

Threats to the Lives of People with Disabilities, Part I: Prenatal Diagnosis of Lethal or Non-lethal Conditions and Disability

Interviewer: Dr. Marie Hilliard, Director of Bioethics and Public Policy at the National Catholic Bioethics Center; Moderator of the October 5, 2010, National Catholic Partnership on Disability (NCPD) Webinar listed above

Interviewee: Dr. John Bruchalski, OBGYN, founder of the pro-life Tepeyac Family Care Center, northern VA; Presenter on the October 5, 2010, NCPD Webinar (listed above)

MH: We have seen such an evolution in what is available to help parents address the health needs of their baby before birth. Discuss how prenatal testing has changed over the last 20 years, not only from a medical perspective, but also in terms of its purpose.

JB: Historically, we screened pregnant women older than 35 at the time of their delivery because they were at the highest risk of developing Down syndrome, and we offered them genetic counseling, and amniocentesis or chorionic villus sampling. We needed to take cells from the developing child to make the definitive diagnosis. Was there a way to predict who was at risk for having an affected child without having to resort to invasive, pregnancy threatening procedures? In the mid 1980s we found a marker in the mother's blood, a low maternal serum alpha-fetoprotein that was associated with a risk of Down syndrome and we began to offer it to women younger than 35. With further research during the 1990s, human chorionic gonadotropin, HCG, the "pregnancy hormone" and unconjugated estriol, a "female hormone" were used in combination with the maternal AFP to improve the detection rates for Down syndrome and trisomy 18. These three markers taken together were called the "triple screen", and they are used to modify the maternal age related Down syndrome risk. With this test, the detection rate for Down syndrome is 70%. Some years later, inhibin A was added to the triple screen now called the "quadruple or quad screen" to increase the detection rate to 80%.

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Over the last two decades, to this regimen of biochemical screening markers have been added ultrasound findings that are reflective of a child in utero with genetic anomalies. In the mid 1990s, we found that children with Down syndrome had fluid on the back of their necks, called “nuchal translucency”. This is an ultrasound find that can be seen several weeks after conception rather than several months, and appears to be an early sign of a broad range of fetal, chromosomal, genetic and structural anomalies. Today the technical procedure for looking for this finding is standardized and data from the United States and the United Kingdom have demonstrated that when this measurement is taken along with two first trimester serum analyses; free beta HCG, and pregnancy associated plasma protein A (PAPPA), we can begin to screen for Down syndrome and other illnesses in the first trimester. The triple and quad screens are only good screening tests in the second trimester, after 13 weeks.

Today we screen for genetic diseases earlier in the pregnancy with increasing accuracy? The purpose is to give the woman options for abortion of the ill child at an earlier gestational age when the termination can be done theoretically safer. Also, the purpose is to decrease the need for invasive testing such as amniocentesis or CVS, which carry with it an intrinsic risk for miscarriage and loss.

MH: What tests are routinely given in any pregnancy at this time?

JB: Depending on your geographic area, and the resources that you have access to, and the professional training of your healthcare providers, all will determine what tests are done routinely and when during the pregnancy. Ideally, our American College of OB/GYN suggests all women should be offered screening tests before 20 weeks of pregnancy, the half way point, regardless of age. After the first trimester, the quad screen and an ultrasound exam are offered. If the patient presents in the first trimester, the nuchal translucency along with the biochemical markers should be offered along with the second trimester screens. Since all of the above tests have false positives

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and false negatives, an integrated or a set of “sequential screening tests” are ideally recommended.

MH. Under what conditions are non-routine prenatal tests encouraged?

JB: Non-routine prenatal tests, such as amniocentesis and CVS, are encouraged based on many factors: number of fetuses, previous obstetrical history, family history, availability of early detection ultrasound, recommendation by a geneticist or high risk OB doctor, or the need to have a definitive diagnosis and not just a numerical risk to make the decision for an earlier abortion.

In our practice, we sometimes use invasive diagnostic testing to plan the delivery of a child with a condition that needs the specialists at the tertiary referral hospital rather than the community hospital we usually deliver at.

MH: What is the difference between a screening test and a diagnostic test?

JB: A “screening test” is essentially for Down syndrome, trisomy 18 and trisomy 13, and it targets a group of children in utero that have an increased chance of being sick, from 60 to 95% depending on what test is done and when it is performed; whose parents then choose to have a “diagnostic test” such as an amnio or a CVS which increases the chance to nearly 100% for the child in question to have the disease. The diagnostic tests will also identify sex chromosome problems, large deletions or duplications of chromosomes and chromosomal mosaicism. The screening test give you a statistical probability while the diagnostic test is much more definitive. Without the screening tests first, the diagnostic invasive tests could cause a miscarriage in healthy unborn children on the order of 1 in 700 to 1 in 100 cases.

MH: Is there a difference in how results from each are provided to expectant parents? Are parents receiving accurate information on what is considered a confirmed diagnosis, verses an indication of a diagnosis based on a screening test?

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JB: As a clinician I receive from the laboratory the numerical information regarding the patient's age related risk and a revised numerical risk based on age, the serum analyte levels and the nuchal translucency measurement if available. Then once I receive this numerical information, I must communicate the "risk" to the parents. This numerical risk in theory should enable the parents to balance the risk and the consequence of having a child with the particular problem against the risk and consequence of an invasive diagnostic test. Because patients have personal values about abortion, this numerical risk can be contrasted with numerical risk in the general population and the age related risk before screening.

I believe that most parents are receiving accurate information but statistical risk is a very difficult idea to wrap your hearts and souls around when considering if your child is "sick". We imagine the worst oftentimes; how do you quantitate fear and anxiety? How do you inject doubt into a joyful expectation of family?

MH: Do expectant parents understand the purpose, and most importantly the risks of prenatal testing?

JB: Absolutely not in too many cases. I still have patients that were "routinely" given a screening test, and they received an adverse level, and were then told they needed to do an invasive procedure to confirm the screening test. Moms want to take care of their unborn children, they want to make sure they are healthy. A test that doesn't jeopardize the wellbeing of their child is often accepted. However, in a significant percentage, the realities of what the answer from the screening test give are not thought through. Would I want to do an amnio on my child and risk a miscarriage of a healthy baby? Would I even consider an abortion if my child was ill? How would my husband react to the news of an ill child?

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MH: Have we seen a move from using such testing to foster the birth of a healthy baby to prevention of the birth of a baby with a disability?

JB: Today, the OB/GYN is sued on the average 4-6 times in their professional career. Because of the belief in the “perfect outcome”, and the unreal expectation that prenatal medicine is perfect and all adverse outcomes should and can be detected and predicted with very little surprises, and the very real reality of the law suit based on “wrongful birth”, there is a move to “prevent” the birth of a baby with a disability or disease. Many moms after declining the screening or diagnostic test, one or more times, continues to be asked by the healthcare providers of the practice, “Are you sure of your decision?” which is then documented in the chart multiple times. Many patients feel harassed or judged if they even consider bringing into this world a child with a disability, or the desire to accept what God gives rather than finding out before the delivery.

MH: And now we consider prenatal diagnosis ... what is a poor prenatal diagnosis?

JB: A poor prenatal diagnosis is simply a diagnosis that is “incompatible with a long life” expectancy either during the gestational period, while the child is living in the mother’s womb; or after the umbilical cord is cut, and the child is outside the mother’s womb. It can also be used to indicate a child whose life may not be worth living due to decreased mental capacity or significant physical or biochemical illness and abnormality.

MH: What is the significance in the use of the words "poor" or "adverse" when attached to a prenatal diagnosis, and how do the use of such terms impact advocating for those whom society has judged not to have a “quality of life”?

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JB: Mothers want to spend time with their sick children. The only time they may have with their child is before the cord is clamped, because the child is so sick that their life may be short lived. Illness is a part of life as is suffering.

MH: Does anyone else wish to comment on the use of these terms? All too often “dignity of life” and “quality of life” are used . Who is most likely to receive a Poor Prenatal Diagnosis?

JB: Anyone can hear this language. Having an unborn child with a genetic, biochemical, and/or structural condition that jeopardizes a “wished for life” during the first or second trimester when abortion is easily available and legal is criteria for possibly hearing this term. Because the word “poor” has different connotations for the doctor and the mother or parents, based on their experience and background, the question is difficult to answer.

MH: How many pregnancies are affected?

JB: It is hard to state. If you are looking for perfection, the average Mom gives birth to a child with any anomaly almost 5% of the time. What is considered a poor prenatal diagnosis for the doctor may not be for the patient, and vice versa. As a resident, I aborted a child because of an AFP test that increased the risk for Down syndrome only slightly. The mother was so traumatized by the news, she refused the diagnostic test and aborted the child that evening, despite the fact that the father of the baby was perfectly ok with the slight increase in risk. She was under 30 years of age and the result itself, was enough of worry to continue the pregnancy and the life of her unborn child.

MH: We are aware of statistics indicating that 90% Of unborn babies diagnosed with Down Syndrome will be aborted, and in England a study indicated 86% of those with neural tube defects such as Spina Bifida will be aborted. Furthermore, one study indicated that 92 % of women enrolled in prenatal care would consider abortion. How many pregnancies with a Poor Prenatal Diagnosis result in an abortion?

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JB: The number is hard to wrap our heads around. We live in a society that demands no illness, nor imperfections. These numbers are accurate. My cousin with Down syndrome once asked me if he was an endangered species? I had no words for him.

MH: What does “incompatible with life” mean?

JB: Incompatible with life means different things to different people. To some it means the child will die during the pregnancy or shortly after birth. To others it means that the child will have severe limitations of thinking or acting or “living” that will bring a quality of life that is not worth living.

MH: Is this a medical term?

JB: No incompatible with life is not a medical term, but an emotional, and psychological and physiological one.

MH: Are parents unaware that “termination” is actually an abortion?

JB: From my experience on both sides of this issue, once “terminating” children with poor prenatal diagnoses, to now hospicing them in their mother’s wombs; parents may intellectually distance themselves from the reality of the abortion they have chosen for their sick child as a defense mechanism, but internally, at the level of the heart, the reality that they shortened the time they spent with their sick child is palpable and persistent. On a deep level, they know the reality was they could not handle their child’s illness.

MH: A study by the American Congress of Obstetricians and Gynecologists indicated that 90% of respondents justified abortion for fatal fetal anomalies, and 63% justified abortion for nonfatal anomalies. What do you think is the

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motivation of medical providers for recommending abortion on such a routine basis?

JB: The motivation of the medical profession is threefold: one is misguided compassion with the belief that both patients, parent and unborn child, would suffer less if the child was not allowed to live; second the reality of lawsuits for wrongful birth are a daily issue in our profession, and thirdly, many medical professionals believe that abortion is good medicine in certain situations, a “necessary evil” so to speak .

MH: Is this bias toward abortion common in medical training?

JB: Abortion is presented either as difficult but good medicine in certain circumstances, or as a “necessary evil”. Especially in OBGYN where IVF children are oftentimes referred as “designer children”, perfection is demanded, and imperfections are not tolerated. This adds to the mistaken belief that we can eliminate pain and suffering and sometimes we need to end the life of the child before it is “viable”. The common presumption of academic medicine is that abortion is good healthcare. If you are prolife in an interview situation, they are looking to see if you are radical in that belief and would actively try to limit someone else’s options.

MH: What is the impact of care for parents choosing to carry to term following a Poor Prenatal Diagnosis, given the bias of abortion as the preferred management of Poor Prenatal Diagnosis?

JB: Most parents who carry children to term with disabilities get the awkward question or stare that speaks loudly from the providers or the nurses involved, “Why are you doing this? Don’t you know the suffering you will cause your child and your family?”

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However, there are more and more healthcare professionals who are sick of the current state of affairs and admire the return to a caring civility towards children with disabilities diagnosed in the womb. I am seeing that in my experience with our perinatal hospice program. I am also seeing many doctors thankful for providing real options. Up till now, abortion is the stressed option and the one most taken because another way is not presented.

MH: Are parents receiving sufficient/adequate information in order to give informed consent around prenatal testing and carrying their baby to term?

JB: I suspect not. Perinatal hospice programs are not very common. Cold statistics are not easily translated into understanding of what this diagnosis entails. Most women do not speak to other women who have made the choice of carrying their child to term. Most women truly look to their provider to give the answer to what they would recommend in this situation, to help them make their decision.

MH: What do these abortions entail?

JB: Using medicines that cause the uterus to contract, the child is delivered early. Rarely today, do we use surgical procedures. Occasionally if the placenta stays behind we use surgery to remove it.

MH: How do hospitals manage the care of parents aborting due to a prenatal diagnosis

JB: Usually, hospitals identify the exterior of the door with a symbol, in our case a butterfly, which designates the pregnancy and delivery in that room is not normal and will involve the death of the child either from an abortion or a prior fetal demise in utero. There are usually nurses with bereavement counseling to care for the patients who chose the abortion. Often the parent

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asks for a member of the clergy to come afterwards. Everything is done to say this was a merciful choice, and a healthy approach to a very sad situation. The mother is then monitored for a time afterwards and sent home. Her stay at the hospital is away from other moms with healthy children. Pictures are taken, footprints are printed, memory boxes are offered. Memorial services are now done at many hospitals to try to address the long term human emotions of having a sick child that had to be delivered early.

MH: Since so often abortion is mischaracterized as a solution, and, in fact, creates a whole other set of issues for parents, are such issues addressed?

JB: Once again, having been on both sides of this issue, parents who have aborted due to poor prenatal diagnosis need the support for the side effects that come with unfulfilled expectations surrounding the birth of your child; dealing with the death of a child that oftentimes, the parents do not want to hold or see.

MH: How do we best provide outreach to parents receiving a Poor Prenatal Diagnosis?

JB: Recognizing that these situations present a fast-moving dynamic as more testing provides more information and recognizing that the baby's situation is sometimes changing AND that complications may develop within the pregnancy...

The best outreach is to give the parents the option that abortion is not the only solution for their sorrow. Tell them that possibly the only time they have with their child is in utero, before the cord is cut, and that you can help them hospice their child so the five questions can be answered before their child is no more: I love you, please forgive me, I forgive you, I am sorry, and good bye.

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MH: How can you help parents “Reframe Their Story”?

JB: Affirm their shock and grief, educate them about male and female grief-need to elaborate on this point with a few more sentences & refer to toolkit; offer your care for them as bereaved parents; encourage them to slow down as they should not be rushed to make decisions that do not allow them to be first and foremost bereaved; remind them they have a responsibility for this vulnerable baby, as parents, to the best of their abilities even now; remove abortion euphemisms gently, advise them regarding the option of carrying to term, or if the diagnosis is lethal, the availability of perinatal hospice; assert that any early good-bye is not the easy way out.

MH: In addition to the parents served, are there other benefits to local service?

JB: Yes. All Obstetricians will be interested in a service that will help their patients with the aftermath of a poor prenatal diagnosis. That is one reason why abortion providers are sometimes on speed dial. Many doctors are not so invested in that the outcome is abortion as they are in simply not wanting to invest themselves in the situation. Be that service that takes on the investment. This is a great way to evangelize the community. Even if an obstetrician is not supportive, you can always be the supportive community that shows the obstetrician why this support is needed.

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