Medicaid's Postpartum Tubal Sterilization Policy's Effect on Vulnerable Populations

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Medicaid’s Postpartum Tubal Sterilization Policy’s Effect on Vulnerable Populations

By: Katherine Turner

A Capstone Submitted to the Graduate Faculty

of Georgia State University

in Partial Fulfillment of the Requirements for the Degree

MASTER OF PUBLIC HEALTH

Atlanta, GA 30303
Medicaid’s Postpartum Tubal Sterilization Policy’s Effect on Vulnerable Populations

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Author’s Statement Page

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______________________________  Katherine Turner
Acknowledgements

I thank Dr. Bruce Perry for his consistently thoughtful advice, direction and leadership during my time in the School of Public Health. I thank Carrie Whitney, who graciously introduced me to the program and readily agreed to serve on my capstone committee. Finally, I thank my friends and family for their encouragement, patience and proofreading skills.
Abstract

After the forced sterilizations of low-income and minority women were exposed in the 1970’s, new Medicaid policies were put into place in order to protect vulnerable populations. The revised policy included a mandatory consent form and a waiting period of 30 days between consent and procedure, as well as a presentation of the form at time of procedure. Although these policies were enacted to protect vulnerable populations, research has shown they are ineffective and act as barrier to women receiving the post-partum tubal sterilization that they desire. The policy has been shown to have a disproportionate detrimental impact on minority populations, and it has created a two-tiered health care system in terms of sterilization. The unfulfilled requests lead to many inadvertent consequences, including higher rates of unintended pregnancies, abortions, loss of self-efficacy, and higher costs for the Medicaid system. In order to ensure equitable treatment of Medicaid patients in regards to tubal sterilization, the 30-day waiting period should be rescinded. Additionally, to confirm that patients are fully knowledgeable of the implications of the tubal sterilization, the form and any ensuing consent should be rewritten to meet literacy standards for the target demographic. This analysis will include a history of the issue, an examination of relevant research, a policy analysis and recommendations to enhance healthcare equity.
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Chapter I: Tubal Sterilization: When, Why, How, Who, Where?

1.1 Introduction

Following centuries of legally sanctioned, forced sterilization that regularly targeted women with low socioeconomic status, little educational attainment, and minorities Medicaid put new policies into place to right the human right violation. The new policy was intended to protect these vulnerable populations from unwanted sterilization by providing a waiting period; thereby, granting greater autonomy. However, the policy has led to barriers to access for vulnerable populations in the most critical time period for receiving a tubal sterilization—following a birth. This barrier to receiving the most popular form of tubal sterilization, a postpartum tubal sterilization (PPTS) leads to loss of self-efficacy in the same vulnerable populations it was intended to empower. This capstone offers a history of the issue, a review the literature, a policy analysis and recommendations for the future.

1.2 History

Although the practice of sterilization is widely popular, it has a controversial history that led to the current Medicaid consent process and paperwork. Female sterilization dates back to 1881; however, coercion and ill-formed consent have long been the cause of legal and social problems (Wulf, 1981). Eugenic based sterilization was first used in the late 19th century with the goal of eliminating procreation of “criminals, the insane, alcoholics, orphans, delinquents and those unable to support themselves” (Beckwith, 1976, pg. 46). Added to this group, social prejudice against minorities largely influenced the rise of eugenics in the early part of the 20th century and contributed to the negative connotation (Kevles, 1985).

The socially unacceptable characteristics, minorities, and ethnicities that were targeted through negative eugenics were put into law in the early 20th century when 31 states passed
legislation allowing the practice (Garver, 1991). These laws were often targeted at women with low socioeconomic status and African Americans (Garver, 1991). The Supreme Court upheld the practice in the famed Buck v. Bell decision (1927), which granted the right to have a “feeble minded” woman sterilized after she gave birth out of wedlock (“Buck v. Bell,” n.d.). The decision was later used in the Nuremberg Trials in defense of the eugenics atrocities perpetrated by the Nazis. The association with Nazis caused eugenics and forced sterilization to lose popularity with the public in the U.S. Due to its dark history, the inclusion of sterilization in the War on Poverty, specifically the Family Planning Services and Population Research Act of 1970 was controversial. The law granted access to birth control to welfare recipients (Stern, 2005). Although forced sterilization lost popularity in most states by the early 1970’s, the practice still makes headlines today. In 2010, the state of California was found to have coerced 148 inmates in two different prisons into sterilization between the years of 2006-2010 (Schwarz, 2014). Clearly, the problem of forced sterilization has not been fully addressed by the Medicaid consent process and policy.

1.3 The Policy

The Medicaid sterilization consent policy has not changed since 1978, when the 30-day waiting period was enacted. The current policy reads:

Sterilization procedures are limited to persons who are at least twenty-one (21) years of age or older at the time of signing the informed consent form. A person over the age of 21 that is incapable of giving informed consent will be ineligible to receive Medicaid payment for the sterilization. The person must voluntarily sign the informed consent form at least thirty (30) days, but not more than 180 days, prior to the sterilization procedure. Sterilization for individuals institutionalized in correctional
facilities, mental hospitals, or other rehabilitative facilities are ineligible unless ordered by the court of law. Hysterectomies performed solely for sterilization are ineligible for Medicaid payment.

Basic Plan- Benchmark Benefit Package, 2013

1.4 Procedure Safety & Effectiveness

Tubal sterilization is considered one of the most effective and safest forms of birth control. Its failure rate of 0.0% - 0.4% is much lower than other forms of birth control (Westhoff & Davis, 2000). Several different procedures fall under the category of tubal sterilization, but the most reliable is partial salpingectomy, where a segment of the tube is removed. This procedure has the lowest failure rate and is considered by many to be the most effective form because a "pathologist is able to confirm complete tubal cross sections" (American College of Obstetricians and Gynecologists, 2013, pg. 393) (Creinin & Zite, 2014).

Like every form of birth control, tubal sterilization does carry some risk: according to the CDC, there are 1-2 mortalities for every 100,000 tubal sterilizations performed (most mortalities are anesthesia related) (Westhoff & Davis, 2000). Due to the low pregnancy rate with tubal sterilization, the rate of ectopic pregnancies within 10 years of tubal sterilization (7.3 per 100,000 tubal sterilizations) is still lower than other forms of birth control with higher failure rates (Peterson et al., 1996). Some studies have found women who received tubal sterilization under the age of 30 are more likely to experience adverse effects such as greater probability of regret (Curtis, Mohllajee, & Peterson, 2006) and an associated risk of menstrual disorders (Shy et al., 1992). Additionally, tubal sterilization is not recommended for the morbidly obese or for those who would be at undue risk using anesthesia (Committee on Health Care for Underserved Women, 2012).
However, there are certainly benefits to tubal sterilization as compared to reversible methods of birth control or no birth control at all. In a 12 year study with 58,240 women who had undergone tubal sterilization in Demark, only 1.2% experienced an unintended pregnancy (Helm, Lidegaard, & Vestergaard, 2009). Compared to reversible methods of birth control, which fail about 12.4% within one year (Peterson et al., 1996), there is a significantly lower rate of unintended pregnancy with tubal sterilization. Added benefits include the avoidance of unnecessary hormones and ease of upkeep (Potter et al., 2012).

1.5 Women’s Desire to Achieve Sterilization

Female sterilization is the most widely used birth control method in the world with over 200 million users (Curtis, Mohllajee, & Peterson, 2006). Within the United States, approximately 600,000 tubal sterilizations are performed annually (American College of Obstetricians and Gynecologists, 2013). Over 10.3 million women (24%) between the age of 15-44 rely on tubal sterilization for birth control, making it the second most popular form of birth control in the country behind oral contraceptives (Chandra, Martinez, Mosher, Abma, & Jones, 2005) (Daniels & Mosher, 2013). The procedure can be done postpartum or unrelated to pregnancy (referred to as an interval sterilization). Fifty percent of tubal sterilizations are performed within 48 hours of 10% of all births in the U.S. (Westhoff & Davis, 2000). Any sterilization in the days following childbirth is considered postpartum tubal sterilization (PPTS). Women who undergo cesarean sections are more likely to receive their desired post partum tubal sterilization (Zite, Wuellner, & Gilliam, 2005). PPTS are considered superior because of its inherent convenience (patient is already at hospital), its lower failure rate compared to other methods, and it essentially eradicates the chance of unintended pregnancy within the months following birth (American College of Obstetrics and Gynecology, 2003). Within regions, populations consistently choose similar birth
control methods, which suggest choices are more so influenced by societal and medical values whether than health insurance options (White, Potter, Hopkins, & Grossman, 2014).

Although usage of tubal sterilization crosses racial and socioeconomic barriers, but is most common among women with lower levels of education. Women who have a high school diploma or GED, are four times more likely to be sterilized compared to those who hold a bachelor’s degree (Daniels & Mosher, 2013). Women with lower levels of educational attainment are also more likely to use sterilization as preferred form of birth control and more likely to use public resources (i.e. Medicaid) (Mosher, Martinez, Chandra, Abma, & Willson, 2004) (Zite, Wuellner, & Gilliam, 2006). Within the Medicaid population, postpartum sterilizations represent 80% of all tubal sterilizations – meaning policies that restrict or add barriers to obtaining postpartum sterilizations have a much wider effect than they might on the general public or privately insured (Potter, Stevenson, White, Hopkins, & Grossman, 2013).

This paper will explore the system and its effects. Current research literature cites two main barriers for Medicaid recipients who seek postpartum tubal sterilization:

1. The form must be signed in the presence of medical personnel, 30-180 days in advance of the procedure. It must be presented when checking in to the hospital, which leads to logistical problems for women who were unaware of the wait limit, early births, and who give birth on weekend or holidays when clinics are closed.

2. The reading level and overall design of the consent form is not patient friendly and impedes understanding of the implications of the procedure. The consent form is between an 8th and 9th grade level when the National IRB standard recommends no more than a 6th grade reading level for consent forms (Paasche-Orlow, Taylor, & Brancati, 2003).
Chapter II: Literature Review

2.1 Effect of Medicaid Waiting Period Sterilization Policy

The current Medicaid sterilization consent policy, which was last updated in 1978, was put into place to guard against coerced sterilization of the vulnerable populations that Medicaid supports. In order for it to be effective, it would need to ensure knowledgeable consent and enable requested sterilizations. However, according to research this often not the case. Due to difficulty of logistics, little to no research has been done to assess the value of the 30-180 day waiting period for sterilization consent.

The greatest available indicator of the success of the policy is the number of women who are receiving the sterilization that they request. A retrospective chart review in Chicago completed from March 2002-2003 concluded that of the Medicaid-insured population 46.7% did not receive PPTS compared with 42.7% of the privately insured women. The most cited reason for not receiving tubal sterilization were lack of Medicaid consent form (37.3%) (Zite, Wuellner, & Gilliam, 2006). These findings show the great barriers that are created through the strict rules surrounding the Medicaid consent form that are keeping women from receiving their desired PPTS and placing an undue burden on the Medicaid-insured community.

A 2005 retrospective, record-review based study found that 46.9% of the Medicaid study group did not receive their desired PPTS. In fact, only 49.8% of African American women received requested PPTS. This is particularly troubling when coupled with the finding that even “after adjusting for socio-demographic characteristics African Americans remained significantly more likely to experience an unintended pregnancy than a white woman” (Borrero et al., 2010, pg. 124). African American women are therefore more likely to have unintended pregnancies,
while simultaneously facing greater barriers in receiving the effective, permanent birth control that they request.

The burdens imposed by the Medicaid policies are compounded by the fact that the majority of Medicaid tubal sterilization are postpartum (MacKay, Kieke, Koonin, & Beattie, 2001). Postpartum tubal sterilization is especially important within the Medicaid community because in many states postpartum coverage ends after 60 days. The compressed time period of coverage combined with the 30-day consent form and the realities of newborn care make interval tubal sterilization unlikely for those insured by Medicaid. As an added barrier, interval tubal sterilization is difficult because in 2010 less than 25% of clinics offered interval sterilization (Frost, Gold, & Bucek, 2012).

The timing of PPTS, and use of effective birth control is crucial considering that nearly one third of births occur within 18 months of a previous birth (Finer & Zolna, 2011), demonstrating a clear need for effective birth control in the postpartum period. A cohort study of women with Medicaid-paid deliveries who wanted to delay pregnancy for at least two years shows that after six months, only 17% had been sterilized (although an additional 44% said they would prefer to be sterilized). Of the women who had unfulfilled tubal sterilization requests, 45% were relying on less effective birth control, which has been linked to rates of unintended pregnancy (Potter et al., 2014). This shows the disparity between women’s preferred method and actual usage, which leads to questions about the unmet demand for permanent contraception options.

For women who do not receive the postpartum tubal sterilization that they request, the effects can be life changing: in a 2009 study at a large public hospital 31% percent of the women who requested the procedure did not receive it. Within one year, nearly half of those who did not
receive the requested tubal sterilization became pregnant when compared with less than a quarter of the control group becoming pregnancy (see Table 1) (Thurman & Janecek, 2010).

Table 1. Pregnancy rate of women who do not receive PPTS compared with control group

<table>
<thead>
<tr>
<th></th>
<th>Control (did not request PPTS) (N=1,031)</th>
<th>Did Not Receive Requested PPTS (N=133)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnancy within 1 year</td>
<td>22.3%</td>
<td>46.7%</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

(Thurman & Janecek, 2010).

The women who were surveyed did not indicate that they had changed their mind about the PPTS—meaning that the new pregnancies were unintended. This data suggests that women who have unfulfilled sterilization requests have less access to other contraceptive means or are aware that the possibility of another pregnancy without permanent contraception is high. In fact, other studies have confirmed that women who do not receive their requested PPTS turn to less effective forms of birth control: at an 18 month to a 2006-2008 study follow-up, 74% of women were using birth control methods with failure rates between 10%-18%. Out of the 120 women studied 10% reported a pregnancy in the interim (Potter et al., 2012). Clearly, many women who do not receive their requested PPTS turn to less effective forms of birth control which may lead to more unintended pregnancies.

The following table (Table 2) displays the eight access related barrier studies that have been done to date.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Study Design</th>
<th>Population Studied</th>
<th>Key Findings</th>
<th>Key Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borrero, et al.</td>
<td>Unintended pregnancy influences racial disparity in tubal sterilization rates</td>
<td>Cross-Sectional study of 2002 National Survey for Family Growth data</td>
<td>Women between the age of 15-44 (n=7,258)</td>
<td>Minority women are more likely to experience unintended pregnancy which could contribute to the higher rate of tubal sterilizations within the same population.</td>
<td>Healthcare providers should take special care in counseling women who experience unintended pregnancy on future birth control options in order to avoid regret.</td>
</tr>
<tr>
<td>Gilliam, Davis, Berlin &amp; Zite</td>
<td>A qualitative study of barriers to postpartum sterilization and women's attitudes toward unfulfilled sterilization requests</td>
<td>Qualitative, in-depth interviews</td>
<td>Low-income women in Chicago who requested, but did not receive PPTS</td>
<td>Unfulfilled PPTS requests were most often due to missing Medicaid consent form, fear of the procedure, and misgivings</td>
<td>Counseling should emphasize information about procedure and include alternative method options</td>
</tr>
<tr>
<td>Grady, et al.</td>
<td>Does a history of unintended pregnancy lessen the likelihood of desire for sterilization reversal?</td>
<td>Cross-sectional study of National Survey of Family Growth Data</td>
<td>Women 15-44 who had undergone tubal sterilization (n=1,418)</td>
<td>Unintended pregnancy was not associated with stronger desire for sterilization reversal when compared to control.</td>
<td>To minimize tubal sterilization regret adequate counseling and consent are needed.</td>
</tr>
<tr>
<td>Potter, et al.</td>
<td>Frustrated demand for sterilization among low-income latinas in El Paso, Texas</td>
<td>Prospective Study, interviews</td>
<td>Women with at least one child who had taken part in an earlier study on birth control pill users (n=801)</td>
<td>Access to different methods of birth control is limited for low-income women. Therefore, it cannot be assumed that the type used is always the preferred method.</td>
<td>Limit barriers to birth control methods for low-income women to ensure preferred birth control method is obtained.</td>
</tr>
<tr>
<td>Potter, et al.</td>
<td>Unmet demand for highly effective postpartum contraception in Texas</td>
<td>Postpartum women in Texas who wanted to delay childbirth for at least 2 years (n=800)</td>
<td>At 6 month follow-up 44% relied on less effective birth control, even when more permanent means were desired. Large discrepancy between requested method and usage.</td>
<td>Reduced barriers to effective forms of birth control and improved counseling.</td>
<td></td>
</tr>
<tr>
<td>Thurman and Janeczek</td>
<td>One-year follow up of women with unfulfilled postpartum sterilization requests</td>
<td>Group of Texas women who had unfulfilled postpartum tubal sterilization requests (n=133)</td>
<td>46.3% of the group with unfulfilled PPTS requests became pregnant within a year compared to 22.3% of the control group</td>
<td>In order to avoid unintended pregnancy barriers to access preferred forms of birth control should be dismantled.</td>
<td></td>
</tr>
<tr>
<td>Zite, Wuellner &amp; Gilliam</td>
<td>Barriers to obtaining a desired postpartum tubal sterilization</td>
<td>Publically insured women who requested a postpartum tubal sterilization (n=799)</td>
<td>Medicaid consent process was the most common reason for unfulfilled postpartum tubal sterilization request</td>
<td>Hospital changes to put in place a system that checks for consent form at time of delivery.</td>
<td></td>
</tr>
<tr>
<td>Zite, Wuellner &amp; Gilliam</td>
<td>Failure to obtain desired postpartum sterilization: risk and predictors.</td>
<td>Postpartum women who desired PPTS (n=712)</td>
<td>46% of women who desired PPTS did not receive it. Being under the age of 25, African American or having a vaginal delivery were associated with not receiving PPTS.</td>
<td>Providers should counsel women on all contraceptive options as many women will not receive their desired PPTS.</td>
<td></td>
</tr>
</tbody>
</table>
2.2 Literature Review on Consent Form as Barrier to Access

In order to truly comply with the Medicaid policy as written the patient should fully understand risk, benefits and long-term consequences of the procedure. However, establishing consent through a written form is difficult if not impossible if patients are unaware of the implications of the forms they are signing. Twenty five percent of U.S. adults are considered to have low literacy skills, which impede their understanding of medical consent forms (Paasche-Orlow, Taylor, & Brancati, 2003). A suitable reading level for a low literacy population is 4-6th grade; the Medicaid sterilization consent forms averaged nearly an 8-9th grade reading level (Paasche-Orlow, Taylor, & Brancati, 2003) (Zite, Philipson, & Wallace, 2007). Research has shown that many women do not understand the implications of the consent form they are signing or the effects of the procedure they are agreeing to for their future fertility. The readability of the form is crucial because women with lower levels of educational attainment are more likely to use sterilization as preferred form of birth control and also more likely to use public resources (i.e. Medicaid) (Mosher, Martinez, Chandra, Abma, & Willson, 2004).

Misconceptions about the permanence of the procedure could lead to years of regret and mistrust of the medical community. In a 2011 study, researchers developed a questionnaire for women insured through Medicaid. The ‘Postpartum Tubal Sterilization Knowledge Questionnaire’ (PTSKQ) was tested in a clinical setting to better tailor counseling efforts. Eleven content experts gave qualitative and quantitative feedback, resulting in seven questions that encompassed the effects of PPTS. The researchers rewrote the questions to account for low literacy readers and tested both questionnaires on a group of Medicaid recipients. With the original wording, 34% of women tested incorrectly answered a question about the permanence of the procedure; compared with only 15.7% with the low-literacy version. Overall the new low
literacy version was deemed to be valid in terms of knowledge of PPTS, effective in communication and easy to interpret by the target demographic of low literacy patients (Zite & Wallace, 2007). The tool would be helpful in a clinical setting to hone how much counseling should occur before consent is given.

### 2.3 Readability of Form

According to literacy experts the current Medicaid Title XIX form is more difficult to understand than current patient education and informed consent recommendation allows (Zite, Philipson, & Wallace, 2007). Other assessments have found the consent form to have a poor layout that impedes understanding and small fonts that are difficult to read (Zite & Wallace, 2011). In order to improve the readability of the form, a 2007 study scored the consent form on 20 areas of comprehension. Using the Readability and Processability Form (RPF) researchers examined the form on five components: micro processing, integrative processing, macro processing, elaborative processing, and meta-cognitive processing. Researchers made a more easily understandable consent form aimed at a low literacy target demographic. It retained all vital information, but added a purpose statement, mental images and minimized extraneous details (see appendix). It also took advantage of basic readability format by using double spacing, a larger font and defining uncommon terms. The final product was found to be at a 6th grade reading level, which is on the low level of the American average (Subramanian, Doak, & Doak, 2006).

In a follow-up study a randomized controlled trial tested the current Medicaid Title XIX sterilization form against the low literacy version to assess women’s understanding of tubal sterilization. In an Obstetrics/Gynecological clinic located in the Southeast, women age 21-45 were randomly allocated between the groups. Using questions from the Behavioral Risk Factor
Surveillance System (BRFSS), a research assistant assessed the women’s socioeconomic status, literacy skills and knowledge of tubal sterilization and then randomly administered one of the two survey (N=201). The literacy version scored better on understanding across all categories:

Perhaps most disturbing, after reading the current Medicaid consent form nearly 35% within the target demographic thought PPTS were easily reversible. Over 11% of women did not know that there were other available birth control options that were just as effective as tubal sterilization, implying that women could be choosing a procedure based on effectiveness without knowledge of birth control methods that would better address their fertility goals (Zite & Wallace, 2011). The low-literacy version addressed these problems, and showed improvement in general knowledge of PPTS as well as about the Medicaid consent’s procedure (see table 2). The low literacy version would most likely improve adherence and reduce barriers. A limitation of the study was that it only included English speakers; more research is needed among Spanish speakers, who represent a growing portion of Medicaid funded PPTS and may experience other language and cultural barriers.

Table 3. Participant’s knowledge of Medicaid Consent Policy and PPTS (Zite & Wallace, 2011)

<table>
<thead>
<tr>
<th>Tubal Sterilization Knowledge-Related Items and Overall Composite Score</th>
<th>Standard Medicaid Consent Form Correct</th>
<th>Low-Literacy Medicaid Consent Form Correct</th>
</tr>
</thead>
<tbody>
<tr>
<td>In a few years, if I change my mind the doctors can easily fix my tubes so that I can have another baby</td>
<td>65.7%</td>
<td>81.4%</td>
</tr>
<tr>
<td>There are other forms of birth control that work as well as having my tubes tied, but can be stopped or removed if I decide to have another baby</td>
<td>88.9%</td>
<td>97.1%</td>
</tr>
<tr>
<td>Now that I’ve signed the form, I can get my tubes tied in 30 days (about 1 month).</td>
<td>69.5%</td>
<td>93.1%</td>
</tr>
<tr>
<td>How many months after you sign this form will your consent (signature) expire?</td>
<td>19.2%</td>
<td>52.9%</td>
</tr>
<tr>
<td>Overall sterilization-related knowledge</td>
<td>49.0%</td>
<td>77.5%</td>
</tr>
</tbody>
</table>
Women insured through Medicaid are not adequately informed of their options through consent procedure and counseling. A qualitative, longitudinal study recruited 34 low-income women to examine attitudes about cancelled or postponed sterilization procedures. The conclusion of the study was that sterilization counseling should include more information on the surgical procedure, assessment of risk, development of a contingency birth control plan, and an increased emphasis on self-efficacy. Most strikingly, 60% had already requested tubal sterilization during a previous pregnancy. These findings point to the need for comprehensive counseling and consent forms (Gilliam, Davis, Berlin, & Zite, 2008).

Clear language could have a major effect on the number of women who choose to undergo postpartum tubal sterilizations. Studies have indicated that many women do not understand all the implications of the procedure and might regret the permanence of their decision (particularly if done at an early age) (Mosher, Martinez, Chandra, Abma, & Willson, 2004). A low literacy version of the form should be combined with counseling to ensure that women have a good understanding of all contraceptive choices in order to avoid coercion (Zite & Wallace, 2011).

The following table (Table 4) displays the four literacy related barrier studies that have been done to date.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Study Design</th>
<th>Population Studied</th>
<th>Key Findings</th>
<th>Key Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borrero, et al</td>
<td>Racial variation in tubal sterilization rates: role of patient-level factors</td>
<td>Cross-Sectional Survey</td>
<td>Women 18-45 who had undergone tubal sterilization (N=193)</td>
<td>African American women were more likely to be misinformed about permanence of procedure (62% vs. 36% white women)</td>
<td>Consent forms and counseling needs to be improved and adjusted to meet the patient's literacy level.</td>
</tr>
<tr>
<td>Zite, Philipson, Wallace</td>
<td>Consent to Sterilization section of the Medicaid-Title XIX form: is it understandable?</td>
<td>Evaluated current Medicaid Title XIX-SCF for readability developed a new form using Readability and Processibility Form (RPF)</td>
<td>n/a</td>
<td>Readability and comprehension was improved after re-development of Medicaid sterilization consent form.</td>
<td>Adjusting Medicaid sterilization consent form to account for low literacy rate of population will improve comprehension.</td>
</tr>
<tr>
<td>Zite and Wallace</td>
<td>Development and validation of a Medicaid Postpartum Tubal Sterilization Knowledge Questionnaire</td>
<td>Qualitative</td>
<td>n/a</td>
<td>Created a valid, low literacy postpartum tubal sterilization knowledge questionnaire to assess patient's knowledge and tailor counseling appropriately</td>
<td>The questionnaire be implemented in order for healthcare professionals to assess counseling needs.</td>
</tr>
<tr>
<td>Zite and Wallace</td>
<td>Use of a low-literacy informed consent form to improve women's understanding of tubal sterilization: a randomized controlled trial</td>
<td>Randomized Controlled Trial</td>
<td>Women in an OBGYN clinic waiting room, age 21-45 (N=201)</td>
<td>The group who read the low literacy version of the consent form better understood the permanence of the procedure, and the Medicaid consent process</td>
<td>The low literacy consent form should be implemented in order to facilitate understanding of procedure's implications among all populations.</td>
</tr>
</tbody>
</table>
CHAPTER III: Implications of Policy

The analysis will show there are significant implications of the policy including the creation of a two-tiered system, the impact on African American and Hispanic women, the rise of unintended pregnancies, growing Medicaid costs, the impact of the Affordable Care Act, and lowered self-efficacy.

3.1 Two-tiered System

In addition to being ineffective in protecting the vulnerable population it is meant to guard, the Medicaid consent policy is also unjust. It essentially creates “a two-tiered system of access” because private insurance has no equivalent barriers to access in regards to postpartum tubal sterilization (Borrero, Zite, Potter, Trussell, & Smith, 2013). Privately insured women are able to give consent during delivery and are not bound by an official consent document with waiting period (Brown & Chor, 2014). By legal definition, if a law treats two groups differently, but not with the goal of benefitting the disadvantaged group then that the law is unjust (Brown & Chor, 2014). The current policy widens the healthcare gap by both preventing necessary care and causing harm by failing to prevent an unintended (but avoidable) pregnancy (Brown & Chor, 2014). Medicaid coverage often ends 60 days after birth leaving women in a coverage gap for contraception (“Pregnant Women,” n.d.). Making the lost opportunity for reliable, permanent birth control even more important for the vulnerable population.

More than half (64%) of Medicaid paid births are unintended. Among privately funded births only 48% are unintended (Sonfield, Kost, Gold, & Finer, 2011). When compared with privately insured women, those who depend on Medicaid are not receiving reliable forms of birth control or adequate education and counseling. Therefore, “Medicaid consent rules violate the standards of beneficence and maleficence. By treating privately and publically insured
individuals differently- It fails the justice standard” (sic) (Brown & Chor, 2014, pg. 1350). These findings are problematic considering the inherently vulnerable populations that Medicaid exists to serve. The low-income status of Medicaid recipients, and often times ensuing low socioeconomic status, makes the group less likely to be able to secure contraception with their own limited means. Women insured through Medicaid are more likely to experience unintended birth than privately insured women, but through current policy are being barred to access from desired PPTS through an unjust 30-day waiting period.

3.2 Impact on African American and Hispanic Women

Minority members comprise 59% of non-elderly Medicaid populations (“Distribution of the Nonelderly with Medicaid by Race/Ethnicity,” 2013). Clearly, at nearly 60% of the effected population minorities comprise a large proportion of the population that is effected by the Medicaid PPTS policy. Troublingly, a 2009 study found that minority women were more likely to hold misconceptions about contraceptives (Borrero et al., 2009). Considering the history of sterilization and eugenics targeting of U.S. minorities and ethnic populations, these numbers become more problematic. The same groups who were targeted for coerced sterilization are now being barred from access to desired sterilization through the policies that Medicaid set forth. Instead of protecting these populations’ right to make family planning decisions, the policy is in effect rescinding the autonomy of recipients by disallowing choice of birth control methods as is offered in the private insurance market. Although it is not the intended consequence of this policy, it often ends in unintended pregnancy.

This suggests that there are more social and medical differences that influence a woman’s decision to receive a tubal sterilization. This makes sense in light of Medicaid’s national policy which guarantees access to tubal sterilization provided the patient is able to acquiesce to the
consent process. Considering the added importance of regional and social influence combined with higher rates of sterilization in African American and Hispanic communities, a closer examination into the specific barriers faced is warranted. Data from the National Survey of Family Growth (2006-2010) found that within Medicaid paid PPTS white women were more likely to receive permanent sterilization than her African American or Latina counterparts (White & Potter, 2014). Yet, privately insured African American and Hispanic women were more likely to receive tubal sterilizations than their publically insured counterparts. So the question becomes why are these publically insured minority women having lower percentages of tubal sterilizations than publically insured white women or their privately insured counterparts? The barriers to tubal sterilization have born out in other studies. In a qualitative study respondents said that they chose to have tubal sterilization because they were “done with childbearing, older age [more common among African American respondents], difficulty with child rearing, sense of control, addictions, and family influences” (Borrero, et al., 2009, pg. 126). Among the study group their doctors had rejected half of the women in the non-sterilized African American’s request for sterilizations. Additionally, women reported system level barriers—particularly the Medicaid consent forms that kept them from procuring the tubal sterilization they requested (Borrero et al., 2009). Although U.S. racial and ethnic minorities comprise the majority of the Medicaid PPTS target demographic they face unique barriers in receiving the desired procedure.

Using data from the National Survey of Family Growth researchers examined the likelihood that women will have a tubal sterilization after each pregnancy (as opposed to overall likelihood) (White & Potter, 2014). Researchers looked at data from 20,497 births between 2006-2010. For their sample they narrowed their results to women who were having at least their second child, over the age of 21 who were publically or privately insured. Among Medicaid paid
patients, white women were more likely to receive permanent sterilization than their African American or Latina counterparts. African Americans and Latinas who are privately insured are more likely to receive requested PPTS (White & Potter, 2014). In the months following delivery, white, privately insured women had the highest rates of interval sterilizations. As noted earlier, interval sterilizations are rare for Medicaid patients— and in 2010 less than 25% of clinics offered interval sterilization (Frost, Gold, & Bucek, 2012). This finding is significant—Medicaid insured minorities had the lowest rates of PPTS per birth even though other studies have found that they have higher rates overall. This implies that the barriers associated with the Medicaid consent policy disproportionately affect minorities.

Rates of fulfilled PPTS vary by age and race (which is attributed to many reasons including doctor’s bias and influence), but studies concur that “Young age, African American race, request in the second trimester, and vaginal delivery were significantly associated with not undergoing sterilization” (Zite, Wuellner, & Gilliam, 2005, pg. 794). Out of women age 21-25 only 39.8% received requested PPTS. Less than half of African American women received requested PPTS. The result of the policy is that many women who are insured by Medicaid (in some groups over 50%) are not receiving the PPTS that they desire. These figures imply that the policy is not fulfilling its purpose of enabling women’s reproductive wishes, and instead acting as a hindrance. On a knowledge test regarding tubal sterilization given post-birth, a group of African American women scored significantly worse than a similar group of white women (65% as opposed to 80%) (Borrero et al., 2011). Within the Medicaid insured population, 62% of African American women and 36% of white women thought that fertility could be easily restored following a tubal sterilization (Borrero et al., 2011). This demonstrates the need for
comprehensive counseling and education services before any contraceptive use, especially a permanent procedure such as tubal sterilization.

3.3 Unintended Pregnancy

Like any policy implemented on a wide scale, Medicaid’s PPTS policy creates unintended consequences. However, these consequences are quite serious and include an estimated 29,000 unintended pregnancies every year, which translates to 10,000 abortions and 19,000 unintended births (Borrero, Zite, Potter, Trussell, & Smith, 2013). Additionally, the barriers the policy creates costs the U.S. a significant amount of money because of the missed opportunity for effective, desired birth control the denied PPTS request represents (Borrero, Zite, Potter, Trussell, & Smith, 2013). A 2010 study followed up with women who had unfulfilled requests for PPTS- within one year 46% of the women were pregnant. Only 22.3% of the control group became pregnant in the same period (Borrero et al., 2010). These unintended births cost the state and Federal Medicaid programs over $11 billion a year—half of the total amount spent on public births (Sonfield, Kost, Gold, & Finer, 2011).

Sixty four percent of Medicaid paid births were unintended; however, the same study found that among privately funded births only 48% were unintended (Sonfield, Kost, Gold, & Finer, 2011). Clearly, women who depend on Medicaid are receiving neither reliable forms of birth control nor good education/counseling. One of the reason for unintended pregnancies is that such a large proportion of women rely on birth control methods with comparatively high failure rates (i.e. Condoms and pills) (Mosher, Martinez, Chandra, Abma, & Willson, 2004).

Additionally, African American and Latina women are significantly less likely to use a highly effective method of birth control than Caucasian women of the same parity. The reverse is true for condoms, which have a failure rate of 12% (Dehlendorf et al., 2014). Since African
American and Latina women are more often affected by unfulfilled tubal sterilization, their subsequent use of a less effective form of birth control could be adding to the burden of unplanned pregnancies. But it is also important to note that condoms are the most widely available form of birth control. It is not that women do not want to use birth control, but when faced with more barriers, they become less likely to use it.

### 3.4 Medicaid Costs

Several states have started programs that charge women for sterilizations in an effort to save money on the upfront costs of the procedure, which can be quite costly. In Texas, Medicaid patients were charged $200 for post-cesarean tubal sterilization and $1,000 for post-vaginal birth tubal sterilization. The dramatic increase in number of cesarean section within the population and almost complete elimination of post-vaginal birth tubal sterilization indicates the policy was not effective in reducing costs. Adding costs to patient for tubal sterilization is counter productive and ends up costing the state’s Medicaid program more money as the cost of a cesarean section is more costly than a vaginal birth and tubal sterilization combined (Thurman, Harvey, & Shain, 2009).

In 2004, Oregon Medicaid created new charges for post-vaginal birth tubal sterilization within the Emergency Medicaid (EM) population. However, EM patients who delivered via cesarean sections would still be eligible for state funded tubal sterilizations. This policy was put in place explicitly to save money. However, evaluation of the policy found the opposite to be true. The post-vaginal delivery tubal sterilization rate dropped from 9.9% to 0.9% over two years in the EM population. Conversely, the post cesarean section tubal sterilization jumped from 18.8% to 23.5% in the same period. More money was spent overall and fewer women received PPTS. It was regarded as a missed opportunity for women who wanted to receive tubal
sterilizations because this community is unlikely to engage with the health community on a regular basis (Rodriguez, Edelman, Wallace, & Jensen, 2008). Clearly, charging Medicaid populations for tubal sterilization will only lead to increased cesarean sections (which are more costly for the state) or unfulfilled sterilizations, which inevitably lead to higher rates of unintended births.

Although tubal sterilization has a much higher initial cost than other forms of birth control, it is more reliable over time resulting in a lower cost if it used for two years or more. In a span of nine years, tubal sterilization is the least expensive of any type of birth control; on average tubal sterilization saves $5,907 per procedure compared to other forms (Sonnenberg, Burkman, Hagerty, Speroff, & Speroff, 2004). Considering that most women use some form of birth control until around age 50 and the average age for tubal sterilization is 30- resulting in a time span easily double the nine years needed to make the procedure financially beneficial. Likewise, shifting women away from desired tubal sterilization could also backfire—due to the high cost of unintended pregnancy birth control methods with low-effectiveness rates have the highest absolute costs (Sonnenberg, Burkman, Hagerty, Speroff, & Speroff, 2004).

Although it can be difficult politically, offering effective forms of birth control saves money in the short- and long-term for Federal and state Medicaid systems. In 2008, spending $2 billion in publically supported family planning services helped avoid $7 billion in unplanned pregnancy costs that would have fallen on the Medicaid program (Frost, Zolna, & Frohwirth, 2013). Also, newer options in tubal sterilization lessen up-front costs for Medicaid. Essure, the first permanent, non-surgical birth control option, works through insertion of a spring-like device to the fallopian tubes. It can be implanted in a clinic setting under mild sedation and could save as much as $1,178 over traditional tubal sterilization (Kraemer, Yen, & Nichols, 2009). Essure
can be inserted six weeks after delivery, (‘‘Essure,’’ 2014) but most Medicaid post partum coverage cuts off at 60 days, which gives Medicaid patients with new babies a very narrow window to have the procedure done.

A 2013 study examined the cost-effectiveness of permanent sterilization of Medicaid patients from a health care payer perspective. They used modeling to compare the current policy with a hypothetical policy, which would reduce barriers to receiving a PPTS. With the associated cost of 29,000 unintended pregnancies averted, the Medicaid system could save $215 million annually with a reduced barrier approach to tubal sterilization. Additionally, it would honor the wishes of women in regards to their own reproductive systems (Borrero, Zite, Potter, Trussell, & Smith, 2013).

3.5 Impact of Affordable Care Act

Current Federal Medicaid policy gives states the option to offer Medicaid coverage to pregnant women who earn up to 185% of the Federal Policy Level (‘‘Pregnant Women,’’ n.d.) (185% of the FPL for a single woman in 2014 is $21,589.50, excluding Alaska, Hawaii, and Washington D.C.) (‘‘2014 Poverty Guidelines,’’ 2014). Currently, Medicaid pays for an estimated 40-50% of all births in the U.S. Expanded Medicaid in states would cover women up to 138% of the FPL thereby increasing coverage for more births and perhaps more relevantly extending coverage in many states to postpartum care. This would give many women access to family planning services who would not have had the opportunity previously and could result in expanded opportunity for interval sterilization for women who did not receive their desired postpartum tubal sterilization. (‘‘Medicaid and Women’s Lifespan,’’ 2012) (Sonfield, 2012)

The expansion of Medicaid in 27 states under the Affordable Care Act has had many repercussions in the medical community. However, the law’s effect on birth control rates is
unclear at this point. In theory adding more women to Medicaid would create opportunity for more interval tubal sterilizations if the desired PPTS were not fulfilled. As of November 2014, nearly four million low-income adults are in the coverage gap—due to states’ refusal to expand Medicaid ("The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid – An Update | The Henry J. Kaiser Family Foundation," 2014). The largest share of the people affected are low-income minorities with low educational attainment who live in Southern states. A group that also demonstrates other trends (including high unintended pregnancy rates and high rates of Medicaid paid pregnancies), are more likely to have misconceptions about birth control, and more consistent barriers to PPTS. The convergence of these facts with the lack of coverage should be taken into account when considering Medicaid expansion and the return rate on publically funded family planning.

3.6 Social Cost & Lowered Rates of Self-Efficacy

Apart from the great cost shouldered by the Medicaid system, unintended pregnancy leads to great individual and social costs. Fifty percent of pregnancies are unintended and associated with substance use during pregnancy, delayed prenatal care, low birth weight, and preterm delivery (Finer & Zolna, 2011). On societal level unintended pregnancies adds to the financial burden of medical costs, childcare costs while on a personal level women who have unintended pregnancies are more likely to sacrifice personal and career goals (Bartz & Greenberg, 2008). Repeating unintended pregnancies become more probably when effective birth control is not used, is probable (nearly one third of births occur within 18 months of a previous birth). This is why allowing and encouraging women to take control of their own fertility through the use of effective birth control is critical. In 2012, ACOG strongly encouraged Medicaid to redesign the sterilization consent form in order to provide equal access to all
populations to the urgent procedure (Committee on Health Care for Underserved Women, 2012).

It is both condescending and unjust to levy restrictions on the Medicaid group-- implying that they are not able to make the right decision for themselves and their fertility.
CHAPTER IV: Recommendations and Limitations

4.1 Recommendations

According to the American Congress of Obstetricians and Gynecologists (ACOG)’s Committee on Health Care for Underserved Women, “policies and procedures that remove barriers to and increase efficiency in performing postpartum sterilization could reduce cancellations of the procedure” (Committee on Health Care for Underserved Women, 2012, pg. 212). The same groups who were targeted for coerced sterilization are now being barred from access to desired sterilization through the policies that Medicaid set forth. In order to address this disparity, Medicaid must change its regulations to allow for full-knowledge consent by those seeking tubal sterilization and undo as many barriers as possible in order to achieve their goal of unadulterated birth control related decision-making.

In order to address the ineffectiveness of the 30-day waiting period and the two-tiered insurance system it has created when compared to the privately insured, the 30-day waiting period should be rescinded. The extended time frame has not been shown to limit regret or coercion, but has proven to act as barrier to access to desired PPTS. Due to the great burden on individual and society the policy should be quickly changed to enable more women to make the birth control decision that best fits their fertility needs.

In keeping with the original intent of the 1978 sterilization policy and to prohibit coercion, better counseling and education on verbal communication and health literacy needs to be developed for practitioners. Women counseled during prenatal and postpartum periods are significantly more likely to use a highly effective form of birth control (i.e. “Sterilization, IUD, pills, patch, ring or shots”) (Zapata et al., 2014). Women with Medicaid coverage benefit the most from counseling, which demonstrates the need for comprehensive contraceptive counseling. The PPTS knowledge questionnaire created by is a great tool for assessing patient’s knowledge
of the effects of PPTS and the Medicaid consent process. Having patients take the seven question quiz before counseling session would not add an undue burden to patient or medical staff, and would improve communication, understanding, and shape the conversation in terms of the patient’s birth control needs and understanding. By pairing the questionnaire with tailored to need counseling and the low-literacy consent form created by full, knowledgeable consent will be much more likely. By assessing the patient’s knowledge of tubal sterilization and future fertility plans, the most appropriate form of birth control can be administered. Even in the event of inadequate counseling, the low-literacy consent form would make the permanency of tubal sterilization very clear to patients. These measures would more closely promote the intent of the original policy change by making relevant information transparent and accessible to patients, thereby removing the barrier and possible detracting force.

4.2 Limitations

There are some limitations to these recommendations. First, while the low-literacy version has been tested in pilot studies and was developed by content experts, it has not been tested on a wide scale or with a non-English speaking population. Secondly, there is no assurance that by removing the 30-day waiting period coercion and bad practices would not return. Some form of oversight by the already over-taxed Medicaid agency must be formed.

In general, many of the studies that have been done in this field have tested only small populations that may not be generalizable on a national scale. Some of the studies used only retrospective data, which in this case may be less reliable and leave a lot of unanswered questions. Some studies are done on models where much care was taken to include all known problems and intervening issues, but models are not as reliable as other forms of data or research. Also there is no research on whether the 30-day waiting period is an effective guard against
coercion or results in lower levels of regret. Although it would be difficult to realistically gather such data (Borrero, Zite, & Creinin, 2012), more research needs to be done to more accurately predict the fallout of the waiting period removal.
Chapter V: Conclusion

The 1978 Medicaid policy was written with the noble intention of protecting vulnerable populations from coerced sterilizations; however, it has transformed into a barrier to access of the most reliable form of birth control for the same vulnerable group of women. The 30-day waiting period has been found to be ineffectual in protecting vulnerable populations from regret as compared to privately insured women who are not bound by a waiting period. Research concludes that the barrier it creates disproportionately affects low-income minorities with low educational attainment. African American women, younger women, and women who deliver vaginally are much more likely to have unfulfilled PPTS requests compared with women of similar parity. The realities of Medicaid coverage and unlikelihood of interval sterilization mean that for women who do not receive their requested PPTS unreliable forms of birth control become the most likely option leading to unintended pregnancy and higher costs. Additionally, the convoluted, technical consent forms leave many women unaware of the implications of the procedure they are authorizing.

Unfortunately, the current form is not low-literacy friendly and must be changed to address this crucial issue of readability and comprehension. Access can be improved, while maintaining autonomy, by rescinding the 30-day waiting period, implementing better counseling practices (including a low-literacy questionnaire) and improving the readability of the consent form. This will allow for women insured through Medicaid to take control of their fertility leading to lower numbers of unintended pregnancies and abortions. Fewer barriers to access will add to women who are insured through Medicaid more agency in decision making, which was the original goal of the policy.
Chapter VI: Bibliography


doi:10.1016/j.contraception.2005.08.006


doi:10.1016/j.ajog.2014.01.037


A. Current Medicaid Sterilization Consent Form: Title XIX-SCF

(The Medicaid Consent Form,” n.d.)
B. Low-literacy
Modified Medicaid Sterilization Consent Form: Title XIX-SCF

Modified Title XIX-SCF

Consent to sterilization

Section I: purpose of this form
The purpose of this form is to show that I have decided not to have (any more) children. In order not to have children, I will have a surgery called sterilization, which is an operation to make it impossible to have children. When I sign this form, I will be sure that this operation is what I want for myself and/or my family.

Section II: other decisions that I could have made (alternatives to sterilization)
There are many kinds of birth control that could keep me from becoming pregnant. I have talked about all of these with my doctor or nurse. After doing this, I have decided that instead of using those birth control methods, I want to become sterile. I understand that most of the time, becoming sterile cannot be changed or reversed. If I decide to become sterile I will not be able to have children now or in the future.
I also understand that the operation for sterilization can fail, but that this does not happen very often (to be included for vasectomy only: I will need to practice some method of birth control for about 1–3 months after my sterilization or until my doctor says the operation was successful).

Section III: timing

I understand that I have 30 days (around one month) after I sign this consent form before I have the sterilization operation. During this time I can change my mind and decide not to become sterile. If I decide not to become sterile, I will not lose any help, medical care or benefits from programs that get Federal funds, such as A.F.D.C. or Medicaid.
If I do sign this form and consent to the sterilization operation, my consent will run out 180 days (about 6 months) after I sign this form.

Section IV: sterilization operations (procedures)
There are two common operations for becoming sterile. For women it is called tubal sterilization and for men it is called a vasectomy. These and any other sterilization operations have been explained to me. I understand the risks, benefits and possible discomforts that can happen if I have one of these procedures in order to become sterile.

My doctor or nurse has answered all of my questions.

Section V: signing this consent form
I, ____________________________, understand that
I will become sterile by an operation called ____________________________.
I am 21 years old with my birthday on ____________________________
(include month, day and year).
I also agree to the release of a copy of this form and my medical records about the operation to representatives or employees of the Department of Health, Education and Welfare to make sure that all Federal laws were followed.
I have received my own copy of this consent form.
My signature _____________________________________________
Date ____________________________

I am willing to provide the following information (this is not required.) My race and ethnicity is one of the following (please check the box that applies):

- American Indian or Alaska Native
- Asian or Pacific Islander
- Black (not of Hispanic origin)
- Hispanic/White (not of Hispanic origin)
C. Postpartum Tubal Sterilization Knowledge Questionnaire

Postpartum Tubal Sterilization Knowledge Questionnaire

For each question, place an X in the box next to your answer. Please answer each question.

<table>
<thead>
<tr>
<th>Question</th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Now that I’ve signed the form, I can get my tubes tied in 30 days (or about one month).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Now that I signed the consent form, I must have my tubes tied.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. After having my tubes tied, there is NO chance that I could get pregnant again.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. If I get pregnant after having my tubes tied, it can be dangerous.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. When I have my baby, I will still be able to have my tubes tied if I forget the consent form and the hospital does not have a copy.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6. In a few years, if I change my mind, doctors can easily fix my tubes so that I can have another baby.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7. There are forms of birth control that work as well as having my tubes tied, but can be stopped or removed if I decide to have another baby.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Zite & Wallace, 2007)