

Präimplantationsdiagnostik und Pränataldiagnostik — Ethische Aspekte

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Hämatologie heute 18.-20.04.2013
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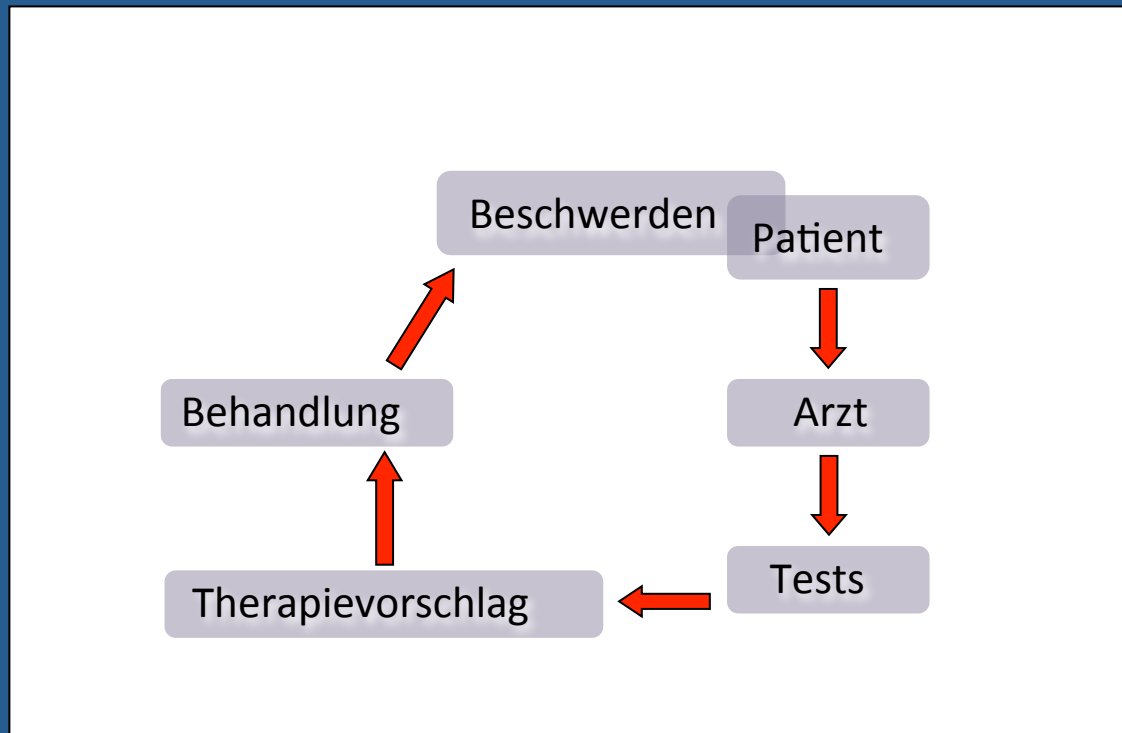


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1. **Ärztliche Handlungslogiken**
2. **Krankheiten heilen als Argument der PID/PND**
3. **Selektion: Is a new eugenics afoot?**
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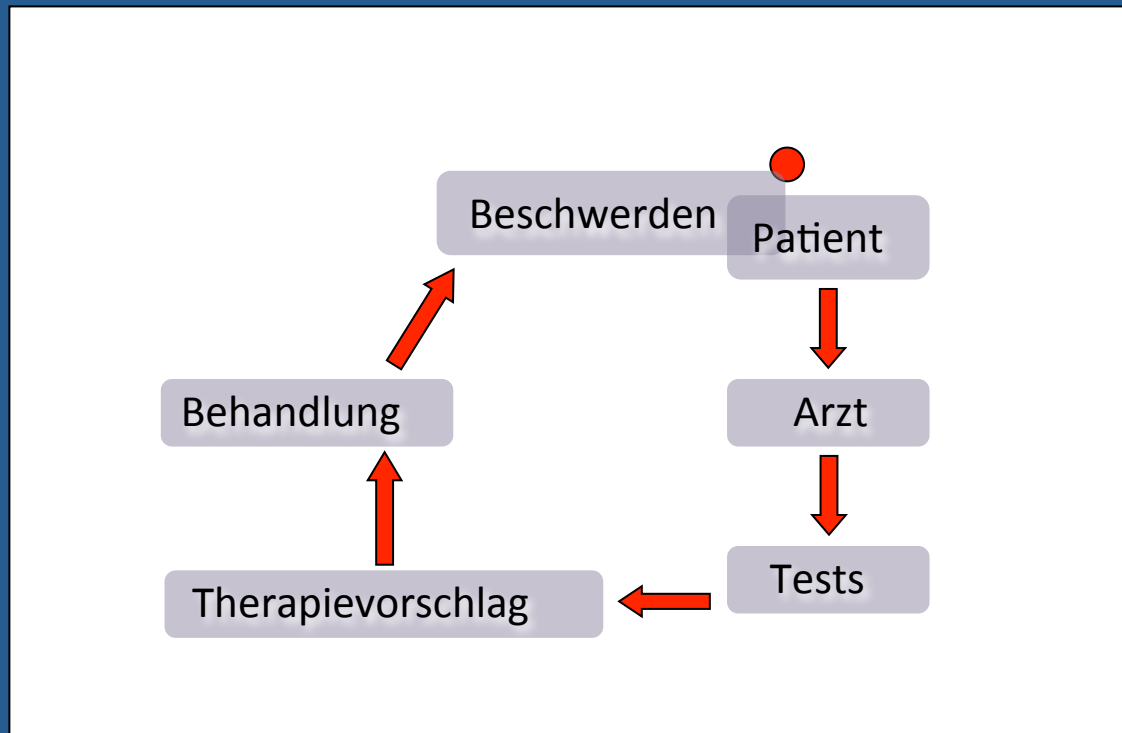


Der “klassische” diagnostisch- therapeutische Zirkel



Nach Paul 2001

Der “klassische” diagnostisch- therapeutische Zirkel

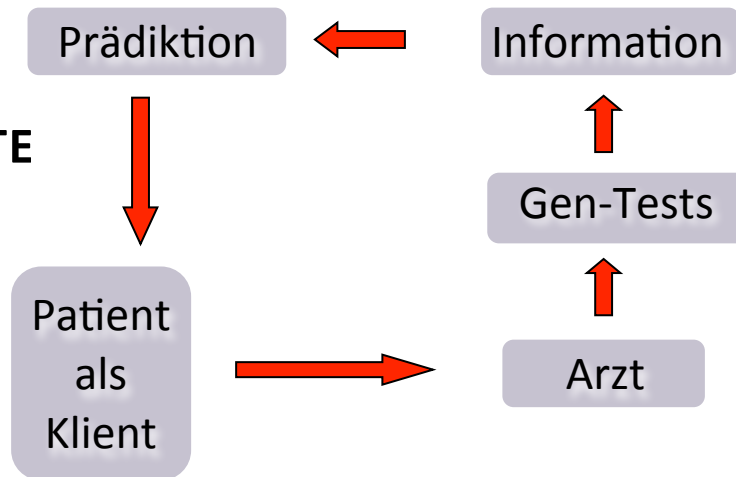


Nach Paul 2001

Prädiktive Molekulare Medizin-Genetische Tests



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Konsequenzen

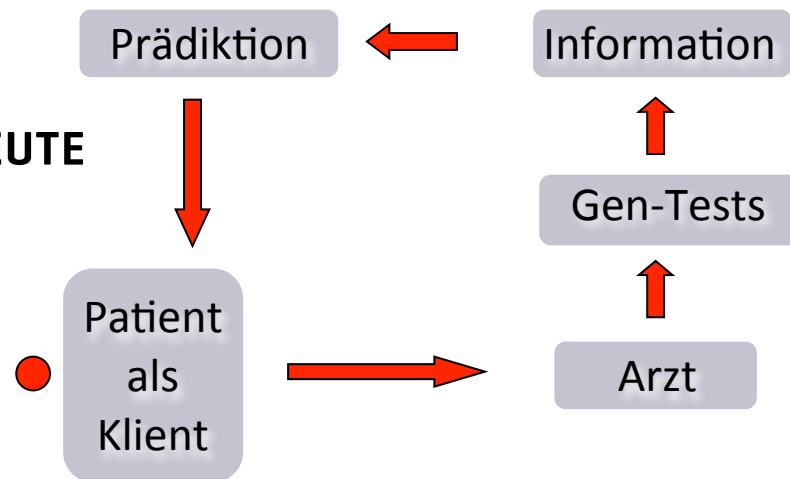
...Unausweichlichkeit (**ggfs. keine Therapie, keine Prophylaxe**)
 Langfristige Lebensänderung (prädiktiv – präsymptomatisch)
 (Verlust an Autonomie ohne die Privilegien des Krankseins)
 Erbllichkeit...
 (Familie, Familienplanung)

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“Krankheiten heilen” als Argument

Argumentationsgang:

- Krankheiten verursachen Leid
 - Es gibt eine moralische Pflicht für Ärzte, dieses Leid zu lindern/beheben
 - Wenn Mediziner/Forscher nicht dem Gebot der Heilung folgen, auch wenn es möglich wäre, dann handeln sie unmoralisch
-
- PID und PND bieten das Potential zur Linderung oder Heilung
 - Gegenüber diesen Heilungschancen ist die Zerstörung menschlicher Embryonen/Feten als moralisch nachrangig zu bewerten



Nach Badura-Lotter

“Krankheiten heilen” als Argument

- Beseitigt werden soll nicht primär die Krankheit, sondern das durch sie verursachte Leid
- Leid wird nicht nur durch körperliche Schmerzen erzeugt sondern auch durch
 - Einschränkung oder Verlust der Handlungsfähigkeit
 - gesteigerte Abhängigkeit von sozialer Zuwendung

PID / PND und Diagnostik ohne Therapie

- **Selektion contra Würde**

Hanna Arendt: „Unverfügbarkeit des Anfangs“

Habermas: „... selber den Anfang für eine neue Handlungskette setzen...“

Recht auf Identität

Anerkennung und Selbstkonstitution

- **Problem der Risikoabschätzung**

- **PID: „positive Selektion“ vs. PND: „negative Selektion“**



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The "slippery slope"?

What is immoral about eugenics?

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It is a "given" in discussions of genetic engineering that no sensible person can be in favour of eugenics. The main reason for this presumption is that so much horror, misery, and mayhem have been carried out in the name of eugenics in the 20th century that no person with any moral sense could think otherwise.¹⁻³ In fact, the abysmal history of murder and sterilisation undertaken in the name of race hygiene and the "improvement" of the human species again and again in this century is so overpowering that the risk of recurrence, sliding down what has proved time and time again to be an extremely slick, slippery slope, does seem enough to bring all ethical argument in favour of eugenics to an end.

Summary points

The horrible abuses committed in the name of eugenics through coercive policies imposed by governments have obscured the fact that eugenic goals can be the subject of choice as well as coercion.

In the rush to map the human genome and reap the benefits of new genetic knowledge it has become commonplace to argue that eugenic goals will play no part in how new genetic knowledge is used.

The moral case against voluntary choices to advance eugenic goals by individuals or couples has not been persuasively made.

Given the power and authority granted to parents to seek to improve or better their children by environmental interventions, at least some forms of genetic selection or alteration seem equally ethically defensible if they are undertaken freely and do not disempower or disadvantage children.

However, before dismissing any favourable stance towards eugenics it is important to distinguish what has happened in the past under the banner of eugenics and what might happen in the future. It is important to distinguish between genetic changes undertaken with respect to improving a group of population and genetic change that takes a single individual as its focus.

Efforts to change the genetic makeup of a group or population almost always require third parties to be involved in the personal reproductive choices of individuals and couples. Someone besides the individuals making children has to set a policy and a standard. In our century these efforts have almost always incorporated force or coercion since individuals may not agree with the policy or third parties may seek to force their vision of improvement on an unwilling population.

It is, however, a different matter for couples to undertake their own efforts to use genetic technologies and knowledge to improve the potential of their offspring. Eugenics has not, until the advent of genetic engineering, offered this option. Efforts to change the inherited genetic makeup of a particular person may be the result of third party involvement, but it is far more likely that such efforts will be the result of individual reproductive choice.⁴ To put the point another way, population eugenics involves commanding people to produce desired genotypic or

phenotypic traits. This sort of eugenics is not the sanctioning an individual or couple voluntarily to choose a new trait in their sperm, egg, embryo, or fetus, motivated by what is good or desirable.

The most common arguments against any attempt to avoid a trait through germline genetic engineering of more children with desired traits fall into three categories: worries about the presence of force or coercion, the use of arbitrary standards of perfection,⁵ or inequities arise from allowing the practice of eugenic choices. Worry is not one that seems insurmountable as an ethical argument. Individual choice about germline changes. This may also discount eugenic choices.

Coercion

Certainly it is morally objectionable for governments or any third party to compel or coerce reproductive behaviour.⁶ The right to reproduce with freedom from third parties is one of the fundamental freedoms of ethical traditions. However, the goals of obtaining avoiding disease, or pursuing health with respect to need not involve coercion or force.

A couple may wish to have a baby who has no risk of Tay-Sachs disease or transmitting sickle cell. If they may want a child with a particular hair colour or choice is free and informed then there is no reason why such a choice is immoral on grounds of force or coercion.

The subjectivity of perfection

Some who find the pursuit of perfect children objectionable worry about more than coercion. They are simply not clear which traits or attributes are perceived as perfect or optimal. The decision about whether behaviour is good or healthy depends on the culture, and circumstances that a child will face. The prejudice need not be the inevitable result of choice.

Views about what is perfect or desirable in a human are, more often than not, matters of taste, culture, and experience. But they are not always simply the subjective feelings. There are certain traits—physical strength, speed, mathematical ability, docility, or vision, to name only a few—that are related to health that command universal assent as to their desirability.



Is a New Eugenics Afoot?

SCIENCE'S COMPASS • ESSAY
ESSAYS ON SCIENCE AND SOCIETY

The April 1998 issue of *Life* magazine ran a cover story, complete with a double-helix spanning the length of the page, boldly titled "Were You Born That Way?" The subtitle left no doubt about the answer: "Personality, temperament, even life choices. New studies show it's mostly in your genes."

Life was not alone in promoting such claims. In the past 15 years, *Atlantic Monthly*, *New Republic*, *U.S. News* and *World Report*, *Time*, and *Newsweek*, to mention a few, have all carried coverage of the contribution of genetic factors to human behavior. Coat-tailing in genetic biotechnology's portrayal genetics as the "et" of biomedical science is one of our recurrent themes. The implication is that these genes are a result of the defective individuals or even racial. If aggressive or violent genes, so the argument goes, the argument lies in biomedical therapy in the distant past.

well-born," and referred to a plan to encourage the "best people" in society to have more children (positive eugenics) and to discourage or prevent the "worst elements" of society from having many, if any, children (negative eugenics). Eugenics became solidified into a movement in various countries throughout the world in the first three decades of the 20th century, but nowhere more solidly than in the United States and after World War I, in Germany. In most cases, although not all (France and some Latin American countries were notable exceptions), eugenicists' views were based on the theory of heredity first published by Gregor Mendel in 1866, but not fully appreciated until after 1900.

Given the wide variety of theories of heredity in vogue by the end of the 19th century, biologists were excited to find a single theory of inheritance that seemed to apply across the entire living world from peas to human beings. The most attractive feature of Mendelian genetics was that it was particularly experimental, and quantitative. Early Mendelian geneticists adhered to the unit-character hypothesis, that is, they believed that each trait is governed by a single gene (and its alleles). By the 1920s, the majority of laboratory geneticists recognized that most traits are produced by the interaction of several sets of genes. But this nuance was lost on most eugenicists, who continued to believe in "strong heredity," that is, a direct relationship between the presence of a hereditary determinant (now called the genotype) and the production of a relatively invariant adult trait (the phenotype).

By 1910, several human traits—such as red-green color-blindness, the A-B-O blood groups, hemophilia, and certain varieties of eye color—were found to be inherited in a basically Mendelian fashion. But eugenicists were more interested in the inheritance of social behaviors, intelligence, and personality. Proponents of eugenics carried out elaborate research programs to determine the type of inheritance these traits exhibited (dominant, recessive, incompletely dominant, sex-linked, etc.).

Eugenicists attempted to analyze the inheritance of traits by using correlation studies between relatives and family pedigree charts. The basic assumption was that



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if a trait recurred in families over several generations, it must be genetic. For example, the American eugenicist Charles B. Davenport, director of the Station for Experimental Evolution and the Eugenics Record Office at Cold Spring Harbor, Long Island, New York, constructed elaborate pedigrees for Huntington's chorea, albinism, epilepsy, feeble-mindedness, and thalassemia or "love of the sea" (which he found to be a Mendelian sex-linked recessive, especially prominent in the families of naval officers). Harry H. Laughlin, superintendent of the Eugenics Record Office, studied the inheritance of criminality, feeble-mindedness, and many other deleterious traits in different ethnic and racial groups. He concluded that eastern Europeans, Mediterraneans, and Russian Jews, among others, harbored a large number of defective genes in their populations. Such studies, sprinkled with anecdotes, formed the backbone of eugenic "science."

American eugenicists also strove to disseminate the results of eugenic research to the public and to lawmakers. They supported the idea of positive eugenics, but focused most of their energies on negative eugenics. Eugenicists wrote hundreds of

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„Positive“ und „negative“ Eugenik

„Positive“ Eugenik:
Förderung der Vermehrung günstiger Anlagen

„Negative“ Eugenik:
Verhinderung der Vermehrung ungünstiger Anlagen



Gruppe Arbeitsloser vor der Wall Street, denen
Eugeniker Schilder zum Halten gegeben haben
ca. 1920





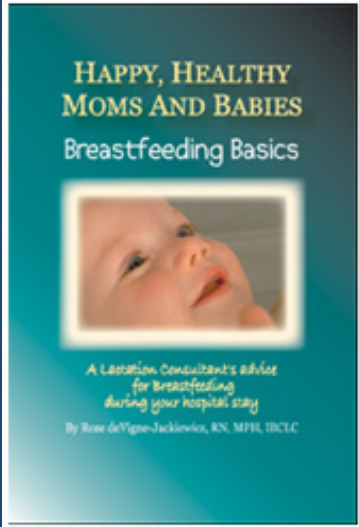
Nach 1945



Healthy Start:
Begin Before Baby's Born



Karriere - Gesunde Mutter,
erfolgreiches Kind
Kinder von gesunden
Schwangeren haben später
bessere Karrierechancen



- **Krankheiten heilen**
- **Im besten Interesse von „wem“? Paare/Frauen/Kinder?**
- **„Natalität“ – Unverfügbarkeit des Anfangs**

**„... selber den Anfang für neue Handlungsketten
setzen ... können“ (Habermas 2001)**

- **Mehr Forschung zu „klassischen“ Therapien?**

