

stipulates this as a condition to giving his consent to an operation or treatment."¹⁸¹ He states that full diagnostic disclosure should also be given where the information is material to the patient's decision to undergo or refuse treatment.¹⁸²

12. Genetic counselling

Closely related to and often overlapping with the diagnostic disclosure of a physician is the informative task of the genetic counsellor. Clarke¹⁸³ describes genetic counselling as what follows when a person asks questions of a health professional (the genetic counsellor) about a medical condition or disease that is or may be genetic in origin. She indicates what proper genetic counselling should consist of by suggesting the following characteristics of a consultation with a client.¹⁸⁴

Firstly, a genetic counsellor should listen attentively to find out what the client's questions and concerns are. It is secondly important that the diagnosis of the individual should be confirmed or clarified and here it might be possible that calculations be made to ascertain the risk of possible recurrence of a disorder from knowledge of a family history and other genetic tests. The information requested by the clients should then be communicated to them in an understandable and appropriate manner. A further element of a geneticist's service should be scenario-based decision counselling, whereby clients are guided in thinking through and considering their individual responses to the various possible options. A final component of proper counselling is the provision of ongoing support to clients and their families.¹⁸⁵

Berry¹⁸⁶ submits that part of a geneticist's role is to work through the various decisions and reproductive options available to potential parents and try to sort out with them the best way forward.

¹⁸¹ *ibid.*

¹⁸² it is submitted that this would often be the case in wrongful life matters.

¹⁸³ 1994. **Genetic Counselling - Practice and Principles: Professional Ethics**
Routledge.

¹⁸⁴ she believes that the person seeking information should be referred to as a 'client' rather than a 'patient', as the former implies that the person is suffering from a disease and which is often not the case.

¹⁸⁵ especially relevant here is the instances where individuals are at risk of developing adult onset disorders - see *infra* where post-counselling support is discussed in more detail.

¹⁸⁶ *op cit* p 29.

Leenen¹⁸⁷ declares that the same principles regulating the general duty to inform is applicable in respect of genetic diagnosis/ counselling. According to Leenen, it has been established in Dutch law that a genetic counsellor should not only inform a client of all relevant aspects, but should also see to it that the client understands the gist of the disclosure.

Fain¹⁸⁸ believes that genetic counselling has increased in both scope and use, as this specialised science has developed over the years. She therefore suggests a new, more complete definition of genetic counselling, as:

“A multi-step process in which the genetic counsellor attempts to help the couple to:

- comprehend the medical facts, including the diagnosis, probable course of the disorder and the available management;
- appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives;
- understand the alternatives for dealing with the risk of recurrence;
- choose the course of action which seems to them appropriate in view of their risk, their family goals and their ethical and religious standards and to act in accordance with that decision;
- to make the best possible adjustment to the disorder in an affected family member and/ or risk of recurrence of that disorder.”¹⁸⁹

This holistic approach to genetic advice is to be recommend and it is suggested that these five steps be closely followed by physicians to ensure sufficient and thorough genetic counselling. This multi-step process of genetic counselling, as described by Fain, will in most instances make an educated decision possible for parents confronted with such a situation.

The criteria of the Council of Europe¹⁹⁰ set for the term “genetic tests for health care purposes” refers to a test which reserves:

- to diagnose and classify a genetic disease;

¹⁸⁷ *op cit* p 73.

¹⁸⁸ *op cit* p 616.

¹⁸⁹ *ibid.*

¹⁹⁰ Anon. 1994, - **Recommendation No. R (92) 3 of the Committee of Ministers to Member States on Genetic Testing and Screening for Health Care Purposes** (Adopted by the Committee of Ministers on 10 February 1992 at the 470th meeting of the Ministers' Deputies).

- to identify unaffected carriers of a defective gene in order to counsel them about the risk of affected children;
- to detect a serious genetic disease before the clinical onset of symptoms in order to increase the quality of life using secondary preventive measures and/ or to avoid giving birth to affected offspring
- to identify persons at risk of contracting a disease where both a defective gene and a correct lifestyle are important as causes of the disease.

With regard to general rules for good practice in genetic testing and screening, various principles were laid down by the Council.¹⁹¹ Concerning the quality of genetic services, the following were laid down:

- proper education should be provided regarding human genetics and genetic disorders, particularly for health professionals and the paramedical professions, but also for any other profession concerned;
- genetic tests may only be carried out under the responsibility of a duly qualified physician;
- it is desirable for centres where laboratory tests are performed to be approved by the state competent authority in the state, and to participate in an external quality assurance.¹⁹²

Gevers¹⁹³ agrees that quality genetic counselling should be provided and states that high levels of proficiency should be expected from counsellors, especially with regard to the communication of information.

Frets¹⁹⁴ has made a study of the problems experienced by patients who have to make reproductive decisions after receiving genetic counselling. The report on her findings reveal the following important aspects regarding their informed decisions:

In a follow-up study of 164 couples, an evaluation was made concerning reproductive decision-making 2-3 years after genetic counselling. The study revealed that 43% had problems making the reproductive decision and had experienced the decision-making process as difficult; had doubts about the decision they had made; or had been unable to make a decision.¹⁹⁵

¹⁹¹ Anon. 199, *op cit* p 113.

¹⁹² *ibid.*

¹⁹³ *op cit* p 10.

¹⁹⁴ 1990. The Reproductive Decision after Genetic Counselling. **Proefschrift - Erasmus Universiteit, Rotterdam, 75.**

¹⁹⁵ it is submitted that if nearly half of all patients find it difficult or impossible to make an informed decision after receiving proper genetic counselling, it would be an even more impossible task if no or insufficient counselling is given.

She¹⁹⁶ conveys that a logistic regression analysis revealed the following factors as independently and significantly associated with problems in the decision-making process: no post-counselling relief; anticipation of a high risk level; relatives' disapproval of decision; the decision not to have a(nother) child; and the presence of an affected child. An interesting finding revealed that 45% of the couples eligible for prenatal diagnosis who decided to have children experienced the decision-making process as difficult, against 23% of couples deciding to have children while prenatal diagnosis was not available. She suggests that a possible explanation for this result is that problems in the decision-making process might only become apparent *after* genetic counselling rather than in the course of it. To remedy this challenge, it is submitted that structured follow-up sessions¹⁹⁷ should occur 3-6 months after genetic counselling to identify couples that would benefit from additional supportive counselling.¹⁹⁸

12.1 Psychological impact of genetic diagnosis

It is possible that genetic counselling could place future parents in a state of emotional confusion.¹⁹⁹ Just being confronted with the possibility gives rise to anxiety and stress. The first spontaneous expectation on the part of the parents is to be reassured that their child is normal.²⁰⁰

There is a distinct difference between diagnostic tests and tests to evaluate the degree of risk involved, which should be made quite clear to the patients.²⁰¹ Psychological test on risk perception have shown that most people find it difficult to correctly understand chances and to deal with the associated level of uncertainty. The level of anxiety engendered by screening²⁰² can be further reinforced by lack of information or clarity in the interpretation of test results. A heightened risk does not necessarily imply that the unborn child actually has the disorder. It is therefore necessary to explore the consequences of informing people that they have a heightened risk.

¹⁹⁶ *ibid.*

¹⁹⁷ see duty to re-contact *infra*.

¹⁹⁸ indicating that a physician's duty to support and continually advise a patient should not stop after the initial consultation.

¹⁹⁹ see fn (3 below) *infra*.

²⁰⁰ Anon. 1994, *op cit* p 52.

²⁰¹ *ibid.*

²⁰² Anon. 1994, *op cit* p 53.

Frets²⁰³ reports that feelings of guilt²⁰⁴ played an important role in half of the couples confronted with a reproductive decision after receiving genetic counselling. She suggests that genetic counsellors should focus on understanding counselees' feelings, especially concerning: acceptance of apparently irrational considerations²⁰⁵ and support with/ understanding the role played by guilt towards parents or an affected sibling.

Gevers²⁰⁶ reports that the prevention of the birth of handicapped children, made possible by genetic testing, is a social issue. He suggests that there could be a conflict between the clients' right to self-determination and the interests of future children and asks whether the counsellor does not have a responsibility towards future children with a high risk of being born with serious birth defects, to convince the clients/ parents not to have any children. He answers that although such a view could have honourable motivations, the genetic counsellor may never allow his professional opinion to be superceded by personal norms and values.²⁰⁷

12.2 Time of diagnosis/ genetic counselling

12.2.1 Diagnosis prior to conception²⁰⁸

If people are aware of the risk at this stage, all possible courses of action regarding their offspring are still open. Genetic diagnosis also creates opportunities to discover, at an early stage, a susceptibility to disorders which occur later in life.²⁰⁹ That risk may perhaps be reduced by adapting their environmental factors and/ or lifestyle.

12.2.2 Prenatal diagnosis

Prenatal diagnosis could be not only in the interests of the parent(s), but also in the interest of

²⁰³ *op cit* p 90.

²⁰⁴ "Guilt feelings were more predominant in couples with an affected sibling than in those with an affected spouse." *ibid*.

²⁰⁵ as these feelings indicate the influence of unconscious motives.

²⁰⁶ *op cit* p 13.

²⁰⁷ see discussion *infra* on the influence of geneticists' subjective views on the procreative decision of patients.

²⁰⁸ Anon. 1994, *op cit* p 63.

²⁰⁹ there are some diseases (cystic fibrosis) where it is not yet possible to detect all carriers of the trait in question - in this context in particular, the importance of providing good information cannot be understated.

the unborn child.²¹⁰ Based on prior notice, the expectant parents can opt for any course of action, based on their personal views.

12.3 Excessive information

To further complicate the matter of correct information disclosure, a physician should be wary not to "over-inform" his patient, as excessive information hampers a rational decision, which is tantamount to no information at all.²¹¹ The question as to what sufficient information would be must be answered on a case-by-case analysis and it is suggested that the "reasonable medical practitioner" test should be applied.²¹² If a patient should ask to be fully informed concerning his medical condition, the physician's duty to disclose is extended and *full* information should be communicated.²¹³ The reason for this is the prevalence of patient autonomy in South African medical law.²¹⁴

12.4 Value of proper information - consequences

The legal consequences²¹⁵ of a medical intervention performed without the patient's lawful consent are that the doctor or hospital may incur liability for breach of contract;²¹⁶ civil or

²¹⁰ "With prenatal diagnosis, results which indicate the presence of a predisposition to a disorder usually involve severe disorders for which no treatment is available. In such cases, the available courses of action are rather limited when compared to diagnosis carried out prior to conception. The only choice available to the parents of the unborn child are to terminate the pregnancy or to accept the birth of a child with the disorder."

²¹¹ **SA Medical & Dental Council v McLoughlin** 1948 (2) SAH 355 (A) and **Castell v De Greef** *supra*.

²¹² Physicians often have a close relationship with their patients and therefore would in the vast majority of cases know how to best approach and inform each particular patient. If a relatively unknown or new patient must be informed, a common sense approach should be applied: To bombard an average layperson with detailed aspects of a highly technical nature would probably only confuse a patient and do more harm than a superficial explanation would. Each patient's individual intellect, education and development should guide a physician in determining the correct level of information needed.

²¹³ even if this disclosure would be harmful or shocking to the patient.

²¹⁴ **Richter v Estate Hamman**, **Castell v De Greef** *supra*.

²¹⁵ in South African law.

²¹⁶ **Behrmann v Klugman** 1988 (W) - unreported.

criminal assault (a violation of physical integrity);²¹⁷ civil or criminal *injuria* (a violation of *dignitas/* privacy);²¹⁸ negligence;²¹⁹ and/ or the doctor or hospital may be unable to recover a professional fee;²²⁰ medical regulations and ethical codes will in addition magnifying the extent and seriousness of such misconduct. Van Oosten²²¹ aptly sums-up the basis of the principle of proper disclosure:

"This²²² applies irrespective of whether or not the intervention was administered with due care and skill and eventually proves to have been beneficial to the patient, the reason being that the violation perpetrated by the doctor who performs the wrongful or unlawful intervention is one against the patient's physical integrity or *dignitas/* privacy rather than one against his health."

Hondius²²³ debates on what sanction would be best used against a physician who failed to give any or insufficient information to his patient in the Netherlands. He raises the question if a physician under such circumstances could not possibly argue that the prejudicial consequence would have materialised whether he has forewarned the patient of its possible occurrence or not. It is reported²²⁴ that this question has been answered in the French law in the following way: If the failure to inform has deprived the patient of an opportunity to exercise a choice in the matter, such prejudiced patient should have a claim for financial compensation.

Earle²²⁵ reports that an action for trespass²²⁶ against the physician who performs a medical intervention on a patient without informed consent is often instituted in America, whilst an action for battery is also possible.

²¹⁷ **Stoffberg v Elliott; Lampert v Hefer** 1955 (2) SA 507 (A); **Esterhuizen v Administrator Transvaal; Richter v Estate Hamman, S v Binta** 1993 (2) SACR 553 (C), **S v Kiti** 1994 (1) SACR 14 (E).

²¹⁸ **Stoffberg v Elliott.**

²¹⁹ **Lymbery v Jefferies, Dube v Administrator Transvaal** 1963 (4) SA 260 (W), **Richter v Estate Hamman, Castell v De Greef** *supra*.

²²⁰ **McCallum v Hallen** 1916 ODP 74.

²²¹ *op cit* p 167.

²²² *ie* principle of proper disclosure.

²²³ *op cit* p 1696.

²²⁴ *ibid.*

²²⁵ *op cit* p 632.

²²⁶ "...an action in trespass, thereby conflating the torts of medical negligence and medical trespass." *ibid.*

"In America, a doctor's duty required by courts in disputes is that of reasonable disclosure regarding the probable consequences and dangers falling within his knowledge. Consent based on such disclosure can be said to have been informed, and the degree of disclosure required is a question for the court."²²⁷

In England, it is reported,²²⁸ that medical intervention without any consent amounts to battery,²²⁹ while imperfect or insufficient consent could constitute negligence, which is the dominant cause of action in England. Earle writes that negligence would be found were the physician in question's conduct "departs from general and approved medical practice and is based on things said and not said".²³⁰ He explains that the standard of the legal duty of care concerning the provision of information is a physician-based one.²³¹

12.5 Case law developments in South Africa

Although the duty of disclosure has been generally adhered to by South African physicians through the years, the pertinent judicial acceptance and far-reaching importance²³² thereof only recently came under the spotlight in the judgment of **Castell v De Greef**.²³³ Legal principles concerning forensic medicine in general, but also wrongful life litigation specifically, were established in this landmark decision. Some have even suggested that a new category of personality rights, *ie* the right to self-determination or freedom of choice has been created by this judgement.²³⁴

With regard to direct wrongful life application, the following rules were entrenched:
It was established beyond doubt that the doctrine of informed consent applies to South African

²²⁷ *op cit* p 631.

²²⁸ *ibid.*

²²⁹ *T v T* (1988) 1 All ER 613.

²³⁰ *Clark v MacLennan* (1983) 1 All ER 416.

²³¹ see *infra* where the "Bolam principle" is discussed.

²³² Van Oosten *op cit* p 993.

²³³ *supra.*

²³⁴ "...the court appears to have introduced, in so many words, the patient's right to self-determination or freedom of choice as a separate and distinct category of personality rights in South African medical law." Van Oosten *op cit* p 178.

law.²³⁵ No consent can therefore legally be given by a person for the infringement of any right (*in casu* personality rights)²³⁶ without the necessary knowledge- basis from which appreciation of all relevant aspects and consequences related to the future infringement²³⁷ transpires.

Secondly, the court stated that patient autonomy is of greater importance than medical paternalism.²³⁸ The court shifted the emphasis from a professional medical standard of disclosure to a patient autonomy standard of disclosure, as the decision to undergo or refuse a medical procedure has now been solely reserved as that of the patient.

In the third instance the court found that the duty to inform a patient is based on contract.²³⁹ It is submitted that a physicians are nevertheless concurrently bound by a delictual duty to disclose, as the *boni mores* would still expect from a physician to act in accordance with the general level of proficiency found in the medical fraternity.²⁴⁰

Another vital foundation laid down by the court is that if a reasonable patient would have though certain information relevant/ important and if the physician could be expected to reasonably have foreseen that the patient would have though it important, then the physician

²³⁵ Ackermann J, 420 G-H: "I am constrained to disagree, inasmuch as I am of the view that *there is not only a justification, but indeed a necessity, for introducing a patient-orientated approach in this connection.* It is important, in my view, to bear in mind that in South African law (which would seem to differ in this regard from English law) *consent by a patient* to medical treatment is regarded as falling under the defence of *volenti non fit injuria*, which would *justify an otherwise wrongful delictual act.*"

²³⁶ Barnard, Cronjé and Olivier 1994. **The South African Law of Persons and Family Law**, Butterworths, (3rd edition) 6: "The right to personality property is a personality right. A person's right to his good name, his honour *and his corporeal integrity* are examples of personality rights as the object of the person's right in these instances is an aspect of his personality."

²³⁷ as consent can only be given based on information, it is obvious that proper disclosure must precede consent - see, however, the *pactum de non petendo* discussed *supra*, where prior agreement is reached that no claim would arise from a future injury.

²³⁸ Ackermann J on 421 C-D: "It is, in principle, wholly irrelevant that her (the patient's) attitude is, in the eyes of the entire medical profession, grossly unreasonable, because *her rights of bodily integrity and autonomous moral agency entitle her to refuse medical treatment.* It would, in my view, be equally irrelevant that the medical profession was of the unanimous view that, under the circumstances, it was the duty of the surgeon to refrain from bringing the risk to the patient's attention."

²³⁹ a doctor is therefore under a separate contractual obligation to furnish a patient with the necessary information - Ackermann J on 425 E-F: "In the South African context the doctor's duty to disclose a material risk must be seen in the contractual setting of an unimpeachable consent to the operation and its *sequelae.*"

²⁴⁰ see ch 4 for a more detailed discussion on professional negligence.

does not fulfill his duty if this specific information is not given through to the patient.²⁴¹

"Instead, the question is now whether or not the *reasonable patient* would have regarded the risk or danger as significant, or whether or not the doctor was or could have been aware that the *individual patient* would regard the risk or danger as significant."²⁴²

A final important principle that was laid down was that it is for the court to make the final decision whether a physician acted negligently under the particular circumstances and not the physician's peers or other colleagues in the medical field.²⁴³ In the same way a physician has a duty to inform his patient on any medical procedure, a genetic advisor is under an obligation to fully inform his patient concerning genetic and procreative matters.

Nijs²⁴⁴ indicates that a physician's failure to properly inform a patient concerning possible fertility, alternative contraceptive measures could have been used and the unwanted pregnancy avoided.²⁴⁵

12.6 Position overseas

The **Castell** court referred to various overseas jurisdictions and indicated that the most have principally the same contention regarding specific patient disclosure.²⁴⁶ Grubb,²⁴⁷ however,

²⁴¹ it is therefore not important whether the *physician* assesses a risk to be serious or unusual or remote, but rather what the patient would consider as significant or not - special reference is made in **Castell** to the position overseas, as discussed from fn 140 *ao*.

²⁴² Van Oosten *op cit* p 998.

²⁴³ Van Oosten *op cit* p 996: "Expert evidence might also have a bearing on the material nature of risks, provided it is borne in mind that the matter will not be concluded on the basis of expert evidence alone, but will ultimately be decided by the court."

²⁴⁴ 1989. Het kind en de rekening fout, schade en schadevergoeding naar aanleiding van een mislukte sterilisatie. *Rechtskundig Weekblad* (52:22), 1156.

²⁴⁵ "Als de gynaecoloog de informatiefout niet had gemaakt, dan had het echtpaar de kans gehad aanvullende anticonceptiva te gebruiken: zo had een zwnagerschap kunnen worden vermeden" *op cit* p 1162.

²⁴⁶ The North Carolina Supreme Court decision of **McPherson v Ellis** 287 SE 892 N.C. (1982) is quoted as indicating the American position: "In determining liability by whether a reasonable person would have submitted to treatment had he known of the risk that the defendant failed to relate, no consideration is given to the particular quirks and idiosyncrasies of the individual. His supposedly inviolable right to decide for himself what is to be done with his body is made subject to a standard set by others. The right to base one's consent on proper information is

reports on English law which has applied²⁴⁸ the so-called "Bolam tests"²⁴⁹ whereby the medical profession itself determines whether specific conduct is in accordance with accepted medical practice or not:

"Medical men are therefore put in a very favourable position. While the law imposes a duty of care, uniquely, the medical profession sets its own standard of care."

He²⁵⁰ further informs in this regard that the majority view²⁵¹ of English courts is that the "Bolam test" should also be applied as benchmark for cases involving contraceptive advice.²⁵² Grubb writes that:

"The fact that the courts rely very heavily on expert evidence in cases of medical

effectively vitiated for those with fears, apprehensions, religious beliefs. Or superstitions outside the mainstream of society."

The **Castell** court also referred to the South Australian case of **F v R** (1983) 33 SASR 189 and the recent Australian High Court case, **Rogers v Whitaker** (1993) 67 ALJR 47 and stated: "In both cases the matter was approached on the basis of the doctor's duty of care to the patient, breach of which would constitute negligence on the doctor's part. As already indicated, the matter is approached somewhat differently in South African law, the enquiry being whether the defence of *volenti non fit injuria* has been established and in particular whether the patient's consent has been a properly informed consent."

Van Oosten *op cit* p 176 sums up the **Castell's** view in this regard: "The court prefers to place the doctor's duty of disclosure and its concomitant, the patient's informed consent, within the framework of the wrongfulness element (with *volenti non fit injuria* or voluntary assumption of the risk of harm as a justification) rather than the fault element (intention - which the court, incidentally, does not refer to in this context - or negligence) of delict."

²⁴⁷ 1988. *op cit* p 12.

²⁴⁸ in **Sidaway v Bethlem Royal Hospital** (1985) A.C. 871(see wrongful conception ch p6) the failure to disclose a risk on injury arising from a therapeutic procedure was at hand.

²⁴⁹ **Bolam v Friern H.M.C.** (1957) 1 W.L.R. 582 - a doctor's failure to disclose is not negligent if he has acted "in accordance with a practice accepted as proper by a reasonable body of medical men skilled in that particular art."

²⁵⁰ *op cit* p 13.

²⁵¹ this "right of the doctor to decide everything" has been criticised by Lord Templeman and Lord Bridge in **Sidaway** 904, who believe that it should be up to the courts to decide whether a patient has received "sufficient information to make a 'balanced judgement'".

²⁵² in **Gold v Haringey Health Authority** (1987) 3 W.L.R. 649 it was found that a physician who failed to inform a patient of the small risk that nature may reverse the surgery and also neglected to advise the patient of a surgical alternative with a smaller risk of failure, was not negligent because of the application of the "Bolam test".

advice is explicable, because judges are very anxious not to trespass on a doctor's clinical judgement of what should be disclosed in the patient's best interests where the patient's health is at stake."²⁵³

Earle²⁵⁴ also refers to the influence of the "Bolam principle"²⁵⁵ on various jurisdictions and shows that this standard is constantly being eroded by courts in the context of advice and information²⁵⁶ given to patients in judgements where "courts assert their own primacy over medical practice."

He believes that, although the *Sidaway* decision adopted a paternalistic and physician-orientated approach which aligned informed consent with professional duty, it did not leave the issue in medical hands alone. The gravity of this rule is also tempered by the fact that it was a decision of first instance and "what has become the *Bolam* test was part of a summing-up to a lay jury."

13. Emphasis on information

The nature of disclosure could have varying focus-points.²⁵⁷ Information could be imparted for the single purpose of obtaining the patient's consent as an exercise of his right to self-determination,²⁵⁸ or it could be imparted for the protection of the patient's health and other

²⁵³ *ibid.*

²⁵⁴ *op cit* p 631.

²⁵⁵ "A rule that a doctor is not negligent if he acts in accordance with a practice adopted at the time as proper by a reasonable body of respectable medical opinion." - *op cit* p 633.

²⁵⁶ "What has become apparent is that, in respect of the *Bolam* test, there is a difference between treatment and information. Because as a general rule the judiciary lacks medical expertise, *Bolam* is only able to be eroded in the courts in respect of the standards of disclosure of inherent risks that are to be required of physicians by the law." - *op cit* p 638.

²⁵⁷ Van Oosten *op cit* p 169 distinguishes between two main categories of disclosure, *ie self-determination disclosure* (which serves the purpose of procuring the patient's effective consent as an exercise of his right to self-determination), classified as either diagnosis disclosure, disclosure of the course of events and disclosure of complications on the one hand; and *therapeutic disclosure* (with the purpose of procuring the patient's informed consent) on the other hand.

²⁵⁸ *eg* where a general practitioner informs a patient of a simple procedure or injection that will be administered during a consultation.

health related matters.²⁵⁹ It is suggested that the information needed²⁶⁰ to make an informed wrongful life/ birth/ conception decision, would fall under the last mentioned category.²⁶¹

A subtle distinction, therefore, exists between general informed consent on the one hand and informed decision-making in wrongful life type situations, on the other. When consent is given in the general sense, a patient gives his "permission" to a physician to apply his medical expertise on a specific ailment or condition (usually) in his own body. It is my submission that informed decision-making in cases of wrongful life is much more complex and often has far-reaching implications in religious, social and financial spheres.

In these cases parents place all their trust in the accurate genetic analysis of a medical professional in order to decide whether a foetus in a high risk group of genetic anomaly must be given the opportunity of life or not. It is submitted that this great responsibility magnifies the importance of quality information, as these parents have to weigh all the information given to them by the doctor²⁶² and make a decision based on these facts.

Clarke²⁶³ emphasizes the fact that genetic counsellors are in principle there to inform clients about a specific genetic condition or risk and not to make procreative decisions on their behalf. She writes, however, that many confuse this task and assign different duties to them:

"Some clinicians in other branches of medicine still expect genetic counsellors to give their patients instructions as to whether they should have children or be sterilized or undergo prenatal diagnosis and possibly have a termination of pregnancy (genetic counsellors do not do this); they make inappropriate referrals of families who do not wish to be seen."²⁶⁴

She²⁶⁵ identifies two distinct instances where informed consent can cause difficulties in

²⁵⁹ the so-called "therapeutic disclosure" - **Dube v Administrator Transvaal**.

²⁶⁰ a patient should be familiarized with and prepared for the proposed medical procedure, eg sterilization/ genetic test and should be informed of the nature of his condition and instructed on how to behave before, during and after the procedure.

²⁶¹ eg the case of **Behrmann v Klugman**, where the defendant-doctor failed to inform the plaintiff-patient to have a sperm count before resuming intercourse with his wife without contraception after having undergone a vasectomy - see ch 6.

²⁶² as the expert.

²⁶³ *op cit* p 5.

²⁶⁴ *ibid*.

²⁶⁵ *op cit* p 8.

providing genetic counselling. The first is the issue of complexity: where clients are confronted with technically complex choices they can not effectively give an informed consent without adequate understanding.²⁶⁶ Ethical problems arise when counsellors fail to adequately explain the possible choices to the clients. The second concern relates to genetic screening programmes which often offer “minimal information and cursory discussion.” These screening programmes have also in past generated social problems such as racial discrimination against black Americans found to carry sickle cell disease and have similarly caused problems of stigmatization of thalassaemia carriers.²⁶⁷

14. Application to wrongful life litigation

The physician’s duty to inform is extremely relevant to most instances of wrongful life.

Teff ²⁶⁸ appropriately declares:

“...the true rationale of ‘wrongful life’ ability is the parents’ right to make a properly informed decision.”

Foutz²⁶⁹ states that proper medical information is similarly relevant to wrongful conception/ birth actions. In these cases the doctor, for instance, has a duty to inform his patients after a sterilization operation of the remote possibility that they could once again become fertile as reported cases exist where the effect of sterilization has been naturally reversed.²⁷⁰ If a physician neglects to fulfill this duty he could be held accountable for the resulting damages. He further states that in a typical wrongful life action a disabled or genetically impaired child does not assert that the physician-defendant’s medical negligence caused his detrimental condition. The plaintiff rather alleges that the defendant breached his duty to properly inform his/ her parents, in due time of the existing genetic defect in their child, or of a greater than normal risk of abnormality in their pregnancy.

Since it can be accepted that parents would act in their child’s best interests, the plaintiff suggests that upon receiving this legally required information from the defendant, his/ her

²⁶⁶ which can be attained through proper guidance and explanation.

²⁶⁷ *op cit* p 9.

²⁶⁸ 1985. The Action for Wrongful Life in England and The United States. *International and Comparative Law Quarterly* (34), 423.

²⁶⁹ 1980. *Tulane Law Review* (54), 488.

²⁷⁰ see ch 11.

parents would have prevented the pregnancy or would have ended the pregnancy by obtaining an abortion. Thus, had the defendant not breached his duty to inform, the physically challenged child would not have been born and would not have to suffer from impairments until the end of its often short and painful life. It is therefore of vital importance that physicians fully inform patients of the medical procedures intended by them, the results of tests done and also any other relevant facts concerning the health or reproductive plans²⁷¹ of patients in order to escape liability.

Legemaate²⁷² reports on liability for wrongful conception actions in failed sterilization procedures. He explains that the physician can be held liable either because of negligent performance of the sterilization itself or based on a failure to properly inform the patient or on account of both.

“Een bekend voorbeeld van een ingreep waarbij zowel aspecten inzake gebrekkige informatie aan de orde kunnen zijn als een onjuiste uitvoering van de ingreep is de sterilisatie van vrouwen. Binnen het geheel van civielrechtelijke procedures op het terrein van de gezondheidszorg, vormen die over mislukte sterilisatie een belangrijk deel. In een aantal van deze procedures wordt de arts verweten dat hij de ingreep technisch niet correct heeft uitgevoerd, ten gevolge waarvan de vrouw in kwestie zwanger is geworden. In andere gevallen houdt het verwijt aan de arts in dat hij de vrouw niet had geïnformeerd over het geringe misluktingsrisico van de sterilisatie. In sommige procedures gaan deze beide verwijten samen.”

15. Disclosure for abortion

In *Lifchez v Hartigan*²⁷³ it was decided that the right to privacy included the right to obtain information in order to decide whether to terminate a pregnancy.

When discussing the issue of informed decision-making, it is apt to specifically consider the life or death decision that wrongful life/ birth parents has to make when confronted with the possibility of an abortion.²⁷⁴ Proper information is vital in these cases as the plaintiff-child will

²⁷¹ such as dangerous genetic genes detected in the patient or known hereditary diseases in the patient's family history.

²⁷² 1996. *op cit* p 105.

²⁷³ 735 F. Supp 1361, 914 F. 2d 260 (1990), 111 S. Ct. 787 (1991).

²⁷⁴ Berry *op cit* p 34 submits that: “Although in the future clinical genetics is likely to involve treatment of genetic disease and prevention of disease in those at risk, at present prevention is very dependant on prenatal diagnosis and selective abortion

pertinently argue that his parents would have aborted him while a foetus, if they only had the necessary medical findings²⁷⁵ of his disabled/ impaired future at the time when an abortion could still be requested.

The defendant-physician should accordingly realize the magnitude of the parent's choice and keep this in mind when considering the duty to inform. It would seem only human that the opinion of the physician²⁷⁶ will have great influence on the final outcome of the matter.²⁷⁷ It is therefore of utmost importance that all the relevant information is given correctly, timely and accurately. Instances where an interpretation of results must be made to advise prospective parents must also be handled with extreme caution. It would be wise under these circumstances to consult with a colleague in order to obtain a second opinion.²⁷⁸

As plaintiff-parents in wrongful life cases could be influenced by various factors when considering the abortion option, one writer²⁷⁹ mentions that:

"Although lack of funds for abortion may influence the outcome of a woman's choice or affect her ability to implement a decision not to bear a child, *lack of relevant and reliable medical information precludes informed choice altogether.*"²⁸⁰

Grobe²⁸¹ reports on further infringements of the right to be informed and gives as an example the governmental intrusion of physicians' duty to inform brought about by a recent judgment, **Rust v Sullivan**.²⁸² In this case the Supreme Court of the United States of America upheld

of affected fetuses."

²⁷⁵ and thorough genetic testing/ proper inquiries would have made these findings known.

²⁷⁶ as the specialist and professional.

²⁷⁷ van Oosten *op cit* p 168 comments: "While it may be true that the doctor is medically in the best position to judge the necessity or desirability of an intervention, considerations other than medical ones are often also relevant to the patient's decision to undergo or refuse an intervention. Such considerations normally fall outside the doctor's sphere of competence."

²⁷⁸ Sheperd, L. 1996. Sophie's choices: Medical and Legal responses to suffering. *Notre Dame Law Review* (72:1),115.

²⁷⁹ Anon. 1987. Wrongful Birth Actions: The Case against Legislative Curtailment. *Harvard Law Review* (100), 2026.

²⁸⁰ my emphasis.

²⁸¹ 1992. The future of the "wrongful birth" cause of action. *Pace Law Review* (12:3), 717.

²⁸² 111 S. Ct. 1759 (1991).

rules governing state benefits pursuant to the Public Health Services Act, not to promote abortion as method of family planning. The court's decision has the result that physicians may not *counsel, refer or even provide information regarding abortion* as a method of family planning to recipients of public health services. It is suggested that such restrictions will severely hamper physicians in practising their profession. Grobe²⁸³ rightly fears that women's abortion rights may be adversely affected²⁸⁴ if physicians are relieved by the state from their duty to inform patients properly. It is important to recognize that the public health patients affected by the abovementioned judgment are entitled, like all other patients, to have "a liberty interest in being free from unwarranted governmental intrusion in the informed consent dialogue necessary to medical self-determination."²⁸⁵ Grobe²⁸⁶ hereby pleads for acknowledgement of the common law duty to disclose material information.²⁸⁷ It is submitted that this viewpoint should be supported.²⁸⁸

15.1 Subjective influences

Another pressing aspect relevant to the doctrine of informed consent that is often overlooked, is the effect that personal beliefs and opinions of the person on whom the duty to inform lies have on the accuracy and acceptability of the disclosure in question. Shepherd²⁸⁹ reports on a study which showed that various genetic counsellors interpret the same information in different ways, as a result of being influenced by external factors such as personal experience of suffering, understanding of disabled people, religious beliefs, training, moral upbringing,

²⁸³ *ibid.*

²⁸⁴ and that recognition of wrongful birth actions might accordingly be reversed as a result.

²⁸⁵ *op cit* p 719.

²⁸⁶ *ibid.*

²⁸⁷ and states that this commonly recognized duty between physician and patient has in the past regularly founded liability in medical negligence cases.

²⁸⁸ Anon. 1994, *op cit* p 55 - Termination of pregnancy for genetic reasons: if, after a test result has indicated the existence of heightened risk, prenatal diagnosis reveals the presence of a severe disorder, most parents decide to terminate the pregnancy.

The individual has to set things straight regarding conflicting emotions and the clash between the image of a much-wanted child and that of a handicapped child. Nevertheless, in subsequent pregnancies, most women again opted for prenatal diagnosis.

In addition, some had feelings of guilt, eg for having passed on the disease or for having decided to terminate the pregnancy.

²⁸⁹ *op cit* p 103

personality,²⁹⁰ general sense of compassion *et cetera*.

It is my submission that parents/ patients are not only entitled to comprehensive information but also have the right to *objective* clinical information. This directive would ensure that patients would not subtly be influenced in their decision-making by obtaining information tainted by the physician's own personal beliefs and attitudes. This is especially true since medical practitioners' own opinions are not constant. Sheperd²⁹¹ makes reference to a study in which it was shown that interpretations of medical statistics vary as time goes on and more accurate tests are developed.

Clarke²⁹² agrees that the supplier of information has a profound influence on the decision made by an individual seeking genetic counselling:

"The decision as to whether or not to terminate a pregnancy affected by a sex chromosome anomaly (of minor importance in comparison to a diagnosis of Down syndrome) is influenced by the background of the person who gives the information: more terminations are performed if an obstetrician gives the information than if it is given by a genetic counsellor."

An important consideration in this regard is to assess what tests are accurate enough to be recommended to and performed on patients. Andrews²⁹³ explains that while chromosome analyses or karyotyping²⁹⁴ were done in earlier years, more modern tests have since been introduced which are generally much safer for the foetus, but not in every instance necessarily more accurate.

"...the ultimate decision to undergo or forego a medical intervention, should rest with the patient as master of his own body and life and not with the doctor."²⁹⁵

²⁹⁰ whether the medical practitioner is a natural optimist/ pessimist.

²⁹¹ *op cit* p 113: "Since the introduction of prenatal testing, genetic counsellors have undergone a substantial change of heart what odds are high risks and what odds are low risks."

²⁹² *op cit* p 18.

²⁹³ 1992. Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks. *Houston Law Review* (29:1), 165.

²⁹⁴ whereby a small sample of amniotic fluid is subtracted from the womb and then tested - see ch 11.

²⁹⁵ Van Oosten *op cit* p 169: "The doctor's ethical duty to heal does not create a legal right to heal."

To ensure that this is possible, information-suppliers should be aware of the fact that their opinion is highly regarded by patients and that their appraisal could dramatically influence the final decision of the patient. It is accordingly contended that counsellors should try to "screen" their information before communicating it through to their patients, to ensure that only²⁹⁶ the necessary scientific facts reach their patients. It is important a patient has the opportunity to make a subjective and discrete decision concerning his/ her own body, as the main purpose and function of informed consent is to protect the patient's right to self-determination, freedom of choice and also to encourage rational decision-making.²⁹⁷

Berry²⁹⁸ has similar views on the genetic counsellor's duty to truthfully inform a patient. She feels strongly that accurate information has to be given at all times, whether good news or bad. Five relating aspects are discussed by her in this regard: Firstly, the geneticist's personal concerns must not influence the information.²⁹⁹ Secondly one must consider the particular impact on the affected individual.³⁰⁰ A third consideration for a counsellor is the impact of results on the parents of the affected child. In this respect it is important that geneticists be kept fully informed about the effectiveness of new treatments and evaluation procedures. Fourthly a geneticist should consider necessary and unnecessary truths, as many clients could be made unnecessarily anxious about possible or potential harm that is substantially remote. A final aspect to take into account is the reality that affected individuals might suppress the true facts.³⁰¹

Berry,³⁰² in conclusion, debates whether it is not the duty of the genetic counsellor to guide the

²⁹⁶ It would obviously be impossible to fully negate the human factor in this respect as every human is subconsciously influenced by his personal ideas and believes. If genetic counsellors would nevertheless make a concerted effort to be absolutely objective, it is likely that a much better and more acceptable result will be obtained.

²⁹⁷ **Castell v De Greef**, 409.

²⁹⁸ *op cit* p 31.

²⁹⁹ "The geneticist must endeavour to give the couple as accurate an outlook as possible, remembering that it is as serious an error to give a couple an incorrectly high recurrence risk which may deter them from further pregnancies as to give them too low a risk, resulting in their having a further affected child." *ibid*.

³⁰⁰ "An individual who is only mildly affected with, for example, *neurofibromatosis* needs to know the full range of the gene's potential manifestations so that he or she can decide whether or not to take the 50 per cent risk of transmitting the gene to the child, or whether to request prenatal diagnosis if it is available." *ibid*.

³⁰¹ it is advised that great sensitivity should be applied in cultures and traditions where women have a low status in society as it is possible for a woman found to be a 'bad gene carrier' to lose a potential husband, security and status.

³⁰² *op cit* p 42.

patient into making a morally responsible decision. Is it not irresponsible of a medical professional to allow the continued pregnancy of a woman carrying a foetus with a high risk of a severe disorder? Should the counsellor not exert some pressure on such a woman to undergo prenatal test in order to obtain a definite diagnosis? The obvious answer to this question should be a resounding "no".³⁰³

Eriksson *et al*³⁰⁴ ask whether the true duty of a physician is to merely inform or to advise the patient. They come to the conclusion that through giving proper information, the physician makes it possible for the patient to make up his own mind. Only if a physician is specifically asked for his personal opinion, should it be offered.

*"Met behulp van de informatie maakt de arts - dat is de bedoeling - de aanstaande ouders zo wijs, dat ze zelf de beslissing kunnen nemen over wat er verder gebeuren moet. Het is hun gezin dat er al dan niet komt, en het zijn hun kinderen."*³⁰⁵

Although a medical advisor must give his professional opinion on the relevant risks attached to a particular pregnancy and also has to inform the client on the expected malignant nature and characteristics of a possible hereditary disease, it still remains the sole decision and prerogative of the patient to decide on the matter.³⁰⁶

Bensing³⁰⁷ suggests that the detection of medical conditions are perceived differently by patients than by physicians, as medical professionals generally seem to focus more on the importance of the bio-medical diagnosis itself, than on the effect of the knowledge thereof on the patient.³⁰⁸

Gevers³⁰⁹ writes that all communication is tainted with subjective values. He reports that even

³⁰³ Berry concedes *ibid* that: "The medical adviser may feel that the loss of the pregnancy is less of a disaster than having an affected child but it is the parents themselves who have to live for the rest of their lives with the result of their decision."

³⁰⁴ *op cit* p 32.

³⁰⁵ *ibid*.

³⁰⁶ see *supra* and particularly the decision of *Castell v de Greef*.

³⁰⁷ *op cit* p 1.

³⁰⁸ the detection of a rare hereditary disease in a patient could be a scientific achievement for a physician, whilst the knowledge thereof could drastically alter the affected individual's (and his family's) future plans to have children *etc*.

³⁰⁹ *op cit* p 14.

when a physician is not asked for his personal opinion, the physician would inadvertently structure his advice in a specific manner that could convey a positive or negative message. He summarises:

*"Als elk ander communicatieproces, zal erfelijkheidsadvisering nooit geheel non-directief en waardenvrij kunnen zijn."*³¹⁰

Bensing³¹¹ distinguishes two basic patient-needs that physicians should be aware of. The first is appreciation of what precisely the patient expects from the physician³¹² and secondly the patient wants to perceive that the physician understands his position and subsequently expects support, respect and acceptance from the physician. Bensing explains that the first is a cognitive need,³¹³ the second is an affective need³¹⁴ and both are equally important.

15.2 Perception of risks change

Shepherd³¹⁵ declares that physicians do unwittingly influence patients in providing calculated risk assessments during informative sessions. He³¹⁶ explains that there is a fluctuating point of view held by genetic counsellors on what high risks are and what odds are seen to be low (or acceptable). The professional viewing/ consideration of these odds differ as years go by and as medical technology advances. In addition to this uncertain state of affairs, counsellors characterize a potential disability to be a high or a low risk, depending on their personal assessment of the severity of the disability. This has the effect that even a minute chance to inherit a serious genetic disorder, is seen as a "high risk":

"Thus, the assessment prospective parents receive from genetic counsellors and physicians regarding the extent of risk for a condition reflects not only statistical

³¹⁰ *ibid.*

³¹¹ *op cit* p 3.

³¹² *ie* the reason for the consultation.

³¹³ the so-called "problem-solving related coping with a patient" or the need to know and understand.

³¹⁴ the "emotional orientated coping with a patient" or the need to feel known and understood.

³¹⁵ 1996. Sophie's choices: Medical and Legal responses to suffering. *Notre Dame Law Review* (72:1), 103.

³¹⁶ *op cit* p 114.

probabilities but also the professional counsellor's feelings³¹⁷ about certain conditions."

16. Boundaries of disclosure/ Who may know?

Andrews³¹⁸ debates what classes of persons should be entitled to receive information obtained through genetic testing.³¹⁹ He does this to establish where the limits/ boundaries of their liability should lie. He reports on an American case, *Munro v Regents of the University of California*,³²⁰ where the court required that a patient should fall within a "reasonably high-risk group"³²¹ of genetic disease,³²² before it would expect from a physician to specifically test the

³¹⁷ Here we find an extremely important aspect of the *duty to inform* a patient. A medical professional or genetic counsellor has a legal duty to properly inform a patient of all *relevant* information. This information is required for the patient to make an informed decision. In cases where a patient seeks genetic information, it is of great importance that the counsellor's professional opinion, based on scientific results, are given to the patient objectively. Here there is no place for any personal views and/or beliefs (ethical or religious) to influence the given advice. Care must be taken that scientific results are not indirectly influenced or adapted through the subjective interpretation of results or in the communicating of the final advise to the patient.

In extreme circumstances, irrelevant and/or additional subjective opinions of physicians or genetic advisors may totally change the initial decision of the patient or at least, the decision that would have been made, had the proper objective results been given. In such circumstances it could be said that the duty to inform was not properly adhered to (and as a result such advisor could be held accountable for consequential damage).

³¹⁸ *op cit* p 163.

³¹⁹ Clarke *op cit* p 6, also verifies that uncertainty exists in practice to whom a diagnosis has to be established or confirmed, especially where the client or family does not readily accept the finding or in instances where others have a real interest in the results: "There is then the difficulty of deciding whether one's primary duty is to the referring professional (who want's a diagnosis made, if possible), or to the immediate family (who want time to accept their child's set of abilities and problems), or to the extended family (if another branch of the family might want the diagnosis established because of implications for them), or to the child in question (whether the child is best served by being diagnosed and thereby categorized, or by remaining undiagnosed and therefore a unique individual."

³²⁰ 263 Cal. Rptr. 878, 882 Ct. App. (1989).

³²¹ Clarke *op cit* p 6 writes: "How do we distinguish between degrees of risk? Between low or 'acceptable' risks, and high or 'unacceptable' risks?" It is therefore a very difficult and certainly a subjective matter whether a risk is acceptable or not. It is submitted that physicians/ counsellors should be guided by existing (objective) practice guidelines when considering each case.

³²² it is theoretically-mathematically possible to establish whether a patient falls in a high-risk group of a specific disease by taking into account several factors such as ethnicity, gender, cultural background, living conditions (often dictated by economic circumstances) and many other considerations, eg Tay-Sachs disease is a quite rare condition, but is found in much greater frequency in the Jewish communities of

patient for such a disease and before a higher level of adherence to the duty of disclosure would be expected. *In casu* the court found that there is no general legal duty on a physician to *sua sponte* suggest testing for and treatment of possible genetic diseases. It is argued that recognition of such a duty would not create a new duty on physicians, since similar conduct has already been expected from physicians in successful wrongful birth actions.³²³ It would be correct to say that if a patient is fully informed of all risks and possible consequences of genetic disease, the physician has properly fulfilled his duty to inform and has thereby placed the patient in the position to make his own decision on whether to be actually tested or not. Clarke³²⁴ concludes that:

“Information about a person's genetic make-up may be of interest not only to the individual but also to other members of their family, to their employers, their life-insurance company and possibly other agencies, including the state. When does this interest in a person's genetic constitution give the interested party a *right of access* to that information?”

The following measures are suggested³²⁵ to prevent inadvertent breaches of confidentiality: Obtaining consent before examining medical records, obtaining consent before obtaining samples or doing tests on family members, taking care that sensitive information is not passed on to other branches of a family, taking care not to reveal “raw” laboratory results and finally clearly distinguishing between samples taken for research purposes and those taken to provide information for the family, while obtaining separate consent for these separate purposes.

16.1 Information to family members

With regard to the transfer of genetic information to family members, the following aspects are discussed by Leenen.³²⁶ As point of departure one must realise that the general rules concerning secrecy and privacy is certainly applicable to genetic information.³²⁷ This is obvious, as genetic data is often of a sensitive nature, while it usually has direct relevance to family members as well.

Eastern Europe as well as in a specific French community in Canada.

³²³ such as in *Turpin* where actual testing and treatment were never really considered.

³²⁴ *op cit* p 12.

³²⁵ *ibid.*

³²⁶ *op cit* p 75.

³²⁷ in principle, therefore, genetic information about a patient (without his consent, that is) may not be disclosed to any third parties, even if they are family members.

An interesting challenge arises where a patient gives consent to disclosure of his carrier status of a dangerous hereditary disease. Can un-volunteered information concerning such a hereditary disease³²⁸ be disclosed to unsuspecting family members? The dilemma lies in the fact that while these family members have a real interest in the information, they do not have the luxury of choice in the matter of receiving this life changing information. Not only is there no possibility of prior agreement on the matter,³²⁹ but the mere fact that information is available is already an indication that all is not well.³³⁰ Leenen believes that a therapeutic privilege could rescue a physician from this dilemma, where serious harm would result as consequence of disclosure.

This brings us to another difficult complication, namely the question whether there is a legal *duty on the physician-counsellor to actually inform family members*.³³¹ Such a duty would muster much criticism, as the physician has no relationship with this group of people. It would also be ludicrous to expect a medical professional to look up family members that might be scattered around the globe. Leenen³³² is of the opinion that a duty to inform relatives would only be thinkable if they are easily reachable and affected by a relative serious condition.³³³

Further interesting intricacies relating to the physician's duty "to let the truth be known" that could arise between spouses will now be considered. One such possibility is where it is established during genetic testing that the apparent father of the child is in fact not the father.³³⁴ The situation is further complicated if the child in question is born with a genetic defect, whereupon the couple decides not to have any further children.³³⁵ It is submitted that a

³²⁸ which will inevitably influence his/ her life in a drastic manner.

³²⁹ see fn (3 above) *supra*.

³³⁰ if a family member was not at risk of being affected, the knowledge of a hereditary disease in the genealogy would never have come under discussion.

³³¹ *op cit* p 75: "Vraag is of de arts, indien de patiënt toestemming heeft gegeven de familieleden in te lichten, dan ook de juridische plicht heeft dat te doen." - see discussion *supra*.

³³² *ibid*.

³³³ the Committee of Ministers of the Council of Europe has the following viewpoint on the matter. - Anon. 1994. *op cit* p 51. "In conclusion, the committee would also like to address the importance which the results obtained by genetic screening have for the family. If a person is shown to be a carrier of a mutation, this information is also important to brothers, sisters and, possibly, for other members of the family."

³³⁴ Leenen reports *ibid* that between 5 -20% of all Dutch children born from married parents are conceived by someone other than the husband.

³³⁵ *ie* on the mistaken belief that *they* have conceived the diseased child, while the hereditary aberration was in fact transmitted by the illegitimate third party.

physician will under these circumstances be expected to enlighten the faithful spouse of the fact that the congenital abnormality was caused by a third party.

Leenen,³³⁶ in conclusion to the troublesome situations created by the relevance of genetic information to multiple parties, summarises the requirements that must be proved in order to succeed with a defence of conflict of interests as follows:

- the genetic counsellor will have to prove that all has been done to actually obtain consent from the patient in question;³³⁷
- that the information in question will in all probability prevent serious harm to the relatives;
- that the examination or treatment cannot proceed without the relevant information;
- that the breach of secrecy is the only possible solution;
- that not more information than what is absolutely necessary will be compromised;
- that the information will only be released to the consulting physician of the patient or the family member; and
- that in all aspects, the patient's personal life will be infringed as little as possible.

16.2 A duty to re-contact?

Clarke³³⁸ suggests that a genetic counsellor should give a client post-counselling. Individuals could be supported by providing care and counselling in the management of the disorder through: regular management clinics for patients with specific conditions; long-term co-ordination of care for those who need regular surveillance; occasional clinic appointments, as well as follow-up support in the family home by specialist genetic co-workers. She writes that if home visits are not possible, telephone contact is an acceptable alternative.

Andrews³³⁹ debates the question whether there exists a general duty on physicians to re-contact patients. If test results which have been obtained from earlier analysis are given new meaning through more advanced technology and broadened knowledge, the question arises whether the patients in question should be re-contacted or not.

With the development of new technology and advanced genetic science, physicians are

³³⁶ *op cit* p 78.

³³⁷ (but in vain).

³³⁸ *op cit* p 4.

³³⁹ *op cit* p 169.

progressively able to derive new relevance from existing genetic data.³⁴⁰ Geneticists could possibly show concern for a previously unknown genetic condition or disease through application of the newly acquired knowledge to existing test results. Should they be expected to share this breaking news with the relevant patient and/ or his family? In some instances the newly discovered information could have life or death implications for a patient.³⁴¹ Andrews³⁴² emphasises the necessity of developing a workable system by which these “informative updating sessions” could be made a practical reality. He suggests the use of computers linked to a networking system to solve this problem.³⁴³

Berry³⁴⁴ states that:

“For the geneticist to fulfil this role satisfactorily first and most obviously there is a need for an accurate diagnosis, accurate test results and accurate interpretation of these findings. As genetic diseases are often rare, there may be a need for detailed library searches and access to appropriate computerized databases. This is particularly important in view of the very rapid progress being made in the field of gene mapping and identification. A disease for which no molecular test was available last year may well be established as readily detectable this year.”

Although there does not exist any substantive local authority on this specific issue, it seems³⁴⁵ correct to presume that there should be a legal duty on physicians to make known any new dangers that patients might be unknowingly suffering from.

In the American case of **Schwartz v United States**,³⁴⁶ the explicit duty to re-contact patients

³⁴⁰ Berry *op cit* p 37: “As ultrasound becomes more widely used and its definition improves, a large number of structural defects may be detected.”

³⁴¹ *eg* where such a patient could be timeously warned of a dangerous condition that can be effectively treated or even avoided through proper care or medication.

³⁴² *ibid.*

³⁴³ It is submitted that a web-site, specifically dedicated to inform patients that have previously been earmarked as possible genetic disease- carriers, could also be considered as an effective alternative. Physicians can hereby list the names of patients that could not be re-contacted by more conventional means on a web-site, indicating that new information on their specific genetic aberration/ condition is available. The patient will now be aware of the fact that he/ she could possibly be at risk and will be in the position to decide whether to inquire further about the new developments or not.

³⁴⁴ *op cit* p 29.

³⁴⁵ legally-theoretically.

³⁴⁶ 230 F. Supp. 536 E.D. Pa. (1964).

with new information was first acknowledged. *In casu* the facts were the following: The navy used "umbrathor ink"³⁴⁷ on personnel, which later was found to cause severe irritation in the area of application, having the potential to even cause tumour growth in the sinuses. The court recognized a duty on the state to search through all records in order to find out who were the patients treated with this substance lived and to contact these people and warn them of possible danger. In a later analogous case, **Tresemmer v Barke**,³⁴⁸ it was similarly stated that: "Defendant owes a duty of care to all persons who are foreseeably endangered by his conduct, with respect to *all* risks which make the conduct unreasonably dangerous".

Andrews³⁴⁹ states:

The court held that, "A mere 20 percent chance does not establish a 'reasonably probable causal connection' between defendants' negligent failure to provide the AFP test and plaintiffs' injuries. A less than 50-50 possibility that defendants' omission caused the harm does not meet the requisite reasonable medical probability test of proximate cause."³⁵⁰

In the case of **Taber v Riordan**³⁵¹ the court found that the post-treatment duty to disclose can also be seen as part of the physician's duty not to abandon the patient and that a physician who unilaterally ends the relationship while the patient still needs treatment, abandons the patient.

16.3 Who's duty is it?

It could be argued that the duty to re-contact and/ or re-diagnose is placed specifically on the physician³⁵² because he is probably the person in the best position to locate and inform patients of their particular medical condition. A general post-treatment duty to disclose relevant information could certainly be seen as part and parcel of the physician's duty not to abandon

³⁴⁷ applied in the nose for the use of x-rays in the nasal area.

³⁴⁸ 150 Cal. Rptr. 384 Ct. App. (1978).

³⁴⁹ 1992. *Torts and the Double Helix: Malpractice Liability for Failure to Warn of Genetic Risks*. *Houston Law Review* (29:1), 168.

³⁵⁰ existing information about a patient will subsequently take on new meaning.

³⁵¹ 403 N.E. 2d 1349 Ill. App. Ct. (1980).

³⁵² as opposed to a state duty or local government obligation.

his patient.³⁵³ Once this duty to re-contact has been established,³⁵⁴ it is relevant to ascertain whether the particular relationship between physician and patient is of a superficial nature or not.³⁵⁵ It could be expected that the duty to re-inform would be clearer defined in cases where a close and long lasting physician-patient relationship exist, than would be the case where a patient only once consulted with the specific physician. Where a genetic advisor,³⁵⁶ however, has only once been consulted to ascertain specific information, the duty to re-contact should still be adhered to.

16.4 Others re-contacted?

Many related questions arise in this regard: Does there exist a corresponding general duty to inform third parties and/ or relatives about genetic risks and dangers? Should the wife of a patient, for example, be warned of genetic anomalies in her husband that might affect his health in the later stages of his life, or would that only be so if the aberration would affect the health of their (future) children? Will a close relative have the right to insist on this information? How will sufficient proximity of relations be established? What classes of third parties have sufficient interest in the matter to also be entitled to such information? Is this information not essential to prospective parents in order to make an informed decision on future children and reproductive decisions in general?

Andrews³⁵⁷ is of the opinion that there are certain circumstances where the physician will have a duty, to inform the spouse of a patient affected by genetic anomaly, disease or other serious condition. This will be the case where, for example, test results confirm that the patient/spouse suffers from a contagious or transmittable disease or condition, such as AIDS.

In spite of the duty to inform patients and to be generally involved with the well-being of the patient, the final decision concerning reproduction still lies with the individual/ mother.³⁵⁸ This

³⁵³ Andrews *op cit* p 170.

³⁵⁴ *eg* through an existing doctor-patient relationship or based on contractual principles.

³⁵⁵ or whether there has lapsed a long period since the patient has initially been examined.

³⁵⁶ it is submitted that the role of a general practitioner and the type of relationship with the patient is totally different from that of a genetic specialist, as last-mentioned professional regularly deals with particular individual cases on a short-term basis.

³⁵⁷ *op cit* p 177.

³⁵⁸ protected by a right to privacy.

was again emphasised in the cases of *Planned Parenthood v Danforth*,³⁵⁹ judging that a woman may have an abortion without her husband's consent and *Planned Parenthood of Southeastern Pennsylvania v Casey v Casey*,³⁶⁰ where the judge stated that the mother does not even have to inform the father about her decision to abort.³⁶¹ It would therefore seem correct to assume that not even the father of an child would be able to prove sufficient grounds to obtain genetic information of his wife/ girlfriend, if this would infringe on the mother's right to privacy concerning their child.³⁶²

In some instances relatives of a patient suffering from a genetic disease would have a clear interest in the results of tests done for genetic anomalies, since they also could be possible carriers due to their family relations.³⁶³ Legal policy seems to dictate that there is less need for a duty to inform spouses concerning genetic anomalies of their partner, than for instance informing partners of contagious diseases and violent tendencies.³⁶⁴ A reason for this approach could be the (near) practical impossibility of contacting relatives when considering time and cost implications. A physician's duty to inform is therefore limited only to those groups of people directly at risk of harm.

16.5 Methods of disclosure

Practical alternatives to the traditional manner³⁶⁵ of informing patients of medical conditions or warning/ advising relatives are: Physicians could supply patients in the waiting room with

³⁵⁹ 428 U.S. 52, 69 (1976).

³⁶⁰ 112 S.Ct. 2791 (1992).

³⁶¹ this position is in accordance with the current South African abortion laws - see ch 3.

³⁶² if the mother would suffer from an infectious disease, it is clear that all parties in danger of infection would have a right to be informed of this risk.

³⁶³ eg the condition of "*porphyria*" - this genetic defect is only triggered when carrier comes into contact with barbiturates and could therefore be avoided if prior knowledge about the condition is obtained.

³⁶⁴ because these conditions pose a direct risk to the partner or relative, whereas genetic anomalies merely pose a risk to possible future children.

³⁶⁵ *Andrews op cit* p 182 states that the vast majority of physicians exclusively use consultation or examination time to discuss relevant information concerning the disease or possible risks with patients. Often this short and regularly interrupted conversation is not sufficient and doesn't serve it's purpose. If relatives needs to be contacted, or if patients are re-contacted, many physicians delegate this important task to their subordinates who merely phone to the last known address and do not pursue the matter further of the contact information is incorrect/ outdated. The question remains: to what lengths should a physician go in finding numbers and contact persons?

informative pamphlets on the reality and the prevalence of genetic diseases, as well as the compilation of genetic risk groups; patients sitting in the waiting room could be asked to fill in questionnaires on family backgrounds and other relevant genetic information helpful to the physician in detecting genetic anomaly, instead of expecting patients to read outdated magazines; the use of computers (possibly linked to police information networks) could also be implemented in tracing previous patients and unknown relatives.³⁶⁶

Until the time when more sufficient ways³⁶⁷ are found to inform and identify people suffering from hereditary diseases, we must conclude that this mammoth task should remain on the shoulders of physicians and that of health care providers.³⁶⁸

Legemaate,³⁶⁹ although he acknowledges that auxiliary methods of informing patients such as pamphlets, cassette and video tapes, posters, checklists and so forth are helpful, warns that these methods must never take the place of the traditional oral information session.

Hondius³⁷⁰ has also raised the question whether information should be given orally or in writing. He is of the opinion that a combination of the two is the most effective, as information via brochures only is not always appropriate for every individual instance, while there is a real possibility that a patient who has been emotionally affected by a medical intervention could fail to grasp everything discussed by the physician.

16.6 A contractual relationship

In most cases of medical treatment the patient and doctor enter into a contract of letting and hiring of work or *locatio conductio operis*.³⁷¹ As a general contractual requirement both parties

³⁶⁶ see *supra*.

³⁶⁷ On the long run the solution to place an information-burden on physicians is not the most efficient method to spread the necessary information effectively. The fact is that people need information on genetic diseases before they are tested. Only a small percentage of people believe or realise that they might suffer from a genetic anomaly and accordingly undergo genetic tests. To solve this problem of ignorance, Andrews *op cit* p 184 suggests that basic education on genetic abnormalities is given at school level.

³⁶⁸ and that these professionals should be held accountable if they do not comply with their duty to inform.

³⁶⁹ *op cit* p 206.

³⁷⁰ *op cit* p 1695.

³⁷¹ Strauss *op cit* p 69, also **S v Progress Dental Laboratory (Pty) Ltd and Another** 1965 (3) SA 192 (T).

have to reach agreement or consensus on the important terms and conditions of the contract in question.³⁷² It is submitted that there exists a distinct correlation between the pre-contractual negotiations before an ordinary contractual agreement and the informative session by a physician before the patient actually consents to the perceived medical intervention or treatment suggested by the physician.

16.7 Liability for failure to inform

Grubb³⁷³ mentions that from an English viewpoint, liability resulting from medical procedures is mostly based on negligence. He mentions, however, the exemplary case of **Thake v Maurice**³⁷⁴ where the court found that a physician can similarly be held liable on breach of contract and therefore also in the absence of negligence.³⁷⁵ *In casu* the court judged that the physician gave an implied guarantee of success regarding the performance of the sterilization procedure, based on the fact that he *neglected to inform* his patient of the possible failure of the operation and also neglected to warn his patient of the risks involved, if he resumed sexual relations before first undergoing a fertility test.

Legemaate³⁷⁶ explains that the mere fact that a physician has failed to provide proper information to a patient,³⁷⁷ will not by itself be sufficient to result in liability for the physician. The plaintiff-patient will firstly have to prove that he in fact suffered damage as a result of the failure to inform.³⁷⁸

A plaintiff will further have to prove that there exists a causal link between the wrongful conduct and the resultant damage. The patient asserts that he would not have given consent to the particular medical intervention in question, had he been properly informed. The question then

³⁷² see ch 2 for a more detailed discussion on the contractual principles regulating the physician-patient relationship.

³⁷³ 1985. *The Cambridge Law Journal*, 30.

³⁷⁴ (1984) 2 All ER 513, discusse *supra*.

³⁷⁵ see also ch 2 regarding the physician's contractual guarantee and ch 6 in respect of wrongful conception actions.

³⁷⁶ *op cit* p 204.

³⁷⁷ *ie* in breach of his duty to inform - (wrongful conduct).

³⁷⁸ *eg* damage resulting from a pregnancy after a failed sterilization - see wrongful conception ch 6.

arises on who the burden of proof is.³⁷⁹ Legemaate reports on a wrongful conception action based on a failed sterilization procedure, where the Utrecht court³⁸⁰ found that no causal link was proved, because the patient failed to indicate that she would have chosen an alternative procedure had she been properly informed. He is nevertheless convinced that such an action should in principle succeed and does not see the proof of causation as a major stumbling block.

The following aspect to consider is the conduct of the medical professional under the circumstances. Legemaate states that the point of departure should be the level of proficiency that could reasonably be expected from the physician at the particular time. He once again refers to the issue of failed sterilizations to address the point. He writes that although a number of physician are held liable for a failure to properly execute the sterilization procedure itself, many physicians are sued for their failure to inform the patients of the small failure rate associated with the particular procedure in question.³⁸¹

16.8 Dutch guidelines for disclosure of information

Beer³⁸² reports on the special statutory regulations concerning the disclosure of information as found in the seventh title of the Dutch Civil Code:³⁸³ It is submitted that these statutory provisions could be used as helpful guidelines in determining where emphasis should be placed for patient protection and could indicate what conduct is legally expected from medical professionals.

Artikel 1653c

*Indien de patiënt te kennen heeft gegeven geen inlichtingen te willen ontvangen, blijft het verstrekken daarvan achterwege, behoudens voor zover het belang dat de patiënt daarbij heeft niet opweegt tegen het nadeel dat daaruit voor hemzelf of anderen kan voortvloeien.*³⁸⁴

³⁷⁹ Legemaate conveys that there is Dutch support for the opinion that the burden of proof lies on the medical practitioner to repute a causal *nexus*.

³⁸⁰ *Rechtbank Utrecht* 26 juli 1995.

³⁸¹ both grounds of negligence could fall together as well.

³⁸² 1991. **Aansprakelijkheid voor Medische Fouten: Vanuit Juridisch oogpunt gezien** Koninklike Vermande BV. Lelystad, 12.

³⁸³ *Zevende Titel A van het Vierde Boek van het Burgerlijke Wetboek wordt een nieuwe titel ingevoegd, luidende Zevende Titel B, de overeenkomst inzake geneeskundige behandeling:*

³⁸⁴ a paraphrased summary of this quotation is: where a patient has made it clear that he does not want to be informed, such wish should be respected, unless the consequences thereof is disproportionately prejudicial to the patient or others.

Artikel 16531

Onverminderd het in artikel 1653b, tweede lid, tweede volzin, bepaalde verstrekt de hulpverlener aan anderen dan de patiënt geen inlichtingen over de patiënt dan wel inzage in of afschrift van de bescheiden, bedoeld in artikel 1653i, dan met toestemming van de patiënt. Indien verstrekking plaatsvindt, geschiedt deze slechts voor zover daarvoor de persoonlijke levenssfeer van een ander niet wordt geschaad. De verstrekking kan geschieden zonder inachtneming van de beperkingen, bedoeld in de voorgaande volzinnen, indien het bij of krachtens de wet bepaalde daartoe verplicht.³⁸⁵

Onder anderen dan de patiënt zijn niet begrepen degenen van wie beroepshalve de medewerking bij de uitvoering van de behandelingsovereenkomst noodzakelijk is en degene die optreedt als vervanger van de hulpverlener.³⁸⁶

Artikel 1653m

In afwijking van het bepaalde in artikel 16531, eerste lid, kan de hulpverlener zonder toestemming van de patiënt ten behoeve van statistisch of ander wetenschappelijk onderzoek op het gebied van de volksgezondheid aan een derde desgevraagd inlichtingen over de patiënt of inzage in de bescheiden, bedoeld in artikel 1653i, verstrekken indien aan de volgende voorwaarden is voldaan:

Het vragen van de toestemming is in redelijkheid niet mogelijk;

Het onderzoek dient een algemeen belang;

Het onderzoek kan niet zonder de desbetreffende gegevens worden uitgevoerd; en

De persoonlijke levenssfeer van de patiënt wordt daarvoor niet onevenredig geschaad.³⁸⁷

³⁸⁵ A paraphrased summary of this quotation is: A medical professional may not disclose any information of a patient to third parties without the explicit consent of the patient. Disclosure of information under these circumstances may only take place if there are no infringement of a personal nature. Disclosure outside of the mentioned scope of consent may, however, take place where it is so provided in an act.

³⁸⁶ a paraphrased summary of this quotation is: Assistant medical staff and all additional service providers who are necessary for the medical treatment agreement and their replacements are to be considered in the same privileged position as the physician.

³⁸⁷ a medical professional may also disclose patient information without consent for statistical and scientific purposes in the context of public health, under the following circumstances:

- where it is reasonably not possible to obtain consent;
- where the examination serves a general purpose;
- the examination in question cannot be performed without the relevant data;
- the patient's personal sphere is not disproportionately prejudiced by the disclosure of information.