Medical Sociology Confronts the Human Genome

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I cannot seem to let go of birth, of the midwives, of what they have taught me of birth - and from that of death, illness and of life. Birth is a touchstone for me, a grounding, the place I stand.

So when I came to the study of genetics, of the increasing "geneticization" of everything, it was from the perspective of birth. First, and most simply, that means I looked at what this new genetics means for birth, how this will - and does - shape the experience of women who bear children.

More fundamentally though, it is from an understanding of what birth means that I see genetics.

Genetics offers itself as a science - as such, it presents itself as a neutral exploration of facts, an uncovering of a previously ordered world. And yet, we know quite well genetics comes from somewhere, stands somewhere, and sees the world from that place.

That place, that larger hegemony in which genetics grows, is the world view of late twentieth century Western thinking. I can only in the limited space available here, 'shorthand' this, but there are a few key elements of that world view to which I'd like to draw your attention. First is that it is a profoundly individualizing standpoint: a perspective that assumes the isolated individual as the Starting point. Just as in sociology itself, when we say that the essential question is how the social comes to be, how people come together, we accept the assumption that in our essence we stand as individuals, apart.

This is not the way the world looks for one who is grounded in birth as a reality: we grow in and from other people's bodies. That is not an abstraction or a metaphor, but a deeply physical reality. What we have done in the contemporary world is made birth and connectedness the abstraction, and the isolated individual the reality, the essential truth. Oddly, at the same time and place that I address the British Medical Sociology Association the Society for the Protection of the Unborn Child meets. If you look at their literature, their strange and disturbing photographs of fetuses, you can see the point that I am making: ultrasound imaging has made the fetus visible - but at the cost of making the woman in whose body it is cradled invisible. We are left with "man in space" imagery of the free floating fetus, with the woman turned into empty space. This "scientific" picture of the fetus reifies its isolation by erasing its connections, its embodiment within another body.

The root of this, I believe, is patriarchal ideology. I mean that in its very specific, technical sense: not the rule of men but the rule of fathers. In a motherbased understanding of the world, from the perspective of birth, people are what mothers grow, are made of the nurturance, sustenance and care that brings forth a child. In a patriarchal system, a person is what grows out of a man's seed. In a patriarchal System, when we speak of "blood ties,"
we speak of seeds, genetics - the only completely bloodless part of procreation. Our contemporary system is no longer a pure patriarchy, but is modified to recognize the seeds of women as well. Women are understood to be 'related' to their children in the same - and only in the same - way that men are related: through their seeds. Children are "half his, half hers," and might as well have- grown in the backyard.

Genetics is the most obvious and direct scientific descendnet of patriarchal thinking: an attempt to understand the meanings of things, perhaps the meaning of life, by understanding genes, the bits of RNA, DNA - the updated version of seeds. The Human Genome Project is an attempt to map the human genome, the distribution of genes on chromosomes, to find where each gene lies, and ultimately, what each does. Its proponents are given to waxing eloquent, calling It the holy grail, expecting to find the meaning of life within its C,G,A, and Ts. Its critics frequently describe it as the ultimate reductionist project. And reductionist it surely is. But to define it as the ultimate reductionist project is in a way to accept its underlying premise that we are reducible to our genes. Or, as Alan Spector has put it, the soul has moved into the gene. Genetics attempts to explain people, our physical condition and our social presence, by going back to the beginning, the moment of zygotic zero, when sperm joins egg and the seed is established. Spector is not wrong when he speaks of the soul: In a patriarchy, this is the secular moment of ensoulment.

In a patriarchal ideology, the seed contains all it could be. It is pure potential. Everything else becomes background. Look at a green field. A mother-based world view sees the rich green earth springing forth with life. A patriarchal world view sees seeds put in dirt, in soil. Think about those words we use for the very Earth: dirt, soil. That which is precious and life-giving has moved into the seed; the Earth itself is but dirt, only a place. And so it is that the fetus, the embryo, the zygote, the code becomes essentialized, while the woman, the connections, the social become invisible.

The Human Genome Project is in a sense much like the man-on-the-moon project of 25 years ago. It pulls together a lot of the scientific community, gives it a finite goal, and inspires much talk about human control. But as I think about the human genome project, the words of a Leonard Cohen song keep running through my mind: "No, they'll never, they'll never reach the moon now. At least not the one they're after."

I know this is a minority viewpoint, but I would argue that extraordinarily little has come out of human genetics so far. The basic thing we have is the tea-leaf reading aspect: it is possible to read the chromosomes like tea leaves and make some predictions. In some cases the predictions are quite clear. If the geneticists observe an extra 21st chromosome, for example, the person will have Downs Syndrome. But what exactly that means for the person is not at all clear. If observed in pregnancy, it might mean that the fetus is not strong or well or functional enough to survive the pregnancy and will miscarry, possibly before the results are returned. Or it may be born early and die. Or it could grow into a person with some degree of mental retardation. That could be quite severe or it could be a relatively minor disability. It might turn into a person whose life will be spent locked up in some nightmarish institution; or It might become a person living in a pleasant house down the street. The exactness of diagnosis does not translate into any exactness of prognosis, and no individual prognosis can tell us what social life will offer.

Nor is it clear that a rich and full understanding of genetics will lead to treatment. Consider the case of sickle cell anaemia, where they have in fact a pretty good idea of the cause: the precise molecular structure of the gene is known and for several decades the specific molecular change in sickle cell haemoglobin that is responsible for the condition has been
known. And the treatment? Pain relief and antibiotics. The same treatment you would give if you hadn’t a clue what caused it.

But the Human Genome Project doesn’t actually need to produce much in the way of cures or even explanation to have its impact. As we say in the watchword of our faith: Situations defined as real are real in their consequences. If we come to believe that the human condition our bodies and souls, our health and our hopes, are genetically determined, that has consequences.

It is so easy to be intimidated by the technicalities, the genetics of genetics, that we might forget what we are doing here… Start bandying about terms like alleles, double helixes and the like, and most of us rather glaze over. But all that this is about is predictions and the predictions are of questionable value. And predictions - perhaps especially predictions of questionable value - are something that medical sociologists have quite a bit of experience with. And so the question I am asking in this paper, as a medical sociologist, is how are genetic predictions used? What are the meanings and consequences of the predictions stemming from genetic testing?

The most widespread use of genetic predictions at this point is in prenatal diagnosis: and so back to-the midwives. I will explore what the consequences of genetic predictions in pregnancy have been for clues as to what awaits us with the growing use of genetic testing.

And specifically, the midwives I have chosen to go to, to ask these questions, are the midwives of the Netherlands. The Netherlands remains unique among Western countries in having a fully developed, independent profession of practising midwives, not subservient to the medical profession. That means that they are able to bring an alternative understanding, a birth-centred understanding, to their practice and to their use of the available prenatal genetic and related screening. The Dutch word for midwife is vroedvrouwen, or "wise women." In genetics to date we have had much information, but a decided lack of wisdom: I have turned to these Dutch midwives to see if they have some wisdom to bring to bear on these thorny questions. How are they using prenatal diagnosis, how do they see women using this information, and what can that tell us about how people can and will - perhaps should - use the new genetics.

The research I am drawing upon here was conducted as part of a Fulbright Fellowship at the University of Groningen in the Netherlands in 1994. Data presented in this paper came from a series of focus groups conducted with practicing Dutch midwives from all regions of the country. The groups discussed a variety of prenatal diagnostic technologies, not all of which were strictly "genetic" tests, but included ultrasound screening (called "echoscopie" or "echos") as well as maternal serum screening (the "triple test"), chromosome testing and DNA testing. With all of this mixed bag of technologies, the focus is on prediction, which to me is the essence of what genetics means today: do I, does he or she, have "the gene for.."

What is predictable, or believed to be predictable, varies enormously, and there is much talk about a slippery slope: In prenatal diagnosis, the slope is usually graphed as moving from diagnosis and abortion for conditions incompatible with life, passing through the firm but contested territory of Downs Syndrome and neural tube defects, floundering on the rocky terrain of socially undesirable conditions like deafness on down to obesity, bounding along the questionable areas of "gay genes" and "alcoholism genes", and finally crashing into the great moral abyss of sex selection.

In this paper, drawn from the larger project, I am only going to discuss three sets of circumstances: prenatal diagnosis of conditions which are invariably fatal, in which the baby will die no matter what; the ways that prenatal testing changes the timing of learning of a
disability which would have become apparent at some later point; and the issue of ‘reassurances’, the false and implied guarantee offered by prenatal testing. In no way should this be read as a complete discussion of prenatal testing. Nor are my criticisms to be read as a complete condemnation of all prenatal testing under all circumstances. Rather, what I am saying is that wise women working with predictive testing have found enormous problems. We are in the process of dramatically expanding predictive testing with the rapid progress of genetic testing. What can we learn from the experience of the vroedvrouwen?

WHEN THE BABY’S DEATH IS INEVITABLE

Ethicists who evaluate prenatal diagnosis are often most comfortable with those situations in which the fetus is diagnosed with an inevitably fatal condition: it might not survive the pregnancy, or even if brought to term and born alive, would die shortly thereafter. In such instances, prenatal diagnosis is generally understood to present no-ethical dilemmas. An abortion simply brings the inevitable to a more rapid conclusion.

Such an approach, like the medical model of pregnancy itself, is both product oriented and fetocentric. The medical model of pregnancy is the model or understanding that is taken-for-granted in most of the western world. The purpose of pregnancy is to make a (healthy) baby: the point of all prenatal and birth management is to achieve that goal. The focus in obstetrical care is on fetal outcome, with the woman variously known as the carrier, host’, environment or barrier.

Midwifery, in contrast, is focused on women. That inevitably includes in the management of pregnancy and birth trying to help the woman have the healthiest possible baby. But it also means trying to give her a “good birth”, a pregnancy and birth that make her feel good about herself as a mother, as a woman. It is not just the making of babies, but the making of mothers that midwives see as the miracle of birth. There is a general preference for prenatal rather than postpartum visits: Helping the woman is what midwifery is about. And that might very well mean, in a situation where the death of a baby is absolutely inevitable, helping a woman and her family come to terms with that in the best possible way.

In the medical model, the job is to get a healthy baby delivered. If you cannot get that done, then why bother continuing? And that is, in a nutshell, much of the rationale for prenatal diagnosis, and is certainly the logic used for testing for conditions which are incompatible with life. If the baby is going to die anyway, there is no point in continuing the pregnancy. It is a waste of time. And if the woman could have known that and did not, then she has in some sense been duped, made a fool of, wasted her time.

These midwives, in contrast, asked a question that simply makes no sense in the medical understanding of pregnancy. If the baby is going to die anyway, midwives asked, "Why spoil the pregnancy?" The concept of spoiling the pregnancy does not sit well with medically atuned people, largely because the pregnancy, in and of itself, is not valued. Not so for the midwives.

Two midwives in two different groups put it very simply. Considering the possibility of a bad outcome, one said, "Well, do they have to know it? Let them first have an untroubled pregnancy." And another, in a discussion of the possibility of a bad outcome, leaned over and told me quite clearly, "But some of us find a good pregnancy very important, whatever the outcome."

I see two ways of understanding their valuing of a good pregnancy under these circumstances of an inevitable bad outcome. One begs the question: what is the point of life? If life is about accomplishing things, then pregnancies resulting in dead babies are pointless. If life is about living, if it is just this and we only have a finite time to live, then days
spent in joyous anticipation are good days, and days spent in grief are bad days, and prenatal diagnosis of condition inevitably cause death simply moves days from the good to the bad side of the ledger for the woman.

The other way of understanding this - and they are not mutually exclusive – is to postulate that pregnancy has itself a value and a meaning in a woman’s life, and that a good pregnancy and a good birth are good things to have.

Consider the following:

_In our practice was a child with a disorder that was not compatible with life. It didn't have a midrife (diaphragm). Intestines up, heart on the wrong place, etc. This woman had a good pregnancy, a difficult delivery, but she looks back on it very positively. The child lived a couple of hours. Of course they are sad about the child, but also had very positive feelings toward the child. And I saw a couple of pregnant women talking about it, and they said, "You could have seen it on an echo," which is true. "They should have done an echo, then they would have known." And that is how other pregnant people talk about it, like it's nice to know in advance that something is wrong. Theoretically. But they did not know this woman. This woman is very satisfied that she did not know anything in advance because an echo wouldn't have changed it. Yes, she would probably have had a hospital birth and three thousand echos and pressure, and now it is at least a nice pregnancy and positive experience of her delivery. The outcome would have been the same in both cases._

The outcome to which she refers is the loss of a child, a loss that is inevitable, whether by abortion in the first half of the pregnancy or the death of a born child. This is not at all to claim that all abortions are the loss of a child, but for a woman planning on having a child, a diagnosis of a fatal condition has to mean the loss of that planned-on child. She was pregnant, planning on a baby. There will be no live baby, no living child. The outcome, however achieved, is the same.

In another group a midwife described the unanticipated, untested birth of a baby with anencephaly, an absence-of brain development and inevitable death:

_"That night she goes into labor and she gave birth to an anencephaal. She says, "Am I glad that I didn't know!" Because now at least she had a jolly pregnancy. It's really a shame, that baby dies anyway. That's all very sad, but if you know that, that really is quite a burden. She doesn't mind that she didn't know._

A jolly pregnancy: Where is the space for that in the medical model?

One focus group, of midwives from a village in a more traditional and religious area was unique in its opposition to abortion: no other group of midwives could have been characterized as "anti abortion". But even there, with the opposition to abortion, the discussion was both nuanced and continually focused on the needs of the mother. This exchange took place in a discussion of a baby with severe heart disease:

_1st midwife: The children's doctor looked at the baby, everything okay. At night, the baby’s temperature fell down. It had no chance to live outside the uterus. If I had made an ultrasound the disablement was shown. What will be the profit for this woman? She was pregnant very happy, had a very good delivery, was very happy. However the baby died 24 hours later. But it died in her arms. What if we saw it on the echo?_

_2nd midwife: No profit, only much worse I think. This was human._
3rd midwife: Once I made an ultrasound, the baby was an encephal, the child had no head. During the pregnancy the woman said goodbye to the baby. That was very important to that woman, so what is profit or loss?

In the medical model, that is readily answered: profit is time saved, loss time wasted. An abortion is an efficient solution. But between the lateness of the diagnosis, and the fact that these are wanted pregnancies, these abortions are not comparable to ordinary, early abortions to get "unpregnant", where the pregnancy was itself a mistake. These abortions, for the woman, are the death of a baby, without the saving grace of a good birth and a good death.

Another group's discussion of diagnosis of inevitable fetal demise concluded:

1st midwife: But isn't it like that most congenital defects aren't compatible with life - so in fact, yes, it solves the case on its own. It might take a little longer, till after the birth, but the woman has had an unconcerned pregnancy.

2nd midwife: Yes, it looks a bit like putting your head in the sand, but on the other side, that isn't it. It's letting nature take its course.

One of the ways to make sense of what the midwives are saying about "jolly" and "nice" pregnancies which result in the birth of dead or dying babies is to acknowledge the distinction between product and process. The medical model is product-oriented; the midwives are process-oriented.

Let me clarify the distinction with a mundane example. Suppose you have a video camera and are filming your kids. They are mugging for the camera, singing a song, playing, laughing and having fun together, when you notice that you have run out of tape, If what you are trying to do is make a tape, then there is no point in continuing - you should tell the kids, stop it, and maybe try again another day when you have fresh tape. On the other hand, maybe you should just continue to do what you were doing, let the kids finish up, let the fun go on, and forget about getting it down on tape.

Partly this is a difference between product and process, but it is also a way of thinking about what the product is: when filming the family, you are also constructing the family, making those very ties between your children that you seek to capture on film.

And now turn to pregnancy: pregnancy is about making a baby, but it is also about making family, making relationships, making the woman a mother. Even if the pregnancy is not successful in producing a baby, it may very well be successful in its other products. Death and grief and sadness also make a family. By nurturing the woman, her relationship with her partner and her family and friends, her feelings about herself and her lost child, midwives can construct success, satisfaction, family even out of death.

For both the medical model and the midwifery model, the Situation of a fetus whose condition is incompatible with life is the clearest. Within the medical model there is no point in continuing, no earthly reason to finish the pregnancy, and every good reason to find out quickly and be done with it. In the midwifery model, since nothing is going to make the baby any better, one has no reason to learn ahead of time and spoil the pregnancy, burden the woman with untimely grief and a ghastly birth unto-death.

And what can this tell us about the direction of genetic testing beyond prenatal diagnosis? Our destiny may not actually be in our genes, but most assuredly, that is what is being heard: genes "program in" eventualities, serve as harbingers of doom.

How well do people live with predictions of doom? Can we ‘spoil a life’ or part of one, as we can spoil a pregnancy, taking the joy and meaning out of the present by knowing too well (or...
thinking we know too well) where the future lies? I think of people I know who have received very late diagnosis of fatal diseases, whose dying was essentially telescoped into weeks rather than the potential of years that an earlier diagnosis might have meant. Not that more time would have been given to living: more time would have been moved from one to the other side of the ledger. At least for the foreseeable future, genetic diagnosis, the predictive abilities, are far going to outstrip the treatment potentials - just as is true now in prenatal testing.

THE FULLNESS OF TIME

It is not only death, doom and destruction that can be predicted prenatally. More common and more troubling in many ways are the places a bit further down the slope.

Some disabilities - neural tube defects, club foot, cleft lip and palette - are immediately apparent at birth. And some unfold over time. Some of the conditions for which prenatal testing is now available will not show up until middle age. Prenatal diagnosis never tells anything one wouldn't have found out later on anyway. It changes the timing. In having prenatal testing a woman seeks immediately the information she would have had eventually. The reason to seek that information early is that abortion is possible early on. In choosing not to have prenatal diagnosis, a woman may be seen as burying her head in the sand. Several midwives told me about one particular woman obstetrician in the Netherlands who tells her patients who hesitate about having testing that that is what they are doing: burying their heads in the sand. It is the picture of foolishness, turning away from knowledge while exposing oneself to pain. In this, the ‘information age,’ all information is to be valued for its own sake. And it is precisely that which I am questioning.

When I shared a very preliminary version of this paper with American midwives and childbirth educators, one of them used a phrase that resonated for me: the fullness of time. Let it come, let her learn what she needs to know, but all in the fullness of time. Dutch midwives said similar things, though in less eloquent English: "It’s letting nature take its course." Or, in another group:

First midwife: There's time enough to worry about it when the time is right.
Second midwife: When the time is right, yes, well, I do agree with you.

Sounding very much like "burying her head in the sand," one midwife spoke about late diagnosis, information coming past the period when an abortion is possible:

With the echos at 25 weeks and they see something, the pregnancy is spoiled because she has to live with something till birth is coming, because you cannot do anything, or they see the baby has something not with life verenigbaar, compatible with life, what should you do? So I think It is better not to know, just give births and then you will see.

And a second midwife in that group elaborated, explaining that:

The pregnancy is very abstract, you don't make a decision about the child, and when you see the child it is not so abstract any more and you make a decision based on your emotions.

A decision made during a pregnancy, they are saying, cannot be a fully informed decision because it remains an abstraction and the emotions are not there yet. It is an interesting twist on the more usual (male? medical? Western?) notion that emotions muddle and get in the way of informed decisions, that emotions are themselves a pull towards irrationality.

What neither the midwives nor I am saying is that information should be paternalistically or materialistically withheld from women. What we are is are these women who are being
tested making truly informed decisions about the information they are requesting? Do they really want this information? Do they understand what the information will mean to them? And do they understand what it will mean to get the information without the context of the child?

Downs Syndrome presents an interesting example of this problem. It can be absolutely, definitively diagnosed relatively early in pregnancy, as early as 10 to 12 weeks with early amniocentesis or chorionic villus sampling, closer to 18 weeks when diagnosed as part of a mass screening program beginning with maternal serum screening and moving on to definitive diagnosis. At birth, Downs Syndrome is readily identifiable with chromosomal testing, but not always instantly recognizable, especially for the parents. Most of the discussion of Downs Syndrome in midwifery care revolved around disclosure issues: when and how do you tell. An instant appraisal might be actively discouraged. The slowness is valued, the unfolding of knowledge with time. That time, those minutes, hours or days before a diagnosis is given to the parents, serve a purpose. One midwife, telling of a period of several days of confusion before the mother learned the diagnosis of Downs Syndrome said:

*I talked later to this woman and she told exactly these days it was for me to adore my baby. If they told it the first day because they thought immediately about it, I cannot adore her. But she is already in my heart, I adore her, I hear she is not okay, but it does not matter anymore, she is already my daughter.*

In the language of contemporary medicine and psychology, this is called “bonding,” a period in which attachment between mother and baby, and baby and family, is solidified. Pregnancy itself, and the birth process, the midwives claim, serve this purpose. Speaking generally of women bearing babies with problems, one midwife said:

*Some women say that when they discover during the delivery that something is wrong, they say "Fortunately I had nine months to bind to the child and it's my child. It's shocking, but I've had nine months a very nice pregnancy which no one will take away from me." And if they would have discovered while they were still pregnant that the child was not healthy… Indeed you never know: how unhealthy is not healthy? What can you expect? And then you have a lot of doubts and you’re not enjoying your pregnancy any more.*

Midwives talk about the strength that women and families show with the birth of a child with disabilities. The midwives talk about the strength as being there in the woman: I see midwives nurturing women to tap their strengths, playing more of a role in how mothers handle this than perhaps midwives give themselves credit for. But can the woman who can be strong and accepting and loving at birth, who can claim her daughter as her daughter whom she adores unconditionally, that "maybe she's not okay but it doesn't matter anymore," can that woman have those feelings without benefit of the fullness of time? Without the pregnancy, without the child, without the emotions of birth, it is not the same. Prenatal testing, if offered early enough, attempts to bypass all of that, and permit abortions before the child becomes a child. How does one counsel a woman about ending a pregnancy with a fetus that the midwife knows the woman would grow to love? This is the problem, expressed clearly by two midwives in a group’s discussion of counselling for prenatal screening. One midwife says she asks women:

*First midwife: Which deviations do you think you can handle and which not? I think when push comes to shove you’re stronger than you think you are. That's what I see: people who have a child with some kind of deviation are always very strong.*
Second midwife, interjecting: Yes, but then they are facing a fact. I don't know how these people would react when they knew it in the 12th week of pregnancy.

Much the same can be said, I believe, for the way people deal with, rise to, their own illnesses, disabilities, trials and tribulations: people do show much inner strength. And yet, that too comes with the fullness of time.

It is in the nature of this growing world of genetic prediction that we offer information 'out of time', abruptly and without context of lived experience.

One of the troubling directions we are now going in is internalizing a new notion of "seeming" vs. "real" health, with "seeming" health being one's feeling and all the standard measures of healthiness. You can feel fine, have good muscle tone, clear thinking, a steady heartbeat, good appetite, rosy cheeks. But that no longer means you are really healthy. Real health comes from a variety of laboratory and new diagnostic techniques. Screening programs paved the way: cancer, heart-disease, diabetes, are all sold as "silent killers." People who think they are healthy may be harbouring these silent killers, death and destruction lurking within. At what point does one "have" or "get", say, cancer? Early (pre-symptomatic) detection gave us the idea that illness lurks, really there before it makes its presence felt. Genetic testing for predispositions seems to build on this, moving the diagnosis back yet again, to a point preceding its physical embodiment, and into the realm of codes, of predestiny, of tragic flaws within.

When I first began working in the area of prenatal diagnosis, I was struck by the oddness of the language problems that arose: how can one speak of a 'disabled fetus'? A 'retarded' fetus? What exactly is it that a disabled fetus is unable to do that a normal fetus can? A retarded fetus? And try to think of what it means to predict alcoholism genes: can there be an 'alcoholic fetus'? Is a 'gay fetus'? a reductio ad absurdum? With genetic testing for the breast cancer gene, we now can have three year old girls who essentially have breast cancer before they have breasts.

Lived illness, disability, disease, infirmity most often comes in a context, in the course of a life, unfolding itself over time, with good days and bad days spiralling downward. You adjust. What comes to be thought of as a good day was once a very bad day indeed.

When a diagnosis clarifies and names an existing problem, labels it for us, it may be useful. It may also, as we well know from the field of labelling studies, be dangerous, harmful, disruptive, stigmatizing, punitive. What we need to think about as our labelling abilities expand is what are the consequences of labels without the conditions they signify?

One of the comforting stories we tell ourselves is that all of this labelling, diagnosis, prediction, will lead to prevention. We like to believe that if we could identify those people who are prone to, say, middle-age onset diabetes, for example, we could get them to eat properly and exercise, and avoid the disease. And yet we know perfectly well that people with diagnosed diabetes, people who are actively and physically suffering the consequences of their disease, cannot always, or even often, manage the programs designed for them. People with lung cancer smoke: Does anyone seriously think that identifying people with the genetic predisposition for lung cancer is going to stop the 12 year old with the gene from smoking?

And what about the 12 year old without the gene for lung cancer? Not having the "gene" in question does not mean one is home free, not at risk of environmental consequences. Women without the gene for breast cancer have learned that their risks now drop down to the regular risks of breast cancer.
While a diagnosis of having a gene that predisposes towards a particular condition may be experienced as an abrupt diagnosis of doom, a diagnosis of not having that gene implies a false guarantee.

NO GUARANTEES

Midwives know that birth, like life itself, comes with no guarantees. A belief in the health and normalcy of pregnancy and birth is not to be confused with a fantastical expectation of all jolly pregnancies, happy healthy babies, well-adjusted mothers and eternal happiness. While critics of midwifery may fail to understand this, and confuse ‘the midwives conviction about the ‘naturalness’ and healthy nature of pregnancy and birth with a naive, Pollyannaish expectation of happy endings, the midwives themselves hurl this very accusation at the testing process.

The testing, they find, implies for many women a kind of guarantee. Women say they want the testing for reassurance, for security. One group discussed uses of ultrasound:

1<sup>st</sup> midwife: They want to know if everything will be OK.
2<sup>nd</sup> midwife: They want security.
1<sup>st</sup> midwife: Security, yes. They want a kind of security, but then I say they can see a lot, but there are so many diseases they can't see. So it will give you not a real security. You can explain it, but not to all women.
3<sup>rd</sup> midwife: It gives security. "I'm so glad I have seen the baby and the doctor said everything was okay. And you could see the kidneys and the heart. It was quite nice." So I'm scared about that security.

And then the examples follow, in group after group, of women reassured and then surprised.

From another group, in a discussion of a woman who had a child with disabilities in her first pregnancy and then considerable testing in her second:

1<sup>st</sup> midwife: Then she was pregnant again and she really went 20 times for an ultrasound as well in - as in here. This time it's a fantastic child and she wanted to give birth at home. So, there comes some eight-pounder, and it has ONE HAND and nobody noticed that before. Then you stay there and you know, met je mond vol tanden (with your mouth full of teeth, 'speechless.') I felt it soft below my feet. I never felt worse.
2<sup>nd</sup> midwife: And she got the impression, everybody looked at it so many times, there will be no problem that's what you expect, but then…
3<sup>rd</sup> midwife: Yes, it's a kind of false protection.
1<sup>st</sup> midwife: A short time ago we had a woman with very strange (fetal) heart tones, so they made an ultrasound. They told the little heart was all right, there were no abnormalities. The child is born, six weeks after birth it appears the child has a severe abnormality of the heart, which has not been seen on ultrasound. In some ways you can see nice things with It but it also misses some things. The problem is people have so much confidence in it. For them the ultrasound is "when I had an ultrasound it will be all right."

I think the midwives tell each other these stories not just to carp about inaccurate testing, but because it raises a fundamental issue in the meaning of testing, an issue we would do well to think about as genetic testing increases. Testing is about control, as if information led to control. Several midwives mentioned women wanting early ultrasounds to reassure them about miscarriages. But all that early ultrasound will tell them is what they already knew: that they are at that moment carrying a fetus. That you can see it on Monday doesn't mean it will be there on Tuesday.
That is why midwives aren't just irritated by these false negatives, these false reassurances, but as one said, scared by that security. Some see this as a product of changing times. "But it suits in these times we live in, we want to arrange everything, we want to control". Some recognize it as very specifically an American way being exported to the Netherlands. As midwives find their clients asking for more testing, some say it is the city women more than the village women, or the ones who 'read everything'. Some say it is the media, the magazines, the stories. Some see the push as coming from some of the research centres within the Netherlands. But all are aware of these winds of change as a new search for security. And it scares them.

It scares them because this isn't just about pregnancy. This is about motherhood and about life itself. In counsellling people, one midwife says:

> It has something to do with someone's personality, the way he copes with deformation in life, isn't it? Like he can accept, or not, a child with a handicap. I always explain it is not true that you don't have to worry anymore when the pregnancy is passed. You are eager to have a healthy child, but after a chorionic villus sampling, an amnio, an ultrasound and birth, your worries are not over yet. When the child is there you still have your concerns. Can he walk along the street on his own, and near the water, I hope he gets no accident, and I hope he doesn't get some wrong friends. It is a process, all life long isn't it? Somehow or somewhere you have to let it go, you cannot control everything, and maybe you have to start to let it go at the beginning. You should dare to leave some questions without an answer.

The demands of the Information age drive us towards getting all of the answers. Perhaps wisdom lies in not always doing so, in making wise judgements about which information we want, and which information we do not, about when we want information and when we want to wait.

We are not to live forever. There are no happily ever afters, Life is a very scary place and you're not getting out of here alive.

This human genome project hasn't only been about a search to know - it's been about control, as if information led to knowledge and knowledge led to control. This is clearly not about making people better off - we as sociologists ought to know that. People don't get better off one at a time: we are and we remain social beings. Postal codes are still our best predictor of infant mortality rates.

As medical sociologists we should know this: not only in social life, but even in that area of life known as medicine, as illness, as the body, reductionism won't work, not to explain, not to help. There have been a few exceptions, certainly, just enough to keep it funded. The odd gene that prevents a particular kind of protein from being metabolized and creates havoc is found: and from that, all health, all illness, all bodily states are believed to be found in the genes.

But essentially, in our essence, in our fibre and being, we are not isolated pre-programmed bits of DNA. We are part of our social world, deeply entwined with one another. That is the wisdom of the vroedvrouwen, of the midwives: an understanding of the connectedness. It is an understanding, a wisdom that sociology - when it is working right - shares, a sense of our connectedness, our context, our social essence.

And what we need, as we muddle through this life, is probably less information and a lot more wisdom.