

# **Ansvarsetik, videnskab og eksistens - etiske aspekter af genetisk testning og genetisk rådgivning i forhold til bioetik- kens rolle i den 'post-normale' videnskab**

En normativ-etisk undersøgelse af ansvarets teori og en undersøgelse af, hvorledes ansvaret har plads på forskellige niveauer i praksis, når genetiske test sættes i brug. De tre synsvinkler hvorunder den hermeneutiske undersøgelse af ansvarsteorien anskues er: testpersonens perspektiv, klinikerens praksis samt videnskaben i en videnskabsteoretisk kontekst.

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# English Summary

## **Ethics of responsibility, science and existence – ethical aspects of genetic testing and genetic counselling in relation to the role of bioethics in ‘post-normal’ science**

### **Introduction**

Responsibility as a core ethical concept is the main theoretical focus of the dissertation. The concept has become one of the central ethical concepts, also in the context of science and technology. The main research question is *What is an ethics of responsibility? How do main factors influence genetic testing and genetic counselling? What is the role of Bioethics in the light of responsibility, when science is post-normal science?* And the question is seen as inseparable from certain considerations about epistemology, ontology, subjectivity and inter-subjectivity. The question is answered in part I through a systematic reading of three theoreticians to whom the concept of responsibility plays a role in their general philosophy, and in particular for their ethics: Jean-Paul Sartre, K.E. Løgstrup and Hans Jonas. For all of them, ethics is integrated into their epistemology and their interpretation of the concepts of subjectivity, inter-subjectivity and a few ontological-ethical terms of importance: The normative importance of non-knowledge/‘ignorance’, future, freedom and determinism. Because of the hermeneutic nature of the investigation into responsibility with the methodological demand for application in order to reach and understanding, and because of the bioethical frame of the project, the particular understanding of responsibility is interpreted through the praxis of genetic testing and counselling in part II. The phenomenological analysis calls for the first-

person perspective, which for the perspective of the 'client' is thoroughly described through the basis of two studies, of quantitative and qualitative nature. These illustrate subjective and inter-subjective aspects of responsibility. The clinician's perspective is primarily analysed through a description of the area of specialisation, examples from consultations and discussions of the concepts of autonomy and non-directive counselling. In part III a more general account of modern science is attempted. There are trends in philosophy of science attempting to establish different diagnoses of modern science, such as post-academic science, post-normal science and knowledge production as being in a 'mode 2'. All these attempts to describe science provide a new possibility for integrating normative elements in science. It is possible to interpret them as trends that can correlate with normative elements from an ethics of responsibility: The importance of the subject is acknowledged inter-subjective essentials along with ontological-ethical elements are elucidated in the descriptions, such as the importance of acknowledging ignorance and the difficulty of separating descriptive and normative.

## **Method**

The dissertation understands itself in the hermeneutic tradition of interpretations of texts, and the importance of the hermeneutic circle between part and whole: Ideas of responsibility are seen as theoretical phenomena *and* in practical examples: Application is a necessary element of understanding. The 'methodological hermeneutics' is as such an inspiration, but more radically the dissertation understands itself in the line of the philosophical hermeneutics, where interpretation is seen as the basics of what it means to be human. With the further development of this philosophical hermeneutic in inspiration from its views on the relationship between descriptive and

normative: The human being is also seen as basically responsible in its inter-subjective relations. However, the main theoreticians are all from the phenomenological tradition, though they all combine their view with something else: Existentialism, ethics, theology they still insist on important phenomenological aspects such as: The importance of first-person perspective, experience as bodily experience, inter-subjectivity as a basic challenge to the subject, the perception of the world as a negation of being and the subject who is also an object for technology. Even though the dissertation itself does not provide phenomenological descriptions, it draws on the main theoreticians' phenomenological insights as indispensable.

## **Part I**

### **Theories of Responsibility**

**Jean-Paul Sartre's** phenomenology from *Being and Nothingness* is an account of the subject as a consciousness that perceives 'being' by *negating* the perceived, and who perceives as a bodily existence between other bodily existences; the body is subjectively experienced and objectively observed. The existentialist philosophy of Sartre depicts the individual with a focus on 'choice' as a formative concept, which is a necessity for the individual facing contingency. Choosing is an activity in anxiety and insecurity, since there are no objective standards to be found or to be met. Not acknowledging this uncertainty and seeking false certainty is called 'living in bad faith'. There are two different modes of being in order to describe being-for-itself and being-for-others. *Nausea* is the early Sartre's narrative description and bodily reaction to the realisation of contingency. Also in fiction, in one of the plays, we find Sartre's famous dictum about inter-subjectivity: *Hell is other people*.

This statement is formative for the general understanding of ethics in Sartre's philosophical authorship – and the claim in this dissertation is that freedom and thereby also ethics is central in the reading of Sartre. However, an ethical reading of Sartre can follow different leads, particularly in connection to the perception of breaches in the line of the authorship. Regardless, there are elements of a conflicting relationship, a situational ethics in appeal-help relations, reification and sub summation of the other and traces of a positive ethics. The early Sartre is more pessimistic with regard to the possibility of an ethics, whereas the Sartre of *Existentialism is a Humanism* is more optimistic, and it is in this book we find the formulations concerning the concept of responsibility. Every individual is responsible for all its actions – and the responsibility for ones choice is a representative responsibility: Choice represents setting of value for all of mankind as a universalistic idea. Sartre's main example is a young man who seeks his advice. The young man expects guidance from philosophical or ethical theory, but Sartre does not provide any specific advice on preference between two possible actions, but instead he emphasises in his answer the *freedom* of the other to choose for himself. Freedom includes responsibility for action – and for choice of advisor! The human being is condemned to freedom.

For the bioethical context, Sartre's philosophical analysis of the relationship between subjectivity and ethics contains valuable insights concerning the importance of experience, the bodily character of experience, the agony of choice, scientific knowledge as a quest and as bad faith, anxiety and uncertainty as the basis for choice, which are all concepts that can be used for interpreting human life in light of natural sciences, and that particularly can shed light on the practice of genetic testing

and genetic counselling. Existential freedom as interpretative tool toward for example genetic destiny is also an important insight to be gained from Sartre. However, the problem of inter-subjectivity remains an unsatisfactorily solved phenomenon in Sartre's works.

**K.E. Løgstrup** also belongs to the phenomenological tradition of philosophy and he regards the subject's first-person perspective as an inevitable starting place for experience, intentionality and choice and his concept of the individual in some respects also reflect the existentialist lonely, constrained, choosing and interpreting being. However, inter-subjectivity plays an even greater role for Løgstrup than for Sartre, since his main philosophical insight is also a normative idea: The very fact that people surround and influence other human beings calls for what he calls *The Ethical Demand*. People are forced to co-exist with each other – and they cannot escape coexistence. Løgstrup's underlying phenomenon characterising the relationship is *Trust*, and the metaphor by which he describes interaction between people is 'the hand': Interaction between human being is *holding a little piece of the existence of the other in one's hand*. Løgstrup is not naive in regard to the thinking that people always take proper care of each other, or that they always act in accordance with ethical rules, but his characterisation concerns the fact that people are always under an obligation, and they can try to live up to it or fail to do so – this does not influence the characterisation of the human being as 'a responsible existence'. The concept of responsibility is not universally interpreted in Løgstrup, who is specifically critical towards the ethics of Immanuel Kant and his categorical imperative. However, the responsibility is radical in the sense that the individual is isolated in the ethical decision-making even though it is forced upon the individual by the other – and

the demand is silent in the sense that there are no direct recommendations of behaviour. The meeting with the other takes place in natural trust that is revealed in for example communication, where all communication is seen as opening up to the other: We are the destiny of each other but often enough we ignore this! Every specific situation calls for an interpretation of how actions can be to the benefit of the other. Obedience to the demand can only be performed in unselfishness. This understanding of inter-subjectivity as an ethical relationship is in danger of being abused as a power relation: There is a responsibility towards the other, but it is still necessary to respect the freedom of the other and not assume the responsibility of the other – in a violent action against the other.

The relationship between people is also regulated by norms and rules that reflect the ethical demand, but is historically shaped and can change. It makes co-existence easier to have rules and to act according to the norms; since this makes it unnecessary to make an actual interpretation of the situation every time to seek what is best for the other. Rules and regulations protect us from each other. However, it can be necessary to break the norms in order to act according to the ethical demand. The norms also reflect the fact that the interpretation of the ethical demand changes in time: Politics in the shape of democracy is one example, but another could be that love or affection does not necessarily take the shape of monogamous marriage, but there are other forms of existence for love where the other can be respected as loved and as other. However, even though the ethical demand and the interpretation hereof can change, it can never be interpreted so that it abuses the other and makes him or her 'means to my own goals'. Determinism plays a role in Løgstrup's ethics because he does not believe that the human being is free in the way Sartre does.

Nevertheless, his understanding of responsibility is just as strong. To Løgstrup, however, life is inseparable from a created order. The *frame* of life is given and ‘free choice’ and ‘free will’ are illusions as independent phenomena. The human being is determined to fail in most situations and is determined by historical factors. In a sense it is also determined to be responsible. This definition of the human being and the fact that no human being can seek true answers or specific rules that can be followed that suspend the demand to interpret the situation in order to find what is best for the other makes Løgstrup state there is no Christian ethics, only his own humanistic version – that of course is inspired by the Judeo-Christian tradition, and takes Jesus of Nazareth as a main example of someone who interprets and live according to the ethical demand.

For the bioethical context Løgstrup’s discussion of the way humans are dependent on each other and thereby the importance of inter-subjectivity for the constitution of the subject and of ethics: choice, interpretation and trust is of use in the context of genetics, with regard to both the clinical situation of genetic testing: the meeting between the client and clinicians. But it also illuminates the understanding of the perspective of the client – and the relationship to the biologically related family. Genetics as dependence of the other – and as obligation – makes Løgstrup’s metaphor of ‘the holding of a piece of the other’ take on a whole new dimension. Some reservations towards the concept of biology and also of scientific knowledge is necessary. There is no ethics springing from the knowledge of scientific facts, however, there is no absolute boundaries between the descriptive and the normative level.

**Hans Jonas** is, on the international scene, the theoretician in this dissertation who has brought the philosophical concept of responsibility into the ethical debate, and has had most influence on bioethics, especially environmental ethics. The focus on the subject is moved towards more metaphysical themes in the ethics of Jonas in his main ethical work *The Imperative of Responsibility – an ethics for the age of technology*. He is originally from the phenomenological philosophical environments in Germany and he still acknowledges the importance of the first-person perspective and the bodily character of experience, but his metaphysical inclinations lead him further on. The human being is subject for technology, but to a large extent it has also made itself the object of technology. Homo faber is the proper characterisation of the human being rather than homo sapiens.

With regard to responsibility as the main ethical concept, Jonas argues that technology today has changed the situation for ethics and left an ethical vacuum. Power has increased tremendously because of the increasing possibility to influence the future. Precisely this future, and the beings that are to live in this future, is the most important issue for the ethics of Hans Jonas. He criticises all former kinds of ethics, the ethics of antiquity for having too narrow a scope for example geographically, and the ethics of Immanuel Kant for not securing the continued existence of the human being in the future, and not considering the future as such. Jonas reformulates the categorical imperative: *act so that the effects of your actions are compatible with the permanence of genuine human life*. The ethics of Jonas is thus concerned with the human being, but tries to go beyond an anthropocentric conception of ethics by including the interest of others too. However, the human being as the key ethical actor is still thought as necessary.

Scientific knowledge is of great importance in ethical decision-making, and Hans Jonas advocates thorough investigations into comparative futurology. Here, he argues that the bad prognosis must precede the good prognosis so that no unnecessary risk is taken. Knowledge calls for humility – and calls for acknowledging the ethical importance of ignorance. If we have taken the first step, technology has a certain *tyranny* that forces the following step upon us. The vulnerability of human existence and of nature gives us a great power over it, and thus great responsibility – as Løgstrup also formulates it. Jonas' archetype of responsibility is the infant whose cry calls for the care of other. As such, there is no absolute boundary between descriptive and normative. Both the parental responsibility and the political responsibility has this character of power over the other – in respect for the freedom of the other and respects for the future that is theirs.

Bioethically, Hans Jonas' focus on the way technology has changed ethics makes him the primary ethics of science theoretician. However, his dictum of the ethical importance of ignorance and the responsibility for the other has primarily been used in the environmental sciences, but also in medical ethics and genetics.

Within **analytic philosophy** we find the systematic discussion of the challenges to the moral responsibility in the form of determinism and the lack of free will – and here trends from this type of philosophy is represented as a **deterministic and reductionist objection to responsibility** presented by the Danish philosopher Kasper Lippert-Rasmussen, along with a presentation of and the context and challenges internally as it is seen in the discussion between P.F. Strawson and Galen

Strawson. The objection to moral responsibility takes its point of departure in a strict definition of the constitution of the 'moral agent': A creature is morally responsible for a certain incident, only if this creature has a will and the ability to let it be guided by moral considerations, and that the incident is *relevantly* connected to the creature's enacting its will (and is in full control of its will). As such, autonomy and free will becomes key concepts – and in a sense the approach takes the opposite starting point by trying to define what standards a creature 'must live up to' in order to meet the criteria for holding responsibility. The other theoreticians infer from their general philosophical or epistemological accounts that persons are responsible beings, and responsibility becomes part of what it is to be human. This would be concluding from the 'natural inclination towards free will', is one of the arguments from the determinist! However, being a determinist, hard or soft (Løgstrup would qualify as a soft determinist), does not in itself lead to a rejection of the possibility of moral responsibility, since there is a choice between being a compatibilist or a non-compatibilist: What can or cannot be compatible concepts are freedom and responsibility. As a central discussion of whether or not it is possible to be responsible is whether or not there is, in the particular situation, *a possibility of alternative actions*. Also, there is a discussion of whether or not a person is responsible when the action in question is not in accordance with this person's true self, identity or values.

Within this tradition and way of discussing moral responsibility there is a discussion of the credibility of both the deterministic and the (soft) determinist position. There are no knock-down arguments for either position, but both find the other untrustworthy! The determinist argues that it is much more convincing that responsibility is an illusion along with free

will since it is quite hard to argue that very many people or very many situations meet the criteria for having moral responsibility – or free will. The other position, defended by the one who argues for free will or (soft) determinism, argues that if the hard determinist rejects moral responsibility, he or she underestimates the importance of inter-subjectivity and what a so-called ‘objective attitude’ following from the lack of moral responsibility would mean in social interaction between people.

This determinist and reductionist discussion of responsibility is not applied in the bioethical context as the other theories of responsibility; however, it is included, because this discussion is closer to a classic scientific idea of how to discuss such ideas of ethics. The thesis in this dissertation is, however, that ethics is changing and science is changing, and as such there is room for the type of ethics of responsibility developed here with subjective and inter-subjective features.

## **Part II**

### **Genetic testing and genetic counselling as area for an ethics of responsibility: the perspective of the test-person and the perspective of the clinician**

There are different kinds of genetics test, but the focus here is on the pre-symptomatic testing of adults from the **perspective of the test person** (also called the client). The analysis is based on observations from two Danish studies of cancer genetic counselling which have both been successfully defended as PhD dissertations: A quantitative survey by Ellen M. Mikkelsen and a qualitative interview study by Mette Nordahl Svendsen. There is great difference in methodology between the two studies, even though they both focus on the first per-

son perspective. In the qualitative study there is far greater focus on inter-subjectivity and the problems of studying science and the ethical aspects hereof, particularly from a phenomenological and hermeneutic standpoint. The quantitative study, however, has a much larger empirical basis, and it lives up to other standards and is easier to compare with other empirically founded, international studies of the effects of cancer genetic counselling.

The first and largest study of clients in genetic counselling by Ellen Mikkelsen is a study of women in counselling for breast and ovarian cancer – compared to two other groups of women: one group awaiting mammography and one reference group randomly selected from the general population. The timescale was 12 months and in this period the women were asked to answer three times, using self-reported questionnaires based on different predefined scales to measure anxiety and depression. The general aim of the project is to learn about the effects of cancer genetic counselling, particularly with respect to depression and anxiety. There seems to be a small reduction of anxiety and no effects concerning depression. Also, it is concluded that there is a tendency to better remembrance of the particular individual's risk status if it is communicated in numbers as opposed to only in words.

As for the *qualitative* study by Mette Nordahl Svendsen, the interviews are conducted as conversations in the clinic and in the home of the clients of cancer genetic counselling, a multi-sited ethnology. She calls her dissertation *The Space in the Gap*, which describes very well how she illuminates and interprets the universe of the client as someone who balances between scientific information and other types of information and experience – and understands the 'gap' between the two con-

cepts as a 'space' in which to make decisions concerning life: to be tested or not, to contact relatives or not, to give in to anxiety or not. There are different rationalities at play and the subject is to a high degree constituted by the inter-subjective experiences with disease and death. And the biological and social relations are not always the same, so the actualisation of moral responsibility towards almost or completely unknown relatives, can give rise to new perspectives on the relative ethical concept of responsibility. Besides, the concept of a 'risk person' is interesting, because expert categories have a tendency to be formative for identity – but what is a risk person in a risk society that is different from Sartre's view of the individual? And what does it mean compared to Løgstrup's concept of how we are 'subjected or exposed to each other' in an inescapable way?

For the client genetic testing and genetic counselling is seen as a possible way of 'acting' – supported by the medical system – against a destiny that is otherwise determined and unavoidable. But with genetic testing and science there is a way to 'fight back'. As such, these practices are highly existential and ethical in the interpretation of life and action! The information often comes as a somewhat imprecise or estimated risk, in numbers or words, and the way the information is taken in can be seen in light of Sartre's discussion of bad faith, choice as constituted in anxiety and the existential freedom and responsibility to interpret one's own life and destiny. The interpretations receive inspiration from both the scientific and the experiential world: Risk calculation, memories, ideas of luck and the importance of age are combined in the 'space' where decision-making is thought to take place – even though the knowledge is characterised by 'gaps' and inconsistencies if viewed with a narrow conception of rationality based on causality.

Sartre's negating consciousness is a complementary understanding of perception along with his focus on the bodily character of experience. Responsibility issues are both in connection to biological relatives in the entire family across generations, spouses, children and unborn children. The social activity of 'kinning' is what connects the biological and the social relations. Even though there is a discussion of biological responsibility, this is also constituted by the discussions of the importance of inter-subjectivity.

The **clinician's perspective** is approached by describing by the professional meeting of client and clinician where a process of communication takes place. Both presymptomatic testing of adults and prenatal testing are types of tests that are prevailing in the discussion. Genetic counselling is normatively justified as a practice that has as its aim to secure persons and families with genetic handicaps or diseases optimal lives and to ensure risk persons options for action. The practice of the genetic counsellor is non-directive in order to ensure patient autonomy and informed decision-making. However, there is a tendency in the field to acknowledge the term shared decision-making as guiding. Nondirective counselling is often pragmatically defined as the withholding of direct recommendations. Through discussions of when the counsellor actually can be said to be directive and what the expectations of the clients are, the concepts are shown to be vague and problematical. Often the discussion centers on the answer to the question: *And what would you do in my situation, doctor?* Instead of discussing whether or not this question should be answered it is more interesting to discuss how different answers can help the client to his or her decision and how the clinician can be empathic, and do counselling instead of 'teaching'. For this discussion, Seymour Kessler's models are presented for how to

counsel in accordance with different ideals: Teaching and counselling, respectively. Through different examples of dialogue, it is discussed how Sartre's ideas of the subject and ethical issues of responsibility are handled. The traditional bioethical concept of autonomy is criticised for having a rationalistic and isolationistic account of the individual.

### **Part III**

#### **Bioethics and philosophy of science: Philosophy of science as connecting link between ethics and science**

Ethics of responsibility can be said to correspond with the newer descriptions of the philosophy of science. Bioethics can gain from a more thorough knowledge of the developments in philosophy of science, since bioethics is concerned with science and technology, and since both of these concepts are under development. Particularly, the research environments of History and Philosophy of Science (HPS) and Science and Technology Studies (STS) and Sociology of Scientific Knowledge (SSK) are of inspiration. The concept of responsibility has become important in the sociological literature, here exemplified by Anthony Giddens. He connects his account of science and society as both being concerned with 'risk' and not claiming certainty with the account of the new freedom in what he calls the 'end of tradition and the end of nature'. Scientific scandals are described in terms of risk. The use of science is a quest for control from the politicians' side – in their attempt to avoid both scare campaigns and cover-ups. In this case, there is a focus on responsibility in the handling of scientific knowledge and in the search for responsible persons.

In the classical theories of science with the ideal of objectivity, there is a limited place for ethics, and in the most positivistic understandings an even hostile attitude towards the idea of

values in science. However, both in the theories of Thomas Kuhn with his idea of 'normal science' and in the study from Robert King Merton and his development of the CUDOS-norms there is a new place for normativity. The theories presented in part III all have some kind of relationship to either of the two thinkers.

John Ziman presents in the framework of his post-academic science his idea of **PLACE** normativity as an alternative to CUDOS – a contemporary attempt to characterise the scientific practice. Ziman gives a naturalistic account of science with recognition of cultural and individuals, which gives a less sharp portrait of science with more modesty but still with passion for the past and the future.

The philosophers Funtowitz and Ravetz present their concept of **post-normal science** in as a further development of the Kuhnian 'normal science', which is described as puzzle-solving. In the post-normal science the challenges to science cannot be solved within a normal scientific paradigm. They describe the situation as the following: *facts are uncertain, values at dispute, stakes high, and decisions urgent*. Risk and insecurity must be handled, but cannot be solved. They focus on the two factors: systems uncertainty and decision stakes. In post-normal science a more humanistic approach is needed, because traditional scientific accounts cannot solve the problems. Decisions are to be made with a reverse ideal of problem-solving: *Hard decisions are made on soft facts*. Questions concerning environmental issues are often seen as cases: Mad cow disease in the UK for example. Core science, applied science, professional consultancy and post-normal science have an increasing degree of decisions stakes and systems uncertainty.

Their problem-solving strategies are also different, which is of importance for the understanding of ethical aspects.

**Mode 2 knowledge production** is a concept developed by six authors and is an attempt to diagnose the situation of science today. Knowledge production is said to have moved from a mode 1 to a mode 2: *The old paradigm of scientific discovery ('mode 1') – characterised by the hegemony of theoretical or, at any rate, experimental science; by an internally driven taxonomy of disciplines; and by the autonomy of scientists and their host institutions, the universities – was being superseded by a new paradigm of knowledge production ('mode 2'), which was socially distributed, application oriented, trans-disciplinary, and subject to multiple accountabilities.* The new situation may not be entirely new, however, the authors argue that there are significant tendencies that have changes science: The importance of contexts of application, the degree of trans-disciplinarity, diversity in knowledge production, high degree of reflexivity, new forms of quality control. Most of these trends have to do with the intensified relationship between science and society. This relationship is analysed further by three of the authors Helga Nowotny, Peter Scott, Michael Gibbons in the second book *The new production of knowledge: the dynamics of Science and Research in Contemporary Societies*, where the main new concept is the *Agora*. This term is the Greek word for market place and is an illustration of the necessary interaction between science and society – which is not a pollution of pure scientific ideals of objectivity, but rather a liberation from this constraining idea that can further scientific creativity and provide the appropriate space for the normative evaluation and implicit normative elements can be made explicit. Science has become more complex, but the context is in a way also acting back and refusing to be tamed by scientific methods and be reduced to fit into

the laboratory. As such the old scientific norms are in a crisis and scientific action must find new norms and acknowledge and communicate that it is not only mode 1 and only positivistic search for true knowledge, but also mode 2, with all its implications. This provides us with a new way of perceiving the role of 'the expert'. Expertise today is transgressive, collective and socially distributed.

All these characteristics are seen as a possibility of rethinking science, and this dissertation welcomes the possibility of the new room for ethics and bioethics. Of course, the ideas of these theories of science have been criticised, for example Peter Weingart's critique, that it is not new, not empirically sound, and instead just an example of a few scientific disciplines that have become politicised and politics having become scientified. However, the post-normal science and the new knowledge production seems to reveal elements of science that are trustworthy, here examples are discussed within the field of genetics: The Comparative Genomics Projects have mode 2-characteristica, the consensus conference on genetic testing arranged by Teknologi Rådet seems to be an example of characteristics such as socially robust knowledge and the new type of experts. Also the Medical Technology Assessment of genetic testing for specific cancers seems to seek the new normativity, however, failing in actual performance due to lack of knowledge of normative methodology. These three examples are seen as illustrations of an ethics of responsibility.