

# Power to the Patient?

## Studying the power balance between patient and GP in relation to Web health information

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## Abstract

Web health information is stated as converting the asymmetric power balance between patient and medical doctor. Is it or is the influence of health information retrieved on the Web on the power balance overestimated? To analyse the patient-GP relationship, this study applies the resource dependency theory (Emerson, 1962) that is part of the “social exchange theories”. This theory defines social power over actor B by actor A as the dependence of actor B on the resources of actor A. The dependence on a resource is directly influenced by the value and the availability of the resource for actor B and by the concepts of perceived risk, uncertainty, perceived severity and trust, and in an indirect way by the charisma and legitimate authority of actor A. A social relationship is mostly a matter of mutual dependence and a matter of balancing operations. In a situation of balanced mutual dependence, the intentions of both actors may be fulfilled. Each actor has ways to resist his dependence and the exertion of “resource power” can come with a cost. Resources of dependence and resistance on the macro-, meso- and micro-level are considered. The concept of information is discussed and the Web as a source of health information and how people seek health information is analysed. A mixed research method is applied consisting of an online survey for patients and non-patients, analysis of 24 patient-GP video-recorded consultations, ethnographic follow-up interviews with the patients and the GPs participating in the observations, three focus groups with patients and non-patients and two discussions with groups of GPs. The results show that the Web has the potential to narrow but not to bridge the information and knowledge gap between patient and GP, because health information is only one of the resources of dependence of a patient. The patient remains dependent on important resources of the GP other than information. So, despite health information through the Web, the patient-GP power balance remains asymmetric. Health information through the Web mainly influences the communication between patient and GP. For the patient-GP power relationship to be balanced, all resources of dependence must be considered, also those on the meso- and macro-level. Patient empowerment is a valuable concept but health information through the Web is not a silver bullet to achieve this.

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### 3.3 Empirical research conclusions

Let us go back to the central problem statement: “Studying the power balance between patient and general practitioner (GP) in relation to Web health information”. The basic research question has been split up into **three research questions**:

1. What is the *power base* of the patient-GP relationship?
2. What role does (*health*) *information* fulfil in the power relationship between patient and GP?
3. What role does *Web health information* fulfil in the power relationship between patient and GP?

#### What is the power base of the patient-GP relationship?

The empirical research has confirmed that **the concept of dependence on resources is at play in the patient-GP relationship**. Respondents indeed recognise their dependence on the medical profession’s right and skills to label and diagnose, its license to prescribe medication and allow sick leave and its access to the patient’s medical file. Most of them do not think that “power” applies to the relationship since they relate the concept to coercion and they are aware that a GP cannot oblige them to do anything. GPs too feel uneasy relating the patient-GP relationship to power. The choice that has been made to choose a power definition linked to the concept of dependence seems indeed better suited for the patient-GP relationship than the classic *Weberian* definitions.

As well as respondents of the Web survey, patients participating in the focus groups and patients interviewed after having been observed declared that **they recognise the GP’s information and his knowledge in particular as resources they have less or not at all and on which they depend**, certainly in a situation in which the resource is “valuable” and is reinforced by the “strengthening factors” of uncertainty or perceived severity. They also recognise the different characteristics of the GP’s medical knowledge and their own. The doctor thus radiates “Aesculapian power” as Brody called it: “The power arises from the healer’s possession of the knowledge of a body of obscure and complex facts and theories, a variety of practical skills for manipulating instruments and body parts, and experience in the application of this knowledge and skill in a range of practical settings” (1992, p. 16). GPs also recognise the power of their knowledge, thus “resource power”. However, this does not mean that patients consider it normal that the GP’s medical authority is automatically transferred to other knowledge domains (be it that GPs during the discussion with GPs mentioned that they still feel that they have some authority in domains other than the medical). Respondents do not consider the GP’s knowledge infallible, nor the GP omniscient; respondents are aware that a fallible human being stands behind the role.

**Chronic patients who gained experience with their disease and treatment may succeed in catching up with the GP’s information and knowledge on their disease and treatment.** They develop a more critical attitude, are more vocal, request more involvement and are more inclined to take the final decision about the treatment than “regular” patients. Chronic patients want to be more in control. This may result from their suggestion that GPs have a lack of knowledge in regard to a specific disease (after all, a GP is a generalist) and because a

chronic disease can exert great influence on a person's life. Nevertheless, chronic patients also remain dependent on the GP's other resources and may become dependent on the GP's knowledge when confronted with one other than their chronic disease. A patient consults a GP when in need which means that the patient was not able to solve an issue without the intervention of the GP anymore. Van Nuland and Goedhuys call the phase before going to the doctor the "zero line" (2012, p. 25), referring to the GPs being the first and the hospitals the second line (For more information on the different "lines" in Belgian healthcare, see section 1.4). The patient-GP contact, thus, places the patient in a vulnerable position from the start. Any patient, even a chronic one, starts the consultation in a situation of dependence.

A patient also disposes of resources a GP depends on; the relationship is indeed a matter of **mutual dependence**. The GP needs the patient's goodwill and information to enable him to make a correct diagnosis. Since GPs seem to be intrinsically motivated to achieve the best for their patients, the GP's dependence on this should not be underestimated. GPs also are in need of a long-lasting, trustful relationship to enable them to do their job: taking care of patients. However, patients are aware that informing the GP correctly is to their own advantage. This could be considered an indication that the patient's dependence on the GP's knowledge is higher than the GP's dependence on the patient's information. Respondents also know that the GP economically depends on them (and GPs do too), but at the same time they realise that GPs have more than enough patients which sometimes even moves GPs to refuse new patients. Some respondents stressed that it is not always easy to find another GP accepting new patients. Patients seem to know that they are allowed to switch doctors if they want to (although they are not acquainted with the Belgian Law on Patient Rights), but most patients seem to be loyal to their GP (which means that they stay with the same GP for a long time). If it "clicks" between patient and GP and the relationship is trustful (which does not necessarily equal "close"), trust and the relationship in itself become resources of the GP on which a patient depends and makes it difficult for patients to change GPs. GPs may "know" the personal and sometimes, intimate life of their patients. This is the kind of confidential "Personal information", one of the eight types of information described in section 2.3.3.

These characteristics **distinguish the GP's role from that of a specialist** which is on average more biomedical. The "first line"—the GPs—fulfil a role with a different added value compared to specialists and mutual trust often is a key element in the relationship. The results of the Web survey illustrated that most of the patients seem to trust their GPs. Respondents are aware that they sometimes have no other choice than to trust, but it does not seem blind trust. Patients recognised the different roles a GP may fulfil and on which they may depend. GPs confirm that they fulfil these roles and that they develop a holistic approach. The GP is a healer of course (treating multiple medical issues and different diseases), but he may also be the coordinator or "filter" in case of a complicated treatment, a coach related to health behaviour, a guide in the healthcare system and fulfils a psychosocial role towards lonely and troubled people and patients having to live with a serious condition. GPs still have status and authority. Many respondents of the Web survey are aware that they exhibit unhealthy behaviour and almost half of them state that they are afraid to get ill due to that behaviour. This could mean that they are conscious that one day they could need a doctor. The resource dependency theory describes the mutual dependencies as balancing

operations and the relationship is at its best if the dependencies become symmetric. This does not seem the case in the patient-GP relationship. The power asymmetry in the relationship is confirmed by the GPs. Moreover, a patient may also become dependent on his disease or treatment. Being dependent on a treatment equals being dependent on technology and/or the GP's skills and/or the GP's license to prescribe the treatment or medication.

While the patient-GP relationship is a matter of mutual dependence, GPs during the discussions with **GPs reported their decreasing dependence on patients**. The finding that patients have become less dependent on their GPs as the only central point of contact in healthcare of course makes GPs less dependent on their patients too. Moreover, patients are, amongst others, backed-up by pharmacists who also give them some medical advice. Pharmacists as consultants to patients on the use of medicines is even promoted by the "Koninklijke Academie voor Geneeskunde van België" (Royal Academy for medicine of Belgium) and that organisation even suggests examining the possibility of allowing pharmacists to prescribe certain medication (KAGB & ARMB, 2018). Specialisation and professionalisation also contribute to less dependence of a GP on his patients. Furthermore, GPs do not live only for their patients anymore; they also strive for an acceptable work-life balance.

However, the confirmation of the dependence of patients on the resources of GPs **does not mean that patients are subjected to their dependence without resistance**. If a GP exerts his power by behaviour considered disrespectful by the patient, if the GP's information or communication are considered ineffective by the patient or if a GP makes a medical mistake, misses a diagnosis or did not take the action the patient would have expected, patients may move to another GP or consult other information sources and try to acquire the knowledge themselves. Patients could also ask for mediation as foreseen under the Belgian Law on Patient Rights, but it turns out almost no respondent knows this law. In these cases, patients feel that their trust has been violated. This seems to be related to the expectations a patient has towards the patient-GP relationship and it, therefore, differs from patient to patient and from situation to situation. The patient's dependence on the GP's resources is dynamic. As a patient expressed during the focus group discussions talking about her GP: "he is not a good one [...] but at this point in my life, it's a good enough GP". The Web is one of the sources patients can consult to find health information or share experiences. When patient and GP live through a serious medical issue together to the full satisfaction of both, the mutual trust may be strengthened. Serious medical issues could, therefore, be considered "proof points" (McKean, 2005, p. 123): the relationship is put to the test and the more advantageous the result is for the patient, the stronger the trust in the doctor becomes. As McKean, analysing customer loyalty, states: "This degree of trust and loyalty remains dormant until it has been tested" (2005, p. 123). A bad patient experience undermines his trust.

**Respondents seem to underline their expectation of egalitarian treatment by the GP** (see Figure 88). This finding is not new (Korsch, 1989, p. 250) but it apparently is not realised yet. **They reject the obviousness of the GP deciding the treatment**. Blau states that for authority "To be legitimate, compliance to authority must thus be approved" (1989, p. 201). The results indicate that exactly that compliance is not self-evident anymore. This is illustrated in Figure 88. The core of the patient-GP relationship is still the doctor and his medical knowledge and related medical skills. But the legitimate authority the GP possessed in the

past is gradually being replaced by patients requesting to be treated in an egalitarian way and not as bodies or subordinates.

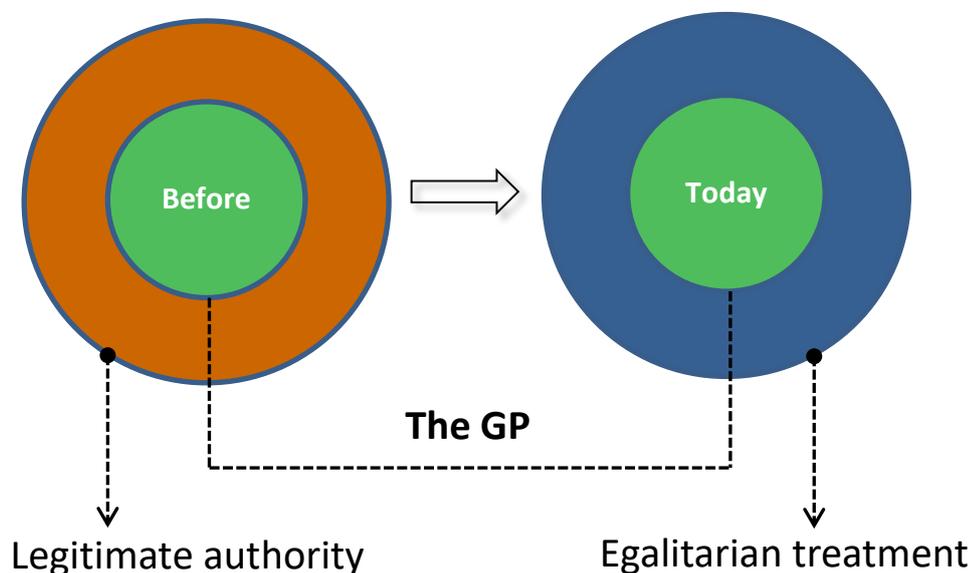


Figure 88: From legitimate authority to egalitarian treatment

The empirical research also discovered a **contradiction between patients' empowerment discourse and their behaviour during a consultation**. While patients during the ethnographic interviews following the observations and the focus groups expressed resistance against the GP's dominance of power, rather passive patients were observed during the 24 consultations. The finding that patients are much less vocal during the consultation than they intend to be confirms earlier research by the Dutch institute NIVEL in 10 European countries (van Dulmen et al., 2005). The researchers of this study call their results "universal". The GP clearly leads the consultation, asks mainly closed-ended questions, is predominantly the one opening and closing the different phases of the conversation (by verbal and or non-verbal signs) and accepts incoming telephone calls without apologizing or patients being irritated. He controls the decision-making process. No real common decision-making moment on the treatment could be observed: the GPs prescribed treatments without the formal consent of his patients. During the focus groups, exactly this contradiction has been discussed and participants confirmed they do not always put their empowerment discourse into practice. While a health issue may be sensitive for a patient, the GP is simply carrying out his job with the certainty and routine that is his own. Participants also mentioned that the logistic environment of the consultation may make a patient feel uneasy. The observations indeed showed mainly a confrontational setting expressing that the patient is in someone else's domain. That feeling may be strengthened by the sometimes long waiting times in an overcrowded waiting room preceding the consultation and by the incoming telephone calls during a consultation. In addition to this is the finding that the respondents of the Web survey considered the doctor's job important in society and carrying a lot of responsibility and thus, having status. Finally, since patients go to the GP when in need, they start off the consultation in a situation of dependence. All these elements could also contribute to a

certain distance between patient and GP and to patients “undergoing” the consultation. 17% of the Web survey respondents doubt that their GP is always telling them the truth and 88.2% state that they always tell their GP the truth, 2.7% state that they do not and 9.1% is uncertain. These figures again illustrate that some respondents express some reservations regarding the relationship with their GP. The GPs for their part consider a certain distance between patient and GP essential to the therapeutic relationship. However, respondents state that they consider it normal that the GP leads the consultation since it is his job to diagnose and propose a treatment. This could also explain why more survey respondents stated that it is up to the GP to take the final decision about the treatment than respondents answering that it is up to the patient. The patient-GP interaction during a consultation could be considered an “institutional practice” (ten Have, 2007, p. 178) characterised by “an *institutional* pre-allocation of questioning rights and answering duties [Italics in original]” and by “ritualization” (Ainsworth-Vaughn, 1998, p. 176). Ten Have rightly stresses that, for example, the fact that the GP asks more questions than the patient could be a sign of “professional dominance” as well as of “the overall sequential organization of the encounter” and both actors “pre-structured” roles (West, 1984, p. 32). It could even be stated that the interactional dominance of the GP is “natural” since he has more tasks to perform than the patient (ten Have, 1991, p. 140) and he is the one from whom the final diagnosis and therapy prescription is expected (Davis, 1988, p. 241). Moreover, the communication between patient and GP during a consultation is not a regular conversation and some patients are not used to its specificities, for example, that it sometimes leans towards becoming more of an interview (Shuy, 1993, p. 21) or an interrogation (ten Have, 1991, p. 162) with the GP asking the questions and the patient mainly just answering them. However, while the observed GPs are clearly leading the consultation, topics are often raised by the patients and the GPs remain flexible to give their patients the latitude they need to express themselves; they even sometimes tend to stimulate patients to talk through their “non-verbal listening behaviour” (Osler, 2014, p. 23).

Applying the resource dependency theory, it can be stated that if there is dependence, there is “resource power”, but **the power does not need to be exerted**. Patients sum up a huge number of characteristics a GP should have and they could all be related—from the point of view of a patient—to having a feeling of control: clear and accessible information and effective, empathic communication and a respectful and humane treatment prevent a patient from feeling dependent on the GP, even if he is. The patient’s situation of dependence on the GP’s resources forms the power base in the relationship. Participants of the focus groups seemed to be aware of this. At the same time, they stated that GPs did not abuse their power and if they did (for example, by communicating in an inappropriate way), this was a reason to break up the relationship. Exerting power may come at a cost. “Cost” is a concept part of the “resource dependency theory”. The cost can go both ways: GPs know that they are also allowed to stop the therapeutic relationship, be it that they seldom do. There seems to be a general consensus between respondents in general and GPs: the GP has more power, but he should not abuse it. It confirms a point made in the literature review: possessing power in itself does not need to be negative; the issue is what the actor with the power overweight does with his power.

However, a GP’s efforts to not give a patient the feeling of losing control cannot exclude a patient feeling dependent on **resources situated on the meso- or macro-level**. The

healthcare system in general and the related bureaucracy are resources on the meso- and macro-level sometimes leading to distinct feelings of dependence in patients, strengthened by uncertainty. GPs also feel that administrative measures and evidence-based regulations limit their freedom to prescribe, be it that the GPs interviewed participating in the observations stated that they consider these measures positive. The meso-level clearly influences the patient-GP relationship. GPs stated during the discussion with GPs that patients and doctors as advocacy groups have gained in power. GPs consider the Belgian Law on Patient Rights a sign of increased patient power. They also felt that patients are influenced by (sometimes contradictory) health information from mass media, by patient advocacy groups and by healthcare organisations like “health insurance funds” stimulating patients to ask for a second opinion. They do not consider themselves the sole access point to healthcare anymore. Some patients skip the first line or even do not have a regular GP.

### **What role does (health) information fulfil in the power relationship between patient and GP?**

Except for health information related to the diagnosis, patients are generally **satisfied with their GP’s information and communication**. GPs state that they adapt their communication to each individual patient. Respondents of the Web survey state that they generally understand their GP’s explanation and that they dare to say it when they do not. Participants in the focus groups were aware that communication is also a means they can use to their advantage. 62.6% of the respondents of the Web survey state that they tell their GP when they do not agree with his diagnosis. This is the majority of the respondents, but remarkably less than the number of respondents stating that they tell their GP when they do not understand what their GP tells them (95.8%). This could again be a sign of the distance separating patient and GP and of patients afraid to destroy a trusting relationship.

A critical element in the patient-GP relationship is related to **the patient’s control or feeling of control**. Recognizing that, on average, a GP knows more about medical matters than his patient, does not mean that the GP has the exclusive right to decide which treatment has to be carried out. On the contrary, patients seem to be well aware that they are the ones having to sweat out the treatment—“it is my body!”—thus, they want to be involved in the decision or even decide themselves (but not all). This could be considered a decrease in the influence of “legitimate authority”. In this study, “legitimate authority”, has been defined as to “permit someone else to make decisions for them for some categories of acts” (Lindblom in Scott, 2006, p. 20). Many of the respondents want to keep their autonomy. The choice for a treatment should therefore, be the result of a dialogue. Sometimes, the choice process becomes a negotiation, GPs ascertain. In cases of far-reaching illnesses, treatments (for example, for cancer) or medical decisions (for example, related to euthanasia) that have a great impact on their quality of life, the respondents’ awareness that it is up to them to decide is even higher. They consider that they have the right to know the reasoning behind and justification of a proposed treatment. In contrast to this finding stands that the Web survey indicated that, while patients seem in general satisfied about the interpersonal communication with their GP (except for information on the diagnosis), a majority of the respondents indicated not (always) having the feeling of being able to influence the care they get from their GP. They therefore seem to lack a feeling of control related to the decision on the treatment. This is regrettable since the patient’s understanding of and involvement in

the chosen treatment is an important condition to his commitment to adhere to it. As stated by Nettleton: "If doctors were better communicators, the problem of non-compliance might be alleviated" (2013, p. 132). Not only has the doctor to be convinced that a certain treatment is the best solution, so must the patient. A patient's adherence to a treatment should be based on intrinsic motivation. This is even more important due to the sometimes *temporality* of the power relationship: respondents declare that the GP cannot control what they do at home. The concept of "temporary inequality" has been pinpointed by Miller (1986, p. 4). If a GP wants his patient to adhere to a treatment, influencing him during the consultation will not suffice.

The patient's dependence on the GP's resources does not preclude that **patients trust their GPs**. In the Web survey, different questions were related to trust and they all confirmed that most patients trust their GPs. Moreover, most patients are loyal to their GP (which means that they stay with the same GP for a long time) and are satisfied with them. Luhmann relates trust to the motivation of an actor (1979, p. 41) and most respondents of the Web survey declared that they believe in the good intentions of a doctor and that their GP does what is best for them. However, being satisfied does not equal being *fully* satisfied: 64.3% of the Web survey respondents declared that they were "certainly satisfied" and 26.3% "rather satisfied". The ethnographic follow-up interviews of the observations shed some light on the difference between being "certainly" and "rather" satisfied. First, some patients are critical towards certain aspects of the service surrounding the consultation as for example, long waiting times. Second, certain patients are not happy with certain aspects of the GP's behaviour, like asking a patient to undress when not really necessary. Thirdly, some patients are unsatisfied with certain aspects of the organisation of healthcare in general; as for example, the fact that a patient has to give the payment in advance and only gets a refund later. These elements of dissatisfaction do not seem to weigh enough for the patient to break up the patient-GP relationship and, consequently, do not seem to be fundamental. A violation of the patient's trust on the contrary, is.

**The basic factors influencing satisfaction and trust** indicated by the interviewed patients could be structured on three levels in order of their given importance. The three levels are illustrated in Figure 89. At the core, trust in and satisfaction about the biomedical capabilities of the GP are situated. This is still the essence for the respondents. Around this core, there is the trust and satisfaction based on the fact that a patient is treated respectfully like an equal human being. The outer layer represents all aspects of the service the GP offers. It is not because healthcare is not a regular economic market that patients are satisfied with less service. Complaints of customers are often related to "simple things" (Jan van Bel, 2007, p. 64). Service-related issues are influencing the level of satisfaction but do not seem sufficient motivation to break up the relationship and, by implication, on the patient's loyalty to the GP. Issues related to the way a patient feels treated and to the biomedical domain on the other hand, may be. On the level of the biomedical treatment, a possible tension should be mentioned between a GP's advice and the patient's satisfaction. GPs during the discussion with GPs mentioned that what is best for a patient does not always coincide with what would satisfy a patient.

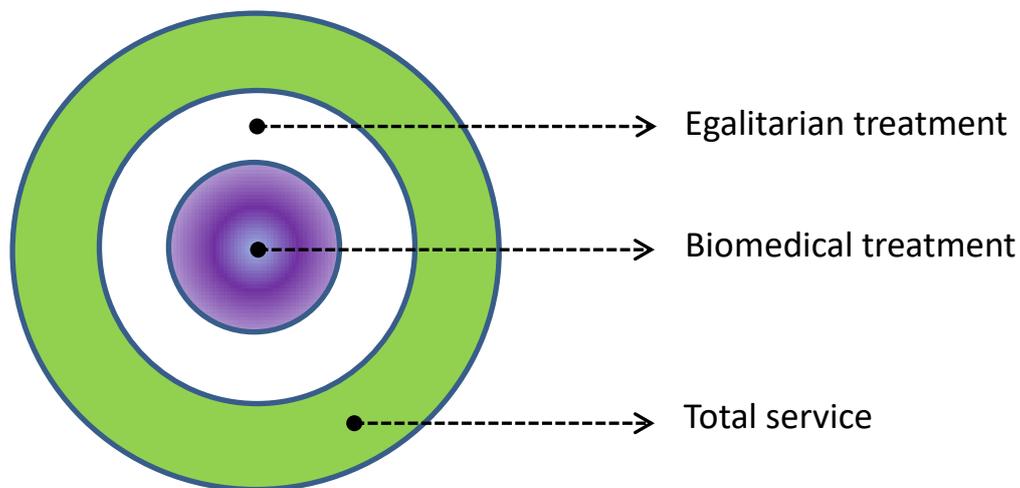


Figure 89: Three influencing factors of trust and satisfaction

**A trustful relationship reflects an honest one** in which patient as well as GP assume their responsibility. For a GP, it means that he admits to having made a medical mistake and doing everything possible to make things well again. 73.1% of the respondents of the Web survey state that they think their GP would admit to a medical error. Only 10% of the respondents seem convinced that doctors in general would admit to a medical error. People trust more in people they know than in systems which illustrates the importance of the personal aspect in the patient-GP relationship: GPs are related to the “facework commitments” part of the healthcare system (Giddens, 1990, pp. 83-85). But the trust has to be mutual: a GP should believe in his patient’s honesty (for example, when asking for sick leave) and a GP must be able to count on the patient’s honesty towards him (for example, not asking for a second opinion behind the GP’s back or not adhering to the treatment without telling their GP). “Shopping around” by patients is considered a sign of lack of trust by the GPs and of a too “consumerist stance”. It may be a reason for a GP to break off the relationship. 78.3% of the respondents of the Web survey state that they always adhere to the prescribed therapy. This is self-declared and it is of course, not sure that all these respondents in reality always adhere to the treatment. But the participants of the focus groups seemed to realise that it is to their advantage to do so. The choice for a specific type of practice (solo, duo or group) is personal and situation-bound. Respondents recognise the advantages as well as the disadvantages of GPs working alone or with other GPs.

## What role does health information through the Web fulfil in the power relationship between patient and GP?

The results of the Web survey as well as the ethnographic follow-up interviews with the patients observed and the focus groups lead to the same conclusion: **respondents are aware of the potential of the Web as well as a health information source as the risks and its possible negative side effects.** They also are aware that health information through the Web still needs to be adapted to each individual patient's context and situation. They are conscious that health information does not bridge the knowledge gap between patient and GP. Nevertheless, many of them to a greater or lesser extent seek health information through the Web. Their doubts about the accuracy of the Web health information does not lead them to ignore its existence. Uncertainty sometimes incites them, or so does missing health information. The Web is clearly not considered an infallible health information source by the respondents which confirms other research (see section 2.4.2.4.1).

**GPs too recognise the Web's advantages as well as disadvantages as a source of health information** which also confirms earlier research (see section 2.4.2.4.2). They relate the fact that patients seek health information through the Web to a general societal trend towards more participation and less unquestioned respect for those in power and they do not consider it a sign of distrust towards them. They confirm that they also sometimes seek information through the Web. GPs state that seeking health information through the Web requires appropriate skills. Instead of creating more patient autonomy, GPs assume that health information through the Web may also increase the patient's dependence on the medical profession. It can create uncertainty and provoke a person's need for a medical consultation. Moreover, a patient will often still need a doctor to contextualize the Web health information and to "translate" it into a tailor-made diagnosis and treatment. Here again, the difference between information and knowledge and between the patient's and the GP's knowledge are palpable. Indeed, some respondents become more worried due to the health information through the Web. Some patients, therefore, consciously do not consult the Web for health information and respondents report that some GPs advise them not to consult the Web. Sometimes, the Web moves others to give unsolicited medical advice to a patient.

**Health information through the Web does not fundamentally change the power imbalance between patient and GP** (certainly not when a patient is really in need, for example, in case of a serious disease), but **it has the potential to narrow the information gap between patient and GP** (just as any other source of health information). Information is one of the GP's resources a patient depends on and a GP, due to the Web, has increasingly become one of the sources offering health information. The Web also serves as a tool to exchange experiences with peers and even to avoid a doctor's consultation in case of what a patient perceives as a minor ailment (by self-diagnosis and self-medication). But for many medical issues, respondents declared that they depend on the GP's skills to diagnose and for which they consider a face-to-face encounter is needed. None of the patients interviewed reported having used the Web to compare healthcare providers or hospitals; some used the Web as a "Yellow Pages" to find information on a possible alternative GP. The empirical research thus teaches us that health information through the Web above all may influence the interpersonal communication between both actors. It may support patients feeling

more in control by being better informed on health issues and thus, being more vocal. This is an outcome the GPs interviewed appreciate because they know that the patient's involvement is a condition for adherence to the treatment. Health information through the Web makes it easier for patients to question the GP's information and obliges the GP to be more accountable and justify his medical reasoning. It allows the patient to increase his influence during the consultation and if needed, to force through an extension of its duration. Besides, the power of communication (influence and persuasion) of themselves and of patients is recognised by the GPs. The exercise of influence is mutual and GPs reported during the discussion with GPs that their influence has less impact than in the past. Consulting the Web and using the health information thus found during the consultation (openly or not) is one way for a patient to enact his participation which could be considered a form of symbolic resistance against his dependence on the GP's resources. It may turn one-way communication during a consultation into a dialogue. In some cases, a patient is even capable of complementing the GP's information. The darker side of respondents seeking health information through the Web is that it may, by the same token, misinform people. It may complicate the communication during the consultation since the GP may have to correct the potentially biased view of the patient on his symptoms, diagnosis or treatment. On the one hand, it may increase the time pressure on the GP (and time is a scarce resource in healthcare), on the other, it may lead to patients demanding examinations the GP considers unnecessary. Due to the health information through the Web, patients may overestimate their medical knowledge and behave as real consumers wanting their desires to be fulfilled at all costs. It may even cause patients not to consult a doctor at a time they should. GPs during the discussion with GPs stated that patients mainly may have a feeling of possessing more power, power they do not have in reality. As put by one GP: patients are still "stuck in a straitjacket". **It seems obvious that health information through the Web may lead to positive as well as to negative outcomes.**

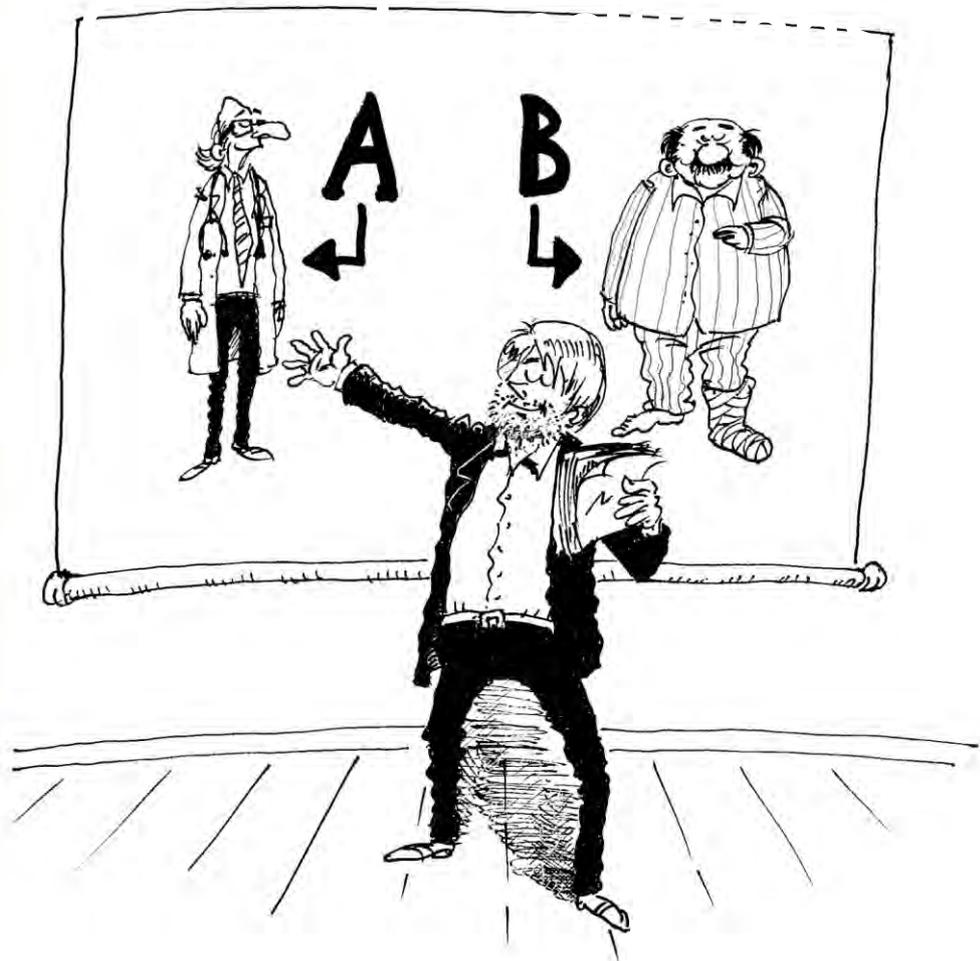
**The positive outcome of Web health information is therefore conditional.** First, not all respondents seeking health information through the Web tell their GP that they do. This can be due to their own doubts about the accuracy of the Web health information, because they have looked for information without a specific goal (they did just because it is that easy) or because they are afraid to imperil a trustful patient-GP relationship. Second, the condition is that they have access to the Web, that they know how to search for health information, that they find the information they are looking for and that they know how to interpret that information. The results of the Web survey illustrate that this is not self-evident. Chronic patients are more critical towards health information through the Web than "regular" patients. Supposing that they have acquired more knowledge about their disease and treatment, it may be assumed that chronic patients are better "crap detectors" (Rheingold, 2012, p. 77) than common people.

Only one of the patients interviewed reported that his GP referred him to a health information website. A global conclusion cannot be drawn from only 24 observations, but it may be said that, precisely because some people seem to have problems finding the correct health information, GPs, often being the first contact of a patient, can play an important informational role by referring patients to trustful websites.

Despite the existence and the use of health information through the Web, the power balance between patient and GP remains imbalanced. Indeed an “equalization tendency” (Beck, 2010, p. 165) between patients and GPs can be discerned, but only related to the resource of dependence “information”. The Web does not seem to be a real “knowledge leveller” (Hardey, 2003, p. 214; Snelders & Meijman, 2009, p. 13) and the dependence of a patient on other (very often stable) resources of the GP remains. While most respondents seem satisfied about the information they get from their GP, they do not always have the feeling of being able to influence the decision on the treatment. Informing a patient and giving a patient a sense of control seem to be two different things. Health information (through the Web) should not be considered a miracle solution to patient empowerment.

# Chapter 4

## General conclusions





## 4 General conclusions

Let us go back to the central problem statement: “Power to the patient? Studying the power balance between patient and general practitioner (GP) in relation to Web health information” and to the hypothesis developed based on the literature review (see section 2.5).

The central problem statement has been split into three research questions: 1) What is *the power base* of the patient-GP relationship? 2) What role does *(health) information* fulfil in the power relationship between patient and GP? 3) What role does *Web health information* fulfil in the power relationship between patient and GP? The answers to these questions are summarised hereunder in section 4.1. A summary of the relevance is also included.

Thereafter in the Discussion in section 4.2, a number of deepening considerations are given related to important aspects of the central problem statement: on patient empowerment (in section 4.2.1), on the Web as a patient empowerment tool (in section 4.2.2) and on the resource dependency theory as a theoretical framework to analyse the patient-GP relationship (in section 4.2.3).

The chapter General conclusions ends with a section on the implications of the analysis for practice.

### 4.1 Brief summary and relevance

#### THE POWER BASE OF THE PATIENT-GP RELATIONSHIP

The “resource dependency theory” has proven to be a useful theoretical canvas through which to analyse the power relationship between patient and GP and better suited to the patient-GP relationship than traditional definitions describing power as consciously exercised domination or coercion. It defines the *dependence on resources* as the power base. An asymmetrical interpersonal power balance means that one actor is more dependent on the resources of another actor than vice versa and that there is “resource power”. The more *important* and *scarce* a resource is, the more dependent an actor may be. The relationship is a matter of mutual dependence: patient and GP depend on each other’s resources. The balancing operation between the mutual dependencies of both actors is highly dynamic and differs from patient to patient and from situation to situation. The distinction between *stable and dynamic resources* made in this study has also proven to be relevant. The balancing operation may be dynamic, but the dependence of a patient on certain resources of dependence is more stable than on others, for example, the patient’s dependence on the GP’s resources the license to label and to assign the sick role (including the right to prescribe medication and allow sick leave) is less dynamic.

The literature review identified resources of dependence of patient and GP on the micro-level (interpersonal relationship) as well as on the meso- (healthcare) and macro-level (society). The empirical research made clear that a patient indeed depends on resources on

the micro-level (information, knowledge, skills, attachment, the relationship and time) as well as on the meso- (the medical profession's body of knowledge, its license to label and assign the sick role) and macro-level (bureaucracy and technology). The GP in turn also depends on resources on the micro-level (information, economic dependence and time) and macro-level (bureaucracy and technology). Patient and GP thus both depend on bureaucracy and technology on the macro-level. Both actors have ways to resist their dependencies.

Becoming dependent for a patient often equals losing control which frequently means ending up in an uncomfortable, uncertain, vulnerable and/or stressful situation. Becoming dependent may provoke "reactance". The interviewed patients explained that they want to have control, at least to a certain extent. Having control or a feeling of control is exactly what empowerment is. Bringing about patient empowerment is therefore a complex process in which many resources of dependence on different levels play a role. Focussing on one of the patient's resources of dependence (as for example, health information) in itself may influence the power balance and contribute to patient empowerment, but it does not accomplish this fully. To obtain a balanced power relationship between patient and GP the other resources of dependence of both actors and their ways to resist their dependencies on the three levels have to be considered too.

The analysis also makes clear that the resources on the different levels are interfering with each other and that their importance—it cannot be repeated enough—may differ from patient to patient and from situation to situation. Uncertainty, perceived risk, perceived severity and trust have proven to be possible factors strengthening the patient's dependence on the GP's resources. There is a difference between a patient going to the GP for a cold and a patient confronted with a rare disease or with cancer. Power interpreted from the point of view of dependence on resources clearly is complex and highly dynamic. Looking at the patient-GP relationship from the point of view of "resource power" allows a different view on their power relationship to develop.

#### **THE ROLE OF (HEALTH) INFORMATION IN THE POWER BALANCE**

(Health) information has been identified as one of the resources of the GP a patient depends on. It is also a resource of dependence for the GP. Indeed, during the consultation, the patient wants to be informed about diagnosis and treatment, while the GP in turn needs the patient's information to make a correct diagnosis and to enable him to propose the most suited treatment. A patient however often starts the consultation in a situation of need and thus dependence, if not, he would not consult his GP. Moreover, the GP indeed depends on his patient's information to enable him to set a correct diagnosis and propose the most suited treatment, but it is of course in the patient's interest to deliver the GP the necessary information. Therefore, the resource information on which the patient depends seems more valuable to the patient than that the information of the patient on which the GP depends is valuable to the GP. Health information is an example of a *dynamic* resource: a patient with a cold more or less knows his diagnosis (he mainly needs a confirmation, medication or sick leave) contrary to a patient with a rare disease for which information may be very valuable, and sometimes also rare if the number of experts specialised in that disease is limited.

The distinction between information and knowledge has been made and therefore knowledge is a resource of dependence different from information. The participants of the focus groups also recognised the difference between their "expertise" and the knowledge of the GP which he acquired through training, experience and access to sometimes shielded

information sources. The Web survey as well as the group discussions and the ethnographic follow-up interviews with patients determined that most patients participating recognise their dependence on their GP's knowledge. He possesses the "ability knowledge" necessary to convert his knowledge in a diagnosis and treatment. It would seem that the information and knowledge gap may be narrower with chronic patients having experience with their disease and treatment and may therefore have developed an expertise of their own. But even they can become dependent on the GP's knowledge, for example, when confronted with one other than their chronic disease, and they also remain dependent on other resources of dependence of the GP.

#### **THE ROLE OF (HEALTH) INFORMATION THROUGH THE WEB IN THE POWER BALANCE**

The Web has made the resource "(health) information" exceedingly available. Most patients and GPs participating in this study are well aware of the potential of the Web as a source of health information. It is used amongst others by patients sometimes simply because it is easy, or goal-oriented to fill in health information gaps left by doctors and other providers, before as well as after a consultation and sometimes, also in the phase before going to the GP. In these cases, it may make the patient less dependent on the GP's resource "information" and even sometimes, in the case of what the patient perceives as minor ailments, prevent a patient from having to go to the GP, allowing him to turn to self-medication (provided that his self-diagnosis is correct). It even can turn the patient into an information source for the GP since a patient can come up with relevant health information that was unknown to the doctor. It allows the patient to have more informational control and can make the patient less dependent on the GP's resource "information". It makes, more than in the past, the GP one of the many health information sources a patient may consult. It also may increase the patient's potential to influence his GP, something that was much more difficult when the GP was almost monopolising health information. It could therefore be stated that indeed an "equalization tendency" (Beck, 2010, p. 165) can be established, but mainly related to the resource of dependence "information". Indeed, the Web survey as well as the group discussions and the ethnographic follow-up interviews with patients made clear that the Web does not enable them to close the *knowledge* gap. Health information sought by patients may create uncertainty, misinformation and increase the patients' dependence on the GP's resources, information and knowledge. In many cases, the patient still needs the doctor's knowledge to interpret or contextualize the health information retrieved on the Web and other information sources and to convert it into action or to a clear decision not to act. The Web does not seem to be the "knowledge leveller" (Hardey, 2003, p. 214; Snelders & Meijman, 2009, p. 13) some have hoped for. Moreover, the dependence on the GP's knowledge also remains because people doubt the correctness of the Web health information or have difficulties in finding the requested information (due to the way the Web offers health information as well as to the way people seek health information), as the Web survey pointed out.

Finally, looking for, selecting, understanding and using Web health information requires different types of literacy, notably media literacy which is important, and of course technical access. For health information through the Web to contribute to patient empowerment, certain conditions have to be fulfilled.

## THE RELEVANCE

This study confirmed that there are at least three reasons why analysing the patient-GP relationship from the point of view of dependence is relevant and why it is important that patients have a feeling of control and why healthcare should avoid creating a feeling of disempowerment. **First, a feeling of control and loss of autonomy and increased dependence may be unhealthy and provoke resistance. Second, a patient feeling in control may be more intrinsically motivated to carry out/adhere to his treatment since he more consciously chose a specific treatment. Thirdly, patient empowerment also means taking responsibility for one's health and thus prevent getting sick by developing healthy behaviour. Therefore, people need to have the feeling of being able to do that and avail of the necessary self-efficacy. Empowering patients is therefore much more than just an option.**

The analysis made clear that health information is only one of the GP's resources a patient depends on and to achieve patient empowerment, other resources (also on the meso- and macro-level) have to be considered too. Health information alone does not lead to a patient-GP power relationship in balance and the Web as a source of health information—technology—is not a silver bullet to achieve it. It has the *potential* to influence the power balance between patient and general practitioner by narrowing the information gap between both and increasing the patient's possibilities to influence. Moreover, an informed patient does not equal a patient having control or having a feeling of control which is what empowerment means. The observations analysed in this study showed GP's informing their patients on the diagnosis and the treatment while concurrently maintaining control over the direction of and the communication during the consultation and, more importantly, over the decision-making process. An informed patient thus can feel/be disempowered. As such it would seem that Dent is right stating that the medical dominance of the medical profession is "renegotiated" and "reconfigured" but not demised (Dent, 2006, p. 465).

**Communication is the means to inform and influence (patient and GP in both directions) and the Web as a source of health information is a valuable possible tool to contribute to it.** Communication can also be used to exert power but that is neither to the advantage of the patient or the GP. Communication is also a means for the GP to empower a patient. A GP can involve his patient in the decision-making process by giving him (the feeling of having) control, hereby strengthening the patient's intrinsic motivation to adhere to a treatment and by creating or strengthening the self-efficacy the patient needs to be in control. He can also try to decrease the patient's dependence on resources other than those on the micro-level (for example, bureaucracy) and help to support his patient's skills to be in control, such as (media) literacy. Media literacy is especially important when the Web is used as a source of health information.

However, increasing the (different forms of) literacy of patients, for example, and helping them to develop their skills to have and handle control is complex and transcends the GP's sphere of influence; it is the responsibility of, amongst others, the government and its agencies. The same goes for creating a health care system that is transparent enough to be accessible for even the least literate amongst us and thereby decreasing the patients feeling of dependence on bureaucracy. That same Belgian healthcare system should also change the basis of its financial dynamic to allow patients the time needed to support them to develop the behavioural change that leads to shared decision-making and self-efficacy, and to disease

prevention. Achieving patient empowerment therefore is the responsibility of every actor involved.

But the start lies on the interpersonal level. In the first place, it lies with the GP who has to realise that he indeed has “resource power” through the patient’s dependence on his resources and that he must be prepared to share the control with his patient; just informing his patient is not enough, certainly not if the goal is a patient taking responsibility for his own treatment and health. A GP must consciously endeavour for his patient to have (a feeling of) control on condition, of course, that the patient wants to have control. If it is right that of the two actors the GP is the most powerful, it is up to him to make the first move. Having the most power is an opportunity to do good. But of course, the secondary initiative also lies with a patient having the will to be empowered. Patient empowerment cannot be imposed and for some being dependent represents comfort. Other patients may want to be empowered but lack the skills: they should be supported to develop these skills. Literacy in general and health and media literacy are examples of necessary skills. It will be most useful to develop a tool to help a doctor map the level of empowerment a patient wants to achieve. If the GP does not allow the patient’s influence and control it is up to the patient to enforce it, if necessary with the help of the Web. However, power should not be the main characteristic of the patient-GP relationship. Both actors and the patient in the first place are better off with a trustful, egalitarian relationship based on mutual respect.

## 4.2 Discussion

### 4.2.1 Patient empowerment

**SEVENTEEN IMPORTANT DEEPENING CONSIDERATIONS** are made in relation to patient empowerment. They are listed hereunder and will be discussed one after the other.

- Patients do not blindly accept the GP taking the final decision about the treatment.
- Recognising their dependence does not equal undergoing it without opposition.
- The patient-GP relationship in itself may create dependence.
- A patient’s satisfaction does not equal an obedient GP.
- GPs are becoming less dependent on their patients.
- The difference between the patients’ self-declared narrative on shared decision-making and their behaviour in real life.
- The importance of communication as a means.
- Giving information and allowing control are two different things.
- Chronic patients as prototype of empowered patients.
- The patient must want to be in control.
- Patient empowerment requires decreasing dependence on different levels.
- Power does not need to be exercised.
- The GP’s dependence on resources on different levels.
- The concept of “power” has a negative image.
- Dependence is not in all circumstances negative.
- A balanced patient-GP power relationship is not a mere theoretical exercise.
- The patient-GP power relationship “must at least strive to be fair”.

**Patients do not blindly accept the GP taking the final decision about the treatment.**

The process of informing is different from that of decision-making and patients also see these as two different elements of a consultation. There seems to be a difference between acknowledging that the GP knows more and accepting blindly the GP's decision about what action has to be taken. Neither the status attributed to the medical profession nor the patients' dependence means that patients **blindly** accept that the GP takes the final decision about the treatment. Patients seem to trust their GPs: a majority of the respondents (but not all!) state that it is up to the GP to take the final decision on the treatment. However, it is not blind trust; it is trust based amongst others on information and communication. A doctor presently has to justify his medical advice. Patients seem to be well aware that they will be confronted with the consequences of a treatment—"It is my body"—and if they do not want to take the final decision, the decision about what has to be done must at least be taken *in concert* with them. They maintain their autonomy—the GP does not "own" his patients—and they at least want to be involved. Assessing one's quality of life before, during or after medical treatment is the patient's prerogative. The Web survey showed that the majority of the respondents state that they follow the GP's advice for a certain treatment (which does not equal following the treatment *meticulously*), following or not following a discussion about the best suited treatment. This should not come as a surprise: most of the patients interviewed stated that they go to the GP expecting a solution to their (medical) problem and that it then makes no sense not to follow his advice. This may explain why the majority of the respondents of the survey leave it to the GP to take the final decision on the treatment. Only 6.6% stated that patient and GP should decide together. However, a large group stated that it is up to them to make that final decision. This does not necessarily mean that one large group is delegating total control and that the other is claiming it. When considering the adherence to the treatment, it may not even be negative for the patient to take the final decision since this could mean that he is persuaded of its need. No matter who wants to take the final decision, in any case, there is a need for "shared decision-making"—which is related to the concepts "collaboration" and "deliberation" (Elwyn & Edwards, 2016, p. 2).

The outcome with 39.2% of the respondents commenting on the question "who should take the final decision on the treatment" stated that it is up to them (and not to the GP) could be considered a **decrease in the influence of "legitimate authority"** (Lindblom in Scott, 2006, p. 20). It is the "legitimacy" of authority that seems to have declined. It is not self-evident anymore that a patient "voluntarily" leaves it up to the doctor to decide which treatment should be applied: a large group of patients seems ready to leave the final decision for (and the responsibility over) the treatment to the GP but this is conditional. This could be considered a demand for more control, therefore empowerment, and could be framed in the general societal trend towards more "self-expression" as ascertained in the World Values Survey<sup>72</sup>, and to the sociological trends of "egalitarianism" and "participation". A doctor seems considered less as infallible and omniscient. An illustration of this is the advertisement "The doctor is not always right" (De dokter heeft niet altijd gelijk) (see Figure 90 ) in the periodical of "RWS/Recht op Waardig Sterven" (The right to die in dignity). The copy states: "Your whole life you took your own decisions. Why would you leave the important decision

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<sup>72</sup> Site of the World Values Survey <http://www.worldvaluessurvey.org/WVSContents.jsp> consulted on January 7, 2018

on the end of your life to a doctor? Decide yourself on the end of your life [...]” (“De dokter heeft niet altijd gelijk,” 2012).



Figure 90: An advertisement stating that “The doctor is not always right”

The ethnographic follow-up interviews made clear that patients recognise that their GP can make mistakes and they consider this human: “Everybody can make a mistake”. Experts are also plagued by biases (Gobet, 2016, p. 240) and it looks as if patients are aware of this. Most patients also stated that the recognition of their GP’s knowledge is bound to his biomedical expertise.

Moreover, patients also realise that a GP’s knowledge is relative since in certain cases he has to refer his patients to specialists. That many patients want to decide together with their GP about the treatment, but that the number of persons stating that they want to be the sole decision-makers is limited could be related to the so-called “paradox of choice” discussed earlier (see section 2.2.4.1.2.1): being allowed to choose and , therefore, to decide is a sign of freedom (and we all want to be as free as possible), but it also involves risks. On the one hand, deciding, certainly in serious healthcare matters, is not easy since weighing up arguments may be very complex and sometimes even technical (requiring esoteric knowledge). On the other, deciding means taking responsibility and not all patients want to take responsibility (Henwood et al., 2003, p. 604).

**Recognizing their dependence does not equal undergoing it without opposition.**

Patients do not proceed to “total surrender”. The analysis in this study made clear that patient and GP have different ways of resisting their mutual dependence. Resistance must not be seen as only overt confrontation. Besides actual resistance (for example, by going to another doctor), the patient can develop forms of “symbolic resistance” that do not change the power imbalance, but may express the patient’s disagreement with the imbalance. Giving negative comments about a GP to the interviewer of this study or on the medical profession as a whole, on the Web or by other means are examples (see Figure 91). Just because the patient seems to undergo the imbalance during the consultation does not mean he accepts it since a consultation is a form of “temporary inequality” (Miller, 1986, p. 4). Some interviewed patients stated that their GP does not have the ability to control what they do at home. The dependence is “situational” (Parsons in West, 1984, p. 59): it is not in all cases absolute or continuous, it can change from situation to situation and it may last long and sometimes only last a moment. One patient during a follow-up interview formulated it as “a patient cannot claim anything, but he can refuse anything”.



Figure 91: The memorial advertisement published on May 15, 2016 in the Flemish newspaper *De Standaard* relating a woman’s death to a medical mistake.

**The patient-GP relationship in itself may create dependence.**

It would also seem that the nature of the patient-GP relationship in itself creates dependence. For many patients, this is patients specific. Resources of dependence like “affection” and “attachment” (on the micro-level) lift the patient-GP relationship up to transcend a pragmatic consumer-provider relationship: patients as well as GPs describe a

good patient-GP relationship as “it clicks”. Factors directly strengthening the dependency—uncertainty, perceived risk, perceived severity and trust—and indirectly, charisma (when a person has or combines personal qualities like “courage, decisiveness, firmness, kindness” (Brody, 1992)), also may increase the patient’s dependence on the GP’s resources. The GP disposes over confidential and intimate “personal information” on his patients: biomedical information of course, but sometimes also on personal, private matters. A GP also develops a “holistic perspective” on his patients which creates added value exactly because medicine in general is increasingly specialised and fragmented. Some GPs treat the whole nuclear family and carry out home visits. They can have more insight into the family dynamics than each individual family member. The GP is in certain cases even considered the patient’s advocate towards specialists treating him next to the GP’s roles as a guide in the healthcare system—the “access point of the expert system” (Giddens, 1990, p. 83)—, as a coach related to healthy behaviour and “notifier” (spotting health issues which a patient may not be aware of), as someone offering psychosocial support (sometimes, the only human contact a lonely person can have), as a kind of “medical filter” able to refer patients to the right specialists. A trustful relationship should therefore also be considered a resource of dependence that should be added to the overview in section 2.2.4.4 of resources on the micro-, meso- and macro-level.

**Patients do not all expect a *close* relationship but they require a *trusting* one.** The trust in the GP is influenced by the patient’s feeling that the GP is involved, is honest and takes the time needed, the way the GP communicates (giving voluntary and customised information attuned to the foreknowledge of the patient, using plain language, also about the diagnosis, even in cases of doubt) and the feeling that the GP allows the patient to be vulnerable. Patients state that the trust has to be mutual: a GP clearly showing that he doubts if his patient really needs sick leave is expressing distrust towards his patient. GPs for their part expect their patients to take responsibility for their treatment, allow the GP his own expert opinion, not to go *GP shopping* or misuse their GP, trust their GP’s expertise and skills and to be honest about their symptoms and the way they execute the treatment.

The durability and continuity of the patient-GP relationship are important distinctions from specialists in a hospital who are generally considered more distant. The results from the Web survey illustrated that most patients are indeed loyal to their GP: they stick to the same GP for a very long time. The patients are aware that building a trusting relationship takes time. Starfield states that it takes a patient-healthcare provider relationship two to five years “before its full potential is achieved” (*The world health report 2008: Primary Health Care Now More Than Ever*, 2008, p. 51). It seems to make switching to another GP more difficult. If a trustful relationship is built, a patient wants to preserve it, even more if he is vulnerable. This may be another explanation why some patients turn to alternative medicine or consult the Web for health information without telling their GP. It may well be that Belgian patients have the legal right to switch doctors and that they are independent of one specific GP. The Web facilitates finding basic information on GPs. This dissertation again confirms that the Belgian law on Patient Rights is unknown to people, but that does not prevent many patients from being aware that they are allowed to choose doctors and move to another GP if they would like to. This study however, also ascertained a psychosocial obstacle to changing GPs. A trustful patient-GP relationship is a resource of dependence patient as well as GP depend on.

The main reasons for changing GPs indicated by the interviewed patients are because they move house, because their GP stops his practice or due to their own physical development (for example, a young girl in full physical development can prefer a female doctor while at some age the gender difference becomes less sensitive). But **every patient-GP contact is a “trust proof point”**, as McKean calls it, going from “a typical interaction to handling a major customer crisis” (2005, p. 123): “The more significant the trust proof is, the greater the trust that is built, and therefore, the greater the loyalty”. McKean calls trust, when it has not been tested, “conceptual” (2005, p. 124). A patient “hopes” that his GP is trustworthy and that the GP also trusts him and it is only when a problem arises that the hope can be “believed”. He herewith joins Luhmann’s view (1979, p. 25). Whether an action is positive or negative can only appear after the action and the “problem of time is bridged by trust”. Patient and GP together overcoming a medical crisis can lead to a strong and lifelong relationship, as has also been ascertained by patients and GPs. An example of such a significant “trust proof point” is a medical mistake. Honesty also means admitting to having made one, patients during the ethnographic follow-up stated. Most of them understand that a mistake in diagnosis or during treatment can be made—everyone can make mistakes—, but they do not accept that the one making the mistake denies it. If the doctor admits it, takes responsibility for it and does whatever possible to correct it, the patient’s trust can be restored. If not, it can mean the end of the relationship. Almost 3 in 4 of the participants of the Web survey think their GP would admit to having made a medical mistake, but they have greater doubts in relation to doctors in general.

Questions related to the type of the practice—solo, duo or group practice—did not lead to a clear-cut conclusion on patients’ preferences. Patients usually seem to choose a GP close to their home and not for a specific type of practice. When a solo working GP develops his practice into a duo or group practice, patients seem to stick to the practice. Participants in the focus groups recognised advantages as well as disadvantages of group practices. Some patients go to a group practice but prefer to always be seen by the same GP. The more a patient considers a personal relationship with his GP important, the more he seems to prefer to always have the same GP, certainly with whom a trustful relationship has been built and for medical issues the patient considers important. Chronic patients going to a solo practice seem more satisfied than chronic patients going to a group practice.

People and patients exhibit a high level of loyalty to their GPs combined with a high level of satisfaction, according to the Web survey. Satisfaction is related to the patient’s expectations. Most patients are satisfied to very satisfied about their GP. It should be noticed that their satisfaction seems also to be influenced by their satisfaction about the affordability of healthcare in general. However, the follow-up interviews with patients participating in the video-recorded consultations illustrate that **loyalty does not equal total satisfaction**. It is not because healthcare is not a regular economic market that patients are satisfied with less service. Even loyal patients may have criticisms related to certain aspects of the service surrounding the consultations as for example, long waiting times, and the features that the ideal GP should have are numerous. Patients expect a GP to be accessible and available (sometimes quickly when needed) and nearby. Trust and therefore satisfaction are also undermined by bad “micro experiences” as for example, a GP asking his patient to fully undress without it being necessary. A lot of these characteristics summed up by patients in the focus groups are related to communication, be it that the core of the relationship

remains the GP's capability to diagnose and heal and his "technical" skills (for example, taking blood without problems or removing a stitch). Just as their satisfaction is also related to their satisfaction about the affordability of healthcare, the dissatisfaction also seems sometimes related to characteristics of the healthcare system in general (as for example, the fact that a patient has to pay in advance and only gets a refund later). Some patients also changed GPs out of an experience that undermined their trust: the relationship did not survive a bad experience during a serious "trust proof point" and the dissatisfaction got the upper hand above their satisfaction. "Loyalty" and "satisfaction" are different concepts, as is already known for some time in the commercial world (Gitomer, 1998, p. 54): customers may for example, be satisfied without being loyal or customers can also be unsatisfied and nevertheless, loyal. Loyalty is considered an indication of a trusting relationship. High satisfaction seems to be the basis for trust and both are together the basis for loyalty (Eeckman, 2009, p. 15).

All these elements once again underline the particularity the patient-GP relationship represents for many patients. It may also be interpreted as if stopping the relationship or threatening to stop it may, for the doctor, indeed be a valuable way to resist his dependence or to exercise "resource power".

**A patient's satisfaction does not equal an obedient GP.**

For patients, satisfaction does not mean an obedient GP either, a consultation sometimes is a negotiation. None of the patients interviewed had a "consumerist" attitude, for example, thinking they have the right to claim medication and considering the GP as a mere provider of a service just as any other service in a market economy. They all understand that a doctor may have good reasons not to prescribe certain medication. They expect honesty from their GP, for example, prescribing medication or sick leave only when needed and nothing more or less. **Prescribing medicine and sick leave too easily and without real necessity is associated with being "a bad doctor"**, patients interviewed stated.

While there is only limited distance between a GP and his patients, patients as well as GPs consider it important that the distance remains. Almost half of the respondents of the Web survey stated that they think that they could not be a *Facebook* friend of their GP. The distance seems to be needed to preserve the therapeutic relationship that is based on confidentiality and honesty on the patient's part. It is also needed because a doctor's diagnosis and treatment does not always coincide with what would satisfy a patient: a patient's satisfaction does not always coincide with that patient's best interests. Nevertheless, one patient states that a doctor would not "refuse a treatment that a patient absolutely wants". This remark may be considered an indication of a certain level of "negotiation" in the patient-GP relationship. On the one hand, a GP wants to keep his patient for financial reasons (a GP economically depends on his patients) and because he wants the best for him; a patient going to another GP is losing the opportunity to heal his patient. On the other, exactly because the GP wants the best for his patient and because he considers himself not a mere provider of a service, the GP does not want to give in to the patient's every whim. The patient on his part may have a certain desire, but does not want to sacrifice the relationship for it. This illustrates well their mutual dependence and the balancing operation between them. Besides, the concept of "negotiation" is well-known in the

literature on the patient-doctor relationship. Roter and Hall refer to “a spirit of exchange” and use the term “reciprocity” to describe “things people can do for, or give to, each other” (2006, p. 17). They refer to Emanuel and Emanuel to describe “four ideal forms of the doctor-patient relationship: paternalism, consumerism, mutuality, and default”. Only in the mutuality model, the “power in the relationship is balanced” (2006, p. 27). Here the link can be made with the “resource dependency theory” again: negotiation is a way to try to obtain balanced interdependence.

### **GPs are becoming less dependent on their patients.**

This study also suggests that GPs are becoming less dependent on their patients. Belgian GPs are to a lesser and lesser extent working alone but moving to duo and group practices allowing them a better work-life balance. They are sometimes supported by a secretary and telephone system. It would seem that in Flanders the GP who is available to his patients day and night is becoming extinct. The Belgian “Orde der Artsen” (Order of Physicians) has even recently included in its Code that doctors are not allowed to do excessive overtime and that can be sanctioned if they do. The motivation of the Order is that too much overtime is not only bad for the doctor’s health, but also for the quality of the care he delivers (Majeur, 2018). GPs in the discussion groups mentioned increased professionalisation as a cause, meaning that it leads to less personal contacts with patients. Certainly young GPs would seem to have less ambition to be the central point of contact for a patient anymore. Martine, a 60 year old Flemish GP working alone and having been a GP for 34 years, puts it sharply<sup>73</sup>:

“The main objective of duo and group practices consists mainly in obtaining individual leisure time (thus, for the physician). Often they see, for example, with two doctors no more patients than a solo physician. But they have a lot more free time! And the patient in this picture? He is of secondary importance! The patient is reduced to a "grateful object" that puts money in the barn. If one doctor cannot see the patient, then the other will see him/her... An "emotional relationship" (do not misunderstand), I mean a more empathic relationship in which one is really involved with a patient, in which one is really worried about what the patient has or experiences, disappears and makes room for a mere distant contact”.

GPs also blame the healthcare system for their growing independence from their patients. They state that they are not the only central point of contact for patients anymore compared to 30 years ago. Patients go directly to the Emergency Department and parents go with their children to pediatricians and other specialists; the growing specialisation (ear, nose throat, ...) encourages patients to skip the first line. Patients are backed-up by pharmacists who also give some medical advice. Hospitals are promoting their services and specialists are giving lectures to the general public through this again instigating people to make direct contact with that specialist. “There are more possibilities for patients to find their thing outside of the GP,” a GP stated.

The growing specialisation and segmentation in medicine creates a tension: on the one hand, patients can go directly to a specialist and skip a consultation with a GP, on the other, exactly

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<sup>73</sup> Quote from an email received from a GP on September 2, 2017. Identification information of the GP is known by the researcher.

due to the specialisation and segmentation the holistic approach of a GP becomes increasingly important to them.

**The difference between the patients' self-declared narrative on shared decision-making and their behaviour in real life.**

There may be a difference between the patients' self-declared narrative on shared decision-making during the interviews and in the focus groups and their behaviour in a real life situation. Not for the first time a contrast is found between the ideal patient-doctor communication and reality (Furst, 1998, p. 233). It is striking that the observation of 24 patient-GP consultations has shown rather passive patients and GPs clearly controlling the consultation and decision-making. While the patients declared that they were satisfied to very satisfied about their GPs, the ethnographic follow-up interviews at the same time indicated that some patients had criticisms about certain aspects of their GP's behaviour or on service-related elements. However, there were no signs of these critical elements during the video-recorded consultations. These recordings are of course, only snapshots of the relationship and resistance may also be expressed in a "covert" and "subtle" way (Stimson in Tuckett et al., 1985, p. 80) that is difficult to detect when analysing only one consultation. Different explanations could be given.

The distance between their self-declared attitude and the video-recorded passivity during the consultations has been put on the table at the end of the three focus groups with patients and people considering themselves healthy. Some participants stated that changing GPs is easier said than done. They recognised that being vocal requires skills and that time pressure and the spatial arrangement of the consulting room as well as the patient's vulnerability and dependence may discourage patients to resist. The GP's authority, status and the distance between patient and GP—distance that patients as well as GPs recognised to be necessary for the therapeutic relationship—may contribute to the patients' passivity during the observations. The authority, status and distance of the GP may be amongst others a possible explanation why some patients turn to alternative medicine or consult the Web for health information without telling their GP.

The patients' dependence is also one of the possible explanations for their passivity (Peterson et al., 1993, p. 228). As mentioned before, the follow-up interviews with patients revealed that since building a trustful patient-GP relationship takes time, patients seem reluctant to change. It would seem that a patient also wants to be considered "a good patient" expressing this attitude by passivity and compliance and "fears about the repercussions of becoming more actively involved (e.g. being labelled 'difficult' or receiving lower-quality care)" (Frosch et al. in Joseph-Williams, Edwards & Elwyn, 2016, p. 43). This finding confirms how patients consider the relationship with their GPs as very important, certainly because the GP often fulfils different roles that distinguish him from specialists and doctors in a hospital. This could be a reason for them not to show an assertive attitude. It then could be interpreted as an expression of their dependence. However, while the GPs observed are clearly leading the consultation, topics are often raised by the patients and the observed GPs are friendly and sometimes very empathic and they remain flexible to give their patients the latitude they need to express themselves. This could be referred to the "friendship frame" (Davis, 1988, p. 341) mentioned in section 2.2.4.3.1.1: a friendly

relationship as a way to “bring about the desired behaviour” (Jacobson, 1972, p. 43) and allowing a doctor to exercise more power (Jacobson, 1972, p. 102).

Of course, calling the patients’ attitude during the consultation “passive” is taking a stand. After all, the patient-GP consultation is a form of an institutionalised conversation focussed on a clear goal set by a patient expecting the GP to achieve it. It seems logical that the patient does what the GP asks to enable him to achieve the patient’s goal. Allowing the GP to lead the consultation is considered logical by patients and is not necessarily considered an illustration of the exertion of power.

But by the same token, it could also be seen as an expression of “hegemony” (Gramsci in Wendt, 2001, p. 21), where patients “willingly” participate in their own domination. The notion of resistance supposes that an actor wants to equalise the mutual dependence and resists one-sided dependence. Analysing the power relationship between men and women, Miller states that if a woman accepts the man’s conception of her, “she will not recognise that there is a conflict of interests or needs” (1986, p. 14). Mirrored on the patient-doctor relationship, it would mean that if a patient in a situation of unequal dependence accepts the situation and does not identify the situation as conflictual, he may not feel the need to resist.

### **The importance of communication as a means**

This study established the importance of communication as a means to support the patient’s control or feeling of control in the patient-GP relationship. Patient empowerment stands for having control or having the feeling of control over one’s health and healthcare. Communication can contribute to decreasing (the feeling of) being dependent. When the GP informs his patient in plain language and the patient feels well-informed, he will be less dependent on the GP’s resource information in that situation. But a GP cannot make his patient independent from his legal right to label. In that case, a GP can, from his behaviour, the way he communicates, the spatial arrangement of the consulting room and the way he organises healthcare, try to give his patient a sense of control. This of course also applies to the GP’s non-verbal communication: he should not consider a telephone interruption and typing without telling his patient why and what as self-evident. The GP must be aware that he has communication as a means to realise “transformative power” (Wartenberg, 1990, p. 203).

The focus groups identified characteristics a GP should have which leads to the patients’ view on *the ideal GP*: he should be empathetic, attentive, be knowledgeable, have integrity, have a willingness to listen and is a good listener, behave open-mindedly, is a good communicator, is open, honest and friendly, takes his patients seriously and is trustworthy. He keeps eye-contact, takes the time needed, follows-up on his patients, has decision-making skills and radiates a certain level of self-confidence, he develops a tailor-made and personalised approach (he takes the patient’s wishes and characteristics into account when proposing a treatment), clear information explained in plain language and given to the patient without the patient having to ask for it, being a good listener and being an all-rounder, to be committed and social and to refer to specialists if needed and in due time.

## Giving information and allowing control are two different things.

West concluded from his research of doctor-parent encounters (on children with epilepsy) that *giving information* and *allowing control* are two different things. A doctor involved in his research kept tight control over the course of the consultation which did not prevent him from informing the parents (1977, p. 19). Informing a patient does not equal empowering a patient, but it is an important condition for patient empowerment. Joseph-Williams et al. stated that “a patient’s capacity to participate seems linked not only to how much knowledge they have (i.e. about treatment options and knowledge of their own personal preferences), but also to how much power or influence they feel they have in the decision-making encounter, i.e. their perceived ability to make use of this knowledge” (Joseph-Williams et al., 2016, p. 44). “[...] shared control of the consultation, decisions about interventions or management of health problems with the patient” is mentioned by the U.K. Department of Health as an important element of the philosophy of patient-centredness (Illingworth, 2016, p. 41). The Web survey results indicate that exactly this still seems to be a problem: not more than 13.8% of all respondents declared having the feeling of being able to influence the care they get from their GP. 38.4% stated that they do not and 47.8% that they sometimes do.

What goes wrong with the communication style of GPs that results in the feeling of not having control? The results of the Web survey taught us that a large majority of the respondents understand what their GP is telling them and that they tell their GP if they do not understand. The ethnographic follow-up interviews also highlighted how many patients tell their GP if they do not understand and even when they do not agree with his diagnosis. This is at least what respondents self-declared and it contrasts with the rather passive attitude determined during the observations. Indeed, other research came to the conclusion that patients are often reluctant to ask for clarification and Svarstad even uses the term “communication conspiracy” to describe a situation in which the patient behaves as if he understands and the doctor behaves as if the patient understands (Roter & Hall, 2006, p. 128). Moreover, discontent has been ascertained by the Web survey in relation to the information GPs provide on their diagnosis: slightly more than one in three of the respondents declare not getting enough information on what the GP thinks about the diagnosis. This ascertainment confirms other research. Research has, for example, shown that the patient’s willingness and ability to take medication is seldom a conversation topic during the consultation when drugs are prescribed (Makoul et al. in Shaw & Baker, 2004, p. 724). It would seem that the patient’s and the doctor’s interpretations and expectations about information “disclosure” differ. Faden et al., analysing “information preferences of patients and information-giving practices of neurologists” demonstrated that

“In general, patients preferred detailed and extensive disclosure of almost all risks even when they were quite rare. Further, information about alternative therapies was highly valued [...]. By contrast, the physicians indicated that they were likely to disclose only risks with a relatively high probability of occurrence [...]. Moreover, the physicians were much more likely to agree with the view that detailed disclosure of information regarding drugs would decrease positive placebo effects, increase side effects through the power of suggestion, and decrease compliance. Patients expressed a completely different view. They believed more information would

increase their confidence in the drug, improve their compliance, and generally serve to make them feel more comfortable with the therapy they were receiving” (Roter & Hall, 2006, p. 130).

It would seem that GPs still strive to have informational control, from their point of view, for the sake of their patients. Their communication style, including their information strategy, can be the obstacle as well as the lever for the patients to take control and thus, for patient empowerment. The analysis of the 24 video-recorded patient-GP consultations predominantly show GPs maintaining control over the course of and the communication during the consultation and the decision-making process. Roter and Hall state that “physicians have primary control over patient participation in the medical visit by providing at least a minimal framework of information within which the patient can arrange thoughts and formulate questions” (Roter & Hall, 2006, p. 132). The patients’ empowerment discourse, in line with the general sociological trends like “egalitarianism”, “participation”, “consumerism” and others clashes with those GPs trying to keep control. The GP’s kindness towards his patients could be called “a clever ‘packaging’ of power” (Wodak, 1996c, p. 44). Previous research indicates that not all doctors are receptive to informed patients (Henwood et al., 2003, p. 605). But keeping informational control often is only an illusion since it may only last a consultation. **It seems as if those GPs intending to keep informational control are still reasoning from a communication science paradigm that is totally outdated today:** that of a linear, one-way and extremely simplified communication process supposing a passive receiver of the sender’s messages as in the Shannon-Weaver communication model from 1949 (Loisen & Joye, 2016, p. 167). It is as if they overestimate the effectivity of their influence. It has been said before (see section 2.2.2 on the difference between power and influence) that the effectivity of influence may weaken in the absence of the influencing actor (Stemerding, 1971, p. 31). **The availability of the Web as a source of health information can contribute to a decrease in that effectiveness.** Today, many patients supplement imperfect or incomplete information provided by a doctor through their own search for information, amongst others through the infinite health information on the Web and via the Internet through their lay referral network. If the patient’s search leads to an indication that the doctor did not tell the whole story, the patients may not adhere to the treatment and the trustful relationship may be undermined. In today’s information environment and with today’s patients’ empowerment attitude, it makes no sense for a doctor to try to influence the balancing operation to his advantage by informational control since many patients have their own ways to set up counter balancing operations. To say it with Aujoulat et al.: “an empowering relationship implies that the professionals have to unlearn being in control” (Aujoulat, d’Hoore & Deccache, 2007, p. 16). McCartney writes: “professional doctors should liberate patients” (2012, p. 288). Ultimately, this supports the doctor’s final goal: healing his patient. Indeed, “the patient who understands is far more likely to cooperate with her future treatment” (Faulder, 1985, p. 114). But for a patient to understand, the GP must understand the patient. Therefore, the GP has to exceed the biomedical model and listen and take into account “the voice of the lifeworld” (Mishler, 1984, p. 193). Taking into account that there exists “alternative medicine” besides traditional medicine is part of it. It is striking how many respondents of the Web survey comment that doctors do not discuss alternative medicine (see appendice 14). Alternative medicine seems part of many patients’ lives.

## **Chronic patients as prototype of empowered patients?**

The results of the survey make clear that the attitude of the chronic patients differs from that of the average non-chronic patient. Chronic patients are more vocal, more demanding and show more initiative to take and keep control. They are less satisfied with and have less confidence in their GP. Respondents who are chronic patients report doubting more that their GP knows more about medical matters than they do. They prefer a GP working in a solo practice. They indicate more that it is up to themselves to take the final decision about the medical treatment when compared to non-chronic patients and they consider the Web a less good health information source more than non-chronic respondents. They indicate more that they tell their GP that they do not agree with a diagnosis when compared to non-chronic patients. It could be stated that chronic patients have developed more an attitude of empowered patients.

The discourse related to chronic patients is that they should, for their own advantage, move to the self-management of their disease (Tattersall, 2001, p. 227). This may be related to the concept of the “expert patient”. Expert patients are “involved”, they take “an active part in managing their own care are” (Shaw & Baker, 2004, p. 724) and are “reflexive” (Fox, Ward & O'Rourke, 2005, p. 1307). But the concept seems to worry the medical profession as much as it is considered something positive (Shaw & Baker, 2004, p. 723). This type of patient would seem to be “troublesome” (Thorne, 1993, p. 54) and too time-consuming—there is the scarce resource again -“time”-, “unreasonable” and “demanding”. Maybe these are reasons why “often professionals cling to power in their engagements with patients, controlling information and dismissing efforts by patients to theorise or explain their condition” (Fox et al., 2005, p. 1300). Thorne uses the wording “control struggles” to describe the relationship between chronic patients and their healthcare providers (1993, p. 54). This may be considered an indication that **empowered patients require an attitude change by the providers** (who have to allow the control by patients) as well as a change to the healthcare system (which has to allow more time for patients). In its healthcare policy the Belgian government stresses the importance of empowerment of chronic patients and “the need to encourage health care providers to make sufficient time to adequately inform the patient and also to involve their environment in care and treatment” (2016, p. 35). It should however not be neglected that healthcare providers should allow patients to also have control.

Yet, a chronic patient may be confronted with diseases other than his chronic disease and then he may fall back into the situation of “a regular patient”. Moreover, even a chronic patient remains dependent on the GP’s license to label, to prescribe medication and to allow sick leave. And of course, not all chronic patients are alike.

## **The patient must want to be in control.**

Both actors have to be open to support patient empowerment: the GP has to allow and support it (and be conscious that he has “resource power”) and the patient must want to be in control. Patient empowerment cannot be imposed by a doctor. As stated before, having control—which also implies taking responsibility—is not the wish of every patient. People may feel confronted with too many responsibilities than they can bear and then the freedom of

having control may become “onerous” (Brehm & Brehm, 1981, p. 389). The results of the Web survey confirm that **not every person wants to have total control**: many respondents declared that it is up to the GP to make the final decision about a treatment.

In addition, a patient must also **be capable of taking control**; it requires skills. From that point of view, to achieve patient empowerment acquiring the skills is more important than acquiring knowledge (Wallack, 1990, p. 50). Patient empowerment is, for example, related to health literacy (Zarcadoolas & Pleasant, 2009, p. 319).

Defining patient empowerment also as “Having control over the management of one’s condition in daily life” means that a patient also has to **take responsibility** for being healthy by developing healthy behaviour which is not a minor challenge. The respondents to the Web survey also indicated the following health issues (in order of the importance indicated by the respondents): too little physical exercise, too much stress, not enough sleep, an imbalanced diet, too much alcohol and smoking. 44% of the respondents stated being afraid of falling ill due to unhealthy behaviour. What is even more important is that a large majority declared being able to do a lot to prevent getting sick. Staying healthy is to a large extent a matter of developing a healthy behaviour. In Belgian healthcare, the need is clearly felt to invest more in the prevention of diseases than in healing them. In 2017, in the European Union, on average not more than 3% of the health budget is spent on prevention, against 80% to the treatment of diseases (“Belgium: Country Health Profile 2017, State of Health in the EU,” 2017; “Commission diagnoses the state of health in the EU,” 2017). More than 30% of the diseases are due to unhealthy behaviour.

**Patient empowerment requires decreasing dependence on different levels.**

This consideration is related to the patient’s dependence on resources on the meso- and macro-level. It has been noted in this study that an individual patient has no or only very little influence on these resources. This confirms what has been stated by other scholars before: **patient empowerment can only be achieved if the dependence on other resources on the other levels is also decreased as much as possible**. It also means that a GP can contribute to his patient’s empowerment but cannot achieve it totally. Indeed, a GP usually can only do little about, for example, disempowering bureaucracy in a healthcare organisation or the patient’s dependence on technology (for example, because he needs a scan). If patient empowerment is to be realised, all actors on all levels have to strive to achieve it together. The Web survey as well as the analysis of the focus groups indicated that most participants have more trust in their GP than in the healthcare system as a whole and that their trust in the system is also influenced by their experience with their GP. If their experience with “the first line” is bad, they may consider this a first bad taste for the rest of the healthcare system.

In this context, it is important to be aware of the existence of a possible “empowerment paradox” (Wendt, 2001): the discourse of patient empowerment may collide with a reality in which a patient is imprisoned in a cluttered tangle of regulations.

While patients try to become freer from their dependencies, medicalisation and commodification of their body and mind tends to make them more dependent on the medical profession.

☑ **Power does not need to be exercised.**

Communication can be used to inform, to influence and to empower, but also to exercise power by the GP as well as by the patient. This study established that it is to the advantage of neither of them. Dependence creates **the ability to exercise “resource power”** but it does not need to be exercised. Patient and GP need each other to achieve their common goal: taking care of the patient. The follow-up interviews with the GPs indicate that they do not consider themselves mere providers of a service, they chose their profession to help people. Mutual trust is essential to the relationship. “There must be trust present to gain trust” (Wendt, 2001, p. 41) and thus, trust is incompatible with power exertion. The follow-up interviews indicated that patients believe in the good intentions of their GP, which is, according to Luhmann (1979, p. 41), the base of trust. The exertion of power often seems to lead to resistance and it can come with a cost. Therefore, patient and GP are better off when the patient-GP relationship remains in the communication mode since this can lead to a “win-win situation” (see Figure 92 below).



Figure 92: Cartoon - Patient and GP are better off when the patient-GP relationship remains in the communication mode leading to a “win-win situation”

This research indeed confirms the importance of staying in the “communication mode” in the relationship (see section 2.5). Since patient and GP are interdependent, **it is to the advantage of neither to move the relationship into a relationship in which tangible power and resistance against the mutual dependencies determine the dynamic** (see Figure 93). In case that, due to circumstances, the relationship moves to the power mode, both actors have legal rights to turn to. However, the Belgian law on patient rights still seems to be too unknown and the Web today does not seem to give a reliable and complete informational answer to the Belgian patients looking for qualitative criteria to choose another GP.

Patients during the follow-up interviews stated that they did not have the feeling that their GPs abuse that dependence while they could.



Figure 93: Cartoon – Exertion of power is to the advantage of neither the patient nor the doctor.

#### The GP's dependence on resources on different levels

This consideration relates to the GP's dependence on resources on the different levels. GPs reported that they feel increasing control from bureaucracy, a resource situated on the macro-level. Their freedom is limited by an increasing number of administrative measures, be it that the interviewed GPs state that they consider these measures positive.

On the meso-level, in healthcare in general, the GPs recognised the increased power of patients as a group. They consider patient rights as a sign of that increased patients' power. The patients' attitude seems also fed by (sometimes contradictory) information and communication in mass media and organisations like "health insurance funds". But the GPs interviewed reported that GPs as a group also gained more power.

Due to this changed and more critical behaviour, patients in general may have the feeling of possessing more power, but as individuals and thus, on the micro-level, they do not really have more power, GPs stated. Patients may have a subjective feeling of having more power, but they are still "stuck in a straitjacket", as put by one GP. Indeed, the patients' dependence varies from situation to situation but it seems that the GP still is their

"[...] trusted lighthouse on the shoreline, and with a calm sea you don't need it. And the more turbulent the sea becomes, then they are always happy that that permanent lighthouse stays there, and if he falls down, then we put it back up".

as a GP formulated it during the discussion with two groups of GPs (see Figure 94). The survey results confirm that in general, people trust their GPs, be it that the GP must earn it. Moreover, the medical profession as a whole, despite a sociological trend towards

“egalitarianism”, still has **status and prestige**: people value the role doctors are playing in society; some patients still “look up to them”. They consider the GP’s job “important”. Patients do not consider the GP’s job an easy one and are aware that it carries a lot of responsibility.



Figure 94: Cartoon - The GP is the “trusted lighthouse on the shoreline”

The GP thus still seems to have “Aesculapian power” as Brody called it: “the power the physician possesses by virtue of her training in the discipline and the art or craft of medicine” (1992, p. 16). The GPs also confirmed this during the follow-up interviews as well as the discussions with groups of GPs. If the patient-GP relationship is trustful, it in itself also creates dependence of the patient on the GP.

**The concept of “power” has a negative image.**

It is interesting to note that the research also indicated that the concept of “power” has a negative image. Most respondents—doctors as well as patients—linked it to domination and coercion, and therefore, did not identify it as a characteristic of the patient-GP relationship. Besides this study highlighting this phenomenon, instead of mere power theories related to domination, the resource dependency theory also illustrates that power in itself is not a bad thing: it is what the possessor of power does with his power that matters (Klitzman, 2008, p. 301). “Consciousness raising” (Serrano-García, 1984, p. 185) is therefore, important: patient and GP have to be (made) aware that they have power through the dependence of their mutual resources and that balanced mutual dependence is the key to a trustful patient-GP relationship.

**Dependence is not in all circumstances negative.**

The patient remains dependent on the GP’s knowledge and on his other resources and so, asymmetry remains. But is dependence in all circumstances negative? The Japanese scholar, Doi, uses the word “amae” to describe the dependence of a child from his mother,

dependence representing warmth and love (Doi, 1981, p. 7); a kind of dependence that seems to be an integral part of Japanese culture. The Japanese seem to consider dependence as something positive. Alison Pilnick and Dingwall even suggest “that asymmetry lies at the heart of the medical enterprise: it is founded in what doctors are there for” (2011). Indeed, a patient goes to the doctor because he can achieve things the patient cannot, otherwise, he would not go. The question may arise if, in Western Europe, we might not be too focused on independence while in reality, human beings are interdependent for their survival? Are we not toying too much with “the liberty of the individual” (Doi, 1981, p. 87)? A feeling of dependence may even be comfortable if it is linked to dependence in trustful people. Self-reliance could even push a patient towards helplessness (Doi, 1981, p. 22). The discourse on the imbalanced power relationship is based on the principle that the imbalance is negative for the patient. But that does not seem necessarily to be the case in all situations and for all patients. The question is what a patient wants and what the GP does with his patient’s dependence. He can use it for the best as well as for the worst. Empowerment does not mean striving for independence, Regenmortel states, it is about “autonomy in connection”; interdependence remains (2008, p. 22). Independence, control and thus, patient empowerment should not be idealised. They are not the holy grail (Rissel, 1994).

**A balanced patient-GP power relationship is not a mere theoretical exercise.**

Striving to get the power relationship between patient and GP in balance is not a mere theoretical exercise. The Web survey as well as the analysis of the follow-up interviews with patients led to the suggestion that the status surrounding a GP in the past still exists but has decreased and gives way for a more egalitarian approach by the GP. Maybe in the past, the status and legitimate authority of the GP made a patient obey (albeit that non-compliance is not a new phenomenon) (Snelders & Meijman, 2009), but presently this seems less efficient in bringing a patient to adhere to a treatment; this study indicates that compliance is not self-evident anymore. A patient follows a treatment because he has to be intrinsically motivated for it and not just because a doctor tells him to do so. The patients should not comply to a treatment but adhere to it; **compliance** is a word that is related to a paternalistic view on the patient-doctor relationship (McAllister et al., 2012). The GP has to strengthen the patient’s sense of self-efficacy (see Figure 95), the patient’s own conviction that he is able to carry out the treatment. This is even more important when the objective is to move towards greater prevention of diseases, thus of patients taking more responsibility for their health. This finding again points out that communication is not just a matter of communication.



Figure 95: Cartoon – The GP’s communication is a means to create the patient’s intrinsic motivation to adhere to a treatment

There is much at stake. On the one hand, there seems to be a link “between communication and physiological processes, but it also suggests the value of strategic communication intervention to enhance delivery of health care and promotion of health” (Kreps, 2014, p. xiii). On the other, with certain diseases, a patient retains essential determinants to his healing, for example, in the case of a diabetes patient who has to change his eating habits and who should exercise more (Weed & Weed, 2013). A patient having (the feeling of having) control is more engaged and more motivated to take active part in his healing process. Empowering patients is therefore much more than just an option. But there is still work to be done: more than 1 in 3 respondents of the Web survey declared not having the feeling of being able to influence the care they get from their GP. McAllister cites the assumptions about the results for healthcare of empowering people: they “will (a) make more rational healthcare decisions to maximise their health and wellness (b) decrease dependence on healthcare services and (c) ultimately contribute to more cost-effective use of healthcare resources” (McAllister et al., 2012). As he states, “these consequences remain to be proven”. But powerlessness and disempowerment may lead to bad health (Marmot, 2015, p. 62) and this makes patient empowerment the responsibility of society and of everyone able to empower someone else.

**The patient-GP power relationship “must at least strive to be fair”.**

If it is true that the power relationship between patient and GP is not balanced, it “must at least strive to be fair”, Furst states (1998, p. 251). Sennett points out that equality is an illusion since people’s talents differ. The challenge is to rightly judge “when and where [inequality] can be avoided, when and where it must be accepted” (2003, p. 262). As an answer towards inequality and dependence, he proposes **the concept of “respect”**. For him, it includes granting autonomy to others which he describes as “accepting in others what one does not understand about them” (2003, p. 262). In their study, Beach et al. reported that the patients in their focus groups attributed additional meanings to the concept of “respect”

(2017, p. 2080). Besides autonomy, also dignity, integrity and vulnerability are mentioned as aspects of respect. Participants predominantly related respect to “treating patients like persons” and “treating them equally”. This study ascertained patients’ demand for an egalitarian relationship with their GPs. Beach et al. state: “Respect is fundamental to all human interactions and especially important in healthcare, where its presence allows for some level of patient dependency without fear of mistreatment or abuse” (2017, p. 2076). Sennett states that patients should be allowed “to participate in the terms of their own dependency” and considered “competent” to do so (2003, p. 178). He calls “reciprocity” “the foundation of mutual respect”. A relationship is an exchange that does not need to “equalize resources”, he states, inspired by Mauss’ study of gifts exchange in archaic societies (Mauss, 2012). Whoever benefited has to give something back and it is the exchange that creates respect.

Mauss’ view, from another angle, underlines that asymmetry in the patient-GP relationship following imbalanced dependence on resources does not need to be negative. If the relationship is considered an exchange, mutually obligating actors returning the equivalent of what has been given, there need not be a problem with the asymmetry in the relationship. In his conclusion, Sennett places the ball in the court of the most powerful in the relationship: **“In society, and particularly in the welfare state, the nub of the problem we face is how the strong can practice respect toward those destined to remain weak”** (2003, p. 263). In this study, it means that it is up to the GP to make the first move towards his patient’s empowerment. It is an opportunity for him to turn his power into “power to” for the patient (Hearn, 2012, p. 6). The objective is to make a patient as independent and autonomous as he would like to be and show him respect.

It is interesting to relate Sennett’s concept of “respect” to the plea Freire is making on the need for a “dialogue” in his classic work, “Pedagogy of the oppressed” (1996). Participants in the focus groups themselves indicated that the consultation should take the form of a dialogue and the follow-up interviews with patients illustrated that they tend to respect a GP’s position or decision, even if it does not match theirs. GPs during the interviews used the words “partnership”, “collaboration” and “deliberation”. These last two “core behaviours” are related by Elwyn and Edwards to the concept of “shared decision making” (2016, p. 2). For Freire, a “dialogue” is essentially a positive method applied by oppressor and oppressed to liberate humankind. It requires “love for the world and of people”, the absence of arrogance, “an intense faith in humankind”, hope and mutual “critical thinking”: “Without dialogue there is no communication, and without communication there can be no true education” (1996, p. 73). Freire, who focuses on teaching, uses the wording, “Authentic education” and also, referring to Furter, **“Authentic humanism”** (Furter in Freire, 1996, p. 74). For him, liberating the oppressed should not be a matter of “pseudo-participation but committed involvement” (1996, p. 51). Just as respect, a dialogue must be mutual.

With Sennett and Freire empowering people—allowing them to have control over their own lives—however, is above all a matter of respect and of humanism. In medicine, it stands for a real paradigm shift (Millenson, 1997, p. 348).

## 4.2.2 The Web as a patient empowerment tool

**EIGHT IMPORTANT DEEPENING CONSIDERATIONS** have to be made in relation to the Web as a patient empowerment tool. They are listed hereunder and will be discussed one after one.

- Web health information is not a substitute for the GP's knowledge.
- The Web increases the patients' capabilities of influence during the consultation.
- In Belgian healthcare, there is no equivalent alternative to the medical doctor.
- Web access is only the strictest minimum.
- The possible negative side effects of consulting the Web for health information.
- Patients developing a more consumerist stance.
- The importance of media literacy.
- The Web is a tool to realise an objective.

### **Health information found on the Web is not a substitute for the GP's knowledge.**

Despite health information through the Web, the traditional identified imbalance of power between patient and doctor remains.

In the first place, it has already been mentioned that today's Web offers data, information and not knowledge and a distinction has been made between the patient's and the GP's knowledge. The health data and information found on the Web by a patient is not a substitute for the GP's knowledge. Earlier research confirms for example that peer-generated health information for example through social media does not replace the doctor's advice (Rupert et al., 2016, p. 1195). The Web does not neutralise the patient's dependence on the GP's resource "knowledge". Participants of the focus groups recognised that uncertainty or perceived risk and severity are factors strengthening their dependence on their GP's resource "knowledge", while it can also feed resistance and trigger a patient to try to acquire more information or knowledge. But the knowledge of patient and GP is not zero-sum: it is not because a patient acquires more knowledge that the knowledge of the GP decreases.

In the second place, analysis based on the "resource dependency theory" and thus, looking at the dependence of a patient on the resources of his GP and the extensive overview of the resources of dependence on the micro-, meso- and macro-level of patient and GP of which they mutually depend, illustrates that a patient depends on much more resources of a GP than just "information" and "knowledge". Health information through the Web narrows the information gap between patient and GP but not the patient's dependence on other resources of which the GP disposes as, for example, his license to label and to assign the sick role expressed by his legal right to prescribe medication and allow sick leave. In addition, these resources have been called "stable resources"—meaning not influenced by the situation or context of the patient-GP relationship, contrary to a "dynamic resource" like information.

Moreover, respondents of this study also recognised their dependence on bureaucracy and from an unclear and confusing healthcare system and, consequently, of resources on the meso- and macro-level, dependencies which they as individuals have the feeling they have to undergo.

In addition, **many patients start the consultation from a position of dependence** and thus, in a weak position: they are ill, vulnerable and in need of help. This is also confirmed by

patients identifying the disease and treatment (for example, through regular medical controls) as resources of dependence. The follow-up interviews with the patients identified a phase before consulting the doctor in which patients try to manage their illness themselves, amongst others through self-medication. Van Nuland and Goedhuys call the phase before going to the doctor **the “zero line”** (2012, p. 25), referring to the GPs being the first and the hospitals the second line (For more information on the different “lines” in Belgian healthcare, see section 1.4). A patient visits the doctor when he cannot manage the illness or the consequences of being ill himself anymore: a person is confronted with a persistent problem, the GP may have the solution. The patient expects the GP to restore his “equilibrium”; to help him regain control over his life. He consults the GP when in need, he depends on him for a further step in his healing or treatment. For the patient, the consultation starts in a situation of primary dependence. Preston states: “[...] when they are sick, they regress to the most irrational dependency” (1981, p. 153). This study nuances his statement. Dependency there is indeed, but it certainly is not “most irrational” for all patients. At the same time, vulnerability may hamper resistance against the dependence.

While it is not the ambition of this study to weigh different resources of dependence against each other, it would seem that **the resources of the GP on which the patient depends create greater dependence than those of the patient on which a GP depends**. The GP also depends on his patient’s resources as for example, economic dependence and the GP’s dependence on the patient’s information allowing him to diagnose. The analysis made of the dependence of patient and GP confirmed that the relationship is a matter of mutual dependence or interdependence, but it would seem that a “good” relationship is even more important for the patient than for the GP. First, it would seem that in Belgium there is sometimes a GP shortage (Salumu, 2017) which means that the demand for GPs is greater than the supply and the GPs have no shortage of patients. They even sometimes refuse new patients (Goethals, 2017). This makes the GPs economically less dependent on their patients. This is symbolised by, at times, the crowded waiting room of the GP. Second, of course, a GP has difficulties making a diagnosis without a collaborating patient and, as such, also depends on his patient’s information. But patients during the follow-up interviews clearly stated being aware that collaborating and informing their GP in an honest way is to their own advantage.

#### **The Web increases the patients’ capabilities of influence during the consultation.**

In this dissertation, “influence” has been defined as “changing an actor’s preferences” or “perception of the situation” by “argumentation” (see section 2.2.2). The Web increases the patients’ capabilities of influence during the consultation and it tends to make the information exchange and thus, the influence more mutual.

In the first place, Web health information may influence the interpersonal communication during the consultation since it allows the patient to make the consultation a dialogue instead of one-way communication with the GP as the only one disposing of the informational basis. GPs indeed recognise that the Web allows their patients to be more involved in their healthcare and they seem to consider it positive. Access to health information through the Web may support a patient to be more vocal. **The Web seems to induce a kind of “driving effect”** on the GP (see

Figure 96): the easy availability of health information through the Web facilitates the patient's possibility to check the GP's information and medical reasoning or to prepare him for communication with his doctor.



Figure 96: Cartoon – The Web as a source of health information can have a “driving effect” on the GP.

In the second place, **it allows patients to influence the content of the consultation.** A supplementary health information source like the Web supports patients to develop their own position and arguments and, for example, voice treatment preferences (Ziebland et al., 2004). GPs reported during the follow-up interviews that people are better informed about health(care) subjects than in the past.

While health information through the Web thus would seem to have only limited influence on the power balance between patient and GP, it may have an influence on the interpersonal communication between patient and GP and on the patient's potential to have an informational impact during the consultation. Health information through the Web may lead to a feeling of being more in control and facilitate “reskilling”, as Giddens calls it, a kind of “reappropriation” of “technical expertise” by “lay agents” (1990, p. 144; 1997, p. 141). It can be considered feeding—to use the terminology inherent to the resource dependency theory—the “balancing operation”.

GPs report that this seems to make the consultation more difficult and stressful for them. Patients using the Web as a source of health information may make the consultation longer and it thus seems for the patient a possible means to force more time ; in this study, “time” has been considered a scarce resource of which the patient as well as the GP depend. It could be assumed that the stress arises from the fact that in Belgian healthcare, a GP must have many patients and consultations to earn a living. A movement from volume to value (Elwyn & Edwards, 2016, p. 5) (in which time becomes less scarce) could reduce the tension.

**In Belgian healthcare, today there is no equivalent alternative to the medical doctor.**

In Belgian healthcare today, there is no equivalent alternative to the medical doctor. Indeed, a doctor has a number of characteristics: either he has these characteristics resulting from his affiliation with the medical profession or they are personal characteristics. Patients depend on a doctor for the characteristics related to his membership of the medical profession, whatever the situation and context of the patient and whether the patient is consulting the Web or not. This category of characteristics is indeed legally attributed to each representative of the medical profession and the doctor has the monopoly over them: the doctor is the only one allowed to label something formally as a disease, to prescribe medication and to grant a patient sick leave. These are “stable” resources of dependence a patient cannot escape if he wants the help of a medical doctor. Therefore, this study suggests that the power balance between patient and GP remains imbalanced to the advantage of the GP and that health information through the Web has the potential to make the imbalance a bit smaller and more specifically due to an decreased dependence on the GP’s resource “information”.

**Web access is only the the strictest minimum.**

Al-Shorbaji mentions three challenges for the Internet to be used as a source of health information: “quality of health information on the Internet, information and communication technology infrastructure, and ability to translate information to policy and action” (Al-Shorbaji, 2012, p. 3). The results of this dissertation confirm his statement. The quality of the Web health information is not homogeneously reliable and participants in the research justly do not blindly trust it. Web access and access quality as a condition is obvious. That translating the health information on the Web into empowerment behaviour is not self-evident is also confirmed by this study. Respondents seek health information on the Web but do not always tell their GPs. This can also be motivated by their doubts about the Web health information quality. The Web offers huge amounts of information on healthy living but the Web survey showed that respondents exhibit behaviours about which they are aware that they are unhealthy. This again demonstrates the gap that may exist between information and behaviour, between knowing what to do and doing it. This underlines that Web access in itself does not suffice and, therefore, that technological-deterministic view on the Web as a source of health information is not suited for purpose. It means that the ambition of governments to enable technical access to the Web everywhere and to the same extent for everybody is an important condition, but that it has to be accompanied by activities increasing the literacy and skills of people. Technical access to the Internet alone will not suffice (Meinrath et al., 2013, p. 309; Zillien & Marr, 2013, p. 64). The United Nations considers access to the Internet a human right. But a human right is not a matter of just technology and considering the computer a “deus ex machina”, solving all our social, economic and even personal problems, is an illusion (Shallis, 1984, p. 5). The Internet should not be considered a simple fix (Banaji & Buckingham, 2013, p. 162). Web access is only the *the strictest minimum*.

## The possible negative side effects of consulting the Web for health information

GPs in this study stated that the trend to make use of the Web as a source of health information fits well with the general societal trend of citizens being more vocal, more critical and not automatically respecting those in power. Most patients interviewed during the follow-up interviews were well aware of certain risks and most of them did not consider the Web health information infallible. They are aware that the Web health information has to be adapted to each individual case. The uncertainty characterising today's Web health information requires that the online information's "credibility still needs to be endorsed by healthcare professionals" (Mendes et al., 2017, p. 1080). They also do not always find what they are looking for. This is not surprising given the oversupply of information on symptoms, diseases and treatments on the Web of which the credibility is not always very clear.

GPs, however, reported during the follow-up interviews that some patients, based on health information through the Web, developed their own self-confident view on the diagnosis and treatment without having the medical background for a correct interpretation. Participants of the focus groups said that health information through the Web can lead to the overestimation of one's health and medical knowledge. During the consultation, the GP first has to frame and correct their view and information.

Patients know that Web health information sometimes may create worries and uncertainty instead of reassurance and giving "meaning". GPs report that, based on what patients found on the Web and the misdiagnosis they deduced from it, some patients consult their GP too late.

Patients, nevertheless, seek health information on the Web, not only for themselves, but also for significant others, some of whom have no Web access. Why? Two reasons are clearly mentioned. The first is that they seek health information through the Web as a response to uncertainty, for example, when waiting on the results of a medical examination takes too long. The second reason mentioned is that the Web search supplements information already received (for example, on the results of a blood test or a scan or on the side effects of medication) or missing information from the doctor. This research indeed identified that people judged that the GP's information on the diagnosis can be improved. Apparently, some people bridge the distance between that need for information and the information they get from their GP by turning to the Web.

While some people consult different websites, *Google* is the most common search engine used. GPs referring patients to specific websites in this research seem to be exceptions. None of the respondents reported having used the Web to compare doctors or hospitals. A patient with the intention to move to another GP can use the Web to look for names, addresses and telephone numbers—the yellow page function of the Web—but will have to use other information sources if he wants to compare the healthcare offer or learn something about the quality of specific providers or organisations since that kind of information on Belgian GPs is only scarcely available on the Web.

## Patients developing a more consumerist stance

In some cases, the earlier mentioned "driving effect", in which a patient checks his GP's information and knowledge, moves patients to develop a **more consumerist stance**. When

considered “a way of life” consumerism can be defined as “an excessive, even pathological preoccupation with consumption” (Shaw & Aldridge, 2003, p. 35). A patient then develops an attitude of having the right to claim things, for example, a specific treatment or medication. He even tends to steer the consultation. This can lead to patients demanding examinations the GP considers unnecessary and sometimes the consultation even becomes a “power game”. The interviews with the GPs clarify that they do not accept this, consider this attitude to be overstepping the mark and see this as a reason to break up the relationship with the patient, but GPs state that it seldom goes that far. The consumerist stance could be considered an extreme example of a patient resisting his dependence by a “balancing operation” not only to achieve balanced interdependence but also to turn the asymmetrical balance to his advantage. With this attitude, he moves the relationship from the “communication mode” to the “power mode”. The concept “cost” in the “resource dependency theory” (see section 2.2.3.4.2) can be used to describe what happens if the GP judges that his patient-consumer crossed a line and puts an end to the relationship. Exercising power, which is what a consumerist patient does, may come at a cost. But, as stated before, the same goes for a doctor exercising power. Inlander et al comes, after critical analysis of medicine in the United States, to the conclusion that consumerism is the solution to what goes wrong in American medicine and they state that consumerism will lead to “partnership between provider and customer” (Inlander et al., 1988). The position of this study is that it will rather lead to conflicts to the disadvantage of the patients since on average they are the most vulnerable and dependent. The only solution is mutual respect and a mutual egalitarian attitude since patient and doctor need each other to achieve their common goal.

### **The importance of media literacy**

In the context of the subject of this dissertation, the importance of media literacy must be stressed, one of the forms of literacy mentioned in section 2.4.2.5.2 on the hurdles related to health information seeking. Traditional mass media as for example, newspapers, magazines, radio and television developed their own internal processes to select and judge information based on professional and ethical criteria. The journalistic process with checks and double-checks increased the chances that the information offered was correct. While not infallible, the reader, listener or viewer could be reassured by the reliability of the information. Even then, a media critical attitude was recommended but many information sources on the Web have no journalistic intermediary or even any intermediary at all, which moves the responsibility for selecting, judging and checking information directly to the one seeking the information. This situation underlines the growing importance of media literacy skills of which a critical and independent attitude towards all media form the basis (Segers & Bauwens, 2010, p. 19). Cohen-Almagor, discussing the “dark side” of the Internet state that the readers’ responsibility should be promoted (Cohen-Almagor, 2015, p. 145). Media education to all ages on traditional media by all stakeholders involved remains important but should be expanded to digital media, not just related to its technological aspects but also to its content (Bauwens & Segers, 2010, p. 221). Media literacy, of course, not only relates to the consumption of media since many people and also patients are today also producers of information (Deuze, 2018, p. 240). Besides Deuze underlines the responsibility of all: “people who use media, companies offering products and services in media, institutions and

governments manifesting themselves in media” and producers of software and hardware (2018, p. 242).

Close attention should be paid to those socio-economically vulnerable amongst us. Mariën relates digital exclusion to social exclusion (2016, p. 351), but underlines at the same time that there is no linear relationship between both. For her, based on a nuanced view on risk groups, a sustainable e-inclusion policy should be developed taking personal as well as structural factors into account (2016, p. 352).

**The Web is a tool to realise an objective.**

In healthcare, the Web is not an end in itself; it is a tool to realise an objective. The use made of it makes it positive or negative (Rice & Katz, 2001, p. 429). Edward Tenner convincingly illustrated how technology can have all kinds of unintended consequences and while the Web clearly offers a huge number of possibilities in the field of health information from which a patient can benefit, it would not be clever not to remain critical (Tenner, 1997). The Web can, for example, also increase the patient’s dependence on the medical profession by creating the need for the GP’s knowledge due to the uncertainty created by the Web health information. This underlines how the potential of the Web as a source of health information to be used is, besides being a technological issue, also a matter of people using it for that purpose and of those offering health information on the Web (see Figure 97 below).



Figure 97: Cartoon - The Web is a potential source of health information

It is not difficult to understand where the discourse of the Web as a lever for empowerment comes from. The Internet has been embraced as “a scarcity-fighting machine” in a period where information was scarce, information access restricted and experts monopolized

knowledge (Andrejevic, 2013, p. 10). But the Web transformed the scarcity into an “infoglut” requiring additional skills to make efficient use of it. It stresses, for example, the importance of different forms of literacy to enable any citizen to use the full potential of the Web health information. The answer seems not to be just unlimited and fast access to an unlimited number of information sources but education (Shenk, 1997, p. 211). The different types of literacy are related to this.

The Dutch media network KRO-NCRV broadcasts a television contest called, “Dokters vs Internet” (Doctors versus Internet) in which three doctors on one side and three laymen on the other compete to be the first to find the right diagnosis amongst others after hearing the description of the symptoms by real patients<sup>74</sup>. The doctors have to find an answer based on their knowledge and experience, the laymen are allowed to consult the Web. The programme describes itself as “responding to the increasing need to find out via the Internet what is happening when confronted with aches and pains”. As an informational program, it has its merits: every disease is explained in a very accessible manner. But as a symbol, it may express a doubtful message: it sets the medical profession in opposition to the Web. The Web has the potential to be a useful tool for doctors as well as for patients and the Web does not replace doctors, an impression that the TV program can create. **The Web is a supplementary source of health information with a huge potential for everybody.**

These reflections are of course, based on the Web as it is today and the analysis of this dissertation stands as long as the Web’s characteristics, those of the (health) information offer on the Web and the skills needed to search for health information, do not fundamentally change.

#### **4.2.3 The resource dependency theory as theoretical framework to analyse patient-GP interaction**

In this study, the resource dependency theory has been applied (Emerson, 1970) and hence the patient-GP relationship has been analysed from the point of view of dependence on resources. This approach fills in a gap in health communication and patient-provider communication. It provides a supplementary perspective on the patient–doctor relationship since it helps to understand the (power) dynamics underlying the communication dynamics. The analysis based on the resource dependency theory helps to understand the patient better and may facilitate attuning the communication and empowerment approach to each individual patient. There is a need for the measurement of patient empowerment (McAllister et al., 2012) and the “resource dependency theory” and its focus on dependence and interdependence may be a valuable theoretical construct for this measurement. The overview of resources of dependence in section 2.2.4.4 (extended with the patient-GP relationship as a supplementary resource of dependence of the patient on the micro-level) may serve as a valuable tool, also to be applied to healthcare systems with different characteristics than Belgium’s. Each healthcare system may lead to a different power balance.

The resource dependency theory and the definition of “resource power” is not often used, certainly not in studies related to healthcare, which makes it all the more interesting. This

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<sup>74</sup> Site of KRO-NCRV <https://www.kro-ncrv.nl/doktersvsInternet> consulted on September 17, 2017.

study has enriched the theory with the concepts “strengthening factors” and the distinction between stable and dynamic resources. The classic definitions of power related to coercion were considered only applicable to exceptional situations within the patient-GP relationship and therefore, the need was felt to look for an alternative theoretical concept of power. The research proved this choice to be the right one. Patients as well as GPs did not on average associate their relationship with domination or coercion, but they recognised their dependencies on each other’s resources. Most patients and GPs have no intention of exercising power, the power relationship is simply the consequence of the dependence and the dependence increases to the extent that the resources are important to the one in need of them and are scarce. Dependency means that it exists even if it is not observable. The dependence and thus, the power relationship simmer in the background, but it nevertheless influences the communication, for example, by what a patient does not do. However, the exertion of the power, the resistance against it and patient empowerment on the other hand, may well be observable.

The respondents in this study did not associate the relationship with their GP with power and they did not desire to have more power. But, just as the GPs, they interpreted power in the sense of the classic Weberian definitions with coercion and, therefore, as something negative. However, when the definition of power within the resource dependency theory is applied— “resource power”, they definitely want more power because they want more (feeling of) control and being (or feel) less dependent.

Reviewing the patient-GP relationship from the point of view of dependence on resources allows a better understanding of each individual patient. This should, of course, not lead to manipulation. Understanding the patient better should therefore be considered as an end in itself, not as a means to manipulate him for the purposes of healthcare. If it is true that the GPs still seem to desire being in control in their relationship with their patients, understanding the patient better could thus be considered a way to manipulate the patient more to keep control. Wartenberg calls manipulation “a morally suspect social practice” and he cites two reasons (Wartenberg, 1990, p. 112). First, he refers to Kant stating that a human being should be the end, not a means, which is unsure with manipulation. Second, he states that manipulation includes the assumption that the actor manipulating is able to make a better choice than the manipulated actor which is not necessarily the case.

Instead, a better understanding of the patient and of the power balance in the patient-GP relationship should be an opportunity to humanise care and to develop a real humanitarian approach towards the patient. As stated by Mishler: “Humane care is effective care and to be effective care must be humane” (1984, p. 191).

### **4.3 Implications for practice**

This study has unraveled the power base of the patient-GP relationship, the role of (health) information as a power resource and the role of Web health information in the power balance between patient and GP. It has developed a clear theoretical framework with the (mutual) dependence on resources as its core concept. The framework has been considered useful for analysis. At the same time, since it seems that the transition from communication theory to health communication practice is not evident (Ruben, 2016), this study reckons

that it is a challenge to construe the framework into practical guidelines and recommendations applicable on the micro-level, notably during the consultation and on other occasions a patient has contact with his GP.

However, this study laid the foundation for a different perspective on the patient-GP relationship. Understanding the dependence dynamics hidden behind the patient's communication may help to better understand the patient's communication behaviour and to tailor the communication goals better to every individual patient. The same goes for patient empowerment: not every patient wants to be in control and not everyone wants control to the same extent. For every patient, it can mean something different (Roberts, 1999).

The study may create an even greater awareness of communication as a means serving different objectives. It is, for example, not realistic to try to create patient empowerment solely by informing a patient; informing a patient does not equal empowering a patient. While it is an important aspect and itself a challenge, patient empowerment also needs the strengthening of the patient's self-efficacy. This has become clear thanks to the overview of the different usages and communication approaches that have been discussed. It is thus important "to assess individual desire for control" (Walker, 2001, p. 33). To achieve this, GPs must be aware of their "resource power" and of their apparent desire to remain in control. The next step is that useful tools could be developed to help a doctor to map the patient's wishes in the field of control and therefore of patient empowerment. However, it must be clear that patient empowerment may be an abstract concept to patients (Ceulemans, 2010, p. 12). A sick patient mainly wants to get better and regain his autonomy. Therefore, the tool to be developed has to be simple and focussed on practical aspects of what a patient considers patient empowerment.

This study again confirmed the importance of health information. The (amount of the) information does not guarantee meaning and health information through the Web can lead to a positive as well as to a negative informational outcome. Just simply offering information does not suffice, only access to information sources does not either. The Web is only one information source a patient consults next to peers, mass media and others. Patients need information tailor-made and accessible to avoid a reverse effect, namely that it creates or increases uncertainty. It is not the quantity of the information that counts, it is the quality. The importance for some patients to be guided by the doctor or others towards trustworthy websites, through this supporting their media literacy, is also clear. Indeed, patients have to be supported to increase the (different forms of) literacy and to develop their skills to have and handle control. This is also the responsibility of, amongst others, the government and its agencies.

The dependence on the three different levels help to make clear that patient empowerment is the result of common efforts towards empowerment on these different levels. A GP can support a patient by negotiating for a patient with bureaucracy. A doctor working in a hospital has to realise that while he may be developing empowerment behaviour towards his patients, the way the healthcare organisation is organised and behaves towards patients can be extremely disempowering. But on the micro-level, the GPs possibilities to decrease the patient's dependence on resources on the meso- and macro-level is limited. This study may increase the awareness for the need for a common approach in organisations towards

patient empowerment and it underlines again the responsibility of government and its agencies. Patients are in need of a transparent and accessible healthcare system that is characterised by a financial dynamic that allows patient and GP to together fully collaborate to achieve disease prevention and develop the patient's self-efficacy.

The start of patient empowerment lies on the interpersonal level. Above all, it lies with the GP who has to realise that he indeed has "resource power" and that he must be prepared to share the control with his patient. A GP must consciously pursue for his patient to have (a feeling of) control on condition that, of course, the patient wants to. It is up to the GP to make the first move.

It seems important to communicate the insights this study offers, first, to healthcare providers and, second, to everyone related to the healthcare offer in the second place. The resource dependency theory and the concept of "resource power" should be integrated into the education of doctors in medical faculties and of nurses. Communication as a means and not as a final goal should be taught. It is a way to listen to patients even more attentively. However, a dose of realism is called for. Since patient empowerment is an educational and complex process, it is an illusion to suppose that it can be achieved through a short-term course or training alone (Kieffer, 1984, p. 27), be it that empowerment courses and trainings can be useful for patients and for all actors concerned.

Special attention should be given to disadvantaged people, they are the most dependent, hence the most vulnerable.

## 5 Limitations

It is sometimes stated that the research analysis should be conducted by more than one researcher and the present study has been done by only one. There was no way to escape this with a study done by one researcher outside of office hours. But the researcher received analytical help with the analysis of the Web survey and with observations of the patient-GP consultations. More important even is the fact that a complex mixed research approach has been developed which allowed triangulation. The fact that a quantitative analysis is combined by different qualitative methods decreases the possible bias created by an analysis conducted by only one researcher.

This study covers a vast array of subjects. The overview of resources on the micro-, meso- and macro-level and the ways to resist these dependencies is so extensive that not every aspect of every resource could be investigated.

A complex mixed research approach has been developed. The advantage is that results confirm each other and so, strengthen the global conclusions. The disadvantage is that for the study to be feasible, it was necessary to stick to the general outlines of the analysis and conclusions and not to go into detail concerning, for example, socio-demographic characteristics of respondents, their gender, age, etc.

## 6 Suggestions for further work

This dissertation offers a huge number of possibilities for further research.

The theoretical framework based on the resource dependency theory and the application of the concept of “resource power” opens up new potential avenues for research and critical discussion on the patient-provider relationship, since it offers a new angle for analysis. This has not often been applied in healthcare. It offers the opportunity to refine the power base in the patient-GP relationship. Hopefully, the analysis will inspire other scholars to challenge it and to further elaborate or develop the framework.

**SEVEN MAIN SUGGESTIONS for further work are given.**

**FIRST**, this study offers the opportunity to deepen specific aspects of the theoretical analysis that have only been discussed skin-deep.

Research could, for example, focus not on how “resource power” is obtained but how it is given (Hess, 1984, p. 228). It has been stated that, for a doctor, there is nothing wrong with having the power dominance as long as he makes positive use of it, for example, to empower his patient. But how does he do that?

Another possible aspect for further research is to analyse how and when the communication mode moves to the power mode. It has been established that it is to the advantage of neither the patient nor the GP for the relationship to evolve into a relationship where power is exercised since this may initiate resistance and break down the trust in the relationship. But what ignites the exertion of “resource power”? What makes a GP or a patient exercise his power? Understanding this dynamic can help to avoid it. A special focus could also be the influence of gender and other demographic characteristics on the power relationship and on the way “resource power” is exercised. Faulder states that “female patients are more at risk of having their wishes disregarded” (1985, p. 4).

Yet another possible aspect is the relationship between *control* and *responsibility*. Patient empowerment means having control or having the feeling of being in control. Does a patient striving for empowerment also accept the full responsibility? Is the weight of responsibility an obstacle for patients to strive for empowerment?

Another aspect that could be analysed further is how patients cope with their empowerment and their ‘free choice’ (Salmon & Hall, 2004).

Finally, this dissertation gave an overview of resources of dependence of patient and GP on the micro-, meso- and macro-level. Not all resources mentioned on the meso- and macro-level came back during the empirical research. There is potential for research also there.

**SECOND**, it seems interesting to study how the communication and empowerment needs of a patient can be identified and mapped by a healthcare provider. It seems clear that some patients want to be as independent from their doctor/GP as possible, while dependence for other patients brings mental comfort. This study mapped four usages of communication, but it became clear that it would be wrong to assume that every patient wants to be informed, influenced or empowered. A tailor-made approach should be developed. But how does a doctor/GP identify what his patient preferences are and which “health agenda” (Sturt, 1998, p. 46) he has in mind? How could a doctor map the patient’s profile concerning his will to be

empowered or not? Therefore, a tool mapping the patient's information, communication and empowerment wishes would be useful. Flynn, Smith, and Vanness developed a "scale for measuring preferences in participation" (Suárez Vázquez, Del Río Lanza, Suárez Álvarez & Vázquez Casielles, 2017, p. 910) that could be a basis for study. Bastemeijer et al. designed a taxonomy of key elements valued by patients also useful to develop "a tool, meter or questionnaire" as, for example, autonomy, partnership and empowerment (Bastemeijer, Voogt, van Ewijk & Hazelzet, 2017, p. 880). Inspiration could also be found in studies done on perceived or personal control (Walker, 2001, p. 12). Once the tool is developed, research can be done on its integration into the communication training of medical and nursing students. In the Belgian government's note on its health policy related to patient empowerment, 'Patient Reported Outcomes' (PROMs) and 'Patient Reported Experience Measures' (PREMs) are mentioned as topics for further study (*Algemene Beleidsnota: Gezondheidsbeleid*, 2017, p. 7). The concept of "resource dependence" should be taken into account when developing questionnaires or other tools to map patients' feelings and experiences towards their healthcare.<sup>75</sup>

**THIRDLY**, further research could be focussed on applying the theoretical framework on the power relationship between patient and specialist within a healthcare organisation. This study zoomed in on the patient-GP relationship which is at the base a dyadic relationship. While the study also discussed resources on the meso- and macro-level, it left the influence of the healthcare system on the micro-level out. But how do the relations of dependence, thus of "resource power", function if, apart from patient and GP, the pharmacist, the specialist and the healthcare organisation are forming a network of dependence on resources? How does that influence the power balance and are there different power balances at play? What form does resistance take? Has the concept of patient empowerment to be reviewed in a hospital situation and what role does the healthcare organisation fulfil? In the same line of thinking, it seems interesting to carry out the same research in other countries to try to map the influence of the characteristics of each healthcare system on the power balance.

**A FOURTH RESEARCH** topic suggested is related to applying the theoretical framework on the Internet. This study was concentrated on the Web as a source of health information and it carefully touched on diagnostic consumer apps since some of them were also considered sources of health information. On the one hand, it would be interesting to zoom in on the "quantified self" movement and the way it increases or decreases the owner's dependence on healthcare providers and their knowledge or skills. On the other, it would be of interest to research the influence the Internet has on the power balance in general, as for example, the Internet of things and e-health: do they influence the patient's dependence on the doctor's resources and do they lead to empowerment (Sebban, 2015, p. 142)? The theoretical framework can also be applied on specific applications of e-Health as for example, telemedicine or having access to a patient portal or digital medical files.

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<sup>75</sup> The Federal Center of Knowledge for Helthcare (Federaal Kenniscentrum voor de gezondheidszorg) of the Belgian Government states that it plans to study the impact of PROMs and PREMs on healthcare and "to discuss whether a protocol for implementation of specific PROMs and PREMs is appropriate to improve care for adult patients". See <https://kce.fgov.be/nl/study-program/studie-2016-03-hsr-implementatie-en-meerwaarde-van-proms-en-prems-in-de-belgische-zorg> consulted on April 21, 2018.

**FIFTH**, it would be interesting to zoom in on situations of patients without a GP since this study focussed on the patient-GP relationship. What about people in Belgium without a GP as is more the case in big cities and with people from other cultures? Since they tend to go directly to a hospital or to the Emergency Department, what does the phase before going to a doctor look like and does the Web play a major role since these patients do not appeal to the first line? Is dependence on resources also at play in such situations and if yes, do they differ from the patient-GP relationship?

**A SIXTH RESEARCH TOPIC** could be the influence that alternative medicine exercises on the power balance and on the patients' dependence on the resources of a doctor or of the medical profession as a whole.

**FINALLY**, this study looked closely at the power balance experienced by Flemish patients. Would the conclusions be the same if French-speaking Belgians were researched? Moreover, what about the theoretical framework applied to other cultures? This study mentioned that dependence is considered differently in Japanese culture. This gives a taste of the potential of this research angle.

## 7 Dutch summary

Er wordt gesteld dat gezondheidsinformatie via het Web de asymmetrische machtsbalans tussen patiënt en arts sterk verandert. Is dat zo of wordt de invloed van gezondheidsinformatie gezocht op het Web op de machtsbalans overschat? Om de relatie tussen patiënt en huisarts te analyseren, past deze studie de “resource dependency theory” toe (Emerson, 1962), die deel uitmaakt van de “social exchange theories”. Deze theorie definieert sociale macht over actor B door actor A als de afhankelijkheid van actor B van de “resources” van actor A. De afhankelijkheid van een resource wordt op directe wijze beïnvloed door de waarde en beschikbaarheid van de resource voor actor B en door de concepten van gepercipieerd risico, onzekerheid, gepercipieerde ernst en vertrouwen, en op een indirecte manier door het charisma en de legitieme autoriteit van actor A. Een sociale relatie is meestal een kwestie van wederzijdse afhankelijkheid en een kwestie van evenwichtsoefeningen. In een situatie van evenwichtige wederzijdse afhankelijkheid kunnen de intenties van beide actoren worden vervuld. Elke actor heeft manieren om weerstand te bieden aan zijn afhankelijkheid en machtsuitoefening kan ook een kost met zich meebrengen. Afhankelijkheidsbronnen en weerstand op macro-, meso- en microniveau worden beschouwd. Het concept van informatie wordt besproken en het Web als een bron van gezondheidsinformatie en hoe mensen naar gezondheidsinformatie zoeken, worden geanalyseerd. Een gemengde onderzoeksmethode wordt toegepast die bestaat uit een online enquête voor patiënten en niet-patiënten, de analyse van 24 video-opnames van patiënt-huisartsconsultaties, etnografische follow-up-interviews met de patiënten en de huisartsen die deelnamen aan de observaties, drie focusgroepen met patiënten en niet-patiënten en twee discussies met groepen huisartsen. De resultaten tonen aan dat het Web het potentieel heeft om de informatie- en kenniskloof tussen patiënt en huisarts te verkleinen, maar niet te dichten omdat gezondheidsinformatie slechts een van de resources van de huisarts is waarvan een patiënt afhankelijk is. De afhankelijkheid van de patiënt van andere belangrijke resources van de huisarts blijft. Ondanks de gezondheidsinformatie via het Web blijft de machtsbalans tussen patiënt en huisarts dus asymmetrisch. Gezondheidsinformatie via het Web beïnvloedt vooral de communicatie tussen patiënt en huisarts. Wil de patiënt-GP-machtsrelatie in evenwicht zijn, dan moeten alle resources die afhankelijkheid creëren worden beschouwd, ook die op het meso- en macroniveau. “Patient empowerment” is een waardevol concept, maar gezondheidsinformatie via het Web is geen wondermiddel om dit te bereiken.