Cancer patients' trust in their oncologist

Hillen, M.A.

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General introduction
INTRODUCTION

“It is trite to describe the health professional’s relationship with his or her patient as a relationship of trust, yet the description encapsulates the very heart of the relationship.”
Margaret Brazier and Mary Lobijoit [1]

Trust is the lubricant of society. Without it, many things would not function adequately, and society would disintegrate [2]. We are so used to trust others, that we are often not even aware of doing so [3]. Yet, we constantly need trust to leave things to the care of others because we cannot keep everything safe ourselves all the time. We lack time, so we trust our children to a day-care center. We lack skill and materials, so we trust the pilot to safely fly us abroad. Thus, on a daily basis, people put trust in their close ones, as well as in those less familiar.

This thesis is about patients’ interpersonal trust in their care provider. Moreover, its contents are empirically orientated. Nonetheless, trust research in any field never stands alone: research on patient-provider trust is inspired by a wide range of disciplines, ranging from philosophy to management research. Theory from other disciplines may provide relevant insights into patient-provider trust. Literature on trust is so extensive, that it is simply impossible to do justice to everything that has been written about its meaning, definition, construction, functions, facets, and forms, from various philosophical and scientific viewpoints. Nevertheless, before focusing on trust in the medical setting, I will first shortly touch upon the broadness of literature on trust.

What is trust?

Trust is considered an elusive concept. O’Hara [4] described it as “the truly mysterious, barely known entity that holds society and ourselves together, the ‘dark matter’ of the soul” (p. 14), and Fugelli [5] even spoke about “the God particle (…) the fuel, the essence, the foundation of general practice” (p. 575). This religious approach to trust leaves so much room for the unknown that it suggests it is impossible to empirically unravel trust. Yet, originating from many different disciplines, scholars have attempted to describe and make tangible what trust entails. In addition to more ethical and philosophical reflections on trust, empirical study has been conducted from the perspectives of management, communication, sociology, economics, political science, as well as social and clinical psychology [6,7]. How trust is approached is largely dependent on the discipline. Social psychologists commonly approach trust on an interpersonal level, i.e., occurring between two people. (Clinical) psychologists study the personal characteristics that cause a
particular person to trust in a specific situation or across situations. Sociology looks at the situational, social, and institutional structures that may or may not create conditions for trust to occur. Finally, economists may even look at trust as a rational choice mechanism wherein benefits and costs of trusting or not trusting are weighed [6].

McKnight and Chervany [7], reviewing a multitude of trust conceptualizations across disciplines, created a typology, distinguishing six types of trust conceptualizations. Within a specific situation, one may distinguish someone's trusting intention, i.e., willingness to depend on a specific other. Trusting behavior refers to the act of depending on the other in a particular situation. Trusting beliefs are people's inclinations to believe in the other person's trustworthiness. System trust, the focus of sociological research, is broad and situation-unspecific, referring to one's beliefs that the impersonal structures are in place to enable anticipating a successful future endeavor [8]. Dispositional trust is a person's consistent tendency to believe in the good will of others. Thus, it is specific to the one who trusts, but not to the situation. Finally, a person's situational decision to trust describes his or her intention to trust every time when encountering a specific situation, irrespective of the person of the trustee, because the benefits in these cases outweigh the costs. It may be clear that trust exists on many different levels [9].

The divergence across disciplines to capture the meaning of trust is hardly surprising. Aspects important to trust in one situation (e.g., parent-child relation, business relations) are irrelevant in others (physician-patient), and vice-versa. Yet, despite all variation in trust definitions, researchers throughout disciplines emphasize two characteristics that appear inherent to trust [9]. First, trust entails a willingness to be vulnerable upon someone or something else [10,11]. To trust is to voluntarily delegate power to someone or something else, creating vulnerability to the misuse of this power. Second, however, the trustor holds a confident expectation of the trustee, believing that the other party will use this power for the good of the trustor [12]. In addition to these two characteristics, conditions have been identified that are required for trust to arise. First, trust occurs only when the situation contains some extent of risk, i.e., there is the possibility that something is lost if the trustee does not act appropriately [9]. Second, there is interdependence, i.e., the trustor cannot reach certain goals without the help of the trustee [9].

Various other general characteristics of trust have been described, but inconsistently. Trust is thought to be often unconscious. People usually only become aware of it once trust is damaged or when in a particularly vulnerable situation [3]. It has been posited that trust is more likely to occur, and is strongest, in close relationships [13]. In more unfamiliar situations, some form of guarantee, e.g., a contract, hallmark or
diploma, is often required. When more such guarantees are needed, scholars have debated whether actual trust is still occurring: can we still speak of trust when both parties have signed a contract [14]?

To further understand what trust is, it is insightful to distinguish it from what it is not. Trust should not be confused with satisfaction, which is a retrospective evaluation, whereas trust is anticipation about future behavior [15]. In other words, to trust is, according to De Zulueta [16] to “venture into the unknown” (p. 2). Trust can also be distinguished from the related concept of confidence, which is both thought to be more rational, and to involve less of a risk than trust [17,18].

Taking together these characteristics of trust, is it possible to arrive at a satisfactory general definition of trust? We may conclude that, in any situation and on any level, trust can be defined as the optimistic acceptance of a vulnerable situation which is based on positive expectations of the intentions of another individual or institution [10,19,20].

**Trust in the medical setting**

**Distinctive features**

When people are confronted with illness, they have to rely on health care professionals. In this particular setting, trust takes on specific characteristics. People who are ill, instead of leaving something of theirs, need to leave themselves to another person’s care [21]. The alternatives to doing so are often particularly unattractive, and may entail more sickness or even death. Thus, to trust is often the most appropriate, or the only possible, response to illness [22]. Moreover, people who are ill frequently do not function as they normally would, because disease impairs them physically and/or mentally. Such impairments impact how they can and will interact with care providers. For example, someone’s usual autonomous behavior may be diminished by physical disability, fatigue, anxiety or depression. This may be especially restricting because the knowledge gap between physician and patient is so large. Ill people generally lack the knowledge and skill to treat their own sickness and have to refer to someone who can. Finally, whereas in most situations people can trust on their close ones for important matters, people who fall ill cannot. For most patients, medical experts are not among their close relatives or friends and they consequently need to trust a person unfamiliar to them. Patients therefore need to assume that an unfamiliar doctor acts in their best interest, as there is no official contract forcing the physician to do so. Only implicitly do physicians promise to practice for the good of their patients, in the many variants of the Hippocratic oath [23].
aforementioned characteristics may create a strong vulnerability in patients and a strong dependability upon doctors. This may induce a strong emotional component to a patient’s trust in a physician [10].

**What is trust in a physician?**

Consistent with broader trust definitions, patients’ trust in a physician is conceptualized as involving vulnerability and a positive expectation of the physician’s future behavior [10,24-26]. Hall et al. [10] have most elaborately defined trust as the optimistic acceptance of a vulnerable situation in which the patient believes the physician to care for his interests.

Several of the trust types distinguished by McKnight and Chervany [7] may be relevant when considering a patient’s trust in his or her physician. A patient’s interpersonal trust may vary across situations and physicians. It may be the product of someone’s trusting disposition, situational decision to trust or system trust. It may manifest itself in trusting behavior. Nonetheless, most researchers of physician-patient trust have addressed and assessed patients’ trusting beliefs, or the extent to which patients believe the physician to be trustworthy. A patient’s trust is thought to be composed of several trusting beliefs, or dimensions of trust. Patients may be trustful about some, yet simultaneously less trusting about other physician characteristics. The trusting beliefs that scholars distinguish vary, with sometimes more focus on physician acts or obligations, and other times more emphasis on physician personality or traits [10]. For example, McKnight and Chervany differentiate between beliefs about the physician’s benevolence, honesty, competence, and predictability [7], whereas Mayer et al. distinguish benevolence, integrity, and ability [11]. Hall et al., after an extensive review of the literature on trust conceptualizations, distinguish five dimensions of trust relevant for the medical situation [10]. First, Fidelity refers to the physician advocating the patients’ interests. Second, Competence concerns the physician’s medical and interpersonal skills. Third, Honesty entails telling the truth and avoiding intentional falsehoods. Fourth, Confidentiality is the physician’s adequate handling of sensitive information. Fifth, Hall et al. distinguish an overarching dimension, labeled Global trust. This dimension is presumed to capture a more holistic, unexplainable or irreducible component of trust. The five dimensions specified by Hall et al. were qualitatively validated [10]. Nonetheless, quantitatively, patients appeared to approach trust more holistically, barely distinguishing between its separate dimensions [17].
A possible erosion of trust

Traditionally, patients’ trust in physicians has been strong. In the last two decades, however, fear has grown that trust may be declining. As in other settings, patients’ interpersonal trust in their physician does not stand on its own. Patients’ trust on other levels, e.g., in physicians or health care in general, may influence patients’ interpersonal trust, and vice versa. A lack of trust in the healthcare system as a whole may hinder the development of patients’ trust in a physician. Reversely, when trust in a particular physician is damaged, this may affect a patient’s trust in health care overall.

Several developments have inspired the fear of an erosion of trust. First, many countries have seen a transition towards a more commercial organization of health care, often involving (financial) incentives for cutting down costs [14,27]. Along with this, health care has become more fragmented and interdisciplinary, which might come at the expense of continuity of medical relationships [28,29]. Second, the traditional paternalistic role of the physician has shifted, resulting in increased patient autonomy [30,31]. Concurrently, the rise of internet has provided patients with improved access to medical information, allowing more self-determinism in medical decision making [32]. These changes might cause patients to be more critical of their physician and, thus, diminish the self-evident nature of their trust.

Indeed, patients’ trust in health care seems to have decreased somewhat over the last few decades [14,27]. At the same time, however, patients’ trust in their treating physician appears invariably strong [27,33,34]. This may be a good thing, as interpersonal trust becomes even more important when public trust diminishes [13]. It moreover suggests patients’ trust in their physician is so fundamental that it is not directly influenced by changes in healthcare organization [10]. Nevertheless, societal changes may eventually exert their effects on interpersonal trust. O’Neill argues that society has seen an increased hankering for a world full of guarantees, void of uncertainties [35]. As we have posited before, trust is by definition a means to reduce risk and uncertainty; it is needed when and because there are no guarantees. Therefore, if society and its people become more intolerant towards uncertainty, trust may become increasingly formalized, leaving less room for voluntary trust.

Physician-communication and trust

Only recently, attempts have been made at systematically investigating physician-patient trust. Although trust is widely recognized as crucial to the physician-patient relation, and the concept has been extensively discussed in the academic literature and public debate [36-38], trust also appears difficult to investigate. Some have even argued that, because of
its abstract and ambiguous nature, it is not possible to fully empirically capture trust [6].
As a result, researchers have for a long time shied away from empirical trust research [10], and presently, it is still in its infancy; the concept of trust is often treated carelessly [13] and most studies rely on retrospective patient-reports [39].

Most research of physician-patient trust addresses how it is established, identifying correlates of patients' trust [39]. Patient characteristics, e.g., age [10,40,41], gender [42], education [43,44], race [44-47], and attachment style [48], have been linked to the strength of patients' trust. Physician characteristics, such as attire [49] and gender [50], have also been regarded. However, the relationship of many of these fixed attributes with trust has until now remained inconsistent. Elements of healthcare organization, e.g., continuity of care [51-53], visit duration [47], and the degree of choice in selecting a physician [52], have shown a somewhat stronger relation with patients’ trust. Most predictive of patients' trust, however, appear characteristics of physician communication. This is not surprising, as interaction is thought to form the basis of interpersonal relationships [54]. De Haes and Bensing [55], in a conceptual model of medical communication, identify ‘fostering the relationship’ as a first and necessary communication goal. They argue that without trust, none of the other goals of medical communication, e.g., gathering and providing information or decision making, can be pursued optimally. In this sense, trust may be comparable to the ‘therapeutic alliance’, i.e., the ‘collaborative and affective bond between therapist and patient’ [56-58]. Strong therapeutic alliance has consistently been found to predict therapeutic outcomes, even regardless of the psychological intervention [59]. Similarly, trust is not only a goal in itself, giving doctor-patient relationship meaning, but additionally has instrumental value, as it is essential to effective medical encounters [10]. If doctors can employ their communication to optimize trust, this may benefit the medical relation itself, all subsequent medical communication and, possibly, treatment outcomes. Which precise communication behaviors are most beneficial to trust, however, has until now remained unclear [6].

The oncology setting

Most existing research on physician-patient trust has been conducted in unspecific medical fields, such as the primary care setting, involving relatively healthy patients [10]. Although any medical situation entails a sense of uncertainty for patients, some conditions may provoke a stronger urgency to trust. In the oncology setting, trust in physicians is particularly important to patients [13]. When faced with a cancer diagnosis, patients will often experience extreme vulnerability and strong dependency on their healthcare professionals. Such feelings are instigated by the life-threatening nature, uncertain
prognosis, and impactful treatments associated with a cancer diagnosis [60]. Although these characteristics are not exclusive to oncology, they warrant specific research attention to trust in this particular setting.

**A research agenda for investigating cancer patients’ trust in their oncologist**

From the previous, it has become clear that little substantial empirical evidence about patients’ trust in their physician is available and that insight into patients’ trust might be particularly relevant in the oncology setting. Presently, several issues are unclear, warranting thorough investigation. First, although the importance of cancer patients’ trust in their oncologist is acknowledged, we lack insight in how patients’ describe and construct such trust. The five dimensions of trust specified by Hall et al. [10], which were founded within the less severe primary care setting, may not all be similarly relevant to oncology patients. Additionally, other issues could play a role in oncology that are of less importance in other medical fields. Second, unclear is whether existing trust questionnaires accurately capture cancer patients’ trust. Three scales have thus far been developed, all in the primary care setting, aimed at assessing patients’ interpersonal trust in their physician [17,61,62]. Of these, the *Physician Trust Scale* was most recently developed, and is currently used most to assess patients’ trust [6]. If, however, cancer patients have different constructions and explanations of trust than primary care patients, these scales may not be valid in the oncology population. Third, we know little about factors contributing to cancer patients’ trust. More specifically, how oncologists’ communication behaviors may promote interpersonal trust is still largely unclear. Little systematic research has convincingly identified specific communication behaviors predictive of cancer patients’ trust. Empirical evidence in this field is much needed, because, as argued by de Haes [55]: “Rather than convincing healthcare professionals of the relevance of communication skills on ideological grounds, the field will benefit in the long run from gaining precise evidence to substantiate its effectiveness” (p. 288). More insight into contributing factors to cancer patients’ trust could thus be used to improve oncologist awareness of the importance of good communication. Moreover, it could yield specific clues about how oncologists may contribute to trust through their communication behaviors, which may be employed to enhance their training. Increasing numbers of cancer patients may benefit from such improved training, as cancer is more and more turning into a chronic disease, resulting in more long-lasting relationships between patients and oncologists.

How can these lacunas in research of cancer patients’ trust in their oncologist best be approached? Goudge and Gilson [6] synthesized previous literature from different
settings to set an agenda for future research on trust. They suggest a stepwise approach for trust research in any particular setting. The meaning of trust should be investigated first, by means of qualitative research. Second, the assessment of trust should be enabled by developing a measurement tool. The quality and validity of this tool should be determined, and its sensitivity to predictors of trust should be established [7]. Finally, experimental studies can examine whether particular interventions influence the level of trust, allowing a distinction between cause and effect [63]. Until presently, experimental methods have rarely been used in trust research. They may appear suitable only for economically oriented trust research, which examines rational choice mechanisms. Such studies, assuming a task or game approach, may investigate under what conditions people decide to co-operate, or trust [64]. For physician-patient trust research, however, such a co-operation oriented approach is not suitable as it largely ignores the emotional component trust entails. Systematically manipulating physician communication in clinical practice may prove unfeasible as well as unethical, as it could expose patients to less than optimal communication. Such practical and ethical issues may be minimized when physician-patient trust is examined using a scripted video-vignettes design [65-67]. Scripted video vignettes have been introduced to allow systematic investigation of how specific elements of communication impact on trust. They have previously also been used in related fields such as educational and social research [68-71]. The video vignettes comprise short visual depictions of pre-written (hypothetical) events. In medical communication research, multiple variations of a scripted vignette are generally created, depicting a consultation between care provider(s) and patient(s). Except for varying particular elements of communication, all other content of the vignettes is kept constant. The role-played video vignettes are viewed by ‘analogue patients’ (APs), who may be either (former) patients or healthy people instructed to imagine themselves in the place of the patient observed in the video [72]. After viewing the video vignette(s), APs’ perceptions or evaluations of specific aspects of the videotaped consultation can be assessed, in this case trust in the observed physician.
AIMS AND OUTLINE OF THIS THESIS

Aims

Following the stepwise approach proposed by Goudge and Gilson [6], we sought to advance knowledge about cancer patients’ trust in their oncologist. We addressed the meaning, measurement, and predictors of cancer patients’ trust. The ultimate goal was to reach an understanding of how oncologist communication contributes to trust. Therefore, we originated from the following three research questions:

1) How do cancer patients construct and explain trust in their oncologist?
2) Can we reliably and validly measure cancer patients’ trust in their oncologist?
3) Is cancer patients’ trust influenced by how the oncologist communicates?

To address these questions, we aimed to

1) Qualitatively investigate the meaning and construction of cancer patients’ trust in their oncologist
2) Develop a measure to reliably and validly assess cancer patients’ trust in their oncologist
3) Experimentally assess whether and how oncologist communication impacts on cancer patients’ trust
Chapter 1

Outline

Part 1: How do cancer patients construct and explain trust in their oncologist?

To gain an overview of the empirical research on cancer patients’ trust thus far, we first performed a literature review. Chapter 2 displays this inventory of empirical research on the strength, predictors, and consequences of cancer patients’ trust in their oncologist. Next, we sought to gain more insight in cancer patients’ conceptions and explanations of their trust in their oncologists. To do justice to the richness and complexity of the phenomenon of trust, two in-depth qualitative studies were performed. First, in Chapter 3, we performed semi-structured in-depth interviews with a heterogeneous sample of 28 cancer patients. We asked them about the nature, the strength, the development, predictors, and consequences of their trust. Moreover, patients commented on dimensions of trust distinguished in previous research on patients’ trust in their physician. In Chapter 4, a separate smaller sample of 9 Turkish and Arabic immigrant cancer patients was interviewed about these same topics. These patients were interviewed in Dutch, Arabic, or Turkish with the help of an interpreter.

Part 2: Can we reliably and validly measure cancer patients’ trust in their oncologist?

Next, we developed a questionnaire to assess cancer patients’ trust in their oncologist. The questionnaire was adapted from the existing Physician Trust Scale, which was developed for primary care patients by Hall et al. [17]. Based on our qualitative results, we adapted the scale to the oncology setting. Next, we validated the newly developed Trust in Oncologist Scale in a sample of 423 patients with cancer. Cancer patients from four oncology departments of two hospitals were surveyed within one week after a consultation with their oncologist. Dimensionality, internal consistency, test-retest reliability, and construct validity of the scale were assessed. Chapter 5 describes the development and validation results of the Dutch Trust in Oncologist Scale. To allow cross-cultural use of the questionnaire, we translated it into English and validated it among a sample of 175 Australian cancer patients from three Sydney hospitals in Chapter 6.

Part 3: Is cancer patients’ trust influenced by oncologists’ communication?

We undertook an experimental investigation using scripted videotaped scenarios, ‘video vignettes’, to assess the impact of oncologists’ communication on patients’ trust. (Former) cancer patients viewed videos of an enacted medical consultation, in which aspects of how the oncologist communicates were systematically varied. After viewing, patients reported
their trust in the observed oncologist on the newly developed Trust in Oncologist scale. A total of 345 patients who presently or previously suffered from cancer were recruited through cancer patient organizations and hospital outpatient oncology clinics. Scripted video vignettes are a relatively new tool for research of medical communication research. Their development is not straightforward and comes with many methodological choices and dilemmas. Chapter 7 lists these methodological issues and their possible approaches encountered during video-vignettes development. Based on these issues and previous methodological literature, we provided a framework for developing and administering video vignettes in five phases. In Chapter 8, we tested how variations in the oncologist’s communication of competence, honesty, and caring impacted on cancer patients’ trust. Whereas chapter 8 tests these effects for all patients collectively, different patients may perceive and evaluate communication differently. Consequently, oncologist communication of competence, honesty, and caring may impact trust differently, depending on patients’ personality characteristics such as attachment style and health locus of control. Chapter 9 describes first, how patients’ attachment and health locus of control correlate with trust directly, and second, how they may moderate the effect of oncologist communication on trust. In Chapter 10, we investigated the impact of patient selection approaches on research results. Medical communication researchers frequently recruit patient participants for their studies through patient organizations. Unclear is how representative the experiences and opinions of these patients are for the whole patient population under study. We included both cancer patient organization members and hospital outpatient clinic patients into our study, allowing us to compare results between the two groups. We tested how the two groups differed with respect to socio-demographic characteristics, reported trust, and the impact of communication on trust. In the last chapter, Chapter 11, we synthesize our findings from the different studies, discussing them in the light of the broader empirical literature, determining their implications and providing perspectives for future research.