STRIKING THE RIGHT BALANCE
PATIENT'S RIGHTS AND OPPOSING INTERESTS WITH REGARD TO HEALTH INFORMATION

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1. Introduction

The relationship of confidentiality between doctor and patient dates far back in time. The Hippocratic writings on medical ethics from around year 300 BC are often mentioned as the source of doctors' ethical duty of confidentiality. At the time of Hippocrates, the doctor-patient relation was that of a personal relationship. Today a patient's relation to the health sector is much more complex. During treatment a patient may come into contact with a number of different health care professionals and health care institutions and there is thus often a need to exchange information regarding the treatment. The application of e-health (electronic patient files, telemedicine etc.) paves the way for an efficient exchange of patient data among health care professionals and care institutions. However, a widespread dissemination of sensitive information may jeopardize the confidential relation between doctor and patient. Furthermore, the information about a patient collected in the health sector is becoming increasingly important in a number of other settings such as those connected with health administrative functions, research and educations, social sector functions, and insurance and employment relations. There is thus a wide range of persons, authorities, and institutions that may have an interest in gaining access to patient information, and this raises the question of patients' rights and how these rights should be balanced against opposing interest and rights.

Patient's right to confidentiality and privacy are often equated. However, although both concepts of rights deal with the patient's private life, they must be distinguished as they have different scope and to some extent serve different purposes. Patient's right to self-determination is also closely related to privacy and confidentiality as respect for the patient's right to informational self-determination is a way of recognizing the patient's privacy rights. Consequently, patients have various rights in regard to patient information.

The paper aims to examine to which extend patient's rights to confidentiality, privacy and autonomy are recognized in connection with collection and use of health information, and how these rights are balanced towards medical and administrative interests in efficiency.

2. The concept of confidentiality

As mentioned by way of introduction, the confidential nature of the doctor-patient relationship dates far back in time, and rules of confidentiality have long been common in codes of medical ethics as well as in legal regulation. Confidentiality rules in the health care sector are concerned with *confidential information* which the patient have entrusted the doctor or another health care person in *confidence*, that is with the expectation that this information will not be divulged to a third party without the patient's prior permission. Confidential information is normally defined as information which there is a substantial public or private interest in keeping secret.

Confidentiality rules are often equated with *privacy* rights and it is true that both confidentiality and privacy deals with the protection of private information. However, as already indicated, the concept of confidentiality exceeds the concept of privacy because it has to do with information disclosed within a confidential relationship. Beauchamp and Childress (2001:340) explain the difference this way:

> "An infringement of a person's right to confidentiality occurs only if the person (or institution) to whom the information was disclosed in confidence fails to protect the information or deliberately discloses it to someone without first-party consent. By contrast, a person who without authorization enters a hospital record room or computer data-bank violates rights of privacy rather than rights of confidentiality"

Accordingly, confidentiality is associated with a *relationship*, which is not necessarily the case with regard to privacy. The relational character of confidentiality also fosters another crucial feature of the concept of confidentiality; that is the linkage to *trust*. The patient's relation to health care professionals is founded on trust and confidence. Rules of confidentiality provide the patient with a kind of assurance that he can trust the doctor, and trust is, for many patients, a precondition to reveal confidential information to the doctor. Accordingly, if there is a breach of confidentiality there is at the same time a violation of a trust relation.

Another important component of the concept of confidentiality is the connection to patients' *autonomy* rights. Patients may decide to reveal confidential information to third parties in which case there may be a loss of confidentiality and privacy, but no violation of these rights as the patient himself has decided to do so.

According to Beauchamp and Childress, an ethical principle of confidentiality may be *justified* by means of three types of ethical argument; namely consequentialist arguments, rights based autonomy and privacy arguments, and finally by referring to fidelity. These ethical arguments are also reflected in the legal basis for rules of confidentiality. The *consequentialist arguments* refer to the interest in being able to provide proper care and treatment for patients. If patients fear that physicians will reveal information to third parties, they might be reluctant to contact the physicians or to disclose the full medical history, and this could hamper the doctor's possibility to give a diagnosis and to make recommendations regarding the best possible treatment. This concern is e.g. reflected in rules and regulations which endorse confidentiality while at the same time allowing derogations from confidentiality requirements where substantial public or private interest speaks in favour of this. Accordingly, the consequentialist arguments are concerned with the interest in promoting the best consequences seen from the perspective of the patient, the health care professionals and that of public health. *Autonomy* and *privacy* arguments do not focus on the consequences but on the value of autonomy and privacy in itself. According to this line of thinking, respecting persons autonomy and privacy are valuable in itself despite of possible bad consequences. It has to do with paying respect for the patient as a person. This point of view is also supported in the legal regulation of confidentiality where the patient's consent in a number of situations is necessary if information is to be disclosed to third parties. Finally, *fidelity* arguments also support a right to confidentiality as fidelity draw attention to the obligation to keep promises, to fulfil agreements and maintain relationships.

3. Stakeholders and interests

It is not only the patient and the doctor who have interests with regard to the use of health data. There are a number of other stakeholders and interests involved, and the individual stakeholder may also have various interests. Consequently, it is a demanding task to navigate this complex, legal minefield.

The *patient* is certainly a very important stakeholder. However, patients have a number of different interests in regards to the use of health data. First and foremost, most patients' priority is to receive proper treatment and care in order to retain good health, and they would normally favour any collection and use of health information which could be beneficial in this regard. On the other hand, patients would normally not like confidential information to be disclosed to third parties who is not involved in the actual treatment – at least not without their prior consent. That could be to an insurance company, the employer, the social services, the police, a researcher, and maybe even their relatives. Accordingly, patients also have an interest in privacy and an interest in having influence on who should have access to their personal data.

The *health care services* could also be considered a stakeholder. There are various ways of organising the health care services at a national level (Hervey & McHale 2004). Some countries favour a strong public involvement in health care, and have a health care service which is primarily financed through taxation. In other countries financing of the health care services is primarily based on an insurance system which in many cases is combined with a public financed health insurance scheme for citizens not covered by a private health insurance. Irrespective of the organisation of national health care services, there is a public health interest in having a healthy population, and consequently also in interest in the use of health information to the benefit of public health. Seen from a public health perspective it would be beneficial to allow for a free flow of information among health care professionals as this is supposed to support public health. Furthermore, collecting patient data for administrative and planning purposes or quality control is also considered important. On the other hand there is also an interest in preserving patients' confidence in the health care services in order to ensure that patients do not abstain from contacting their physician because they fear that private information will be disclosed to persons, authorities or institutions which they would not like to have access to their private lives.

Health care professionals also have interests in regards to the use of health information. In order to provide proper treatment and care, health care persons find it necessary to have easy access to all necessary and available information about an individual patient. On the other hand, it is also important for health care professionals to maintain a trustful relationship to the patient and health care professionals would, consequently, also support some kind of confidentiality rules.

Finally, information about particular patients may also be of interest for a number of other stakeholders, such as insurance companies, employers, public authorities (e.g. social services, the police and schools) and private persons like relatives and friends.

In some situations the interests of the patient go hand in hand with the interests of other stakeholders. Patients would normally like their physician to have all necessary information in order to make a proper diagnosis, as well as patients would allow the social services to have access to information which is necessary to document a right to social benefits. However, even though there are mutual interests, it is still important to reflect more carefully on the legal framework, including considering which importance should be paid to patient autonomy with regard to disclosure of information.

In other situations their may be a conflict of interest, e.g. if the police wants to get access to information about persons who have been treated at the emergencies, or if an employer would like to get detailed information about an employee's current and previous health situation. Consequently, in many situations it might be necessary to make an assessment of which interest should prevail. In the last part of this paper I will discuss a few selected situations where conflicts of interest may occur and where there is a need to make a balancing between opposing interests. The scope of the paper does not allow for a comprehensive analysis, and I will, consequently, restrict the focus to situations where a conflict of interest is not immediately apparent, but might however show to be at issue. Apart from drawing on international legislation I will include examples from an empirical study of case law from the Danish Patients Complaints Board.[1]

4. Communication among health care professionals

A patient's relation to the health care sector is more complex nowadays than at the time of Hippocrates. During treatment and care a patient may come into contact with a number of different health care professionals and health care institutions, thus, it is often needed to exchange information regarding the treatment (Sokalska 2004). A patient, who contacts the General Practitioner (GP), may be referred to hospital treatment, and it is necessary to provide the hospital with certain information about the patient's symptoms and diagnoses. At the hospital a number of persons will be involved in the treatment and care, and when the hospital treatment is completed, it may be necessary to provide the GP with information so that she can continue and follow up on the treatment. The question is whether this form of communication between health care professionals is an infringement of the patient's right to confidentiality.

It is often claimed that communication among professionals who are actively involved in the treatment of an individual patient, is based on a *presumed* or *implied consent*. When a patient gives his informed consent to the proposed treatment, this also implies consent to communication of information which is necessary to provide the patient with proper treatment and care. This line of reasoning is reflected in WHO's Declaration of the Promotion of Patients' Rights in Europe which stipulates (in principle 4.1) that "Consent may be presumed where disclosure is to other health care providers involved in that patient's treatment".[2]

Another line of arguments stress that the professionals involved are all bound by a duty of confidentiality and that, consequently, there could be no violation of confidentiality rights as the information stays within a *"circle of confidentiality"*. Article 8.3 of EU Directive 95/46/EC on the Protection of Individuals with regard to Processing of Personal Data is an illustrative example of this position. According to this provision the prohibition against processing of sensitive data shall not apply where personal data is required for – amongst other purposes – medical diagnosis and provision of care and treatment provided these data are processed by "… a health care professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy".[3]

The Council of Europe Convention on Human Rights and Biomedicine is not very explicit in regards to confidentiality rights. The Convention addresses the right to private life and information in article 10, but neither the wording of this provision nor the explanatory report illuminate whether exchange of patient data within the health sector is outside the scope of patients' right to confidentiality. However, the question is addressed in Council of Europe Recommendation R (97) 5 on the protection of medical data which stipulates (in principle 4.4 and principle 7.3.d) that data may be processed without an explicit consent if permitted by law and provided it is necessary for preventive medical purposes or for diagnostic or therapeutic purposes with regard to the patient. This indicates that, in principle, disclosure of information to other health care professionals could be a violation of the patient's right to private life as laid down in article 8 of the European Convention of Human Rights (ECHR), but that this right could be restricted in accordance with the conditions set out in ECHR article 8.2.

In other words the legal basis of communication among health care professionals may either be the presumed or implied consent of the patient or a sufficiently clear legal basis in law as stipulated in ECHR article 8.2. In case of the latter the other conditions laid down in article 8.2 must also be fulfilled which means that it must be necessary in a democratic society to ensure free communication among health care professionals in order to protect e.g. public security or for the protection of health.

Normally, patients do not oppose that health care professionals involved in their treatment and care receive necessary information. However, there may be disagreement about which health professionals are legitimately involved and to which extend it is required to provide these professionals with information. A decision from the Danish Patient Complaints Board may serve as an example.

> The patient, a young woman, was receiving psychiatric care at a hospital. At time of the ordinary winter holiday, she asked to be discharged from the hospital to spend the vacation with her husband and daughter. The hospital staff opposed her decision because they assessed it would be better for her to stay at the hospital, but as her condition was not of a kind that could justify compulsory care they had to discharge her from the hospital. It was decided that she should contact the local psychiatric team which would receive information about her treatment. However, the hospital also informed her GP about her medical condition and of her being discharged from the hospital. When the patient came to know about the communication to the GP, she filed a complaint to the Patients Complaints Board claiming that her right to confidentiality had been violated as she had not given permission to inform the GP and as he was not presumed to be involved in her treatment. The hospital staff argued that they found it necessary to inform the GP as he would be involved if it turned out to be necessary to take the patient into compulsory care while she staid with her family during the vacation. This argumentation was supported by the Patients Complaints Board which did not find that her confidentiality rights had been infringed.[4]

The case is interesting because it illustrates the interest of patients in being informed and having influence on who should have access to health information. The Patients Complaints Board's position is based on consequentialist arguments favouring what is considered to be in the patient's best interest whereas it does not acknowledge autonomy and privacy arguments.

The possibilities of sharing information among health care professionals will improve extensively along with the implementation of a comprehensive system of electronic patient records and networks in the health care services. This would represent a further challenge to patients' possibilities of having influence on their personal data, and it is crucial to consider this development more carefully.

5. Communication to persons, authorities or institutions outside the health care sector

Compared to the situation outlined in the previous paragraph the situation is different when third parties outside the health care sector wish to get access to confidential patient data. When health data are disclosed to other health professionals they are normally used in compliance with the purpose of collecting the data and they are preserved within a "circle of confidentiality". This is not necessarily the case if it is requested to disclose health data to an insurance company, the patient's employer or to the social authorities.

Patients expect confidentiality and will normally wish to have influence on who should have access to his or her personal data. However, in certain situations the interest of third parties in getting access to patient information may overrule the patient's right to confidentiality. As the space does not allow for a comprehensive analysis, I will only touch upon the communication to third parties in situations where a patient has applied for social benefits. This situation resemble – to some extend – to the situation addressed in the previous paragraph because the patient himself would have an interest in disclosing information in order to obtain a social benefit. However, in case the patient will not permit the disclosure of information the social services might claim that it is in the public's interest to have full access to information to ensure that only persons who fulfil the criteria are granted a benefit. Consequently, the questions is whether it is necessary to try to obtain an explicit consent to disclose data or if consent is not required because substantial public interests speak in favour of disclosing information

Looking into the international rules and regulations there seems to be some uncertainty about how this question should be answered. The EU Directive 95/46/EC on processing of personal data accepts (article 8.2.e) that sensitive information may be processed without the individual's consent if it is necessary for establishment, exercise or defence of legal claims. The European Convention of Human Rights protects the right to private life in article 8, but it is possible to intervene in this right if it is in accordance with law and necessary in a democratic society in the interest of e.g. the economic well-being of the country or for the protection of health and of the rights and freedoms of others. The case law of the European Court of Human Rights may shed light on this assessment.

> In M.S versus Sweden[5] the European Court of Human Rights found that a hospital's submission of a patient's medical record to the Swedish Social Insurance Office without her prior consent entailed an interference with her right to respect for private life guaranteed by ECHR article 8.1. However, the court also found that the disclosure was justified under article 8.2 as the purpose was to enable the Social Insurance Office to determine whether the conditions for granting compensation had been met and it could thus be regarded as having pursued the aim of protecting the economic well-being of the country. Furthermore, the Office had a legitimate need to check information received from the patient herself to determine whether her claim was well-founded, and in addition, the contested measure was subject of important limitations and accompanied by effective and adequate safeguards against abuse.

Consequently, it seems that both EU law and human rights law gives priority to an administrative interest in making a right decision and pursue legal claims instead of putting an emphasis on the individuals right to confidentiality and right to decide if he would like to sacrifice some of his privacy to obtain a social benefit.

Opposing to EU and human rights law, Danish legislation require an explicit consent from patients to disclose information when the social services consider an application for social benefits. The Danish Patient Complaints Board receives a number of complaints where patients feel that there confidentiality rights have been violated in connection with disclosure of information from patients' files to the social services. In most of these cases the patient has given an explicit consent, but is nevertheless surprised when he or she learns about the specific kind of information which has been provided for the social services. Often the doctors have revealed information which the patient did not believe could have any relevance to the application of a social benefit, and patients feel that their privacy has been infringed when social workers learn about e.g. psychiatric conditions or abortions from their medical history. A case from the Danish Complaints Board could serve as an example:

> A patient suffering from a back condition had applied for a sick allowance, and the social services had asked for and got the patient's permission to collect medical information about the condition. The hospital forwarded the patient's medical file to the social services, but apart from information about the back condition this file also included information about the patient having alcohol problems. The patient learned about that when the social worker confronted him with his possible alcohol problems and he filed a complaint to the Patients Complaints Board. The hospital explained that the patient had given consent, and, consequently, there could be no breach of confidence. The Patients Complaints Board, however, found that the patient's right to confidentiality had been violated. The request from the social services on information was imprecise, but it was the hospitals responsibility to clarify the request and the scope of the patient's consent before disclosing confidential information to the social services.[6]

This case illustrates that even in situations where patients consent have been obtained, it is still important to ensure that the consent is sufficiently informed and explicit to enable the patient and the health care professionals to have a more detailed picture of exactly which pieces of information is covered by the permission to disclosure.

6. Concluding remarks

Confidentiality, privacy, trust and autonomy are closely interrelated in connection with the use of patient information for various purposes. The topics addressed in this paper show that confidentiality can not be reduced to respect for privacy rights. Confidentiality is also about sustaining a trustful relation between the patient and the health care services and this relation is also dependent on the respect shown to patients by the health care professionals. Respecting patients as persons imply respect for the patient's autonomy. Patients must be informed about and included in the activities performed by the health care professionals – and this also applies to the collection and disclosure of information. One might claim that in many situations patients do not have a choice. If they want proper treatment and care, and if they need to have a sick allowance, they have to accept the disclosure of information. Consequently, asking consent is a mere formality. However, asking permission also involves that patients are properly informed about the communication and it confirms that patients are taking seriously as persons - and this might support the trust patients have in the health care services.

Looking at the legal framework, it seems that patient's autonomy is not given significant legal attention as a component of confidentiality. Whenever substantial competing interests are involved – like the interest in providing good patient care and administrative efficiency - the patient's autonomy interests are easily down graded. This might be problematic as it affects the interest in preserving a trustful relation between the patient and the health care services.

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[1] An analysis of the case law is part of my Doctor Juris (LL.D) dissertation "Fortrolighed i sundhedsretten – et patientretligt perspektiv" (Confidentiality in health law – a patients' rights perspective"), Thomson, Copenhagen 2005.
The survey includes 550 decisions from the Patients' Complaints Board which deals with complaints regarding breach of confidentiality and denied access to health data.

[2] WHO, "A Declaration on the Promotion of Patients' Rights in Europe", 1994

[3] See also recital 33 to the Directive which stress that derogation from the prohibition to process sensitive data is justified, particular where processing of data is carried put for certain health related purposes and by persons subject to a legal obligation of professional secrecy.

[4] Decision number 9914203. The decision is available in Danish at www.pkn.dk

[5] M.S. v. Sweden, 27/8 1997

[6] Decision number 0128606. The decision is available in Danish at www.pkn.dk.