identifying risks and benefits, respecting the pregnant woman's autonomy, and using non-directive language to overcome researcher enthusiasm and the therapeutic misconception.⁸⁴ Harrison, Golbus, and Filly, Frigoletto et al, and Ruddick and Wilcox each mentioned some form or process for discussing risks and benefits with the pregnant woman considering maternal-fetal surgery.⁸⁵ Fletcher and Avery also called for candid discussions of risks and benefits with pregnant women, while Chervenak and McCullough have argued that physicians should direct the informed consent process because they could answer any questions the pregnant woman and her

⁸³ Mark J. Bliton, "Ethics: "Life before Birth" And Moral Complexity in Maternal-Fetal Surgery for Spina Bifida," *Clinics in Perinatology* 30, no. 3 (2003), 449-464; Bliton and Zaner, "Cutting Edge," 346-360.

⁸⁴ Annas and Elias, "Perspectives," 353-354; Charles Bosk, "Sociomedical and Ethical Dilemmas in Fetal Medicine," in *Genetics and the Law III*, ed. George J Annas and Aubrey Milunsky (New York, NY: Plenum Press, 1984), 381; Barclay and others, "Ethics," 1555; Fletcher, "Fetus as Patient," 772-773; Roger L Shinn, "The Fetus as Patient: A Philosophical and Ethical Perspective (and Discussion)," in *Genetics and the Law III*, ed. George J Annas and Aubrey Milunsky (New York, NY: Plenum Press, 1984), 321. A few early exceptions to the procedural focus include Bosk, who raised concerns about "coercion by medical kindness" that could pressure women to consent, along with Annas and Elias and Jonsen, who observed that most women arrived convinced the procedures would help and wondered how informed consent could account for such conviction.

⁸⁵ Frigoletto, Birnholz, and Greene, "Antenatal Treatment," 2497; Harrison, Golbus, and Filly, "Management," 777; Ruddick and Wilcox, "Operating on the Fetus," 13-14.

family had about the procedures.⁸⁶ While these steps and concepts may be necessary for achieving informed consent,⁸⁷ they not sufficient for addressing the “ethics of maternal-fetal surgery.” These informed consent procedures focused on patient or participant comprehension of clinical information and clinicians’ obligations, but overlooked how pregnant women made sense of clinical information, experienced their interactions with clinicians, or even the processes by which pregnant women made such decisions at all.

The limitations of focusing on a procedural informed consent model of ethics came into sharp focus with the development of open-uterine surgery to repair spina bifida.⁸⁸ In developing an open-uterine procedure for a life-limiting, but not necessarily life-ending defect, it became very clear that maternal-fetal surgeries were about more than “rescuing babies”⁸⁹ and that decision-making was more complex than calculating risks and benefits and signing informed consent documents. To understand the ethics of maternal-fetal surgery, including open-uterine surgery to repair spina bifida, clinicians and ethicists needed to – and still need to – identify the moral concerns that emerge in women’s actual circumstances, as well as the ethical issues identified in informed consent documents.

⁸⁶ Fletcher, "Fetus as Patient," 772; Avery, "Some Questions," 2498; Chervenak and McCullough, "Ethics 2007," 428.

⁸⁷ For an illustration and critique of Chervenak and McCullough’s physician-led informed consent procedure, see Chapter III, pp 89-93, below. See also N. Scott Adzick, "Open Fetal Surgery for Life-Threatening Fetal Anomalies," *Seminars in Fetal & Neonatal Medicine* 15, no. 1 (2010), 1-3.

⁸⁸ Bliton and Zaner, "Cutting Edge," 346-347.

⁸⁹ Monica J. Casper, "Operation to the Rescue: Feminist Encounters with Fetal Surgery," in *Fetal Subjects, Feminist Positions*, ed. Lynn Morgan and Meredith Michaels (Philadelphia: University of Pennsylvania Press, 1999), 101-112.

Clinical Ethics Consultations: Attention to Values

Beginning with Albert Jonsen, a small but vocal group of ethicists have argued that maternal-fetal surgeries require more openness to and focus on personal experience than on a procedural approach to achieving informed consent. The ethicists argued that decision-making for maternal-fetal surgeries was about more than risk / benefit calculations, that the particular circumstances of a family's decision-making were important, and that how clinicians present and talk about the procedures mattered. They also emphasized that more research was needed to understand the moral complexities of maternal-fetal surgeries. With the introduction of open-uterine surgery for spina bifida, their concerns about and the opportunity to learn about this kind of decision-making came to the forefront of ethics in maternal-fetal medicine.

Even as early as 1984, Fletcher and Jonsen noted that informed consent for in utero procedures required more attention and special precautions because of the “possibility that some pregnant women may be likely to disregard their own well-being for the sake of the fetus.”⁹⁰ They also noted “the possibility that clinical investigators will convey enthusiasm for new but unproven approaches to fetal therapy,” contributing to participants’ therapeutic misconception.⁹¹ When the “special precautions” have continued, the greatest emphasis has been on offering impartial or “non-directive” information and involving ethics consultants.⁹²

⁹⁰ Fletcher and Jonsen, "Ethical Considerations," 15.

⁹¹ *Ibid.*, 15.

⁹² Howe argues, against Chervenak & McCullough, that “non-directive” may be taken as abandonment because “non-directive” approaches refuse to engage with what matters most to women. Bliton and Zaner recognize this potential abandonment and try to engage the questions

In another article that same year, however, Jonsen notes that decision-making about maternal-fetal surgeries involves more than information, risk, and benefit calculation. In his essay, "The Ethics of Fetal Surgery," Jonsen considers how to account for the experience of prenatal surgery: for the activities that occur in a spirit of uncertainty, hope, and adventure as much as under scientific protocols and ethical rationality. Jonsen asks whether, because of the hopes with which patients and clinicians approach fetal surgery, *informed faith* might be more accurate than the *informed consent* framework. Jonsen explains that the women and their families who come to the program (at UCSF) are coming towards "the substance of things hoped for the evidence of things unseen," the New Testament verse manifest in their experience of their pregnancy.⁹³ He explains, "these parents have, in a profound sense, decided in faith before the 'informed consent' process begins. If they come as far as our program, they come as pilgrims."⁹⁴ Annas and Elias make a similar observation based on their experiences, and Bliton and Zaner report the same phenomenon 12 years later with open-uterine surgery to repair spina bifida.⁹⁵

Jonsen suggests embracing the spirit of adventure instead of dismissing this faith as an insufficiently rational basis for decisions. He acknowledges that fetal surgery is "a serious scientific enterprise, a cautious therapeutic endeavor" with "weighty

with potential patients / participants. Bliton and Zaner, "Cutting Edge," 349-350; Chervenak and McCullough, "Comprehensive Ethical Framework," 12-13; Howe, "Ethical Issues," 453.

⁹³ Jonsen, "Ethics," 366. Jonsen is quoting Hebrews 11.1

⁹⁴ Ibid., 365-368.

⁹⁵ Annas and Elias, "Perspectives," 353; Bliton and Zaner, "Cutting Edge," 357.

consequences for the fetus, for the parents, and for the providers of care.”⁹⁶ But Jonsen also reflects that being involved in fetal surgery has alerted him to the need to “appreciate the profoundly emotional or symbolic roots of the issues of reproductive ethics (in order to) begin to speak in rational categories of research and informed consent and to approach them with cautious reason and critical analysis.”⁹⁷ In other words, he learned to pay attention to the experiences that may influence, surround, and exceed the vocabularies – so reliant on principles of autonomy and beneficence – that typically are used to address the ethics of maternal-fetal surgery.

Similar concerns reemerged over a decade later with the development of open-uterine surgery to repair spina bifida. The shift in ethical questions occasioned by the procedure prompted the physicians at Vanderbilt University Medical Center to involve clinical ethicists in designing an informed consent process to meet these complex and shifting ethical issues.⁹⁸ For Mark J. Bliton, one of the ethicists primarily involved with the protocol, along with the more typically framed ethical concerns about risk and benefit, maternal-fetal dyad, and autonomous and authentic informed consent, maternal and fetal vulnerability emerge as crucial questions for considering maternal-fetal surgery for spina bifida. Yet, the complexities of this procedure and these women’s experiences required more attention than accounted for in conventional informed consent protocols.

⁹⁶Jonsen, "Ethics," 368.

⁹⁷Ibid., 368.

⁹⁸ Mark J. Bliton, "Imagining a Fetus: Insights from Talking with Pregnant Women About Their Decision to Undergo Open-Uterine Fetal Surgery," in *Handbook of Phenomenology and Medicine*, ed. S. K. Toombs, Medicine and Philosophy (Dordrecht: Kluwer Academic Publishers, 2001), 397.

The challenge was to provide that attention in a way that was helpful to pregnant women and their families, as well as to the researchers and clinicians studying the procedure.

As Bliton explains, open uterine surgery to repair spina bifida requires looking beyond the limited ethical appraisal of the “conventional rubric of patient, i.e. women’s autonomy” to examine the vulnerability and hope that emerge in women’s experiences of the procedure, which are oftentimes framed in terms of religious faith or hope.⁹⁹ For Bliton and Zaner, any informed consent process for this or similarly complex procedures needed to include the opportunity for pregnant women and their families to identify their own values and how these values relate to considering the procedure.¹⁰⁰ As Zaner notes, the central goal of the ethicists’ involvement was

to ensure, as far as possible, that each couple acquires serious understanding of all aspects of the procedure, including risks and theoretical prospects of benefit, as well as difficulties to be faced in the future, whether they proceed to surgery or not . . . At the same time, we try to help them gain renewed understanding of their circumstances and moral frameworks, especially to appreciate how the variety of potential aftermaths might fit into their lives.¹⁰¹

Concerned by the limitations of only focusing on informed consent, the maternal-fetal surgery team at Vanderbilt University Medical Center designed an innovative informed consent process for their elective, experimental protocol, intended to ensure that “serious understanding”: information about risks and benefits was only the beginning.

The informed consent process for Vanderbilt’s experimental protocols included two days of consultation and counseling with health care providers in the key specialties

⁹⁹ Bliton, "Parental Hope," 600.

¹⁰⁰ Bliton and Zaner, "Cutting Edge," 349.

¹⁰¹ Richard M. Zaner, "Discovering What Matters in Fetal Surgery," in *Fetal Surgery & the Moral Presence of the Fetus* (Vanderbilt University, Nashville, Tennessee: 2000), 2.

(pediatric neurosurgery and perinatology, neonatology, and anesthesiology) ultrasounds, meetings with financial advisors and social workers, a tour of the Neonatal Intensive Care Unit (NICU), and a final session with clinical ethics consultants. The process also included significant “time off” (1/2 a day to 1 day) for pregnant women and their partners to reflect on what they learned and how they were thinking about their decision. Through this process both families and ethics consultants could identify and reflect on the clinical details and moral experiences that shaped decision-making.¹⁰²

The two-day consultation process was designed with additional time for reflection to account for and allow space for multiple perspectives, vulnerabilities, and reflections on open-uterine surgery to repair spina bifida, including two meetings with the ethics consultants. Bliton explains that this process for ethics consultations, understood as a form of inquiry, “must be specifically attentive to the finely textured, subtle context of multiple interactions among physicians, patients, spouses, and others who may be variously involved in such consultations.”¹⁰³ Such inquiry depends first and foremost upon careful attentive listening, whereby one learns *what moral issues are actually at stake* in a given situation for the persons involved. This listening, in turn, is rooted in the ethics consultant’s willingness to reflectively share the vulnerabilities and uncertainties raised by the situation presented. Bliton asks,

In other words (even though the gravity and meaning of the issues cannot be the same for both of us) how might I possibly find out what is important to you, or anyone else, in such a context unless I am willing to share temporarily the questions and uncertainties you face?¹⁰⁴

¹⁰² Bliton, "Imagining a Fetus," 397-398.

¹⁰³ Richard M. Zaner, "Voices and Time: The Venture of Clinical Ethics," *Journal of Medicine & Philosophy* 18, no. 1 (1993), 24-28; Bliton, "Imagining a Fetus," 398.

Sharing and pursuing these questions allows for the shared task of imagining and considering the complexities of and possible outcomes of the situation.

Bliton and Zaner emphasize the obligation of the physicians and other health care providers to ensure “informed *understanding* by every involved person,”¹⁰⁵ which included providing clear and accurate information, alternatives, and likely aftermaths, as well as identifying how women’s understandings emerged and how their experiences of moral issues and clinical circumstances were relevant to their decision-making. Bliton and Zaner argue that “moral responsiveness in clinical settings must be guided and informed by facts that are specific to each particular situation.”¹⁰⁶ They identified important social and moral themes and circumstances from clinical consultations with pregnant women, their families, and with clinicians offering open-uterine surgery to repair spina bifida.¹⁰⁷ Typical informed consent procedures, which focus on information and calculating risks and benefits, leave clinicians unprepared for identifying, let alone

¹⁰⁴ Bliton, "Imagining a Fetus," 398. Thereby avoiding the problem of abandonment through neutrality as described by Howe. See, Howe, "Ethical Issues," 453.

¹⁰⁵ Bliton and Zaner, "Cutting Edge," 350.

¹⁰⁶ Ibid., 346.

¹⁰⁷ The key themes include: the moral community that includes a fetus already granted the status of desired, named child; the technological imperative fostered by prenatal diagnosis and ultrasound visualization of the fetus;¹⁰⁷ misunderstandings of and social stigmas against disability;¹⁰⁷ and conflicts between the scientific framework of experimentation and religious worldviews / life-worlds that prompt many couples to interpret their diagnosis, their journey to the maternal-fetal center, and their decision about open-uterine surgery to repair spina bifida in terms of their religious faith and hope. Annas and Elias, "Perspectives," 353, made a similar observation about in utero procedures for lethal conditions: “by the time parents reach the major medical centers involved in this research, they have already made up their minds to go ahead with what they consider the last hope their fetus may have.” See also Bliton and Zaner, "Cutting Edge," 346-360, Jonsen, 367.

probing that moral and social themes which may, in fact, be crucial to women's understanding of their decision, and to the "ethics of maternal-fetal surgery" as a whole.

Clinical Ethics Consultation: Experiences of Faith and Hope

While Jonsen suggested recognizing "informed faith" instead of focusing on "informed consent" in discourses about the ethics of maternal-fetal surgery, in their accounts of ethics consultations with women considering open-uterine surgery to repair spina bifida, Bliton and Zaner demonstrated the importance of an ethics beyond informed consent. In conversations with clinical ethics consultants about the actual circumstances and experiences of considering this procedure, women identify faith and hope as crucial factors in decision-making, rather than or in addition to clinical risks and benefits. One question from Bliton and Zaner, then, is how clinicians, researchers, and ethicists can understand this kind of decision-making that does not rely on the calculation so often promoted as informed consent.

For example, Bliton focuses on the attitude of "living in hope" that gave meaning to and helped make sense of pregnant women's decisions about open-uterine surgery to repair spina bifida. As he and Zaner discovered,

the decision reached by a couple to undertake the explicit and well-documented risks intrinsic to the procedure – balanced only by what doctors call "theoretical" or "potential benefits" and what couples call "hope" – seemed to make sense only in light of such a profound attitude.¹⁰⁸

The clinical presentation of risks and benefits that grounds typical understandings of informed consent have little influence on women accustomed to or committed to making major decisions from their experiences of faith and hope.

¹⁰⁸Bliton, "Parental Hope," 598.

Barbara Bluestone Rothschild, Sue E. Estroff, and Larry R. Churchill made similar observations in their study of informed consent and decision-making for open-uterine surgery to repair spina bifida. They were invited to investigate the informed consent process for a research protocol on open-uterine surgery to repair spina bifida at the University of North Carolina, Chapel Hill.¹⁰⁹ Rothschild, Estroff, and Churchill noted that given the uncertainties of diagnosis and decision-making, participants' faith was a significant feature of their experience. The authors explain,

invoking deeply felt religious beliefs, activating practices and communities of faith, and plumbing the foundations of their values was nearly universal among these couples. The force and influence of these personal fundamentals was substantial, often eclipsing statistical expressions of risk and benefit.¹¹⁰

Rothschild, et al note that the couples they interviewed described strong faith, belief in God's plan, and God's guidance throughout their decision-making. Many prayed or sought signs of God's guidance, and offered "the sense that they had been given a challenge they could meet or a burden God knew they could bear."¹¹¹ The authors observe that for these participants, "confidence in God's plan and acceptance of divine fate were often intermingled... The feelings and beliefs were of extraordinary significance to these participants, who, in many cases, had never explored their most

¹⁰⁹ It is important to note that the Chapel Hill protocol was a research protocol, not an elective protocol like the VUMC elective series. The elective series was offered as an innovative therapy with the possibility of benefit, however uncertain. Chapel Hill offered a research protocol, designed to investigate and learn about the procedure, with a clear emphasis on the possible risks and uncertainty of benefit.

¹¹⁰ Barbara B. Rothschild, Sue E. Estroff, and Larry R. Churchill, "The Cultural Calculus of Consent," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 583-584.

¹¹¹ *Ibid.*, 584.

profound beliefs as fully as at this time of crisis.”¹¹² Further, Rothschild et al note that as far as consent procedures are concerned, maternal-fetal surgery

requires many levels of analysis and reflection, and different types of information. Couples may understand adequately the risks and benefits of the procedure and discuss these ably with the study team while telling family members, and independent researchers, that divine guidance sent them a sign to join the study. These simultaneous accounts are accurate and valid and the consent can best be understood in light of both reasons.”¹¹³

The authors also observe the “substantial differences between the institutional and researcher focus on scientific data, accuracy, and risk benefit calculators, and the influences on decision-making identified by the couples we interviewed. Each party in the process seems to be persuaded by their own vocabulary and fundamental moral and cultural principles, but these are not necessarily held in common.”¹¹⁴

The similarities between Bliton and Zaner’s experiences with women in VUMC’s elective protocol and Rothschild, Estroff, and Churchill’s experiences with women in UNC’s research protocol emphasize the importance of moral and social factors in decision-making, beyond the medical risks and benefits addressed in informed consent documents. Bliton and Zaner, and Rothschild et al, warn that overlooking or avoiding the importance of religious language, beliefs, and hope in decision-making increases pregnant women’s and the families’ vulnerability to “the judgments, enthusiasms, and biases of surgeons and others on the team, but [they are] also vulnerable to their own beliefs about the surgery and its potential outcomes.”¹¹⁵ This emphasis, on the

¹¹² Ibid., 584.

¹¹³ Ibid., 591.

¹¹⁴ Ibid., 591.

experiences and motivations of those making the decisions, calls for a different kind of ethics consultation and a different kind of informed consent process than is typically understood.¹¹⁶

Further Research: Women's Experiences and Decision-making

The question Rothschild, Estroff, and Churchill raise for informed consent in experimental research is whether and how the informed consent process can take account of the variety of social and moral influences on decision-making. Rothschild et al note, "the current consent requirements presume a clinician-researcher locus for patient decision-making, implemented as if there were few other formative influences."¹¹⁷ Their preliminary research shows how limiting this presumption can be. They observe that many participants are already close to a decision, if they have not already made one, prior to the formal consent and consultation process. In addition, they explain, "some of the most influential components of decision-making - cultural codes and spiritual beliefs - can be resistant and occasionally even impervious to the conventional medical understandings of risk and benefit."¹¹⁸ These authors conclude, "A critical reappraisal that accounts for these realities in designing and implementing informed consent

¹¹⁵ Bliton and Zaner, "Cutting Edge," 357.

¹¹⁶ Bliton and Zaner's three-day protocol was used at UNC-Chapel Hill where Rothschild, Estroff, and Churchill conducted their research on the informed consent process and participant decision-making.

¹¹⁷ Rothschild, Estroff, and Churchill, "The Cultural Calculus of Consent," 591.

¹¹⁸ Ibid., 592.

processes for experimental clinical research is needed.”¹¹⁹ Rothschild et al also identify a need for research on “post-procedure assessments and reassessments by the parents of their decisional calculus,”¹²⁰ or how parents’ understand their own decision-making and how it affects their lives. Like Bliton and Zaner’s accounts of ethics consultations with women considering open-uterine surgery to repair spina bifida, Rothschild, Estroff, and Churchill’s research demonstrates the importance of parents’ experiences in understanding the moral and social components of decision-making.

Bliton and Zaner’s work, along with the research by Rothschild, Estroff, and Churchill, illustrates the limitations of the most prominent discourses around the “ethics of maternal fetal surgery,” including open uterine surgery to repair spina bifida. The medical discourses focus on the justification and validation of experimental procedures, while the social discourses focus on whether the maternal-fetal relationships is framed by the concept of the fetus as a patient or as a women’s health issue. These two discourses continue to influence the ways clinicians and ethicists typically frame ethical issues, in terms of informed consent procedures and protecting women’s autonomy. While all of these considerations are important features for understanding the ethics of maternal-fetal surgery, neither the medical, nor social, nor even informed consent discourses attend to or address women’s experiences with maternal-fetal surgery or how women’s actual circumstances – including the medical, social, and moral factors such as faith and hope – influence and shape what matters in their decision-making. For all the debates, there has been little recognition in the medical and social discourses, especially in leading publications, of how to identify, address, and take account of – how to understand – what

¹¹⁹ Ibid., 591.

¹²⁰ Ibid., 592.

matters in the ethics of maternal-fetal surgery. Focusing on open-uterine surgery to repair spina bifida, Bliton and Zaner's work, along with the research by Rothschild, Estroff, and Churchill, points to women's experiences and women's accounts of decision-making as an important, but often overlooked discourse about what matters in maternal-fetal surgery. In recognizing the importance of those overlooked accounts from women who considered open-uterine surgery to repair spina bifida, my research seeks to learn about and learn from women's experiences with and decision-making about this procedure, including their experiences with ethics consultations. By learning from women's accounts of their experiences, I hope both to deepen clinicians' and ethicists' understandings of these issues, and to learn from women's experiences with ethics consultations. My research took me, first, to the few accounts available in the professional literature, published in a special symposium edition of *Clinics in Obstetrics and Gynecology*, as presented in Chapter III. These accounts raised further questions about how to understand what matters for women's decision-making about this procedure and whether and how women's accounts are recognized as important when presented in the medical and surgical literature.

CHAPTER III

ABSENT VOICES: PARENTS' EXPERIENCES WITH OPEN-UTERINE SURGERY TO REPAIR SPINA BIFIDA

Soliciting Parents' Stories

In 2005, Larry R. Churchill and Mark J. Bliton guest edited a unique symposium in *Clinical Obstetrics and Gynecology*, entitled “Parental Voices.” This volume was designed and constructed to demonstrate the importance of the social and moral dimensions in decision-making, to offer concrete suggestions for clinicians and researchers to improve the information and consent processes for maternal-fetal surgery, and to help spur more discussion in the published literature on open-uterine surgery to repair spina bifida. The idea for the symposium grew from the recognition that in the passionate debates about open-uterine surgery to repair spina bifida, a significant set of voices – “Parental Voices” – was missing. In attempts to include what is one crucial set of perspectives, Churchill and Bliton solicited reflections and stories from five parents who chose open-uterine surgery to repair spina bifida through the VUMC elective protocols, inviting these parents to write about their experiences in their own voices. The journal also included a story of one couple’s experience as told by Richard M. Zaner, an ethics consultant from the elective series at Vanderbilt; a detailed report of qualitative research on decision-making and informed consent by Rothschild, Estroff, and Churchill; and another report of women’s experiences with fetoscopy by Deborah Blizzard; and finally, Bliton’s reflections on parental hope and scientific uncertainty from his series of

consultations with families considering the procedure. Churchill and Bliton explained the significance of these essays with the following:

the aim is to bring to light the facets of the experience that are likely to be overlooked in qualitative methods, scientific or legal analysis, or even in ethical analysis as it is typically conceived. Listening to “Parental Voices” is a crucial beginning to good ethics and effective patient care.... this kind of understanding is a core task of ethics in maternal-fetal surgery.¹

This “Parental Voices” symposium in *Clinical Obstetrics and Gynecology* demonstrated the importance of listening to “Parental Voices” and the importance of considering what matters in the ethics consultations and informed consent processes for these kinds of experimental procedures.

Churchill and Bliton asked for parent’s reflections on how the diagnosis of spina bifida was presented during and after the second trimester ultrasound, as well as how those presentations affected the family’s perceptions and attitudes about maternal-fetal surgery. They asked what health care providers needed to understand about patient experiences and how each family described the importance of their decisions about abortion and the surgery. Finally, Churchill & Bliton asked each family to reflect on what their encounter with spina bifida meant to them at the time at the time they wrote, several years after the surgery, and if there was one thing they could change about their experience, what it might be. In eloquent, thoughtful, and vivid language, each of the families tells a story about their experience and decision-making around open-uterine surgery to repair spina bifida. Emotional and personal experiences figure prominently in these powerful reflections, as do the importance of religion and spirituality, the centrality of families and support groups, and the importance of “ordinary kindness and courtesy”

¹ Larry R. Churchill and Mark J. Bliton, "Foreword: Parental Voices in Maternal-Fetal Surgery," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 511.

in clinical encounters. As Churchill and Bliton observe, the courage, resourcefulness, and vulnerability of these families shines through and challenges typical understandings of ethics in ways that far exceed traditional understandings of medical decision-making and informed consent.

The crucial point for ethics, as highlighted by Churchill and Bliton, is that “in getting to the truth of things, it is important not only that we tell our story, but that others listen and respond to us in ways that reveal dimensions we would not have otherwise seen.”² In the sections that follow, I will highlight key themes that emerge in “Parental Voices”, using the parents’ own descriptions of their experiences and what mattered to them. The themes typically have been overlooked by the medical and ethical discourses discussed in Chapters I and II, but are crucial to understanding the families’ experiences with open-uterine surgery to repair spina bifida. Exploring how the families understood their own diagnosis experiences and underlying motivations to do something, the roles of clinicians and the role of ethics consultations, as well as religious beliefs and values, played in their decisions to pursue open-uterine surgery to repair spina bifida can indicate important areas and specific questions for further research.

Themes in the Families’ Stories

Diagnosis of Disability

The families’ first encounters with spina bifida in the second-trimester ultrasound, usually between 16-20 weeks, turned out to be a pivotal moment in their experience of the pregnancy and in their subsequent interactions with clinicians, heavily laden on both

² Ibid., 509.

sides with often unstated attitudes about disability. Dean and Lesley Kennedy describe learning about spina bifida as “the dagger that would pierce our hearts, as did all the negative possibilities and connotations that went with it. NEVER walk, never talk, never have control of bladder or bowels never, never, never.”³ Emily Gonzáles-Abreu wrote about the “fear, anger, and pain” that accompanied her pregnancy after the diagnosis of spina bifida.⁴ Her much desired pregnancy turned into a “nightmare” after the physician told her and her husband about the condition, but gave them nothing but “cons” and worst case scenarios. Researchers in this area confirm that quite often, clinicians’ negative descriptions of disability influenced parents’ understanding of the diagnosis as well as their subsequent interactions with health care providers.⁵ Manuel González-Abreu corroborates his wife’s description of their traumatic diagnosis experience – it was “like a death sentence”: “Your child will never walk. She will be a vegetable. You don’t want to have this child.”⁶ He states, rather bluntly, that the words the physicians used “take center stage” in the rest of the family’s story. Alfred Lyons makes a similar observation about

³ Dean Kennedy and Leslie Kennedy, "Parental Voices: Our Journey of Grace," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 534.

⁴ Emily E. Gonzalez-Abreu, "Parental Voices: For Angeline: A Mother's Reflection and Emotional Struggle with the Loss of a Typical Child and How She Stumbles into an Unexpected World of Special Needs and the People Who Live There," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 519-520.

⁵ Hilmar H. Bijma and others, "Parental Decision-Making after Ultrasound Diagnosis of a Serious Foetal Abnormality," *Fetal Diagnosis & Therapy* 20, no. 5 (2005), 322; Chaplin, Schweitzer, and Perkoulidis, "Experiences of Prenatal Diagnosis of Spina Bifida or Hydrocephalus in Parents Who Decide to Continue with Their Pregnancy," 151-152; Catherine M. Shaer and others, "Obstetrician-Gynecologists' Practice and Knowledge Regarding Spina Bifida," *American Journal of Perinatology* 23, no. 6 (2006), 355-356.

⁶ Manuel M. Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset: A Child's Answer to Life's Biggest Challenges," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 528.

the shock of the diagnosis. He writes, “Still, as our joy suddenly turned into crisis, it was difficult to fully take in and digest the information we were being given. We heard only the words ‘paralysis,’ ‘wheelchair,’ ‘incontinent,’ ‘developmentally disabled,’ and ‘decision’.”⁷ The negative direction of the diagnosis conversation became a foundational element in each family’s experience from that moment.

The significance of these diagnosis conversations – their influence on the rest of the pregnancy and decision-making for families – cannot be overstated. The “Parental Voices” articles, and the interview excerpts presented in Chapter VI below, show the power of those first moments for parents learning about their child’s spina bifida. The range of emotional and moral experiences in these stories should serve as a reminder that families’ decision-making and attitudes towards the procedure are likely to have been “informed” and influenced by such deeply personal experiences *before* they arrive for the informed consent process. Obstetricians and perinatologists need to be attentive to how they present pregnant women and their families with such diagnoses. Clinicians, researchers, and ethicists involved with open-uterine surgery for spina bifida need to be aware of and attentive to those influences. As another example, Alfred Lyons explains that after all the horrendously negative information they received from their local perinatologist, even the measured or neutral information from the Vanderbilt physicians seemed a world of improvement and the outcomes more positive.⁸ Ethicists and other clinicians may need to identify, probe, and address explicitly such shifts in perception, including parents’ initial diagnosis experiences, to assist parents in their understandings

⁷ Alfred Lyons, "Parental Voices: One Parent's Thoughts on Fetal Surgery " *Clinical Obstetrics and Gynecology* 48, no. 3 (2005), 541.

⁸ *Ibid.*, 541.

of risks and benefits and possible outcomes for choosing surgery and not choosing surgery.

“Doing Something”

A significant component in evaluating potential risks, potential benefits, and possible outcomes are the deep motivations to “*do something*” that can emerge from the experience of a spina bifida diagnosis and the glimmer of hope parents see in the experimental prenatal surgery. Alfred Lyons explains, “The most traumatic period in the lives of parents with disabled children is the period between the moment it is learned that their child has a handicap and the time they learn what they can do about it.”⁹ Manuel Gonzáles-Abreu writes even more forcefully,

Somehow we decided to have the surgery well before meeting with the fetal surgery team. Of course, we knew there were serious risks involved, but we were going to do everything in our reach to give our daughter a better chance at life... We had come to Nashville in search of hope, and hope we found. The fetal surgery offered hope for our daughter. It empowered us, as parents, to do something to improve her chances to live a more ‘normal’ life.¹⁰

Or, as Richard Zaner recounts his experience of talking with a family, Mrs. Morris tried to explain their struggle with the decision for surgery, “I only know that we just have to try to help, you understand, Dr. Zaner? We cannot just sit idly by and do nothing, not if there is even the slightest chance that we might be able to help, *to change things* for our

⁹Deborah Blizzard, "A Trying Experience: Fetoscopy and Maternal Decision-Making," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 574-594. Deborah Blizzard identifies the social pressures to “do something” or “to try” in her research on women’s decision-making about fetoscopic procedures. She notes that these pressures to “try” go to deeply rooted assumptions about healthy pregnancies, maternal responsibilities, and the desire for action in response to difficult and desperate circumstances.

¹⁰ Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 529-530.

baby.” (Italics mine)¹¹ The underlying need to be active – to “do something” or “to help” – in response to the prenatal diagnosis of spina bifida represents a constant theme in these accounts. As explained in Chapter II, the early prenatal procedures were justified – by clinicians and desperate parents – in terms of “rescue” or “doing something” to save fetuses with lethal conditions. The desire to “change things” that Mrs. Morris raises in Zaner’s reflection carries the same motivation, typical of responses to spina bifida and this procedure: to “do something,” often, to do *anything* that might make the potential outcome different. Spina bifida is not a lethal condition, but a disabling one, with a complex, multifactorial presentation. For parents who are continuing their pregnancy after hearing the catalogue of possible disabilities and suggestions in favor of termination, a sense of despair often leads to the search for options *other* than awaiting the birth of their disabled child.¹² Many parents focus on the possibility of helping their child, the hope of changing their child’s possible outcome for the better, sometimes overestimating the potential benefits but more importantly, by minimizing or rejecting the risks of death or additional compromise from prematurity. This (often religious) hope serves to represent a set of attitudes that, for many couples, are not dependent on clinical information. The hope of changing things for the better, while ignoring the harms and potential risks of the procedure, needs to be addressed by more than non-directive language intended to neutralize the “therapeutic misconceptions” about this procedure.¹³

¹¹ Richard M. Zaner, "Parental Voices: Randal Lewis Morris Was Born," *Clinical Obstetrics & Gynecology* 48, no. 3 (2005), 558.

¹² Bliton, "Parental Hope," 602-603.

¹³ Chervenak and McCullough, "Comprehensive Ethical Framework," 12-13.

Clinicians' Communications

While non-directive language is acknowledged in the literature as one means of avoiding the potential ethical pitfalls in conversations about open-uterine surgery to repair spina bifida,¹⁴ parents' accounts identify other ways clinicians' language, communication, and interactions with patients matter. Clinicians' presentation of, attitudes towards, and knowledge about spina bifida and the prenatal surgery have a significant influence on parents' experiences, as do clinicians' interest in and concern for families' experiences, values, and decision-making process, including their hope that the procedure will help their child. Jason and Susan Williamson, for example, emphasize the importance of clinicians' kindness, honesty, and attention to and respect for their emotions and values.¹⁵ They explain, "It is important for doctors to seek out the value system of their patients and connect with them on that level. Only then can they truly establish trust, which is essential for transmitting information and allowing people to arrive at their own choice with peace of mind."¹⁶ Dean and Lesley Kennedy make a similar point, observing that clinicians need to be compassionate in their presentation of information, but also in the information they gather from the families. The Kennedys write,

As future parents of a child with any disability, we needed open, honest, and informative words *combined with listening ears [italics mine]*— ears that would at least appreciate, if not agree with, who we were as people

¹⁴ *Ibid.*, 13.

¹⁵ Jason Williamson and Susan Williamson, "Parental Voices: The Positive Impact of Medical Professionals," *Clinical Obstetrics and Gynecology* 48, no. 3 (2005), 517.

¹⁶ *Ibid.*, 517.

and our very well-thought out, well-prayed through decision-making process.¹⁷

These observations from the Williamsons and the Kennedys highlight two crucial moral elements of these procedures that are of the kind that, as Churchill and Bliton point out, are often overlooked in typical research, publications, and even clinical work. First, that the deeply rooted hopes and values families hold – which often are framed as religious – have a profound influence on decision-making, often as much or more than the clinical information. And second, parents look for, and appreciate as helpful, the formal and informal opportunities to talk about and reflect on those values. The accounts from parents about the importance of these values, and the importance of opportunities to reflect on them, should prompt an examination of the informed consent procedures and ethics consultation processes in place for such complex maternal fetal surgeries. Chapters VI and VII, for example, will present detailed accounts of and suggestions for ethics consultation for in utero surgery, but the need to focus on beliefs and values, though perhaps overlooked in most medical and ethical discourses, has been raised before and is still in need of attention.¹⁸

Religious Belief and Values

As discussed in Chapter II, even as early as 1985, Albert Jonsen raised the importance of considering the “informed faith” of couples pursuing fetal surgery, as much as their “informed consent.” Jonsen’s suggestion that clinicians learn, as he learned, to attend to the “profoundly emotional or symbolic roots of reproductive ethics”

¹⁷ Kennedy and Kennedy, "Parental Voices: Our Journey of Grace," 534-535.

¹⁸ See pp 58-62 in Chapter II, above.

finds an echo, 20 years later, in parents' accounts of their experiences with open-uterine surgery to repair spina bifida. Manuel Gonzáles-Abreu, points to what he sees as a

need for health care professionals to know and understand the religious background and the set of values framing the lives of their patients. Parents will be able to make sense of their personal decisions inasmuch as those decisions conform to what they hold sacred and important in their lives.¹⁹

His wife, Emily, explicitly frames her narrative in terms of her faith, which she begins by quoting Psalm 139 celebrating God's creation of the person in the womb,²⁰ while the Lyons family, the Kennedys, and the Williamsons each mention how their faith helped them cope, make sense of, and eventually decide about the procedure. As Zaner recounts in his story of the Morris's decision, faith is a crucial part of the experience from diagnosis to decision. He relates a conversation where Mrs. Morris encourages her husband's faith:

You just have to believe. I mean, would this place and all these caring and professional people offer something that they thought would really hurt me, or Randal? Aren't they doing it because they believe it will help? And shouldn't we accept that? You have got to have faith, real faith. *All that lack of data about benefit that we have been told about is, sure, very frustrating, but that is just where our faith has to take over [Italics mine].* And besides, God will see us through. God brought us here, God will see us through.²¹

In Zaner's narrative, faced with the uncertainties created by the lack of clinical data about outcomes, Mrs. Morris's faith in God extends to faith in the research team offering the procedure. Even though, as she explains in her conversation with Zaner, her understanding of the procedure and her belief that it would help were different after two

¹⁹ Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 530.

²⁰ Gonzalez-Abreu, "Parental Voices: For Angeline:," 518.

²¹ Zaner, "Parental Voices: Randal Lewis Morris Was Born," 560.

days of counseling than they were when she and her husband arrived, her faith persists and continues to influence her pursuit of the procedure. Zaner's account of Mrs. Morris's experience, along with the direct accounts from other parents in the symposium, highlights the need to recognize and try to understand how couples' faith influences their understandings of and decision-making about the procedure.²² These accounts also highlight the need to consider whether and how the clinical ethics consultation process can assist couples in making decisions congruent with their beliefs and values.

Ethics Consultations and Changing Understanding

Mrs. Morris's changed understanding – and the increased uncertainty she and her husband share – illustrates the second theme mentioned: the importance of time and the availability of clinicians to discuss the values and beliefs guiding decision-making. In particular, these values and beliefs require discussion in the specific context of the new, and possibly changing clinical information about the diagnosis and prognosis for their fetus. Zaner describes the ethics consultation process designed to give parents time to reflect on and address the clinical and the social and moral factors of decision-making. He writes,

The first ethics meeting was conceived as the occasion to try and raise all the hard questions, as a way, first, to test how well and thoroughly the couple had actually thought about and understood their future baby's condition; second, to figure out what themes needed further explanation; and third, the best way, we believed, to ensure ourselves and others that when decision time came, each couple understood as much as possible, they could, more reasonably than otherwise, give genuinely informed

²² A fuller discussion of faith and decision-making will be discussed in Chapter V below, and further examples of faith and decision-making will be presented in Chapter VI.

consent, if that's what they decided, or to refuse the offered surgery in as informed a manner as circumstances permitted.²³

The process was long, challenging, and emotionally intense for the parents considering the procedure and, at least in Zaner's account, often for the ethics consultants as well.

The Kennedys were their surprised when a nurse at VUMC offered them time and space "to breathe and to be alone" if they needed it at any point, and they were equally surprised to discover that such time for reflection was important to them. Similarly, the Williamsons describe their encounter with the ethics consultants as helpful, but also challenging. They describe the ethics consultant's activities:

[He] probed our beliefs and value systems with provocative questions and challenging lines of reason. Of all the people we had experienced up this point, this was the first time we had hard questions posed to us from a source other than ourselves. This was a very beneficial process because, by enabling us to verbally articulate our decision-making process to another person who asked relevant questions, this meeting forced us to make sure that we were thinking through our choice carefully.²⁴

Such an intensive, challenging process – deliberately focused on learning about each family's "individual situation, validat[ing] our feelings and concerns, and help[ing] us continue down our path to a decision"²⁵ – was an unusual experience for many parents considering the procedure.²⁶ The Vanderbilt experience with the elective protocol for the surgery was innovative in its approach to the ethics consultation process for the surgery

²³ Zaner, "Parental Voices: Randal Lewis Morris Was Born," 554.

²⁴ Williamson and Williamson, "Parental Voices: The Positive Impact of Medical Professionals," 515.

²⁵ *Ibid.*, 515.

²⁶ The ethics consultation process was also an unusual experience, at least initially, for many clinicians and researchers involved with open-uterine surgery to repair spina bifida. As we shall see below in Adzick's descriptions of the current state of maternal fetal surgery, pp 89-93, even now, most facilities focus on achieving informed consent rather than encouraging ethics consultation. Also, see below, Chapter VII, p 209-212 for description of specific features of the design for Vanderbilt's ethics consultation process for this procedure.

as much as it was innovative in offering the first open-uterine procedure for spina bifida. Parents' accounts of *their* experiences specifically mention, and are appreciative of, that process, both in the "Parental Voices" and in my research, as Chapters VI and VII below will show. These accounts should be an indicator of the importance of ethics consultation in their decision-making and the need for continued work and understanding in this area of ethics and decision-making.

The Relevance of Publishing Parents' Stories

The journal in which all of these stories are told was intentionally designed to bring attention to parents' experiences in receiving the diagnosis of spina bifida and in their interactions with clinicians from diagnosis to decision. It also focused on how religious faith and values can influence decision-making, and the importance of a detailed process of informed consent, including ethics consultations, for understanding these experiences and these procedures. By providing an occasion for parents to reflect, in published form, on their own experiences, Churchill and Bliton were interested in documenting some of the key personal, moral, and social issues that influence and shape decision-making in this complex, experimental maternal fetal-surgery. Bliton, Zaner, Churchill, and others were calling for attention to these issues for years.²⁷ Published as a forum to show that basic informed consent and "perioperative counseling," which primarily focused on medical and clinical information, was *insufficient* for women and families to make decisions, this "Parental Voices" symposium demonstrated several

²⁷ Bliton, "Imagining a Fetus," 410-413; Bliton and Zaner, "Cutting Edge," 349-350; Jonsen, "Ethics," 368; Lyerly and Mahowald, "Maternal-Fetal Surgery," 162-163; Zaner, "Discovering What Matters in Fetal Surgery," 1-2.

crucial themes and dimensions frequently missing from the medical and ethical perspectives regarding this procedure. Churchill and Bliton argue that all of these ethical dimensions are important *to the clinicians* who work with pregnant women and their families from prenatal diagnosis through decision-making and the conclusion of the pregnancy. They reemphasize clinicians' and researchers' need to pay attention to parental stories and experiences because "obstetricians and other health professionals, for better or worse, inevitably figure in to these stories and help to shape and interpret their meaning."²⁸ Social and moral factors like religious beliefs, responses to disability, along with pressures to "do something," and the kindness or coldness of clinician encounters shape decision-making far in advance of any formal informed consent process for maternal-fetal surgical procedures. Understanding the circumstances, values, and backgrounds of the women and families considering open-uterine surgery to repair spina bifida is a crucial part of ethically sound research, at the investigational phases and, should the procedure be offered electively again, a crucial part of ethically sound patient care. In that light, an ethics consultation process that works to identify and address these moral features may help potential patients make sense of their options and make decisions that "fit" in their lives, and can help clinicians understand how risks and benefit calculations emerge from and affect patients' lives. Though the "Parental Voices" symposium was important because it focused critical attention on social and moral factors of this procedure, and because it focused attention on the need for an ethics consultation process that addresses those factors, these concerns continue to be neglected in much of the professional literature regarding open-uterine surgery for spina bifida.

²⁸ Churchill and Bliton, "Foreword," 510.

The Problem, Part I: Assumptions About Ethics

A brief survey of articles on open-uterine surgery for spina bifida published from 2006 to the present shows little or no acknowledgement of social and moral issues, no other calls to rectify the lack of understanding and research on decision-making, and no recognition of the complex questions about clinical ethics consultations identified in “Parental Voices” that still need to be addressed. Most articles describe a medical / scientific information based consent process, when ethical issues are mentioned at all, and most presume that open-uterine surgery for spina bifida will eventually become standard of care, with very little, if any, acknowledgement or recognition of the extensive moral and social issues affecting pregnant women and families considering the procedures. They make little or no reference to vulnerability, to social or religious values, to meanings of disability, of abortion decisions, of the impact of disability on family, or to the practice of including space in ethics consultations for these kinds of reflections and discussions.

Justification and Validation (Again)

Since 2006, publications in the leading journals about developments in maternal fetal surgery, in particular for open-uterine surgery to repair spina bifida, remain focused almost exclusively on the medical and, only occasionally on, the social stories of the procedures and the ethical issues involved: justification for experimentation, validation of research, and perhaps some discussion of the fetus as patient or potential maternal-fetal

conflicts.²⁹ As a primary example, consider the February 2010 edition of *Seminars in Fetal and Neonatal Medicine*, devoted to “Advances in Fetal Surgery,” and guest edited by N. Scott Adzick, an eminent maternal-fetal surgeon from Children’s Hospital of Philadelphia. This series of articles focused almost entirely on justification of experimental fetal surgeries. While Adzick’s introductory article summarizes the current status of open-fetal surgery for fetuses with life-threatening conditions, and gives specific recommendations for their prenatal and perinatal management, there is almost no mention of the moral dimensions of these still controversial procedures. He does make brief mention, in discussing the perioperative management of fetal surgery patients, that the risks and benefits justifying fetal surgery have to be weighed with each patient, noting,

For the fetus with a life-threatening malformation, the risk of the procedure is small when compared with the potential benefit of salvage. The risks and benefits for the mother are more difficult to assess... Risks to the mother must be weighed against the risk of fetal loss or the burden of raising a child with a severe malformation.³⁰

There is no discussion, however, of how such risks and benefits to pregnant woman and fetus are to be identified or weighed, or whether the possibility of salvage always justifies the risks of fetal loss and further compromise from prematurity. The presumption seems

²⁹ N. Scott Adzick, "Fetal Myelomeningocele: Natural History, Pathophysiology, and in-Utero Intervention," *Seminars in Fetal & Neonatal Medicine* 15, no. 1 (2010), 9-14; Brown and others, "Paediatrics-Based Fetal Care," 1617-1619; Chervenak and McCullough, "Ethics 2007," 426-431; Fichter and others, "Current Trends," 271-286; Kirstin Golombeck and others, "Maternal Morbidity after Maternal-Fetal Surgery," *American Journal of Obstetrics & Gynecology* 194, no. 3 (2006), 834-839; Jancelewicz and Harrison, "A History of Fetal Surgery," ; Mark P. Johnson and others, "Maternal-Fetal Surgery for Myelomeningocele: Neurodevelopmental Outcomes at 2 Years of Age," *American Journal of Obstetrics & Gynecology* 194, no. 4 (2006), 1145-150; Lyerly, Little, and Faden, "Critique," 34-39; Oluyinka Olutoye, "Fetal Surgery: Coming to a Center near You?," *Journal of Intensive Care Medicine* 23, no. 1 (2008), 67-69; Shaer and others, "Obstetrician-Gynecologists' Practice and Knowledge Regarding Spina Bifida," 355-362.

³⁰ Adzick, "Open Fetal Surgery for Life-Threatening Fetal Anomalies," 1.

in favor of surgery with little discussion of alternatives or what supports the presumptions in the first place. Similarly, Adzick's article "Fetal Myelomeningocele: Natural History, Pathophysiology, and In Utero Intervention" gives even less space to any ethical issues other than justification of the procedure.³¹ He writes,

Prior to 1997, we considered only fetuses with life-threatening anomalies and very poor predicted outcomes as candidates for fetal surgery. However, the severe morbidity and significant mortality of MMC, combined with the promising results of animal research as well as the development of diagnostic ultrafast fetal magnetic resonance imaging (MRI) studies led to consideration of prenatal intervention for this disorder.³²

Adzick makes no other distinction between the ethical issues of operating to salvage a fetus that would die before or shortly after birth and operating, as with myelomeningocele, on a fetus that would otherwise be delivered at term and likely survive. He makes little mention of how pregnant women make sense of these kinds of clinical options, let alone the implications for women's lives after a decision for or against surgery. Adzick offers a brief description of the MOMS trial and the risks and benefits it hopes to validate, but, again, no consideration of what that scientific validation will mean for offering the procedure to pregnant women in the future.

Another article in the same journal, by Jan A. Deprest and colleagues from University Hospitals, Leuven, Belgium, addresses the development of, justification for, and differences in scientifically validating fetal surgery in North American and European contexts, including surgery for myelomeningocele. Deprest et al observe that myelomeningocele "leads to life-long morbidity and burden," implicitly highlighting

³¹ Adzick, "Fetal Myelomeningocele: Natural History, Pathophysiology, and in-Utero Intervention," 11.

³² *Ibid.*, 11.

typical social views that disvalue spina bifida as a condition to be avoided, by prevention or termination. He writes that “in view of the prognosis, many pregnancies are terminated and at this point, there is not much hope for an improved post-natal management strategy eventually altering outcome. All hope is therefore focused on prenatal intervention to improve outcomes.”³³ Deprest et al seem to suggest that there is no *expectation* for improved post-natal management and so the focus of medical attention should shift to prenatal intervention. What the authors call a “hopeful” focus on prenatal management is not, however, a universally shared attitude. Open-fetal surgery is rarely performed in Europe, and while Deprest et al see this as a limitation from physician attitudes, rather than scientifically based, the authors do not articulate whether those attitudes are against open-uterine procedures as too invasive, against risking fetal death for a non-lethal condition, or against altering the status quo where many fetuses are terminated after a diagnosis of spina bifida. Nor do the authors question whether pregnant women may share such attitudes, or even whether the attitudes themselves – including the attitude that “all hope is therefore focused on prenatal intervention” – should be investigated. Instead, Deprest, et al simply claim that “if the NIH-sponsored ‘MOMS’ trial demonstrates decreased morbidity in fetuses with MMC undergoing surgical repair, open fetal surgery will inevitably have to be placed on the European agenda once more...”³⁴ with the implication that the open uterine surgery for myelomeningocele will be validated, and, as their article title suggests, will be “a clinical reality.”

³³ Jan Deprest and others, "Fetal Surgery Is a Clinical Reality," *Seminars in Fetal & Neonatal Medicine* 15, no. 1 (2010), 60.

³⁴ *Ibid.*, 64.

Mark Paul Johnson, on behalf of the North American Fetal Therapy Network (NAFTNet) presents similar confidence in experimental progress with the goal towards establishing and validating clinical interventions for a variety of congenital conditions. Johnson describes the creation of NAFTNet – a collaborative research cooperative of fetal treatment centers and specialists in North America aimed at designing and scientifically validating prenatal therapies – including surgery – for congenital conditions. According to Johnson, the goal of NAFTNet is to collaborate rather than compete for patients and research funding, given the rarity of many of the conditions they attempt to treat.³⁵ In Johnson's article, and in the development of NAFTNet, the emphasis is on the justification and validation as the key ethical concerns of in utero procedures, with no mention of extra-clinical features or even implications for clinical care of pregnant women considering such procedures.

The focus on justification and validation has been part of the medical discourse of ethics in maternal-fetal surgery for many years and both justification for and validation of new procedures are indeed important. What is problematic, especially at the current stage in the development of maternal-fetal surgeries, is the underlying and unquestioned assumption that these are the *main* ethical issues raised by such procedures.

Ethics as Informed Consent (Again)

A limited focus on justification and validation may be expected in the articles by Adzick, Deprest et al, and Johnson, which are written by and for clinicians, but those

³⁵ Mark P. Johnson, "The North American Fetal Therapy Network (Naftnet): A New Approach to Collaborative Research in Fetal Diagnosis and Therapy," *Seminars in Fetal & Neonatal Medicine* 15, no. 1 (2010), 52-53.

limitations and norms of presentation are more problematic in articles that claim to address ethical considerations associated with maternal-fetal surgeries. For example, in 2002, Frank Chervenak and Laurence McCullough published a significant essay offering a “Comprehensive Ethical Framework for Fetal Research and its Application to Fetal Surgery for Spina Bifida.”³⁶ They addressed five elements to be addressed if research on fetal surgery was to be ethically grounded.³⁷ In their summary, Chervenak and McCullough say they have “provided a comprehensive approach to managing the transition from innovation in fetal surgery to clinical trials, to offering fetal surgery to pregnant women as a standard of care for the management of fetal anomalies,”³⁸ and they apply these elements to experimental fetal surgery for spina bifida.

Chervenak and McCullough’s framework is widely regarded for its relevance on concepts of autonomy and beneficence. On that basis, their 2002 article offers a procedural approach to some of the ethical issues of justification for experimentation in fetal surgery and the validation of the research process. Likewise, Chervenak and McCullough make significant assumptions about the moral status of the fetus as a patient and the relationship between the pregnant woman and fetus. However, as I have illustrated above, the moral dimensions associated with maternal-fetal surgery extend much farther than Chervenak and McCullough’s reliance on procedural notions of autonomy and beneficence. Also, and perhaps most troubling from two ethicists, their

³⁶ Chervenak and McCullough, "Comprehensive Ethical Framework," 10-14.

³⁷ The five elements they included are as follows: the recognition of the fetus as patient, the initiation and assessment of clinical trials, physician-led, nondirective consent process, no restrictions based on women’s abortion preference, and physician obligations to refer to clinical trials (appealing to benefit for future patients).

³⁸ Chervenak and McCullough, "Comprehensive Ethical Framework," 13.

framework in no way addresses or even acknowledges the multitudes of vulnerabilities that women experience and that may be coercive. Their framework mentions the technological imperative, therapeutic misconception, and science by press conference, in respect to which they offer non-directive language and scientific reporting as “powerful antidotes” to these potential roadblocks to ethical research and informed consent. As we have seen in the “Parental Voices” accounts, however, and as we shall see in women’s descriptions in Chapter VII, the multiple and complex moral and social dimensions of these decisions extend beyond the typical medical and ethical discourses available and need explicit attention in the clinical context in which they emerge.

Chervenak and McCullough have published one of the widely acknowledged frameworks for considering the ethics of fetal surgery if through no other means than through frequent publication of the same kind of frameworks. Furthermore, the framework has not changed³⁹ to accommodate shifts in maternal-fetal surgery from lethal to non-lethal conditions, and has not changed to incorporate challenges to and critiques of their construction of the fetus as patient – which some might say is the hallmark of a coherent framework for ethics. However, that framework seems most flawed in its real limitations in recognizing women’s and families’ accounts of morally relevant issues in open uterine surgery to repair spina bifida. This conceptual framework, which is often proposed as a basis for designing and conducting informed consent processes for new in utero procedures, assumes procedural and structural approaches to ethical issues – a focus on informed consent and autonomy– are sufficient. This procedural understanding of ethics creates the potential for harm by overlooking the social and moral complexity in

³⁹ The framework offered in the 2002 article is almost identical to the frameworks offered in subsequent articles by Chervenak and McCullough. See Chervenak and McCullough, "Ethics 2007," 426-431; Chervenak and McCullough, "Ethics 2009," 237-244.

deeply personal decisions, as well as the clinical uncertainty about these surgeries.⁴⁰ For example, in Adzick's description of the perioperative management of fetal surgery patients, he describes the process of informed consent used at Children's Hospital of Philadelphia. Based on the elements outlined by Chervenak and McCullough,⁴¹ Adzick's description merits quoting at length:

Following completion of the evaluation and patient selection, a team meeting that includes fetal / pediatric surgeons, obstetricians, anesthesiologists, a nurse coordinator, nurse practitioners, operating room nurses, and a social worker is held to discuss with the family each step of the proposed surgery and postnatal care, as well as the risks, benefits, and alternatives to fetal intervention...these risks are clearly outlined and discussed, prior to obtaining consent for treatment. This forum provides the family an opportunity to ask questions and make decisions carefully and knowledgably. Finally, there are potential psychological risks such as the mother feeling 'coerced' into having fetal surgery performed. It is critical that perioperative counseling for these women and their partners / families gives 'permission' to the women to decide against the surgery."⁴²

The emphasis in Adzick's description on clinical information is typical for the scientific / research model of informed consent. There is no mention of time for reflection, and only brief mention of potential psycho-social risks if the woman feels coerced. There is, likewise, no mention of concerns that the very structure of the physician-led informed consent might be coercive in ways not addressed by "permission" to decide against

⁴⁰ This harm from overlooking moral and social issues is distinguishable from the potential harm of Zaner's more robust understanding of ethics, namely, the potential emotional harms *from* examining difficult moral and social issues. This type of harm will be discussed more fully in Chapter VII, below. The bias underlying Zaner and Bliton's understanding of ethics consultation is this: although engaging couples in questioning the medical, social and moral issues emerging from their experiences risks potential emotional or psychological harm, raising as many of these issues as possible in advance of a decision presents greater opportunities for women and their families to give genuine informed consent.

⁴¹ Chervenak and McCullough, "Comprehensive Ethical Framework," 10-11.

⁴² Adzick, "Open Fetal Surgery for Life-Threatening Fetal Anomalies," 2.

surgery.⁴³ Finally, there is no mention or discussion of women's values, beliefs, or decision-making process as important to their experiences or to their interactions with clinicians.

Adzick's underlying assumption about ethics appears to be that the medical information is sufficient for decision-making. In other words, the researcher's responsibility extends only to the clear presentation in a non-directive manner of the fullest degree of information. The concern, arising from Adzick's, and from Chervenak and McCullough's comprehensive framework informed consent process is the message that social and moral factors, such as women's personal / moral concerns and commitments are not important to their decision-making or to the clinicians offering them the surgery. Though this message may not be explicit or even intended in Adzick's language, clinicians' and researchers' assumptions about ethics are clear: requirements for a "careful and knowledgeable decision" and ethical informed consent are met by a process where evaluation, selection, and control of the process are structurally secured in the hands of clinicians and researchers.

⁴³ Bosk, "Sociomedical and Ethical Dilemmas," 367. Early in the conversations about maternal-fetal surgery, Charles Bosk makes a similar observation about coercion, noting "The solution to problems of uncertainty does not simply rest with finding a better slide rule. Here I would offer one caution. In our zeal to do the right thing in the right way, we need to install procedures for respecting both parental autonomy and parental privacy. Consulted by so many, talked to so thoughtfully and thoroughly, parents need permission not to feel coerced by medical kindness. Parents have the right to refuse fetal therapy without feeling criminally negligent for not doing the best thing for their baby." The question here is whether Adzick's mention of granting parents 'permission' to decide against surgery is sufficient or whether the entire structure he describes of the meeting with all of the medical personnel and information, in one session, does not illustrate Bosk's concern exactly.

The Problem, Part 2: Limited Impact of Parents' Accounts

Adzick, Chervenak, and McCullough and other dominant voices in the field of maternal fetal surgery presume that a clinically based, procedural approach to informed consent is sufficient for decision-making about open-uterine surgery to repair spina bifida, in part because such an approach refers to ethical themes in the scientific and social discourses presented above. Only a small number of clinicians have recognized that maternal-fetal surgeries raise questions more complex than allowed for in the typical informed consent process.

Out of more than two-dozen publications in the literature on maternal-fetal surgery since 2006, three articles deserve to be highlighted because they raise questions about the eventual transition from experimental procedure to standard of care. Written by experts in the field – Joseph Bruner, Shinjiro Hirose and Diana L. Farmer, and Shaun M. Kunisaki and Russell W. Jennings⁴⁴ – each of the articles raises questions, concerns, and even doubts about what the MOMS trial might show and what features – medical, social, and moral – might need additional consideration.

Bruner points out that the control group of the MOMS trial will actually provide the most new information, rather than the in utero procedure group. He observes, “Conceivably, aggressive management of newborns with spina bifida at selected centers of excellence could result in outcomes comparable to those seen after intrauterine

⁴⁴ Bruner, "Intrauterine Surgery in Myelomeningocele," 471-476; Shiroje Hirose and Diana Farmer, "Fetal Surgery for Myelomeningocele," *Clinics in Perinatology* 36, no. 2 (2009), 431-438; Shaun M. Kunisaki and Russell W. Jennings, "Fetal Surgery," *Journal of Intensive Care Medicine* 23, no. 1 (2008), 33-51.

surgery.”⁴⁵ Bruner also emphasizes the necessary recognition that “intrauterine repair of MMC is elective surgery and it does not save life – even under the best conditions it can only threaten life,”⁴⁶ something that bears repeating in ethics consultations with women and their families. Similarly, Hirose and Farmer point out that “it is not clear whether or not prenatal repair of MMC is truly beneficial when compared with standard postnatal therapy.” They continue, noting that

As of now, there is little evidence that prenatal repair of spina bifida improves neurologic function – sensory, motor, or urologic. MMC is the first non-lethal disease under consideration and study for fetal surgery. As a result, potential improvements in outcome must be balanced with maternal safety and well-being in addition to that of the unborn patient. The current multi-center trial should provide answers regarding the benefits of fetal surgery for MMC.⁴⁷

Even this acknowledgement from Hirose and Farmer, that significant questions remain about benefit, stands in contrast to publications that assume the MOMS trial is the only step to be fulfilled before this procedure is accepted in more countries, including European countries and in South America.⁴⁸ Kunisaki & Jennings also raise questions about balancing risks and benefits for maternal-fetal surgery. They argue that “mothers need to be aware that no prenatal intervention is universally successful in terms of improving fetal well-being. The morbidity and mortality associated with the delivery of a premature baby should be openly discussed prior to fetal intervention.”⁴⁹ Taken together,

⁴⁵ Bruner, "Intrauterine Surgery in Myelomeningocele," 423.

⁴⁶ *Ibid.*, 423.

⁴⁷ Hirose and Farmer, "Fetal Surgery for Myelomeningocele," 433.

⁴⁸ Deprest and others, "Fetal Surgery Is a Clinical Reality," 59-60; Olutoye, "Fetal Surgery: Coming to a Center near You?," 67-69.

⁴⁹ Kunisaki and Jennings, "Fetal Surgery," 33-52.

and when compared with other articles' enthusiastic optimism for the inevitable validation of open-uterine surgery to repair spina bifida, the questions raised by Bruner, Hirose and Farmer, and Kunisaki and Jennings seem cautious and reflective, which they are indeed. But while they challenge the dominant framework that focuses solely on information and autonomy in informed consent, even their cautions do not address the fundamental questions about ethics consultations and the need to raise and address social and moral issues identified by Churchill and Bliton, Rothschild et al, Zaner, Blizzard, and the parents who contributed to the 2005 *Clinical Obstetrics and Gynecology* "Parental Voices" symposium.

Focusing Attention on Women's Stories

The seeming neglect in the professional medical and surgical literature about the importance of social and moral factors in decision-making for maternal-fetal medicine has contributed to assumptions that typically constructed informed consent procedures are adequate for addressing these issues. However, as more attention is directed to this complex set of issues the gaps in clinicians' and researchers' understanding of how pregnant women and their families actually make decisions about open-uterine surgery for spina bifida becomes more evident. Even so, we need more focused attention on women's experiences, from diagnosis to decision-making and beyond, to understand how the medical, social, and moral dimensions influence women's experiences with and decision-making about this procedure. While the MOMS trial may contribute significant data and information to the process of decision-making about the procedure, the controversy is likely to continue about what that data means and how to interpret it the

context of clinical patient care. In particular, the question will remain of how women understand such clinical information in light of their social contexts and ongoing moral experiences in considering open-uterine surgery to repair spina bifida. As Bliton observes,

given the complexity and scope of issues amid the intense controversy generated by maternal-fetal surgery, both advocates and skeptics are likely to overlook the moral and spiritual experience of hope in a pregnant woman's decision-making about fetal surgery for spina bifida...⁵⁰

He explains that advocates and skeptics of the procedure are unlikely to agree on what the scientific data shows, and argues that regardless of the disputes,

Careful attention will need to be given to the ethical issues that remain unresolved, including the need to identify and establish legitimate ways to handle the issues surrounding maternal and fetal vulnerability at previable gestational age, which is when the defect is often diagnosed and likewise, when fetal repair is likely to be performed.⁵¹

As the MOMS trial comes to its fruition and if the procedure is offered electively, as it was before, then identifying and addressing social and moral issues and developing procedures for addressing them with potential participants becomes even more crucial. To that end, my study was designed to add another effort to identifying the moral and social experiences of women considering open-uterine surgery to repair spina bifida. The goal was to talk directly with the women who made their decision in the VUMC elective series and get *them* to identify what matters, what helps with making sense of these experiences. Learning about and from women's experiences can raise awareness of these issues and suggest concrete efforts to shift from a focus on informed consent procedures to improving ethics consultation and decision-making processes for women in the future.

⁵⁰ Bliton, "Parental Hope," 596.

⁵¹ *Ibid.*, 596.

PART II: DEVELOPING METHODOLOGIES AND METHODS

Methodologies and Method?

Pursuing my questions about women's experiences with and decision-making about open-uterine surgery to repair spina bifida proved to be a two-fold challenge: it was a challenge regarding both methodology and method. I make the distinction here between the methodological questions, by which one approaches a problem with a particular framework and set of activities, and the question of method, by which one develops one's frameworks and activities reflectively through performative and emerging understandings of the problem. The methodological questions are the ones that obviously confront any research project, especially those with human subjects – the reporter's questions: who, what, when, where, how, and why.¹ The questions of method, on the other hand, are more easily obscured even though they are just as crucial to moral inquiry. The sense of method I outline here is one discovered in the activities of inquiry – in each undergoing of or encounter with the problem,² though they can be prepared for and anticipated, imagined and freely-phantasied³ in advance. Methodological questions guided me from the inception of my project to the front door of each woman's home. Questions of

¹ M. Sandelowski, "Whatever Happened to Qualitative Description?," *Research in Nursing & Health* 23, no. 4 (2000), 337. Methodological questions might ask what resources will address the questions? How are the resources acquired? Who are potential participants? Who will be contacted? How will they be contacted? What provisions are made for safety and accountability? How will data be collected? How will it be analyzed and reported?

² Some will challenge the distinction as false and claim that the theoretical debates about and underpinnings of various methodologies do the same as work as a focus on method. I maintain the distinction, first, to emphasize the experiential and practical implications of method and, second, to emphasize the performative, iterative aspects of method. Method is a practice that one engages in and reflects on during the engagement, during each similar yet distinct engagement.

³ Bliton, "Imagining a Fetus," 393-394; Richard M. Zaner, "Phenomenology and the Clinical Event," in *Phenomenology and the Cultural Disciplines*, ed. M Daniel and Lester E. Embree (Boston: Kluwer Academic Publishers, 1994), 53-54. Free-phantasy variation is the term for imaginatively varying the features of a presented situation or circumstance to make clear which features are constant and essential.

method, however, engaged me as I walked into each woman's life, kept me open to and oriented towards what I might learn from each during our interview – and kept me attuned to our mutual vulnerability to harm and misunderstanding, both in the encounter and in my ongoing analysis and reporting.⁴ The methodological questions asked, “How *can* I contact and communicate with the women who considered open-uterine surgery to repair spina bifida?” The questions of method asked, “How *should* I to talk with and listen to the women who considered open-uterine surgery for spina bifida?” Together they asked, “How *do* I tell these stories?”

Methodological questions and questions of method are deeply entwined and have informed each other throughout this project, from preliminary research and design to interviews to analysis and reporting. They represent different tasks, however, and one of the goals of this project is to highlight the importance of questions of method in moral inquiry and research on understandings about ethics. The first chapter of this section, Chapter IV, will describe the methodological questions, guided by Adele Clarke's expansion of grounded theory methodologies in *Situational Analysis: Grounded Theory After the Post-Modern Turn*. This chapter will detail my methodologically oriented research design. Chapter V addresses the underlying and interweaving questions of method for conducting interviews, supported in part by Pierre Bourdieu's work on understanding and reflexive sociology, and in part by Richard Zaner's work on attunement and ethics in the clinical encounter. The chapter then looks at questions of method and analyzing interviews through William James's work on belief and

⁴Bliton, "Imagining a Fetus," 399. For example, discussing his own interviews with couples considering the decision about maternal-fetal surgery, Bliton asks, “In other words (even though the gravity and meaning of the issues cannot be the same for both of us) how might I possibly find out what is important to you, or anyone else, in such a context unless I am willing to share temporarily the questions and uncertainties you face?”

pragmatism, along with Alfred Schutz's phenomenology of the common-sense world of working. Method and methodology together provide a framework for eliciting women's stories and analyzing the meanings they give to their experiences.

CHAPTER IV

RESEARCH METHODOLOGIES

Adele E. Clarke's Situational Analysis

Adele E. Clarke, a prominent sociologist and feminist thinker, focuses on the sociology of biomedical sciences, women's health, and the development of qualitative research methodologies. One of her principle publications, *Situational Analysis: Grounded Theory after the Post-Modern Turn* offers complex theoretical reflections on shifting concerns in qualitative research and offers practical descriptions of and demonstrations of approaches to research that “explicitly include analysis of the full situation, including discourses – narrative, visual, and historical.”¹ Clarke was trained in grounded theory,² a qualitative methodology which, most briefly, uses a systematic, “micro-analytic” approach to qualitative data to “unearth” meaning and empirically ground theories about social life and phenomena.³ Clarke's work attempts to move

¹ Adele Clarke, *Situational Analysis : Grounded Theory after the Postmodern Turn* (Thousand Oaks, Calif.: Sage Publications, 2005)xxxiii.

² Grounded theory was developed in *Discovering Grounded Theory* (1968), by Barney Glaser and Anselm Strauss, and updated by Anselm Strauss and Juliet Corbin in *Basics of Qualitative Research: Techniques and Procedures of Developing Grounded Theory* (1998).

³ Clarke, *Situational Analysis* ; Barney G. Glaser and Anselm L. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (London,: Weidenfeld and Nicolson, 1968); Anselm L. Strauss and Juliet M. Corbin, *Basics of Qualitative Research : Techniques and Procedures for Developing Grounded Theory*, 2nd ed. (Thousand Oaks: Sage Publications, 1998), 87-143.

beyond some of the theoretical and practical limitations of grounded theory, and move grounded theory “around the post-modern turn.”

Clarke critiques grounded theory for preserving the “American strains of positivist and scientific research” from which it emerged, including a lack of reflexivity about research processes and products, oversimplification of analysis and understandings of social processes, and a search for “purity in research methodologies.” Clarke wants to “regenerate” grounded theory by pursuing “the methodological implications of the post-modern [which] primarily require taking situatedness, variations, differences of all kinds and possibilities / relationality very seriously in all the complexities, instabilities, and contradictions.”⁴ Clarke sees the challenges of post-modernism as opening access to different resources for understanding a given situation.

Clarke’s *Situational Analysis*, first and foremost, offers a qualitative research methodology that grants access to multiply complex social phenomena, and second, offers tools for a systematic approach to data collection and analysis. In the first, her model for looking at a particular situation more broadly opens up additional sites of research. Clarke observes that

Current research trends of studying new forms of data and including multiple kinds of data in one study – now called multi-site research – are cutting across all the social sciences, history, and varied professional domains. Disciplines themselves are being reconfigured and new disciplinary formations established. “Borrowing” new kinds of data and methods across disciplinary borders has become common, producing

⁴ Clarke, *Situational Analysis* xvii. Rather than rehearse Clarke’s review of and analysis of grounded theory, however, I will direct the readers to the first chapters of her book *Situational Analysis*, while I focus on some of the practical applications her methodology suggests to my own research, in particular, in designing projects that draw on “interviews, ethnographic, historical, visual, and / or other discursive materials, including multisite research.”

hybrid multi / trans-disciplinary projects and the study of documents, media, and visual materials of all kinds is everywhere taken up.⁵

In the second, Clarke models “mapping techniques” for moving the researcher through her coded data by mapping and organizing key themes and discourses. The goal is to see what is available and what is missing in understanding the situation under investigation.

I take advantage of Clarke’s recognition of the particularities of situational analysis, and other methodologies, and her invitation to consider other approaches alongside situational analysis. Clarke suggests that researchers

*collect data that can explicitly address the salience or lack of salience of any of these issues for the situation at hand... [that] we also need to design our research from the outset in order to explicitly gather data about theoretically and substantively underdeveloped areas that may lie in our situations of inquiry.*⁶

The charge to look beyond what is readily available to confront “the inadequacies of our own understanding”⁷ led me to consider other stories of and understandings of open-uterine surgery to repair spina bifida.

In my research design, I both make use of and diverge from Clarke’s emphasis on “non-human actants” and the “full situation of inquiry.”⁸ Clarke’s situational analysis recognizes and encourages identification and analysis of “non-human actants” in terms of what gets focused on as “in the situation,” what social arenas are involved, and what the

⁵ Ibid. 146.

⁶ Ibid. 75-76.

⁷ Ibid. 75.

⁸ Ibid. 146. Non-human actants include technologies, spaces and structures, institutions and social organizations, along with publications and other types of media. These non-human actants require a variety of analytic tools to make sense of the “full situation of inquiry.”

key themes in those discourses are.⁹ She introduces the idea of qualitative researchers as “bricoleurs,” piecing together and “assembling project specific tool-kits for a broad repertoire of available concepts and approaches – selecting what they believe are the ‘right tools for the job.’”¹⁰ She continues, explaining, “I am interested in developing interesting and *useful* methods of analysis, useful tools with which to approach a wide array of research projects with quite heterogeneous forms of data.”¹¹ In my search for the absent voices in the medical and ethical discourses or stories about the procedure, I encountered and had to determine ways to identify and analyze just such “heterogeneous forms of data,” just such “non-human actants” as the “Parental Voices” essays, websites, blogs, interviews, magazine and newspaper articles, videos, and photographs relating to open-uterine surgery to repair spina bifida. Clarke’s openness to multiple sites of research, including both human and non-human actants in a situation, helped me think about these multiple sources of women’s understandings about the procedure and about the multiple domains where women’s experiences occur and have meaning – at home, online, in their communities, before and after their encounters with various medical settings. Though I agree with Clarke’s argument, that researchers’ “analytic focus needs to go beyond the ‘knowing subject’ and be fully on the situation of inquiry broadly covered, including the return to discourse,”¹² I diverged from Clarke by centering on and focusing on the women’s voices that have been overlooked or relegated to the background of the full situation. Using that focus, I looked at how women learned about

⁹ Ibid. 64-65.

¹⁰ Ibid. 146.

¹¹ Ibid. 146.

¹² Ibid. xviii.

and understood their possibilities and what they have done to make sense of their possibilities after the decision. I wanted to foreground women's viewpoints and contributions to understanding this procedure.

By arguing for the importance of access to multiple research sites in methodology design, Clarke's work provided an important frame for my own. However, in the process of research design, as described in the following sections, the limits of methodology became apparent and the demand for attention to method, or attunement to the circumstances at hand, emerged. Thus, while *methodological* concerns guided research design, concerns about *method* as a practice guided the actual research encounters. Attention to both methodology and method, however, proved necessary for reporting or telling women's stories, as Section III, below, will demonstrate.

Research Design:

There were four distinct steps to designing an appropriate research methodology to address the gaps in the medical and ethical literature on open-uterine surgery to repair spina bifida. The first step was the preliminary research identifying themes and possible questions to pursue as preliminary data leading to the second step, the decision to select open-ended, face-to-face interviews as an appropriate methodology for eliciting women's accounts of their experiences. The third step was identifying and contacting potential participants in a way that invited participation with minimal intrusion into the lives of those who may not be interested. Finally, the fourth step was the combined interview and analysis phase, which shows some of the limits of a methodological focus and the need for attention to method.

Preliminary Research

One of the first tasks of qualitative research methodologies is recognizing an area of human experience in need of investigation and identifying questions to ask of that area of human experience.¹³ In this study, looking at the available accounts and published stories about open-utero surgery to repair spina bifida highlighted the significant gaps and missing voices in those stories. Though considerable resources highlighted professional concerns about potential conflicts in decision-making and procedures designed to manage those conflicts,¹⁴ until the September 2005 “Parental Voices” issue of *Clinical Obstetrics and Gynecology*, almost nothing in the professional literature identified what features of the procedures or moral concerns were important to women making decisions about their fetuses in the midst of their pregnancies. For many laypersons researching the procedures, however, the Internet offers access to other stories about open-uterine surgery to repair spina bifida. Personal and family websites and “blogs,” online communities devoted to patients who have undergone the procedures, and published interviews in local, national and religious newspapers and magazines are all available and provide a different set of perspectives on the surgeries. I looked to both of these resources – the “Parental Voices” articles and the various “PNS4SB” websites – as important investigative sites that would help me better understand women’s experiences with the procedure.

¹³ Valerie J. Janesick, "The Choreography of Qualitative Research Design: Minuets, Improvisations, and Crystalizations," in *Strategies of Qualitative Inquiry*, ed. Norman K. Denzin and Yvonna Lincoln (Thousand Oaks: Sage Publications, 2002), 51-54.

¹⁴ See section on maternal-fetal conflicts above, Chapter II pp 41-45.

My analysis of the “Parental Voices” articles in the special edition of *Clinics in Obstetrics and Gynecology* and my analysis of “PNS4SB” websites were similar in process.¹⁵ The “Parental Voices” articles were easily accessible and few in number, but I had to be more systematic in my approach to the websites available.¹⁶ Most searches of prenatal surgery for spina bifida yield links to the MOMS website, links to various “Fetal Treatment Centers,” links to personal blogs and family websites, and links to articles about the “Hand of Hope” picture. For my research, the family websites and the links to articles and interviews with parents who considered the procedure pointed to areas for further investigation. I critically analyzed a representative selection of these websites, including personal or family blogs, as well as interviews in local, national, and religious newspapers and magazines, looking for key themes and common concerns.¹⁷ More specifically, I looked at each website and article to identify the key narrative features such as what themes and ideas structured the story, what the goal of the document was, whether scientific, religious, or ethical issues arose in the story, and what kinds of information each article or website offered, such as personal experiences, references or

¹⁵ The key themes of the “Parental Voices” articles have been identified in Chapter III, above, pp 72-82. The descriptions of these themes are both brief and broad, as here I was focused on preparing myself for interviewing women. The analysis of the published materials, however, is fascinating and will likely form an additional branch of research in the future.

¹⁶ I used a variety of search engines – Google, Yahoo, and more recently, Bing - to search for website and articles about open-uterine surgery to repair spina bifida. I used multiple search terms such as “prenatal surgery,” “fetal surgery,” “in utero surgery,” “spina bifida,” and combinations of the terms, which produced huge numbers of results, up to 402,000 hits for the search term “fetal surgery for spina bifida,” though many blogs and articles linked to each other or referred to each other, and many articles came up repeatedly under different search terms (MOMS, Samuel Armas stories, Michael Clancy picture, Physicians for Life). I tried to include a variety of blogs and local-newspaper interviews, along with the broader articles that consistently appeared in search results. I not only documented my access to each article, but also saved them as bookmarks, screen shots, and text files so as to capture some of the always-ephemeral Internet discourse about this procedure.

¹⁷ Clarke, *Situational Analysis* 145-179; Strauss and Corbin, *Basics of Qualitative Research*

links to other sites, statistics, or fact-sheets. Constant comparison of themes among the different resources helped identify possible topics and questions for my interviews with women who had considered this procedure.

Preliminary Data:

The professional literature, as described above, identified questions of scientific justification and validation, the moral status of the fetus and women's reproductive choices, and achieving informed consent as important ethical concerns in open-uterine surgery to repair spina bifida. Some explicitly addressed the just-below-the-surface issues of disability and selective abortion for disability, but most focused on the scientific and procedural concerns for research integrity and the centrality of providing non-directive clinical information during the informed consent process.¹⁸ In the "Parental Voices" edition of *Clinical Obstetrics and Gynecology*, the different families focused on the devastation and confusion of diagnosis, the impetus to do something, and the importance of clinician communications in shaping their experiences. They all discussed the importance of religious faith and hope, and identify the ethics consultation process as a crucial element of their decision-making.¹⁹ In the online accounts and interviews, similar themes emerged repeatedly and indicated areas of concern for families considering open-uterine surgery for spina bifida.

The bulk of the personal accounts included four main themes. They reaffirmed the devastation and trauma of a prenatal diagnosis of spina bifida, while offering hope, pro-

¹⁸ See Chapter II above, pp 56-59.

¹⁹ See Chapter III above, pp 80-82.

life imagery and language, and encouragement to “choose life” rather than abortion. They also gave enthusiastic descriptions of the “miraculous” surgery, and stories showing that they have no regrets about choosing the risky procedure. A few brief examples will highlight these themes.

Parents talked about their experience of diagnosis, for example, as traumatizing and causing great despair. As one mother wrote in her blog,

A perinatologist confirmed that our baby had hydrocephalus and spina bifida. He basically told us that our child could end up being a vegetable in a wheelchair. Retardation, no mobility, bowel and bladder problems, learning disabilities, financial devastation, marriage problems, too much for our other children to handle...he went *on* and *on* and *on*...He seemed to think it was his duty to warn us of the worst possible scenarios and convince us that we needed to terminate the pregnancy.²⁰

Others described the diagnosis as “devastating” or that they were “in despair” after hearing that their child would have such problems. On the other hand, most of the blogs and interviews described a shift in perspectives towards accepting their child’s disability that occurred when they realized “It wasn’t really devastating. It was just different. We had to learn some new things.”²¹ And, as another mother described in her blog, the change in attitude was abrupt.

It was all so unfair. This [spina bifida] only happens to one in 1,000 babies – so why did it have to happen to my baby? Then the truth settled on me. Out of all the parents God could have given a 1-in-1,000 baby to, he chose me! What a blessing! He knew I would be the best mother in to this baby and I determined that I would not let Him down.²²

²⁰ Cheryl, *We Made It Sweet Baby: Cassidy Anne's Story* (2000, accessed 8/10 2008); available from <http://www.benotafraid.net/stories.asp?filter=Spina%20Bifida>.

²¹ Rachel Coleman, *Praying for Patience* (2007, accessed 8/10 2008); available from <http://www.motheringheights.net/featured-contest-essays/2007/5/17/praying-for-patience-by-rachel-coleman.html>.

²² Colleen, *Let Me Decide* (2000, accessed 8/10 2008); available from <http://www.benotafraid.net/story.asp?id=126>.

Julie Armas, whose son Samuel is the subject of the famous “Hand of Hope” or “Fetal Hand Grasp” photo,²³ describes a similar recognition shortly after receiving the diagnosis of spina bifida. She told interviewers for the *Christian Index*, a Baptist publication,

Somewhere along the way, I decided that my faith was in the Lord and that I would, through the power of the Holy Spirit, show the world how a Christian deal with such a nightmare. It became easier when God began to show us signs that fetal surgery was His will for our precious child.²⁴

Whether parents in these accounts chose open-uterine surgery to repair spina bifida or not, the shift from the devastation of the prenatal diagnosis to the acceptance of their child’s disability was a process that occurred when they decided not to accept “society’s definition of imperfect or defective” for their child.²⁵

In these stories, abortion was not an option, and for many, the opportunity to undergo open-uterine surgery to repair spina bifida was an opportunity to help other “unborn children” by highlighting life before birth and options other than selective abortion for disability. The Armas family, for example, chose to continue their pregnancy because, as father Alex explained,

Our convictions are grounded in beliefs established through our upbringing and through what the Bible clearly states is wrong and right. Abortion is wrong. Life in the womb is God created, even with birth defects. God does not make mistakes.²⁶

²³ Michael Clancy, *Story of The "Fetal Hand Grasp" Photograph*(Michael Clancy, 2001, accessed 8/10/2008); available from <http://www.michaelclancy.com/story.html>.

²⁴ J. Gerald Harris, *Couple's Faith, Commitment Impact Senate Hearings on Abortion* (Baptist Press: News with a Christian Perspective, 2004, accessed 8/11 2008); available from <http://www.scbaptistpress.org/bpnews.asp?ID=17485>.

²⁵ Physicians for Life (PFL), *Spina Bifida Surgery in Utero* (1999, accessed 8/11 2008); available from <http://www.physiciansforlife.org/content/view/258/1/>.

²⁶ J. Gerald Harris, *Samuel and Zachary - Victims of Spina Bifida, Answers to Prayer* (Christian Index, 2006, accessed 8/11 2008); available from <http://www.christianindex.org/1890.article>.

Julie and Alex Armas allowed *USA Today* to photograph and write an article about their experience, according to Julie, to teach others that there are options other than abortion. They have told their story in multiple venues, and their experiences with open-uterine surgery to repair spina bifida are often cited in other websites and articles. Their prominence is due in part to Samuel's role as the youngest fetal surgery patient at the time – at 21 weeks gestational age – but in larger part, due to the famous “Fetal Hand Grasp” photo taken during that surgery. Photographer Michael Clancy captured a controversial image of the fetus's hand outside of the womb, which has been printed and reprinted in pro-life magazines, websites, and articles as an illustration of life in the womb “challenging the world to open its eyes to the reality of nascent human life.”²⁷ The Armas family and Clancy view the photograph as a ministry, as one article on the Physicians for Life website explains, because “he [Samuel] literally reached out from the womb to save other infants from the horrors of abortion.”²⁸ Websites such as Physicians for Life and Youth for Life, alongside the National Right to Life Committee have shown the striking image in the hopes of encouraging women to pursue the “third option” instead of abortion after a prenatal diagnosis of spina bifida.²⁹

²⁷Jonathan Imbody, *An Update on Samuel Armas: A Flash of Life* (National Right to Life Committee, 2003, accessed 8/11/2008); available from http://www.nrlc.org/news/2003/NRL10/an_update_on_samuel_armas.htm. The controversy stems from Clancy's assertion that Samuel, the fetus, reached his hand out of the womb and grasped the surgeon, Dr. Bruner's hand, demonstrating the life and activity of the fetus in the womb. Dr. Bruner, on the other hand, explains that the fetus was anesthetized and immobile, and that at 21 weeks, the fetus is not capable of intentional movement. Bruner says hand fell out at the end of surgery and he lifted the hand with his finger. Clancy and other pro-life advocates are still petitioning for Bruner to make the “truth” of the photo public and vindicate Clancy's claims. The website, www.michaelclancy.com, gives Clancy's perspective. The debunking website, www.snopes.com, reviews the evidence against Clancy's claim for the “Hand of Hope” image.

²⁸ (PFL), *Spina Bifida Surgery in Utero* (accessed).

Many of these articles and websites focused on the “third option” of maternal-fetal surgery and like articles in the professional literature on prenatal diagnosis, emphasize the importance of doing something – anything – that might help their child-to-be, no matter what the risks to the pregnant woman or even the risks of death or prematurity for the fetus.³⁰ Most family blogs or websites described open-uterine surgery to repair spina bifida as a “miracle of modern medicine” and articles in the general media echo that description, referring to the procedure as a “bold and experimental procedure.”³¹ Descriptions ranged from the clinical to the melodramatic, and while most gave some description of the significant risks of the surgery, the emphasis was on the potential benefits and the positive outcomes. For families still reeling from their child’s prenatal diagnosis of disability, the reports of “a new hope for treating disease in utero”³² and of medicine that “grants unborn children rights as patients”³³ led many to investigate and ultimately to pursue maternal-fetal surgery, no matter what the risks.

Stories from the interviews and family websites tended to emphasize that the surgery was worth the risks and that it helped avoid the possibility of future regrets. On many of the personal websites, families explained that they have no regrets, whether their child was born prematurely and died or had serious complications, or whether the surgery

²⁹ Ibid.(accessed) ; Paul Harris, *Holding Hands: Samuel Alexander Armas's Story* (Youth for Life, 2003, accessed 8/10 2008); available from <http://joseromia.tripod.com/samuel.html>.

³⁰ Bliton, "Imagining a Fetus," 405-406.

³¹ Claudia Kalb, *Treating the Tiniest Patients*(2003, accessed 8/10 2008); available from <http://www.newsweek.com/id/59540>.

³² Soledad O'Brien and Sanjay Gupta, *Good Morning America: House Call (Transcript)* (Cable News Network (CNN), 2003, accessed 8/11 2008); available from <http://www-cgi.cnn.com/TRANSCRIPTS/0310/08/ltn.16.html>.

³³ Pia de Solenni, *Miracles of Life: The Beltway Goes in the Womb*(2003, accessed 8/10 2008); available from <http://old.nationalreview.com/comment/solenni200309301002.asp>.

appeared to minimize their child's projected disabilities. One woman, for example, described the dangerous pulmonary edema that kept her in the hospital after she had maternal-fetal surgery for her child's congenital diaphragmatic hernia. She said, "I'm glad I did this for my first baby," who is healthy and active at four years old. But she acknowledged the challenges that came with her surgery, noting, "I don't know if I could do it again." On the other hand, another family who had surgery to correct lesions on their baby's lungs, lost the child shortly after his birth, and yet they have no regrets. The mother explained that the surgery "Was the only thing we could do...I never wanted to wonder later 'what if?'" Julie Armas gives a similar explanation for risking the procedure:

If he dies, that's horrible for me, and for us...But not for him. The worst thing might be if we don't do this and this is standard treatment when he's 21 and he says, "Why didn't you know about that?" and we say, "We did, but we didn't do it for you."³⁴

For Julie and Alex Armas, and for others, the risks of losing their son were less than the risk of missing an opportunity to help him.

In many articles and on many family websites, underlying each of these themes – disability, abortion, the promise of surgery, and avoiding regret – was a deep vein of religious, particularly Christian, belief.³⁵ For parents who professed religious faith in God's control, the devastating diagnosis, their opposition to abortion, and the hopes generated by an experimental in utero procedure, as well as their acceptance of their child's disability and the varied outcomes of the procedure were deeply important to their experiences with and decision-making about open-uterine surgery to repair spina bifida.

³⁴ Harris, *Holding Hands: Samuel Alexander Armas's Story* (accessed).

³⁵ Bliton, "Imagining a Fetus," 408.

These brief examples from online and print resources identified some of the key themes for understanding women's experiences and they indicated areas for further investigation.

Interview Design:

Talking to women directly, asking them to identify the moral issues and decision-making processes that shaped their experience seemed to offer a crucial perspective for learning, as Zaner asks, what matters in fetal surgery:³⁶ a perspective I decided to pursue in my attempt to understand women's experiences and decision-making. I chose face-to-face interviews, rather than a questionnaire or a phone interview for several reasons. I was not looking for information, in the sense of answers to specific questions that one could expect to learn through questionnaires or surveys. I was looking for reflections on and descriptions of experiences, trying to understand how women talked about and thought about their decision-making for open-uterine surgery to repair spina bifida. From my experiences and training in clinical ethics consultation, as well as from the literature on ethics consultations for this procedure,³⁷ and the interviewing resources from reflexive sociology³⁸ I began on the assumption that the task of understanding – of identifying, observing, and analyzing what matters – would be more likely to succeed if undertaken together, in person, face-to-face in a conversational setting. As sociologist Kathy Charmaz explains

³⁶ Zaner, "Discovering What Matters in Fetal Surgery," 2.

³⁷ Bliton, "Imagining a Fetus," 397-398; Bliton and Zaner, "Cutting Edge," 349-350.

³⁸ Pierre Bourdieu and Loïc J. D. Wacquant, *An Invitation to Reflexive Sociology* (Chicago: University of Chicago Press, 1992)115-139; Pierre Bourdieu, "Understanding," in *The Weight of the World: Social Suffering in Contemporary Society*, ed. Pierre Bourdieu (Cambridge, UK: Polity Press, 1999), 607-625.

Entering the phenomenon means being full present during the interview and deep inside the content afterwards. Not only does this focused attention validate your participants' humanity, it also helps you take a closer look at what you are gaining. Entering the phenomenon means that you care to sense, feel, and fathom what having this experience is like, although you enter your participants' lives much less than the ethnographer does... we enter phenomenon to discover what is significant from the viewpoints and actions of people who experience it.³⁹

I approached interviewing as an effort in discovery and co-creating – in the listening to and sharing the significance of an event or experience.⁴⁰

I decided to conduct the interviews in each woman's home, rather than at the central location of VUMC for two main reasons. First, to avoid the power and violence of intrusion reinforced by location – physical and social.⁴¹ Asking women to come to a research facility, where they were once part of an experimental protocol, to participate in a different, though related, research project created the unacceptable possibility of seeing the women as research objects, even while attempting to create the possibility of open communication.⁴² Second, conducting the interviews in women's homes allowed them to control my access in terms of location and length of the interview, while allowing them to remain in a setting where they are (presumably) comfortable. Conducting the interviews in their home or office would be more of a physical intrusion, but it re-emphasized that I

³⁹ Kathy Charmaz, "Premises, Principles, and Practices in Qualitative Research: Revisiting the Foundations," *Qualitative Health Research* 14, no. 7 (2004), 981.

⁴⁰ *Ibid.*, 981; Zaner, "Voices and Time: The Venture of Clinical Ethics," ; Zaner, "Phenomenology and the Clinical Event," 39-66.

⁴¹ Bourdieu, "Understanding," 610-611; Clarke, *Situational Analysis* 2-10, 52-59.

⁴² Bourdieu, "Understanding," 611-612; Clarke, *Situational Analysis* 74-75.

would be a guest in their lives, who asked to be invited in and who would leave at their request, who wants to understand rather than exploit their experiences.⁴³

A similar concern for understanding and minimizing the potential violence of the research setting led to my decision to ask for interviews with the women who considered the procedure rather than with the women and their partners. A constant concern in the ethics literature centered around whether the pregnant woman might feel coerced into undergoing open-uterine surgery to repair spina bifida, even by her spouse or significant other. The dominant, though disputed,⁴⁴ strategy for protecting her autonomy was that each woman would be given the opportunity to speak to health care professionals or ethics consultants alone.⁴⁵ More compelling than the professional arguments for protecting women's autonomous decision-making, however, was the recognition in the "Parental Voices" accounts that the pregnant woman's experience was qualitatively different than her partner's.⁴⁶ As Alfred Lyons wrote in his "Parental Voices" essay,

⁴³ Zaner, "Phenomenology and the Clinical Event," 43-47, 55-58.

⁴⁴ Bliton and Zaner, "Cutting Edge," 351-352; Chervenak and McCullough, "Comprehensive Ethical Framework," 12-13; Edmund G. Howe, "Unicorns, Caravaggio, and Fetal Surgery," *Journal of Clinical Ethics* 12, no. 4 (2001), 337-339; Howe, "Ethical Issues," 446-457.

⁴⁵ Disputed because such a strategy imposes the medical model of individual decision-making as normative, which disregards the social (familial, communal) process of decision-making that most women used. Women face potential coercion if they cannot speak freely in spouses or family AND potential coercion if they are separated from their support systems by medical models of decision-making and informed consent procedures that demand conformity: a dilemma which only highlights their multiple vulnerabilities. I chose to impale myself on the 'need to speak freely' horn of the dilemma and offer women the chance to tell their stories without spouses or partners present.

⁴⁶ Gonzalez-Abreu, "Parental Voices: For Angeline:," 517-526; Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 527-533; Kennedy and Kennedy, "Parental Voices: Our Journey of Grace," 534-539; Lyons, "Parental Voices: One Parent's Thoughts," 540-547; Williamson and Williamson, "Parental Voices: The Positive Impact of Medical Professionals," 512-517.

It became more and more apparent that Karen and I were on the same journey but experiencing it in different ways. Her experience was profoundly visceral and personal. She was actually carrying the baby and would undergo the surgery, should we elect to proceed with in utero intervention...I found myself in a supportive role...⁴⁷

The concern for offering each woman an opportunity to speak freely of her experiences, and the recognition that her experience was a deeply personal, embodied experience from the moment of diagnosis to decision, led me to offer the interview to the woman alone, to give her a chance to tell her story as she was primarily affected, at least physically and possibly emotionally as well.

Finally, I included an offer to each woman to pay for childcare during the interview. I was not certain, prior to first contact with each woman, how much her child with spina bifida, or other children, might know about her experience with and decision around the procedure. The "Parental Voices" articles and websites for the procedure indicated that experiences with decision-making for this procedure were difficult, including considerations of abortion, responses to disability, and responses of family and community. I wanted to limit the possible emotional harms to families if disturbing conversations were overheard or shared by the child with spina bifida or other children in the household, so I offered to pay up to \$75 for childcare during the interview.⁴⁸

⁴⁷ Lyons, "Parental Voices: One Parent's Thoughts," 542.

⁴⁸ In addition to the \$50 I offered as compensation for each woman's time during the interview, funding for this compensation, for childcare reimbursement, and for my travel expenses came from a \$2000 grant from the Vanderbilt Institute for Clinical and Translational Research or VICTR program (#VR300 Women's Experiences with Medical, Ethical and Moral Issues of Open-Uterine Surgery to Repair Spina Bifida, 09/04/2009).

Identifying and Contacting Participants

My potential participants were the women who came to Vanderbilt University Medical Center to consider the elective, experimental procedure between 1996 and 2003, before the beginning of the MOMS trial.⁴⁹ During the experimental protocol, 230 women came to Vanderbilt University from all over North America⁵⁰ to be evaluated, to learn about spina bifida and the surgery, and to decide whether to undergo the procedure. 177 women chose to have the surgery, and 53 women chose not to have the surgery. I wanted to learn about the variety of women's experiences with and decision-making about open-uterine surgery to repair spina bifida,⁵¹ not just from those who chose the surgery and those who endorsed the procedure.⁵² This meant that I might have contacted women who did not want to be contacted, who did not want any further involvement with Vanderbilt University or open-uterine surgery to repair spina bifida, whether because they regretted

⁴⁹ There were two reasons for not contacting MOMS participants. First, Bliton, Churchill and others proposed the inclusion of an ethics / decision-making component in the MOMS trial's evaluation of open-uterine surgery to repair spina bifida. The proposal was turned down, and it was unlikely that a dissertation-level research proposal would have been approved mid-trial. Second, after the MOMS trial concludes, if open-uterine surgery to repair spina bifida is offered at all, it is likely to be offered as an elective procedure, just as it was before the MOMS trial. Therefore, the insights and experiences of women who considered the procedure *as an elective procedure* are most likely to be helpful to clinicians offering and women considering the procedure in the future.

⁵⁰ Women came from almost all fifty states, Puerto Rico, Canada, Mexico, and even the United Kingdom. Source: Personal communication with Mark J. Bliton, 4/2009.

⁵¹ Blizzard, *Looking Within* 54. Blizzard argues that "it will be informative to cast a wider net and identify and interview women who chose not to undergo the procedure, just as it will be particularly useful to interview women who wanted the procedure but could not afford it or were denied its use in the manner desired."

⁵² If I only contacted those who had already publicly spoken or created websites, I risked reaching only a biased population. It is likely that those who did contact me contacted me because they had good outcomes or were content with their decisions. Contacting a sample from the elective series, however, kept open the possibility and the opportunity for women with different experiences to participate if they so chose.

their decision, lost their child, chose termination of the pregnancy after their visit to Vanderbilt, or any number of imaginable reasons. Even though I designed the interviews to create minimal disruptions in the lives of the women I sought to interview, there was no avoiding the ethical implications and pitfalls of my intrusion into their lives *just by inviting participation*,⁵³ let alone the intrusion, however brief, of entering their homes and lives. On the one hand, I risked causing harm by bringing up experiences long since buried, forgotten, or even just integrated into their lives and I risked probing too deeply into difficult, possibly upsetting topics. On the other hand, I was offering an opportunity to tell their stories, to communicate with me and through me, with others, about what mattered to them in this crucial experience. One of the first challenges, then, was determining how to contact women and invite their participation with minimal interruption, or in a way that allowed them to ignore the invitation if the risks and disruption were too great.

The least invasive means by which to contact women, and one which required only limited access to Protected Health Information (PHI), was by contact through the United States Postal Service. I sent letters⁵⁴ describing my research and my goals of identifying the experiences, concerns, and decision-making for open uterine surgery to repair spina bifida. I invited women who had considered the procedure during the elective, experimental protocol to contact me if they were interested in talking about their experiences by participating in my research.

⁵³ Bourdieu, "Understanding," 608.

⁵⁴ The letters were generic so as not to indicate whether the recipient had surgery or not in case someone other than the intended did receive them.

I sent letters to women within a roughly 600-mile radius of my location in Nashville, Tennessee, or roughly the equivalent of a one-day drive. This meant that my initial round of letters went to 69 women within a 9 state radius of Nashville.⁵⁵ From the first round of letters, 25 letters came back “return to sender” and with 13 of those, I was able to identify a more recent address and resend the letter, so presumably, 57 letters found their intended recipients. In total, 12 women contacted me, via phone or email, about the research project and 11 initially agreed to the interviews. If they emailed, we arranged time for a brief phone call. If they called, we did the preliminary conversation at that time.⁵⁶ In the initial call, I read a brief description of the study and asked each woman if she wanted to participate. I then asked some brief demographic questions (see Appendix B) about her child with spina bifida and her family, which often led to a short narrative of her experiences and identified some themes that would emerge again in our face-to-face interview. The preliminary phone conversations often offered clues to what mattered or to themes that I should pay attention to if they arose again. Finally, after asking if she had any questions for me and if she still wanted to participate, the woman and I arranged for a time and place to meet, most often in her home.⁵⁷ After the phone conversation with each participant, I immediately assigned her a pseudonym, wrote a

⁵⁵ I included the option in my IRB proposal to send a second round of mailings if I did not receive enough responses, but that precaution was unnecessary.

⁵⁶ As a brief note on research, the recruitment phase was an interesting time in the sense of having to be prepared at all times for phone calls that required significant attention and orientation, not unlike the interviews themselves. The somewhat novel experience to have to be instantly ‘on’ if participant called is an example of the challenges of careful research, and also is an apt example of the attention, orientation, and readiness required of ethics consultation. This theme will be explored further in Chapter VII below.

⁵⁷ In six out of eight interviews: Interviews 1, 3, 4, 7, 8, and 11 were in home. Interviews 5 and 9 were in public locations – the participant’s office and a restaurant, respectively.

verbatim account of our conversation, scrubbed all identifying features from emails and verbatims, and entered the family data from the questionnaire into the RedCAP survey software.⁵⁸

The final step in contacting each woman who agreed to participate was preparing myself for the interview itself by reviewing each woman's verbatim and questionnaire data, going over the open-ended interview guide, and reflecting on the method of inquiry in which I was engaged. I reminded myself that the issues we would be discussing mattered to these women in deeply personal ways that I may not understand, but that the discipline, the effort, the method was towards understanding.⁵⁹

Interviewing and Analyzing: The Need for Method

The interviews were designed to be recorded, one-on-one conversations, which could be analyzed for key themes in women's experiences with decision-making for open-uterine surgery to repair spina bifida. In my research proposal design, after reviewing informed consent documents, which contained a description of the project, goals, and protections (see Appendix C), I would begin by asking each woman to tell me

⁵⁸ Vanderbilt University (VUMC), "Redcap Survey," (Nashville, TN: Vanderbilt University, 2008), 1. "RedCAP Survey is a web-based tool for building and managing online surveys. This product was designed to provide our research users with an alternative to Survey Monkey and similar services where data are hosted outside the university."

⁵⁹ I am indebted to my mentor and dissertation director, Mark J. Bliton for the multiple lessons on attunement in ethics consultation. Before my first 'solo' consultation, he reminded me 1) that these decisions are important for families in ways that in the end, I will not be able to fully understand, let alone appreciate, 2) that it is okay for the 'family face' to be presented and maintained, because emotional armor serves a purpose, and 3) that I have to risk misunderstanding in profound ways, and yet, I have to try to understand. These attunements proved helpful time and again in consultations, and in the interview conversations I had during my research. Personal communication with Mark J. Bliton, 5/12/08.

her story from the beginning, whatever she wanted to tell me, and use the interview guide to probe key themes or areas where she might elaborate.

This *methodology* was both appropriate and inadequate – it worked, and yet its limitations opened up and highlighted the need for attention to what I understand as *method* in conducting this research. I anticipated some disjuncture between my methodological preparation and the actual experience of the interviews. However, though I researched, read about *method* and *attunement*, and strategized ways of being attentive, each interview exceeded the design in ways that called for reflective interaction on my part, as the interviewer trying to learn from the difficult presentations by and in conversations with each woman.

I designed the interviews, for example and as discussed above, to include only the women. This design was based on the idea that first, she was most directly affected physically and perhaps emotionally and socially as well,⁶⁰ and second, that it might be easier for her to speak freely about some of these experiences or difficult emotions without her partner or child(ren) present. Theoretically and methodologically sound, this design required constant evaluation and adjustment in the interviews. Four of my eight interviews were one-on-one interviews with the women who considered the procedure, as per my research design. In the other half, the woman had a spouse, a parent, and / or her child(ren) present – observing, contributing to, and distracting from the “interview” as designed, but adding rich layers and complexity to the experience and to the understandings I gained. The interviews demanded attention to what each woman intended to share more than attention to what I intended to learn. Some interviews, for

⁶⁰ Darling, "Parents, Physicians, and Spina Bifida," 10-11; Kirpalani and others, "Quality of Life in Spina Bifida," 293-297.

example, were solely conversational, as designed. In others, the women showed me scrapbooks and homemade videos that they used in community or religious educational settings. They gave me copies of birth announcements explaining their child's spina bifida and the results of in utero surgery, or copies of magazines where they gave interviews about their experiences. They took me around their homes to show me the modifications they put in to support their child's mobility, independence, and inclusion in family activities. They invited and welcomed me in to their experiences in ways that exceeded my carefully constructed interview designs, and my methodological resources could not account for such intimate encounters with participants. The actual interviews demanded a reflexive method of responding to each woman in each encounter, as she presented herself and told her story.

Though I planned on beginning and conducting my analysis along with or at the same time as I conducted the interviews, that relationship between interviews and analysis became more complex and the line between them grew blurry in the experience of research. Situational analysis, based as it is in grounded theory, encourages simultaneous or ongoing "constant comparative analysis" and thematic coding, whereby the researcher immerses herself in the data (transcripts, documents, etc) continuously coding and identifying themes from one transcript or field-note or document to the next.⁶¹ I intended to follow this methodological practice from one interview to the next, making use of my earlier document analysis and the verbatim texts from phone calls with each woman. I was also aware, however, from my readings on method that analysis was a critical piece of method oriented towards understanding – and so I began considering

⁶¹ Clarke, *Situational Analysis* 1-36; Nancy Press, "Qualitative Research: Thoughts on How to Do It; How to Judge It; When to Use It," *Genetic Medicine* 7, no. 3 (2005), 157-158; Strauss and Corbin, *Basics of Qualitative Research* 55-71.

how attention to method might enrich and prepare me for the actualities experienced in using my methodologies. My reflections on method rely on key themes from Pierre Bourdieu, Richard Zaner, William James, and Alfred Schutz, and strive towards understanding both in conducting the qualitative interviews with women and in analyzing the data, the stories that emerge.

CHAPTER V

METHODS IN ETHICS

Before my first interview, I had progressed through all of my methodological work – preliminary research, design, contact and recruitment, and even some of the initial phone conversations with participants. The attention to methodological concerns through each stage of research design created the possibility for successful interviews and a richly productive qualitative research project. Yet, each activity also provided occasion to encounter the limitations of methodology for preparing me, as a researcher, to conduct the actual interviews, and to analyze and report on the stories that would emerge. The question of method emerges, then, first as a question of method for conducting the interviews, of listening to others' stories, second, a question of analyzing that content, and third, a question of reporting on the data, or retelling others' stories. In particular, these are questions of attention and of preparation, questions of reflection and learning, and questions about retelling the other's story in ways that promote understanding, not just the gathering of facts: questions that made my research project a social and a moral endeavor as well.

The initial phone conversations, for example, put these questions of method into sharp relief before my first interview took place. Each woman sounded uncertain and hesitant when asking about participation in the project and yet most also sounded eager, even anxious to speak about their experiences, responding to broad questions in great detail and with rapid, pressured speech, telling me more than I had asked in the limited

and specific phone questionnaire. I had initially designed the interviews to be open-ended, to encourage each woman to tell her own story and to emphasize what she found to be important in her experiences. Yet, the combination of eagerness and hesitancy in each of the initial phone conversations heightened my awareness of each woman's multiple vulnerabilities and raised the question of how to conduct or participate in the interviews responsibly. What might be fitting ways to ask them about what was important in their stories in the interview? How could I identify what mattered in the systematic analysis of the interview data? Even more challenging, to what extent could I retell significant portions of each women's story, while remaining intentionally aware of and taking account of the vulnerabilities she describes and demonstrates? To foreground that awareness and effort towards taking account, I tried to think in terms of method, understood initially as a set of reflective practices that would help me remain open to and possibly better understand these women's stories about their experiences with open-uterine surgery to repair spina bifida.

Taking cues, and clues, from my previous experiences in a series of clinical ethics consultations, there seemed to be important similarities between the conduct of an ethics consultation – specifically the issues, concerns, and questions elicited in that sort of conversation – and the conduct of research interviews that might elicit a significantly similar set of themes to identify and interpret.¹ Just as ethics consultations seek to identify and remain faithful to significant moral factors found in the complex layering of contexts, values, and persons found in real clinical encounters, in the role of interviewer I

¹ Some of these themes – the importance of diagnosis experiences, faith, and framing decision-making – have been established already in Chapter III, and served as part of my preparation and attunement for this research into moral experience and decision-making. These themes, and others, will be further described and illustrated in Chapters VI and VII below.

would experience the complexities of each interview situation and seek to learn by interacting with these women through careful listening and alert observation, as well as by asking my own questions. Identified by Richard M. Zaner as a kind of *attunement*, this practice has parallels in Pierre Bourdieu's work on understanding in reflexive sociology, which will be explored in the sections that follow. Bourdieu and Zaner share a concern for inquiry where we learn by trying to identify and possibly understand certain themes and activities, all the while reflectively considering whether or not, and how, the actual circumstances and directions of the conversation – and its meanings – change in those interactions. Learning about both clinical and interview situations, then, and incorporating insights from each, required an appreciation for the moral meanings associated with this kind of inquiry into women's experiences and beliefs.

The idea of attunement conveys such an embodied sense of engagement within a situation – and with the others in that situation – including feelings, senses, past experiences, and physical presence. Attunement places significant emphasis on social relations, intimacy, and intersubjectivity, as important elements for acquiring knowledge or information. To prepare myself for conducting interviews with the women who considered open uterine surgery to repair spina bifida, I carefully read key selections from both Pierre Bourdieu's work on reflexive sociology and understanding, and Richard M. Zaner's work on phenomenology and clinical ethics consultation. Each offers a method for attunement – of reflective orientation – that moves beyond seeking *answers* to the pursuit of an ever-elusive but possible *understanding* of another's experiences. In the sections that follow, I will consider each of their reflections on method for social and moral encounters in interviews and ethics consultations. For the remainder of the chapter,

I will consider the method of preparation for analyzing and understanding interview data about women's experiences and decision-making. In particular, the sociological and phenomenological elements found in the work of William James and Alfred Schutz help me understand key features and structures in decision-making that can identify and signpost important themes emerging from the interview data. The third question of method, storytelling, will be discussed in Section III, alongside the stories women shared.

Method and Conducting Interviews

Pierre Bourdieu: Reflexive Sociology and "Understanding"

Pierre Bourdieu, a French sociologist, anthropologist, and philosopher devoted a significant portion of his work to evaluating and challenging traditional methodological concerns in social science research, including what he saw as a "methodologism" that divorced concern for method from the actual circumstances of research.² In particular, through one of his later essays on "Understanding," Bourdieu is helpful in thinking about both the activities and experiences of the researcher in the research relation, and in thinking about methods for analyzing and conveying the meaning participants assign to their experiences.

Bourdieu's key sociological insight is that research itself is inherently and unavoidably social and, as such, its activities include the potential violence, dominance, and distortion that occur in typical, often asymmetrical, social settings. One of his goals in calling for a reflexive sociology is to bring awareness to and develop strategies to

² Bourdieu, "Understanding," 607.

counteract those potential distortions. He asks the researcher to be aware of the ways her social location affect the interview and to be aware of the intrusion of her presence in the life of the research participant. Bourdieu suggests deliberate efforts to minimize those effects, through matching the socio-economic and other aspects of ‘cultural and linguistic capital’³ between interviewers and interviewees to counteract power asymmetry.⁴

In my project, there was no way to balance the age, economic, or educational differences between me and the women I interviewed, but I took Bourdieu’s injunction seriously in designing the interviews and preparing myself to enter each woman’s home. I let the interviewee determine the location of our interview (in home, at her office, in a public place), as well as our physical locations during the interview. In some interviews we sat at the kitchen table (Interviews 1, 3) or across a conference room (Interview 5), in others, we shared a couch or faced each other, sitting in living room chairs (Interviews 4, 7, 11), in still others, we conducted the interview in an unmistakably social encounter of a shared meal (Interviews 8, 9). Though Bourdieu says the interviewer sets the rules of the interview,⁵ one primary rule I established was to let the women determine how and where they would be most comfortable speaking with me.

For Bourdieu, one crucial set of concerns rests with the need to explore the researcher’s impact on communication and understanding within the actual interviews. In describing the activity of paying careful attention to the circumstances at hand, to monitoring one’s own influence – intentional or unintentional – Bourdieu calls for

³ Ibid., 608.

⁴ Ibid., 608, 610-613.

⁵ Ibid., 609.

not only the reflexivity synonymous with method, but a *reflex reflexivity* based on craft, on a sociological ‘feel’ or ‘eye,’ [that] allows one to perceive and monitor *on the spot*, as the interview is actually taking place, the effects of the social structure on that which is occurring.⁶

He asks for active and methodical listening that takes into account the differences in perceptions between the interviewer and interviewee, as well as differences in the “cultural and linguistic capital” each brings to the conversation. For Bourdieu, this type of research relationship

combines a total availability to the person being questioned, submission to the singularity of a particular life history: which can lead, by a kind of more or less controlled interaction, to adopting the interviewee’s language, views, feelings, and thoughts – with methodical constructions, founded on the knowledge of the objective conditions common to the entire social category.⁷

All of which means, at minimum, that the researcher should not enter the research relationship without a willingness to share her own biases and a reflective humility regarding her own biases about the experience the project, and its questions. She also needs a substantive idea of the goals of the interview, and a more than basic knowledge of objective conditions of the participant – the social as well as the material contexts of the participant’s experience. The researcher ought not enter an interview with preconceived expectations about what has meaning and how, but neither ought she enter the interview without significant preliminary or background knowledge of the situation or experience. In other words, the interviewer has a responsibility to prepare herself for learning *from* the interviewee by learning *about* the interviewee’s circumstances.

A responsible and effective interview relationship requires some effort towards situating oneself in the place of the interviewee. In my project, this preliminary work

⁶ Ibid., 608.

⁷ Ibid., 609.

began in the early stages of research – including reviewing the professional medical and ethical literature as well as the various personal accounts in the “Parental Voices” journal and online. It continued through constant comparative analysis of the themes emerging from these accounts in addition to reviewing the verbatims and field-notes from each woman’s phone conversation before our face-to-face conversation. Bourdieu insists that

This preliminary process of information gathering is what enables constant improvisation of pertinent questions, genuine hypotheses based on a provisional, intuitive representation of the generative formula specific to the interviewee, in order to push that formula toward revealing itself more fully.⁸

Being aware of and attuned to as many possible meanings as are available – through research, past experiences, and imagination – creates the possibility for understanding to emerge. Or, as Bourdieu explains, “...it is only when it rests on a prior knowledge of the realities concerned that research can bring out the realities it intends to record.”⁹ The researcher is committed to and responsible for preparing herself for the interviews through information gathering and reflection on previous experiences.

For Bourdieu, the possibility of bringing out the realities of a social experience emerges only through the open communication established in a well-constructed interview. The researcher’s method of preparation, of attunement described above – awareness of one’s effects, active listening, and preliminary work – enables the research participant to speak of his or her experience in a unique encounter. Bourdieu explains,

By offering the respondent an absolutely exceptional situation for communication, freed from the usual constraints (particularly of time) that weigh on most everyday interchanges, and opening up attentions which prompt or authorize the articulation of worries, needs, or wishes discovered through this very articulation, the researcher helps create the

⁸ Ibid., 613.

⁹ Ibid., 618.

conditions for an extra-ordinary discourse, which might have never been spoken, but which was already there, merely awaiting the conditions for its actualization.¹⁰

The carefully constructed interview, along with the researcher's attunement, creates a time and a space where the interviewee can, possibly, reflect on and clarify her understandings of her experiences. Bourdieu describes some of his interviewee's self-analysis:

We had the feeling that the person being questioned took advantage of the opportunity we offered for self-examination and took advantage of the permission or prompting afforded by our questions and suggestions (always open-ended and multiple, and at times reduced to a silent wait) to carry out the task of clarification – simultaneously gratifying and painful – to give vent, at times with extraordinary *expressive intensity*, to experiences and thoughts long kept unsaid or repressed.¹¹

The *expressive intensity* that Bourdieu describes, and that I experienced in those first phone conversations with my participants, offers the researcher intimate access to the participants' self-understandings of, stories about, and the meanings of their experiences. It also places an increased responsibility on the researcher in terms of telling those stories and relating those experiences to others.

The entwined questions of analysis and reporting are among Bourdieu's final concerns in "Understanding"¹² and, as we shall see, are among the primary concerns for Zaner's phenomenology in the clinical encounter.¹³ The task, for Bourdieu, is to represent

¹⁰ Ibid., 614.

¹¹ Ibid., 615.

¹² Ibid., 622-626.

¹³ Richard M. Zaner, *Ethics and the Clinical Encounter* (Englewood Cliffs, NJ: Prentice Hall, 1988) ; Richard M. Zaner, *Troubled Voices: Stories of Ethics and Illness* (Cleveland, Ohio: Pilgrim Press, 1993) ; Richard M. Zaner, "On the Telling of Stories (Unpublished Draft)," in

the stories and self-understandings of participants as clearly, fairly, and movingly as possible – to do justice to their experiences and reasons while critically engaging those experiences and reasons.¹⁴ He presents the potential of the transcribed interviews to “touch and move the reader, to reach the emotions, without giving in to sensationalism, they can produce the shifts in thinking and seeing that are otherwise the precondition for comprehension.”¹⁵ Bourdieu offers specific strategies for transcribing interviews and publishing the transcripts, including headers, prefatory remarks, and editing linguistic ‘tics.’¹⁶ Through precise attention to the details of transcription, Bourdieu explains,

We have therefore striven to transmit to readers the means of developing an attitude towards the words they are about to read, which will make sense of them, which will restore the respondent’s *raison d’être* and their necessity; or more precisely, to situate themselves at the point in social space at which all the respondent’s views over that space emanate, which is to say that place in which this particular worldview becomes self-evident, necessary, taken for granted.¹⁷

Eliciting participants’ stories and experiences, by inviting their participation in the interview, the researcher takes on responsibility for how the stories, experiences, and meanings shared by her interviewees are analyzed, represented, and retold in other venues. Bourdieu notes that the researcher is always already constrained by or oriented by the interpretive schemes of participants and by their own perspectives, but the same

Ethics Histories in Clinical Medicine: Essays in Honor of Richard M Zaner, ed. Osborne P Wiggins and Annette Allen, Philosophy and Medicine (Springer, 2010),.

¹⁴ Bourdieu, "Understanding," 623. Zaner is also keenly aware of the problematic characteristics encountered in such a task and in his later work, he explored the possibility of writing narratives as a way to express faithfully the details of these experiences. See below, pp 164-166.

¹⁵ *Ibid.*, 623.

¹⁶ *Ibid.*, 622. As Bourdieu explains, “Transcription, then, means writing, in the sense of rewriting. Like the transition from written to oral that occurs in the theater, the transition from the oral to the written, with the changes in medium, imposes infidelities which are without doubt the conditions of a true fidelity.”

¹⁷ *Ibid.*, 625.

method of preparation that evoked such stories during the interviews is necessary in the creative yet faithful presentation of those stories. With the awareness of one's effects on a particular circumstance or reading, active 'listening' to the text as to the person, and preliminary work that involves imagining possible meanings the attunement, the method of research continues from interviews to analysis and reporting.

Bourdieu offers a way of thinking *beyond* the methodological concerns that are so important for project design *toward* the methods of preparing oneself to engage in and enact the research in relation with the participant or interviewee. In thinking through my project, I share Bourdieu's concern for understanding and being deliberate about my self-presentation as a researcher, my communications with my participants, and the public representations of my research before, during, and after each research encounter. A similar method of attention and deliberation, of *attunement*, emerges in Richard M. Zaner's work on phenomenology of the clinical encounter, and provides a second frame for thinking about and preparing myself to elicit, analyze, and represent women's stories and experiences with open-uterine surgery to repair spina bifida.

Richard M. Zaner: Phenomenology, Clinical Ethics, and Telling Stories

Richard M. Zaner, a phenomenologist and clinical ethicist, was instrumental to the development of the ethics consultation process for Vanderbilt's open-uterine surgeries to repair spina bifida.¹⁸ Zaner also frequently turned his phenomenological analysis toward the method, the *practice* of clinical ethics consultation. His reflections on the

¹⁸ Zaner, *Troubled Voices* ; Zaner, "Phenomenology and the Clinical Event," ; Richard M. Zaner, *Conversations on the Edge: Narratives of Ethics and Illness* (Washington, D.C.: Georgetown University Press, 2004)

complex interactions of clinical ethics consultation parallel many of Bourdieu's concerns for reflexivity, point to ways attunement can open understanding in social interactions, whether in clinical ethics consultations, interviews, or data analysis. Zaner also poses questions about his responsibility for the stories and experiences shared by others throughout his years as an ethics consultant.

I am here examining Zaner's focus on ethics consultations in close connection with Bourdieu's works on sociological interviews because both demand reflective attention to the actual circumstances, to relationships within the circumstances, and to awareness of one's own actions in light of the power inherent in either role – clinician or researcher. Both are concerned with appropriate engagement in their work and with reflecting on and learning from that engagement. For Zaner, as an example, the ethicist's task has both therapeutic and philosophical aspects.¹⁹ In the first aspect, the task is discovering what matters in *this* set of circumstances for *these* participants and in the second, the task is reflecting on each circumstance as an *example* from which further understanding and additional meanings about the practice *and* the circumstance can emerge. These concerns are crucial for my methods of research and for my areas of research – moral experience, understanding, and ethics consultations.

Clinically presented problems, moral issues, alternatives, and outcomes are *context specific* and require, according to Zaner, “a strict focus on the *situational definitions* of each involved person.”²⁰ This means the ethics consultant must clarify not only who is involved and why, but what they understand about the situation and what meanings they assign to the various features of the circumstance as a whole. As Zaner

¹⁹ Zaner, "Phenomenology and the Clinical Event," 39-40.

²⁰ *Ibid.*, 40.

explains, “To understand the clinical situation, there is nothing for it but to try one’s best to get at the concrete ways the participants themselves experience and understand the situation, and endow its various components (objects, people, things, relationships) with meaning.”²¹ Zaner points out that in clinical situations,

Moral issues are presented for deliberation, decision, and resolution solely within the contexts of their actual occurrence. To find out and understand what’s going on in any clinical event – what’s troubling the people, what’s on their minds, and thus to know what has to be addressed and how – requires cautious attentive probing of their ongoing discourse, conduct, the setting, and other matters presented as constituting the specific context.²²

Like the improvisational questioning in Bourdieu’s interviews, such probing, discovering what matters, is a challenge that requires the ethicist to be *attuned* to, sensitized to the broader circumstances in which participants’ experiences or stories emerge. The sensitizing or attunement occurs through “fertilizing one’s imagination” with previous experiences and free-phantasy variation,²³ drawing from multiple sources such as literature, history, and music, and most importantly, other persons involved in the experience – similar to the elements of Bourdieu’s preliminary research. Zaner’s lesson for my project is to reinforce and make even clearer the importance of deliberate attunement to the other who tells me of her experience, who makes meaning through her story. As Zaner explains,

²¹ Ibid., 40.

²² Ibid., 40.

²³ Bliton, "Imagining a Fetus," 393-394; Zaner, "Phenomenology and the Clinical Event," 53-54. Free-phantasy variation is the term for imaginatively varying the features of a presented situation or circumstance to make clear which features are constant and essential. I maintain the phenomenological spelling, versus “Fantasy,” to maintain the distinction between imaginative phantasy and common understanding of fantasy as unreal or false.

The people whom I met in these clinical encounters sought not only to tell me and others what they were going through, with all their uncertainties and ambiguities, but wanted me to listen while at the same time helping them assimilate their sense of themselves and their beliefs.²⁴

Zaner describes ethics consultations where people tried to process how complex information and changing circumstances fit in with their beliefs and experiences, or changed the possibilities and choices they faced. Though I was asking women about their past experiences, in some cases a similar process emerged of working through those uncertainties and ambiguities, of working through that process of assimilation again. Elements of their experience, such as the decision or the surgery itself, were in the past, yet in our interviews, the women reflected on those elements as part of an ongoing story, a continuing experience with spina bifida and their decision about choosing prenatal or post-natal repair. Zaner describes the attunement or preparation, from information gathering to opening oneself to the uncertainties and ambiguities of the other's story, as a necessary part of clinical ethics consultation. It also became a necessary part, in my research, of understanding women's experiences with maternal-fetal surgeries.

Ethics consultations often involve helping people make sense of their experiences in the midst of complex familial, clinical, or professional relationships. Thus, attunement also includes creating a deliberate openness to as many available meanings, ambiguities, and uncertainties in an experience as possible. Zaner notes that the ethics consultant enters an ongoing relationship between patient and physicians, which also may include other family members, community members, or other health care providers. His reflections on the relationship between and practices of physicians and patients emphasize the ethics consultant's focus *is on that relationship* as it is shaped by each

²⁴ Zaner, "On the Telling of Stories," 18.

participant's biographical situation, their experiencing of and interpreting of each other, and their own interpretations of their relationship. These complex relationships, in particular the patient-physician relationship, need attention on their own, as well as in relation to the questions or issues of the situation because *each participant* brings her own unique meanings, circumstances, and social location to the relationship.²⁵

The complexity of such clinical encounters makes the ethics consultant's job, according to Zaner, part detective work, part enablement and empowerment. He describes his task as helping participants

identify what is at issue for each person, to help each become alert to and consider their respective moral frameworks; to help delineate, weigh and imaginatively probe the available options that are most reasonable and fitting within those respective frameworks; and to help each attain clarity about the 'stakes' so as to enable them to live with the outcomes or aftermaths of needed decisions.²⁶

Important questions can be raised about what kinds of activities might contribute to the enablement and empowerment that Zaner includes as part of ethics consultation. In this way we see parallels between Zaner's work on ethics consultation and Bourdieu's work on interviews: the method is less prescription than orientation. Zaner emphasizes suspending or bracketing typical understandings to attend to the particular circumstances

²⁵ Bourdieu and Zaner both point to the asymmetry of social relationships. Bourdieu points to the asymmetry of the researcher-participant relationship, while Zaner observes that the patient-physician relationship is marked by asymmetry (the physician's knowledge and skills, the patient's ignorance and incapacity), the patient's radical vulnerability from illness, and the necessity of profound intimacies – physical, emotional, and social – that treatment often requires, and that often take place between or among strangers. Zaner describes several shifts, from recent decades, in how participants understand the “inherently moral enterprise” of medicine, including a shift from unilateral to reciprocal decisions, a shift from power-over to power-with in decision-making, and awareness that the possibility for physicians to take advantage of their patients also includes the possibility for physicians to take care of their patients with restraint and wisdom. Zaner's concerns for asymmetrical power and calls for restraint are not limited to physicians, but are applicable to clinicians broadly understood, including ethics consultants. See Zaner, "Phenomenology and the Clinical Event," 41-45.

²⁶ Ibid., 47.

at hand. This shift of attention allows for the careful identification of the possibilities of and effects of uncertainty, error, and deception on understanding, and in that way is a key element of free-fantasy variation, which is a means of “possibilizing” the different understandings, decisions, and actions that may emerge.²⁷ These activities of careful and specific attention to the circumstances at hand create the possibility for the ethics consultant to “place oneself in the lived experience of the patient” – another complex set of activities that Zaner calls “affiliation.”²⁸ For Zaner, affiliation is a specific orientation towards and effort “to understand that woman’s circumstances from her own perspective, as she lives and understands it – disclosed contextually through her discourse, word choice, paralinguistic features, and bodily demeanor.”²⁹ Shared talking and listening is the method for and access to such understanding, and to reflect on the cases from which such talking and listening emerge “is to learn about moral life from the clinical circumstances of those who actually face difficult situations.”³⁰ This is, for Zaner, the method of clinical ethics consultation.

Many of Zaner’s concerns for method in clinical ethics consultation – the attention, the preparation, and the orientation, overlap with or are shared by Bourdieu’s concerns for method in interviewing, and so they were both crucial to my method for moral inquiry into women’s experiences with open-uterine surgery to repair spina bifida. Both Zaner and Bourdieu are interested in learning from their conversation partners, in not harming those partners, and in helping those partners. Their access – ethics

²⁷ Ibid., 49-52, 53-54.

²⁸ Ibid., 58-59.

²⁹ Ibid., 59.

³⁰ Ibid., 59.

consultations or sociological interviews – and what they expect to receive – understanding or data – shapes the priority given to each of those aspects.

For Zaner, ethics consultations are therapeutically oriented and he seeks to understand the experiences of his interlocutors. His focus is on helping, on not harming, and on the possibility of learning from others. Bourdieu, on the other hand, pursues interviews to gain data about particular human experiences. The emphasis in his work, then, is on learning from others, on not harming, and then, perhaps, on the possibility of helping.³¹ In my project, Zaner's work helps me critically engage Bourdieu's method for interviews because my interest, too, is in helping: by learning about what matters in women's experiences to help inform reflective practice in future encounters in ethics consultations. Zaner and Bourdieu each have different access going in to the experience of consultations or interviews, and ultimately each has different expectations of what should emerge. Nonetheless, the reflective practices outlined above were important influences for the development of my own method in this project.

While Zaner and Bourdieu focus on method in the intersubjective, social encounters of ethics consultation and interviewing, method is also required in the *analysis and reporting* of clinical work or research. The responsibility for the story of the patient, or research participant, then, is of crucial significance to both Zaner and Bourdieu, and to my work in eliciting, analyzing and presenting the stories of the women I interviewed. Method, as attention to circumstances, relationships, and activities of the clinician or researcher, in addition to focusing on the participant and her story, can bring

³¹ It is important to note that for Bourdieu's concerns about research, helping is understood in the broader social sense of identifying and illuminating social phenomena rather than in a therapeutic sense for a particular interview subject.

needed rigor to analyzing qualitative interview data and to telling the stories that emerge.³²

Method and Analyzing Interviews

William James and Alfred Schutz

Methodologically, analysis of interviews takes the form of multiple readings, iterative coding, and thematic memo-writing to highlight and categorize concepts.³³ In addition to these methodological activities, there is also a method of analysis. In my project, this method requires paying attention to how the women made sense of the experiences or, following Zaner, trying to understand and retell participants' stories faithfully and fairly, with attention to and focus on the stories as *their* stories.³⁴ My interviews produced particular kinds of understanding – stories and voices and moral themes – rather than a data set of answers to set questions. Making sense of those stories and experiences requires paying attention to each woman's emphasis, learning from what she focuses on in her story.³⁵ This method, both as a kind of attunement and appraisal,

³² Bourdieu, "Understanding," 608.

³³ Charmaz, "Premises, Principles, and Practices in Qualitative Research: Revisiting the Foundations," 986-988; Clarke, *Situational Analysis* 83-143; Strauss and Corbin, *Basics of Qualitative Research* 51-71, 87-99.

³⁴ Zaner, "On the Telling of Stories," 18.

³⁵ E.g. – women who preferred to focus on God's will vs. medical information as crucial for decision (TR 11), on normalizing disability rather than highlighting difference (TR 4), or highlighting difference in each child, rather than viewing disability as defective or negative (TR 8, TR 9).

contributes to and directs my analysis of women's experiences with and decision-making about open-uterine surgery to repair spina bifida.

In this light, I need to explain several themes in the philosophical and sociological work of William James and Alfred Schutz that provide helpful frames for analyzing and understanding the experiences of the women I interviewed. James and Schutz have a mutual concern for intersubjective understanding – the question of whether understanding another's motives and actions is possible – and both ask what contributes to those motivations and actions. They investigate how different elements, or structures of the social world – stocks of knowledge, biographical situation, and pragmatic beliefs – influence choice among projects of action. These investigations provide an access to and a framework for understanding others' actions, which, in my project, means identifying themes in those elements or structures *during* the interviews with women and *in* the transcripts of women's stories. As with the other stages of my research process, James and Schutz do not provide a specific procedure for analyzing the data, but instead offer a particular kind of preparation. Their analysis of the structures of belief and decision-making helped focus my "sociological eye,"³⁶ to be alert to the *types* of themes and elements that *might* emerge through the interviews, without predetermining or closing off which types *would* emerge.

³⁶ Bourdieu, "Understanding," 608.

Intersubjectivity

Schutz's work has been helpful, from the beginning of my analysis, in raising the possibility of understanding the experience of another human being, and of understanding one's own experience. Maurice Natanson, in his introduction to Schutz's *Collected Papers, Vol 1, the Problem of Social Reality*, describes intersubjectivity as Schutz's clue to understanding social reality, accessible by focusing on common-sense world of working.³⁷ Schutz is intrigued by the *possibility* that we could be in the world together and "grow old together,"³⁸ instead of existing as anonymous and incurious strangers. He explores the question of how we understand each other, including understanding our activities and the meanings those activities have for us and he uses the idea of interpretive understanding or *verstehen* to explain the possibility of intersubjectivity.

Schutz is concerned "with the understanding of social action as the meaning which the actor bestows upon his actions, i.e., the meaning his action has for him,"³⁹ and sees three issues that shape our interpretive understanding of the other. First, Schutz explores *verstehen* as an "experiential form of common-sense knowledge of human affairs," where humans in daily life interpret the world from the outset as meaningful, including the actions of others. At its root is the "general thesis of reciprocity of perspectives" or, more plainly, the idea that our standpoints are roughly, though not

³⁷ Maurice Natanson, "Introduction," in *Collected Papers of Alfred Schutz : The Problem of Social Reality*, ed. Maurice Natanson (The Hague: Martinus Nijhoff, 1962), xxx; Alfred Schutz, *Reflections on the Problem of Relevance* (New Haven,: Yale University Press, 1970)25-26.

³⁸ Alfred Schutz, "On Multiple Realities," in *Collected Papers of Alfred Schutz : The Problem of Social Reality* ed. Maurice Natanson (The Hague: Martinus Nijhoff, 1962), 220.

³⁹ Natanson, "Introduction," xxxiv-xxxv.

entirely, interchangeable, and that in general, we share a set of beliefs about the world similar enough to allow communication.⁴⁰ Natanson explains,

Motives and goals are as inescapably part of the other's behavior as they are of my own. When I encounter a man acting in the social world, I know that I must understand him as a human being, and this means that his actions mean something to him as well as to me, relative to his world as well as to mine, and are ultimately rooted in the interpretive scheme he has created for living... But this is typified and taken for granted.⁴¹

As Schutz scholar Ronald Cox explains, we take that intersubjectivity for granted and “for all practical purposes, we can get along together,”⁴² until and unless something comes along to raise questions about how we communicate in the first place.

The possibility of questioning the typifications and ‘taken-for-grantedness’ of such understanding raises the second issue: the philosophical and epistemological problem of interpretive understanding. For Schutz, intersubjectivity is rooted in and understood through the *lebenswelt*⁴³ or “the Life-world that encompasses the rich totality of common sense experience linked through by the individual in his concrete experience.”⁴⁴ Schutz explains,

⁴⁰ Ronald R. Cox, *Schutz's Theory of Relevance: A Phenomenological Critique*, *Phaenomenologica* (The Hague ; Boston: Nijhoff, 1978)18.

⁴¹ Natanson, "Introduction," xxxv.

⁴² Cox, *Schutz's Theory of Relevance* 18.

⁴³ Alfred Schutz, "Some Leading Concepts of Phenomenology," in *Collected Papers of Alfred Schutz : The Problem of Social Reality* ed. Maurice Natanson (The Hague: Martinus Nijhoff, 1962),136. Schutz describes the *lebenswelt* as derived “from things inherited and learned, from the manifold sedimentations of tradition, habituity and his own previous constitution of meaning, which can be retained or reactivated, his *store of experience* of his life-world is built up as a closed meaningful complex. This complex is normally unproblematical for him, and it remains controllable by him in such a way that his momentary interest selects from the store of experience these things which are relevant to the demand of the situation. The experience of the life-world has its special style of verification. This style results from the processes of harmonization of all single experiences.”

Our everyday world is, from the outset, an intersubjective world of culture. It is intersubjective because we live in it as men among other men, bound to them through common influence and work, understanding others and being an object of understanding for others. It is a world of culture, because from the outset, the life-world is a universe of significance to us i.e. a framework of meaning (*Sinnzusammenhung*) which we have to interpret...⁴⁵

How, then, do we interpret the meaning of our actions, let alone the meaning of another person's actions? And, if our interpretive understanding of the other is taken for granted in the life-world, can we explain the ways we question what is typified and taken for granted?

For Schutz, the concrete experience of human beings provides access to that question, as "the ground for understanding the meaning of *verstehen* in the third sense, as a method particular to the social sciences."⁴⁶ As Natanson explains, the social scientist looks at others who

are not only objects for his observation, they are beings who have their own pre-interpreted world, who do their own observing; they are fellow-men caught up in social reality. These 'objects' then are second-order constructs, and the method of *verstehen* is employed in the social sciences in order to come to terms with the full subjective reality of the human beings they seek to comprehend.⁴⁷

Understanding has to be intersubjective, what Schutz calls a "we-relation"⁴⁸ because the social scientist, not unlike the ethics consultant, seeks to understand the motivations,

⁴⁴ Natanson, "Introduction," xxxv.

⁴⁵ Schutz, "Concepts," 133.

⁴⁶ Natanson, "Introduction," xxxv.

⁴⁷ *Ibid.*, xxxvi.

⁴⁸ Schutz, "On Multiple Realities," 219-221.

actions, and experiences of other human beings *who also have a stake in understanding* those motivations, actions, and experiences.

In my interviews and analysis, asking women to explain their motivations was the first step towards understanding their choices, actions, and experiences. The second step is the attunement, from James and Schutz, towards the different types of motivations, and the elements or structures of social reality that influence those motivations. Schutz's concern for intersubjective, interpretive understanding directs my analysis towards identifying and understanding women's subjective reality: what they see as relevant to this experience and decision.

In-order-to-motives and Because-motives

An underlying feature of Schutz's project of interpretive understanding is the possibility of understanding another's motives for particular actions, which is most helpful in seeking to understand another person's actions according to how *they* understand their actions. Action, for Schutz, is an ongoing process, devised in advance, based on a preconceived project, whereas the 'act' is the completed action or outcome of the action.⁴⁹ Action depends upon phantasying⁵⁰ or anticipation of future conduct, or more precisely, visualizing "the state of affairs to be brought about by my future action before I can draft the single steps of my future acting from which this state of affairs will

⁴⁹ Alfred Schutz, "Choosing among Projects of Action," in *Collected Papers of Alfred Schutz : The Problem of Social Reality* ed. Maurice Natanson (The Hague: Martinus Nijhoff, 1962), 67-68.

⁵⁰ "Phantasy" is a phenomenological term used to describe a deliberate process of imagining and identifying features of a given situation. See fn. 20, p 147.

result.”⁵¹ This projecting of the completed future act is in the future perfect tense or *modo futuri exacti*, in which “the action *will* already *have been* accomplished.” Decisions and actions in current circumstances are based on past experiences projecting a completed action into an imagined future.

For Schutz, the complicated time sense is important in understanding motives and actions because the *modo futuri exacti* is based on my past experiences – on knowledge and past actions in my biographically determined situation. It is also projected towards the future to determine appropriate action in the present. More particularly, Schutz’s time sense is important because it distinguishes between and clarifies his two types of motive.⁵² Schutz describes “in-order-to motives” as those directed towards future, projected reasons for action. On the other hand, “because-motives” describe past experiences that determine the possibility of an act.⁵³ In-order-to motives are subjective and relevant to the actor in the midst of the action. The because-motive is an objective category (accessible to the observer) that helps reconstruct the accomplished act.⁵⁴ Or, as Natanson explains,

Motives which involve ends to be achieved, goals to be sought for, are termed ‘in-order-to’ motives; motives which are explained on the basis of the action background, environment, or psychic deposits are called ‘because’ motives... but the because-motives which could explain certain aspects of my projecting, their causal conditions, remain obscure and marginal to my awareness.⁵⁵

⁵¹ Schutz, "Projects of Action," 68.

⁵² *Ibid.*, 69.

⁵³ Schutz, *Reflections on the Problem of Relevance* 49-51.

⁵⁴ Schutz, "Projects of Action," 69-71.

⁵⁵ Natanson, "Introduction," xxxix.

People are aware of their in-order-to-motives as they are choosing among projects of action, but Schutz argues that because-motives are not as accessible in the midst of choosing. He writes, “Only insofar as the actor turns to his past, and, thus, becomes an observer of his own acts can he succeed in grasping the genuine-because motives of his own acts.”⁵⁶ In-order-to motives and because-motives influence one’s choices and actions and current actions become past experiences that will influence future choices. Given these potential influences, the possibility of understanding both types of motivations might lead to a more nuanced understanding of particular actions or experiences. For example, in the “Parental Voices” essays and in my interviews with women about choosing open uterine surgery to repair spina bifida, women describe both types of motivation to explain decision-making. Schutz’s division of motivations offers a way of distinguishing between women’s goals or wished-for outcomes and the sedimented, social features of knowledge and biographical situation – both of which reveal influences on their decision-making.

Stock of Knowledge at Hand

Alfred Schutz explored the because-motives that shape action through William James’s concept of “the stock of knowledge at hand.” In one’s stock of knowledge “beings and objects are from the outset perceived typically and with in a horizon of familiarity. What is new and different is recognized as unusual because it arises against a background of the ordinary.”⁵⁷ The stock of knowledge is one’s heuristic for the

⁵⁶ Schutz, "Projects of Action," 72.

⁵⁷ Natanson, "Introduction," xxix.

common-sense world – a series of typifications of things that happen, things that work, things that are given. As such, one’s stock of knowledge is both rooted in and continues to shape one’s biographical situation and the possibilities and motivations available for choices and actions.

In *Pragmatism*, James explains that one’s stocks of knowledge come from a variety of sources, the “multiple worlds” each person inhabits and include beliefs, observed facts, and past actions. Further, the stocks of knowledge at hand adapt and expand to incorporate new and unfamiliar experiences. James writes, “your mind in such processes is strained, and sometimes painfully so, between its older beliefs and the novelties which experience brings along.”⁵⁸ The process of expanding one’s stock of knowledge, according to James, is one we avoid when possible, and when it is unavoidable, we expand as little as possible.⁵⁹ He explains,

Our minds grow in spots; and like grease-spots, the spots spread. But we let them spread as little as possible: we keep unaltered as much of our old knowledge, as many of our old prejudices and beliefs as we can. We patch and tinker more than we renew. The novelty soaks in; it stains the ancient mass; but it is also tinged by what absorbs it. Our past apperceives and cooperates; and in the new equilibrium in which each step forward in the process of learning terminates, it happens relatively seldomly that the new fact is added *raw*. More usually, it is embedded, cooked, as one might say, or stewed down in the sauce of the old.⁶⁰

We are used to expanding the horizons of the familiar, or the known elements of what Schutz calls our common-sense world of working, because typifying and incorporating

⁵⁸ William James, *Pragmatism* (Cambridge, Mass.: Harvard University Press, 1975), 74.

⁵⁹ *Ibid.* 27. James explains that in such cases, we find some mediating idea, which is then adopted as the true one. “It preserves the older stock of truths with a minimum of modification, stretching them just enough to make them admit the novelty, but conceiving that in ways as familiar as the case leaves possible.”

⁶⁰ *Ibid.* 74-75.

new events is one of the basic activities of that world. As Natanson writes, “from childhood on, the individual continues to amass a vast number of ‘recipes’, which serve as techniques for understanding or at least controlling aspects of his experience.”⁶¹ Our conservatism in expanding old and comfortable ideas does not mean we avoid new experiences, or that we are limited in the number of ideas, in the elements that make up our stock of knowledge. In fact, James argues that it is helpful to have *extra* stocks of knowledge, to deploy in different circumstances. James explains,

Since almost any object may someday become temporarily important, the advantage of having a general stock of *extra* truths, of ideas that shall be true in merely possible situations, is obvious... whenever such extra truth can be practically relevant in one of our emergencies, it passes from cold storage to do work in the world and our belief in it grows active.⁶²

Our stock of knowledge helps us make sense of new information, new experiences, and new ideas that irrupt into and interrupt our daily life – in James’s words, the stock of knowledge at hand helps us determine what is *true* in a given situation.

This truth in our stock of knowledge is constantly challenged and tested by new experiences, but, as James points out, many of its elements are inherited and, for the most part, unquestioned, as we move from one project or experience to another. James explains, “Truth lives, in fact, for the most part, on a credit system. Our thoughts and beliefs ‘pass’ so long as nothing challenges them, just as banknotes pass so long as no one refuses them... We trade on each other’s truths.”⁶³ Rather than tediously investigating every truth, every element of our stock of knowledge from the outset, we make use of the inherited every-day truths that constitute our inherited every-day world.

⁶¹ Natanson, "Introduction," xxix.

⁶² James, *Pragmatism* 89.

⁶³ *Ibid.* 91.

And for the most part, in most of our social interactions and decisions, this unintentional strategy works and reinforces itself. As Natanson writes,

It is clear that for certain problems a person's stock of knowledge is more than adequate and that for other situations, he must improvise and extrapolate, but even improvisation proceeds during typically possible lines and is restricted to the individual's imaginative possibilities. Those possibilities, in turn, are grounded in the stock of knowledge at hand. Finally, the typifications which comprise the stock of knowledge are generated out of a social structure. Here, as everywhere, knowledge is socially rooted, socially distributed, and socially informed. Yet, its individual expression depends on the unique placement of the individual in the social world.⁶⁴

Our stocks of knowledge, made up of typifications, assumptions, beliefs, and recipes for understanding and action, are socially rooted, and yet, as Schutz explores, they have a deeply personal, individually sedimented structure and expression. Zaner explains in introducing Schutz's *Reflections on the Problem of Relevance*, "the" world becomes transposed into "my" world in accordance with relevant elements of my biographical situation.⁶⁵ Understanding the decisions, actions, and experiences of another human being requires knowing something about their stock of knowledge at hand, but as that stock of knowledge is determined by and contributes to his or her specific biographical situation. In my project, analyzing women's stories can identify stocks of knowledge that inform their decision-making. James and Schutz raised my awareness and careful attention to the knowledge structures that women may draw upon in their decision-making, in their personal experiences with open-uterine surgery to repair spina bifida.

⁶⁴ Natanson, "Introduction," xxix.

⁶⁵ Schutz, *Reflections on the Problem of Relevance* xxvii.

Biographically Determined Situation

Zaner notes that according to Schutz, “at any moment then, I find myself in a biographically determined situation which, although only in a small way due to my own experience, I must define and come to terms with in order to make my way in the world.”⁶⁶ I inherit my unique stock of knowledge from my parents, family, and social context, “my position in space, time and society,”⁶⁷ but I also add to it with each new experience. My stock of knowledge at hand, however, is determined by my social context and past experiences, and determines what experiences, actions, and choices are available to me to add in a given situation. As Schutz explains,

There is a selection of things and aspects of things relevant to me at any given moment, whereas other things and other aspects are for the time being of no concern to me or even out of view. All this is biographically determined, that is, the actor’s actual situation has its history; it is the sedimentation of all his previous experiences. They are not experienced by the actor as being anonymous but as unique and subjectively given to him alone.⁶⁸

In choosing among projects of action, I do not use every element of my stock of knowledge, but only those that I deem relevant to the situation at hand, based on previous experience and belief regarding what actions are available to me. Or, in Natanson’s words,

My biographical situation defines the way in which I locate the arena of action, interpret its possibilities, and engage its challenges. Even the determination of what an individual can modify or not modify is affected by his unique situation. The funded experience of a life, what a phenomenologist would call the ‘sedimented structure’ of an individual’s

⁶⁶ Ibid. xviii-xix.

⁶⁷ Schutz, "Projects of Action," 76.

⁶⁸ Ibid., 77.

experience, is the condition for all subsequent interpretation of all new events and activities.⁶⁹

A situation, an idea, a choice, an action are only real to me,⁷⁰ are only possible in relation to my biographically determined situation and the stock of knowledge available from my past experiences. For my project, analyzing the elements of women's biographically determined situation can identify themes and key experiences that women use in decision-making. Identifying these themes not only is ingredient to identifying what was most important in these women's stories, it helps to refine my analysis from one interview to the next. Additionally, in the final stages of retelling, below, these themes can provide imaginative variations that may help ethics consultants and others interesting in understanding women's experiences with this procedure.

Definition of a Situation and Pragmatic Belief

There are several features of meaning which are important to mention. For example, although the elements of my biographical situation and my stocks of knowledge are inescapable in terms of their influence, I do have some say over which elements I use, over the *ways in which I define a situation*. My definition depends, in part, according to

⁶⁹ Natanson, "Introduction," xxvii.

⁷⁰ William James, *The Principles of Psychology* (New York,: H. Holt and Company, 1918)296-297. James explains, "The *fons et origin* of all reality, whether from the absolute or the practical point of view, is thus subjective, is ourselves. As bare logical thinkers without emotional reactions, we give reality to whatever objects we think of, for they are really phenomenon, or objects of our passing thought, if nothing more. But, as *thinkers with emotional reactions*, we give *what seems to us a still higher degree of reality to whatever things we select and emphasize WITH A WILL*. These are our *living* realities; and not only these, but all the other things which are intimately connected with these."

Schutz, on what I give attention or reality in the moment, based upon my plan of action or project at hand, on the *province of meaning* upon which I focus.⁷¹

James and Schutz talk about the different sub-universes or finite provinces of meaning, respectively, which make up the common-sense world of a person's daily life.⁷² These provinces of meaning⁷³ include the world of working, religious or scientific worlds, dreams, and fantasies. Schutz writes, "Each province of meaning is a coherent arena of concern and interest which is unified or coherent in virtue of a common theme, a common ground of interest. This common theme unifies a set of experiences constituting the province."⁷⁴ Each province of meaning is internally consistent, is limited by its theme, and frames the possibilities and actions available to the person. As Zaner explains, "our every action, thought, and deed in the life-world is guided by and founded on a whole system of relevances" but the "accent of reality is bestowed on one or another finite province of meaning as a function of one particular project at hand."⁷⁵ Each world is "real" as long as it has been given the accent of reality and is not challenged by circumstances beyond its explanatory capacity.

When such circumstances arise, both James and Schutz describe the transition from one world (i.e. world of working) to another (e.g. religious or scientific explanations) as a shock or what Schutz calls "discontinuation," that calls for attention

⁷¹ Schutz, *Reflections on the Problem of Relevance* 23-24.

⁷² Schutz, "On Multiple Realities," 229-258.

⁷³ Schutz called them "finite provinces of meaning" rather than "sub-universes" to emphasize the meaning bestowed by the actor in each province of meaning, instead of an ontological understanding of these 'worlds.'

⁷⁴ Schutz, *Reflections on the Problem of Relevance* 24.

⁷⁵ *Ibid.* xix-xxi.

and a definition of the situation.⁷⁶ James argues that when confronted with uncertainty and the shock of a situation that does not fit within the contours of my world of working, my operative province of meaning, an I look for ideas or beliefs that banish the future's uncertainty. For James in particular, a person's beliefs or ideas that help ameliorate the shock of transition from one finite province of meaning to another, or that help mediate between old ideas and new experiences, have "cash-value" in defining the situation at hand, including possibilities for action. These beliefs will provide an outlet for our activity, giving us "something to press against"⁷⁷ and will have the "marks of rationality" which James describes as "a strong feeling of ease, peace, rest...the transition from a state of puzzle and perplexity to rational comprehension full of lively relief and pleasure."⁷⁸ Such ideas, such beliefs are, in James's terms, "good for so much" as they make a practical difference in the situation at hand⁷⁹ and are oftentimes determinative of both the definition of our situation and the choices or actions we see as possible.

James and Schutz's concepts of provinces of meaning and the pragmatic value of belief in defining the possibilities available in a given situation are helpful concepts for analyzing women's experiences with and decision-making about open-uterine surgery to repair spina bifida. Like the reflective attention to biographically determined situations, James's and Schutz's consideration of finite provinces of meanings offers another access point to key themes in women's stories, namely, how women frame their situation and

⁷⁶ The definition of the situation, and possible actions incorporate and are determined by the particular circumstances, one's biographical situation, and one's stock of knowledge.

⁷⁷ William James, "The Sentiment of Rationality," in *Writings: 1878-1899* (New York, NY: Library of America, 1896), 515-518.

⁷⁸ *Ibid.*, 504.

⁷⁹ James, *Pragmatism* 34.

experiences and what definitions and beliefs they find most helpful in their decision-making.

Decision-making

William James makes the argument, repeatedly, that decisions are made by more than intellect, no matter how much we would like for rationality and objective evidence to be sufficient. He begins his *Pragmatism* lectures by arguing that everyone has a philosophy or a basic temperament that guides their thinking,⁸⁰ and in *The Will to Believe* he argues that “the most interesting and valuable things about a man is his ideals and over-beliefs.”⁸¹ For James, wish, will, sentiment, and intellect shape our decisions, and as we have seen, each of those elements are rooted in and continue to shape our stock of knowledge at hand and unique biographical situation.⁸² There are circumstances where a genuine option – a live, forced, momentous option – cannot be decided on intellectual grounds alone, circumstances where there is not enough coercive evidence one way or another.⁸³ In open-uterine surgery to repair spina bifida, for example, women are often faced with clinical uncertainty about outcomes for both prenatal and postnatal repair. Their choice, then, often reflects deeper motivations, beliefs, and values.

Faced with a genuine option, James argues that faith or belief, the “passional nature” can and should play a part in the decision or action, particularly if that faith or

⁸⁰ Ibid. 1.

⁸¹ William James, "The Will to Believe," in *Writings: 1878-1899* (New York, NY: Library of America, 1896 (1992)), 451.

⁸² Ibid., 464.

⁸³ Ibid., 451.

belief may bring about a good or desired outcome.⁸⁴ As James observes, “Objective evidence and certitude are doubtless very fine ideals to play with, but where on this moonlit and dream-visited planet are they found?”⁸⁵ Given the uncertainties of a particular circumstance, insisting that decisions and actions be understood as “well-defined problematic alternatives”⁸⁶ and chosen by intellect alone seems irrational at best.⁸⁷ James argues that in practical and philosophical affairs, “the whole man is at work within us – intellect, will, taste, and passion co-operate...in the total game of life, we stake our persons all the while.”⁸⁸ Trying to understand what we have at stake, or trying to understand what another has at stake, requires deliberate attention to the other features in decision-making: the affective histories, emotions, and experiences of others. Efforts at understanding are complex interactions, which are easily embarked upon in our taken-for-granted daily lives, but which reveal themselves as risky undertakings with uncertain outcomes when we try to understand the other’s experience in greater detail as in the activities of case of ethics consultations and qualitative interviews. James and Schutz provide a framework for deliberately attending to these relevant features in my attempts to understand others’ motivations, behaviors, and actions in women’s stories about open-uterine surgery to repair spina bifida.

⁸⁴ Ibid., 458-464.

⁸⁵ Ibid., 464.

⁸⁶ Schutz, "Projects of Action," 83-84.

⁸⁷ James, "Sentiment," 525. In the *Sentiment of Rationality*, James scathingly takes die-hard rationalists to task, noting that “the absurd abstraction of an intellect verbally formulating all its evidence and carefully estimating the probability thereof...is ideally as inept as it is actually impossible.”

⁸⁸ Ibid., 525-527.

Method and Storytelling: Retelling Women's Experiences

By raising the question of intersubjectivity and attempting to understand motivations, James and Schutz highlight key concerns for ethics consultants and qualitative researchers – concerns for me – by asking how we communicate and by flagging the possibility of miscommunication in social situations. The focus on stocks of knowledge at hand and one's biographically determined situation bring structural focus to the key themes in women's stories that influence their decision-making and may help others understand such circumstances, including ethics consultants. Finally, defining one's situation and thinking about decision-making based on more than intellect, as James and Schutz want to suggest, raises analytic questions about how ethics consultations contribute – or not – to understanding women's experiences and decision-making. James's and Schutz's attention to these structures of the social world serve as guides for analyzing women's stories, opening the possibilities of understanding, and as Bourdieu suggests, for doing justice to each woman's story and viewpoint, without necessarily entering into it.⁸⁹ This attunement also prepares the way for the final question of method – retelling these stories so that others can learn from them. Or in Zaner's phrase, understanding and telling women's stories without putting them in the dock, or worse, the stocks. My intention is for the following chapters to manage those ambitious goals.

⁸⁹ Bourdieu, "Understanding," 623.

**PART III: RETELLING WOMEN'S EXPERIENCES AND REFLECTING
ON DECISION-MAKING**

Presenting Data or Retelling Stories?

From September 1, 2009 to November 22, 2009, I traveled over 5000 miles conducting face-to-face interviews with women about their experiences with and decision-making about open-uterine surgery to repair spina bifida. I drove to Missouri, Arkansas, North Carolina (three times), and Eastern Tennessee, and I flew to Northwest Arkansas and the North Carolina Piedmont. Six interviews were in the woman's home, one was at her office, and one in a local restaurant. Four interviews were with the woman alone. In two, the woman's husband and children were present, in one I dined with and spent the evening with the woman and her two children, and in one, the woman's mother participated in the interview while the woman's husband and children were in and out of the house on a busy Saturday. The conversations ranged in length from 30 minutes to over three hours, though an hour and half was average. In total, more than 17 hours of recorded interviews and over 5 hours of dictated field-notes yielded 395 single-spaced pages of transcripts.

I interviewed three women who chose not to have open-uterine surgery (TR 1, TR 5, TR 9), and five women who chose to have the procedure (TR 3, TR 4, TR 7, TR 8, TR 11). Their children's spinal lesions ranged from L3 to S1, and their outcomes (at between six and ten years of age) varied. All but one (TR4) were shunted between five days and two years of age; three used a wheelchair (TR1, TR3, TR8), two used braces (TR9, TR 11), and three did not require assistive devices for mobility (TR 4, TR 5, TR 7). Five children were catheterized intermittently (TR 1, TR 5, TR 7, TR 9, TR 11) two required diapers (TR 3, TR 8), and one (TR 4) had no bowel or bladder issues. All the children were mainstreamed in public elementary schools except for one child (TR 3), who

attended a private Christian school.¹ All of the parents but one (TR 4) reported some learning disabilities or cognitive delays, ranging from mild to significant. All of the parents were still married and while most of the children with spina bifida had siblings, (TR 1, TR 4, TR 5, TR 7, TR 8, TR 9, TR 11), one is an only child (TR 3) and only two had younger siblings (TR 1, TR 11).

This basic demographic information, collected in the initial phone conversations and gleaned from the transcripts of the face-to-face interviews illustrates the need for deeper investigation into these women's experiences. My data point to the uncertainty inherent in prediction and the variations in outcomes for spina bifida, which persist regardless of choice about surgery. The basic demographic data is also typical of the information many women receive when they receive their diagnosis – so many children with lesions at this level have this level of mobility, so many children at this level have a different level of bowel and bladder continence. For women trying to make sense of a prenatal diagnosis of disability, the numbers are difficult to evaluate and it is even harder to understand what such predictions mean for their child.

Many qualitative research projects produce and analyze the types of demographic information described above. My project, however, had a different focus. By asking women to tell me their stories I hoped to learn about and understand their experiences with decision-making: how women made decisions and what they saw as important moral elements in their decision-making, now, years after choosing prenatal or postnatal repair. I discovered early on that their moral experiences with open-uterine surgery to repair spina bifida, their stories, began before they even learn about the procedure. Their moral

¹ Lindsay had Osteogenesis Imperfecta (OI) as well, so the private school was as much to allow care for the OI as it was to care for her spina bifida issues. Also, as a reminder from Chapter IV, all names are pseudonyms assigned after my first contact with each woman.

experiences continue years after their choice to have or not have the procedure, and though many of their stories shared similar structures and sequences of events, each woman interpreted different facets as being important in *her* experience. One challenge is to identify those common elements and to do justice to those unique facets of each woman's unique experience:² to tell her story and learn from it as part of the larger story of open-uterine surgery to repair spina bifida.

Of the many aspects of research and ethics consultation, the question of storytelling seems to be the one most in need of a prescriptive methodology, some guidance on what to do with the stories one has accumulated. And yet, the retelling, the storytelling also demands a method, an orientation and effort rather than a prescriptive methodology. As Zaner asks, in reflecting on his experiences with ethics consultations

How can we, after serious listening or observing, talk or write, when what we must talk or write about is so unique, so singular in its immediacy and potency, and for that very reason seems contrary to everything we hope to do, so utterly unrecoverable? ... How put the unconditional into words, tell the unqualified uniqueness of individual people and their actions, emotions, relationships, and circumstances? And how thus to go on and write about these very encounters – standing at still another remove from their utter immediacy – without obfuscating or distorting the very things that mattered most while we were still enmeshed in the moment, in the circumstances that have left such deep marks?³

For Zaner, the activity of writing, of describing what happened, is part of the method of clinical ethics consultation. It is an act of discovery, a part of analysis, and part of the research process. Zaner explains,

Rather than simply 'data-gatherer,' much less mere recorder of facts and collector of clues, the sense of writing-as-discovery suggests that the writer is more inquirer than recorder, more interrogator than settler of

² Bourdieu, 622-623.

³ Zaner, "On the Telling of Stories," 23.

disputes, more in the posture of one still learning than one of having already learned.⁴

The demographic information I learned from the interviews is only the beginning, the first and most obvious layer of their stories. In describing the interviews, and my reflections on them, I am challenged to learn more, to ask what can be learned from women's stories, what they want others to know about their experiences. To that end, Chapter VI focuses on telling women's stories and focuses on the particular themes they emphasized as important to their experiences. Chapter VII tries to learn from women's experiences about ethics consultations. In each, listening and telling stories play a crucial role in understanding women's experiences with open-uterine surgery to repair spina bifida.

⁴ Ibid., 26.

CHAPTER VI

LEARNING ABOUT WOMEN'S EXPERIENCES

Though there is no prescriptive methodology for retelling a given story or set of stories, James and Schutz once again provide a framework and point of access to women's stories – this time in *structuring* the retelling. Focusing on themes in women's stories – as examples of James's and Schutz's phenomenological categories – can clarify which elements are important across multiple interviews. At the same time, such “free-phantasy variations” create the opportunity to return the focus to telling particular experiences, to telling a particular woman's story as both unique and illustrative.

Women's unique and deeply personal experiences with diagnosis and learning about their child's disability can be considered more broadly in terms of Schutz's “in-order-to” motives and the necessary, difficult expansion when their taken for granted “stocks of knowledge at hand” are insufficient. The themes of prayer, faith, and the importance of social context that consistently emerge can be understood both in terms of James's pragmatic value of religious belief and Schutz's “biographically determined situation.” Similarly, women's recollections of and reflections on decision-making can be framed in Schutz's “definition of the situation” and choosing between projects of action, and James's “forced, live, momentous” choice. Finally, finding out about women's experiences of living with their decisions provides access to several “because” motives, motives perhaps not available while in the midst of decision-making. In this way, the retelling about women's “because” motives can show how their stocks of knowledge at

hand have expanded and are still expanding as they encounter new challenges. Probing the examples from multiple stories helps identify the themes and categories, which then allows me to focus on particular stories that highlight the themes or exemplify the categories. This method of “storytelling” allows the women’s voices to come through, within a method of inquiry that highlights recurrent themes about moral experiences and decision-making for further reflection.

Diagnosis and Disability: Insufficient Stocks of Knowledge

Among the women I interviewed, the first stage or step in their journey with decision-making for open-uterine surgery was the diagnosis of spina bifida itself. In those few moments during an ultrasound exam, these women and their husbands experience “shock” as the normal pregnancy they expected and were preparing for vanishes, and an uncertain future filled with difficult decisions emerges. In Schutz’s or James’s terms – their taken-for-granted world or province of meaning is called into question and they must shift into a different province – a medically oriented world – where they must expand their everyday stock of knowledge that suddenly has become insufficient. The women do not use such terms, certainly, nonetheless, these descriptions have been established to structure our understandings of the multiply complex experiences of the women I interviewed.

Most of the women began their pregnancies with little or no knowledge of spina bifida, even those in the medical profession, as was the case with Angela Dominguez (TR 5), or those who had worked with disability organizations, like Cathy Johnson (TR 1), who did fundraising for the March of Dimes. When they received a diagnosis of spina

bifida midway through their pregnancy, the experience was often unexpected and almost always devastating and “heartbreaking” as Dottie Geller (TR 7) explained. Most women were informed of some kind of spinal or brain anomaly during a routine ultrasound, though one learned through an elevated alpha-fetoprotein result (TR 11), and each woman was sent to confirm the diagnosis of spina bifida with a level-II ultrasound done by a high-risk obstetrician. Their stories indicate that most of these conversations were abrupt, discouraging, and unpleasant. Lila Slater (TR 8) and her husband David had a fairly typical story of a terrible diagnosis with an unfamiliar clinician. She said,

He did the ultrasound and came back in the room and used a whole bunch of big words. And said, ‘We have a problem.’ Threw a whole bunch of big words at us and was ready to walk out the door. And we said, ‘Wait a minute! What does that mean?’ and he said all those big words at us again and walked out the door. (TR 8.1 3:20)¹

The ultrasound technician was the one who actually explained what “myelomeningocele” meant to Lila and David and sent them on their way to get more information and consult with their own obstetrician.

Lila and David’s story is also typical of others. The women I interviewed remembered that the information they received from clinicians was depressing and emphasized the ‘worst-case scenario’ they could expect. The diagnosis came with an immediate offer of pregnancy termination as an acceptable option, but as Lila explained, “abortion was nothing we would ever consider doing, no matter how bad the prognosis.” (TR 8.4 19:40). Many women, like Mandy Ball (TR 11), felt that their perinatologist or high-risk obstetrician was pushing termination (TR 11 12:35): the obstetrician ended up telling her she either had to “terminate the pregnancy or accept the diagnosis” (TR 11

¹ The numbers within the parentheses indicate the time stamp for the recording. For example, TR 8.1 3:20 indicates the transcript of Interview 8, part 1, time 3:20.

13:35). Lila and David, meeting with a genetics counselor at a Catholic hospital, were supported in their decision not to terminate, but Lila's father and sister both disapproved, asking, "Why would you want a baby like that? (TR 8.4 20:21). The push towards termination and avoiding disability from family is not unique to Lila's story. Dottie Geller also received pressure from family members to terminate, in particular from her grandmother. She explained,

D: It was my grandmother told me horror stories about spina bifida children she'd had in class.

V: She was a teacher?

D: Yeah. Their mothers would have to come to school and clean them, and how stupid they were...

V: Oh wow.

D: And all that kind of stuff, and how they couldn't get around on their own.

V: Ok.... So, was she trying to convince you not to have the baby?

D: Right. She wanted me to abort the boy. And umm...I could not talk to her for a while... (TR 7 40:25)

Whether the pressure came from clinicians or family members, the immediate recoil from spina bifida and its accompanying disabilities added to the stress of receiving the prenatal diagnosis and complicated the choices available to each woman. The diagnosis forced an examination of her knowledge about disability, her beliefs about termination, and her understanding of what spina bifida meant to their future. For many, pursuit of the prenatal surgery emerged with the "in-order-to-motive" of changing that uncertain future. The most helpful illustration of these particular aspects of women's experiences is Erin Strickland's story.

Erin Strickland's Diagnosis Experience:

Erin was living in Mexico with her husband and two young daughters when she got a diagnosis of hydrocephalus 18 weeks into her third pregnancy. Her local obstetrician sent her to a larger city for a level-II ultrasound, which confirmed the hydrocephalus. Her local OB suggested she plan on being followed by her OB back in the United States and that she plan on delivering there. Erin followed his advice and went, with her mother in Arkansas, to the high-risk OB in Little Rock. He also confirmed hydrocephalus and confirmed Erin's other worry: her daughter had spina bifida. They told Erin that her daughter's lesion was at L1 and asked her immediately and repeatedly if she wanted to terminate. Erin said the repeated questioning and asking, "Are you SURE?" were upsetting and she felt like saying, "I don't appreciate your acting like she's trash in my uterus" (TR 9 27:15). Every time they asked, "Are you SURE?" she told them neither she nor her husband had any interest in termination, and finally they sent her to the Spina Bifida Clinic at Arkansas Children's Hospital. In rapid speech, alternating between humorous deprecation and still-brittle anger, Erin described the spina bifida clinic as a further onslaught of diagnostic and prognostic misery:

E: So anyway, we went to Children's Hospital and had the consult for a day long - and that was extremely depressing. Because! When you go in to that setting - and this is what I tell other parents, be warned, you need to brace yourself for that meeting - because if you have never been exposed, except for watching the Jerry Lewis telethon every year...

V: Right

E: You go in... and they present a pamphlet, and they pull it out and they're like, "Let's start with hydrocephalus because it's the most obvious an there's going to be shunts and probably corrective surgeries and the shunt will need to be replaced, and every so and so years... And there can

be heavy mental retardation associated with that, and then let's move past hydrocephalus, there's obviously the neural damage to the legs - at L1, she won't walk, and so..."

V: Uh huh

E: "And so, there's that...oh, does your home have ramps? You'll need to do that? Oh, and ok, she could have a latex allergy - so is your carpeting, does the back of your carpeting have latex? Do you use laundry detergent that has latex in it? Do you ..." All of these bombarding... Then there's like the diet issues - "Ok, you're going to have to switch to a really high fiber because you're going to have bowel problems, and let's talk about the urological issues. They're are going to be - need to be cathed, probably every three to four hours over the course of her lifetime. You're going to have wash your hands first and sterilize, and have an option...and by the way, they can have crossed eyes and vision problems, and...." I mean...They present a laundry list of every possible thing that could be associated with spina bifida. [Laughs, a little bitterly] (TR 9 30:16).

Erin said she understood why they were trying to help parents "guard their expectations" about their child's future, but for Erin, this tactic was not helpful and the experience was still difficult for her to discuss. As a scientist herself, Erin saw the doctors and nurses at the spina bifida clinic as operating on a "downward bias." She said that their perspective was biased because they saw the worst cases most often while the kids who were doing better came in less frequently. Even with this recognition, however, the "doom and gloom" affected Erin and her husband Dan, who had joined her in Arkansas, making it seem like they "had a black cloud of oppression over us in Little Rock" (TR 9 36:20). In this frame of mind, they went to Vanderbilt, hoping to learn whether open-uterine surgery to repair spina bifida was an option for their daughter and what it might do.

At Vanderbilt, Erin said, she and Dan encountered an entirely different attitude towards their child and towards their options and decision-making process. Though the perinatologist was ebullient and optimistic, telling them "Your child WILL walk!" their visit with the pediatric neurosurgeon was more sobering and realistic, including the

possibility of life-long dependency for their daughter. For the first time, Erin and Dan considered and vocalized the possibility of abortion to each other. She explains,

E: We literally crawled out of the neurosurgeon's office. And that was the only time in the whole process - Dan and I went to a coffee shop across the street and we said, and that was the only time we said, "Are you having ANY second thoughts about termination?" and that's the only time that reared its head. As I said, the religious issue was the initial thing, but then when we got to that point, we were like... [Grimaces] because we believe...we would almost be...it would almost be the nicer thing to do for the sake of the child...not for our own convenience, but for the sake of the child. And then we both sat there for about 30 minutes and went, "NO." But now we realized we're on a rough road (TR 9 41:16).

Even though Vanderbilt's clinicians gave them a more accurate diagnosis (L4 instead of L1, for example), Erin remembered that the uncertainty of the medical details seemed overwhelming at times. As the reality of their daughter's diagnosis slowly sunk in, Erin and Dan prayed daily and went back to their hotel each night, discussing what they had learned and what the clinicians had told them about their daughter's future. Ultimately, in light of the information and consultations they received at Vanderbilt, Erin and Dan decided that the risks of death or prematurity from the prenatal surgery were too great and chose to wait to repair their daughter's spinal lesion after her birth.²

Erin's story illustrates several key themes in the initial experience of prenatal diagnosis and open-uterine surgery for spina bifida. The diagnosis came as a shock, upsetting Erin's expected, desired, and prepared for pregnancy. Erin knew a little about spina bifida from reading in preparation for her first two children, but the actual details and implications of the diagnosis were overwhelming and unsettling, forcing Erin and

² As an interesting side note, according to Erin, she and Dan were so impressed with the information, the counseling, and the support they received at Vanderbilt that they chose to deliver there and have their daughter's spina bifida repaired by the neurosurgeon. Erin also said she recommends the program at Vanderbilt, with its emphasis on education, to other women who receive a prenatal diagnosis of spina bifida.

Dan to expand their available “stock of knowledge at hand” and reconsider previously unquestioned beliefs and assumptions. The primary instance is the question of abortion, because, like many others, Erin received significant pressure to terminate the pregnancy after the diagnosis of spina bifida. For Erin, a vague, religiously-based hesitation guided her initial dismissal of abortion as an option, but as she and Dan learned more at Vanderbilt, the option became, briefly, a live option.³ As Erin and Dan processed more of what they learned, incorporating it into past experiences and prior beliefs, they decided to continue the pregnancy and to continue investigating open-uterine surgery, *in order to* determine what might help their child have the best possible future. The process forced them to examine their “in-order-to-motives” for pursuing the surgery, including their taken-for-granted views about disability and parenting, about technology, and about their faith. As Erin said early in our interview, “I don’t know where you are from a religious standpoint, but obviously, people in this position, if they’re not religious before they get there, they quickly become so...” (TR 9 9:30). The shock of diagnosis and having to expand their stocks of knowledge about spina bifida and disability forced Erin and Dan to explore their beliefs and how their new experiences fit into their new world, shaped by spina bifida.

Prayer, Faith, and Community: Belief and Biographically Determined Situation

Other women I interviewed echoed Erin’s account of how important faith became, highlighting a second set of key themes: how belief and one’s biographically determined situation shape experience and the choices available in a given situation.

³ James, "Will to Believe," 458.

James writes eloquently of the pragmatic benefit of faith, especially in situations where believing may affect an uncertain situation, contributing to a positive or desired outcome. If one's inherited and operational beliefs can positively influence a circumstance in situations where we cannot "always wait with impunity til all the coercive evidence shall have arrived..." then James endorses and encourages acting on one's faith.⁴ For women who believed that God had a plan for them and would give them signs to show what they should do, acting in light of that belief – looking for those signs – created possibilities for verifying and confirming that belief in that plan. Schutz's idea of the biographically determined situation is another helpful way to understand these possibilities, as something that shapes the interpretation a person gives to a particular experience. In these cases, women's biographically determined situations shaped how they processed and understood the diagnosis they received and the options before them, including how they determined and interpreted the appropriate stock of knowledge at hand in a situation.

Lila Slater and her husband, Dan, for example, were "strong believers" and after their diagnosis, they had been doing a lot of praying, with each other, and with their "church family" as they researched and decided to go to Vanderbilt. As Lila said,

It was all seeming to point in that direction. And my husband and I are the kind that... we follow... what we believe to be the right path until it completely shuts down in front of us, and then we realize, that was probably not what was intended (TR 8.2 2:45).

In their interpretation, all the signs pointed to Vanderbilt and so they went. Their church fully supported their decision, helping with child-care for their two-year-old son, creating a rotating schedule for church members to come do Lila's laundry, cooking, and babysitting for every day of her 16-week bed-rest. A favorite cousin, as close as a sister,

⁴ Ibid., 472.

came down unannounced on the last day of her consultations, and helped Lila and her husband ask questions during the final meeting before the surgery. Just before her actual surgery, a van full of church members drove the six-plus hours to Nashville to pray with her before the surgery. Further, Lila and David had just sold their home, so they had part of the money, which meant they could have the surgery even though the insurance had initially denied coverage. When the insurance company later agreed to pay for the procedure, Lila and David saw further proof that they should have the surgery.

For Lila and David, all of these were signs along the path. Lila described her last meeting with the doctors and ethics consultants, who asked her why she wanted to do the surgery. She explained her reasoning and the answer she gave to the ethicist's probing:

Then, all of the way the other pieces kind of fell together, and the way the insurance company [came through]...and the way it all kind of wove together, I said, "We just really think God wants us to have the surgery." He [the ethicist] said, "Well, what if it doesn't work that way? What if God doesn't want you to have the surgery and wants you just to take it as it is?" and I said, "OK, but if you believe that, then you've put Him into a box... We've left the door open."s (TR 8.3 12:10)

For Lila, belief in God's plan and God's guidance meant being open to God's possibilities, following the path until it "shuts down in front of them." Following the signs was a demonstration of their faith and even the confidence and clarity of her answer to the ethicist's question verified God's guidance. She explained,

L: They just kind of went [cocks head to the side as if thinking] "Huh." And I don't even know where that comment came from because I couldn't...I couldn't have repeated that kind of clarity in any other moment in my *life* probably, but it was one of those things. If I say, "He doesn't want this," then I end it there. But if He says, and I think He does and if this is the path... and if He does [want to stop the surgery], He'll shut it down..."

V: But at least if it gets shut down, it's God doing it, not you doing it?

L: Right!

V: Am I understanding that?

L: Right! Yeah! It's not a decision that we made. (TR 8.3 13:30)

I tried to be clear in my conversation with Lila, to make sure I understood her explanation for their decision to pursue open-uterine surgery. For Lila and Dan, God's plan for them, for their child, included the open-uterine surgery to repair spina bifida, and each step along the path toward that surgery verified and confirmed their belief in that plan and in their interpretation of the situation. The decision for surgery was God's decision, not theirs. From their perspective and in their experience, God would either continue opening doors to the surgery, or would set up an unmistakable and insurmountable roadblock. All Lila and David's decision-making required was that they be open to God's plan – they did not have to make the decision by themselves.⁵

Other women shared similar stories – Carin Miller explained that she and her husband, George also relied on God for their decision-making, that for them, “It was like there wasn't really a decision” (TR 3 10:15). They prayed for guidance, and just “felt a peace” about having the surgery (TR 3. 3:57), which was how they knew it was the right thing for them to do. Cathy Johnson had a similar experience with praying for peace, though she and her husband, Brian, decided to wait for post-natal repair of their daughter's spina bifida. Cathy explained that they spoke to their pastor before coming to Vanderbilt:

⁵ Lila's account of their “decision that was not a decision” sets up a rather crucial question for ethics and ethics consultations, namely, of whether it is beneficial or harmful for ethics consultants to question and probe such “decisions.” This question will be discussed more fully in Chapter VII below.

And I was just telling him how anxious I was ‘cause I was really scared that we were going to get there and not know, “Should we do it or should we not do it?” um... To me, that was more frightening than the actual surgery... The more frightening is to know that you are making a decision for this little baby and what one is going to be the right choice?” (TR 1 23:17)

Cathy’s anxiety lifted the next day when the whole church prayed with them before they left for Nashville. She explained,

But I just felt very uneasy before that prayer, you know, my stomach, you know, very emotional, just “I don’t know if we’re going to know the answer” and the, when that prayer was over, my tears dried up and I just felt confident, you know, we’re going to go and get the answers. We have two days to talk to these people and it’s going to be made very clear to us. (TR 1 23:55).

After two days of medical consultations and conversations with the social workers and ethics consultants, Cathy and Brian, decided not to pursue the surgery. As Cathy wrote in her journal at the time, which she read excerpts from during our interview, “We feel like we made the *only* choice. Not one thing anyone mentioned made us feel like we should do the surgery.” Everything pointed to not doing the surgery, she explained, before continuing her reading, “And I wrote a note to Katy, [reading] ‘and I hope you agree, and know that we had only your best interests in mind.’” (TR 28:34). For Cathy and Brian, God’s guidance and their faith that God would guide them, was demonstrated in the clarity of the medical consultations, but their peace came from the church’s praying to God for that guidance.

Another woman I interviewed, Jackie Hutton, told me an even more dramatic story of God’s guidance, and how belief in God’s plan helped bring about God’s plan for their child. Jackie wanted to tell me her story, “their amazing story,” because it shows the

Lord at work and they tell it any time they can, to give “as many people as can hear it” a chance to hear it.

Jackie Hutton’s Story: The Power of Belief

Jackie and Rob had been married for four years before their first, uncomplicated pregnancy and childbirth, which was later followed by a devastating miscarriage. They waited a while before trying again, but were excited and expecting another easy pregnancy – perhaps even a home birth – when they got pregnant again in 2002. Their local midwife identified the spinal abnormality, however, and sent them to Asheville, to a high-risk OB for a level-II ultrasound. Jackie explained

And you know, she was using things like “The head was not formed correctly.” She said something like “Banana shaped” and “The feet were already clubbed” and... “There was fluid in the brain.” She explained to us spina bifida...right now, just how it happened, just what it was. Because up until that point, I didn’t know what spina bifida was, so she went on to describe things about our baby, you know...things that were already not good. (TR 4 12:10).

Their daughter’s lesion was low, L5, but big, and the high-risk OB gave them the usual uncertain prognosis. They were told, “Your baby may or may not live, may or may not walk, may have no bowel and bladder function.” She may “have a quality of life and she may not, depending on the fluid in the brain.” She’ll have lots of surgeries, including a shunt soon after birth, she might have some mental defects and she might not: “the list went on and on and on.” (TR 4 13:00). Jackie and Rob were given the options of finishing the pregnancy, of abortion, or of surgery during pregnancy. Jackie said, “We *knew* this was the baby the Lord had given us and we were not going to abort – that was never an option for us” (TR 4 15:44). However, the diagnosis was still devastating and

Jackie and Rob were overwhelmed by uncertainty and worry. Jackie described how in the midst of this medical crisis, they turned to their faith for guidance. Jackie explained,

J: You know that [abortion] never even entered our mind. So, she just told us to go home and think about it and they scheduled me another appointment with her. And as soon as we got to the car, we just broke down. And just prayed.

V: Sure. Yeah.

J: You know we just prayed, "Lord, we don't understand. But you know what's going to happen here. You know our baby. You know the purpose that you've got for her. And [Jackie gets teary-eyed]...we know that it's all going to be ok."

V: Sure

J: And so at that point, we just gave her over to the Lord. And we just said, "Whatever is going to take place, we know that it's Your plan." And we just give her...because she did tell us it was a little girl...

V: Right!

J: So we just at that point handed us all over to God and said, "Show us what to do." We have no idea what to do. Show us what to do." And so, we come home...a long ride from Asheville. (TR 4 16:45).

Jackie explained that after giving their daughter to the Lord, they started seeing signs that the Lord was working for her, beginning with the peace and calm they felt after their prayers. Jackie said the signs were everywhere – the ease with which she found information online, even though she was not good with computers; the kindness and clear explanations from the Vanderbilt people, as well as literal signs along the way:

J: Um. You know, everything was going smoothly and it was amazing because we would just see signs everywhere...We would um, be going down the road and we would just see a tour bus that would say "Nashville" on the side of it....

V: Right

J: Or we'd see things that would say "Vanderbilt" or I mean, to me, that's not a coincidence. When you don't see things like that and then they're just there - they're everywhere....

V: Everywhere

J: It's just like, this is the right thing, you know...

V: And at this point, is it the right thing to go to Vanderbilt to learn to or to go to Vanderbilt to have the surgery?

J: To go to Vanderbilt. And so, so we thought, for instance, we went out to eat at a restaurant in Spartanburg, and you know, as soon as we pulled in to the parking lot, you know there's cars everywhere, and we pull in to this spot to park and the car in front of us has a tag on the car that says "Expect a miracle!"

V: Wow.

J: You know?

V: And it just...

J: And we just sat there and just cried, you know, out of joy, because we knew that it was going to be ok.

V: Yeah,

J: And no matter what happened, it was going to be ok. The Lord was doing something...he was working, he was moving and it was just going to be ok

V: Right - these were signs of that...

J: Right! And there was no doubt, in our mind, that He was leading us, and that He was showing us what to do, and you know.... When I tell the story, you know, just in day-to-day life, and you know, none of us are the Christians that we need to be, and we all fall short, and we all mess up, but...you try...you know, but I have never ever been so sure of anything in my life...I've never felt so confident in something. I felt confident I was going to have that surgery. And I felt confident that Hannah was going to be fine. There was no doubt in my mind...

V: Right

J: ...umm.... that the Lord was going to USE the doctors to fix this...she was going to come out and she was going to be fine. (TR 4 21:04).

Jackie and Rob's story took a dramatic turn for them, when their insurance coverage for the procedure fell through just before they left for Nashville. Their faith in God's guidance and God's plan did not waver, though they did not have the \$25,000 needed up front before the doctors would begin the \$45,000 procedure. Their community had begun offering travel money before they left, and so they went to Nashville with \$500 in their pockets to begin the three-day consultation process, sure they were supposed to have the surgery. "I knew we were gonna have that surgery. I knew she was going to be fine. I never doubted for a second. And only God can give you that kind of assurance." (TR 4 49:01). And while Jackie and Rob went through the counseling process and met with ethics consultants, their community rallied to support them. Within three days of having left home, the community began sending money to Jackie's in-laws to pay for the surgery. Jackie got a call from her mother-in-law on Monday evening, and, according to Jackie,

J: She [Rob's mother] said, "My bar is covered with money." I said "What do you mean covered with money?" She said, "I mean, covered with money. We are standing here counting money." And I said, "But um..." She said, "We're counting." She said, "People have been coming all day." What happened was, that our insurance, which would have paid for me to have an abortion *because of* the spina bifida, but they would not pay for the surgery...

V: Right?

J: Well, that lit a fire under our community, my community. And um...everywhere. (TR 4.1 55:39)

When I asked Jackie, to clarify, if she thought people donated money because of the abortion coverage, she said "I think it was because God knew I was going to have this

surgery and He was providing a way for it...and this was how, you know. Um, I didn't know any of these people...they just came" (TR 4.1 57:10). They had the \$25,000 before the surgery, and everything was paid for before she left Nashville "I never paid Vanderbilt one penny out of my pocket." God worked through every aspect of getting them to Vanderbilt, getting them the surgery, and healing their daughter through the surgeon's hands. Jackie explained to me that whenever she meets people, because there are some, who tell her they don't believe in God or believe in miracles, she tells them her story,

J: And that's my cue, you know, to say, "You know, look at this picture! She's...this is a miracle. Let me tell you... this story. Let me tell you what God can do for you if you let him."

V: Yeah

J: And not, like I told you, not because me and Rob are anything special [gets teary], not because we're any more important than the next person...but I believe it's because we believe in God - because we have our total faith in him - and because we knew, we prayed, what he was capable of doing.

For Jackie and Rob, their faith was proved ("redeemed" in Bliton's terms,⁶ "verified" in James's⁷) by the positive outcomes for their daughter: she was born at 32 weeks with full leg movement, full bowel and bladder control, and only a tiny amount of fluid in her ventricles, which has never needed a shunt. She went home at 33 weeks, healthy and hale, and during our interview, came in from playing soccer with her team in the rain. Jackie and Rob say they "know" that God healed her, and they "know" that she no longer has spina bifida – does not have any kind of disability. They believe that their decision was made not at Vanderbilt, but in the car after their initial diagnosis, when they decided

⁶ Bliton, "Parental Hope," 601.

⁷ James, *Pragmatism* 87-88.

to give their daughter to the Lord entirely, and *that* decision, to rely on God, allowed God to do His work. All of the trials along the way, including the insurance complications, were simply so God could show his work in healing their daughter, but as she explains,

J: But you know, because of our mentality - the Lord had a bigger plan. And the miracle wasn't only going to be that Hannah was going to be fine. But the miracle was going to be how...how it all come about. (TR4.2 41:36)

Jackie's daughter, Hannah, was a "miracle" for the whole community, and proof of God's power and care for them.

Jackie and Robb's faith, like Lila and Dan's required them to act, as James would say, *as if* what they believed were true and in doing so, their faith made it true.⁸ For families like the Huttons or the Slaters, their situation, their stock of knowledge and faith determined how they understood their circumstances. Their belief in God's plan determined their choices among available actions, whether it was rejecting the possibility of abortion to following the signs that are clear and obvious to them. Their social contexts and communities, key elements in their biographically determined situation, reinforced their interpretations of God's plan, and for the Huttons, their daughter's healing is an ongoing testimony to the community. These beliefs, rooted in their biographically determined situations and reaffirmed in their social contexts, also contributed to what Schutz and James would call the definition of a situation and to how that definition determines decision-making.

⁸ James, "Will to Believe," ; William James, *The Will to Believe and Other Essays in Popular Philosophy, and Human Immortality* ([New York]: Dover Publications, 1956) 474.

Decision-making: Defining the Situation at Hand

Though the women I interviewed did not begin by asking “What kind of a situation is this?” their definitions of their situations tended to emerge from our conversation in one of two ways. First, some defined their experience with spina bifida and open-uterine surgery as a situation that requires faith and recognition of God’s plan to make a decision. In the second, women defined their situation as one that requires self-education and reflection, which may also include prayer and faith. How they defined the situation at hand strongly influenced that they saw as available options and how they understood what kind of decision they had to make. For some, this definition affected whether they found the ethics consultation process helpful or not. As described above, for example, both Carin Miller and Cathy Johnson talked about giving their decision to God by praying with their families and church communities. While Cathy Johnson saw God’s signs in the clarity of the medical information and consultations, Carin and her husband came to their decision through prayer alone, through recognition that such uncertainty demanded God’s guidance. For Carin, the ethics process was less helpful for their decision than the peace they got through prayer. It was, as she said, a decision that was not really a decision – they just gave it to God. Mandy Ball told a similar, though more elaborate, story of a decision that was not a decision, of a situation that demanded recognition and belief rather than deliberation or questioning. Mandy’s story exemplifies the first, and in my interviews the most frequent, definition of the situation while considering open-uterine surgery.

Mandy Ball's Story: Defined by Faith

Mandy's experience with open uterine surgery to repair spina bifida began before she even got the diagnosis during her first pregnancy. She had gone to the beach with her husband and another couple while awaiting her AFP test results, and she came across a *People* magazine with an article about prenatal surgery at Vanderbilt University. She was fascinated and kept returning to the article, showing her husband and rereading it. When their AFP test results was abnormal and she got a diagnosis of spina bifida from the high-risk OB, who told her she needed "to terminate the pregnancy or accept the diagnosis," Mandy was the one telling *him* about the "third option." From the moment of her diagnosis, she knew she was supposed to have that surgery. She explained,

M: BUT my whole thinking, from the time I...realized that Mark had, that the baby had spina bifida, was that "I'm gonna have the surgery." because my reasoning for that was, "God showed me this in this article. Why did he show me this in this article?"

V: Right.

M: Days, *days* before I find out my baby has spina bifida...I'm supposed to have surgery." SO, that was my thinking. And pretty much, I don't think there's anything that could have talked me out of it at that point. (TR 11.1 13:05)

Mandy wasn't worried about the risks to her, about the risks to the baby – she recognized this as being a situation for faith. She explained, "I felt like God has his hand in this, and I'm supposed to have it. And yeah, there are these other risks, but I don't think that's going to happen to me because God chose me..." (TR 11.1 20:14). Mandy knew what to do from the moment of her diagnosis, and saw the magazine article as God's way of preparing her for the open-uterine surgery and her son's disability. She said, "It was like - everything was put there for me, to prepare me before I ever even knew what spina bifida

was, I was prepared. And that's what I felt like He did.” (TR 11.2 41:20) Mandy was so sure of her decision to follow God’s guidance towards the procedure, that when the ethics consultants at VUMC asked her to share her reasons for wanting surgery, the questions felt like an unwelcome challenge to her beliefs, to her understanding or definition of the situation. She explained,

M: But my...um, what I got so upset about...was that MY reason for having it was not a good enough reason.

V: Huh.

M: That's the way I felt.

V: Ok.

M: Because I felt like GOD had intervened in this and that GOD had brought me to that point that I was there...and that wasn't a good enough reason.

V: Ok. They were looking for what? Something more?

M: Yeah, to me it seemed like they were looking for something more...medical...

V: Like you have a medical reason for doing it?

M: Exactly! Like, they wanted me to say I'm going to do this because I think this is going to help my baby.

V: Right

M: And I definitely was going to do this because I thought it was going to help my baby, but the REASON I felt like it was going to help my baby was because of how I found out about the surgery...I felt like God was leading me there. And I also believed that there could have been, that God could have intervened and showed me, NO, you are not, you SHOULD NOT have this surgery. And I think that probably is the case for some people...when they're making the decision, and they DON'T feel like God's leading them and that's NOT the best option. (TR 11.1 22.03).

Mandy recognized that not everyone has a similar experience of assurance, and that, in fact, her situation could have changed, if God had not wanted her to have the surgery. She was upset and “hurt,” however by the questioning of her understanding because she did not think the ethics consultants shared her beliefs (TR 11.1 27:39). She felt like they were challenging her reasoning because it was religious, as though her understanding of the situation needed to match theirs. Though her reflections on the ethics consultation process will be discussed more fully below, in Chapter VII, they are helpful here in contrasting Mandy’s definition of the situation with even the medical or ethical definitions that require investigation, questioning, and reflection.

The decision that was a recognition, an acceptance, rather than a choice figures prominently in several women’s stories and though important to women’s experiences, occasionally became a challenge to other definitions of the situation at hand, such as clinicians’ understandings. For example, Lila and David Slater saw their situation as one where faith would guide them, where God would point out the path, and Lila became quite vehement with the ethicist and other clinicians, just as Mandy had, when she defended their recognition of God’s path. Jackie Hutton had a similar experience when one of the doctor’s told her, “Well, regardless of her surgery, doctors are going to be her [daughter’s] best friends.” He defined the situation in medical terms and Jackie took exception to his definition:

J: and I said, " No they won't." I said, “No they won't." I said, "I'm here expecting a miracle. And I said, the Lord led me here. I'm here because he has me here. And he is going to use you to fix this." [Dramatic pause]

V: He is her best friend?

J: *Right*. And I said, "Ya'll want to fix what's there...And he's going to do the rest, and she's going to be fine." And I have never felt such confidence.... (TR 4.1 48:42).

Confidence, for Jackie and for Lila, was even further proof that their definition, their understanding was accurate and that God's will was working through them and around them. The definition of the situation determined the kinds of decisions they had to make, including following the signs God gave them, and the kinds of actions they should take, such as choosing the surgery.

In contrast to the women who defined their situations and decisions as requiring nothing but faith and recognition, other women defined their situations as requiring education and reflection for a good decision, though this did not preclude the need for prayer. Angela Dominguez, for example, looked into the open-uterine surgery with the interest, and critical eye, of a medical researcher. She was 35 years old when she got the diagnosis of spina bifida in her second pregnancy, with a six-month-old son, a mother who had just been diagnosed with colon cancer, and with less than 2 years in her first position as medical faculty at a major research institution. For Angela, the situation was defined by multiple social and financial factors as well as multiple medical concerns. These were more prominent in her story than the opposition to abortion and decision to continue the pregnancy that was rooted in their Catholic tradition. She explained,

A: Well, we're practicing Catholics, and I really don't...I really don't. I'm a physician and I see patients and people have diseases and people have illnesses and I decided what was it we were going to have, we were going deal with it. And deal with it the best way possible. And so, we decided not to. Termination was not... (TR 5.2 4:30)

Angela and her husband began educating themselves, visiting multiple specialists and trying to "learn all the details." Angela explained that "Even though I am a physician, I

have never had to deal with a patient with spina bifida, or didn't know much about it, more than what I learn in medical school and all that..." (TR 5.2 3:51). For Angela, the lack of medical information, or lack of proven benefit was a deciding feature, a defining feature of the situation. She said, "and it was just...if they would have told me, this surgery will cure your daughter, I would have done it...but with the only possibly, *maybe* reducing the hydrocephalus part then..." (TR 5.2 21:57) the benefit wasn't enough. Though her religious beliefs guided her away from the possibility of abortion, Angela defined the situation, her experience with decision-making, in terms of medical information and predictions, familial, and financial obligations.

Erin and Dan Strickland made a similar project out of educating themselves, defining their situation in terms of education, questioning, and reflection, which included prayer and faith. Erin said that in spite of its intensity, the three-day process of consultations and conversations at Vanderbilt was extremely helpful as a process of education, helping them understand what they were facing. She said they learned more about spina bifida at Vanderbilt than at any other time in their journey, and that she often recommends other women to the program, even if they aren't interested in the prenatal surgery, just to learn. Erin said that the ethics consultation process was among the most difficult and helpful parts of their experience, because the ethics consultant asked the hard questions that needed to be asked about their situation.⁹

Erin also described another encounter that proved crucial to their definition of their situation, including their understanding of their daughter's diagnosis, their decision for post-natal surgery, and their parenting from that point forward. Erin and Dan met with

⁹ Erin's account of and evaluation of the ethics consultation process will be discussed more fully in Chapter VII, below.

the director of the NICU, to talk with him about their uncertainty regarding their situation and their daughter's future. Erin said that they had recognized him as a Christian, and while they appreciated the ethicist's thoughtful questions and even his probing of their religious beliefs, they wanted to talk to a fellow Christian about their doubts and uncertainty. The NICU director, first and foremost, was available to them, which impressed Erin and Dan as few other doctors have before or since. He spoke with them in their terms and of his own experience, and helped them see that their daughter "had much to celebrate" in terms of her abilities and what she would teach them. He told them they should let their daughter be "self-limiting" and that they should strike the word "can't" from their vocabulary. The NICU director's encouragement and positive perspective on their daughter's prognosis helped them define their situation more optimistically. In particular, Erin and Dan recognized that the forward momentum to "do something," was influenced by the dismal diagnosis they had received in Arkansas and the NICU director helped them look at their daughter's possibilities as having "much to celebrate" instead. As a result, Erin and Dan made the decision not to face the big risks of prenatal surgery: the risks compounding her disabilities by at 12% chance of prematurity or a 5% or 1 in 20 chance of losing her altogether from fetal death during or shortly after the surgery. For Erin and Dan, the conversations with the ethics consultant and with the NICU director helped them redefine their situation in terms of possibility, rather than disability, and make a decision consistent with that new definition, that deepened understanding.

Each woman's or family's definition of their situation shaped their decision-making approach – what counted as "live options" in terms of abortion or continuing the pregnancy, for example, and what counted as evidence or support toward prenatal or

postnatal repair. The definition of the situation – as one of faith and recognition or one of education and deliberation – influenced whether they found the ethics consultation process – the three days of consultation and conversation – helpful or not.¹⁰ Their definition of the situation also influenced how they described their experiences after making their decision and what they see as key elements in their moral experience now.

Living with Decisions: Expanded Stocks of Knowledge

Schutz and James describe the stock of knowledge at hand as plastic and expandable, but warn that it does not expand easily. One's stock of knowledge at hand, one's biographically determined situation, and the pragmatic character of one's cherished beliefs shape the definition one gives to a situation and the experience of decision-making. They also expand the stock of knowledge at hand to prepare for new challenges in new situations, new experiences, which can often be more important than the particular moment of decision. For many of the women I spoke to, the focus over the years has been less on the decision they made and more on living with the consequences in the aftermath of that decision: learning about and taking care of the particular presentations of their child's spina bifida and preparing for future uncertainties. Angela Dominguez and Dottie Geller, for example, both made their decision based on family circumstances and on hope for the best outcome – and when I spoke to them, both were concerned with their child's continuing medical concerns and emerging social issues more than with revisiting or second-guessing their decision for prenatal or post-natal repair.

¹⁰ Which will be discussed more fully in Chapter VII below.

Angela Dominguez's Story: Living with Spina Bifida

For Angela, the minimal benefits of the open-uterine surgery did not appear to be worthwhile when she weighed other circumstances, including family, financial, and work concerns. She explained that with the social complications in their lives and after learning that she would have to be on 12 weeks of bed rest, Angela decided “There were just too many things for me to do...plus I did not feel the benefit for her was so significant” (TR 5.2 17:35). Angela has moments of doubt about her decision, even if not regret. In our interview, Angela reflected out loud,

A: And I, to tell you the truth, I don't think I have put together the fact that we didn't do the surgery and the fact that she has these learning problems. Or that one is in consequence of the other...and I will tell that I still, intermittently...even when I made the decision and I told myself, “You are not going to be allowed to ask yourself ‘What if?’”

V: Because how could you know?

A: Exactly. But I still find myself asking “What if?” Not dwelling on it, but just asking, “What if?” (TR 5.2 38:54)

Though Angela sometimes wonders about her decision not to have the surgery, she tries to focus, instead, on what they face now and in the future.

Her daughter's lesion was L5 / S1, and so Christina has had few mobility issues over the years, and no revisions for the shunt that was placed one week after her birth, but they struggle with the mundane but still troublesome social issues such as Christina's disorganization and learning disabilities. More difficult for Angela, as was the case with the other mothers of children with spina bifida approaching pre-adolescence (TR 7, TR 11), was her daughter's bowel and bladder continence, which was becoming a social, as much as a medical, concern. Angela said she was struggling with what to do, looking into

bladder reconstruction surgery and hearing about experimental spinal nerve surgery,¹¹ but wanting to avoid making decisions about colostomy bags or abdominal fistulas that will affect the rest of her daughter's life. When asked if life with her daughter's spina bifida was different than she had imagined while deciding about the surgery, Angela replied

A: Um...I think it is what I expected because I think we have been blessed with her not having at least motor and neurological disabilities...you know as much as another child could be. So we haven't had to make modifications of our household or modification of the car, things like that that other families also have had to do. We haven't had the back-to-back illnesses associated with shunt malfunction, like other families, and that I *know* can happen. So, in that sense...

V: Right

A: But I can tell you, really, it was only like three years ago that Jose and I, or maybe it was...but we really put our guard down with the idea that she would make it. But for the first few years [she] was such a...this fragile doll that I don't know what...not even a child, a doll, a thing, a porcelain thing, that who knew what's going to happen to her? And what's going to happen when she's eighteen or twenty or twenty-two?

V: Right.

A: Now, we know that she's [unintelligible] you know, that she will survive, hopefully. And she will probably take of her brother, not her brother taking care of her, but we're still very concerned about her learning because we want her to...since...live at her capacity, and even with her incontinence, she can deal with that. I want to make sure that she can *socially* deal with the learning of the progression of independence that she should achieve. (TR 5 51:27).

For Angela and her family, the decision not to have the open-uterine surgery to repair their daughter's spina bifida was in some ways the smallest and least important part of

¹¹ Chuan-Guo Xiao, "Reinnervation for Neurogenic Bladder: Historic Review and Introduction of a Somatic-Autonomic Reflex Pathway Procedure for Patients with Spinal Cord Injury or Spina Bifida," *European Urology* 49, no. 1 (2006), 22-8; discussion 28-9. The experimental procedure for neurogenic bladder is beyond the scope of this research, but I have included the primary reference from the National Library of Medicine. The procedure appears to be raising interest among parents of children with spina bifida, including a 'fan page' on the social-networking website, Facebook, and a fundraising foundation, Sophie's Voice Foundation, in Atlanta, GA.

their experience. For the first years, even with minimal motor concerns and no shunt corrections, Angela and her husband were afraid for their daughter's survival and struggled to care for this "fragile doll" with an uncertain future. As they have slowly "let their guard down," about Christina's survival, they are now faced with a complicated future of different uncertainties: social functioning, intellectual and educational milestones, and achieving independence.

Dottie Geller's Story: Living with Decisions

Dottie Geller chose open-uterine surgery for her son, Aubrey, now nine years old, and like Angela, she occasionally still thinks about her decision and worries about her son's future. Dottie's story of learning about her son's spina bifida and choosing in utero surgery was subsumed in a larger family chronicle of ill-health and medical procedures. Dottie was diagnosed with leukemia in her early 20s and was at the end of her low-dose chemotherapy regimen when she discovered she was pregnant. She chose to have a second-trimester abortion rather than discontinue her chemotherapy, a procedure that was both physically and emotionally difficult. After her chemotherapy was complete, Dottie got pregnant again and gave birth to a daughter, Amber, and two years later, Dottie was pregnant with her son, who she named Aubrey. When Aubrey was diagnosed with spina bifida around 21 weeks, abortion was not an option for Dottie, because of how difficult her past experience had been and because, as she said, "unfortunately by that time, he had already moved. He was, in fact, doing flips in my stomach...and he already had a name. So. He was already a person, and I couldn't do that...and also because of that first pregnancy. I couldn't do that" (TR 7.1 3:16). Though she would not have an abortion, she

was heartbroken about her son's disability and when her sister told her about the procedure at Vanderbilt, she borrowed money and went to pursue it. She said, "I was hoping to improve Aubrey's life. I was hoping not to make...well, the converse of that...equation...is 'Am I going to make him have a hellish life?'" (TR 7.1 47:26). Given the uncertainty of the outcomes for Aubrey, however, Dottie felt that even the minimal and merely possible benefits of the procedure offered her something to do, which made the prenatal surgery worthwhile. She explains, tearfully,

D: And I couldn't... I couldn't [gets teary] I couldn't not do something about it. It's like, when you're stuck in a situation you can't do anything about, you have to do something... and this was a situation I could do something about it, so I did it. (TR 7.1 42.12)

Dottie describes herself as someone who "picks at things" and "puzzles things out" and the in utero surgery gave her a chance to do something for her son. For Dottie, the decision did not appear to be that difficult – she just hoped it would be the best thing.

Dottie didn't have any particular religious faith, but just relied on the hope:

D: Well, I was also hoping that technology had...gotten to...a...making life better stage, at this point...

V: Right.

D: Instead of being a technology for technology's sake

V: Right. Yeah. Yeah.

D: Um...It's hard to decide sometimes. Whether it's technology for technology's sake...or if it's actually making life better. So, I was just hoping...I don't know. I was just hoping that he would be...that maybe he would be, he would grow up to be...someone who solved the problems of spina bifida... (TR 7.1 42:28)

Not unlike the writers of the “Parental Voices” essays in Chapter III, who described relying on religious hope in the face of medical uncertainty,¹² Dottie said she “was just hoping” because this was a chance to “do something” and she needed to “do something” for her son. Dottie said one of the really difficult parts of her decision was talking to the ethics consultant, who made her think about whether the surgery was the best thing to do and kept asking her why she thought it might help. Dottie said she still worried about whether she made the right decision – having the surgery, or even not having the abortion – although she avoided going into any more detail about those decisions. She switched her focus instead to some of the challenges Aubrey was currently experiencing and that they were facing.

Dottie, like Angela, explained that the biggest issues for her child were bowel and bladder control, which were more difficult when Aubrey’s time was unstructured, for example, on the weekends. As he was aging, incontinence was becoming more of a social issue, and Dottie was trying to determine what future options, such as surgery or a colostomy, might be available. In looking at Aubrey’s future challenges, she worried about her past decisions. She explained,

D: I don't want him to grow up and have women turned off...by the way he does...and truly, I hope he doesn't have any sexual problems...because it just...that would be bad... So that's what I really don't know, if it was a good thing that I had him or not... but that's what we did. And that's what we have to deal with. And I hope that he doesn't hate me for it. Which he also could. (TR 7.2 41:19).

Dottie also described some of the concerns she has for Aubrey’s social skills, explaining, “That's right. Aubrey is ah.... *off*... he tells jokes that aren't funny. But he tries so hard. So you're like [gestures indicating groaning]” (TR 7.2 1:58). He has difficulty with fine

¹² See Chapter III, pp 78-80 above.

motor skills, as well as with organization and attention. At one point in the interview, Dottie's husband, Jim, chimed in, describing some of Aubrey's issues:

H: Yeah, a little bit of loss of sensation, around there. Bowel movements are the ones that give him the most trouble. Urinary...more or less is convincing him that he needs to go the bathroom instead of playing video games.

V: Right. Which is the task for any kid...

H: His motor skills aren't quite what they should be...he still has trouble, like eating with a fork...fine motor skills.

V: Ok.

H: So eats with his hands and stuff more than anything.

V: Which is also more fun (laughing with Dottie).

H: Yeah I think it is. It's hard to tell what's really a problem and what is him being stubborn.

V: Sure. How old is Aubrey?

H: Nine.

V: But he doesn't have any problems with movement or walking around?

H: Nope. Other than being a clumsy nine-year old, that's about it. (TR 7.1 21:56)

The difficult thing, which Dottie repeated later, is knowing "what's really a problem."

Dottie's anxieties about her son's social functioning – particularly his relationships with women and sexual functioning in the future – were very deep and real, but like some of the questions about her decision-making, Dottie avoided answering by making jokes and rapidly switching topics. As Dottie said, "I'm hoping I did right. I'm hoping because I don't have anything to compare. There's no Aubrey that didn't go through the surgery..." (TR 7.1 53:41). Dottie may wonder, but can only hope that she made the best choice for

her son. And she and her family can only move forward in taking care of his physical and social issues as they emerge.

Dottie and Angela made different decisions about open uterine surgery for their child's spina bifida, but both have come to a similar place in the ten years since that decision. Both women echoed what others have told me as well: it does not help to second guess their decisions, even though the inevitable "What if?" questions emerge.

Mandy Ball phrases this attitude even more passionately:

M: For me, it was beneficial, but I know that there are other people who have the surgery that don't...that may not feel the same way. I don't know. Every time I went to one of the reunions - I never spoke to anyone at the reunion who regretted having the surgery.

V: Right.

M: And that's another thing - we make the decision, we can't regret the decision.

V: Yeah.

M: It may not have done what you think...but you're doing it, you're finding out the facts, if you're making it by educating yourself - you CAN NOT regret it. Because you can't...I don't see how people could live with themselves if they regretted it...because you won't be able to...I don't see how you could live with yourself if you regretted having something done. Say, you lost the baby, I'm sure the people who had the surgery might think at least if I hadn't had the surgery then the baby would still be here, I would still have the baby...

V: For some of those families, it was God's way of taking care of their child...so she wouldn't suffer.

M: Exactly...

V: It's their way to be at peace.

M: Exactly. You have to know that whatever decision you make is the right decision.

V: Yeah, yeah.

M: You can't regret it even if you decide not to have the surgery...you just have to...you have to make sure that you know what you want to do...

V: Right.

M: And what's best for you and your child. Because if you regret it, and I mean, how could you live with yourself? (TR 11.2 45:01)

Part of the process of moving on, of living with whatever decision one makes is the continuing uncertainty of what behavioral, cognitive, and developmental issues are spina bifida related, and what are individual or idiosyncratic. Carin Miller and her husband explained the difficulty in determining where their daughter was developmentally, because she has osteogenesis imperfecta in addition to spina bifida. Carin explains,

C: But looking back, you don't know. With her bone disorder on top of the spina bifida, she's not, she can't...you can't compare her to a lot of the other kids...because we were hit with a double whammy, you know, when we found out she had the bone disorder she was 3 months old... (TR 3 4:28).

Dottie has similar questions about how much of her son's continence issues is related to his lessened nerve function and how much is because he is an easily distracted nine-year old who would rather finish his video game than pay attention to his body. For parents like Dottie, Angela, and Mandy, whose children are approaching puberty, finding solutions to their physical and social challenges – regardless of the cause – were more important than determining whether those challenges stem from the spina bifida, or whether having the surgery or not having surgery changed their child's physiological or behavioral development.

Women's Experiences with Medical, Social, and Moral Issues with Open-Uterine Surgery to Repair Spina Bifida

The detailed and compelling stories women told me in the course of our interviews often carried similar features, as was expected, and yet some of the most important insights came from the particular individual or family experiences. All of the women began their stories reflecting on the diagnosis of their child's spina bifida and brought their stories forward to include their present experiences and projections into the future, sharing key moments or themes along the way. I have tried to signpost these themes, using categories from William James and Alfred Schutz to frame the stories that best illustrate those themes. James's and Schutz's notion of the "stock of knowledge at hand" which expands, with difficulty, in new situations, highlights the devastation that begins with a prenatal diagnosis of spina bifida, what Emily Gonzalez-Abreu described as "fear, anger, and pain."¹³ The "stock of knowledge at hand" also illustrates the process of reeducation that continues for these women into their present and their future experiences. James's pragmatic value of belief and Schutz's biographically determined situation are concepts that illustrate how women make sense of their diagnosis using resources and belief systems from their past experiences, even as the new situation may put those beliefs into question. The idea of recognizing the importance of defining a situation in order to make appropriate decisions illustrates significant differences in how women approach decision-making. This idea of definition also provides a clue to the certainty with which they make a final decision that is consistent with or coherent in light of their definition.¹⁴ Finally, the coherency of their decision-making process is one of the

¹³ Gonzalez-Abreu, "Parental Voices: For Angeline," 519-520.

ways women live with their decision and address new challenges. Choosing among projects of action, as Schutz explains, is a process rather than a simple choice,¹⁵ and for these women, the stock of knowledge that expanded so abruptly with diagnosis continues to expand with the changing circumstances and situations of women's experiences.

The similar structures of women's experiences allows me to focus on the individual stories and the particular insights they offer about living with their child's spina bifida. These unique stories need attention for multiple reasons. First, these stories need attention as a means of valuing the contributions these women have made to the development of open-uterine surgery to repair spina bifida. There has been little follow-up with this cohort of women from the elective series, and most of the women were eager to learn about the status of the procedure and other women's experiences. Second, these stories are crucial for understanding the complexity of the on-going, lived experiences of women who considered this procedure. In most vivid language and examples, these stories show that life with a child with spina bifida is complicated and becomes more so over the years, whether he or she had in utero surgery or not. Though survival and shunt placement, which the MOMS trial evaluates, are important indicators of the success of the procedure, the more complex, subtle, and varied experiences, including physical, cognitive, behavioral and social factors need to be taken into consideration. Investigating women's experiences can expand clinicians' and researchers' stocks of knowledge, deepen their understanding of spina bifida and the effects of the in utero procedure. These investigations might also provide an important resource for women who receive this diagnosis and consider this surgery in the future, giving them a glimpse of life with a

¹⁴ Zaner, "Phenomenology and the Clinical Event," 47.

¹⁵ Schutz, "Projects of Action," 73-74.

child with spina bifida, beyond the numbers and the statistics. Third and finally, women's reflections on their decision-making process offers the opportunity to reflect on and evaluate the kinds of ethics consultation and informed consent processes that are available when considering in utero surgery and other, similarly complex procedures. The women I interviewed gave detailed accounts of the ethics consultation process – whether they found it helpful or not – and such accounts at the very least highlight the need for reflection on ethics consultations and may even help develop a more robust, nuanced understanding of ethics and decision-making in clinical encounters.

The stories in this chapter, with their shared themes of diagnosis, belief and social context, decision-making, and living with decisions, provide access to the unique experiences of women who considered a innovative, experimental elective procedure. The details of each woman's deeply personal story bring the shared features into sharp focus, as features typically overlooked by the medical and ethical discourses presented in Chapters I and II. Because these features and these themes are so often overlooked, they stand in need of further investigation to give clinicians, researchers, and ethicists a fuller, more nuanced understanding of this procedure and women's decision-making. Further still, their reflections on decision-making, including and especially their descriptions of the ethics consultation process, create an opportunity to learn *from* as well as *about* women's experiences with open-uterine surgery to repair spina bifida.

CHAPTER VII

LEARNING FROM WOMEN'S EXPERIENCES

In addition to the complex medical, social, and moral issues of open-uterine surgery to repair spina bifida, women's accounts highlight the importance of ethics consultations in their decision-making. Since Chapter VI focused on learning *about* women's experiences, this chapter will focus on what can be learned *from* women's experiences. In terms of Zaner's method, which I established in Chapter V, the distinction can be understood as follows: Chapter VI identifies what mattered in the particular circumstances as reported by these particular individuals, while Chapter VII reflects on those circumstances as *examples* from which further understandings and additional meanings can emerge.¹ By looking at women's reflections on the ethics consultation process for maternal-fetal surgery, Chapter VII revisits several key concerns raised in Chapters III and V about methods in ethics consultations. After exploring four important accounts of ethics in clinical encounters, along with women's suggestions for ethics consultation and questions of method in ethics consultation, the sections below will explore questions about whether ethics consultation is helpful or harmful to women considering this procedure and how far the commitments and professional obligations of the ethics consultant extend in her effort to help. Due to its clinical uncertainties, and the associated moral and social complexities, the ethics of maternal-fetal surgery raise sharp

¹ Zaner, "Phenomenology and the Clinical Event," 39-40.

questions about professional obligations of ethics consultants. Bliton observes, for example, that the social and moral

dimensions of experience and the potential meanings are even more subtle, more intimate, harder to explain, and thus likely to yield potential criticism of ethics consultations. There exists a discernable tension between two concerns that directly relate to typical ethical norms. As an ethics consultant, I am confronted with the dual consideration of respect and harm in a mutual responsibility shared with persons I am trying to help.²

Bliton's questions illustrate a significant tension often at the core of ethics consultations:

“Is it more harmful or beneficial to identify and articulate crucial factors that remain unspoken, possibly unacknowledged, and perhaps unimagined?”³ Women's accounts in the “Parental Voices” essays and my interviews with women who considered this procedure present an opportunity, then, to reflect on difficult questions about the goals and methods of ethics consultation. This reflection may itself put those methods and goals into question, however, precisely because that kind of reflection and questioning creates the possibility for a more nuanced understanding of what might be at stake in the actual conduct of such consultation.

² Mark J. Bliton, "Maternal-Fetal Surgery and The "Profoundest Question in Ethics" " in *Complex Ethics Consultations: Cases That Haunt Us*, ed. P. J. Ford and D. M. Dudzinski (Cambridge: Cambridge University Press, 2008), 39.

³ *Ibid.*, 40.

Four Accounts of Ethics Consultations

The goals and activities of ethics consultation have been disputed since the emergence of the field,⁴ and different accounts focus on particular understandings of ethics and of ethics consultations. For my purposes here, there are four related but distinct understandings from which to draw when considering the ethics of maternal fetal surgery. The predominant understanding – that ethical issues are sufficiently addressed by informed consent procedures – has been described by Chervenak and McCullough, and this procedure has been instituted at different research institutions investigating maternal-fetal surgeries, as described by Adzick.⁵ On the other hand, Bliton and Zaner have articulated a more complex and nuanced understanding of ethics consultation, designed to address moral and social features that influence decision-making for maternal-fetal surgery. In addition to these two alternate understandings of ethics consultations, I have presented descriptions and reflections from women and their families who underwent the process described by Bliton and Zaner. In the “Parental Voices” essays described in Chapter III, parents identified important themes that emerged in their experiences and that were addressed in the ethics consultation process. The final set of accounts, presented in Chapter VI and in the sections that follow, comes from my interviews with women who considered the surgery and who found the ethics consultation process helpful, harmful, or both. Probing these four accounts can help us learn from women’s experiences with ethics consultation, can help us identify potential benefits and harms of

⁴ *The Hastings Center Report*, *Human Studies*, *The Journal of Clinical Ethics*, and the *American Journal of Bioethics* are only a few sources for articles and essays detailing the concerns and debates about the goals and methods of ethics consultations, and the question of whether core competencies are necessary for ethics consultants.

⁵ Adzick, "Open Fetal Surgery for Life-Threatening Fetal Anomalies," 2.

ethics consultation more broadly, and can help us consider whether this procedure requires a more intensive and perhaps riskier, but more careful and nuanced understanding of ethics consultation.

Ethics as Information and Autonomy

As described in Chapter III, Chervenak and McCullough's understanding of ethics for maternal-fetal surgery, though accepted in many publications and clinical settings, is limited to clarifying medical information and protecting women's autonomy in choosing maternal-fetal surgery.⁶ The focus on autonomy and on the *procedure* for informed consent serves as a shorthand for the multiple and complex ethical issues these procedures raise, and as such, does not address the motivations, influences, and experiences that are the *content informing* women's consent. Women make decisions about open uterine surgery based on more than just rational deliberation of risks and benefits and on more than the assertion of their autonomous right to make reproductive choices.⁷ In this procedure, for example, many women pursued the surgery, predisposed to have the procedure, to "do something" after an overwhelming and devastating prenatal diagnosis of spina bifida. Understanding such powerful motivations seems critical to giving genuine informed consent, yet these motivations are outside the parameters of a procedural approach to ethics. Adzick's descriptions, for example, of the informed consent conference, his focus on risks and benefits, and even his language of "giving

⁶ Ibid., 2; Chervenak and McCullough, "Comprehensive Ethical Framework," 12-13.

⁷ Rothschild, Estroff, and Churchill, "The Cultural Calculus of Consent," 574-576.

permission to decide against the surgery”⁸ raise no questions about even such an obvious moral concern as the predisposition toward treatment with which many couples approach maternal-fetal surgery. This widely disseminated and commonly adopted view of ethics as *limited to* achieving informed consent is *limited by* a lack of consideration of the content of choices that women confront, including the complex social and moral concerns that contribute to that predisposition. While clarification of medical information and protecting the pregnant woman’s autonomy are important aspects of the ethics of maternal-fetal surgery, they do not sufficiently account for women’s experiences and decision-making.

Ethics as Consultation and Consent

Ethics consultations for the elective series at Vanderbilt, in contrast, were carefully designed to give women and their families the opportunity to consider different perspectives on the surgery and to probe their understanding and moral frameworks so they could make the best decision for their family, rather than simply going from conference table to operating table. Bliton and Zaner participated in the design of the process and continually refined it through their numerous interactions with women and their families. At a conference on “Fetal Surgery and the Moral Presence of the Fetus” in May of 2000, Bliton described this method in a set of guidelines for “Attending to Moral Matters in Fetal Surgery.” He identified seven elements that had been part of the original

⁸ Adzick, "Open Fetal Surgery for Life-Threatening Fetal Anomalies," 2.

design and continued to be “crucial, though not necessarily exclusive substantive issues to be discussed with candidate patients, their partners, and their families.”⁹

The first and most basic, but also most important, element is providing time and space. The protocol required 2-3 days of multi-disciplinary counseling, including “time off” to reflect and process information, as a counterbalance to the urge to “get treated and get home.” The more general elements of the ethics consultation process were the inclusion of “significant others” in the informed consent and counseling process, appropriate financial counseling regarding the \$45,000 procedure, and the disclosure of vested interests of clinicians and researchers. Finally, Bliton described the elements required in the “ethics session” itself, including an explicit discussion of clinical uncertainty, an explicit discussion of all forms of coercion and possible influence on decision-making, and the identification and understanding of significant risks and potential benefits. Bliton noted that there is a difference between hope and expectations and that “unrealistic expectations should be revised by thorough discussion of the existing scientific evidence.”¹⁰

In addition, the process of informed consent required discussion of potential harms to both the pregnant woman and her fetus. These considerations of harm became especially prominent because reliance on “autonomy,” while an important element of informed consent, remains limited in its ability to address crucial elements of the specific kinds of choices that confront these women. As Bliton observes,

The *predisposition to treat* expressed by women seeking maternal-fetal surgery frequently has other potent religious and moral meanings

⁹ Bliton, "Proposals for New Guidelines: Attending to Moral Matters in Fetal Surgery," 2.

¹⁰ *Ibid.*, 7

embedded in it. Those attitudes can powerfully predispose *toward* the slightest indication of benefit – even if simply as a matter of hope – and at the same time distort deliberations of risk.¹¹

The ethics consultation process was designed to address these predispositions, to allow women access to the multiple clinical specialists providing them with information, to help women to process and reflect on the information they received about harms and benefits, and to create opportunities for women to consider the decision in light of their beliefs, experiences, and family commitments. At the same time, this process provided an opportunity for the ethics consultants to learn about what concerns – medical, social, and moral – were important for women considering the procedure.

Bliton and Zaner's accounts of ethics consultation present an opportunity to identify several of the complex social and moral issues women face in considering this procedure. These accounts, however, also generate another set of questions: questions about the methods and commitments of ethics consultation, including the potential for harm from ethics consultations. Bliton and Zaner argue that paying attention to the social, moral, and often religious influences on women's decision-making is as crucial to genuine, ethically sound informed consent as clarifying the potential medical benefits and harms regarding maternal fetal surgery.¹² Reflecting on the possibility that such questions may be distressing or even harmful to women, Bliton and Zaner's efforts to probe these factors require the ethics consultant to be attuned to, to identify, and to consider morally relevant types of harm.¹³ For example, at what point might the probing of the ethics consultants' questions become perceived as harmful to the patient or potential participant

¹¹ Bliton, "Life before Birth," 454.

¹² Bliton and Zaner, "Cutting Edge," 346-348

¹³ Bliton, "Life before Birth," 455.

in research? How might we balance that question with another that asks whether the risks of physical harm from surgery are significant enough to require that women meet with ethics consultants and risk other perceived harms that may emerge from considering these social, moral and even religious factors?

These questions about harm emerged sharply in the Vanderbilt series offering open-uterine surgery to repair spina bifida as an elective surgery. The ethics consultants were concerned both with the potential physical harms to women and their fetuses from the surgery, and with the possible emotional harms from engaging in the social and moral questions about women's commitments, beliefs, and values. This set of questions about the kinds of harms that might need to be identified and addressed becomes even more important in emerging situations where a pregnant woman can be offered – and has the autonomous right to choose – a maternal-fetal surgery that will create serious risk to herself and for the fetus.¹⁴ Though the potential physical harms have been identified in Chapter I above, looking to both the essays from the “Parental Voices” symposium and the interview transcripts from my research can identify and highlight some of the other potential harms, as well as the potential benefits, from ethics consultations.

Ethics Consultation and the Challenges of Making Sense

The “Parental Voices” essays identify important themes and features of decision-making in couples' experiences with open-uterine surgery to repair spina bifida. For example, as described in Chapter III, families identified deep emotional pain from their

¹⁴ Olutoye, "Fetal Surgery: Coming to a Center near You?," 67-69.

diagnosis experiences,¹⁵ the importance and influence of faith on their decisions,¹⁶ their deep motivation to “do something,”¹⁷ and the important influences of family and community, and of clinician interactions. Though very influential in couples’ experiences, these themes exceed the frameworks of non-directive, information focused, physician-led counseling procedures in the “Comprehensive Ethical Framework” offered by Chervenak and McCullough and instituted by Adzick and other maternal-fetal surgeons. These themes and features are outside the purview of such *procedural* informed consent, yet they need to be addressed, as they were in the Vanderbilt ethics consultation process, if clinicians are to help pregnant women and their families considering the procedure. Though more difficult to identify than women’s comprehension of clinical details, these themes and features may be the most influential elements of decision-making, *informing* women’s decisions long before the informed consent process begins.

Identifying and addressing the social and moral features of women’s decision-making may be more difficult than a procedural approach to informed consent, requiring more focused, reflective engagement from the ethics consultant, but engagement with these difficult and influential themes comes closer to the ethical core of “informed” consent. For example, as Zaner says, the hard questions were designed to gauge women’s understandings of the clinical circumstances, but also to identify what themes were

¹⁵ Gonzalez-Abreu, "Parental Voices: For Angeline;," 519-520; Kennedy and Kennedy, "Parental Voices: Our Journey of Grace," 534.

¹⁶ Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 530; Zaner, "Parental Voices: Randal Lewis Morris Was Born," 560.

¹⁷ Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 529-530; Lyons, "Parental Voices: One Parent's Thoughts," 540.

important and to ensure that “each couple understood as much as possible” and that they could “more reasonably than otherwise give genuinely informed consent, if that’s what they decide, or to refuse the offered surgery in an informed a manner as circumstances permitted.”¹⁸ Parents were trying to “make sense of their personal decisions inasmuch as those decisions conform to what they hold sacred and important in their lives,”¹⁹ according to Manuel Gonzalez-Abreu, and the clinical ethics consultation process that Bliton and Zaner helped institute was designed to help parents identify what was important in making those personal decisions.

Most of the writers of “Parental Voices” essays were appreciative of the Vanderbilt ethics consultation process that encouraged them to reflect on their concerns, values, and experiences. They acknowledge that the opportunity to discuss openly the clinical information, as well as their more elusive concerns and values, was helpful. At the same time, the families acknowledged that the ethics consultation process was challenging. Thus, the tension in Bliton’s question still remains: is it beneficial or harmful to raise questions about disability, belief, motivations, family, and emotional responses to their fetus? The Williamson’s description of the ethics consultation process captures that tension clearly:

it was the first time the hard questions were posed to us from a source other than ourselves. This was a very beneficial process because, by enabling us to verbally articulate our decision-making process to another person who asked relevant questions, this meeting *forced us to make sure that we were thinking through our choice carefully*” (italics mine).²⁰

¹⁸ Zaner, "Parental Voices: Randal Lewis Morris Was Born," 559.

¹⁹ Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 530.

²⁰ Williamson and Williamson, "Parental Voices: The Positive Impact of Medical Professionals," 515.

The sense of being “forced” to weigh the multiple and complex features of their experience was difficult, but being “forced” to articulate their decision-making “enabled” the Williamsons to proceed with the surgery confident they had considered their choice carefully. Though “force” is often understood as harmful, in the Williamson’s experience, being “forced to make sure we were thinking through our choice carefully” proved beneficial. While the writers of the “Parental Voices” essays described the ethics consultation process as beneficial in thinking through their decision, for some of the women I interviewed, being “forced to articulate our decision-making process” proved less helpful. The tension between the potential benefit and the potential harm of ethics consultation, highlighted in the Williamsons’ essay, emerges even more sharply in the interview transcripts from my research.

Ethics Consultations as Helpful or Harmful

When asked about their participation ethics consultations, the women I interviewed offered a variety of descriptions including beneficial, hurtful, and challenging. Some women provided detailed descriptions of the ethics consultation process, explicitly identifying what they considered helpful, or, in some cases, what they perceived as harmful. Carefully probing these women’s accounts of ethics consultation and their decision-making can lead to concrete suggestions for future practice and raise relevant questions about the methods and goals of ethics consultations for open-uterine surgery to repair spina bifida.

Perceptions of Ethics Consultations as Helpful

Most women described the clinical ethics consultations as helpful in providing time for reflection and clarifying the medical information and clinical circumstances in which they found themselves. They also described the consultations as helping them discover or reaffirm how their values and beliefs influenced their decisions, and providing the opportunity to deliberately communicate with their partners, making decisions that felt congruent with their beliefs or coherent in light of their values.²¹

Erin Strickland gave one of the more detailed descriptions of the ethics consultation process, including her appreciation for how it helped her make a decision with her husband. Erin and Dan were surprised that the process included questions about “how they were doing” along with their understanding of the medical facts. They appreciated, in particular, the time the ethics consultant provided for reflection. Although Erin described some of the questions as “jarring,” she valued the opportunity to consider other viewpoints and perspectives. She described her encounter with the ethics consultants and the process positively:

E: He [the ethics consultant] was very good at what he did. I'm a scientist myself and I'm used to looking at data, and I liked the way it was handled and presented at Vanderbilt.

V: Ok. What about it? How was it presented to you?

E: um...Well, I guess it depends on...different kinds. I mean, I liked that...well, we were first of all interested, and we assumed that we would just be meeting with medical people - and they had us meet with him [the ethics consultant] and they also had us meet with a lady, and I cannot remember what her role was?

V: Might have been social work?

²¹ Zaner, "Phenomenology and the Clinical Event," 47.

E: Yeah! Social work. And we were like, "This is weird, why do we need to talk about..."

V: Family structure and your financial setting and...

E: and "How are you guys doing with this?" kind of talk... You know what I mean?

V: Sure.

E: But, then we thought - and they explained to us... "We feel like, I mean it's not required yet, but we just felt like we have a responsibility to make informed decisions and that someone is, that you have someone to bounce questions off of and you have someone to even maybe present questions..." "Have you considered?"

V: Right.

E: And they asked very hard questions, but at the time, we were welcoming that because we were in this kind of processing, digesting, chewing, you know what I mean? Going back to the hotel room every night, going, "OK, what did we hear? How does this influence?" And so we appreciated that instead of saying, "You come here for a consult and 24 hours later you're on the...we're doing it." We were actually...what we were told at the beginning was that there was a little bit of time element crunch, like we needed to quickly act...

V: Because you found out at 24 weeks?²²

E: Right. So they were like "you need to quickly act" and we got there, [the ethics consultant]...he said, "You just need to realize you need to *slow* this all down mentally. Because you have a lot to process. And this decision should *NOT* happen quickly because it is a permanent decision that you're going to bear the weight of...for longer than you have to make the decision."

V: From now on.

E: [laughs] You now what I mean?

V: Yeah. Yeah.

E: So you all need to take the time element out and say "I've got to make the best decision."

²² Erin later revisited and revised her timeline. She was 24 weeks gestation when she and Dan went to Vanderbilt, but had received the diagnosis around 18 weeks.

V: Right

E: And then after he said all that, we were like, "That really makes sense." and so that was that...

[dinner is served]

E: And then, like I said, he asked some questions that we were like, "OK, somebody else that might even jar me or hurt my feelings."

[both laugh]

V: Right. He has made me cry more than once in my years under his tutelage

E: But he's a professional, that's he's just...he's bringing in points, and so I don't ever...I mean, I don't ever feel threatened by people presenting other viewpoints or whatever. And I never felt like he was arguing with us or anything like that – he was making sure we were getting a full 360 perspective. (TR 9 9:03)

The process allowed Erin and David to consider the viewpoints and perspectives that may not have been immediately apparent to them, that may not have been part of their “stock of knowledge at hand” or “biographically determined situation.” And the intent of the process – helping them think through the complex features of their experience – was clear to them. Erin and David appreciated being offered time to consider, instead of going straight from medical consult to operating table and they decided not to have prenatal surgery. They reported that their experience with ethics consultation was positive and that they felt “at peace” with their decision, a sentiment that was also typical of other women’s descriptions of “good” experiences with the clinical ethics consultation process.

In a similarly positive reflection on ethics consultation, for example, Jackie Hutton and her husband Rob found the process similarly helpful – and similarly difficult. She explained,

J: I mean, I guess it's like when you were talking to me - if there were doubts there, you know, he [the ethics consultant] would help you think about them...and if it was just "Me, this is my agenda, this is what I wanted" versus "This is what's right" and "This is the best thing"...because, I mean, that is a good thing. Because that is a major decision, and years later, you go back and think "Oooh, I wish I'd done or I wonder if I wouldn't've done this or wouldn't've done that..." You know there's a lot of decisions in my life that I think that about, you know. But...

V: But this is not one of them.

J: This is not one of them. (TR 4.2 1:16:57).

Jackie said she knew, without a doubt, that she was supposed to have the open-uterine surgery, but she also saw the benefit of thinking about difficult issues in such a major decision, in being prepared for the future when you might look back and wonder about your decision. For Jackie, the ethicist's questions helped reaffirm her assurance and her commitments, her certainty about her decision. She reflected,

J: There was never a pause...there was never a question...that I didn't just know the answer back to...

V: Yeah.

J: And like he [Rob] said, I think...

V: So was it helpful to talk all those things out?

J: I think it was....I think it was because...[pauses]

V: For some people it's supposed to be helping them figure it out, but you already knew...

J: But I still think that it was, because it gave me a sense that each time it was like.... [significant look and brief pause]

V: "Oh yeah"

J: "Oh yeah" I mean, because I know, when we went out of there, it was like "Where did that come from?" You know? I told Robb, "From within *me*? Where did that come from that I said 'oh no, doctors will not be her..." you know, where did this empowerment inside of me come from, to know

that I could just be so confident, to know that I could say "This is how it's going to be." (TR 4.2 1:03:53)

Being able to think about and knowing how to respond to the ethics consultant's questions reaffirmed Jackie's understanding of the situation and her sense of being guided by God's will.

Lila Slater had given a similar description of her experience, that she and David had come to Nashville following the signs that pointed towards surgery, and so I asked her about their experiences with the ethics consultation process. She talked about the four days of consultation and evaluation, and I tried to learn what she thought of the process:

V: You all came down there knowing you were going to do this...this was the path...as far as you could tell, as far as everything...

L: But willing to let that door be closed...willing.

V: Uh huh...

L: But it was good. It was good to be challenged. It was good to know up front to know the things that were going to come, as far as the NICU and possible early delivery and bed rest and...monitoring, because they did tell you about that.

V: Uh huh...

L: It was a good process to understand as much as you could understand about exactly what you were doing ahead of time. And to be challenged... Because I could go away with it and the slate was clean and I could see every piece that we possibly needed to make that choice...and it wasn't some willy-nilly fly-by-night decision.

V: Ok.

L: And it was good. Because there were times we we're like 'umm...ok... [makes a face indicating doubt] and we prayed through, what was the discussion, and the question and David and I talked about it and we were like, we're on board, we're together. And it was EVERY step of the way he and I were together. (TR 8.3 23:01)

For Lila, getting all the information from the medical experts, being challenged by the ethicist's questions, and working through their doubt together helped she and David know they had seen "Every piece that we possibly needed to make that choice."

Though Lila, Jackie, and Erin all found the ethics consultation process challenging, they all said they appreciated the questions – whether those questions helped clarify what they were looking for, helped affirm their pursuit of the surgery, or provided the opportunity to communicate with their partners. The women specifically identified the process as helpful in terms of education, of clarifying understanding of medical issues, and as helpful in providing time, slowing the "forward momentum" toward surgery that had been building since the moment of diagnosis. Talking with the ethics consultant, responding to the probing, challenging questions was interpreted as doing "the hard work" at the front end, giving them what Lila called a "clean slate" to move forward, or interpreted as difficult but helpful when the ethics consultant, as Jackie's husband said, "was wanting to get in her head, wanting to know what she's basing her decision on" (TR 4.2 1:02:30). The process was also helpful, according to Erin, in giving them a larger view of their decision and helping them prepare for questions from others about spina bifida, about the surgery, and about their choice. Erin explained,

E: Right. These are professionals...and so, that didn't bother me...and I did appreciate the questions that he had and I appreciated Vanderbilt being supportive and the importance that it placed on the whole person - the whole person's understanding and bringing them to the point where they were able to make a good decision.

V: OK. Good.

E: I don't know. I think our decision... I can't say for sure if our decision was impacted by all those conversations. I'm sure it influenced, but I can't say it would have been different if they didn't have that...but just the education process....since then...how much we learned during those three

days at Vanderbilt...was 90% of the education we received about spina bifida...during our whole...

V: The whole rest of the time.

E: I tell everybody, even if you're not considering it [the procedure], you need to go there for the education you receive. And you know, I've used Vanderbilt's approach...in the questioning... because as you might imagine, once you have a child with special needs, you become the person who gets the midnight call when someone else gets the diagnosis – and I have to do, as a layperson, what you have to do as a professional.

V: Right.

E: Like, asking them the right questions and kind of helping them...and that is how, Vanderbilt – their methods of questioning and bringing you through this has strongly influenced the way I counsel women. (TR 9 11:14)

While Erin found the process at Vanderbilt helpful and even models the practices in her role as “local spina bifida expert,” others found the same process of questioning and “bringing you through this” difficult and challenging, at best, and at worst, hurtful.

Perceptions of Ethics Consultations as Harmful

For some women, questions probing their decisions about the surgery or the values underlying those decisions were perceived as too challenging or difficult to be helpful. For example, Mandy Ball, who knew from the moment of diagnosis that she did not have to make a decision about the procedure, that God chose her to have the prenatal surgery, did not find the ethics consultation process helpful. While others saw the probing questions as attempts, in Zaner’s words, “to help them gain renewed understanding of

their circumstances and moral frameworks, especially to appreciate how the variety of potential aftermaths might fit into their lives,”²³ said she knew

M: ...that their job was to try to talk to me out of the surgery...I think that if you're wanting to have it, then their job is to try to talk you out of it...

V: Or at least make sure that you've thought about everything?

M: Exactly! For liability reasons. That they don't want to be liable. That Vanderbilt did not talk me in to the surgery. And I UNDERSTOOD that...they did not talk me into the surgery [laughs] not by any means did they try to talk me in to the surgery. I felt like they were trying to talk me out of it. (TR 11.1 22:48).

Mandy perceived the ethics consultation as a formality to protect the hospitals' interests rather than a process designed to help her consider different aspects of this decision. She resented questions that she perceived as challenging *her* accounts of *her* experiences and decision, questions she even perceived as attacking her faith. In her own words,

M: Yeah. And when I was there in there...talking about the ethics...these two men...two grey-headed men...

[both laugh]

M: And uh, they were very scientific, scientifically... and I was just... “How dare you question my faith? This is what I believe.” That's how I felt about it.

V: Did it feel like they were questioning your faith, like saying that wasn't valid or something?

M: Right. I felt like maybe they didn't believe in God. So, that was kind of how I felt a little bit.

V: Would it have...mattered if they did? Like, would you have felt better about their asking?

M: It probably would. If I had felt like they were Christian, then...

V: You could have talked about this?

²³ Zaner, "Discovering What Matters in Fetal Surgery," 2-3.

M: Yeah, yeah, I do. For me. And not everyone is Christian, that comes there and decides. But for me...that would have made it a whole lot better for me, if they could have acted like they understood, instead of saying...."You keep talking about God, talking about God. Are we going to be able to change your mind? It doesn't seem like there is anything we can say to you to change your mind."

V: Hmmmm...

M: And I said, "No, there's nothing you can say that would change my mind. You're a man. And my faith is in God."

V: Right. Right.

M: I remember saying that to them, and them saying "OK"

V: Well, at least they took it well!

[both laugh]

M: I mean, they weren't mean...I just felt...any time someone questions your thinking...about that? It's hard. That is hard. I mean...it is hurtful for me to hear people who are non-Christians talking...because it's against what you believe... (TR 11.1 26:23)

For Mandy, the ethics consultants were upsetting because they appeared dismissive of her faith, or appeared to be challenging the reasons she was gave for pursuing the in utero procedure.

Mandy's perception of the ethics consultants' probing questions about her beliefs and motivations as "hurtful" illustrates a potential harm of Bliton and Zaner's approach to consultation. At the same time, the complexities and even inconsistencies in Mandy's own story demonstrate exactly why Bliton and Zaner try to elicit detailed accounts of decision-making. Mandy mentioned at a later point in the interview, when talking about her son's shunt placement, "That was the reason I had the in utero surgery in the first place!" (TR 11.1 39:12) but when talking about her decision, the story she told was the story of divine guidance, beginning with the *People* magazine article. God showed her

the magazine article so she would know about the surgery and help her son avoid getting a shunt. Avoiding the shunt was not part of Mandy's public presentation of God's decision that she undergo the risky procedure, but it emerged as part of Mandy's complex motivations for pursuing the surgery. And yet, rather than addressing, with the ethics consultants, the possibility that her son might still require a shunt after this procedure, as happened when he was two years old, Mandy insisted on her faith that "God has his hand in this, and I'm supposed to have it. And yeah, there are these other risks, but I don't think that's going to happen to me because God chose me..." (TR 11.1 20:26). Her remark that the ethics consultants "would have made it a whole lot better for me, if they could have acted like they understood" (TR 11.1 27:03) illustrates the distinction between a procedural approach, where the clinicians might "act like they understood" rather than question someone's beliefs, and Bliton and Zaner's approach that asks questions *in order to understand*. Though Bliton and Zaner would argue for asking such questions as a way of taking beliefs seriously, Mandy felt challenged by the ethics consultants questions about that faith and saw the questions about what she believes as demeaning, as being "against what you believe."²⁴

For Mandy, the challenges of the ethics consultation process, and her suspicions that they were intended to protect the hospital from liability, outweighed any intended help or benefit. However, there were others who found the process challenging, yet still appreciated the learning process. Angela Dominguez didn't remember as much about the

²⁴ Mandy's suggestion for ethics consultation in the future was to have Christian consultants for Christians considering the procedure. This highlights a challenge Bourdieu identifies for interviews: if the interviewer and interviewee are too dissimilar then it is difficult to build the trust that allows for questioning. However, if there is too close a connection or similarity between interviewer and interviewee, nothing is learned because nothing gets questioned. The ethics consultant faces a similar challenge in communicating with and trying to understand the patient or potential research participant. Bourdieu, "Understanding," 609-612.

ethics consultation process, but her husband did, and when she told him about our upcoming interview, he reminded her

A: ...the one that really made us not going for the surgery was the ethicist. And I don't recall why. But he [her husband] felt like that was something that was very rough, and very tough, and laid everything out on the table. And that was one of the big things that made us decide not to go through with it. (TR 5.2 13:15)

When I said that one of the goals of those ethics consultations had been to help people think through their whole situation, in light of the medical details. Angela recognized her experience in that description.

A: Yes! Yes! And I think that's what he [the ethics consultant] made emphasis on. And that's what...the main, especially my husband, may not have liked how he put it on, but I think it ended up weighing a lot in the deliberation at the end. Umm...I ...I think we left without a decision, but already knowing, kind of, what we were going to do - of not doing it. (TR 5.2 15:52)

The conversations, “laying everything out on the table” were “very tough,” but helped Angela and her husband weigh the medical information with their family circumstances and choose not to pursue the surgery.

For Dottie Geller, the process was difficult, as well, but, like Mandy, it had little influence on her decision. She wanted the surgery for her son because she wanted the chance to do something, and she did not appreciate the ethics consultant who made her think about and tried to get her to explain what she wanted to do. She explained,

D: He made me the think about it. He made me think about it a lot.

V: What did he make you think about?

D: Um...Whether or not...if this would be helping the child

V: Uh huh...

D: Or... or what are your reasons for it, and all that kind of stuff. And they were hard questions. And some of them, I wish he hadn't asked, because he said, "You know, you can still get out of this."

V: Meaning, not have the surgery or have an abortion?

K: Either one.

D: And I couldn't...I couldn't [gets teary] I couldn't not do something about it. It's like, when you're stuck in a situation you can't do anything about, you have to do something. (TR 7.1 36:51)

The ethics consultation process was difficult, but did not affect her decision towards the prenatal surgery. Though her reasons were different, Dottie was just as committed as Mandy was to having open-uterine surgery. If anything, the ethics consultation process that identified, questioned, and tried to understand her predispositions made the experience more difficult than it might otherwise have been.

The difficult and challenging experiences described by Dottie, Angela, and Mandy, and the helpful and challenging experiences described by Jackie, Lila, and Erin, all raise questions about the goals and methods or practices of clinical ethics consultations and how consultations influence women's experiences with decision-making. In particular, the descriptions from the women I interviewed present a unique opportunity to think about and learn from women's experiences with an innovative and deliberate ethics consultation process that is itself based on and committed to learning about and from women's experiences.

Women's Suggestions for Ethics Consultations

The women I interviewed explicitly and implicitly identified things that were helpful and things that were challenging about the ethics consultation process. These

include some of the “dimensions of experience and potential meaning” that Bliton identifies as “even more subtle, more intimate, harder to explain, and thus likely to yield potential criticisms of ethics consultation.”²⁵ Most of the women said they appreciated the depth and variety of information they received, as well as the time and help they were given in processing the information. They said they appreciated the focus on the “whole person” and being encouraged to make decisions they thought were best for their family. They also, as Jackie and Lila discovered, grew more confident in their own decision-making, as they discovered answers to the ethicist’s questions – and their own – in their own experiences and resources. Finally, the ethics consultation process was beneficial or helpful in preparing them to answer questions from their home communities, and from other women facing similar circumstances. Five of the eight women I interviewed told me they had actively counseled or educated other women about spina bifida and open uterine surgery.²⁶ For these women, the various elements of the ethics consultation process – time, information, asking about their experiences and beliefs, and assistance in deliberation – were all helpful in their decision-making, and they implicitly and explicitly endorsed continuing these practices for ethics consultations regarding this procedure.

On the other hand, some women found those same, and other, elements of the ethics consultation process to be distressing or even hurtful. Angela and her husband remember looking at all the facts and information as being “very tough, very rough, laying it all out on the table.” Mandy found the whole process difficult because she saw questions *about* her faith as challenges *to* her faith. She did not see questioning these deep beliefs as helpful at all, especially when she was relying on them in a difficult

²⁵ Bliton, "The Profoundest Question," 39.

²⁶ Cathy, Jackie, Lila, Erin, and Mandy.

experience. Dottie had a similar difficulty with the ethics consultant asking her questions she did not want to answer, probing the very questions that might make her change her mind. She felt like she had to have the surgery because she hoped it would help her son. She had been avoiding the possibility that it might not help and talking with the ethics consultant made her think about those possibilities. For Dottie and Mandy, the ethics consultation process added to their distress in an already difficult situation.

The contrast between different women's experiences of the same ethics consultation process is striking: a process designed to help, that some women *identified* as helpful, was perceived as difficult and harmful to others. Five women, Cathy Johnson, Carin Miller, Jackie Hutton, Lila Slater, and Erin Strickland, described the process as challenging but also helpful, even though they did not think it definitively convinced them one way or another. Instead, it offered them the time to reflect and the opportunity to make their own decision, based on their own commitments and resources, which was a primary goal of the process. On the other hand, Mandy Ball thought that answering questions about her faith – to ethics consultants who did not share that faith – was “hurtful,” while Dottie Geller thought it was distressing that the ethics consultant made her think about questions that she was, admittedly, trying to avoid. One question, then, is what we are to make of Mandy's and Dottie's experiences of distress. Do they fall under the category of “harm” when considering ethics consultations? And, given the variety in women's responses to and reflections on the ethics consultation process for this compelling and complex procedure, what can we learn from these perceptions that may be helpful for considering and developing ethics consultations in the future?

Questions for Methods in Ethics Consultations

The Williamsons' description of the ethics consultation as both "enabling" and "forced" illustrates the tension between potential benefits and potential harms in the practice of and understanding of clinical ethics consultations: a tension that is only occasionally identified in the ethics literature, but is identifiable in interview conversations with each woman in my research. Following Zaner's description, ethics consultation is part enablement and empowerment, part detective work.²⁷ The ethics consultation can be the occasion that enables parents to identify the moral and social concerns that influence how they make sense of and understand their often-changing clinical circumstances. The ethics consultation can also be the occasion for health care providers, including ethics consultants, to understand, in Manuel Gonzalez-Abreu's words, "the religious background and the set of values framing the lives of their patients,"²⁸ empowering families to think through, vocalize and discuss how their circumstances "fit" in their experiences, their commitments and beliefs. The other side of the tension in clinical ethics consultations, however, is that the detective work the Williamsons described, includes the "hard questions" that many people would like to avoid. Though none of the "Parental Voices" reflections are particularly critical of this "forced" aspect of ethics consultations, both Bliton and Zaner were aware of the potential for harm in asking about peoples' most deeply held beliefs. Bliton's concern about benefit and harm explicitly identifies what is only implicit, though available, in Zaner's

²⁷ Zaner, "Phenomenology and the Clinical Event," 47. See pp 139-140 in Chapter V above.

²⁸ Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 520

detective metaphor: that in trying to help like Nancy Drew, the ethics consultant may appear to be as relentless as Sam Spade.

The most obvious examples of potential harm can be seen in the accounts of women who made their decisions by relying on their faith rather than by relying on clinical information and autonomous choice. As described in Chapter VI, for Mandy, Lila, Jackie, and others, their “decision-making process” was as much or more a process of recognition as it was a process of deliberation. Each of these women described their “decision” as the decision to rely on God’s guidance, to trust God’s decision for their fetus regarding the surgery, which they would recognize through prayer and signs. For these women, the “good thing to do” was to pray and be guided by their faith, not to make what Chervenak and McCullough would recognize as an “autonomous decision” based on a clear understanding of clinical circumstances presented by a non-directive physician, or even to engage in questions of clinical uncertainty, influence on decision-making, or unrealistic expectations in Bliton and Zaner’s model of consultation. For these women, God has made the “decision” and so the ethics consultation process was something they were required to do, not something they wanted to do. This understanding of “decision,” and of ethics consultations as “forced,” presents a three-fold challenge to ethics and ethics consultation.

First, the question emerges of how to address the ethical issues raised by this decision if women do not recognize or do not want to consider those issues. Does a focus on clinical information and women’s autonomy allow for questions of faith and the relocation of decision-making authority to a source other than the pregnant woman, *by the pregnant woman herself?* Does an ethics consultation that questions and probes help

women by identifying the ethical issues that such a “decision” may obscure? A procedural, information-focused understanding of ethics as informed consent does not put such moral frameworks into question, even though they may be more influential than women’s grasp of the clinical circumstances required for such a decision. And yet, ethics consultation risks potential harm if questions about faith are seen as a questioning of faith, as in Mandy’s experience.

The second challenge is what to do if beliefs about God’s will for the surgery include a minimization or rejection of potential surgical harms.²⁹ If a woman’s interpretation of medical information rejects the risks described by clinicians as not applying to her, has she acquired an adequate understanding of the risks such that her consent can be genuinely informed? To return to Bliton’s observation about the predisposition to treat and its tendency to distort risk, given this predisposition, in considerations of ethics and informed consent there are important questions to address about whether the professional obligations to not harm mean avoiding questions about whether women’s beliefs themselves may create harm.

More pointedly, in light of these concerns, the third challenge emerges of the extent to which ethics consultants should probe or question women’s beliefs that may overlook or minimize physical harms to the woman from surgery. In particular, to what extent should ethics consultants question women’s beliefs when such questions may be seen as *challenges to belief* and may offer a different kind of harm, emotional harm, as in Mandy’s case? As discussed above in Chapter III, underlying Zaner’s method and Bliton and Zaner’s focus in the ethics consultation process for open-uterine surgery is the bias

²⁹ For example, Mandy claiming that those risks would not happen to her because God chose her for the surgery.

that identifying and addressing these influential beliefs and values is less harmful than leaving them unaddressed, especially because they may minimize the very real physical and emotional harms of such procedures. Some women's accounts may challenge that bias.

Questions of faith in decision-making highlight the tension between perceptions of ethics consultation as helpful or harmful and raise again the questions Bliton asked about professional obligations, about what we understand by "ethics consultations," and about how best to engage in this purportedly therapeutic activity. In light of women's accounts above and in Chapter VI, the Chervenak and McCullough / Adzick procedural consent model appears woefully inadequate to address the more complex, less easily identified but often powerfully influential social and moral features of decision-making. Chervenak and McCullough want to preserve autonomy from influence or coercion from a physician directive, but as a result, their procedure is ill-equipped to identify other, more subtle forms of influence and possible coercion. On the one hand, the question is whether or not this dominant understanding of ethics as informed consent is helpful to women considering such medically, socially, and morally complex procedures. Can women give genuinely informed consent if they have only considered one aspect of this experience – the medical information? Can the ethics consultant claim to have addressed the ethical issues if she does not probe the elements women identify as important for their decision-making? For example, how is the ethics consultant to understand Jackie Hutton's description of interpreting the bumper sticker "Expect a Miracle" as a sign they should have the surgery unless the consultant asks about the meaning behind such a report? Such questions are not meant to evaluate these kinds of interpretations and

motivations, but to clarify their meaning with the women for whom they may be influential. Asking about a bumper sticker has no place in Cherevenak and McCullough's "Comprehensive Framework" and so important moral meanings may be lost.

On the other hand, Bliton and Zaner's process is designed to elicit discussion of motivations and even beliefs that may be decisive in choosing to have a surgery with obvious risks. The difficulty is that if the process is not clearly distinguished from the procedural approach, it may seem or appear that motivations or beliefs are being evaluated, and in some cases, that the ethics consultation is being "forced" on women. Different questions then emerge. If we insist that ethics consultation is important, especially in such surgeries where misunderstandings are likely and can be profound, does that insistence mean that ethics consultants can "force" women to identify and reflect on the moral and social features if they do not want to? Does the insistence on the importance of ethics consultations authorize ethics consultants to probe women's beliefs when women do not want to do anything more than hold tightly to their beliefs, unquestioned?

Rather than getting caught by the question of whether ethics for maternal-fetal surgery has to be reduced to either an informed consent understanding or a forced consultation understanding, looking again at the "Parental Voices" essays and the interview transcripts yields clues to a resolution – or at least a way to hold the tensions together in mind when reflecting on ethics consultations. The recognition of the social and moral character of ethics consultation itself emerges as a key theme in these accounts, where ethics consultation entails a mutual willingness to be open to another's questioning about the social and moral features of such experiences and decision-making.

Manuel Gonzales Abreu emphasized the importance of having trust in clinicians, which developed for him when clinicians had respect for the family's values and beliefs.³⁰ Likewise, Erin Strickland said she appreciated the ethics consultants' focus on the whole person, their beliefs as much as the clinical details and so she was willing to pursue the questions, even though she would have found them "jarring" in a different context. Similarly, the Williamsons' described the ethics consultant as someone who raises "morally relevant questions"³¹ that were difficult for them to articulate on their own. In Bliton and Zaner's accounts of ethics consultation, addressing those values, beliefs, and questions often means engaging families' social and moral influences and motivations more intimately than is allowed for in a procedural approach to informed consent. As noted in Chapter IV above, Bliton asks,

In other words (even though the gravity and meaning of the issues cannot be the same for both of us) how might I possibly find out what is important to you, or anyone else, in such a context unless I am willing to share temporarily the questions and uncertainties you face?³²

In the "Parental Voices" essays and in the interview transcripts, women and families were more willing to engage with the ethics consultants' questions and uncertainties if they accepted the ethics consultants' role as therapeutic rather than evaluative. In contrast, Mandy Ball's insistence that the ethic consultants' role was to "talk her out of the surgery" and protect Vanderbilt from "liability" made her suspicious of the motivations behind their questions and resistant to providing any explanation, beyond her assertions of divine guidance, for having the risky surgery. In these descriptions about what makes

³⁰ Gonzalez-Abreu, "Parental Voices: You Get What You Get and You Don't Get Upset," 530.

³¹ Williamson and Williamson, "Parental Voices: The Positive Impact of Medical Professionals," 515.

³² Bliton, "Imagining a Fetus," 399.

an ethics consultation helpful, or even “hurtful,” as in Mandy’s descriptions, clear understandings of the goals and methods of consultation, and trust or lack of trust in the relationship between the ethics consultant and the family, can influence the family’s willingness to address the social and moral questions raised by this procedure.

Though some may have been distrustful of such questions and unwilling to engage them with the ethics consultant, from these accounts, others discovered *in the process itself* that engaging social and moral concerns with the ethics consultant was helpful in making sense of their experiences and making a decision that fits in their lives. The question remains of what the ethics consultant should do when people are unwilling to address the questions raised by such complex procedures, and this concern, and the question of establishing trust in ethics consultation, remains in need for further reflection. However, the “Parental Voices” and interview accounts from women and families suggest that at a basic level, the commitment to understanding and the professional obligations that concern Zaner and Bliton may demand nothing more – and nothing less – than being available to families, being clear about the goals of consultation, and being willing to engage questions about beliefs and values, harms and benefits with families, *including* questions about the benefits and harms *of their activities as ethics consultants*.

Putting Ethics Consultation in Question

In looking at women’s accounts in the “Parental Voices” symposium, and their accounts in the transcribed interviews, we can identify the potential benefits of ethics consultations – and recognize the potential social, moral, and emotional harms – that questions in ethics consultations may produce. These identifications and recognitions

create an opportunity for ethics consultants to reflect on their own methods prior to, during, and after engaging with others *as ethics consultants*. Following Zaner's commitment to understanding and focus on method, ethics consultants have an obligation to pay attention to the circumstances at hand, to attune themselves to the others in the actual encounter, to actively listen, and to reflect on previous and current experience. Underlying all of these activities, however, all of these aspects of method, is a question the ethics consultant has to engage about ethics consultation: "Is this a good thing to do?" More specifically, is a reflective, nuanced understanding of ethics consultation more beneficial to patients and potential participants in research than a procedural understanding of informed consent?

The question of "Is this a good thing to do?" operates and needs to be asked at every level: in trying to help in a particular situation, as in consultations with women considering maternal-fetal surgery; in considering ethics consultation as a practice and the ways it may be perceived as beneficial or harmful; and in considering the value or risk of putting oneself into question at all, a deeply social and moral question raised by clinical encounters with patients and potential participants in research. For example, Bliton asks, regarding cases that haunt, cases that put the ethics consultant and her own activities into question, "What should I do or say about such strenuous riddles, with their hair trigger emotional depth charges and their abysmal, agonizing outcomes?"³³ Ethics consultants' questions may be perceived as "hurtful" as in Mandy's experience, or they may appear helpful as in Erin's and Lila's experiences, and the potential for those varied

³³ Bliton, "The Profoundest Question," 39.

perceptions puts the intended goals and methods of ethics consultation itself into question.

An understanding of ethics consultation that includes reflective questioning of its own methods keeps the potential for benefit and for harm in the forefront of encounters with patients and potential participants in research. Such reflection is important because, as Bliton observes in this chapter's initial concern for ethics consultation, that "These dimensions of human experience and their potential meanings are even more subtle, more intimate, harder to explain, and thus likely to yield potential criticisms of ethics consultations."³⁴ Looking at women's accounts of their experiences with ethics consultations – with their thoughtful reflections and direct suggestions – emphasizes the need to ask questions about ethics consultations: "Is this a good thing to do?" and to engage, in particular, with the criticism of causing harm. The reflective character of this kind of ethics consultation tests its own biases – that questioning values, commitments, and beliefs is important and beneficial – in each encounter, putting the ethics consultant's method and commitments into question as well. However, in most of the accounts from women who considered open-uterine surgery to repair spina bifida, the method that emerges in this context – described by Bliton and Zaner as preparation, attunement, listening, and reflection – translates into ethics consultations that provide time and information, that ask about women's experiences and beliefs, and that offer assistance in considering the medical, social, and moral issues of this procedure. This understanding and method of ethics consultation helped identify and address important – and challenging – social and moral features for women trying to make sense of their options and trying make decisions that 'fit' in their lives. The complexity of these experiences, in

³⁴ Ibid., 39.

turn, emerges from women's accounts in support of an ethics consultation process that can address the multiple, layered social and moral concerns alongside the medical and clinical uncertainty.

Finally, in answer to the specific comparison, the more reflective and nuanced understanding of ethics consultation has a significant advantage over Chervenak and McCullough's and Adzick's procedural consent model, limited as it is to information and autonomy: a reflective method allows or even demands that the ethics consultant consider and give an account of her activities, before, during, and after each encounter with patients, potential participants in research, and families. A reflective method of ethics consultations includes in its activities an orientation *and an obligation* to be attuned to and respond to the potential harms in the ethics consultation itself. This method of ethics consultation also includes the recognition that only in the practice and undergoing in particular contexts will the ethics consultants, and the persons with whom she consults, determine whether the process is helpful or harmful or both. Attention to the circumstances at hand, engaging with the question of method to discover how to understand others' experiences, and reflecting on past and present activities and experiences to learn are all part of the challenging task of "looking into our sense of values inherent in the performance and activities of ethics consultations, especially when the *basis* for such values is challenged by the intimate experience of injury, illness, disability, and dying."³⁵ Women's experiences with and decision-making about open-uterine surgery to repair spina bifida clearly exemplify the ethics consultant's "intimate experience of injury, illness, disability, and dying" and so offer an important opportunity for reflection on the questions, commitments, and activities – the methods – of clinical

³⁵ Ibid., 38.

ethics consultations. The reflective character of these activities is the greatest strength of the method of ethics consultation described by Bliton and Zaner, the “Parental Voices” essays, and the interviews with women who considered the procedure. Ethics consultations, understood as a tenuous and yet substantive social encounter, puts others’ commitments, beliefs and values into question – but also puts itself, and its commitments, beliefs, and values into question. For those committed to helping women considering open-uterine surgery to repair spina bifida by learning about their experiences and decision-making, such continued reflection on the goals and methods, harms and benefits of ethics consultation is, indeed, a “good thing to do.”

CONCLUDING REFLECTIONS

In the spirit of the ethics consultant who reflects on her experiences and puts her own activities into question, these concluding reflections consider the methods, the data, and the questions that remain after three years, five thousand miles of travel, and eight interviews exploring women's experiences with medical, social, and moral issues of open-uterine surgery to repair spina bifida. I began this project uncertain of what I would learn or how I could best learn it. Taking cues and clues from my own experiences and Zaner's reflections on clinical ethics consultations, the method I used to learn about and learn from women's experiences with open-uterine surgery to repair spina bifida emerged *from* and *in* the questions and the circumstances at hand. The major sections of this dissertation illustrate my method: from paying attention to the circumstances at hand, to determining appropriate methodologies and engaging questions of method, to reflecting on and learning from women's experiences. And, as in Zaner's method, the interview encounters and even in the analysis and retelling that followed, new questions, new circumstances of moral inquiry emerge.

The introduction describes my initial questions of how women make decisions about such clinically, socially, and morally complex procedures, including what resources and processes are available to help them. Part I tries to address these questions by exploring the circumstances at hand in the available medical, ethical and moral discourses about this procedure. Chapter I reviews the medical perspectives on and descriptions of spina bifida and its treatments, including the development of open-uterine surgery to repair spina bifida, while Chapter II presents the multiple perspectives on ethical issues from clinicians, sociologists, and ethicists. As neither the medical nor the

ethical discourse pays much attention to how women learn about, experience, and make decisions about open-uterine surgery to repair spina bifida, Chapter III explores the few parental accounts available. It begins to identify the themes women and their families raise, the concerns they identify as important in their experiences and decision-making. Chapter III also recognizes two limitations, however: first, that other perspectives from women who chose not to have the surgery were still being overlooked, and second, that additional research was needed to establish parents' experiences as a necessary resource for understanding and evaluating open-uterine surgery to repair spina bifida.

The preliminary research in Part I, on medical and ethical discourses about this procedure, demonstrates a continuing and troubling absence of women's voices from discussions of the ethics of fetal surgery. The preliminary research also showed the tendency in the predominant discourses to think of ethics in theoretical terms of justification, validation, the moral status of the fetus, and maternal-fetal conflicts, and in clinical contexts, to think of ethics in terms of procedural approaches to informed consent. Neither understanding is sufficient for addressing the complexities of women's experiences, especially at the conclusion of and evaluation of the MOMS trial, which highlights both ongoing and new concerns for this procedure. In particular, if open-uterine surgery to repair spina bifida is offered again as an elective procedure, it is likely that women and their families will pursue the surgery with similar devastation from their diagnosis of spina bifida, similar religiously-based hope, and similar predispositions to "do something." If clinicians and ethics consultants want to help women understand and make informed decisions about these complex procedures, then both the theoretical and

clinical understandings of ethics must include women's voices and account for women's experiences.

Part II engages with research methodologies and questions of method for research to address these limitations. Chapter IV addresses situational analysis and my preliminary research, while Chapter V engages the question of method in conducting the interviews. Acting as what Clarke calls a "bricoleur," I drew from both sociological and phenomenological resources in my project design, making a deliberate shift from methodology to method in order to be responsible in my encounters with women and in my analysis and retelling of their experiences. The influence of Zaner's method of preparation, attunement, active listening, and reflection was crucial, though not only for my experiences in eliciting, analyzing, and retelling women's stories of their experiences. As my research progressed, women's descriptions of and appreciation of the ethics consultation process allowed for an expanded focus on women's experiences of *ethics consultations*. I learned about how helpful Zaner's emphasis on providing time and information, questioning beliefs and values, and assisting in deliberation was to the women I interviewed, when they were considering such complex issues, even as I learned how Zaner's method was helpful to me, when I developed my method of moral inquiry, of listening to, questioning, analyzing, and retelling women's experiences. Methods for ethics consultation became an important theme in the final section of the dissertation, which also demonstrates the ongoing liveliness of questions about method in moral inquiry, whether clinical or in research.

In Part III of this dissertation, Chapter VI identifies the moral and social themes that women identified as important in their experiences and as influential in their

decision-making. Women's accounts in face-to-face, open-ended interviews give detailed descriptions of their experiences with diagnosis and disability, faith and community, their particular definition of the decision to be made, and their experiences of living with their decision, all of which reemphasize that a more detailed and reflective understanding of ethics is required for this procedure. Many of these themes are beyond the scope of the medical and ethical issues addressed in typical informed consent processes, and so Chapter VII explores clinical ethics consultations as a way to address these concerns. In particular, the accounts in this project illustrate the ways women's experiences with the medical, social, and moral issues of open-uterine surgery to repair spina bifida, especially questions of faith or religious belief, often exceed typical medical and procedural models of ethics as informed consent. The "Comprehensive Ethical Framework" offered in most clinical settings is not, in fact, comprehensive, as it neglects an entire area of moral understanding, including beliefs, values, and motivations. Women's accounts, then, point to an important concern for further inquiry – since a procedural model of informed consent cannot sufficiently address the moral and social factors these women identify as important for decision-making, clinicians and ethicists need to revisit what we mean by "ethics" in clinical contexts of such uncertainty and complexity. An ethics consultation process, like the Vanderbilt process, that probes values, beliefs, and commitments risks potential emotional harm, as some of the accounts above illustrate. And yet, Bliton and Zaner's understanding of ethics and ethics consultations is also more detailed, more reflective and responsive, and allows for the possibility of a different kind of understanding, beyond "information," based on what matters most to women considering this procedure. Between women's accounts of their decision-making for this procedure,

and the continuing adherence to the “Comprehensive Framework” in the professional literature, it is clear how great the need is for further research into women’s experiences and further reflection on ethics consultation.

Women’s accounts are important both for documenting women’s experiences with the medical, social, and moral issues of open-uterine surgery to repair spina bifida, and for the insights and suggestions they offer about clinical ethics consultations and decision-making. These accounts highlight an ongoing concern that clinicians and ethicists actively solicit, engage, and reflect on the experiences of women who considered this procedure in the past when institutions are considering whether and how to offer this procedure in the future. The experiences and accounts of those most affected by this procedure should be included in discussing the ethical issues the procedure raises and in considering how those ethical issues should be raised in clinical contexts, the methods of ethics consultation. Women’s accounts, then, in all their complexity, become part of the circumstances at hand, demand reconsideration of the methods of moral inquiry, and encourage ongoing reflection on this procedure – reflection that began with and continues in the astonishment that “They can do that? That’s amazing!”

APPENDIX

A. STUDY INTRODUCTION LETTER

Dear _____,

I am a graduate student at Vanderbilt University, working with Dr. Mark Bliton to learn about medical decision-making and open-uterine surgery for spina bifida. Over the past 1½ years I have taken part in ethics consultations with pregnant women thinking about the “Management of Myelomeningocele Study”, or MOMS study. I have met over 20 families and been with many women during their surgery or delivery. This work has led me to study how women chose between different medical options for spina bifida.

I am writing to you because records show that you contacted Vanderbilt a few years ago to learn more about treatment for spina bifida and prenatal surgery. I would like to talk with you about your experiences and decision-making when you learned about spina bifida and Vanderbilt’s prenatal surgery options.

Since Vanderbilt started offering it in 1996, over 250 women have asked about elective prenatal surgery to repair spina bifida. Some of these women chose to have the experimental surgery, while other women had their babies’ surgeries done after birth, and still others chose to end their pregnancies. There has been little follow-up with any of these women about how they decided what to do and how they feel about their choices now. As the research project for my doctoral degree, I am talking to many of these women to learn about what was important to them when they faced this hard medical and moral decision. My study will help Vanderbilt and other hospitals understand this difficult decision, hopefully making the process better for women in the future, whatever choice they make.

As part of this project, I would like to talk with you about your experiences with treatment choices about spina bifida. If you would be willing to help with this research please call me at (615) 513-8654 or email me at Virginia.l.green@vanderbilt.edu. During a brief telephone call, I will provide more information about the study and answer any questions you have and we will set up a time for me to visit you in your home for an interview. The interviews will last between 1½ - 2 hours. All of our conversations will be confidential, whether you decide to help with this research or not. If you would like more information about the project, please see the enclosed sheet for contact information for me and for Mark J. Bliton, my advisor.

Thank you,

Virginia L Bartlett
Center for Biomedical Ethics and Society
Graduate Department of Religion
Vanderbilt University
Nashville, Tennessee

B: TELEPHONE SCRIPT AND DATA FORM

This script will guide initial telephone contact with participants.

Introduction:

First, I want to thank you for getting in touch with me about the study of women's experiences with open-uterine surgery to repair spina bifida.

To introduce myself again, I am a graduate student at Vanderbilt University, working with Dr. Mark Bliton to learn about medical decision-making and open-uterine surgery for spina bifida.

As you may know, since Vanderbilt started offering it in 1996, over 250 women have asked about elective prenatal surgery to repair spina bifida. Some of these women chose to have the experimental surgery, while other women had their babies' surgeries done after birth, and still others chose to end their pregnancies. There has been little follow-up with any of these women about how they decided what to do and how they feel about their choices now. As the research project for my doctoral degree, I am talking to many of these women to learn about what was important to them when they faced this hard medical and moral decision. My study will help Vanderbilt and other hospitals understand this difficult decision, hopefully making the process better for women in the future, whatever choice they make.

Procedures:

As part of this project, I would like to talk with you about your experiences with treatment choices about spina bifida. If you agree to participate, I will travel to your home for a face-to-face interview in a one-on-one setting. First, we would talk about study procedures, such as audio-recording the interview and how I will keep your responses confidential. We would read and discuss the informed consent documents and I will answer any additional questions you have about the project. You and I will each sign copies of the consent forms.

The interview will last between 1.5 - 2 hours, and you will receive a \$50 Visa gift card as compensation for your time. If arranging a babysitter for your child or children would make it easier for you to participate in the interview, I will reimburse you for up to 3 hours of childcare. I will be asking you questions about your experiences and feelings, some of which may be upsetting. You may refuse to answer a particular question or questions, and you may stop the recording, the interview, or both at any time. All answers are voluntary and you may withdraw from the study at any time, even after the interview. If you would like, I will share my analysis and any publications from this project.

Do you have any questions about the study goals or the interview process?

Would you like to participate in this study? (Y/N)

What would be the best time and place for me to come see you and for us to have our interview? Place (incl. address) _____
Date: _____ Time: _____

Before I come and talk with you, I would like to ask you a few questions about you and your family. This will help me prepare for our interview and will give me some background for thinking about your experiences. May I ask you a few questions? (Y/N)

1. Participant name: _____
2. Do you prefer email or US mail for contact? Email/Address: _____
3. When did you come to VUMC to learn about open-uterine surgery for spina bifida? _____
4. Did you choose the surgery or did you choose not to have the surgery? (S/N)
5. Please tell me about the child with the diagnosis of spina bifida _____
 - a. Alive (Y/N) If Deceased, what age? ____ Cause of death? _____
 - b. Age _____
 - c. Shunted _____ (at what age?)
 - d. Catheterization _____
 - e. Walking _____ Braces _____ Wheelchair _____
 - f. School: Mainstreamed _____ Special Education _____ Home School _____
 - g. Other: _____
6. Please tell me about the rest of your family:
 - a. Who lives in the house?
 - i. Married/Divorced?
 - b. Other children (Y/N)
 - i. ages _____
 - ii. sexes _____
 - c. Other care providers?
7. Will you be arranging childcare for the day and time of our interview? (Remind that I will pay for the childcare).

Are there any other questions I can answer for you?

So, to confirm, I have our interview schedule for _____ (Date), at _____ (Time), at _____ (Location). Is this correct?

I will send a reminder email _____ or letter _____ 1 week before our interview, and I will call 2 days before to confirm directions and child care arrangements.

Thank you again for your willingness to talk with me about your experiences. I am looking forward to meeting soon.

Goodbye.

C: INFORMED CONSENT DOCUMENT

Informed Consent Document

This informed consent document applies to adults.

Name of participant: _____ Age: _____

The following information is provided to inform you about the research project and your participation in it. Please read this form carefully and feel free to ask any questions you may have about this study and the information given below. You will be given an opportunity to ask questions, and your questions will be answered. Also, you will be given a copy of this consent form.

Your participation in this research study is voluntary. You are also free to withdraw from this study at any time.

1. Purpose of the study:

This study is designed to learn about women's experiences with and decision-making about prenatal surgery to repair spina bifida. Since Vanderbilt started offering it in 1996, over 250 women have asked about elective prenatal surgery to repair spina bifida. Some of these women chose to have the experimental surgery, while other women got their babies' surgeries after birth, and still others chose to end their pregnancies. There has been little follow-up with any of these women about how they decided what to do and how they feel about their choices now. As the research project for my doctoral degree, I am talking to many of these women to learn about what was important to them when they faced this hard medical and moral decision. My study will help Vanderbilt and other hospitals understand this difficult decision, hopefully making the process better for women in the future, whatever choice they make.

2. Procedures to be followed and approximate duration of the study:

a) Interview:

If you consent to being in the study, you will participate in a face-to face, one-on-one interview that will last between 1 ½ to 2 hours.

With your permission, the interview will be recorded. During the interview, you will be asked questions about your experiences with prenatal surgery to repair spina bifida. For example, you will be asked

- how and when you learned about your prenatal diagnosis,
- how you learned about the surgery,
- how you describe your experiences and decision-making about prenatal surgery,
- what or who was important in helping you make your decisions, and
- what was challenging or helpful in the decision-making process for prenatal surgery to repair spina bifida.

Additional topics may come up in conversation, including questions about abortion, disability, science/medical experiments, religious frameworks or beliefs, personal vulnerabilities, and challenges. I will also ask you about any concerns you have at this point in your experience with prenatal surgery to repair spina bifida. Finally, I am interested in any suggestions you have about the consultation and decision-making process that may help other women if the surgery is offered in the future.

You may withdraw from participation at any point.

3. Expected costs:

There are no expected costs for you.

4. Description of the discomforts, inconveniences, and/or risks that can be reasonably expected as a result of participation in this study:

If you choose to take part in the interview, I will ask you questions about your personal experiences and your feelings and thoughts about those experiences. My goal is to learn from you in a respectful way. However, the questions I ask may bring up memories, topics, or emotions which may be private, embarrassing, or painful and which you may not want to share. At any point in the interview, you may refuse to answer any questions or stop the interview. In addition, if you decide at a later date that you said more than you wanted to say, you may contact me and I will erase all or part of our interview. If you experience distress and want to talk to a counselor, I will give you information for contacting Vanderbilt University's counseling services.

5. Anticipated benefits from this study:

a) This study will help obstetricians, surgeons, and other health care providers better understand the experiences and decision-making of their patients after a diagnosis of spina bifida. This study may also help women and their families who face a diagnosis of spina bifida in the future, by making it possible to tell them about other people's experiences.

b) There may be potential benefits to you from this study. You may gain some personal or emotional benefit from thinking about your experiences with prenatal surgery to repair spina bifida, and how those experiences have changed over time. You may benefit from a sense of empowerment through telling the stories of your experiences and through teaching health care providers and other professionals about the concerns and issues you deem most important.

6. Compensation for participation:

You will receive \$50 as compensation for your time in the form of a check from Vanderbilt University. Vanderbilt needs you to fill out a Subject Reimbursement form with your Social Security number and address so that your check can be processed. Checks may take up to six (6) weeks to arrive through the US Mail.

7. Circumstances under which the Principal Investigator may withdraw you from study participation:

If you ask to be withdrawn from the study, I will withdraw you from study participation. You will still receive compensation, even if you choose to withdraw from participation.

8. What happens if you choose to withdraw from study participation:

If you withdraw from the study, I will not contact you again and your interview data will not be included in my research reports. If you wish to withdraw from the study, you may contact me (Virginia L Bartlett) at (615) 513-8654 or my Faculty Advisor, Dr. Mark J. Bliton at (615) 936-2686.

9. Contact Information.

If you should have any questions about this research study or possibly injury, please feel free to contact me (Virginia L Bartlett) at (615) 513-8654 or my Faculty Advisor, Dr. Mark J. Bliton at (615) 936-2686.

For additional information about giving consent or your rights as a participant in this study, please feel free to contact the Vanderbilt University Institutional Review Board Office at (615) 322-2918 or toll free at (866) 224-8273.

10. Confidentiality:

All reasonable efforts will be made to keep your personal information in your research record confidential but total confidentiality cannot be guaranteed.

- I will not put your name on any materials: I will use a code number that only I will have.

- Your name, address, and phone number will be kept in a password-protected file on my computer. I will be the only person who knows the password. Your personal information will not be used on any transcript, any audio-recording, or on any notes.
- Any published version of this research will use pseudonyms (false names) for you and your family. I will omit or alter identifying data such as the city where you live, place of employment, religious institution, or child's school.
- The Subject Reimbursement Form will be kept locked in a secure file that only I can access. I will submit the Subject Reimbursement Form to the Vanderbilt University Finance Office as soon as possible after our interview to protect your confidentiality. The Vanderbilt University Finance office will not receive any information from your participation in the interview.

14. Privacy:

Your information may be shared with Vanderbilt or the government, such as the Vanderbilt University Institutional Review Board or Federal Government Office for Human Research Protections, if you or someone else is in danger or if we are required to do so by law.

STATEMENT BY PERSON AGREEING TO PARTICIPATE IN THIS STUDY

I have read this informed consent document and the material contained in it has been explained to me verbally. All my questions have been answered, and I freely and voluntarily choose to participate.

Date

Signature of patient/volunteer

In addition, please indicate your approval/disapproval of the following procedures by checking the appropriate line.

I agree do not agree to be recorded.

Consent obtained by:

Date

Signature

Printed Name and Title

D: INTERVIEW GUIDE

Interviews with both sets of women are exploratory. The interview seeks to elicit and identify what moral themes or concerns are of importance to the participants, and so not all of the questions below will be asked. The format for these interviews is semi-structured, and so the order of discussion and emphasis on particular questions may change as each interview progresses. Interview elements will include:

- Greetings and friendly conversation
- Review of purpose of project and informed consent elements
- Explanation of recording and interview processes (including stop rules, e.g. you don't have to answer any questions you don't want to; you can stop the interview at any time)

Interview Session: Issues to Explore

1. Personal Narrative: Open-Uterine Surgery to Repair Spina Bifida

A. Please tell me about your experiences with prenatal surgery for spina bifida.

- (1) If hesitant, ask them to start wherever they feel comfortable
- (2) Pay attention for the following elements:

pregnancy story, diagnosis, information received, disability/abortion, learning about PNS4SB, travel to VUMC, evaluation/consultation, decision (surgery/no surgery), going home (birth, termination), living with decision

2. Informing/influencing elements regarding open-uterine surgery to repair spina bifida

A. Health Care Providers

- (1) What did your OB or other Health Care Provider tell you about Spina Bifida?
- (2) What were his or her suggestions about your options?
- (3) How were your experiences with HCPs at VUMC different?
- (4) Please tell me about your experiences with HCPs since returning from VUMC?
- (5) What, if anything, do you wish were different about your experiences with HCPs?

B. Spina Bifida and Disability – Images, understandings, opinions

- (1) What previous experience, if any, did you have with spina bifida or other disability, before your diagnosis?
- (2) How did you imagine your child's spina bifida or disability between your diagnosis and your decision about surgery? Between your decision about surgery and the end of your pregnancy?
- (3) What influenced this image or these images?
- (4) How has your experience with your child's spina bifida differed from or matched up with those images? What, if anything, do you think altered those images?

C. Abortion – information, responses, politics, activities

- (1) In what ways, if any, did abortion come up in your experience? Did someone suggest or did you consider abortion in response to your diagnosis?
- (2) What influenced your decision to terminate the pregnancy/ to keep the pregnancy?
- (3) Has open-uterine surgery to repair spina bifida affected your opinions about abortion? Your activities relating to abortion or abortion politics?

D. Uncertainty/Vulnerability – sources of, responses to

- (1) What kinds of vulnerabilities or pressures, if any, did you experience? (to abort, to surgery, to idea of sacrifice, to isolation, etc)
- (2) Were there any ways in which you felt particularly vulnerable? (Fear of unknown? Being alone? Why me? Other?)
- (3) What kinds of things helped you manage these vulnerabilities or uncertainties?

E. Parenthood – ideas about, response to

- (1) How did you understand your approaching parenthood before and after receiving a prenatal diagnosis of disability? (Were you already parents?)
- (2) How did your understanding of parenthood influence your decision to choose / not choose open-uterine surgery to repair spina bifida?
- (3) How did the idea of being ‘good parents’ relate to your decision, if at all?

3. Decision-making and moral experience:

A. Moral Framework – self-identified, relation to decision and experience

- (1) How do you define your belief system? (Faith? Spirituality? Philosophy of life? Moral framework? Practical/pragmatic? Other?)
- (2) What kinds of things helped you think about your experiences and think about your decisions? Have those things changed over the years?
- (3) How did these beliefs affect your experience and decision?
- (4) How has this belief influenced your experience after leaving VUMC?

B. Informed consent/ consultation process

- (1) Where did you get your information about spina bifida and about the surgery? (Researchers? Web-rings? Books? SBA/support groups? Other parents? Your own family/experience?)
- (2) Did you connect with other open-uterine surgery to repair spina bifida families? If so, please tell me about it (How and why).
- (3) How did you understand the ethics consultation process – its goals, the kinds of things it might or did entail?
- (4) Did the process of moral reflection prior to making a decision influence your decision? If so, how? In what ways was it helpful or

harmful? Did anything you learned or thought about affect your later experiences?

(5) What was helpful about the ethics consultation process? What was difficult or challenging?

C. Decision-making – who, what, when, where, why?

(1) Please tell me about your decision-making process.

(2) Who was involved in your decision-making process? (Family? Clergy? HCPs? Researchers? Friends?)

(3) How was this decision similar to or different from other moral decisions?

(4) What was the most important factor in your decision-making?

(5) What was the most difficult feature of making this decision?

(6) What was the most helpful feature of or factor in making this decision?

(7) In what ways, if any, does this decision or experience come up in your life now?

(8) How have you shared this experience or decision with others, if at all? (Family, Friends, Child(ren), Community)

4. Then and Now – differences, similarities, recommendations

(1) In what ways, if any, has your thinking about this experience changed over the years?

(2) How do you think your decision regarding open-uterine surgery to repair spina bifida has affected your experience with your child's spina bifida?

(3) What things, if any, would you have liked to know at the time you made your decision?

(4) Can you think of anything that you have learned over the past _____ years that might have influenced your decision?

(5) Do you have any recommendations or suggestions for women considering this surgery in the future?

(6) What areas, if any, do you think have been overlooked in the public discussions of spina bifida and prenatal surgery?

- Prepare to take leave, answer any questions
- Thanks for sharing time, thoughts, experiences, hospitality
- Leave card with number and email if they think of anything else
- Request permission to make a follow-up call or visit if needed after reviewing discussion information.

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