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**RISK - ANXIETY  
AND THE MYTH OF INFORMED DECISION MAKING**

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## **RISK - ANXIETY**

### **AND THE MYTH OF INFORMED DECISION MAKING<sup>1</sup>**

My mother went pregnant without risks. This was not because she received a risk-free certificate from some physician. No - in 1970, the year of my birth, being with child was not a risky business. After all, well into the 20<sup>th</sup> century, the German language only knew “risk” as a technical term of the merchants’ tongue. It had become established in everyday language as a synonym of “danger” or “daring”. Driving a car already held risks in 1934. In the sixties, when the idea of disease prevention came up, scientists propagated the filter cigarette as “risk free” tobacco product. So thought my mother was surrounded by risks at the time she was carrying me, she could not yet imagine me as a risk, not to say as a risk to her.

But today, sick people, pregnant women and healthy persons, they all live under the shadow of “risk”. When I read the science page of my newspaper, when my health shop informs me about food options or when I go for a routine check to my gynecologist - everywhere I am in the danger of absorbing risks. For years, my neighbor lives in anxiety because of her increased risk of breast cancer. She worries incessantly about every medical check up and studiously pores over all the guides on “breast fitness - How to reduce your risk of breast cancer”. Almost none of my friends escaped becoming a risk carrier as soon as they were diagnosed “pregnant” by a gynecologist. I remember very well when one of my friends desperately rang my doorbell after the physician had urged her to choose between two risks: The risk of giving birth to a handicapped child and the risk of an abortion induced by the test.

What can this be, a “risk” that spoils the organic food followers’ appetite for meat, that transmogrifies my neighbor’s bosom into a time bomb and that makes my pregnant friend reckoning with disasters? How is it possible that statistical figures that estimate the frequency of occurrences in cohorts conjure up the idiot in my friend’s belly and the insidious death of my neighbor?

How is it possible that statistical calculations can deprive people of their good spirits? To answer this question, I will use the example of genetic counseling. I want to show that the release of scientific - here genetic - terms into everyday language creates risk induced

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anxiety. When my neighbor believes that she carries a genetic command for her early death, and when my friend believes that there is a genetic program running in her belly, they are both adjusted to attach personal significance to abstract risk figures. Gene faith creates an imaginary connection between calculated probabilities on the one side and a unique person on the other side. Genetics pretends to bridge the gap between risk figures and your particular fate. I will illustrate this statement by telling you about Mrs. G. Mrs. G is in her fifth month and is supposed to make an “informed decision” about her pregnancy.

Before I start with Mrs. G., I have to clarify two aspects: First, I will talk about the particular status words such as “gene” and “genetic” have in everyday language. On the one hand, “gene” demands significance, meaning. On the other hand, it cannot signify anything outside the lab. This paradox enables the “gene” to work as a bridge between statistics and real life. Second, I want to point out that genetic counseling is no medical consultation. Risk thinking makes it impossible to follow the art of healing. A physician cannot be oriented towards probabilities without losing sight of the person he is facing. Very often, a pregnant woman is bright-eyed and bushy-tailed until the physician follows his counseling duties and confronts her with risks. The woman leaves this kind of education not as a patient with a diagnosed abnormality, but as a faceless member of a risk class.

## PLASTIC WORDS

Scientific terms that spread in ordinary language, the linguist Uwe Pörksen calls „PLASTIC WORDS“. “Plastic words”, because those terms lose their denotative power and gain lots of connotations when they escape from their original context.

When an information theorist talks to a cyberneticist, both know what they are talking about using the term “information”: An exactly defined quantitative measure of the reduction of possibilities. The word “information” has a precise technical denotation. But in the canteen, when the cyberneticist has lunch with the geneticist, the technical term “information” becomes pop-science. Cheerfully, the geneticist borrows ideas and notions from cybernetics and, with the help of his colleague, speculates on the informational content of the DNA. This geneticist has only a vague idea about information theory. For him, “information” implies something meaningful, and that’s how he imagines “genetic

information". Here, "information" is neither quantified nor precisely defined anymore, and the plausibility of the notion partly comes from its connotations in everyday language. At night, the same geneticist is invited to a public hearing with citizens and politicians. He hopes for good public relations and additional funding. To make it easy for the public, he talks about "genetic information" that is stored in the genes, such as messages are recorded on a tape. The enlightened laity is impressed. Always striving for being informed, it immediately becomes clear to them: "genetic information" is a positive good that is not supposed to lie wasted. They talk about the "code of life" and about the incredible knowledge geneticists gain through gene technology. The word "information" at the same time connotes scientific authority and universal meaningfulness. Nobody asks anymore what it could mean at all. "Information" has become a plastic word, connoting unquestioned authority and denoting anything - nothing.

The fundamental concept of genetics, the "gene", cannot simply count as one of Pörksens Plastic words. No doubt, it is one of the most powerful escapees from the lab into everyday language. But even geneticists among themselves cannot use "gene" as a technical term. Already in 1984, the geneticist Raphael Falk pointed out that the results of molecular biology in the 1970ies have cleared away with the hope that genes could be demonstrated to be units of heredity and development. According to Falk, „gene“ has become what it was at the beginning: A useful hypothesis, a conceptual crutch: "With each new development in molecular genetics, it became obvious that the gene was nothing more than an intellectual device helpful in the organization of data" (Falk 1984, 196). The reference of the word fully depends on the expert who uses it: A population geneticist calculates the frequency of alleles, the molecular biologist analyzes DNA biochemically; a bio cyberneticist estimates signal to noise ratios; and, finally, a physician follows hereditary patterns of diseases. What "gene" signifies in these different contexts does not agree with each other. Therefore, the philosopher of science, Philip Kitcher, proposes the following definition of "gene": „A gene is anything a competent biologist chooses to call a gene“ (Kitcher 1992, 131).

In the lab, "gene" signifies anything. It has no algorithmic or empirical referent - "gene" does not stand for a mathematical function, such as "energy" in physics or "information" in cybernetics, nor does it stand for an observable phenomenon, such as the "chromosome" in biology. But outside the lab, "gene" appears as the basis of life and connotes unlimited manageability.

And it is this paradox, the missing power of denotation on the one hand and the enormous connotative load on the other hand that makes gene-talk so powerful. The word „gene“ works like a Trojan horse. With its help risk thinking is smuggled into every day life.

## **WHAT IS A RISK?**

„You’re at risk“- this statement sounds scary, especially, when it is pronounced by a physician who threatens you with a serious disease. A sentence like this can hardly avoid being misunderstood. In medical statistics, risks are probabilities of occurrences. They tell you something about the frequency of events in statistical populations. A risk of 5% to die of heart attack just says something about the risk population in which the doctor has put his patient. To make his patient compatible with statistics, the physician has to leave aside everything that has traditionally been the basis of the art of healing. He has to ignore the particular, the unique, and the concrete of the person he is facing and consider him a component of a statistical class. „In statistical affairs ... the first care before all else is to lose sight of the man taken in isolation in order to consider him only as a fraction of the species. It is necessary to strip him of his individuality to arrive at the elimination of all accidental effects that individuality can introduce into the question“ a Parisian committee of mathematicians stated already in 1835 (zit. n. Hacking 1990, 81). “Personal” or “individual” risk that is threatening a patient does not exist by definition. I may or may not get heart disease –doctors and statisticians know as much about what might happen to me as an astrologer tossing a coin.

Nevertheless, today, probability curves not only serve medical insurers to calculate their premiums, but they also become increasingly the basis for patient management in medicine. No matter if it is strangury - the pressure to pass water - of elderly men, the uncertainty of being pregnant or the uncle’s early death from heart attack - everything that only a couple of years ago would have been a misfortune, the unpredictable hazards of a particular fate or simply the course of life, today becomes a “risk factor” that has to be managed. Risk calculus creates a new class of service dependents, because the anxiety created by risks has to be diminished or at least supervised. Risk anxiety produces clients whose needs can never be satisfied. All that a geneticist can offer is to continue genetic fortune telling and calculate new risks. There is only one way to eliminate all risks of pregnancy or breast cancer: Extirpation - to remove breasts or fetus.

## THE EXAMPLE OF GENETIC COUNSELING

Genetic counseling is supposed to popularize scientific terms. It is a service rendered by medical geneticists mainly to pregnant women. The service is supposed to enable the client to "make" something that is called an "autonomous" or an "informed decision". What can that mean?

1. The geneticist talks to a laywoman. He has to spell out his knowledge in such a way that normal people can follow him. To do so, he has to find everyday words for notions like chromosomal aberration, DNA-mutation and probability model.
2. Once talked to, the client is urged to make a decision. This decision is, in some way, a decision about life and death, about delivering a child or terminating a pregnancy. Facing the counselor's genetic mumbo jumbo the client inevitably asks herself: What does all this say about me? What does all this mean to me? Genetic counseling is a glaring example of the clash between scientific concepts and everyday meaning.

Let me take as an instance my recording of the genetic counseling session of Ms. G., a baker's wife in Southern Germany. I picked her story out of thirty genetic counseling sessions that I have observed and recorded. It turns out that after the genetic counseling Mrs. G. is no more familiar with scientific thinking than before, but she has learned something, something else: She has learned to see herself from the perspective of an insurance broker or of a health economist; she has learned to objectify herself and to manage this objective self according to information about it.

Mrs. G. is in the 5th month of her pregnancy and she is in good spirits. Her obstetrician has referred her to the genetic counselor at the moment she had told him about the early death of her husband's nephew. The little boy was diagnosed with Cystic Fibrosis. But in her own family she cannot think of anyone with a hereditary disease. So far she has been confident that the child she bears will be healthy. She did not come here on her own, but because of her husband who insisted that she be tested, --- mainly because such tests are available nowadays.

In order to determine the test options, she has to face a risk profile. So he starts the session by asking questions. He copies data from her Mutterpass (identity card? no idea how this clinical chart for the pregnant, this "mother passport" is called in English). Then he

inquires into her own and her husband's past. He starts drawing a family tree, which leads him to questions about grandparents, aunts and nephews. This inquisition about the family history does not yield additional risks, so he moves on to sum up the risk status of this pregnancy. Since a positive pregnancy test has placed her into the population of pregnant women, a table to which the geneticist refers allows him to identify the so-called base risk of her cohort. In other words, the geneticist confronts the pregnant woman with a list of different diseases and handicaps: Spina bifida, harelip, heart diseases, severe mental handicaps.

Her age - she is 34 - puts her into another risk group. The counselor informs her about her risk of 1: 435 that her child might have Down syndrome. Finally, the death of her husband's nephew provokes a difficult calculation with the result of a 0.5% risk for Cystic Fibrosis. These probabilities frame the test options of Mrs. G. And she herself has to decide which tests to undergo and which risks to take - choose the amniocentesis, which could lead to an abortion, or make a simple blood test first? Or, another option with calculated risks - no test at all?

### **THE BASIS OF THE DECISION - THREE GENETIC LESSONS**

Now you have an idea about the situation in which Mrs. G. found herself after being counseled for 30 minutes. After the counselor has made clear that Mrs. G. has to make a decision in any case, he offers her the input of information he considers necessary. He confronts Mrs. G. with antiquated textbook knowledge in genetics. But he skips the first lesson: He takes it for granted that Mrs. G. knows what he means by "genes". Two or three times he uses the word "genes" synonymously with "hereditary factors", in German "Erbanlagen" and then moves on to lesson 2. He shows Mrs. G. pictures with strange worms and says (the following is verbally cited from the genetic counseling session):

**B:** These are chromosomes; Chromosomes are not genes, but the carrier or the packaging of genes. And we have roughly 70 000 genes. They are so small that we cannot see them under the microscope. And such a band - this is how we call this striped pattern - contains roughly one hundred genes, that's the dimension.

Here they are, the "genes". The counselor claims that they are THERE, and points with his finger to the wormlike objects. The fact that Mrs. G. cannot see any genes on that picture is

simply due to the order of magnitude: The geneticist claims that genes are simply too tiny to be seen.

Nevertheless, the geneticist taught Mrs. G. a lesson: He makes her believe that there is something inside of her that she herself cannot see, taste, smell or feel, but that can be observed and assessed by experts. He creates the impression that “genes” are something as real as mice and ants. He suggests that genes are little tiny things in the microcosm of our bodies. The geneticist goes on with lesson 3. He introduces Mrs. G. to gene function, a difficult subject:

**B:** When I had to deal with this topic, I imagined that chromosomes are like bookshelves in the nucleus. There is a huge library, and in the shelves there are single books that are called genes. And many genes together form the chromosomes. Roughly one thousand genes are in the shelves and form the chromosome. The chromosome is the packaging, and the genes are the individual administrative regulations. There is one book with the title “volume nose”,

*- here Mrs. G. leans back on her chair and says: Ah, ja, mhm, mhm -*

subdivided into the nose and how it is supposed to look. Eyes, hair color, everything is regulated here. Gene by gene.

And what you cannot see on the chromosome are mutations in single genes. And they can cause hereditary diseases.

Beyond the reach of human eyes or ears genes are up to some mischief. Not only do they determine one’s appearance from somewhere deep inside, but they also cause diseases. Mrs. G. is flabbergasted. Is she really ruled by administrative regulations written down in her cells?

For a long time I was at a loss trying to make sense of this dialogue, or I should say: monologue. You have to admit that Mrs. G. is neither informed about genetics; nor does she know anything about the child she is pregnant with. At best she is enlightened about the bureaucratic phantasies of German academics. What else has she learned? The counselor has created, or reinforced, her gene faith. The idea that deep inside of her little things called “genes” store information about her health transforms Mrs. G. into a conglomerate of informational bits. This way, she becomes compatible with genetic probability curves. After this preparation Mrs. G. will swallow the following risk



calculations and the demand to become a decision-maker on her own behalf. Gene faith prepares for risk thinking.

### **COST-BENEFIT ANALYSIS**

After the gene lessons, the counselor imputes to Mrs. G. the mathematical characteristics of statistical populations. He talks about her individual risk and calculates her chances at the chromosomal gamble. The calculation results in a risk of 0,5% for a child with Cystic Fibrosis. The counselor leaves it up to Mrs. G. to handle this number:

**B:** You have a risk of 0,5% for Cystic Fibrosis. O.K., if it hits you it is always a hundred percent. But it is still low.

The number does not say anything about the health of the coming child. There is no such thing as an “individual risk”. Probabilities refer to the frequency of events in statistical populations. In case Mrs. G. would give birth to 200 children, one would get it, on average. Maybe the geneticist played hokey during the course in statistics. I guess he himself believes that statistical numbers can be threatening. Anyway - he talks about Mrs. G.’s “individual risk” as if there would be something personal about a risk figure and transforms her good hope into a risky gamble.

Geneticists are not physicians in the traditional sense, rather they are biostatisticians. Though a trained doctor, the genetic counselor cannot make a diagnosis, a prognosis or recommend an appropriate treatment. His "patient" is one not yet born. The only treatment possible is aborting him. All this expert can do is to offer different tests to the woman and urge her to select one according to her lights.

Mrs. G. is now urged to make a decision. The counselor states repeatedly that she has to choose between her options: No testing and accept her present risk status; undergo an amniocentesis without prior testing which would be a 0,5% risk of inducing an abortion; or choose a blood test first to establish Mrs. G.’s and her husband’s carrier status. The counselor urges Mrs. G. to select one of the options he can offer her according to her risk profile.

But how? The counselor suggests something that is an imposition: He urges Mrs. G. to deal with her situation from a manager's point of view. He wants her to weigh the different risks, add her preferences and balance them. But this proposal is perverse: A cost-benefit analysis is reasonable when the real results are quantifiable, when the question is about more or less. A manager who produces hundreds of light bulbs each day might reach a profitable solution by balancing the risks. But it is impossible for Mrs. G. to find a solution that would correspond to her personally. There is no more or less in her case. There is this one child that she was hoping for.

### **GENE-TALK AS PREP-COURSE FOR MANAGERIAL DECISION-MAKING IN EVERY DAY LIFE**

I cannot imagine such an interview taking place at the time when I was born. Any sensible woman of my mother's generation would have left the counseling session laughing or becoming angry at this kind of probabilistic soothsaying [stochastic divining]. It is only in my generation that we developed the ability to think, --- even "feel" --- ourselves in terms of a system, face the future with risk figures and open ourselves to informational flows.

When I looked at Mrs. G. whose answers I was recording, I could see that she too, in the year 2000 was flabbergasted. But the three lessons about genes imparted to her by the counselor obscured the fact that the geneticist did not - and cannot - say anything about what actually will happen. All he can specify on is what might happen, and place the "might" into a statistical frame. All he can do is to list abstract possibilities and their probability of occurrence.

It is one thing that he knows, but quite another that he suggests, convincingly, and powerfully. He infects his client with the belief that there are such things as genes and that these genes determine her fate. By this, he prepared Mrs. G. to take the probability figures as measures for her own personal threat. It seems as if risk calculations would mirror Mrs. G.'s physical and mental constitution. Gene faith works as glue between abstract risk figures and concrete persons. "Genes" pretend to give an answer to the questions probability calculations have to leave open: Whom will it affect, how and why. Now it's supposed to be genes that cause diseases: "Risk" then seems to be the measure of an existing "error", the threat you pose to yourself by being yourself. Apparently, statistical figures refer to the present person. Probability figures look as if they would not come from

the computer but would correspond to biological events. By projecting genes into the invisible depth of the biological microcosm, risk figures are anchored in your own body in a powerful way.

I see genetic counseling as a mirror for a society that believes in the possibility of seizing the future. No matter if it is the office chair that hurts your back or your grandma with a lump in her breast; no matter if it is the vice of sipping or the child refusing to go to school - the present is reduced to a variable in a risk calculation. Because probability calculus links what is now with what might be tomorrow, the eye is fixed on future possibilities. An army of new helpers drums this fixed stare in front into their fellow citizens. To be put off and mobilized by a list of future possibilities they sell as "informed decision making". Genetic counseling is only a very blatant example for this new kind of organized risk enslavement.