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From Clouds to Transparency in the relationships between patient 2.0 & Health care practitioners

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Abstract

We shall review the nature of the relationships between a patient and health care practitioner (e.g., pharmacist, medical doctor) based upon behavioral and natural uncertainty as well as between patients. We then take into account the potential use of the Web in order to reach successful relationships.

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Introduction

This paper studies the nature of the relationship between patient 2.0 and health care practitioners with an emphasis on pharmacists and medical doctors located in France and in the US.

Background description

US and French regulations regarding the healthcare market and the Web are rather different.
US doctors and pharmacist are allowed to advertise their services online and offline. There is strict regulation in France as well as cultural discomfort.
US and Canadian pharmacies are allowed to sell online drugs with prescriptions in contrast to Europe *in toto*.
A common theme in the US and Europe deals with the lack of transparency regarding the prices of health services. As far as we know, there are virtually no websites that list the prices of consultations and medical procedures (treatments, services, operations…) whether it be in the US or in Europe. With much efforts, it is possible to loop up the website (ameli.fr) of the French Social Security and see the prices of consultations by specialists and various technical acts. The information provided is still at itsinfancy.

Relationships between patient / healthcare practitioner

This chapter explores the nature of the relationships between patient and pharmacist on one hand and between patient and medical doctor on the other.
Then, patient to patient relationships will be analyzed.

Based upon the transaction cost theory (7) and work by the late Professor Ciborra(1), there is a need to study the level of uncertainty or complexity of the relationship as well as the behavioral uncertainty, level of trust and goal congruence between the parties.

Trends:
- Financial crisis: health budget limited
- Health Insurances: less reimbursement
- Growing use of the Net
- Privacy required regarding health personnal situation vs use of Web2.0 features

Some definitions related to health, the Web and transaction cost theory (alphabetical order)

Community
Group of people sharing the same interest. Howard Rheingold is supposedly the first to have introduced the notion of Virtual Community. Successful online communities are usually based upon real identities of the users and clear guidelines. There is the notion of a virtual medical community mostly for use of healthcare practitioners based on the same interest to improve the management of specific disease states.

Complexity
When dealing with complexity, we are talking about various levels of uncertainty. It is useful to differentiate between natural complexity and behavioral complexity. There is a need to

study on one hand the complexity of the task and on the other hand the relationships between both parties that is the level of trust and goal congruence.

e-Identity: online and offline identity

Keeping an online Identity or e-Identity is not an easy challenge in most cases and it is even more difficult when dealing with health data, the identity of the patient and health care practitioners. Stealing identities and building online profiles of patients for business purposes are some of the common threats.

Health 2.0

Combination of health data and health information with (patient) experience through the use of ICT. It enables the individual to become an active and responsible partner in his/her own health and care pathway.

ICT

Information and Communication Technology

Internet-Web 2.0

Digital Age's philosopher (3) wrote: "This is the information age, we are knowledge workers, the Internet is a well of information, a knowledge fountain."
The power of the Web to harness collective intelligence: users add value, innovation in assembly.

Patient 2.0

This expression brings together the status of a patient with Web 2.0 features. Patient 2.0 is no longer passive but thanks to the Web 2.0, there is not only access to relevant and adequate information but also a possible active online involvement of the patient.

Privacy

Keeping a high level of privacy while being active on the Web is a challenge. It is all the more difficult when dealing with personal health information. People have the right not to reveal their health specifics and to maintain their privacy but it is a complex process when being active online searching for specific information, asking questions, etc. The privacy issue starts, for example, when using Google while searching for specific topics. It continues with being active in a virtual community or social network.

Transaction

The authors are using the notion of transaction from the transaction cost theory (7). Similar to business arenas, any relationship between patient and health care practitioner can be defined as a set of transactions with relative level of uncertainty. A relationship between a patient and a healthcare professional is never neutral and is by nature hierarchal.

Trust

As we will see, trust is key when dealing with patient health care practitioners. Factors such as honesty, competency and fidelity need to be taken into consideration. (6) There are many articles that emphasize the importance of this "soft" criterion which is usually difficult to deal with. See uncertainty goal congruence and level of trust.

User Generated Content

UGC websites allow users to add content on their own so that it is possible to generate and gather in one place information that would not be accessible otherwise.
For example, www.ComparSante.fr provides tools for users to enter the various prices for the same drugs sold in French pharmacies.

Uncertainty

The natural uncertainty and the behavioral uncertainty are the main factors affecting the

transaction between various parties. Uncertainty can be expressed in terms of complexity of the transaction and level of trust between the parties.

Transaction Costs

Transaction costs appear at each step of the relationship between patients and health care professionals. This ranges from finding the right practitioner, to contract, maintenance and closure of the relationship.

There are different costs related to each phase of the transaction:

Search and Information Costs

These are costs related to determining that the required goods are available on the market, finding a practitioner, checking the credentials, finding the pharmacist who has the most attractive price for a specific drug, etc.

Information Technology and the Web can play a major role for reducing those costs. For instance, it is not rare that potential patient check the Web for credentials (googling the name of the practitioner) and start an email correspondance asking for various details before deciding to come to the consultation.

Bargaining costs

These are the costs related to set up an appropriate contract. Due to the use of insurances, certain costs are less relevant in the patient/healthcare professional relationship. However, it does happen with the costs of technical procedures and consultations of specialists mostly on a one on one basis.

Policing and enforcement costs are the costs of making sure the other party complies with the terms of the contract, and taking appropriate action (possibly legal action) if this turns out not to be the case.

Use of Information Technology in the transaction costs

Effective use of IT can reduce various costs such as finding, contacting and even meeting a practitioner. Note that an indepth review of telemedicine is beyond the scope of this chapter.

Relationships: patient / healthcare professional

Analysis of each position in the case of the relationships with the medical doctor and pharmacist

Trust from a health care provider's perspective is an important component of care. Establishing trust has benefits to the provider, the patient and society in general. Medical ethics deals with decision making outside of strictly practicing care. There has been a shift towards Principle-Based Ethics in which four principles are promulgated. Patient autonomy involves a person's right to guide their own care. A person has the capability and indeed the right to educate themselves about their situation, choose from options and ultimately decide on a course of action. Often, they turn to the internet to find this information. Beneficience is when a provider must consider and act in the patient's best interest. Nonmaleficence consists of the principle of causing no harm. A provider is expected to minimize injury and pain to their patient. The fourth component is justice. Here, care must be considered within the confines of our society; thinking about limited resources, triage issues, society's morals, etc. Trust comes into play in the last three principles. By establishing a trusting relationship, the patient will accept that the provide is considering their best interests (beneficience), will not cause them undue harm (nonmaleficence) and has weighed in on the best option for them(justice).

Besides the moral issues involved, there are some very practical outcomes that come within a trust relationship.

From a patient's perspective, we can see that they will have less anxiety about the course of care. If a trusted provider recommends a hysterectomy for example rather than a trial of a hormone therapy, the patient will feel comfortable that the decision was not unduly influenced by the financial reimbursement expected. If the practitioner advises a woman to divorce a spouse, there is the expectation that her best interests are at heart and that the psychiatrist's personal issues are not influencing the recommendation.

Patients are also more likely to follow through with a medical plan when there is trust. Physicians are taught that up to 50% of prescriptions are not even filled by patients after an encounter. Non-compliance is a real problem in healthcare, especially with chronic disease treatments. Where there is trust, there can be better outcomes.

Healthcare providers can also expect advantages. Certainly, advising a patient to follow through with a plan is much easier if the trust is already established. There is less need to convince or cajole a patient that it is in their best interest to follow through with the recommendation. This helps in terms of provider satisfaction, favorable outcomes and clinic efficiency.

Legally, patients are less likely to litigate where there is a trusting relationship. As defensive medicine is a world wide problem, this may help reduce unnecessary ordering of potentially painful and time consuming tests. It can save time for staff in performing tests as well as for providers needing to overdocument patient notes. Less legal costs will help the tort system function better and improve insurance efficiency.

What can a provider do to establish trust? What can a patient do to find a trustworthy pharmacist? What metrics are available to search out an honorable physician? How does a medical office maintain trust?

Prospective patients generally rely on personal references. Indeed, in my medical practice, approximately 80% of new patient visits come from word of mouth; someone recommended us to that person. By being trustworthy to a current patient, it is likely that they will speak highly of us to a future patient. When a patient's personal physician sets up an appointment with another physician, this implies that they have trust in that specialist. Similarly, if a doctor sends a client to a specific pharmacy for a prescription, it is understood that there is a trusting relationship there. Interactive websites offer an alternative way of getting personal references to help find a trusted practitioner.

Trust can also be established by credentials. The granting body, in effect, is stating that this provider can be trusted based on certain criteria. These may involve diplomas, awards, membership in medical boards and societies, magazine and journal editors acceptance of manuscripts, inclusion in various groups… In this information age, prospective patients often look online for the provider's website, online journals, interviews and webTV. It is understood however that there is misleading information also promulgated online. Rave reviews may not be accurate and complaints may be related to poor outcomes rather than poor medical care. Most readers intuitively appreciate the fact that every unhappy client will complain to nine people while satisfied people only tell four. In a domain where there is tremendous lack of oversight, it is often up to the provider to respond or even correct misleading information. A classic medical scenario is when an independent company rates

physicians based on complications. Though Doctor **A** may have a higher number of complications than Doctor **B**, it would be important to note that Doctor **A** may also see many more patients than Doctor **B** or that they take care of more complicated cases. Physicians may also be limited in their ability to respond to every complaint as they may not have the time to mine the web. Sometimes, there is no way to respond to the information as the site is set up strictly as a sounding board for patients.

The third most common was to establish trust comes from the patient's personal evaluation. It is often said that the physician's staff sets the stage for the patient. A courteous and caring front office person will help establish a positive relationship even before meeting the provider. The office location and décor can likewise set up expectations. A tasteful office in a good location suggests that the practitioner is doing well and therefore is likely to have had good relationships with patients in the past. The provider's demeanor is critical to establishing trust. Is there eye contact with the patient? Are they dressed appropriately? Do they look tired? Is the provider obese or unhealthy appearing? Are they looking at their watch often? What do they say about other providers' care? Many physicians offer a complimentary "meet and greet" appointment to make sure that there is a good fit. I commonly see new clients who have already "interviewed" me via email and/or videoconferencing. Tours of a potential pharmacy can be conducted in person or by virtual reality.

There is a fine line between advertisement, self-promotion and education. In France, for example, physicians are not legally able to advertise whereas in the US, it is common. For example, approximately 10% of a plastic surgeon's income is spent in promotion. One of the authors (DL)has a television program which is educational however clearly it helps the practice grow.

In addition, federal rules in the US prohibit health care entities from releasing a patient's protected information inappropriately. It is, therefore, difficult to advertise a client's excellent response to a provider's care. Another limitation deals with physician charging structure. Generally, providers have limited discussing fees in an open forum. Fears include allegations of price fixing or overcharging and undercharging the competition. There has been a great deal of debate over the idea of offering a money back guarantee. While all of the above is standard practice for other types of businesses, medical care operates under a different set of rules. This can make it difficult for consumers to find out information that may help them make an educated decision.

Back to trust parameters. There are some that a provider can not change. Certain patients may be more comfortable with one gender over another. The provider's perceived age can influence a patient's trust. Religious affiliation and sexual orientation can likewise impact on trust. Sometimes trust is not with a provider per se, but rather with the company or group. Look at online pharmacies. Here the relationship is between the patient and the corporation; there may be no actual pharmacist to discuss things with. The trust involves the expectation that the prescription is filled accurately with a quality product at a reasonable price.

Relationships Patient / MD specialist

Hi	
Not so Stable 'Cloudy'	Clear but Costs to reach & maintain this situation
Patient may switch doctors Use of minute clinics in malls	Key Problem 'Very Cloudy' "Patients with a lower level of trust in their physician are more likely to report that requested or needed services are not provided".
Lo	

Lo   Task Complexity/uncertainty   **Hi**

Limitations of trust

There are times however that trust is not a priority and thus search and information costs are not relevant. Take, for example, the case when someone is in a car accident and is cared for by emergency providers. There is no time for checking on credentials or consideration of personal preferences.

Low complexity of the treatment

When a treatment is standard or of a low complexity, trust parameter may not be relevant and the cost may become a major factor for decision making. Patients may accept a provider who instills less trust in them. As an example, witness the birth of the clinics in the US found in shopping malls or department stores where diagnosis and treatment is available on the spot.

Growing complexity of the treatment

As the complexity of the situation increases, trust issues may become more important. The practitioner must evaluate all available information as it is critical to the proper management of the case. Trust issues come into play when the provider presents a medical management plan to the patient. The rapport will improve compliance and therefore the outcome. Without the trust, a patient may end up jeopardizing their health by not following through with the medical advisements(6).

Relationships Patient - Pharmaceuticals

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Pharmaceuticals are under a great deal of scrutiny lately given that there are so many opportunities for mistakes. In the US and Canada, prescriptions may be obtained online. We often read about someone dying from an overdosage, impurity, interaction or even the wrong prescription being filled. Drugs can be a low risk or high risk situation depending on the product. A simple antibiotic for acne generally can be considered low risk because the failure of treatment may be benign. However, if someone has a true drug allergy and receives the wrong drug, this can cause fatal anaphylaxis. Patients have been able to obtain medications from some online pharmacies even without prescriptions. Due to the necessity of regulation, various groups are getting into the field of patient advocacy and education including pharmacy checker, IPABC, CIPARx and others. Due to the lack of transparency in the pricing of drugs and medical acts in pharmacies, various groups are entering this domain.

Relationships: Patient / Pharmacist

	Lo — Complexity/uncertainty — Hi
Hi Trust Level	Allows pharmacist to advise, suggest another drug: e.g. generic substitute	Steady relationship
Lo	Patient/consumer could decide where to buy if only there was market transparency	Potential problems with pharmacist: price bargaining, service etc.

Switching positions (from unstable to stable)

1. High complexity → Low complexity

In situations where trust levels can not be ameliorated, there is the possibility of decreasing the complexity. In medical care, one option is to parse the problem into its constituent subsets. An example might be where a patient is on a ventilator after a stroke. We may have a neurologist come in to consult on the brain function, a physical therapist to help with keeping the joints flexible, a nutritionist to manage intravenous feeding, a pulmonologist to deal with the lung function, a pharmacist to manage all of the medications, etc. Another example would

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be when a patient receives multiple medications from multiple providers. Not only can there be redundancy but also serious interactions. A pharmacist could interact with the practitioners to improve patient compliance (once a day drug vs. three times a day), increase safety (suggest a less toxic alternative) and decrease poor combinations (alerting the provider of possible catastrophic consequences).

2. Low level of trust → High level of trust using Information Technology

Apart from the human and psychological aspects of raising trust from the point of view of a practictioner, an intelligent use of the technology can help raise the trust for the patient. Health practitioners can use ITC (e.g. Internet TV for broadcasting programs, CRM tools and more) in order to reach a high level of trust with the patients and help them deal with the uncertainty of the situation the best way as possible.

Relationship patient2.0 / patient2.0

Relationships: Patient2.0 / Patient 2.0

	Lo → Task Complexity/uncertainty → Hi
Hi Trust Level	**Stable area**	**Word of mouth from Family/friends** ('real life community') with exceptions from Social Networks with very clear guidelines. There is the danger of getting misleaded.
Lo	Social networks including anonymous inputs can be useful for asking questions related to hard facts such as prices of drugs, consultations, medical acts	Dangerous area where people will not be telling the truth etc. Hearsay from the Web Rumors…

Use of the Web
Patients can use the Web in order to improve their health situation. They may have a high or a low trust level relationship with a health care practitioner involving a complex or simple transaction. A recommendation is to use the potential of Web 2.0 and the interest of the

whole in order to gather 'hidden' information such as the range of prices of drugs, medical acts and consultations of specialists. However this potential does not cover the field of information about the practitioners (reputation, quality of service, professionalism, etc.)

Regarding the framework of task complexity vs level of trust, a careful use of ITC will allow a reduction in transaction costs thus forming more successful relationships.

Clients and health care practitioners can then avoid pitfalls and strengthen their positions.

In the matrix above, we can see that in a low complexity situation such as picking a less expensive pharmacy the trust issues are of minimum importance. If one web posting deviates significantly from the majority of the others, this will not lead a patient astray. It only gets to be problematic when the complexity increases or the trust issue importance increases. As an example, let's say that a patient posts a statement to the effect that a given medication gave them a serious side effect (e.g. Nitrofurantoin and lung damage). Another patient with a complicated health problem that requires that pharmaceutical may read and accept unconditionally the post and refuse treatment. This may lead to dire consequences. Commonly, we also find that a "friend" or a "family member" describes horrendous outcomes from therapies which understandably scare off patients from legitimate treatments. The ability to be anonymous on the Web also reduces the trust issues.

From a high trust perspective, when the posting individual has been identified as a trusted source such as an author or professional, their input can actually be more damaging if it goes against the legitimate advice of a treating provider. Often, the commenting individual has no access to the patient's medical record and has not met and examined them. This may lead to inappropriate comments.

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Conclusion

Web 2.0 and privacy in the healthcare arena do not live well together.

There is still a need to create innovative social health related communities empowering the patients and healthcare practitioners while keeping trust and privacy respected.

In the mean time, it is at least possible to provide a mechanism for patients to improve the transparency regarding health care prices.

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