Telemedicine and responsibility: why anthropomorphism and consent issues muddle the picture

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Abstract

This paper introduces problems arising from the use of devices and systems of Information and Communication Technology (ICT) mediated health care (e.g. telemedicine) and the liabilities and responsibilities arising from that use. These issues are discussed based on the concepts of informed consent, negligence and anthropomorphism. This paper is a review of literature supported by some recommendations by the authors. The paper concludes that the use of suggestions from e-commerce side can and should be followed in the design of telemedicine devices and systems, and the users should be aware of the nature and the use of these devices and systems in various health care situations.

Keywords

Telemedicine, Anthropomorphism, Consent, Patient-Physician Relationship, Responsibility.

1. INTRODUCTION

In telemedicine health care is mediated using different ICT artefacts. Ethical issues in telemedicine are easily left to a lesser degree of attention than they ought to. Many of the solutions of telemedicine exist today only to serve the purposes of better profit and decreased costs of operations. These reasons are valid, but they can not be pursued at the expense of ethics, which is the foundation of medical practice.

When ethical, legal and risk issues in telemedicine, and in ICT-mediated health care in general, are considered the following issues are typically raised (for example Rodrigues 2000, Stanberry 2001 and Wagner 1999):

- Confidentiality,
- Security,
- Consent,
- Responsibility, and
- Liability.

In this article, we will be interested in the responsibility issues related to the field of telemedicine, to which the consent and liability issues are closely tied. Rapid advance of information and communication technologies (ICT) and their central role in telemedicine has created a concern about a patient's ability to identify where the responsibilities are when telemedicine is used. The patient does not necessarily know when an actual doctor-patient relationship is formed or with whom it is formed. ICT intensifies this problem since in telemedicine ICT does not only enable information exchange with physicians or other professionals of health care; it also enables the use of different information systems or devices in the decision making process related to the actual care. This is problematic especially in a situation where the patient is not aware that the interaction originates from a device or a system, not from a clinician.

The lack of ethical procedures, guidelines and standards in the field of telemedicine could be easily blamed on the speed of technological development. This view, however is flawed since many of the legal and ethical issues related to telemedicine are common to health care in general (Stanberry 2001). These issues just emerge in a different fashion when they are considered in the context of telemedicine. In general, the change has been so rapid that legislation and standardization have not been able to keep up with the pace.

This is also the case in telemedicine where legislation is inconsistent varying from reasonable to very strict (Wachter 2002), and where professional guidelines, standards and regulations are either inadequate or do not exist (Stanberry 2001). Due to the development of technology being very rapid, standardization and legislation tend to be reactive, not proactive. This has resulted in telemedicine-specific rules and regulations to come into force after the applications and systems are already in production. However, in order to ensure successful and frictionless adoption of different applications and systems of telemedicine, consideration on how to adopt and integrate them to the health care in general must be made beforehand, not when they are already in production.

2. DEFINING TELEMEDICINE

The concept of telemedicine has various interpretations. Literally telemedicine means "medicine at distance". A more formal definition for telemedicine is provided by the European Commission (1993): "Rapid access to shared and remote medical expertise by means of telecommunications and information technologies, no matter where the patient or relevant information is located".

Amongst others, telemedicine has applications in basic health care (diagnostics and treatment), health education, self-care and research. Due to the broad spectrum of applications the term "telemedicine" is considered too narrow and in some cases it is replaced with terms like "telecare" or "telehealth" to indicate a broader field that involves all health professionals (Coiera 2003). In this text, telemedicine is considered as an inclusive term, which covers all health care professionals and different customers of health care services.

Telemedicine has a long and interesting history. If telemedicine is considered in a broad sense, it came about with the introduction of telephone when Dr. Alexander Bell called "Watson come here, I want to see you" on March 10, 1876 because he inadvertently spilled acid on himself (Hodson 2003). Today, medical practitioners around the globe are starting to realize the potential of telemedicine applications. Powered by modern telecommunication technologies, it is possible to interact with colleagues and patients around the globe. This possibility to overcome geographical distance is considered as the major technical novelty in telemedicine (Raes 1997). Example applications of today include: remote consulting, transfer of images and health data on patients, data mining of patient records for use in medical education, intelligent medical systems (see e.g. King et al. 2002), and interaction with medical hardware such as diagnostic instruments or remote monitoring of a patient either by a clinician or by a system or a device.

3. DEFINING ANTHROPOMORPHISM

Anthropomorphism, which commonly means endowing human characteristics to nonhuman objects or forces, arose initially in the context of theology, where the question was how to understand the nature of God. In the context of ICT anthropomorphism is commonly attributed towards artificial intelligence, robotics or user interfaces (see e.g. Carrier 1990). According to Takeuchi and Naito (1995) through active anthropomorphizing even experts are easily led to act as if the computer software was a social actor, let alone laymen in regard to computers and software such as the patients or physicians using the systems.

Anthropomorphism has intentional and unintentional dimensions. Intentional, or planned, anthropomorphism exists when human-like attributes are purposefully introduced to electronic services and applications in order to provide natural and comfortable interaction, and conversational communication (Takeuchi & Nagao 1993, Marsh & Meech 2000). Non-intentional, or unconscious, anthropomorphism occurs when people humanize the inhuman for example, by attributing human-like attributes to computers and other media treating them like people (Heckman & Wobbrock 2000). According to Heckman & Wobbrock (2000) "With surprising ease, overly trusting consumers may be persuaded to interact with anthropomorphic agents in a way that endangers them." This is even more the case in telemedicine, where the possible danger is direct and ever-present due to the nature of the situation. In the field of telemedicine, intentional anthropomorphism exists for example in applications and systems of telepresence, and in patient-monitoring agents.

Regardless of the potential benefits of intentional anthropomorphism there are some possible risks; especially in the matters of authenticity, trust and credibility (Dowling 2001). Users must be able to discriminate between real and unreal. As Dowling (2001) suggests, the inability to make a distinction between human-oriented and machine-oriented data is of importance; but the authors want to stress the importance particularly in telemedicine and in health care in general, since people must be able to effectively utilize and judge information they receive. If the information is of dubious value, it is unlikely to be incorporated into the individual's decision making (Bengtsson et al. 1999) but if the information received from an intentionally or unintentionally humanized interface is taken uncritically, the questions do not arise even when they ought to.

4. CONSENT

Consent is one of the key issues when ethical, legal and risk issues in telemedicine are considered. Consent is about acceptance and of the need for the patient to give fully informed approval for the physical examination, other health care procedures, and also to the use of electronic data, which contains personal identifiable health data.

In general, two types of consent can be identified: implied and express. Implied consent is behavioural (for example, the patient undresses for the examination). Express consent is explicit; the patient gives permission orally or in writing (Machin 2003). Consent can never be regarded as a paper or mere process, it is essential that the patient knows what the consent is about and what the patient agrees to (i.e. the patient is informed). Without knowing what the consent is about and what the consequences of it are, the patient cannot make sound judgments on the validity of the consent. In addition to being informed, the consent must be valid before the law; the patient must be legally competent and the consent must be given freely. The fourth issue raised by Machin (2003) is a requirement that the consent is appropriate (for example, consent to sterilization does not include bilateral salpingectomy).

Informed consent originally developed from common law principles of non-disclosure. Since then it has developed from various interpretations by the courts and legislatures into patient's right to participate in the decision-making process regarding to the type of treatment the patient is about to undergo (American Association of Endodontists 1997). In the majority of western countries patient's right for informed consent is protected by the legislation. Furthermore, the contents and structure of the content are defined in a detailed level (for example: Connelly 2000). Despite the legislation, due to number and type of different actors potentially involved in the care and because of different interpretations on the contents of the consent, it can be difficult to ensure that the patient has given informed consent, or consent at all.

Different parties related to the care of patients exchange, require and contain different information in such amount that a complete picture of the information flow between the parties can be hard to control – or even to understand. As communication with different parties outside the sphere of health care is required in greater extent, the complexity of exchanged information grows even more. For example, in the case of a chronically ill elderly patient the chain of service might require interaction with transportation, laboratory, general practitioner, specialist, nurses, and so on (Lehto 2000). All of these actors require different information on the patient and they interpret the received information in a unique way.

This kind of cross-referring between and within different actors might cause distortion of the exchanged health information especially when information is conveyed by a human actor between different artefacts of ICT, or when the exchanged information is converted to meet the requirements of different channels and standards used in communication between the artefacts of ICT. Distortion, or even corruption, of the health information can go unnoticed especially if the clinician or patient does not feel the need to question the validity or the reliability of the information conveyed by some artefact of ICT. Distortion and uncritical views towards ICT-mediated health information has direct implication on the consent and care. If the physician presents the information from an artefact of ICT to the patient or to the colleague as facts without verifying the validity and origin of the information the rationale behind the informed consent becomes flawed. Therefore the patient and the physician should always be aware of the origin of the information and of the possible effect of the used information exchange standard or mediating channel.

5. PATIENT-PHYSICIAN RELATIONSHIP IN TELEMEDICINE

Rapid advancement of ICT combined with organizational and social innovations has brought applications of telemedicine from health centers and hospitals to the layman. This change from a process or patient centered health care to consumer health care has created new business models, introduced new service providers and given room for new and alternative treatment methods. As applications of telemedicine become commonplace and multiform, they give birth to new forms of chain of care where the patient-physician relationship is more difficult to construct and, if constructed, it is in general inferior to the non-mediated interactions between patient and physician (Bauer 2003). The change in the relationship and in the duty that follows from the relationship has created a situation where the practice of telemedicine has intensified liability and risk issues, which are inherent in the conventional medical practice.

The purpose of telemedicine is to assist in delivery of health care regardless of the location of patient, health care provider and relevant information. In practice, this means that the patient can access not only their family doctor in the same town or cardiologist in the same country, but also some other health care professional anywhere in the globe. Or, by the nature of telemedicine, the patient can access all three of them. This means that there can be any number of professionals involved in the care of a single patient and these professionals can consult any number of other professionals anytime anywhere in the world during the period of care. The number and

geographical distribution of the physicians potentially participating in the care of a single patient has created a situation where the patient does not always know if and what kind of patient-physician relationship is created.

The relationship between patient and physician is further blurred with the use of technology, which plays a central role in telemedicine. As defined by European Commission (1993) the use of telemedicine is enabled by the use of information and communication technologies. This means that information exchange and communication, even decisions on how and what kind of care is provided to the patient can be based on different applications or information systems. Due to rapid advances in technology, applications and information systems used in telemedicine can range from inexpensive hand-held devices to email or telephone, or even to vast and complex expert systems of health care. In figure 1 we have provided an illustrative example of a potential network of communicating actors and artefacts that can all be related to the care of a single patient.

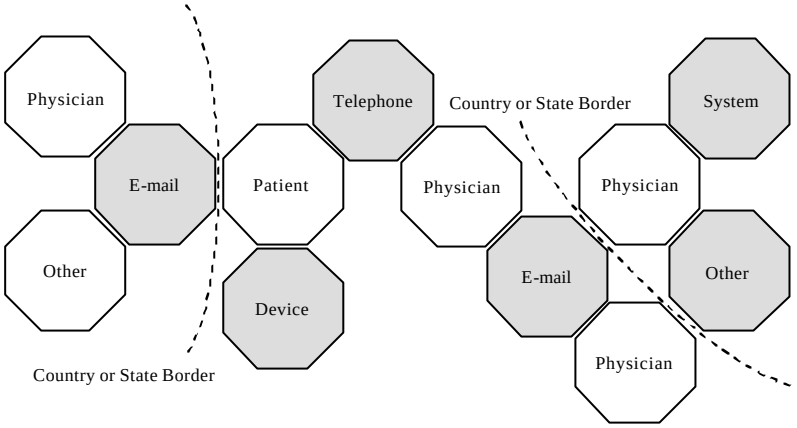

Figure 1. Example of potential actors and artefacts related to the care of a single patient.

This complicated web of different technologies and actors has already had an impact on the patient-physician relationship. When the patient and the physician meet face-to-face, they are generally in a situation where both parties are aware of the professional relationship and respect it. In telemedicine this mutuality is usually not present and the relationship can be formed on the basis of distant interaction without actual (physical) examination of the patient. Information on the patients or of their condition does not necessarily originate from the patient themselves but indirectly from another source, such as devices and applications of telemedicine.

Services and solutions where the patient-physician relationship is not formed or maintained in a traditional face-to-face manner are abundant in the internet. Especially different counseling and guidance services have become common during the last few years. For example, WebMD (http://www.healtheon.com/) which is one of the pioneering companies offering online health services for physicians and the general public provide feedback to the patient via e-mail on the following subjects (figure 2).

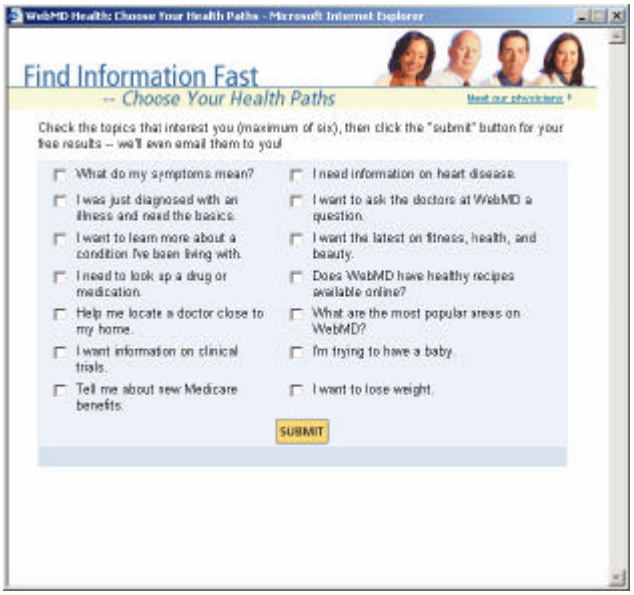

Figure 2. Information request form from WebMD (http://www.healtheon.com/).

Another example where the traditional patient-physician relationship is affected by introducing an artefact of ICT to the chain of care is a device, which provides (semi) automatic care for the patients suffering from diabetes. The device is a product of Medtronic MiniMed Inc. (http://www.minimed.com) and is approved by the Food and Drug Administration (FDA). The device interprets the metabolic situation of the patient and automatically calculates the correct bolus to the insulin pump for use. The bolus is not automatically injected and the product is not intended for every-day use but in our opinion approval of the device by the FDA can be considered as a prelude to a future where adaptable control loop systems are commonplace to self care. A similar device for personal diabetes treatment has also been researched in the EU-project ADICOL, which ended in 2002 (Information Society Technologies 2003).

At the moment physicians are generally aware of the source for their information regarding patients. As the applications and systems of telemedicine are developed enclosing more or less anthropomorphic features, the line between human-originated and machine-originated diagnosis becomes faint. One example of an anthropomorphic interface that mixes real and virtual data - potentially altering engagements between patient and physician (Bauer 2003) - is telepresence. This has a unique place within the applications of telemedicine. For example, at the moment applications of telepresence are utilized in the advanced casualty treatment procedures of the battlefield telemedicine (Riva & Gamberini 2000).

6. WHERE DOES THE RESPONSIBILITY FALL?

Liability and responsibility issues in telemedicine and in health care in general are intertwined with the concepts of malpractice and acts of negligence. Health care professionals have duties that are specific to their field of expertise. In addition, professionals must follow certain standards of health care in order to help their patients. If the professionals neglect their duties or breach standards of care, they commit negligent acts (Ashley 2002). Some of these duties and standards are common to all in the profession. Some of them are dependent on the legislation. In telemedicine the patient and the physicians in the care of the patient can all reside in geographically different locations. Therefore it can be difficult to decide which standards and laws apply.

The role of technology in telemedicine creates an interesting aspect with regard to liability and responsibility issues. It is according to the spirit of telemedicine that a device or system can be used for self-care or self-diagnostics, for example in diabetes. A physician may further use the information from the device or system and base the diagnosis or recommendation on care for the patient solely on that information. If the physician – when using a device or system – acts in accordance with a practice supported by a responsible body of medical practitioners experienced in the relevant specialty and causes direct or indirect harm to the patient, who can be held liable? The answer could be (For other examples, see e.g. Kienze 1999, Tremblay 1997 and McCarthy 2001):

- Equipment manufacturer,
- Equipment seller,
- Equipment operator,
- Maintenance provider,
- Telecommunications company (or other service provider),
- Sponsoring hospital or similar party, such as some governmental institute,
- Patient, or
- Health care provider at either or both ends of the chain of care for:
    - Decision to use or not to use,
    - Inadequate training,
    - Misuse, or
    - Misinterpretation of data.

In general, proving malpractice can be laborious. Before a physician or other health care professional can be blamed for such an act, it must be proven. In addition, the act must meet the criteria for malpractice or negligence in the legislation, which can vary regionally. Proving such an act can be particularly difficult since those who are accused are typically the ones who write the medical records and take a central part in the paper trail, which forms the basis of accusation. This can be even more difficult in ICT-mediated health care where the actual paper trail might not exist, except in the log files of different parties (if even there). And even if malpractice can be proven to have happened, the problem should have been solved before any such situation could even happen due to use of ICT in health care.

First, a patient-physician relationship which is the prerequisite for the duty that follows must be proven. The court may decide that the relationship is formed if some kind of advice has been provided. Then, it must be proven that the following duty has been breached. And finally, the harm caused by the breach must be pointed out (U.S. Congress 1994). If these three issues can be pointed out, the juridical basis for further actions is relatively solid. In telemedicine these issues become murkier, especially due to the lack of appropriate case law (Briggs and Morgan, Professional Association 2004) and due to the mosaic or web-like structure of different actors related in the care of a single patient. For example, in the following scenario proving patient-physician relationship, duty and harm can be difficult: the physician remotely diagnoses a patient on the basis of feedback from different devices and systems. Then the physician consults a number of different colleagues and expert systems for advice and second opinion. Due to the diagnosis received the patient must be treated. The treatment is provided by a group of physicians and other personnel using robotic surgery. Afterwards, different devices and systems are used to control the state of the patient. Some or all of the care provided after the patient has been discharged is done by using approved instruments and systems of self-care and self-diagnostics. Who is responsible in the case of malpractice or negligent act, how such an act and its consequences can be pointed out?

Certain information systems of health care keep extensive logs on what information has been accessed and altered, who has done it and the original record. The paper trail and medical records are replaced with electronic counterparts and access to the information is monitored. In this case, it is not easy to alter or hide information afterwards. However, in general the logging only provides information about the accessed and altered data, it does not necessarily provide sufficient information on the act itself; what has been done and by whom; or moreover, what is thought to be done and whether the act was intentional or not. The interpretation of the action still remains with the actors themselves.

7. PROPOSED SOLUTIONS

7.1 Legislation and International Cooperation

The role of different standards, guidelines and recommendations increases in the working life. Different companies apply different standards and protocols in order to ensure the high quality and efficiency of their products and processes. Especially in health care these instructions are plentiful, yet most of them are not applicable, or are not applied, to the telemedicine in particular. The scarcity of different telemedicine-specific recommendations and instructions suggests that telemedicine has not yet become routinely used and therefore can be regarded as immature (Loane & Wootton 2002). As telemedicine is commonly considered to be one of the most significant ways of providing high quality care for the increasing amount of elderly people, the need for developing these standards, guidelines and recommendations in global cooperation is now – not when different devices and systems of telemedicine are in production and routine use.

As long as legislature is not violated, organizations and individuals related to the care of a single patient can craft their own private agreements on responsibility and liability matters. Therefore, especially in the field of telemedicine, responsible partnering must be employed. Responsible in such a manner that partnering agreements are formed only with organizations and individuals who comply with the relevant standards, guidelines and recommendations of good practice. An issue closely related to responsible partnering is transparency. Transparency in partnering and funding is needed in order for each partner to demonstrate capability, and a commitment to assess its own dependencies and interests. Principles of responsible partnering, informed consent and privacy, amongst others, are included in the eight principles of eHealth Code of Ethics, which was introduced by the Internet Healthcare Coalition (IHC) in the spring of 2000 (Carey 2001).

It is particularly problematic when information systems or devices of telemedicine are unintentionally anthropomorphized. This hinders the ability to treat the applications with the required objectivity. In order to prevent this unwanted anthropomorphism, the type and identity of the corresponding party must be clearly established. Both the patient and the health care professional must be aware that they are using a system, not consulting with another person. On top of this, they must be knowledgeable enough to not trust the system as if it were a person who has a wider understanding of the situations surrounding the actual question at hand. This could be done with technical means by removing the unnecessary intentional anthropomorphism from systems and devices, and by defining distinct means for separating human-oriented information from machine-oriented.

7.2 Advice from E-Commerce Solutions

We agree to a large degree with the danger reducing suggestions made by Heckman & Wobbrock (2000) in regard to anthropomorphic agent design and we are confident that these suggestions can be applied to the field of telemedicine. When applied to telemedicine the design suggestions can assist in limiting threats to the consumers and users of the devices and systems of telemedicine. Heckman & Wobbrock (2000) present five different suggestions in their article:

- Create transparent agents,
- Create humble agents,
- Avoid unnecessary realism,
- Carefully consider agent-mediated persuasion, and
- Facilitate user goals.

The following suggestions are according to Heckman & Wobbrock (2000) and they can be modified to fit the field of telemedicine in the following manner.

Create transparent agents. In the anthropomorphic agent design this principle suggests that the agent should not be a "black box", which presents apparently intelligent thoughts and behaviors. Instead, the agent should inform the user of their intentions and when needed, explain their actions. Similarly, the principle of transparency should be adapted to the devices or systems of telemedicine. The decision making criteria, as well as the utilized health information (or other data) and its origin, should be clearly presented to the user. Furthermore, the device or system should be able to present the rationale behind the use of certain analysis method or algorithm. This kind of transparency should lessen the illusion of infallibility of ICT, and it should assist in decision making since the origins of the decision provided by the device or application are present.

Create humble agents. Anthropomorphic agents should be designed in such fashion that they do not strive to maintain the illusion of life by turning around an unanswerable question. They suggest that the agent should rather inform the users of the boundaries of their abilities. In telemedicine the awareness of the limitations and boundaries of the artefact in question is of utmost importance, since the information provided by them can be utilized in a critical decision making in regard to the health and care of the patients. When the device or system of telemedicine provides results to the user, it should be able to present the error margins and risk factors related to the results. In addition, if the system recommends certain treatment on the basis of the results, it should be able to reflect the error margins and risk factors to the potential risks emerging from applying the suggested treatment. This view is also supported by Don et al. (1992) who consider that systems, which are capable of behaving as interactive partners, should be able to present their limitations frankly. By combining the principles of creating transparent and humble agents, the user should be sufficiently informed about the potential risks related to the use of the artefact and if the user should transfer this knowledge forward, for example to a patient, it should promote aspects related to making an informed consent.

Avoid unnecessary realism. In many areas of user interface design realism is used to provide a better user experience. However, there is no clear indication that realism should result in better user experience. The principle of avoiding unnecessary realism should be applied when device or system of telemedicine is designed. By avoiding unnecessary realism the unnecessary anthropomorphism of the artefact can be reduced. In this regard the impact of the anthropomorphism which could affect to the way we interact with the artefacts of ICT can be, at least partially, removed from the decision making process.

Carefully consider agent-mediated persuasion. In e-commerce and in telemedicine the use of persuasion is a delicate matter. However, the use of illusion to affect to the attitudes and behavior of the user may result in user injury and designer liability. Especially in telemedicine the use of persuasion may have dire consequences on the patient and on the liability of the physician. Therefore, the artefacts of ICT in telemedicine should not persuade the users but merely state the necessary facts it can decipher from the situation.

Facilitate user goals. The facilitation of the user goals should be one of the goals in anthropomorphic agent design, and in the design of devices and systems of telemedicine. The facilitation should not be employed at the cost of the user safety nor should it have a negative impact on the definitive judgment of the user. As a telemedicine-specific aspect, the facilitation of user goals should not muddle informed consent of the patient and it should not impact negatively to the decision making. The facilitation features of the device or system should follow the principle of careful consideration presented above and therefore the manifestation of the features should be carefully considered.

8. CONCLUSIONS

We have introduced the application field of telemedicine, discussed consent, patient-physician relationship and responsibility issues and arrived at some conclusions as to what is necessary to be done in the field of telemedicine. The proposed solutions of this paper are related to legal, international treaty and technical solutions, the last of these three arising from existing solutions from the field of e-commerce. National legislation must be put in place for the clinicians to be able to know who is responsible and to be able to inform their clients on this. International treaties must at least try to harmonize the field so that the individual clinicians can trust the application of telemedicine to be somewhat similar in other states and countries as it is in theirs. Solutions from e-

commerce will hopefully make the use of telemedicine more transparent and remind the clinician or the patient of the potential problems with the automated health care they are applying or receiving.

When health care professionals are consulting each other, they must be aware of all sources of the information used in the decision making process. The same applies to the health care professionals' conduct with the patients. The patients must also be able to know the source of the information, especially if the health care professionals are not physically present. Uncritical reliance on computer generated information on health care issues might bias information processing, and the decision making might thus be based on false premises.

Direct consequences of trusting applications and devices of telemedicine always fall to the patient, but how about the responsibilities and liabilities of those consequences?

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