

ABSTRACT

Patient Autonomy in Prenatal Testing Practices

Vivienne Elena Clark

Director: Lori Baker, Ph.D.

Of Beauchamp and Childress' four principles of medical ethics—autonomy, beneficence, non-maleficence, and justice—autonomy is often given the most priority. However, when it comes to receiving prenatal care, women face a number of external forces that compromise their ability to make autonomous decisions. These forces include: medical professional bias regarding disability and the routinization of prenatal screening tests; insufficient information provided to patients; a wide range of sociocultural circumstances, particularly familial and community pressure regarding pregnancy termination and economical considerations; and collective societal prejudice against disability. If autonomy is to be given primacy in medical ethics, expectant women need to be empowered to make fully autonomous decisions. Physicians and genetic counselors must understand the impact of these factors on women's decision-making, and not allow their biases to sway patients' decisions. Furthermore, steps must be taken to ensure that pregnant women receive social and financial support regardless of their decision. With better information and less influence from biased external forces, women will be better equipped to make autonomous decisions regarding prenatal care.

APPROVED BY DIRECTOR OF HONORS THESIS:

Dr. Lori Baker, Department of Anthropology

APPROVED BY THE HONORS PROGRAM:

Dr. Andrew Wisely, Director

DATE: _____

PATIENT AUTONOMY IN PRENATAL TESTING PRACTICES

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Vivienne Elena Clark

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DEDICATION

I would like to dedicate this project to my family, with thanks for their endless love and support, and to the Baylor faculty who have given so generously of their time and energy to me for the last four years.

CHAPTER ONE

Introduction

Statement of the Thesis

The purpose of this thesis is to present the case for autonomy as the primary bioethical principle for prenatal patients, and to explain barriers that need to be understood by the medical community in order to help prenatal patients make autonomous decisions.

Before defining autonomy, a description of the other three principles of traditional bioethics—beneficence, non-maleficence and justice—is presented in Chapter Two. The case for the priority of autonomy is then made for female healthcare in western medicine. In Chapter Three, prenatal test practices are listed and explained. Knowledge of both screening and diagnostic tests is required to fully explain what is entailed in providing autonomy for prenatal healthcare decisions. The bulk of the thesis is presented in Chapter Four, where barriers to autonomous decision-making in prenatal care are more fully discussed. Understanding these barriers can help lead to relevant changes within the medical community and society as a whole, providing increased autonomy for prenatal patients as they make crucial decisions about their pregnancies.

Prenatal Testing and Patient Autonomy

In her article, “Refusing Prenatal Diagnosis: The Meanings of Bioscience in a Multicultural World” (1998), anthropologist Rayna Rapp describes an encounter with a pregnant African-American woman who, contrary to Rapp’s expectations, made the

decision to refuse prenatal screening tests for her fetus. As the woman explained her concerns and her family members' mistrust regarding the use of her amniotic fluid for experimentation, Rapp tried to allay the woman's uneasiness and assure her that she could refuse to give consent for experimental use. However, as they discussed the issue further, the woman expressed her fear about experimentation based on her perceptions of the history of Black people and medical testing. From the Tuskegee experiments to the "Green Monkey" theory of AIDS experimentation in Africa, the historical context for the woman's decision revealed a deeper sociocultural concern about prenatal testing that greatly influenced her decision.

Thus, despite Rapp's initial expectation that the woman would see the benefit of amniocentesis, a commonly recommended prenatal diagnostic test for this woman's medical history, the advice and expertise of Rapp and the woman's physicians were insufficient and rejected. The patient was more influenced by a variety of familial, cultural, religious, and historical factors. This example highlights a number of the bioethical issues that surround prenatal healthcare.

According to Beauchamp and Childress, the four principles of medical ethics are autonomy, beneficence, non-maleficence, and justice (Beauchamp and Childress, 2001). Autonomy refers to the right of an individual patient to self-determination, free of undue external influence and uninhibited by lack of necessary information. Beneficence refers to the medical professional's responsibility to act in the patient's best interest; its corollary, non-maleficence, is the professional's duty not to bring harm or injury to the patient, frequently summed up in the phrase *primum non nocere*: "First, do no harm." Finally, justice in medical ethics is the idea that the

burdens and benefits of treatments must be made equally available to all members of society, regardless of affiliation. Further explanation of these principles can be found in Chapter Two of this paper.

Of the four bioethical principles, autonomy is frequently given priority over the other three in regard to patient care. Gillon describes autonomy as the “first among equals,” characterizing it as a “necessary component” of the other three principles (2003). This place of honor is primarily due to the importance of individuality and self-determination in Western society as a whole. In fact, autonomy has been described as “a manifestation of western culture” in its emphasis of independent self-actualization (Kara, 2007). Callahan notes that “autonomy is then *de facto* given a place of honor because the thrust of individualism, whether from the egalitarian left or the market oriented right, is to give people maximum liberty in devising their own lives and values (2003).” However, Oishi and Diener suggest that the prioritization of individualistic autonomy is reflective of European American cultural values, not necessarily universal values across the globe (2001). Likewise, Kagitcibasi draws connections between the history of individualism in Western thought and its centrality in certain fields of scholarship, noting that an individualistic conception of autonomy is often unquestioningly assumed as part of the universal framework for understanding healthy, normative human behavior (2005).

With a Western understanding of the importance of individual self-determination, it is not surprising that autonomy has traditionally been given high priority in the field of medical ethics. Varelius (2006) notes that certain bioethicists, including Beauchamp and Childress, regard autonomy as a particularly crucial aspect

of a patient's overall good. In fact, so much importance is given to patient autonomy that some bioethicists argue that a patient should always be allowed to make decisions regarding his own health, even in certain circumstances where others may be better equipped to make decisions about the patient's well-being (Glover, 1997; Beauchamp and Childress, 2001; Gillon, 2003). Patient autonomy is regarded as an intrinsic aspect of personal well-being, above and beyond its "instrumental value" in the patient's decision-making process (Varelius, 2006).

Although the traditional definition of autonomy as self-determination has received criticism for being too individualistic and Western-centric (Superson, 2009; Mackenzie and Stoljar, 2000), the fact remains that autonomy is given particularly high priority in Western and especially American society. Therefore it must be given special consideration in bioethical concerns regarding prenatal testing. In order to equip patients to make autonomous choices regarding prenatal care, one must ensure that patients are receiving care that a) is free of undue coercion, whether by medical professionals or other external influences, and b) provides full information, allowing the patient to understand the effects of her decision with regard to all relevant factors (cultural, familial, economic, etc.).

The main factors affecting prenatal care may be grouped into four distinct categories, with some similarities among them. The first major category is prejudice against disability within the medical professional community itself, regarding both prenatal care and healthcare for people with disabilities. The routinization of prenatal screening tests may also be considered an aspect of this bias, inasmuch as it illustrates an expected attitude toward disability. The second category is insufficient

information given to parents regarding prenatal care, especially for women who are pregnant with their first child. The third category may be described broadly as sociocultural circumstances, encompassing familial, religious, cultural, and social attitudes toward pregnancy, prenatal diagnosis, and pregnancy termination. Related to but distinct from sociocultural concerns are economical considerations, which may limit the ability to receive prenatal care or provide for a disabled child. Finally, collective societal prejudice against disability plays a role in influencing patients' decisions with regard to terminating a potentially disabled fetus or choosing to keep it. Each of these factors will be elucidated further in Chapter Four of this paper.

CHAPTER TWO

The Four Principles of Biomedical Ethics

Bioethics According to Beauchamp and Childress

The principles of biomedical ethics as theorized by Beauchamp and Childress are considered classic standards in this field. While the concepts of autonomy, beneficence, non-maleficence and justice are not meant to be a definitive moral ideal, they do provide a commonly accepted framework for approaching a resolution to ethical issues in healthcare. Before pursuing a detail discussion of the principle of autonomy, which is the primary focus of this thesis, the other three principles of biomedical ethics will be described first.

The Principles of Beneficence and Non-Maleficence

The dictionary definition of beneficence is the act doing of good; active goodness or kindness; and charity. As a philosophical concept, it refers to a moral obligation of humans to take action on behalf of others and remove them from potential harm. The well-known parable of the Good Samaritan in the New Testament is a time-honored example of beneficence. Robbers have badly beaten a Jewish man on the road from Jerusalem to Jericho. A Samaritan man finds him, tends to his wounds and transports him to a nearby inn for continued treatment and healing. The cultural bias of that time would not expect a Samaritan to help a Jew; thus, the action of the Samaritan man, demonstrates an act of kindness that transcends social norms.

The corollary to beneficence is non-maleficence, the moral obligation to not inflict harm on another. This guiding principle of medical ethics is based on the admonition of the classical Hippocratic Oath, “to keep [patients] from harm” (Edelstein, 1943). However, defining the nature of harm can be very difficult. Does it include avoiding the risk of harm? Can one unknowingly cause harm to a patient, causing unintentional pain, and violate this principle? Is the harm to be avoided only defined as physical harm, or should the potential of emotional harm be considered equally valid?

Beneficence and non-maleficence are often linked together and refer to the medical professional’s responsibility to act in the patient’s best interest. Numerous examples of this can be found in the field of emergency medicine, where often the patient may be incapacitated due to a severe accident and require immediate procedures to bring him or her to a stable condition. In more general circumstances, physicians follow the principles of beneficence and non-maleficence by advising patients for treatments that will provide more benefit than harm. They would avoid treatments where the benefits are not adequately proven or where benefits may not outweigh the harm. If patient requests a treatment that is known to produce adverse affects for him or her, the doctor should advise against this treatment (Beauchamp and Childress, 2001).

Whether or not a treatment may be recommended as beneficial can change throughout time. In decades past, amniocentesis was considered a routine tests for women of advanced maternal age; however, it was not a standard test for younger mothers, due to the higher risk of causing miscarriage. However, within the last

fifteen years, Dommergues et al determined that amniocentesis could be performed safely on a selective basis as a follow-up to noninvasive screening tests (2001).

In certain cases beneficence and non-maleficence may be competing factors in determining a patient's best interest. If results from an initial prenatal screening indicate a need for further diagnostic tests, the principle of beneficence would dictate that these tests be performed. However, the principle of non-maleficence could provide a justification to oppose such a test if there are high risks of misleading results that could cause the patient to end the pregnancy without cause. For example, amniocentesis has a false positive rate of 5% when testing for Down syndrome, and fails to detect about 10% of actual Down syndrome cases (Daniilidis et al, 2008). False positive or negative results may cause undue stress on the pregnant woman and could lead to unnecessary terminations of wanted pregnancies.

Economic considerations are not supposed to play a factor in physicians' recommendations regarding individual patient's best interest. What is best for the patient is put first, rather than what is best for his or her family's finances. Addressing the patient's economic situation is a consideration of the fourth bioethical principle, justice.

The Principle of Justice

Beauchamp and Childress' principle of justice directs the responsibility of the medical professional toward both his individual patients and society as a whole. While the focus of the previous principles is primarily on the individual needs of the patient, there is also a community component to biomedical ethics in the principle of justice. Ideally, justice in healthcare gives each patient his or her fair due with

emphasis on a fair distribution of goods and services. Critical factors considered by Beauchamp and Childress in determining just distribution include equal share according to need, effort, contribution, merit, and free-market exchanges (2001). While providing equal access to healthcare for everyone is a noble social goal, such a goal is riddled with problematic implementation that is commonly debated in the political arena.

In clinical practices, however, justice simply requires that physicians strive for the equitable distribution of care among all patients in a particular medical setting. In certain situations, such as a triage station, justice demands that the patient suffering serious trauma from a bullet wound be given precedence for care over the patient with a broken finger. On larger scales, from local to national healthcare systems, the principle of justice manifests itself in equitable distribution of available medical resources within a medical facility or practice regardless of race, sex, and economic or social status.

The Principle of Autonomy

As explained in the introduction to this paper, the three bioethical principles described above, while important, are sometimes given less priority than the fourth principle of autonomy in Western culture. Autonomy is a complex term encompassing the concepts of independence, individuality, and moral decision-making. Beauchamp and Childress define autonomy as, “at a minimum, self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (2001).

Patient autonomy acts as a counterbalance to the power of the physician in the patient-doctor relationship. A physician withholding information or otherwise displaying an active bias is a violation of autonomy, especially when combined with a lack of understanding for the patient's background and personal desires. Both these issues will be discussed later in following chapters.

As a principle rooted fundamentally in respect for an individual's right to self-determination, Beauchamp and Childress' formulation of autonomy is content-neutral. However, other philosophers, in particular Immanuel Kant and his successors, consider autonomy to be an essential condition to achieving a universal morality, rather than simply an ethical guideline. Kantian autonomy dictates reliance on one's individual rationality above all else; therefore, universal morality consists of morals to which all rational persons would subscribe.

Many feminist philosophers have criticized the Kantian formulation and its philosophical legacy, arguing against a radical emphasis on rationality and independence. In particular, oppressive conditions, such as those faced by women and minorities, affect a person's ability to make decisions based purely on reason; therefore, such persons are excluded from autonomy as defined by rationality and independence (Superson 2009). In response to individualistic conceptualizations of autonomy, feminist critics offer the idea of relational autonomy, which rejects an atomistic concept of the self on the grounds that a person cannot be abstracted from his or her social context (Mackenzie and Stoljar, 2000). Such a formulation challenges the notion of autonomy as self-sufficiency. Within a healthcare setting, it causes one to reconsider the necessity of accounting for a patient's sociocultural,

interpersonal, and historical conditions in order to ensure that their autonomy is preserved.

In *Principles of Biomedical Ethics*, Beauchamp and Childress uphold autonomy as a core principle of ethical medical care. Similar to the Kantian approach to autonomy, autonomy in traditional bioethics involves self-governance; each individual patient serves as a law unto himself with regard to decision-making about his or her health. However, Beauchamp and Childress do not suggest that each patient strive for a universal morality with regard to their health. Their content-neutral formulation might be described as the concept of *personal autonomy*, whereas Kant describes the concept of *moral autonomy*. Kantian autonomy is committed to a universal morality, but Beauchamp and Childress are only concerned with autonomy as a concept based on the internal decision-making processes and external actions of particular individuals.

In accordance with this neutrality, autonomy as a traditional bioethical principle is meant to serve more as a guide to action for medical professionals, rather than a philosophical statement on human nature. According to Gillon, the principles comprise “a set of moral commitments, common language and a common set of moral issues,” rather than a method for deciding on a particular course of action (1994). Thus, rather than appealing to higher morality, traditional bioethical autonomy relies essentially upon the notion of “respect for persons,” or the conviction that persons are self-determining individuals capable of making independent decisions regarding their own bodies. Accordingly, the principle of

autonomy is accompanied by specific physician guidelines that may be summed up in five rules:

1. Tell the truth.
2. Respect the privacy of others.
3. Protect confidential information.
4. Obtain consent for interventions with patients.
5. When asked, help others make important decisions. (Beauchamp and Childress, 2001)

Such guidelines are meant to prevent excessive interference by healthcare professionals in patients' lives. However, in order to be considered autonomous, a patient's decision cannot merely be voluntary; it must also be informed. Therefore, it is incumbent on medical professionals to ensure that patients receive sufficient and unbiased information in order to make autonomous decisions.

Beauchamp and Childress' model has not gone without criticism. For example, H. Tristram Engelhardt, one of its foremost critics, notes that in a secular, content-free ethics, it is impossible to define what is "good." Furthermore, because Beauchamp and Childress acknowledge that "authority for actions involving others in a secular pluralistic is derived from their permission" (2001), Engelhardt concludes that one must ultimately appeal to other's permission in order to fashion the other principles of medical ethics (1996). Because of this, all moral authority stems from the principle of autonomy, giving it primacy over the other principles. Autonomy effectively becomes the chief principle in action.

In addition to Engelhardt's criticism, autonomy as it is generally understood within bioethical model has been regarded as a poor moral ideal due to the way it overlooks social relationships and human interdependency. The major critics of traditional models of autonomy were feminist scholars, notably Gilligan (1982), who argued that the model of autonomy and psychological development developed by Lawrence Kohlberg and his predecessors did not accurately reflect the female experience. Gilligan argued that, "for women, identity has as much to do with intimacy as with separation," and emphasized the importance of learning to balance one's interests with those of others rather than using separation itself as the measuring value of and growth. Similarly, Benjamin writes:

The ideal of the autonomous individual could only be created by abstracting from the relationship of dependency between men and women... the other is reduced to an appendage of the subject – the mere condition of his being – not a being in her own right (1988).

Hoagland (1988) rejects the traditional concept of autonomy even more forcefully, referring to it as "a thoroughly noxious concept... that encourages us to believe that connecting and engaging with others limits us."

When critiquing the highly individualistic traditional notion of autonomy, feminist philosophers point out that persons who are subjected to oppression in various forms may have a distorted sense of self that affects their decision-making, even if their reasoning abilities are fully intact. Babbitt argues that women who demonstrate "adequate instrumental reasoning abilities, full and complete information and the capacity to vividly imagine the consequences of her actions," may still choose to defer judgment to another rather than exercising autonomy, as such deference is part of "her social and historical identity to be inferior to men"

(1993). Other theorists invoke more explicit connections between one's autonomy and one's external conditions, particularly for women (Oshana, 2006; Raz, 1988; Brison, 2000). When accounting for financial, cultural, and familial pressures, as well as racial and class-based factors, women frequently do not make fully autonomous decisions in the traditional sense of independent self-determination. These issues within the context of prenatal care were discussed in the previous chapter of this thesis.

In light of these external influences, many feminists have offered reconceptualizations of autonomy known collectively as "relational autonomy." Relational formulations seek to balance the ideas of independent agency with social context, correcting the extremes of atomistic individualism while still allowing a person to maintain some personal agency. On one level, relational autonomy asserts that autonomy does not necessarily require self-sufficiency (Mackenzie and Stoljar, 2000); on another level it promotes a metaphysical understanding of personhood in which persons are shaped by their sociocultural and historical contexts, rather than atomized individuals operating purely by rationality.

The current available evidence indicates that current practices in prenatal care frequently prevent patients from receiving full information regarding prenatal testing in order to make fully autonomous choices according to the guidelines of Beauchamp and Childress. If autonomy, whether in a traditional or relational conceptualization, is still to be given precedence in matters of medical ethics, it is crucial to examine the issues in prenatal care that prevent expectant women from making autonomous decisions, and to seek solutions that will equip women to make self-determined

choices, whether in the traditional model of autonomy or in a more expansive, relational model. These issues will be detailed in the following chapter.

CHAPTER THREE

Prenatal Testing Practices

An Overview of Prenatal Screening and Diagnosis

Before discussing the intricacies of the factors affecting decision-making for prenatal patients, it is important to briefly describe the prenatal tests that are most common in Western medicine. One must also make an important distinction between prenatal screening and prenatal diagnosis. Prenatal screening, including common practices like ultrasonography, refers to tests that indicate potential diseases, conditions, and other abnormalities in a fetus; however, screening cannot fully determine that the fetus actually carries the anomaly in question. A positive screening test is followed by a diagnostic test, such as amniocentesis, which definitively determines the presence of a suspected condition in the fetus. Although it can provide a conclusive result, a diagnostic test cannot provide an analysis of the full extent of the condition, nor can it clearly indicate a prognosis (Scott, 2007).

Prenatal Screening Practices

Although prenatal screening tests cannot identify every possible defect, most tests do cover a range of common anatomic, chromosomal, and genetic defects. Anatomic defects typically consist of neural tube defects, which lead to such conditions as spinal bifida; the term also encompasses other abnormalities such as heart defects or clubfoot. Chromosomal defects most commonly include trisomy 21

(Down syndrome), trisomy 18 (Edward syndrome), and missing or extra sex chromosome abnormalities, such as Turner syndrome. However, chromosomal defects also cover a variety of less well-known chromosomal conditions, as well as mosaic conditions wherein certain cells are affected and others are normal. Certain tests can also identify specific genetic conditions, such as cystic fibrosis, Tay Sachs disease, muscular dystrophy, and countless others; however, many of these must usually be identified with specific diagnostic procedures rather than generalized screening tests.

Screening procedures most commonly include ultrasonography and maternal serum marker tests. They are generally a routine and noninvasive aspect of prenatal care. The best known of these is ultrasonography, which can detect multiple gestation, major anatomical abnormalities, and fetal sex.

A typical first trimester screening is composed of three tests: (1) ultrasonography, which analyzes nuchal translucency, or fluid build-up in the back of the fetal neck; (2) testing for pregnancy-associated plasma protein-A (PAPP-A); and (3) testing for human chorionic gonadotropin (hCG). With sensitivity greater than 98% (Morain et al, 2013), the first trimester screening detects fetal genetic fragments in maternal serum to identify chromosomal abnormalities and heart defects. Although it is so new that the FDA has not yet approved it, the first trimester screening test is already recommended by the American Congress of Obstetrics and Gynecology.

In the second trimester, pregnant mothers may undergo the “triple screen,” a multiple-marker blood test that measures serum levels of hCG, alpha-fetoprotein

(AFP), and estriol. When combined with inhibin A to increase sensitivity, the triple test is referred to as the quadruple test. The triple and quadruple screens are used to identify patients as low-risk or high-risk for neural tube defects and certain chromosomal defects. These screens primarily detect trisomy 21 and trisomy 18, as well as trisomy 6 mosaicism, Turner syndrome, triploidy, and other conditions (Benn, 2002). Screening test results are then analyzed with the mother's age, family or personal medical history, and ethnic background in order to determine the risks of an abnormality in the fetus.

Prenatal Diagnostic Practices

An abnormal screening test result may be followed by optional diagnostic procedures such as amniocentesis and chorionic villus sampling (CVS). CVS analyzes chromosomal and genetic defects and can be performed as early as 10-15 weeks into the pregnancy; amniocentesis is generally not performed until 15-20 weeks, but it can also be used to test for neural tube defects in addition to chromosomal and genetic abnormalities. As opposed to serum testing and ultrasonography, amniocentesis and CVS involve the insertion of needles into the uterus and are therefore considered highly invasive. Such methods carry with them various health and safety risks, including uterine infection, amniotic leakage, and pregnancy loss. According to Alfirevic et al, second trimester amniocentesis increases the risk of pregnancy loss by about 1%, with slightly greater risks for early amniocentesis and chorionic villus sampling (2009).

If a prenatal diagnostic test reveals an abnormality, the fetus in question may be terminated. There are no nationwide records on termination rates for various

conditions; however, in the case of Down syndrome, for example, it is estimated that between 80-90% of women who receive a positive DS diagnosis choose to abort, with variation depending on region and religious attitudes (Kramer et al, 1998; Forrester and Merz, 1999). However, prenatal screening can also help both physicians and patients to prepare for delivery and care in the event of a high-risk pregnancy, should the parents choose not to terminate.

CHAPTER FOUR

Patient Decision-Making in Prenatal Care

Barriers to Autonomous Decision-Making

The story of Dr. Rapp's encounter with an expectant mother described in the introduction to this paper illustrates the difficulties and nuances involved in prenatal counseling and healthcare. In making any recommendations to prenatal patients, the medical practitioner must understand a variety of barriers that may influence the patient's ability to make informed, autonomous decisions. This section describes four main barriers to patient decision-making in prenatal care. The first two are disability discrimination and bias within the medical professional community and within society as a whole. The third barrier consists of the sociocultural, historical, and economic circumstances that shape individual patients' interpretation of medical advice that they receive from physicians and medical counselors. Lastly, the fourth barrier is the lack of clear information provided to prenatal patients. Although distinct from one another, these barriers do not develop in isolation; each of them is influenced by and occasionally overlaps with the others.

Bias and Discrimination in the Medical Community as a Barrier

Bias is defined as a preference or inclination that inhibits one from impartial judgment. Biases can influence the outcome of a decision-making process in a way that is prejudiced and perhaps unfair. They can also lead to recommendations or

considerations that are based on a particular class or category rather than individual merit, resulting in unjust discrimination. Human nature often does not allow personal biases to be identified. This inherent trait of mankind, however, cannot be an excuse for the medical community to ignore their personal biases in how they provide information to their patients. In fact, bioethics requires medical professionals to evaluate continually the influence of their own views on the care they provide their patients.

Medical bias can occur throughout the entire process of healthcare, from how data is collected and analyzed for research to the options that are presented or not presented to patients in the doctor's office. While the biases discussed in this paper are primarily found in a clinical setting, the impact of bias in medical research must also be considered in any recommendation made by a physician or medical counselor.

With regard to prenatal health, physicians and the medical community as a whole often express greater support for prenatal selection than their patients do. Studies in Israel and Western Europe, both Western medical systems, indicate that clinicians are more likely to find termination acceptable in the event of severe disability. In the Israeli study, 97% of clinicians support the termination of fetuses with a prognosis of severe mental retardation, whereas only 69% of patients support elimination in such circumstances (Mishori Dery et al, 2008). Wertz reports that 80% of genetics professionals and 62% of primary care physicians in the U.S. would prefer to terminate a fetus with a Down syndrome diagnosis, whereas only 36% of patients would do so; similarly for a prenatal diagnosis of XXY syndrome, nearly 50%

of healthcare professionals would choose termination as opposed to only 22% of patients (2000).

This disparity is indicative of different priorities for patients and physicians. Pregnant women are more likely to seek to protect their unborn child, whereas physicians are more typically concerned with controlling diagnosed abnormalities (Hunt et al, 2005; Bishop et al, 2004). Unfortunately, this disparity appears to affect how medical professionals present information about prenatal testing and diagnoses to their patients. Wertz's survey indicates that more than 25% of genetics professionals encourage pregnancy termination in the event of severe spina bifida and 13% in the event of Down syndrome; by contrast, only 1% and 2% respectively would encourage continuation of the pregnancy. In total 36% of nearly 500 physicians admitted that they had attempted to direct their patients' decision-making. Not only is such behavior in either direction a violation of patient autonomy, it is also indicative of inherent bias against disability within the prenatal healthcare system.

Clinician bias against disability is perhaps most evident in the case of Down syndrome, as it is one of the best-known conditions that can be identified via prenatal diagnosis. In a study of women who chose to continue pregnancy after a positive Down syndrome diagnosis, Skotko (2005b) reports that a substantial minority of women feels coerced by their physicians to pursue amniocentesis or abort their fetus. Women who choose to continue a pregnancy after a Down syndrome diagnosis report clinicians' use of offensive language concerning Down syndrome; these physicians characterize it as a burdensome and regrettable abnormality to which a

child should not be subjected (Korenromp et al, 2007; Helm et al, 1998; Tymstra et al, 2004; Skotko, 2005a). Expectant mothers report these attitudes and reactions as highly distressing, and many report feeling abandoned by their physicians after choosing to continue a Down syndrome-positive pregnancy (Skotko, 2005b).

Physicians also tend to greatly underestimate quality of life for individuals with Down syndrome compared to estimates on quality of life from people who actually have Down syndrome; in a recent study from Skotko et al. (2011), nearly 100% of people with Down syndrome report being happy with their lives, themselves, and their relationships.

While these patterns are most evident in Down syndrome, similar clinician behaviors (underestimation of quality of life, offensive language, and isolation of the pregnant patient) have also been observed for other conditions, including fragile X syndrome (Skotko, 2005a) and Duchenne muscular dystrophy (Bach, 1992). Such attitudes are indicative of medical professionals' general disinterest in the actual lives and experiences of people with disabilities. These attitudes may stem from the prevalence of the so-called "medical model of disability" in the healthcare system. By viewing a disability as a disease to be eliminated rather than treating the person with a disability in a way that encompasses the person's entire well-being, healthcare professionals will continue to perpetrate negative attitudes toward disability that may affect their interactions with patients, thereby preventing pregnant women from making fully autonomous decisions about prenatal screening and selection.

As another small illustration of bias in prenatal care, it is interesting to note that although the American Congress of Obstetricians and Gynecologists opposes

fetal selection based on sex alone, it does not object to selection against disability (Skotko, 2009). The ACOG argues that the practice of sex-based selection creates “a climate in which discrimination can more easily flourish.” However, they neglect to provide similar protection for the disabled, effectively creating an environment where ableism can flourish even as sexism is discouraged. Although one may not be able to draw a direct correlation between the ACOG’s stance and negative treatment of the disabled, the contrast between the support offered for other minority groups and support offered for the disabled is still striking and noteworthy.

A related medical factor that creates barriers to the ability of patients to make autonomous decisions is the routinization of prenatal screening. As screening and diagnostic tests become a normal and expected part of prenatal care, women feel pressured to undergo screening, viewing it as a responsible maternal action (Press, 2000). In fact, screening tests are often presented as a moral obligation to promote the best interests of the fetus and society of large (Scott, 2007). When prenatal testing is presented as a necessity, patients are urged to comply even with aspects of testing that are in conflict with patients’ personal desires or beliefs (Klein, 2001).

Concerns about routinization are closely related to concerns about healthcare provider bias. If clinicians in general already exhibit an active preference toward the termination of fetuses with potential disabilities, they may present testing services in a way that encourages patient compliance (Press and Browner, 1997). Accordingly, patients are less likely to seek more information about testing when those tests become routine. As an example, a study at a UK hospital found that only 43.5% of expectant women made an informed choice about a Down syndrome testing package

they had accepted (Dormandy et al, 2006). Such pressures from within the healthcare system hamper patient autonomy because patients do not even realize the extent to which they can make an active choice about screening.

Bias against the disabled is not limited to prenatal care; rather, it is endemic throughout the entire healthcare system. In fact, healthcare providers frequently have even more negative views of disability than the general public (Pendo, 2008). Much of this discrimination is not the result of active prejudice, but rather ignorance and attitudes that render the disabled effectively invisible. As previously mentioned with regard to prenatal care, the healthcare system in general subscribes to the medical model of disability, and is concerned more with treating and curing impairments than supporting the health and overall well-being of the disabled, especially if the impairments in question cannot be fixed (Yee, 2012). These attitudes result in the marginalization of people with disabilities from healthcare services.

Just as clinicians in prenatal care greatly underestimate the potential quality of life for Down syndrome-positive fetuses, healthcare professionals in general underestimate quality of life for people with disabilities stemming from other causes. For example, in a survey of 153 emergency care providers, only 18% of the group (including doctors, nurses, and technicians) reported that they would be glad to be alive after a severe spinal cord injury, whereas 92% of a group of 128 patients with serious spinal cord injury reported that they were glad to be alive (Gill, 2000). These kinds of negative attitudes can result in poorer quality care for patients with disabilities. In a study of Duchenne muscular dystrophy patients and their caretakers, Bach (1992) compared quality of life evaluations by patients and care providers and

found that caretakers who greatly underestimated quality of life frequently did not recommend ventilator assistance for their patients.

A 2005 survey of Special Olympics athletes found that many of the athletes were suffering from easily treatable conditions due to lack of good healthcare. 35% of the athletes suffered from tooth decay, and 50% had untreated foot conditions. Women with disabilities also report significant marginalization in receiving medical care. In a survey of 506 women with physical disabilities, 30% report being misinformed about birth control by their physician, and nearly 40% report being ignored by their physicians during their appointments, as the physicians chose to speak with accompanying family members instead. In a subset of this sample of women, one-third report that they were denied reproductive services by their clinicians (Nosek et al, 1996).

Most disturbingly, many physicians are not even trained to care for disabled patients. The Special Olympics survey found that over 50% of medical and dental school deans believe their students do not have sufficient training to treat patients with intellectual disabilities. Medical and dental students likewise echo this assessment, with 51% of dental and 81% of medical students reporting that they did not have enough classroom education or clinical experience on how to treat disabled patients. Cleary-Goldman et al. (2006) found that 45% of practitioners feel their residency programs offered them inadequate or minimal training on Down syndrome patients; Oshima et al. (1998) report similar percentages of untrained physicians in a spinal cord clinic. These high numbers are indicative of the general attitude amongst healthcare providers that ignores and marginalizes disability.

In addition to healthcare provider bias that affects the quality of medical care received, patients with disabilities also experience numerous difficulties with healthcare accessibility. Yee describes the broad range of problems encountered, asserting:

Healthcare services remain deeply inaccessible, from clinic restrooms that do not have grab bars or reachable faucets to health plans that do not have benefit information or notices in alternate formats, from providers that refuse to provide ASL interpretation to insufficient appointment times to enable a person with speech impairments or some developmental disabilities to communicate and follow directions (2012).

Despite provisions in the Americans with Disabilities Act mandating accessible healthcare, patients with mobility impairment often still face physical barriers. A recent survey of 256 subspecialty practices in five major cities across the United States found that 22% were unable to accommodate an obese, hemiparetic patient in a wheelchair. Another 40% would transfer the patient manually, an unsafe practice for both the patient and healthcare workers. Only 9% of the clinics had height-adjustable tables or lifts for exam table access (Lagu et al, 2013). Notably, 44% of gynecology practices were unable to examine the patient in question, a percentage reflecting the prejudiced notion that women with disabilities do not engage in sexual activity and therefore do not need pelvic exams. Additionally, disabled patients report discomfort in clinical settings due to difficulty or even inability to navigate clinic buildings (Pittman, 2013). These barriers are likely to discourage the disabled from scheduling regular appointments or seeking preventative care.

Bias and Discrimination in the Society as a Barrier

It can be argued that the bias and discrimination against the disabled in the medical community is merely a reflection of that same bias in society as a whole. Although discrimination against the disabled may be more prevalent in the healthcare system than in the population as a whole, it is still important to note that people with disabilities face stigmatization and marginalization within society as a whole (Scheid, 2005; Susman, 1994).

Fetal selection against disability is only indicative of broader social mores. For example, while the termination of disabled fetuses may be considered acceptable on the grounds that such infants would be burdensome to their parents, this same practice of selection was met with indignation when healthy fetuses were aborted in multiple gestation pregnancies in Great Britain (Rayner, 2003). Multiple births are seen as an event worthy of celebration, even as society acknowledges the difficulty in raising them, whereas the birth of a disabled child is seen as a drain on the family and society as a whole. These incidents reinforce the notion that “disability” is as much a matter of social stigma as it is a chromosomal or genetic condition (Asch and Wasserman, 2005).

As a result of marginalization and lack of social support, people with disabilities experience poverty at a higher level than the general population:

“People with disabilities account for a larger share of those experiencing income poverty than people in any single minority or ethnic group (in, on fact, all minority, ethnic, and racial groups combined)” (Fremsted, 2009).

In a 2005 survey of working-age adults with a disability, under half reported having employment at some time during the year (U.S. Census Bureau). Those who do have

jobs are frequently burdened by out-of-pocket healthcare costs for necessities like medical equipment and assistance (Yee, 2012).

The notion of the American dream and a comfortable retirement are often not compatible with the responsibilities of raising a disabled child. Outsiders viewing a family with a disabled child may see only long-term hardship with regard to both time and money. Their focus is on the mental, emotional and physical toll of raising the child through adulthood because of the inability of the child to become fully independent. Children without disabilities in the household may be pitied for having to live within the social constraints demanded by a disabled child. For many people, the potential for increased family ties, love and commitment are rarely considered to be strong enough to justify the downsides of raising a disabled child.

The pressures of societal attitudes against the disabled and the expectations of the American lifestyle clearly become an influence in a patient's requests for prenatal care and her decisions following a diagnostic test that indicates abnormalities. However, decisions to reject prenatal screening or the termination of the fetus are made on a regular basis. Factors leading to this decision are often based on the patient's religious or cultural history.

Sociocultural and Economic Context as a Barrier

The effects of a patient's social, cultural, and historical background on her decision-making process are vast and often unseen. When combined with personal and family history, sociocultural and historical context can provide an intricate, multifaceted web in which one might gain a better understanding of the many factors that account for the patient's decisions. Unfortunately, many of these subtleties are

often overlooked in a clinical setting, when healthcare providers are too rushed or do not wish to take the time to inquire deeply into their patients' desires and needs.

In writing about her experience with the African American patient who feared medical experimentation (as described a previous chapter), Rapp, who has studied the sociocultural aspects of prenatal care in-depth, explains:

[The patient's decision] was both the product of individual choice contextualized by kin and community pressure and a response to racially differentiated histories and sentiments concerning medical intervention and experimentation...the imbrication of social history and individual volition, collective position and personal choice—or the intertwined and negotiated workings of structure and agency... (1998).

However, a patient's past sociocultural background is not the only history that influences prenatal patients. A patient's personal reproductive history and fear of miscarriage can become important factors in her decision-making process regarding prenatal screening. In another example of prenatal decision-making, Rapp describes a mother of a Down syndrome child who refused testing for her second pregnancy. This mother observed that the tests can only detect a few abnormalities and therefore had a high likelihood of providing false assurance. Again, both individual history and shared family and community experiences play a role in the decision-making process. Women from families with no known genetic problems, or from countries and cultures that do not offer or support prenatal screening, may also refuse tests. Male partners in particular can play a strong role in influencing women's decision-making. Although the effects vary as far as negative or positive attitudes toward screening are concerned, women are often highly responsive to the influence of their husband or the father of their child.

Religious beliefs and other family influences may also have strong effects on decision-making. In general Rapp finds the following:

Women with potent religious affiliations, strong kinship or other communitarian social support, or powerful reasons anchored in their reproductive histories” are most likely to decide against the biomedical information amniocentesis brings as a basis for accepting or rejecting a particular pregnancy (1998).

Another factor to consider when analyzing the effects of sociocultural context is the environment of the prenatal clinics themselves, which depends on geographical and economic considerations as well. When comparing the rate of patients who accept prenatal screening between two prenatal clinics, Rapp notes that the clinic with a high acceptance rate (70-80%) has a more stable environment with low nurse turnover, allowing patients to develop relationships with their healthcare providers. In contrast, the clinic with a low acceptance rate (30-40%) has routine wait times of two to three hours, frustrating patients to the detriment of the patient-professional relationship. This example demonstrates how the clinic itself provides additional factors that must be considered in a broad socioeconomic context of prenatal testing. Geographic location and local, state, and federal funding are just a few of the factors that can affect clinic quality and therefore the likelihood that women will accept or reject prenatal screening. Crowded, busy clinics in poor communities are likely to be intimidating and discouraging to many women.

The prenatal healthcare found in more low-income regions would generally not provide the level of information found in wealthy parts of the area. This may be related to the educational level of patients in those low-income neighborhoods as well as the operation of the clinic itself. Despite these economic factors, the medical

community is still responsible for giving sufficient and clear information to its patients.

Lack of Information as a Barrier

In order to allow a patient to make autonomous decisions, a healthcare professional must provide information that is relevant, accurate, clearly communicated, and above all understood by the patient. Women who struggle with the language of medical culture may not be able to interpret all the information they receive from a doctor who speaks in medical jargon, or they may not receive adequate clarification, leading to misunderstanding. Rapp recounts her experience with one pregnant woman who refused prenatal testing because she had misunderstood her counselor and believed that amniocentesis had a 50% chance of causing a miscarriage (1998). This misunderstanding is only one example of the issues caused by poor communication between professional and patient.

Language barriers can also prevent a patient from seeking prenatal care. Immigrants, for example, may not be aware that prenatal screening is available to them, or that Medicaid covers prenatal diagnosis. Sherraden and Barrera report that 44% of Mexican immigrant women have limited access to prenatal care due to language barriers and other communication issues (1996). Poverty, which also frequently accompanies language barriers, is another major factor that prevents women from receiving information about prenatal screening. When observing low-income patients in city hospital prenatal clinics, Rapp noted that nearly one-third began receiving prenatal care after the cutoff point for prenatal testing. Such patients

do not even have the opportunity to consider whether or not they would want testing, and therefore are unable to make a fully autonomous choice.

For a patient whose fetus receives a rare or ambiguous diagnosis, such as a trisomy mosaicism, the physicians' lack of knowledge about the condition leads to the patient's lack of information, affect the patient's decision-making process. In the event of a rare diagnosis, a patient may be less inclined to terminate a fetus with a poorly understood condition, whereas a fetus with Down syndrome would be eliminated, since the consequences of Down syndrome are more familiar to most people. However, even well-known conditions like Down syndrome occur on a broad spectrum of severity that a prenatal test cannot predict, due to varying expressivity and penetrance (Hernandez and Fisher, 1996). In that sense all prenatal test results are ambiguous, a fact that should be conveyed to patients rather than only negative or positive information about the condition at hand. Failure to communicate this ambiguity results in patient decision-making based on the fetus' predisposition to a particular condition without a full picture of its potential future (Parens and Asch, 2000).

As previously stated, each of these barriers does not function separately. Their combined effect on a patient's ability to make informed, autonomous decisions is highly blended, resulting in a complex decision-making process and requiring thoughtful explanations.

CHAPTER FIVE

Conclusion

The multitude of factors that can affect patient decision-making can be observed in another example from Rapp, describing the interactions between two geneticists and a Haitian mother whose newborn son had trisomy 9. The geneticists examined the baby and noted his physical defects in technical terms, while the mother spoke of how the baby resembled various family members; in Rapp's words, the mother genealogized while the geneticists pathologized. The mother in question had previously been concerned about the genetic abnormality while pregnant and had considered termination in the event that her son's condition had been Down syndrome, but her unfamiliarity with trisomy 9 and doctors' uncertainty about the extent of the condition, combined with family influence and religious beliefs, had persuaded her to continue her pregnancy. Rather than equating the child with his genetic condition, she viewed him within the context of his family history and lineage. This account beautifully illustrates the difficulties of balancing diagnostic considerations with a patient's experience and background to help her reach an autonomous decision.

In applying Beauchamp and Childress' bioethical principles to this example, the physician applied both beneficence and non-maleficence in her diagnosis and counseling on the uncertainty of that diagnosis. However, in the end, it is the patient's autonomy, colored by myriad external conditions, that resulted in the final

decision. The competing barriers that set the geneticists' medical training in competition with the mother's ignorance of trisomy 9 and strong family preference for continuing with the pregnancy illustrates some of the issues involved in empowering patients to make sound, autonomous decisions.

While it may be important for patients to self-educate in making these decisions, it is often not within the scope of many patients to complete the necessary research or even to find unbiased information. Therefore, it is incumbent on the medical community, biomedical researchers, physicians, and genetic counselors, to understand the impact of their personal biases as well as the biases of the medical profession as a whole on patient autonomy in decision-making. Furthermore, society has a responsibility to support and not discriminate against whatever decision a pregnant woman makes regarding prenatal testing. With better information and less influence from biased external forces, women will be better equipped to make autonomous decisions regarding prenatal care.

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