The impact of online health information on the doctor-patient relationship

Findings from a qualitative study

Susanne Christmann,

MSc in Politics and Communication

Dissertation submitted to the Department of Media and Communications, London School of Economics and Political Science, August 2012, in partial fulfilment of the requirements for the MSc in Politics and Communication. Supervised by Dr. Bart Cammaerts.

The impact of online health information on the doctor-patient relationship

Findings from a qualitative study

Susanne Christmann

ABSTRACT

Against the backdrop of the comprehensive presence and influence of new media, this study focuses on the impact of online health information on the relationship between doctor and patient. Considering the existing literature, three research questions are examined, looking at (1) the impact of online health information on the power relations between doctor and patient, (2) the significance of the information's impact on the relationship, in the sense of opportunities and challenges, as well as (3) the variables determining this significance.

To approach these questions, qualitative in-depth interviews with doctors and a patient organisation representative as well as focus group discussions with patients are conducted. Doctors working in medical practices as opposed to clinical doctors, and the situation as it manifests in the German Rhine-Main Area are focussed on in order to add to the established body of literature by considering previously neglected aspects.

The study finds that online health information contributes to an empowerment of the patient, while the doctor stays important due to an advantage in medical expert knowledge. Online health information can signify both an opportunity and a challenge to the relationship, mainly depending on the information's quality and the patient's capabilities to evaluate the information. Imperfections of both the information's quality and the patients' evaluation capabilities support the necessity of a powerful doctor. However, patients unaware of their limited evaluation capabilities may nevertheless behave more powerful in the relationship, causing discrepancies with the doctor. These results confirm connections relevant to the conceptual framework and literature but also hint to aspects that are worth considering in closer detail. The findings suggest that the doctor-patient relationship is affected by the new media influence, but that new media will not turn upside down the core pillars of the doctor-patient relationship.

INTRODUCTION

'No part of the world, no human activity, is untouched by the new media'.

Lievrouw and Livingstone (2009)

Flight bookings, restaurant selection, dating and shopping, conference calls with business colleagues on other continents, 24-hour news coverage, protest movements, the sharing of the latest holiday pictures or the cultivating of long-distance relationships – in past years and decades these and innumerable other parts of our life have been affected in one way or another by new media. Recently, especially the rise of social media sites has resulted in a complete reconfiguration of communication, exchange and social relations between people.

As the above claim indicates, a variety of researchers stress the enormous, profound and increasing influence new media can have on our society. Castells (2000a) forcefully argues that the 'network society is the social structure characteristic of the Information Age. [...] It permeates most societies in the world, in various cultural and institutional manifestations.' (p. 5). 'New media power' (Bennett, 2003) in the 'Internet Society' (Bakardjieva, 2005) is pointed to with regard to different realms of social life. Theories on mediation touch upon related arguments, such as Silverstone (2005) who talks about the 'media's intrusive ubiquity' (p. 190).

Against this backdrop, the question that inevitably comes to mind is whether the influence of Internet and social media will continue to permeate more and more aspects of our environment, or whether there are limitations to this development or even fields that manage to be unaffected by it. Respective lines of thought are embedded in a more sceptical view on the emphasis of (new) media and their impact (e.g. Fischer, 1992; Williams, 1990). In this light, some have critically analysed the effects of new media on interpersonal relationships, characterised by strong and close ties (e.g. Haythornthwaite, 2002). One underlying motivation for respective examinations is the following question: How does the online world affect one of the central pillars – interpersonal, close relationships – of our real (and originally offline) world?

Relationships to friends, partners and family are the aspects that probably come to mind here first, but these are not the only ones. Marked by connections based on existential matters and urgency rather than feelings or sympathy, another relationship is worth considering in this context: the relationship between doctor and patient. Not only would it be hard to imagine a

world without this relationship, it is further characterised by intimacy, confidentiality and trust – elements that are more closely associated to one's offline rather than online sphere.

Consequently, what impact, if any, could the Internet have on this relationship? It is this question that caught my interest. Specifically, this research is inspired by the following question: *To what extent does online information on health-related issues accessible to patients affect the doctor-patient relationship?*

I will approach this question in the following way: first the relevant existing literature is considered, on the basis of which I outline the conceptual framework that guides my overall research and helps specify my research questions. This research aims to contribute to the existing literature in the field by focussing on aspects that have to date not been considered in depth. Subsequently, I will discuss the choice of methodological approach in view of the research questions. After this, I will present the analysis and discussion of my core findings gained from the data, looking at how they contribute to answering the research questions and how they engage with the theoretical framework. Finally, in the conclusion limitations of this study are discussed as well as suggestions for future research in the field.

THEORETICAL CHAPTER

To put into context the question of how online information affects the doctor-patient relationship, this section presents the most relevant literature in the field and illustrates the conceptual framework that shall guide my research. The research questions for this study are specified as they emerge from the presented literature and conceptual framework.

Literature

In terms of relevant literature, I draw from the following topics: fundamental theories on the relationship between doctor and patient in general, the role of information, knowledge and power in the specific context, and the impact of online information on this relationship.

The doctor-patient relationship: power matters

The doctor-patient relationship and its specific characteristics are widely studied topics in medical and social sciences. Particularly, the development of the specific power relationship, oftentimes linked to the question of trust, has been at the core of respective analyses.

<u>The powerful doctor</u>
Traditionally, the doctor is presumed to be more powerful in that he[1] can influence the patient in terms of advice and medical treatment (Stoeckle, 1987). A variety of theories of power exist that might be relevant in this context. For example, Foucault's (1980) notion of relational power describes how power is in every relationship and thus also in the doctor-patient relationship. Lukes' (2005) three-dimensional notion of power could likewise play a role, as it refers to the ability to shape wants and needs. Looking at the doctor-patient context more specifically, for Broom (2005) the doctor's greater medical knowledge compared to the patient is central for this power position, as the latter has no option but to trust the accuracy of the doctor's diagnosis and recommendations. Arising from the patient's need for the doctor's help, trust is not only referred to as one of the central pillars in this relationship, but also as being inseparable from the patient's vulnerability, 'in that there is no need for trust in the absence of vulnerability' (Hall et al., 2001, p. 615). The patient's oftentimes urgent need for medical care in combination with a lack of medical knowledge may even enhance the doctor's perceived power (Hall et al., 2001). Parsons (1951) describes a reciprocal

---

[1] To guarantee a smooth flow of reading, masculine nouns and pronouns are to be taken as referring to both female and male pronouns.

relationship between doctors and patients which implies a 'functional consensus' (in Stoeckle, 1987, p. 135) of the relation, characterised by the rights and obligations of the doctor and patient being complementary to each other 'in the common task of returning the patient to normal' (in Stoeckle, 1987, p. 134).

Limits to the doctor's power and the more active patient

On the other hand, research considers the possibility of a more active patient in the relationship with his doctor and thus the limits of the physician's power in the relationship. These 'ideas about the relation began with the recognition that the patient might, in turn, influence the doctor' (Stoeckle, 1987, p. 133), leading to an understanding of the relationship as involving negotiation and conflicts.

According to Szasz and Hollender's (1956) 'Mutual Participation' model of the doctor-patient relationship, the individual patient, depending on his specific physical condition, may well influence the relationship with his doctor in terms of treatment. For example, patients suffering from chronic illnesses could, via means of participation, avoid a treatment or cooperate with it. Taking it a bit further, Haley (1963) concludes that the patient is not always the inferior actor in the relationship. Bloom (1963) expands on this viewpoint, criticising the limited view on the doctor-patient relationship. In his eyes, patient and doctor have to be seen in their full social context 'to understand the processes of interaction' (p. 59). Scheff (1968) acknowledges that 'the doctor-patient encounters are in fact negotiations' (in Stoeckle, 1987, p. 161). However, 'the doctor is always one up in influencing the patient in the kind of illness or treatment he thinks is proper' (in Stoeckle, 1987, p. 161).

Others see a redefinition of this relationship in the direction of patients being more and more comparable to consumers seeking medical aid of doctors as 'providers' (e.g. Reeder, 1972; Haug & Sussman, 1969) . Here, the understanding of the medical practice as a service is touched upon. The actual limitation of the physician's power to act is described, among others, by Freidson (1960), as he points out that the patients' social networks and choice possibilities provide them with a certain control over their doctors. These arguments on the patient as consumer are taken up by more recent research such as Eysenbach and Köhler (2002), Eysenbach and Diepgen (2001) or Anderson et al. (2003) in the context of the Internet's influence.

Knowledge, power and information in the medical context

Despite these partially conflicting arguments on the power relationship between doctors and patients, the fact that medicine requires very accurate and very specific knowledge cannot be denied, which suggests a knowledge divide between patients and doctors. As Foucault (1990) puts it, 'medicine creates and maintains a 'social monopoly of expertise and knowledge" (in Turner, 1995, p. 47). So, as suggested by Broom (2005) above, the power of doctors stems to a great extent from their knowledge advantage in their field of specialisation relative to the patient.

Expert and lay knowledge

However, knowledge in the medical context is not necessarily restricted to expert knowledge: while the patient is likely to lack medical expert knowledge, he is likely to be equipped with so-called lay knowledge. According to Pearce (1993), own experiences as well as cultural factors play into the creation of knowledge in individuals, such that 'people draw on many different aspects of their environment and their daily lives to construct medical "truths"' (p. 151). Similarly, Popay et al. (2003) state that lay knowledge is rooted in the places people spend their lives in and can be understood as the meanings they attach to the experiences of these places (pp. 386, 401). So, 'lay knowledge differs from expert knowledge in the sense that it has an ontological purpose' (p. 404). According to Williams and Popay (1994), in the health context, lay knowledge is rooted in the experience of illness.

Vis-a-vis the 'traditional 'medical model' which reflects the perceived lack of relevance of such experiences' (Williams & Popay, 1994, p. 120), lay knowledge would challenge the 'objective' and science-based expert knowledge of medical professionals: most importantly, it questions to what extent the 'objective' expert knowledge permits a proper understanding of health problems in the 'new modernity'. Giddens' (1990) argument of the loss of trust in expert systems and of deference to expert authority in post-modernism supports this point. Instead, as Burrows et al. (2000) add, society today orientates towards multiple authorities, in this case for example friends, media or literature, next to the expert opinion.

Information and knowledge – and power

Referring to the fact that, in general, patients have less medical (expert) knowledge, a considerable amount of research has focused on the question of whether providing patients with more medical information – leading to 'informed patients' as described by Kivits, (2004 & 2006), among others – would change their relationship to their doctor (e.g. Bosslet et al., 2011; Hart et al., 2004). As Kivits (2004) outlines, the possible distance between the doctors'

medical assertions (referring to expert knowledge) and the patients' life experiences (referring to lay knowledge) could give rise to patient's increased search for health information.

Studies have observed a more powerful and autonomous patient when he is equipped with more medical and health information, as it contributes to his knowledge (e.g. Waitzkin & Stoeckle, 1976; Gaventa & Cornwall, 2001). A causal relationship between knowledge and power relations is suggested in these studies. In support of this finding, and linked to Broom (2005) above, Foucault (1977) argues: 'power and knowledge directly imply one another [...] there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations' (p. 27). Nevertheless, it remains contentious whether, and to what extent, increased information results in increased knowledge in the sense of medical expertise or rather lay knowledge, and whether both knowledge types stimulate power (Kivits, 2004; Prior, 2003). Within this context, the impact of online information is the focus of the following section.

Online information and the doctor-patient relationship

The rise and development of Information and Communication Technology (ICT), and the Internet specifically – leading to what Castells (2000b) calls the 'Information Age' with substantial impact on the basis of society – has increased the importance and relevance of questions related to information gathering. According to Hardey (2001), it 'is collapsing the boundary fences around previously carefully guarded information domains that form the basis for professional monopolies such as in medicine' (pp. 388-389).

Being available over distances, anytime and from basically everywhere, the Internet facilitates patients' increased and easy access to information about issues like their health conditions, diagnosis or treatments and medical decision-making (Ball & Lillis, 2001; Mittman & Cain, 2001). Constant updating of and cross-linkages between the different webpages further support a very flexible information search process (Anderson et al., 2003). In addition, the increasing use of social media allows the active contribution of Internet users to online content in that it fosters the production and sharing of information among patients on forums, communities, blogs and network sites (Boyd, 2011; Goldberg, 2010; Mohammed, 2012). In that sense, social media are understood as Internet-based applications 'that allow the creation and exchange of User Generated Content' (Kaplan & Haenlein, 2010, p. 61). Further, the possibility that individuals may prefer to learn from people with whom they are

less connected (Granovetter, 1973), increases the appeal of online support forums and similar platforms.

Several researchers have analysed the impact of the patient's greater information – gained through online sources – about health issues on the doctor-patient relationship. Primarily, these studies stress how the power relation has changed, taking up the earlier elaborations on power in the doctor-patient relationship. Additionally, they outline some opportunities or challenges of the changes to these relationships (Mittman & Cain, 2001).

<u>Power impact</u>

Critically for the question studied here, research suggests that more informed patients are more active with regards to the medical encounter, which indicates a certain empowerment of the patients. Cullen (2006) observes more independent patients with less fear of the unknown thanks to the online health information gained. Specifically, online health information leads to a changed decision-making model with regard to medical issues like treatment options, with a greater influence on decision-making on the part of patients (Cullen, 2006; Morahan-Martin, 2004, Dolan et al., 2004).

Others argue that even though the patient is more involved and retains more control of his health care issues, the doctor is not rendered obsolete (Ball & Lillis, 2001). Agreeing with these observations, Stevenson et al. (2007) cannot see any 'desire to disrupt the existing balance of power, or roles, in the consultation' (conclusion paragraph). Rather, they regard the Internet as serving as an additional information source in support of the relationship with doctors, which does not threaten the physician's position. According to Rice and Katz (2006) 'literature overwhelmingly indicates that the increase in patient health-seeking behavior does not necessarily lead to patients desiring to replace or challenge their physician. Neither does it appear that online health information will replace reliance on physicians' (p. 160). Wald et al. (2007) find that more informed patients are more likely to develop a sense of partnership and collaboration with their doctors. As Kivits (2004) observes, in the consultation situation, patients rarely confront their doctors with the health information they researched, as they are aware of not being medical experts.

Nevertheless, others emphasise that the more engaged patients no longer follow the doctor's suggestions. Due to dissatisfaction with the doctors' accessibility, information and communication, patients look up the information themselves and possibly refuse to follow their doctors' advice (Fraser & Bennett, 1976; Hodson, 1967). The shift from the exclusive focus of medicine from curing to preventing illnesses supports this point. The patients'

information gathering would result in a 'reversed information gap', implying a relationship, in which doctors can no longer tell well informed patients what to do (Anderson et al., 2003; Eysenbach & Jadad, 2001).

In view of these elaborations, Castells (2004) can be considered again, as he argues that the Internet can undermine traditional power bases. Precisely, power would be redistributed away from established elites and towards citizens or formerly excluded groups.

The significance of the relationship change

Highlighting the opportunities these relationship changes provide, Wald et al. (2007) explain that the actual treatment of pre-informed patients is more efficient in terms of time needed to provide them with background information. Further, a more partner-like relationship would result in a more trusting relationship and higher-quality care.

On the other hand, the existing literature stresses the challenges of a change to this relationship. Anderson et al. (2003) point to the discomfort doctors feel 'on having to deal with a patient who is perhaps better informed than [themselves] or who even comes into the office already with a concrete diagnosis and/or therapy in mind.' (p. 78) Explicitly, Hardey (1999) stresses that the patient who is more informed, thanks to the Internet, challenges the medical expertise, which the doctor perceives as a substantial threat to his medical authority (see also Wald et al., 2007). Others support these arguments: as Ball and Lillis (2001) explain, it might become necessary for doctors 'to keep pace' (p. 6) with e-health consumer expectations and rapidly developing internet healthcare. As Cullen (2006) claims, doctors have yet to become used to the more active role of patients in the medical decision-making process.[2]

Kiley (2003) elaborates on these challenges, pointing to the possibility that the abundance of health information available online could result in exaggerated and unrealistic expectations on the part of the patients. Similarly, Mittman and Cain (2001) point to the dangers of patients developing 'self-destructive beliefs [...] and false medical understandings that undermine relationships with their physicians' (p. 57), as patients would favour those over the doctor's advice or develop exaggerated fears of, for example, harmless symptoms and usual medications (Goldberg, 2010). Information technology could thus not only add to the society's information, but 'may also prove to be dangerously dis-informing' (Mohammed,

---

[2] Eysenbach and Jadad (2001) likewise support these viewpoints.

2012, p. 34). This suggests that more information can also be associated with reduced knowledge (Mohammed, 2012).

<u>The role of information quality</u>

This notion raises the question of how relevant the quality of online health information is for the evaluation of its impact on the doctor-patient relationship. Many studies point to the oftentimes poor or at least questionable quality of online information (e.g. Anderson et al., 2003; Eysenbach & Jadad, 2001; Eysenbach & Diepgen, 2001; Kiley, 2003; Cullen, 2006; Jadad & Gagliardi, 1998; Morahan-Martin, 2004; McClung et al., 1998). Low barriers to publishing, the anonymity of content producers and publishers, and low rigor in moderating and filtering online content are some of the central elements that contribute to the quality problems (Goldberg, 2010; Mittman & Cain, 2001).

Moreover, patients' information search skills are found to be limited: most often they make use of general search engines when looking for health information, misspelling medical terms and considering the first page of search results only (e.g. Morahan-Martin, 2004). Additionally, contrary to physicians, patients tend to regard online information as being of relatively high quality (Diaz et al., 2002), raising the popularity of 'random, incorrect and often dangerous antiscientific or pseudo-scientific information' (Mohammed, 2012, p. 61). At the very least, patients think of online information as helping them to deal with stress and anxiety in face with medical issues, even though they admit to finding it often difficult to search for and comprehend helpful medical information online (Gordon et al., 2002; Murero et al., 2001). With regard to the doctor-patient relationship, Murray et al. (2003) claim that whereas physicians judge accurate and relevant information to be beneficial in the treatment, they think of it as harming the relationship if inaccurate and irrelevant.

Conceptual framework

In light of this study's aim to look at the impact of online health information on the doctor-patient relationship, the literature review points to distinct components to be taken into account: the doctor-patient relationship, as shaped and influenced by power and knowledge, in the context of information, and online information more specifically.

Acknowledging the broad scope of theories discussed above that relate these conceptual elements to one other, I focus on some particular arguments among them, contributing to the conceptual framework of this study, to derive precise research objectives. The core connections of the conceptual framework are visualised in illustration 1.

1. In the **doctor-patient relationship**, research consistently suggests that the specific **power structures** between doctor and patient is the central element to be looked at.

2. In order to do so, it must be defined what **power in this context** means. Within the scope of this study, it is most appropriate to refer to a narrow understanding of power here. Referring primarily to the presented elaborations of Stoeckle (1987), Broom (2005) and Scheff (1968), in this study power relates to the specific roles of doctor and patient, in that **the more powerful person is in the position to decide on the patient's health issues** such as questions of medical treatment and therapies.

3. Looking at **how information could affect this power** between doctor and patient, I will consider Gaventa and Cornwall (2001) and Waitzkin and Stoeckle (1976), as they suggest that greater information on health issues contributes to greater power, arguing that **information contributes to greater knowledge**. In turn, considering Foucault (1977) and Broom (2005) I presume that **greater medical expert knowledge**, as opposed to lay knowledge, **contributes to greater power**.

4. In terms o**f online health information** more specifically, and considering the earlier definition of power, the majority of literature indicates that a more informed **patient is empowered**. Acknowledging Castell's (2004) elaborations, it is focussed on what Ball and Lillies (2011) and Cullen (2006) explain, as they refer explicitly to the doctor-patient context: the **patient would not become more powerful than the doctor who remains powerful**. I will thus analyse to what extent this limited empowerment of the patient manifests in my study. As existing literature does not clearly differentiate between Internet and social media with regard to distinct effects on the doctor-patient relationship, such a distinction is of interest here, too.

5. The existing literature shows no final consensus on **the significance of the impact on power caused by health information**: both opportunities and challenges are considered, but not weighed against one another, and the variables that would determine the respective significance are scarcely presented. Referring to e.g. Murray et al. (2003), I therefore want to assess how important **quality of information** is as a variable in this context, and which other variables might play a role.
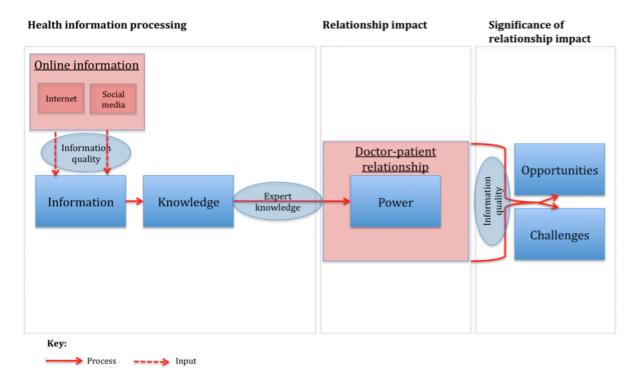
Illustration 1: Conceptual framework (simplified illustration)

Research objectives

Drawing on the conceptual framework, this study's overarching aim is to analyse the impact of online health information on the doctor-patient relationship, such that it may reconcile or highlight divergences in certain aspects of existing studies.

This study looks at aspects that have been largely neglected by the relevant existing literature: first, most of the studies in the field look specifically at the situation in the USA or the UK (e.g Anderson et al., 2003; Ball & Lillies, 2000; Wald et al., 2007; Hardey 2001; Rice & Katz, 2006; Hodson, 1967). However, as Rice and Katz (2006) explain, there might well be 'wide disparities across and within nations and regions' (p. 149) in information-seeking behaviour in the health field. Second, most of the studies look at clinical doctors and patients with serious chronic illnesses like cancer or diabetes (e.g. Stevenson et al., 2007; Rice & Katz, 2006; Ball & Lillies, 2000). Third, most studies discuss online information as a monolithic entity and do not separate social media pages from other Internet pages.

Thus, this research focuses (1) on the situation in one specific region in Germany, (2) looks at medical practitioners, as opposed to clinical doctors, and (3) aims to differentiate aspects related to social media as opposed to Internet more generally whenever possible and useful. Additionally, as the Internet is one of the most rapidly changing innovations of the current

age (e.g. Eysenbach & Jadad, 2001), the question of the impact of online information on the doctor-patient relationship is still worth being explored further.

This study, based on interviews, aims to provide more insights into the overarching question that prompted my research: **To what extent do online health information of patients affect the doctor-patient relationship?**

Based on the literature and conceptual framework, I will focus on the following three specific research questions:

(1) *To what extent and in what way does online health information affect the power relations between doctor and patient?*

(2) *What does the impact of online health information on the relationship actually signify for the relationship, in terms of opportunities and challenges?*

(3) *Which variables determine this significance of online information's impact?*

RESEARCH DESIGN AND METHODOLOGY

This section presents the rationale for having chosen interviewing as a method, the potential constraints in applying this method, as well as the strategy for sampling and recruiting the respondents and the research tools employed.

Rationale

I approach the research questions by qualitative interviewing: medical practitioners are interviewed individually; the patient perspective is included by focus group discussions with patients and one additional individual interview with a patient organisation representative.

Answering research questions that look at the development of an interpersonal relationship requires that personal impressions and insights of those involved in this relationship be identified. The aim of interviewing as a research method is to capture an individual's understanding as well as beliefs and experiences of a specific topic and resulting behavioural attitudes in different settings. (Berger, 1998; Gaskell, 2000). It is therefore selected as the most appropriate research method for this study.

Other research methods that may be considered for answering these research questions are rejected for the following reasons. While surveys also try to grasp people's opinions on specific issues and themes, they usually require a relatively static and standardised questionnaire and thus do not allow for a flexible conversation with the interviewees in which certain trains of thought can be elaborated upon individually. Instead, interviews and focus groups – especially if based on a semi-structured schedule like in this study – allow that unexpected themes can be integrated to which the interviewer can adapt spontaneously. This enables the gaining of unanticipated but nonetheless relevant insights. (Berger, 1998; Gaskell, 2000; Holstein & Gubrium, 1995). Other qualitative methods, such as ethnography or participant observation, may also yield in-depth insights into the doctor-patient relationship (Marcus, 1998). However, due to constraints in time and resources, these alternatives are not viable options for this study.

As for the choice of the specific form of interviews (i.e. in-depth individual interview or focus group interview) for the different respondents, the following procedure is chosen: considering that physicians – for reasons of medical confidentiality or competition – may refuse to talk openly in a group with other physicians, they are interviewed individually. Patients are interviewed in focus groups, because these allow a group dynamic to arise out of

the exchange of the different experiences and viewpoints. This reflects the patients' mutual exchange of information and experiences on health issues and experiences with specific doctors in real life, and thus also creates a certain sense of community. To avoid the disruption of these group dynamics of patients only and to gain additional in-depth and possibly new insights about the patients' perspective, the representative of the patient organisation is interviewed individually and separately from the patients. (Flick, 2007; Gaskell, 2000)

Reflection on method constraints

The choice to do interviews and focus group discussions implies potential challenges. First, the risk that the respondents hardly engage with the topic due to lack of incentive, or unwillingness to reveal insights beyond the superficial due to the personal nature of the topic, is generally difficult to avoid. In this particular case of health-related issues – a relatively sensitive context – this risk is even more pressing. Further, contrary to the researcher's aim to capture the people's thoughts, impressions and experiences, respondents may want to provide 'useful' or 'right' answers in both the individual interviews and focus group discussions, with regard to the topic of study they agree to participate in (Silverman, 2001). Connected to that, not everything stated in the interviews and discussions must be taken at face value: for example, participants – and especially doctors – may want to paint a better picture of the doctor-patient relationship than is accurate.

In addition, the choice of semi-structured interviews also has its drawbacks. Apart from the difficulty of deciding which questions to ask in order to yield useful results, the spontaneous and sensible integration of new topics must be managed. Depending on the interviewer's capabilities and the respondent's involvement, this style of interviewing could thus result in vast amounts of data of which large parts might not even yield interesting or new insights. (Berger, 1998; Flick et al., 2007)

While focus groups can generate the described group dynamics, this form of interview also carries with it some challenges: first, it is likely that the patients' discussions do not yield as in-depth insights as do the individual interviews. Second, not all participants in the focus groups may feel comfortable with the situation such that they refrain from contributing their thoughts (Fern, 2001).

Considering the mentioned limitations, I nonetheless consider interviewing as the most appropriate method of approaching the research questions.

Sampling and recruiting

In the following, the plan for sampling and recruiting of respondents is presented, and the involved limitations reflected upon.

Plan and procedure

My sampling strategy aims at maximising the likelihood of capturing a variety of views on the topic, so that a variation in the sample is guaranteed (Flick, 2007).

Sampling
The initial choice is to focus on to the Rhine-Main Area (Germany), due to the fact that the medical practitioner's profession regarding benchmarking or competition is locally orientated. The sample of respondents has to include both male and female respondents, all of which must at least have the possibility to access the Internet. For all respondents the age group is of relevance, considering that people of different age groups may have a different affinity to and experiences with Internet- and social media related issues.

As for the doctors, the size of the medical practice and the respective specialisation are central variables in terms of sampling: for example, administrative structures may be differently developed in practices of different sizes and some fields of specialisation may have a distinct attitude with regards to, for instance, patient acquisition. The sampling strategy for the patients specifically is less strict as, basically, every person is a patient of various medical practitioners. As only one patient organisation representative is selected, there is not much room for detailed sampling strategies. The central criterion here is that the respective organisation enables the chosen representative to illuminate the patients' perspective from a different angle.

Recruitment
Based on this sampling strategy, a recruitment plan is developed (Flick et al., 2007). According to the presented criteria I interview eight doctors (see table 1)[3]. In order to include some variety of patients' insights, too, I conduct two patient focus groups: one women and one men group, acknowledging that in the face of a relatively sensitive topic, the participants feel less inhibited to talk openly in a group comprised only of their own gender. For the same reason, I recruit patients who know each other to some extent, but avoided too close

---

[3] For reasons of anonymity, fictitious names of all respondents are shown. The practice size is measured in the number of doctors working in the medical practice.

relationships between them. Based on the above-mentioned criteria, I select the patient organisation representative (Christine) from an association focussing on ADHD (attention deficit hyperactivity disorder).

Having grown up in a family of predominantly doctors and pharmacists working in the geographic region I look at for my research, I can make use of personal contacts to recruit the medical practitioners. In some cases, I also make use of the 'snowball strategy' (e.g. Heckathorn, 1997). The patients are chosen via personal contacts, independently of specific doctors, to avoid that patients feel tempted to answer according to their experiences with one specific doctor only.

Table 1: Overview of the recruited doctors

Name	Sex	Specialisation	Age	Practice size
Hans	Male	Internist	66	3
Johannes	Male	Dentist	29	12
Jürgen	Male	Ophthalmologist	55	3
Kirsten	Female	Ear-nose-throat physician	40	1
Marion	Female	Dermatologist	42	1
Peter	Male	Paediatrician	61	1
Thomas	Male	Cardiologist	53	33
Uwe	Male	Lung specialist	64	2

Limitations

This sampling and recruiting strategy could be optimised in a larger research study and without time constraints. For example, further sub-categories (e.g. degree of specialisation) for the selection criteria of doctors could be considered. Additionally, the selection of patients could be stricter: for example, they could be recruited according to their health histories. Furthermore, I am aware that the way I recruit the respondents may skew the gained data: the fact that my personal network in my home region is shaped by my family's network of professional contacts not only helps to recruit a variety of medical practitioners. It might also affect the choice of patients, to the extent that they might be relatively more open to or even more knowledgeable in health issues. I am also aware that, for similar reasons, the respondents I recruit are all of an upper educational and social level.

Research tools

In terms of the core research tools, the interview schedule, data analysis and pilot study shall be presented and their application explained.

Interview schedule

The semi-structured interview style allows me to both pre-structure the interview schedule according to the central themes reflected in the theoretical framework, and integrate topics that arise in the interviews. The interview schedules are adapted for each group of respondents individually (i.e. doctors, patients, patient organisation).

All participants signed a consent and confidentiality form, informing them, among others, about the interview being recorded and later transcribed. Respecting their tight schedule, the doctors and the patient organisation representative chose the location and time of the interview. Usually, these took place in their medical practices or offices. To avoid a noisy or a medical-related location for the focus group discussions, these took place at my apartment. On average, the individual interviews were of 60 minutes, the focus group discussions of around 90 minutes length.

Data analysis

The data obtained from the interviews are analysed using thematic analysis, because of my interest in the respondents' beliefs and the underlying meaning, rather than linguistic patterns (Flick et al., 2007) or truth (Rabiee, 2004). Codes are attached to all transcripts, then clustered together to form the broader themes and sub-themes respectively (Braun & Clarke, 2006). Due to the focus in the interview schedule, the resulting themes are to some extent rooted in the theoretical background of the research questions (Flick, 2002), though the focus is on exploring the themes that emerged in the interviews (Boyatzis, 1998; Fereday & Muir-Cochrane, 2006; Flick et al., 2007). This procedure allows for high analytic incisiveness in the analysis (Charmaz, 2003).

Pilot contribution

A pilot study was conducted in April 2012 with three medical practitioners, to test interviewing as a method[4]. Even though the research question was slightly different, the pilot revealed some useful conclusions for this study; most importantly, the decision to include the perspectives of both doctors and patients. Further, it helped improve the sampling and recruiting strategy and highlighted the challenges of conducting semi-structured interviews, which can now be considered more carefully.

ANALYSIS, INTERPRETATION AND DISCUSSION

This section examines the central arguments around this study's research questions. The following analysis and interpretation is guided by four core themes: first, the effect of patients' online information on the power relations between patient and doctor; second, the opportunities and challenges brought by these changes; third, the core criteria for determining what the impact of these information signifies for the relationship; fourth, additional variables to be considered in assessing the effect of online information on the doctor-patient relationship.

Impact on the power relationship

Both doctors and patients point to an impact of an online-informed patient on the doctor-patient relationship, especially on their power relations.

A more critical patient

Firstly, a more critical patient is observed. Similar to Scheff (1968), doctors emphasise that the patients are more engaged in discussions with them. Sometimes, they would confront their doctors with their self-diagnoses and no longer condone everything the doctor recommends. This relates to the more active patient Cullen (2006) defines.

Hans:

> You certainly discuss more [...] the younger patients don't passively accept everything anymore [...] often, the patient comes with his ready-made diagnosis and basically just wants me to confirm or reject it.[5]

---

[4] These three doctors were approached a second time for the purposes of this study.

[5] The respondents' quotes are own translations from German.

Peter observes more discussions with his patients, too, as they bring up more topics:

> You must be responsive to issues people have read about somewhere, on the Internet. They wouldn't have hit on these ideas in the past, so we didn't have to discuss them.

While patients stress their caution when confronting their doctors with their information, they agree that they are more interested than before in understanding the issues at stake:

> P:[6] I tell him what I've heard and if this and that would work /P: Yeah, I want to have it explained - P: Yes, and then he says, no, not really, because... whatever... But I'd definitely probe until I understand it. /P: Yes! And whether you could do that additionally. [...] /P: The doctor must enlighten the people much more comprehensively than was common and necessary in the past [...] He can't just give this run-of-the-mill answer. (men group)

A more balanced relationship

Secondly, the development of a more critical patient could indicate a certain loss of the doctor's authority as suggested by Anderson et al. (2003) and Eysenbach and Jadad (2001). In fact, the patients' admiration of the doctor's expertise is qualified. For example, patients report they have made decisions against their doctor's advice, based on pre-information:

> Eventually, I disregarded it [doctor's advice], I decided not to undergo surgery, even though he had urgently recommended it. (women group)

Nevertheless, the doctor is not necessarily weaker. Rather, the patient is more involved in the medical encounters. Kirsten:

> It's the mature patient today ... earlier it was more like ‚I have this issue, help me!'. Today, with the information, patients really engage in discussions, ask questions: ‚Do I have to take this, I read about other options' [...] It's more equal, not this big difference between doctor and patient anymore.

The patient representative Christine sums this up, stating that there is no equalisation of doctor and patient, but the patient is more self-conscious:

> For a long time there was this expression of ‚demi-gods in white'. It's definitely not like that anymore. No equalisation, but it's not this absolute respect anymore either. [...] Patients are more assertive [...] maybe also more demanding.

This suggests a certain balancing of power between doctor and patient.

---

[6] ‘P' refers to a focus group participant's remarks, ‘/P' is used when another participant adds to the discussion. The indications ‘men group'/'women group' refer to the men/women focus group.

Trust is key – the doctor stays important

Thirdly, the argument that the doctor's authority remains crucial (Ball & Lillies, 2001; Rice & Katz, 2006; Stevenson et al., 2007) is supported by those who argue that the doctor stays important or becomes even more important: being anxious about the information gained, the patients would turn to their doctor for advice in clarifying the information (e.g. Peter). Most importantly, trust, 'remains the most important element' (men group). In this light some doctors (e.g. Thomas, Jürgen) claim there is no impact of patients' information on the relationship at all: the patient does not develop enough medical knowledge to make profound medical decisions, he still depends on the doctor's advice. Patients agree with that:

> Trust is the most important, like in all those complicated professions ... I don't understand anything of medicine, so I am reliant on the expert, that he tells me what to do. (men group)

Christine complements:

> The doctor remains the expert, otherwise we could treat all of our issues ourselves. And if we can't do that, we need the doctor, to indicate the direction – and that is accepted.

As for the doctors' perspective, Thomas argues:

> The patients learn rapidly that information alone doesn't help them for the therapy. The trust basis is still crucial. The position of the doctor must be emphasised and strengthened, to give patients a certain security.

For Hans:

> Trust is the central pillar and the patient must trust the doctor, and must accept certain instructions [...] otherwise there is no doctor-patient relationship.

Here, the importance of medical expert knowledge in determining the power position becomes apparent (see Broom, 2005; Foucault, 1977): more health information does not make the patient a medical professional. The patient still relies on and trusts the doctor. The patient's empowerment is thus limited.

The special case for dentists

Finally, the power change is more dominant in the patient-dentist relationship, in that the patient develops a strong influence on decisions about treatment options. This is mostly due to the information sought out here being driven by the search for cheaper rather than 'better' alternatives: the latter could hardly be evaluated by the patients. In that sense, the description of patients as consumers (Reeder, 1972; Haug and Sussman, 1969) with greater power due to greater choice possibilities (Freidson, 1960) is relevant. As Johannes suggests,

the relatively low severity of a dental intervention and the fact that patients often have to pay these on their own play a role here, too:

> It's mostly about the costs. Who covers the costs, how can the costs be reduced? And … are there alternatives? […] Ultimately, the patient decides what's being done. It's different for, say, heart illnesses. There, the doctor must say, heart surgery or not […] there's no choice for the patient. For us, it's different… either we extract the tooth or not.

Similarly, this patient underlines the fundamental role of costs of dental intervention:

> Especially at the dentist, … got a cost estimate for a repair – then my brother says: 'are you insane, that's a fortune [all laughing]…, now first thing you get some more estimates' […] Ultimately, I got it repaired for zero euros. (women group)

However, when it comes to the treatment itself, the patient again depends on the doctor, as this requires medical competence. Ultimately, patients cannot force another treatment method onto their dentists:

> You must not let people interfere with your treatment concept if you're successful with it. You must not let yourself be talked into another concept. (Johannes)

So what? – The significance of the information's impact on the relationship

The described power structures changes by themselves do not reveal whether they signify an opportunity or rather a challenge for the relationship.

Opportunities

The facilitation of the medical encounter, improvement of the medical care received, and a partner-like doctor-patient relationship emerged as central opportunities.

Facilitation of the medical encounter

Firstly, the doctors and the patient representative report that a patient who is equipped with high quality information 'understands more' (Kirsten) such that 'the doctor needs to explain less' (Johannes), especially of 'the very basics' (Christine). In contrast, 'conversations with uninformed patients are really difficult' (Jürgen) and 'it is much easier to guide a well-informed patient' (Uwe). Specifically, doctors and patients alike perceive informed patients as asking 'more targeted and good questions' (Uwe) suggesting a link between good information and a better ability to judge medical procedures:

> P: You can ask better questions […] /P: And you can judge better whether what the doctor says is valid, with a certain knowledge of the issue. (men group)

To a certain extent, this validates Wald et al.'s (2007) finding that the medical encounter is becoming more time efficient.

Improvement of the medical care

Secondly, a well-informed patient could also contribute to an improved provision of medical care by the doctor (see Wald et al., 2007), by pointing to relevant details about a specific condition that the doctor could not realistically predict:

> You prescribe medicines and know their core characteristics, but not all rare adverse effects … that's impossible [...] so I'm always glad if the patient had read about the adverse effects … this really facilitates my work. (Uwe)

Peter, too, welcomes the 'co-responsibility of patients' that results from their increased information access. Patients themselves appreciate that the doctor is prompted to keep his medical knowledge up to date:

> P: „The doctor is forced to keep his information up-to-date. Because only if he, too, knows what the other party already knows from the Internet, can they communicate … /P: Yeah, he gets nudged … ,listen, here you're not up to date' – that's great. (men group)

Partner-like and closer relationship

Thirdly, drawing on the discussions between patient and doctor, patients and doctors perceive their relationship to be more partner-like (Wald et al., 2007).

> You're more on one level, not this 'god in white' anymore, you're more like a business partner, with whom I aim at the optimal treatment. (Kirsten)

> **Researcher:** Did the doctor perceive it as bothersome that you were pre-informed?
> **P:** No! Rather partner-like. I asked, doesn't this drug cause husky vocal cords?' – True! We leave it as it is.' (women group)

The view that doctors react positively to pre-informed patients is supported by this participant, who had confronted her doctor with a decision against his advice:

> I really felt sick in the pit of my stomach when I went to see my family doctor again [...] but that was great, the relationship is so good that he didn't have any problem with it at all. (women group)

For the doctors, the more targeted discussions, together with the more partner-like atmosphere in which 'the doctor is more regarded as a person' (Marion), would result in a 'a closer relationship' (Jürgen), as touched upon by Wald et al. (2007).

Challenges

On the other hand, more effort for the doctor and the danger of the doctor being offended are indicated as challenges.

More effort for the doctor

Doctors also report that more discussions mean more effort in terms of medical information and clarification but also time required. They find it troublesome to argue with patients bringing their ready-made opinion, if this is not suitable or false. This is in line with Kiley (2003) and Mittman and Cain (2001). Kirsten:

> Sometimes they bring their ready-made diagnosis, ideas, which you have never heard before. Which isn't unproblematic [laughs] … if you have to talk them out of that.

Marion argues that patients who treat themselves on their own complicate the medical therapy:

> Sometimes, if they feel they are treated differently than they expected, they treat themselves in addition … get their information online, buy things in the pharmacy – obviously this makes the therapy more difficult.

For patients, these viewpoints are comprehensible: specifically, they see that 'stupid questions are annoying' (men group) and patients' vehement claims to be more knowledgeable than the doctor would exacerbate the doctor's frustration:

> It has come to pass that patients claim to know what is to be done, and that can make it more difficult – because, maybe, it's not really always the way they think [laughs]. (women group)

Patients would further 'report about a certain impatience' (Christine) and disgruntlement of the doctor.

Offense of the doctor

A considerable amount of research has pointed to the possibility that doctors feel offended when confronted with information by the patient (e.g. Anderson et al., 2003; Hardey, 1999; Wald et al., 2007). In fact, patients report being careful in confronting the doctor with information, to avoid any upset:

> **P:** You must be very careful about that, the doctor easily takes offence.
> **/P:** Maybe you could say ‚couldn't it be this or that'
> **/P:** But you wouldn't question his competence
> **/P:** At least if you want to go there again [all laughing]. (women group)

However, no doctor states to feel threatened in his medical superiority. Only Hans touches this aspect, concluding that he doesn't see a problem here as long as he feels competent:

> You have to fight more for your position and authority. But I don't think that's a problem. [...] As long as I feel competent, I don't see it as a danger.

The majority of patients stress a positive reaction of the doctor, pointing to his openness, appreciation and 'ease' (men group) in reaction to the patients' information:

> I always prepare my medical history [...] and they are grateful that I know what is going on... they really perceive this very positively – everywhere. (women group)

The determining criteria

These elaborations suggest that two criteria are critical in ultimately determining the impact of online information on the doctor-patient relationship: the quality of the information and the patients' capabilities to evaluate that information – rather than the power relationship change itself. While the presented opportunities assume good quality information and/or an appropriate evaluation by the patient, the challenges tend to relate to low quality information or improper evaluation.

An exception to this conclusion is the risk of the doctor taking offense: being relatively independent of quality or evaluation, it clearly refers to the power balance tipping in the direction of a self-confident, critical patient. However, as the data suggest this challenge to be of low significance, I assess the criteria of quality and evaluation in more detail.

Quality of information

In essence, high quality information provides patients with a solid information base and thus helps them to know more about their illnesses. In contrast, low quality information rather fans fears among the patients and helps to spread untruths or half-truths. This is what Murray et al. (2003) point to and is supported by all doctors. Thomas:

> The big advantage of good information is that patients recognise their problems early and see the doctor on time. But there's also the danger of misinformation, for example offered by natural health practitioners or subjective reports of non-medical groups.

Specifically, the characteristics of social media and the role of the information's publisher are referred to in this regard.

All respondents indicate that social media pages – forums, networks and communities specifically – are in general of worse quality than webpages to which Internet users cannot contribute to or which are predominantly used to consume information:

> Those passive pages, especially the medical Wikipedia, have more ‚power', because they're more objective, written by specialists ... in forums, every layperson can say something, [...] non-specialists exchange views, a lot of rubbish. (Peter)

While patients do not mention quality aspects directly, they find social media pages relatively unattractive as they would be too subjective and not offer facts.

> P: I stopped reading other people's comments. It's too personal and too emotional, so I only look at facts. /P: I think so, too, that on Facebook or chats ... they exchange quite a lot of half-truths there. (women group)

On the other hand, advantageous aspects of social media regarding information quality are mentioned, too: above all, forums in the sense of self-help groups are considered as very helpful. Uwe stresses these advantages most:

> For active patients [...] these forums are really, really important and fulfil many tasks which cannot be fulfilled in the doctor-patient encounters, because the consultation hours are always under time pressure.

Respondents underline that these platforms can serve as self-help groups especially for patients with rare or severe illnesses:

> **P:** Once the diagnosis has been made,... the help can continue amongst one another on those forums, because if one has the same illness, ... and must change the lifestyle, it really helps ... **/P:** Yes! That's a positive development! (men group)

Hans:

> There are these self-help groups, and I really think positively about them [...] Especially for rare illnesses, it's important that you find other people, with whom you can share sorrows, joy and experiences.

In addition, the importance of a scientific information base is stressed, as contributing to good quality information (see Goldberg, 2010; Mittman and Cain, 2001). Johannes and Peter point to the relevance of the information's publisher:

> You have to watch out on which page you are, which source it is, whether it's an expert society behind it, doing scientific work [...]. But obviously, this is hard to tell for the patient. (Johannes)

> When they say 'I've read this on the Internet', I always ask them to tell me, on which page they've read that and which person or institution has published it. (Peter)

Closely related to this point, Christine criticises that 'the majority of scientific publications are not accessible online by the patients'. Against this backdrop, respondents argue that online information cannot provide a patient with a trustworthy and accurate diagnosis, as the information is 'impersonal' (men group), and thus 'the individual case not assessable online' (Johannes).

Evaluation of online information and their quality

As these last quotations imply, a central issue connected to the aspect of quality is that patients as laypersons are not always able to judge the quality of the information. The aspect of evaluation is slightly touched upon by Morahan-Martin (2004) and Diaz et al. (2002). As the Internet is characterised by offering vast amounts of information it is even more crucial to carefully differentiate useful from less useful information in the online context – as a patient admits: he feels 'completely overwhelmed by the mass of information the Internet has to offer'. The interview data reveal that medical knowledge and general education of the patient determine his evaluation capabilities.

For Hans, the limited evaluation capabilities of patients are the central problem with regards to online health information, causing uncertainties and disorientation. He mainly blames the lack of patients' medical (expert) knowledge for the limited evaluation capacities:

> **Researcher:** Would you say patients are more informed about health issues today?
> **Hans:** More certainly … but not targeted, and for many it's anxiety-provoking, because they can't deal with the information professionally. […] The knowledge of illnesses and interrelations barely exists, so when there are statements online, they can't evaluate them […] because it's all unsorted, without relation to frequencies or consequences.

This stresses that the patient as a layperson is oftentimes not able to judge the information's quality. As Mohammed (2012) warns, a lot of information does not necessarily equip the patient with more medical knowledge. Christine, too, describes that (ADHD-) patients often lack the knowledge necessary to differentiate high- from low quality information:

> There are a lot of people who, […] consciously distribute misinformation […] and if you don't know much about ADHD, then you're easily fooled, because simple solutions are presented there, avoiding evil medicine, of course.

The patients themselves admit their limited medical knowledge, stating it would restrict their competent judgment of information:

> I know that [...] you need to study five years minimum to comprehend the background and that, otherwise, I only scratch the surface. (men group)

By a majority of the respondents, the general education level is regarded as strongly influencing the patients' ability to correctly evaluate information and, accordingly, the degree to which they feel anxious for no or the wrong reasons. For example, many of Marion's patients work as journalists at a big media company right next to her practice and have a relatively high level of education. In her experience, the patients' concerns due to online information relate to very severe illnesses only:

> That exists, but mostly for melanoma really, that they're frightened to have skin cancer. They come to see me and think they will die tomorrow, because they've read online, black spot, oh God [...] But that exists for melanoma, ... less so for other issues.

While patients do not directly mention the importance of the general education level, most doctors do. Jürgen:

> Information is helpful only if it is correct, and especially evaluated correctly. Whether this evaluation is appropriate critically depends on the patient's education level.

The broader picture: additional variables

The interview data further suggest that the significance of online information's impact on the doctor-patient relationship in different situations and for different individuals also depends on the variables of doctors' time pressure and differences in information-seeking behaviour.

Time pressure

Many respondents stress the doctors' time pressure as influencing the doctors' reaction to patients bringing information. Doctors would often lack the time to discuss certain issues in as much detail as patients would like, causing frustration for the patients and impatience for the doctors. The impact of online health information could thus signify a challenge for the relationship for reasons independent of the information's quality and evaluation.

For Christine, the issue is the following:

> People often tell me that doctors suffer from time pressure, that they wouldn't explain everything correctly or sufficiently, and that fears are not responded to appropriately [...] and I think the trust suffers from that.

Correspondingly, patients report the doctor's low fee as determining that time pressure:

> **P:** Unfortunately, the superficialities are increasing ... because of the lack of time.
> **/P:** Right!

P: They all want to earn money and their fee is probably very low, so ... it's about the turnover... and the patients fall by the wayside. (women group)

Christine regards the low earnings of doctors as a core problem:

Doctors should get the possibility to spend more time with their patients [...] So, the insurance companies would have to pay them significantly more.

Most doctors do not admit to acting indignantly towards patients because of time pressure. However, according to Uwe, 'the time pressure is problematic' in the doctor-patient relationship. Similarly, Marion describes the shortage of doctors as making the doctor-patient relationship

more difficult, [...] the practices get more crowded, the patients get rushed through and, in turn, get more information from the Internet, maybe incorrect information,... so I think the relationship will definitely become more difficult. Simply for health-policy reasons.

Information-seeking behaviour differences

It further shows that the way online information affects the doctor-patient relationship is influenced by differences in the individual information-seeking behaviour, too.

Age matters

Most respondents indicate that that the age of the patients is relevant: older people use the Internet less and tend to rely more on both offline information ('older people have their media like Apothekenumschau[7]' (Thomas)) and on the doctor's advice (men group). According to Marion, 'younger patients use social media pages like Facebook or medical portals more [than the elderly]'. In fact, a younger patient reports she would use the portal DocCheck and medical applications on her iPhone to look for health information.

The search topic matters

The health topics sought out vary a lot across patients. While it seems that information about specific illnesses, symptoms and therapies are the prevalent topics, another field of interest is the search for doctors and cheaper alternatives (see dentist example above). Most doctors assume that the search for doctors will become more important. Peter:

The people want to know what the doctor does. My child has to have a heart check-up, who is he, does he know how to do that? Do I need to see the paediatric cardiologist, or is the paediatrician okay'?

---

[7] Popular scientific health magazine.

Patients report they would look for specialists for specific interventions:

> **/P:** I would check online: one hospital does the surgery 300 times per year and here, say, 5 times, so that may be a criterion that I then go to the other one.
>
> **/P:** Yeah! The number of cases is important, and you can definitely find that out on the Internet. (men group)

In these different situations, different information channels are used. For the search of doctors, personal word of mouth advice is relied upon rather than for example online rankings:

> Online-evaluations can have an impact... you probably don't go see the doctor with only one point [...] But that's always backed up by word of mouth recommendation, so if a friend tells me, go there ...
>
> /P: Worth much more, yeah! (men group)

Doctors, too, report that 'the medical practice depends on word of mouth' (Uwe). Offline information sources – predominantly personal recommendations – 'are much more authentic with regards to the patients' decision-making' (Thomas). The website of the respective medical practice would be an important channel which complements personal recommendations (e.g. Jürgen, Thomas, Marion). As the evaluation of information about doctors or costs is less reliant on medical expert knowledge than that on therapies or symptoms, a difference in impact on the doctor-patient relationship is assumed (see 5.1.4).

<u>The severity of illness matters</u>

While the first information channel for basic questions are pages like Google and Wikipedia, social media pages are turned to in cases of chronic and 'rare illness' (men group, Thomas). As Granovetter (1973) indicates, in these cases patients would 'renounce personal contacts but turn to contacts on online platforms' (Kirsten). The intensity of the information search is said to generally be higher in case of severe illness:

> Some years ago, a friend suffered from breast cancer and I thought [...] if it were me I'd really go online and [...] check very extensively, not only the nice things. (women group)

Concluding discussion

The analysed interview data provide insights that help answer the research questions. Previous research is seized and added to, and thoughts are presented as to what might be worth exploring further in future research.

Answers to the research questions

Firstly, in the sense mapped in the conceptual framework (see Stoeckle, 1987; Broom, 2005; Scheff, 1968), the findings suggest that **online health information empower the patient**, while **the doctor remains important, because of his advantage in medical expert knowledge**: patients must develop significant trust in their doctors because the health information gathered does not make them medical professionals. This is especially true with regard to medical decisions that depend heavily on expert knowledge. Selecting a cheaper alternative for a standardised, less urgent issue requires less proficiency. So, online information provides a stronger decision basis for the patient in these cases. These findings mirror the limited empowerment of the patient (Ball & Lillies, 2011; Cullen, 2006), and the importance of medical expert knowledge in determining the power balance in the relationship (Broom, 2005) as outlined in the conceptual framework. The results also encourage further research to elaborate on how the patient is more empowered facing different kinds of health-related questions.

Secondly, the impact of online health information on the doctor-patient relationship can signify **both an opportunity and a challenge,** as the conceptual framework suggests. All identified opportunities and challenges imply, to a certain extent, a more empowered patient. The core opportunities are the facilitation of the medical encounter, the improvement of the medical care, and a partner-like relationship. The central challenge is the additional effort for doctors, reflecting concerns of Mittman and Cain (2001) and Goldberg (2010). My data suggest that the **danger of the doctor feeling offended** by a more informed patient **is of little relevance**, going against suggestions included in the literature review (see Anderson et al., 2003; Hardey, 1999; Wald et al., 2007).

Thirdly, the **significance of the online information's impact on the relationship is mainly determined by the information's quality and the patients' evaluation of the information**. Basically, presuming good information and/or an appropriate evaluation of the information by the patient, the benefits for the doctor-patient relationship dominate. While the quality aspect follows the logic of the conceptual framework (especially Murray et al., 2003), **the evaluation aspect appears to be more important than anticipated.** Mittman and Cain (2001), Kiley (2003) and Diaz et al. (2003) indicate this element in the literature review, without being very explicit about it. Future research should definitely focus more on the role of evaluating information.

For the quality aspect, social media should be differentiated more from 'passive' Internet pages. While the identified relevance of the publisher is mentioned in the literature and is certainly linked to social media characteristics specifically (Goldberg, 2010; Mittman & Cain, 2001), 'passive' Internet information should be analysed separately from social media information. The evaluation capabilities are found to depend primarily on the patients' medical knowledge and general education. While the former is considered in the literature (Broom, 2005), the latter could be scrutinised more in this context.

There are two central thoughts connected to this. As **both information quality and its evaluation are imperfect, the argument that the doctor must stay important and thus powerful because of his greater medical knowledge is supported.** On the one hand, limited evaluation capabilities of the patients mirror a lack of the knowledge necessary to judge the information appropriately. On the other hand, even if the evaluation capabilities are outstanding, the limited quality of the information means that good medical knowledge is not delivered. In both cases, the doctor must be trusted. If the information's contribution to medical knowledge is limited, the patient's empowerment is, too.

Beyond this, **patients may not always know that their evaluation capabilities are limited.** This is essentially what the challenge of additional effort for the doctor refers to: patients may think their information provides them with enough medical knowledge to arrive at a certain diagnosis, even though the information is wrong or not applicable for the individual patient. This is what Diaz et al. (2002) and Mohammed (2012) indicate and is more central than expected.

Linking this back to the connections between information, knowledge and power, it shows that information – by contributing to medical expert knowledge (Broom, 2005) – can increase power (Gaventa & Cornwall, 2001; Waitzkin & Stoeckle, 1976). However, the **patient can also take a more powerful position by only feeling that the information makes him more knowledgeable**.

Additionally, I identified two **variables independent of the information itself (and its quality or evaluation), that play a role in determining the overall effect of online information on the relationship**: **time pressure** of doctors and **individual differences in information-seeking behaviour**. These insights are interesting starting points for further examination. For example, one could analyse in more detail how the severity of illness determines the examined effects on the doctor-patient relationship.

My findings both confirm existing literature and highlight aspects that should be emphasised in research to come. This supports the choice to conduct interviews in general, the sampling and recruiting plan, and the orientation of my data collection towards previously neglected fields. The selected sample, aiming to include a variety of insights, helped to gain these nuanced results. However, these results are not differentiable according to the respective sampling categorisations: for example, it does not show that doctors working in big medical practices, as opposed to those in a single practice, have a distinct opinion on the questions at stake.

Limitation: Online information or information in general

It should be noted that the identified influences on the doctor-patient relationship sometimes relate to information in general, and the patient being generally more informed. Even though the data show that most information is looked up on the Internet, other channels remain important. Within the parameters of this study, it is impossible to draw a definite line between impact caused by online information only versus offline and online information jointly. Even so, in many cases, the impact of online information specifically can be ascertained, with help of the core characteristics of the Internet and social media, respectively: for example, the low barriers to creating content on the Internet (Goldberg, 2010; Mittman & Cain, 2001) aggravate the problem of unscientific, subjective information being taken at face value. This example also relates to information quality and evaluation, which legitimises the choice of these elements as central with regard to online information in particular.

CONCLUSIONS

This research was prompted by the question of the extent to which online information on health issues affects the doctor-patient relationship. Based on the existing literature, I focused on the effects on the doctor-patient power structures, the significance of the information's impact on the relationship and the variables determining this significance.

The data gained from interviews and focus group discussions helped answering my research questions: first, online health information empowers the patient, but the doctor remains important and trusted because of his advantage in medical expert knowledge. Second, the respective impact can signify both an opportunity and a challenge for the doctor-patient relationship, strongly being determined by, third, the information's quality and the patients' evaluation of the information. Imperfections in the information's quality and the patients' evaluation capabilities support, in turn, the necessity of a powerful doctor. However, patients may not always perceive their evaluation capabilities as limited, displaying a behaviour that reflects a more powerful position in the relationship, which again causes discrepancies between doctor and patient.

My findings confirm core connections suggested in the conceptual framework: the extent and direction of the impact on the doctor-patient power relations, but also the importance of medical expert knowledge resemble existing literature. At the same time, my findings point to aspects worth scrutinising more in future research, above all, the importance of patients' evaluation capabilities. My findings also suggest incorporating more specifically the differentiation of Internet and social media and the impact of the patients' general education level. The orientation of the data collection towards previously neglected fields has contributed to the identification of these nuanced insights, supporting my choice to do interviews for this research.

This being said, the identified findings are limited. First of all, the presented insights are not generalisable, as they base on just a few interviews that represent a snapshot in time only. Additionally, not all conceptual tenets that could yield further insights are analysed in detail in this study. These could serve as starting point for future research: the concept of mediation could be integrated explicitly, in looking at how medical knowledge or the doctor-patient relationship itself is mediated. Further, having focused on how power relations are affected by online information, I assumed the existence of a 'new media power', but did not look at it in detail. Having stressed the importance of medical expert knowledge, the precise role of lay medical knowledge might be analysed in more detail, too. Finally, the extent to which

doctors, too, make use of online health information, with the respective effects, could also be examined.

Rounding it all off, the doctor-patient relationship is affected by the new media influence. However, the above elaborations indicate that neither Internet nor social media turn upside down the core pillars of the doctor-patient relationship.

Acknowledgements

REFERENCES

Anderson, J. G., Rainey, M. R., & Eysenbach, G. (2003). The Impact of CyberHealthcare on the Physician–Patient Relationship. *Journal of Medical Systems, 27*(1), 67-84.

Bakardjieva, M. (2005). *Internet society: the Internet in everyday life*. London: Sage Publications.

Ball, M. J., & Lillis, J. (2001). E-health: transforming the physician/patient relationship. *International journal of medical informatics, 61*(1), 1-10.

Bennett, W. L. (2003). New media power: the Internet and global activism. In N. Couldry & J. Curran (Eds.), *Contesting media power: alternative media in a networked world*. Lanham Maryland: Rowman & Littlefield.

Berger, A. (1998). Chapter 6, Depth Interviews: favorite singers and recordings. In A. Berger (Ed.), *Media research techniques* (2 ed., pp. 55-62). London: Sage.

Bloom, S. W. (1963). *The Doctor and his patient: a sociological interpretation*. New York: Sage Publications.

Bosslet, G., Torke, A., Hickman, S., Terry, C., & Helft, P. (2011). The Patient–Doctor Relationship and Online Social Networks: Results of a National Survey. *Journal of General Internal Medicine, 26*(10), 1168-1174.

Boyatzis, R. E. (1998). *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks CA: Sage Publications.

Boyd, D. M. (2011). Social Network Sites as Networked Publics: Affordances, Dynamics, and Implications. In Z. Papacharissi (Ed.), *Networked Self: Identity, Community, and Culture on Social Network Sites* (pp. 39-58). New York: Routledge.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

Broom, A. (2005). Medical specialists' accounts of the impact of the Internet on the doctor/patient relationship. *Health, 9*(3), 319-338.

Burrows, R., Nettleton, S., Pleace, N., Loader, B., & Muncer, S. (2000). Virtual community care? Social policy and the emergence of computer mediated social support. *Information, Communication & Society, 3*(1), 95-121.

Castells, M. (2000a). Materials for an exploratory theory of the network society. *British Journal of Sociology, 51*(1), 5-24.

Castells, M. (2000b). *The rise of the network society* (2 ed.). Oxford: Blackwell.

Castells, M. (2004). *The power of identity* (2 ed.). Malden Mass.: Blackwell.

Charmaz, K. (2003). Chapter 15: Qualitative Interviewing and Grounded Theory Analysis. In J. A. Holstein & J. F. Gubrium (Eds.), *Inside interviewing: new lenses, new concerns*. Thousand Oaks, CA: Sage Publications.

Cullen, R. (2006). *Health information on the Internet: a study of providers, quality, and users*. Westport Conn.: Praeger.

Diaz, J. A., Griffith, R. A., Ng, J. J., Reinert, S. E., Friedmann, P. D., & Moulton, A. W. (2002). Patients' use of the Internet for medical information. *Journal of General Internal Medicine, 17*(3), 180-185.

Dolan, G., Iredale, R., Williams, R., & Ameen, J. (2004). Consumer use of the internet for health information: a survey of primary care patients. *International Journal of Consumer Studies, 28*(2), 147-153.

Eysenbach, G., & Diepgen, T. L. (2001). The Role of e-Health and Consumer Health Informatics for Evidence-Based Patient Choice in the 21st Century. *Clinics in Dermatology, 19*, 11-17.

Eysenbach, G., & Jadad, A. R. (2001). Evidence-based Patient Choice and Consumer health informatics in the Internet age. *Journal of Medical Internet Research, 3*(2), e19.

Eysenbach, G., & Köhler, C. (2002). How Do Consumers Search For And Appraise Health Information On The World Wide Web? Qualitative Study Using Focus Groups, Usability Tests, And In-Depth Interviews. *BMJ: British Medical Journal, 324*(7337), 573-577.

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods, 5*(1), 1-11.

Fern, E. F. (2001). *Advanced focus group research*. London & Thousand Oaks, CA: Sage Publications.

Fischer, C. S. (1992). *America calling: a social history of the telephone to 1940*. Berkeley: University of California Press.

Flick, U. (2002). *An introduction to qualitative research* (3 ed.). London: Sage Publications.

Flick, U. (2007). *Designing qualitative research*. London: Sage Publications.

Flick, U., Kvale, S., Angrosino, M. V., Barbour, R. S., Banks, M., Gibbs, G., & Rapley, T. (2007). *Doing Interviews*: Sage Publications.

Foucault, M. (1977). *Discipline and punish: the birth of the prison* (A. Sheridan, Trans.). London: Allen Lane.

Foucault, M. (1980). *Power/Knowledge: Selected Interviews and Other Writings, 1972-1977.* Brighton: Harvester Press.

Fraser, C., & Bennett, A. E. (1976). *Communication between doctors and patients.* Oxford: Published for the Nuffield Provincial Hospitals Trust by the Oxford University Press.

Freidson, E. (1960). Client Control and Medical Practice. *American Journal of Sociology, 65*(4), 374-382.

Gaskell, G. (2000). Individual and group interviewing. In M. W. Bauer & G. Gaskell (Eds.), *Qualitative research: with text, image and sound. A practical handbook* (pp. 39-56). London: Sage Publications.

Gaventa, J., & Cornwall, A. (2001). Power and Knowledge. In P. Reason & H. Bradbury (Eds.), *Handbook of Action Research: Participative Inquiry and Practice.* London: Sage Publications.

Giddens, A. (1990). *The consequences of modernity.* Cambridge: Polity in association with Blackwell.

Goldberg, R. (2010). *Tabloid medicine: how the Internet is being used to hijack medical science for fear and profit.* New York: Kaplan Publishing.

Gordon, M.-M., Capell, H. A., & Madhok, R. (2002). The use of the Internet as a resource for health information among patients attending a rheumatology clinic. *Rheumatology, 41*, 1402-1405.

Granovetter, M. S. (1973). The Strength of Weak Ties. *American Journal of Sociology, 78*(6), 1360-1380.

Haley, J. (1963). *Strategies of Psychotherapy.* New York: Grune & Stratton.

Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in Physicians and Medical Institutions: What Is It, Can It Be Measured, and Does It Matter? *The Milbank Quarterly, 79*(4), 613-639.

Hardey, M. (1999). Doctor in the house: the Internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health & Illness, 21*(6), 820-835.

Hardey, M. (2001). 'E-health': the internet and the transformation of patients into consumers and producers of health knowledge. *Information, Communication & Society, 4*(3), 388-405.

Hart, A., Henwood, F., & Wyatt, S. (2004). The Role of the Internet in Patient-Practitioner Relationships: Findings from a Qualitative Research Study. *Journal of Medical Internet Research, 6*(3), e36.

Haug, M., & Sussman, M. (1969). Professional Autonomy and the Revolt of the Client. *Social Problems, 17*, 153.

Haythornthwaite, C. (2002). Strong, Weak, and Latent Ties and the Impact of New Media. *The Information Society: An International Journal, 18*(5), 385-401.

Heckathorn, D. D. (1997). Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. *Social Problems, 44*(2), 174-199.

Hodson, M. (1967). *Doctors and patients: a relationship examined.* London: Hodder and Stoughton.

Holstein, J. A., & Gubrium, J. F. (1995). *The active interview.* Thousand Oaks, CA: Sage Publications.

Jadad, A. R., & Gagliardi, A. (1998). Rating health information on the Internet: navigating to knowledge or to Babel? *The Journal of the American Medical Association, 279*(8), 611-614.

Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of Social Media. *Business Horizons, 53*(1), 59-68.

Kiley, R. (2003). *Medical information on the internet. A guide for health professionals.* (3 ed.): Churchill Livingston.

Kivits, J. l. M. P. (2004). *Health information on the internet: researching information seekers and practices in a mediated health context.* (PhD), London School of Economics and Political Science.

Kivits, J. l. M. P. (2006). Informed Patients and the Internet: A Mediated Context for Consultations with Health Professionals. *Journal of Health Psychology, 11*(2), 269-282.

Lievrouw, L. A., & Livingstone, S. M. (2009). Introduction. In L. A. Lievrouw & S. M. Livingstone (Eds.), *Major Works in New Media* (Updated student ed., pp. xxi-xl). London: Sage Publications.

Lukes, S. (2005). *Power: a radical view* (2 ed.). Houndmills Basingstoke Hampshire New York: Palgrave Macmillan.

Marcus, G. E. (1998). *Ethnography through thick and thin.* Princeton N.J. Chichester: Princeton University Press.

McClung, H. J., Murray, R. D., & Heitlinger, L. A. (1998). The Internet as a Source for Current Patient Information. *Pediatrics, 101*(6), e2.

Mittman, R., & Cain, M. (2001). The Future of the Internet in Health Care: A Five-Year Forecast. In R. E. Rice & J. E. Katz (Eds.), *The Internet and Health Communication: Experiences and Expectations.* Thousand Oaks, CA: Sage Publications.

Mohammed, S. N. (2012). *The (dis)information age: the persistence of ignorance.* New York: Peter Lang Publishing.

Morahan-Martin, J. M. (2004). How Internet Users Find, Evaluate, and Use Online Health Information: A Cross-Cultural Review. *Cyberpsychology & Behavior, 7*(5), 497-510.

Murero, M., D'Ancona, G., & Karamanoukian, H. (2001). Use of the Internet by Patients Before and After Cardiac Surgery: An Interdisciplinary Telephone Survey. *Journal of Medical Internet Research, 3*(3), e27.

Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., Lee, K., . . . Turner, R. (2003). The Impact of Health Information on the Internet on Health Care and the Physician-Patient Relationship: National U.S. Survey among 1.050 U.S. Physicians. *Journal of Medical Internet Research, 5*(3), e17.

Pearce, T. O. (1993). Lay Medical Knowledge in an African Context. In S. Lindenbaum & M. M. Lock (Eds.), *Knowledge, power, and practice: the anthropology of medicine and everyday life*. Berkeley: University of California Press.

Popay, J., Williams, G., Thomas, C., & Gatrell, A. (2003). Theorizing Inequalities in Health. The Place of Lay Knowledge. In R. Hofrichter (Ed.), *Health and Social Justice. Politics, Ideology, and Inequity in the Distribution of Disease*. San Francisco: Jossey-Bass.

Prior, L. (2003). Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. *Sociology of Health & Illness, 25*, 41-57.

Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society, 63*(04), 655-660.

Reeder, L. G. (1972). The Patient-Client as a Consumer: Some Observations on the Changing Professional-Client Relationship. *Journal of Health and Social Behavior, 13*(4), 406-412.

Rice, R. E., & Katz, J. E. (2006). Internet use in physician practice and patient interaction. In M. Murero & R. E. Rice (Eds.), *The Internet and health care. Theory, research, and practice*. Mahwah, NJ: Lawrence Erlbaum Associates.

Silverman, D. (2001). *Interpreting qualitative data: methods for analyzing talk, text and interaction* (2 ed.). London: Sage Publications.

Silverstone, R. (2005). The sociology of mediation and communication. In C. Calhoun, C. Rojek & B. S. Turner (Eds.), *The SAGE handbook of sociology* (pp. 188-207). London: Sage.

Stevenson, F., Kerr, C., Murray, E., & Nazareth, I. (2007). Information from the Internet and the doctor-patient relationship: the patient perspective – a qualitative study. *BMC Family Practice, 8*, 47.

Stoeckle, J. D. (Ed.). (1987). *Encounters between patients and doctors: an anthology*. Cambridge Mass: MIT Press.

Szasz, T. S., & Hollender, M. H. (1956). A Contribution to the Philosophy of Medicine: The Basic Models of the Doctor-Patient Relationship. *AMA Archives of Internal Medicine, 97*, 585-592.

Turner, B. S. (1995). *Medical Power and Social Knowledge*. London: Sage Publications.

Waitzkin, H., & Stoeckle, J. D. (1976). Information Control and the Micropolitics of Health Care. In J. D. Stoeckle (Ed.), *Encounters between patients and doctors: an anthology*. Cambridge Mass.: MIT Press.

Wald, H. S., Dube, C. E., & Anthony, D. C. (2007). Untangling the Web—The impact of Internet use on health care and the physician–patient relationship. *Patient education and counseling, 68*(3), 218-224.

Williams, G., & Popay, J. (1994). Lay knowledge and the privilege of experience. In J. Gabe, D. Kelleher & G. Williams (Eds.), *Challenging Medicine*. London: Routledge.

Williams, R. (1990). *Television: technology and cultural form* (2 ed.). London: Routledge.

Electronic MSc Dissertation Series

The Media@LSE Electronic MSc Dissertations Series presents high quality MSc Dissertations which received a mark of 72% and above (Distinction).

Selected dissertations are published electronically as PDF files, subject to review and approval by the Editors.