Cancer patients' trust in their oncologist

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Cancer patients’ trust in their oncologist

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Cancer patients’ trust in their oncologist

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Cancer patients’ trust in their oncologist

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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 Lobjoit [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 oriented. 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 endeavour [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
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.
PART I

How do cancer patients construct and explain trust in their oncologist?
Cancer patients’ trust in their physician—a review

ABSTRACT

Objective
Patient's trust in their physician is crucial for desirable treatment outcomes such as satisfaction and adherence. In oncology, trust is possibly even more essential, due to the life-threatening nature of cancer. A review was undertaken of the current knowledge of the conceptualization, assessment, correlates, and consequences of cancer patients' trust in their physician.

Methods
The empirical literature published in peer-reviewed journals between October 1988 and October 2008 was searched, employing all combinations and variations of the following keywords: trust, physician-patient relations, and cancer.

Results
The search identified 45 relevant papers, only 11 of which drew attention to the conceptualization of trust, and five of which focused on trust as the primary subject of interest. Trust in physicians was strong overall. Patient's trust appeared to be enhanced by the physician's perceived technical competence, honesty, and patient-centred behavior. A trusting relationship between patient and physician resulted in facilitated communication and medical decision making, a decrease of patient fear, and better treatment adherence.

Conclusions
A lack of focus on trust and the conceptualization thereof, strong methodological variations between studies and a possible publication bias lead us to conclude that cancer patients' trust in their physician deserves more systematic, theoretically based, research attention. Consequently, studies are needed aimed at gaining a thorough understanding of the nature and impact of cancer patients' trust in their physician and how the interaction between physician and patient may contribute to such trust.
INTRODUCTION

Trust in another person is essential for human coexistence. It is simply impossible to keep every important thing safe without sometimes leaving it to the care of others [3]. If so, we have to believe in the goodwill of these others and make ourselves vulnerable to the violation of our trust [10]. To trust someone, therefore, implies being vulnerable and dependent on others. We often expose ourselves to such a situation, either voluntarily or because we are forced to. Such interpersonal trust has been conceptualized in multiple ways within several disciplines. Generally, interpersonal trust has been found to be stronger than trust in public institutions, and more dependent on actual experiences and individual characteristics, instead of reflecting a person’s global attitudes, values and preferences [73,74]. Although opinions about what interpersonal trust does or does not entail vary, four characteristics recur in definitions of trust. First, trust between two people involves a prediction about the future behavior of the other [75]. Second, someone who trusts holds the positive expectation that the trustee will perform a valued behavior [11]. Third, to trust involves taking a risk, thus creating vulnerability to the actions of the trustee [11]. Finally, when the consequences of breaking trust are more far-reaching, trust is generally stronger. Therefore, trust is usually strongest in close relationships, such as between family members [13].

In the physician-patient relationship, patients have to trust a person with whom no close relationship exists, because of their inability to take care of their own health [13]. The relationship is characterized by a knowledge and power imbalance, whereby the patient often has no choice but to trust the physician. As such, patients’ trust could be considered ‘taken for granted’ or implicit, contrasting with explicit trust, which refers to a more deliberate choice to trust [76]. Patients’ trust in physicians has been defined both broadly as ‘the belief that a doctor is working in the patients’ best interests’ [77, p.2], and more specifically as the optimistic acceptance of a vulnerable situation in which the patient believes the physician to care for his or her interests [10]. The complexity and ambiguity of physician-patient trust complicates its definition. This has resulted in a wide variety of conceptualizations [6], only a few of which were backed up empirically [39]. Much of the literature consists of theoretical analyses aimed at clarifying the concept of physician-patient trust. Such analyses are useful for positioning it within the literature of communication in health care.

Trust can be viewed as indicating the depth of the physician-patient relation [78]. It is generally considered an important component of the therapeutic or working alliance [79,80]. Yet, it should not be considered equivalent because the latter concepts comprise,
in addition to trust, an element of mutual agreement about goals and tasks. Furthermore, trust has been distinguished from related concepts, such as satisfaction, confidence, and distrust. Trust is argued to refer to the patient’s future expectation about an ongoing relationship, whereas satisfaction is more backward looking [15,17]. Although trust is sometimes used interchangeably with confidence, some consider it to be more emotive, and less rational than the latter concept [17]. Others argue that the distinguishing feature is risk, which is associated with trust, but not with confidence [18]. In trust, the risk can either be taken or avoided, whereas confidence is the normal state of being and does not involve considering alternatives. In a situation of confidence, it is less likely that one will be disappointed than in a situation of trust. Finally, trust and distrust are often viewed as two ends of a continuum, whereas others contend that trust and distrust are separable, not opposites [8,81,82]. In this view, both trust and distrust involve expectations about another person’s behavior. Whereas in trust the expected behavior is beneficial, distrust entails the expectation of harmful behaviors. As such, high distrust is also distinguished from low trust, which is the absence of an expectation of beneficial behaviors. A patient may thus at the same time hold a certain amount of trust and a certain amount of distrust of a physician.

Empirical literature of physician-patient trust has been lagging behind theoretical discussion, consisting mostly of cross-sectional research that depends on patients’ self-reports, and rarely using objective measures of physician or patient behavior in relation to trust [83]. Correlates of patients’ trust have been identified mainly. Overall, patients seem to trust physicians with whom a continuous relationship exists [28,51,52], who take ample time in the consultation [47,83], who are informative [46,47,84] and who display caring behaviors, such as intent listening and expressing empathy [47,84,85]. Patient characteristics most consistently associated with trust are attachment style (securely attached patients are more trusting than patients with avoidant or anxious attachment styles) [48] and ethnicity (white patients report more trust than non-white patients) [46,47]. Trust in physicians has also been found to be associated with desirable treatment outcomes, such as more patient satisfaction [17,19], better treatment adherence [86,87], and more willingness to participate in clinical trials [88].

The relevance of trust is assumed to be even greater in oncology care. Cancer patients have to deal with complex medical information, make difficult medical decisions, and cope with uncertain prognosis and intense treatment, with sometimes limited guarantees for improvement [60]. Patients therefore find themselves in an extremely vulnerable situation. As described by Baier [3], they have to leave what they usually value most, i.e., their lives, to the care of their physician. It has been suggested that the life-
threatening nature of cancer and the severity of the treatment might force patients to trust almost unconditionally [13,89].

Although patients’ trust in their physician is generally reported to be strong [10], there is concern that this solid trust is eroding, due to changes in healthcare organization that might pave the way to less continuity of care and less personal attention for the patient [13,39,77]. Other developments, such as increased patient autonomy and improved access to (conflicting) medical information, e.g., from the internet, may also negatively affect the physician-patient relationship [90].

Trust has received considerable research attention in primary care. Research devoted to trust in the oncology setting specifically is scarcer, however. An appraisal of the research literature on cancer patients’ trust in their oncologist seems needed to establish what evidence is available to support claims about the importance of trust in oncology. This paper presents a review of the evidence-based literature on cancer patients’ trust in their oncologist. Characteristics of the studies derived from our search are described. Next, we examine what evidence research provides thus far with regard to 1) the strength, 2) correlates, and 3) consequences of cancer patients’ trust in their physician.

METHOD

We searched the databases PubMed, Embase, PsychInfo, Medline, and Cinahl, employing all combinations and variations of the following keywords: 1) trust, distrust, mistrust, confidence, faith; 2) doctor-patient relations, physician-patient relations, doctor-patient communication, physician-patient communication; and 3) cancer and oncology. The search was initiated in Pubmed and then adapted to the other databases. First, articles were selected if they contained an abstract and were published in English in the last 20 years. This search yielded a total of 262 non-duplicate references. Second, all titles and abstracts were screened by the first and last author independently. Differences were discussed until agreement was reached. For the review, we selected only original papers including an empirical assessment of trust in physicians in adult oncology patients or individuals at risk of developing cancer, leaving 55 papers after the second selection. Third, of papers that could not be selected based on title and abstract only, the full text was studied by both authors. Our final selection included 45 papers (see Figure 1).
RESULTS

Study characteristics

Study characteristics and results are summarized in Tables 1 and 2 for qualitative and quantitative studies, respectively. Thirty-three papers addressed cancer patients’ perspectives on trust in their physician, five of which additionally included their relatives, and six of which additionally included physicians. Four others included only physicians’ perspectives on cancer patients’ trust. Eight papers addressed non-patients’ risk of developing cancer. Over half of the selected papers (25 out of 45) used qualitative methods, mostly consisting of in-depth semi-structured face-to-face interviews. All studies were cross-sectional, except for one qualitative longitudinal study [91]. All quantitative studies were descriptive. In most qualitative studies, trust was not incorporated in the study design, but rather deduced post hoc from the data as moderating the oncologist-
patient relation. Only one study was specifically aimed at gaining a better understanding of cancer patients' trust [13]. Although in almost all quantitative studies trust was incorporated in the design as a separate parameter, it was a primary outcome in only five studies.

Methods to assess trust differed widely. A complete questionnaire or a subscale thereof was used in only six studies. Four of these made use of questionnaires developed in the primary care setting [42,92-94]. Two others used self-constructed questionnaires [89,95]. Other quantitative studies included only one, or a few, items, either adopted from one or several different trust scales, or developed on an ad hoc basis by the authors. Psychometric properties were rarely mentioned.

**Conceptualization of trust**

In 16 qualitative and 18 quantitative studies, the term ‘trust’ was used without any clarification: the investigators did not report what trust encompassed to them, nor to the participants. In the remaining 11 papers, trust was conceptualized in various ways. Kraetschmer et al. [42] mainly emphasized the complexity of the concept, highlighting both its ‘technical (expertise) and interpersonal (e.g., communication, respect) elements’ (p. 318). In several studies, both investigators [92,96,97] and patients [98,99] defined trust as the physician acting as an advocate of the patient’s interest. Elsewhere, patients mostly conceptualized trust as the physician’s genuine concern and ‘being treated like a person’ [100,101]. In Mechanic and Meyer [13], most common in patients’ accounts were the oncologist’s honesty, openness, responsiveness, having patients’ best interests at heart, and patients’ willingness to be vulnerable without fear of being harmed.

**Level of trust**

Eleven studies reported patients’ trust levels. In qualitative studies, patients reported high levels of trust in their oncologists [102] and surgeons [103], respectively. Results of quantitative studies likewise suggest high levels of trust [73,92,93,104]. Moderate-to-high trust scores were reported in two other studies [42,105]. In contrast, lower trust was reported in three studies including specific subsets of patients: patients who had made use of complementary medicine [106], women who underwent breast-conserving therapy [94], and patients in end-of-life care [107].
Chapter 2

Correlates of trust

Patient characteristics

Six studies were focused on cancer patient characteristics associated with trust in their physician. Non-significant results were reported in one of these. Women were found to have stronger trust than men [42]. Results also indicate that older patients are more trusting [42,73,108]. Education level was positively associated with trust [42,108], whereas it did not predict trust in another [73]. Patients of African American ethnicity were found to have less trust than Caucasians overall [93], while elsewhere this was the case only post-visit and not before [73]. Patients with a German nationality were more likely to trust than patients from other European countries [105]. Finally, despite worries that patients' increased access to health-related information, e.g., from the internet, might impact their trust in physicians [109], we did not encounter any study establishing such an association. Oncology professionals did not believe patients' access to online health-related information would harm their trust in their physician [110].

Characteristics of physician-patient interaction

An association between characteristics of the physician-patient interaction and trust was reported in 15 papers. Non-significant results were not encountered.

Physicians' perceived technical competence

A limited ability to assess the technical skills of the specialist might force patients to rely on characteristics that plausibly relate to competence, such as status, references and the outcomes of treatment [13]. Accordingly, having been referred several times to their attending specialist led to high expectations of competence, thus enhancing patients' trust [111]. Physicians' communication of expertise, e.g., displaying efficiency and technical skills or reputation, was associated with patients' trust [13,112-114]. Post-operative complications were strongly correlated with patients' distrust of surgeons [94]. Finally, physicians felt that in bad news conversations, their inability to keep their knowledge of new research up to date caused patients to consider them less trustworthy [115].

Physicians' perceived honesty

Breast cancer patients reported trusting honest physicians most [13,113] and suggested that physicians' honest and straightforward information provision promoted trust when presenting bad prognosis [116]. Finally, African American patients nominated physicians' truth telling as one of the most important aspects for building and maintaining trust [117].
Physicians’ patient-centered communication

Patients suggested that physician behaviors such as listening and caring, providing information and answering questions, which reveal ‘interpersonal competence’, enhanced trust [13]. Behaviors indicating genuine concern, such as intent listening, patience, and caring behavior, promoted trust among women with breast cancer [100,118] and older African American patients [117]. African American patients, who reported lower post-visit trust, perceived their physician’s communication as less patient-centred than Caucasian patients [73].

Organization in the clinical setting

Four studies underscore the importance of time and continuity of care for the establishment of trust. A long-term relation with their GP promoted cancer patients’ trust [96,119]. Having experienced frequent changes of physicians predicted African American patients’ distrust [117]. Finally, among a sample of the general population, visit continuity with a specific provider and longer duration relationships were both associated with higher levels of trust [108].

Consequences of trust

A total of 30 studies investigated possible implications of trust in the physician. None of these reported non-significant findings.

Interpersonal communication

Both breast cancer patients and health professionals emphasized the importance of a trusting relationship as a prerequisite for, and facilitator of, communicating prognosis [116]. Similarly, among older patients, those who described the relationship with their physician as trusting were more satisfied with their physician’s communication than those with a less trusting relation [120]. Patients’ trust in their oncologist enhanced the probability that they would discuss independent written prognostic information with him or her [98], while elsewhere the opposite was reported [130]. Patients’ companions who were more trusting asked the oncologist more questions in bad news interactions [129].
<table>
<thead>
<tr>
<th>First author, year, country</th>
<th>Aims of the study</th>
<th>Sample</th>
<th>Design and method</th>
<th>Role of trust</th>
<th>Findings regarding trust</th>
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<tbody>
<tr>
<td>1. Anvik, 2006, Norway [119]</td>
<td>To describe the role of the GP during initial follow-up of patients with recently treated cancer</td>
<td>23 GP’s, 91 cancer patients (heterogeneous) and their relatives</td>
<td>Cross-sectional; focus group, semi-structured face-to-face interviews and questionnaires</td>
<td>Deduced as outcome from data</td>
<td>Patients stated they trusted their GP’s ability to take good care of them</td>
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<tr>
<td>2. Bernstein, 2004, Canada [112]</td>
<td>To examine the perceptions and attitudes regarding medical error of patients undergoing neurosurgery</td>
<td>30 brain tumor patients within one week of undergoing a neurosurgical operation</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients spontaneously mentioned trust in their surgeon as the most important factor mitigating fears of medical error</td>
</tr>
<tr>
<td>3. Bulsara, 2005, Australia [96]</td>
<td>To investigate cancer patients’ perceptions of the role of the general practitioner, particularly outside of the hospital setting</td>
<td>13 hematological cancer patients</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients valued the long-term close relationship with their GP to promote trust</td>
</tr>
<tr>
<td>4. Butow, 2002, Australia [116]</td>
<td>To obtain patient and health professional views on optimal ways of presenting prognosis to patients with metastatic breast cancer</td>
<td>13 health professionals in breast cancer care (both medical and non-medical), 17 breast cancer patients</td>
<td>Cross-sectional; structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients and professionals mentioned that prognosis was best communicated within a trusting relationship</td>
</tr>
<tr>
<td>5. Coyne, 2004, USA [102]</td>
<td>To gain a better understanding of low-income, rural cancer patients’ attitudes, knowledge and beliefs regarding clinical trial participation</td>
<td>17 cancer patients (heterogeneous) living in a rural area</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients’ trust in their physician was generally high. Some patients relied solely on the oncologist’s recommendations concerning treatment decisions</td>
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<td>6. Davey, 2005, Australia [98]</td>
<td>To systematically compare cancer patients' views on prognostic information provided by their doctor and written prognostic information obtained from a major cancer organization</td>
<td>26 cancer patients (heterogeneous)</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>The amount of trust cancer patients had in their oncologist determined whether or not they would discuss independent information with him or her</td>
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<tr>
<td>7. Davey, 2006, Australia [118]</td>
<td>To investigate how women explore and use information in the context of having diagnostic tests to investigate a breast symptom</td>
<td>14 women who had had a current breast symptom</td>
<td>Cross-sectional; unstructured telephone interviews</td>
<td>Deduced as outcome from data</td>
<td>Women expressed greater trust and confidence in healthcare professionals who provided information and answered questions</td>
</tr>
<tr>
<td>8. Freedman, 2003, USA [121]</td>
<td>To investigate medical encounters between women and their oncologic physicians throughout the breast cancer diagnostic and treatment process</td>
<td>12 physicians in oncology care and 25 female breast cancer patients</td>
<td>Cross-sectional; observations and semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients who trusted their physician indicated to be more willing to adhere to and accept the physician's advice</td>
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<tr>
<td>9. Friedrichsen, 2006, Sweden [115]</td>
<td>To study and explore problems perceived by physicians when breaking bad news to advanced cancer patients about discontinuing or not offering treatment</td>
<td>30 physicians in oncology care</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Oncologists described that a lack of specific knowledge, e.g., of ongoing or published studies, resulted in being considered less trustworthy by patients</td>
</tr>
<tr>
<td>10. Geller, 1997, USA [97]</td>
<td>To learn what women would want to know, and how they would make a decision, if they were offered breast cancer susceptibility testing</td>
<td>80 females (random sample) from a range of ethnic and socio-economic backgrounds</td>
<td>Cross-sectional; focus groups</td>
<td>Deduced as outcome from data</td>
<td>Women indicated that a trusting relationship with a physician facilitated their decision making about cancer susceptibility testing</td>
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Table 1. Continued

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<thead>
<tr>
<th>First author, year, country</th>
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<tr>
<td>11. Goldman, 2004, USA [122]</td>
<td>To explore the perceptions around breast and cervical cancer risk and screening among Dominicans and Puerto Ricans living in Rhode Island</td>
<td>147 adults (74 Dominicans, 73 Puerto Ricans)</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>A lack of trust was often mentioned as a barrier to getting screened</td>
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<td>12. Henman, 2002, Australia [100]</td>
<td>To examine why women with cancer want information, and what they believe to be the important factors influencing their decision making</td>
<td>20 female breast cancer patients</td>
<td>Cross-sectional; semi-structured telephone interviews</td>
<td>Deduced as outcome from data</td>
<td>Physicians' genuine concern, good reputation, and providing patients with sufficient information contributed to solid trust. Trust facilitated decision making and encouraged patients to accept the physician's recommendations</td>
</tr>
<tr>
<td>13. Katapodi, 2005, USA [123]</td>
<td>To identify heuristics that influence perceived breast cancer risk</td>
<td>11 females who had had experiences with abnormal breast symptoms</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients who trusted their health providers had a more reasonable sense of personal control over the disease than distrusting patients. Trust also minimized perceived risk of breast cancer</td>
</tr>
<tr>
<td>14. Knifed, 2008, Canada [103]</td>
<td>To explore the level of knowledge and anxiety in patients regarding the involvement of residents in their surgery</td>
<td>30 neurosurgery patients, most of whom underwent craniotomy for tumor</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients reported high trust in their surgeon, which removed most worries and anxiety about the involvement of residents during surgery</td>
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<td>15. Lacey, 2002, USA [124]</td>
<td>To explore the lived experience of patients with breast cancer using decisional support aids during the prediagnosis, diagnosis, and treatment phases of their disease</td>
<td>12 female breast cancer patients</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients nominated their physician as an important decisional support throughout the treatment. Trusting their physician made seeking a second opinion unnecessary</td>
</tr>
<tr>
<td>16. Lasser, 2008, USA [99]</td>
<td>To describe barriers to and facilitators of colorectal cancer screening among diverse patients served by community health centers</td>
<td>10 primary care physicians, 23 patients eligible for colorectal cancer screening</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Unscreened patients mentioned lack of trust in doctors as a barrier to screening whereas few physicians identified this barrier</td>
</tr>
<tr>
<td>17. Madsen, 2007, Denmark [101]</td>
<td>To gain an understanding of the meanings assigned to patients’ lived experiences during their treatment courses within or outside a trial setting</td>
<td>14 breast cancer and advanced ovarian cancer patients who participated in a clinical trial involving chemotherapy, and 15 who declined</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients rated a trusting patient-physician relationship as very important for the decision to participate in a clinical trial. Trust decreased when women saw too many different physicians during the trials</td>
</tr>
<tr>
<td>18. McKneally, 2000, Canada [111]</td>
<td>To describe the process of decision making and consent to surgical treatment from the patient's perspective, in the context of life-threatening illness</td>
<td>36 esophageal patients, recovered from esophagectomy</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Repeated referral to their attending specialist would enhance patients’ trust</td>
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<td>19. Mechanic, 2000, USA [13]</td>
<td>To examine conceptions of trust among three groups of respondents diagnosed with either breast cancer, Lyme disease or mental illness</td>
<td>90 patients, of whom 30 with breast cancer, 30 with chronic Lyme disease, and 30 with mental illness</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Trust included in design as main parameter; 2 questions about trust: What does trust mean to you? and How do you decide that a person can be trusted?</td>
<td>Physicians’ interpersonal competence and honesty were identified as crucial aspects of trust by patients</td>
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<tr>
<td>20. Oliffe, 2007, Canada [114]</td>
<td>To investigate what might be considered prostate cancer communication competencies in the male patient-physician dyad</td>
<td>59 male prostate cancer patients</td>
<td>Cross-sectional; secondary analysis of semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Trust was built over time and led to feelings of mutual respect, which decreased feelings of awkwardness and vulnerability. Patients trusted their GPs to conduct all necessary examinations</td>
</tr>
<tr>
<td>21. Pollock, 2008, UK [91]</td>
<td>To investigate service users’ experiences of a patient information pathway after a diagnosis of cancer</td>
<td>27 cancer patients (15 lung cancer, 12 head and neck cancer) and 20 of their relatives</td>
<td>Longitudinal; semi-structured face-to-face interviews (one, two, or three interviews per patient)</td>
<td>Deduced as outcome from data</td>
<td>Patients trusted their physician’s professional expertise concerning treatment decisions. This trust allowed them to delegate responsibility for treatment and freed up time and energy</td>
</tr>
<tr>
<td>22. Reid, 2008, UK [125]</td>
<td>To explore the factors influencing the decision to accept or reject morphine when first offered to patients with cancer</td>
<td>18 cancer patients (heterogeneous)</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Trust was mentioned by patients as an important factor in their decision to accept opioids as medication for cancer pain</td>
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<tr>
<td>23. Sharf, 2005, USA [126]</td>
<td>To explore why patients refused recommendations for further diagnosis or treatment of lung cancer</td>
<td>Nine lung cancer patients with documented refusal of doctors' recommendations</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>In all interviews patients expressed distrust in medical authority, such as motives of doctors or health information provided by doctors, as explanations for refusal</td>
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<tr>
<td>24. Torke, 2004, USA [117]</td>
<td>To describe the perspectives of older African American patients in a primary care clinic as they consider a medical decision</td>
<td>25 African American patients &gt;50 years old, who had discussed flexible sigmoidoscopy with their primary care provider</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduces as outcome from data</td>
<td>Patients indicated that trust was built by a healthcare provider's honesty, patience, kindness, interest, and continuity of care</td>
</tr>
<tr>
<td>25. Wright, 2004, UK [113]</td>
<td>To determine how patients with breast cancer want their doctors to communicate with them</td>
<td>39 female breast cancer patients</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduces as outcome from data</td>
<td>Patients appreciated oncologists' display of efficiency, technical skills, reputation and honesty for building trust</td>
</tr>
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<tr>
<td>1. Charles, 2004, Canada [127]</td>
<td>To explore the extent to which breast cancer specialists report practicing shared decision making with their patients, their comfort level with this approach, and perceived barriers and facilitators to implementation</td>
<td>334 oncologists and surgeons in Ontario treating female early-stage breast cancer patients</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>1 four-point Likert question</td>
</tr>
<tr>
<td>2. Daugherty, 1995, USA [128]</td>
<td>To investigate the complex issues around participation in clinical trials, and patients’ perceptions toward these trials</td>
<td>27 cancer patients who had agreed to participate in a phase I clinical trial.</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>One item about motivators for participation in clinical trials, with nine nominal response options, two options of which regarded trust in the referring physician or research oncologist as a major motivating factor to participate</td>
</tr>
<tr>
<td>3. Eggly, 2006, USA [129]</td>
<td>To investigate questions asked by cancer patients and their companions during stressful encounters in the oncology setting in the USA</td>
<td>28 cancer patients (heterogeneous) and their companions</td>
<td>Descriptive; cross-sectional; coding of video-recordings of oncology consultations</td>
<td>Trust as secondary parameter</td>
<td>1 seven-point Likert question</td>
</tr>
<tr>
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<td>4. Gordon, 2006, USA [73]</td>
<td>To examine whether racial differences in patient trust are associated with physician-patient communication about lung cancer treatment</td>
<td>103 patients (22% black, 78% white) visiting thoracic or oncology clinics</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Pre- and post-visit trust as primary parameters</td>
<td>Pre-visit trust in physician was statistically similar in black and white patients (mean score, 8.2 vs. 8.3, resp.; $p = .80$), but black patients had lower post-visit trust in physician than white patients (8.0 vs. 9.3, resp.; $p = .02$)</td>
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<tr>
<td>5. Helmes, 2002, USA [95]</td>
<td>To investigate women’s preferred physician involvement in the decision to obtain genetic testing for breast cancer risk</td>
<td>340 women (population based sample), between 18-64 years old, not ill.</td>
<td>Descriptive; cross-sectional; survey; structured telephone survey and written baseline questionnaire</td>
<td>Trust towards/satisfaction with primary care provider as secondary parameter</td>
<td>Trust in physician together with the belief in powerful others correlated with the decision to leave medical decisions to the provider ($\beta = .318; p &lt; .001$)</td>
</tr>
<tr>
<td>6. Heyland, 2005, Canada [107]</td>
<td>To investigate satisfaction with, and key elements of quality of end-of-life care that are important to Canadian hospitalized patients with end-stage medical disease and their family members</td>
<td>440 patients with end-stage disease, 166 of which diagnosed with cancer and 160 of their family members</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>One of the aspects patients were least satisfied about was trust. The item about trust was one of the items rated most frequently by patients as extremely important and not completely satisfied</td>
</tr>
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<td>7. Jenkins, 2000, UK [104]</td>
<td>To examine reasons for patients to accept or decline participation in cancer clinical trials</td>
<td>204 cancer patients (heterogeneous)</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>One item: <em>I trusted the doctor treating me</em> (response options: yes and no)</td>
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<td>8. Kirschning, 2008, Germany [130]</td>
<td>To find out how far the traditional doctor-patient relationship is affected and changed by the internet-informed patient</td>
<td>536 cancer patients (370 women with breast cancer, 193 men with prostate cancer) and 133 of their relatives</td>
<td>Descriptive; cross-sectional; online survey; structured questionnaire</td>
<td>Trust deduced as outcome from the data</td>
<td>Trust not measured</td>
</tr>
<tr>
<td>9. Kraetschmer, 2004, Canada [42]</td>
<td>To better understand the relationship between people’s trust in their physician and their desire for a participative role in decisions about their medical treatment</td>
<td>606 breast cancer, prostate cancer and fracture patients</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as primary parameter</td>
<td>11 items on a five-point Likert scale, constituting the Trust in Physician Scale[62]</td>
</tr>
<tr>
<td>10. Lansdown, 2008, UK [105]</td>
<td>To examine, via an international survey, the impact of positive and negative interactions on the patient-physician relationship</td>
<td>462 breast cancer physicians, 600 female postmenopausal breast cancer patients</td>
<td>Observational; cross-sectional; online international survey</td>
<td>Trust as secondary parameter</td>
<td>1 five-point Likert question about trust for physicians, 3 five-point Likert questions about trust for patients</td>
</tr>
<tr>
<td>11. Liang, 2006, USA [120]</td>
<td>To explore the associations between physician communication styles and their older patients’ intentions years to get mammography and satisfaction with physician communication</td>
<td>Seven general internists and 56 of their patients &gt;65 years</td>
<td>Mixed methods; observational; qualitative analysis of audio-recorded conversations between patient and physician, quantitative analysis of survey</td>
<td>Trust as secondary parameter</td>
<td>One item: Did you consider the visit with their physician as trusting? (response options: yes and no)</td>
</tr>
<tr>
<td>First author, year, country</td>
<td>Aims of the study</td>
<td>Sample</td>
<td>Design and method</td>
<td>Role of trust</td>
<td>Measurement of trust</td>
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<tr>
<td>Ling, 2006, USA [131]</td>
<td>To assess the association between provider-patient interaction with colorectal cancer screening utilization</td>
<td>2570 randomly sampled respondents, &gt;50 years</td>
<td>Observational; cross-sectional; telephone survey</td>
<td>Trust as secondary parameter</td>
<td>One item: Do you trust cancer information from a doctor or other healthcare professional (response options: yes and no)</td>
</tr>
<tr>
<td>Mainous III, 2004, USA [92]</td>
<td>To examine the relationship between continuity of care and trust in one's physician with stage of cancer among newly diagnosed colorectal and breast cancer patients</td>
<td>119 cancer patients (97 breast cancer, 22 colorectal cancer)</td>
<td>Observational; cross-sectional; survey; structured face-to-face interviews</td>
<td>Trust as primary parameter</td>
<td>11 five-point Likert items, constituting the Trust in Physician Scale [62]</td>
</tr>
<tr>
<td>Newnham, 2005, Australia [110]</td>
<td>To investigate attitudes of Australian health professionals working in oncology to health-related information in the media and on the internet and to patients who search for this information</td>
<td>226 oncology health professionals (physicians, nurses and researchers)</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Perceived patient trust as secondary parameter</td>
<td>One item: Do information-seekers have greater or less trust in their doctors? (response options: greater trust, no difference and lesser trust)</td>
</tr>
<tr>
<td>O'Malley, 2004, USA [108]</td>
<td>To explore factors that predict higher trust in primary care providers, and examine the role of patient trust on the use of preventive services for low-income African-American women</td>
<td>961 African-American females, &gt;40 years</td>
<td>Observational; cross-sectional; telephone survey</td>
<td>Trust as primary parameter</td>
<td>1 five-point Likert question: My doctor cares more about holding down costs than about doing what is needed for my health, and 1 ten-point Likert question: All things considered, how much do you trust your doctor?</td>
</tr>
<tr>
<td>First author, year, country</td>
<td>Aims of the study</td>
<td>Sample</td>
<td>Design and method</td>
<td>Role of trust</td>
<td>Measurement of trust</td>
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</tr>
<tr>
<td>16. Paltiel, 2001, Israel [106]</td>
<td>To examine the use of complementary therapies (CT) by Israeli oncology patients and to compare socio-demographic, psychological, and medical characteristics, attitudes, and quality of life of users and nonusers of CT</td>
<td>1,027 cancer patients (heterogeneous)</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>One item: <em>I trust my doctor...</em> (response options: completely and incompletely)</td>
</tr>
<tr>
<td>17. Salkeld, 2004, Australia [89]</td>
<td>To determine which aspects of the treatment decision process, therapy and outcomes are most important to patients with colorectal cancer (CRC)</td>
<td>175 colorectal cancer patients (102 men, 73 women) who had completed primary treatment</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as one of primary parameters</td>
<td>6 four-point Likert questions about the importance of different aspects of trust in the surgeon when choosing treatment, constituting one factor (<em>Trust in surgeon</em>)</td>
</tr>
<tr>
<td>18. Shepherd, 2008, Australia [132]</td>
<td>To investigate barriers and facilitators for cancer physicians to reaching treatment decisions with their patients and their support of strategies to encourage patient involvement and reflection on treatment options</td>
<td>604 physicians in oncology care</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>1 four-point Likert question: <em>The patient trusts me</em> (response options: never, sometimes, often or always helpful to the treatment decision making process)</td>
</tr>
<tr>
<td>First author, year, country</td>
<td>Aims of the study</td>
<td>Sample</td>
<td>Design and method</td>
<td>Role of trust</td>
<td>Measurement of trust</td>
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<tr>
<td>19. Spain, 2008, USA [93]</td>
<td>To describe racial differences in perceived risk of prostate cancer and to examine whether 1) perceived high risk predicts greater personal responsibility for prostate care; and 2) greater personal responsibility for prostate care predicts earlier, presymptomatic diagnosis</td>
<td>555 newly diagnosed male prostate cancer patients, 348 Caucasian and 207 African American</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>8 five-point Likert items, adopted from the Primary Care Assessment Survey [86]</td>
</tr>
<tr>
<td>20. Waljee, 2008, USA [94]</td>
<td>To examine the effect of treatment-related factors on patient satisfaction with their healthcare experiences</td>
<td>714 breast-conserving therapy patients</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>11 five-point Likert items, constituting the Trust in Physicians Scale [17]</td>
</tr>
</tbody>
</table>
Decision making

Patients considered a trusting relationship with a physician facilitative for decision making about cancer screening [97]. Cancer patients indicated that trust in their physician encouraged them to accept the physician’s treatment decisions and recommendations [89,100]. Indeed, in an international survey, breast cancer patients trusted their physician in recommending the best available medical treatment [105]. Trusting patients seem to feel confident to delegate responsibility about medical decisions to their physician [91,95]. Rural low-income cancer patients with very strong trust in their physicians sometimes even indicated to fully rely on their doctor’s recommendations concerning treatment decisions [102]. Consistent with this trend of decreased patient involvement when trust is stronger, patients with extremely high trust, or ‘blind trust’, favored a more passive role in medical decision making than those with moderate or high trust [42]. Clinicians experienced trusting patients as very helpful to the treatment decision-making process [127,132]. However, whether trusting patients were considered helpful because they assumed a more active or a more passive role does not become clear, and might even vary across physicians.

Patients’ emotional distress

Patients facing brain tumor surgery emphasized the great importance of trust in their surgeon in reducing their fear of the occurrence of medical error [112]. Likewise, neurosurgery patients’ worries about the involvement of physicians in training (residents) in their care were greatly reduced by trust in their surgeon [103]. Patients’ trust in their healthcare providers was associated with a decrease of their perceived risk [123].

Adherence to medical advice

A sense of trust in the physician was related to patients’ willingness to accept, and adhere to, the physician’s advice throughout the diagnosis and treatment [121]. Elsewhere, trust in physicians was mentioned as an important factor in patients’ decision to accept opioids as medication for cancer pain [125]. Consistently, distrust of physicians’ motives and health information was an important consideration for lung cancer patients to refuse recommendations for further diagnosis or treatment. [126]

Patients with high levels of trust in their physician made more use of cancer screening [93,99,108,122,131]. Consistently, the greater colorectal and breast cancer patients’ trust was, the earlier the cancer stage at diagnosis [92].
The willingness to participate in a clinical trial, not seeking a second opinion and not using complementary medicine also express the intention to act on the physician’s advice. Indeed, trust was found to reduce the inclination to seek a second opinion [124] and promote the acceptance of the physician’s advice to participate in a clinical trial [101,104,128], while distrust increased the likelihood of complementary therapy usage [106].

**DISCUSSION**

**Main findings**

This review identified 45 studies that empirically investigated cancer patients’ trust in their physician. Still, a lack of focus on trust, little conceptual clarity, and strong methodological variations between studies lead us to conclude that cancer patients’ trust in their physician is a topic that requires more systematic and theoretically based research attention. Trust was the primary outcome in only five studies, and although nearly all quantitative studies included some trust measure, only six of these employed a full trust scale of which psychometric properties were reported. Research suggests strong overall trust in physicians, although three studies reported lower trust. Patients trust physicians who they perceive as technically competent and honest, who display facilitative behaviors and with whom a continuous relationship exists. Such trust is associated with a facilitation of the communication and medical decision-making process. Moreover, trusting cancer patients worry less about treatment and are more likely to adhere to medical treatment and advice.

**Relation to findings in other medical fields**

The main themes emerging from this review resemble findings of patients’ trust in physicians in other patient populations. Like cancer patients, other patients trust physicians who display facilitative behaviors and who are perceived as competent [46,47,133]. Such medical skills cannot always be accurately assessed by patients. Their judgment will therefore be strongly influenced by the physician’s reputation, status, and interpersonal communication, such as explanation skills [10,112]. Subtle differences between patient groups also emerge. This review found an emphasis on physicians’ perceived honesty as a correlate of trust, while literature of other patient groups
Chapter 2

emphasizes physicians’ informativeness \[46,47,133\]. Honesty appears to extend beyond mere information giving. It involves a more profound, general attribute of the physician’s character, perhaps even referring to the physician’s integrity \[134\]. Such a need for honesty about crucial health prospects and developments might arise from the life-threatening nature of cancer. The correlates of trust identified in this review largely overlap with the aspects of trust that have been frequently described in the non-oncology literature, i.e., 1) fidelity, which is pursuing the patient’s best interests, 2) competence, referring to the physician’s presumed medical and interpersonal skills, 3) honesty, which is telling the truth and avoiding intentional falsehoods, and 4) confidentiality, which entails the adequate use of privacy-sensitive information \[10\].

Consequences of trust in physicians in cancer care also largely resemble those identified in other medical fields: among other patient groups trust appeared to facilitate communication \[61\], improve treatment adherence \[87,135\] and reduce the inclination to seek a second opinion \[15,17\]. Affective correlates of trust, however, might slightly differ between patient groups. Cancer patients attached much importance to the effect of trust on (a reduction of) fear, worries, and perceived risk, while in studies in other medical fields, patients’ satisfaction with care was mainly emphasized \[24\]. The severe treatment associated with cancer care might cause fear about what could go wrong, leaving less room for considerations regarding satisfaction. However, whether observed differences between cancer patients and other patient groups are a reflection of differences in research focus, rather than in the experience of trust, cannot be concluded at present.

Limitations of the studies reviewed

Our findings may suggest substantial knowledge of cancer patients’ trust in their physician. However, several shortcomings of the studies reviewed here hamper such a conclusion. First, few researchers addressed cancer patients’ trust systematically. In almost all qualitative studies, trust was not the initial subject of interest, but an outcome deduced from the data. In quantitative studies, trust was often incorporated in the design as one of many variables. As a result, little attention was paid to the conceptualization of trust. Even if discussed, definitions vary between studies \[10\]. Consequently, different researchers, and even different participants within studies, might be referring to dissimilar matters. Authors might have paid little attention to a definition of the concept because trust was an accidental outcome and not their main or initial research interest. Often they appear to assume that a ubiquitous concept like trust does not require additional clarification: patients will automatically understand what it means. Alternatively, they may not want to venture upon the definition of such an ambiguous concept.
The second, related, limitation is that measures of trust varied between quantitative studies. Most studies employed subscales or even single items for which validation commonly lacked. A few studies used validated scales developed in the primary care context mainly. The use of pre-existing questionnaires in a new setting without assessing their reliability and validity has been shown to be problematic [6]. Therefore, it is unclear whether these scales can be employed to validly capture cancer patients’ trust. Moreover, these questionnaires have been developed assuming a multidimensional view of trust, consistent with theoretical and qualitative literature, which both suggest that patients’ trust has various dimensions [39]. However, in practice, these scales have consistently behaved one-dimensional, suggesting that patients have a holistic view of trust in their physician [17,52]. This discrepancy between quantitative and qualitative findings could suggest that, although several dimensions do exist and do influence trust, patients do not distinguish among them [10]. As yet, we cannot determine whether cancer patients view trust similarly one-dimensional, or whether they distinguish separate dimensions.

Third, since the design of none of the studies was experimental, and only one was longitudinal, no inferences can be drawn about the directions of effects. Although we classified the results as ‘correlates’ and ‘consequences’ of trust, presently it cannot be established whether a presumed consequence of trust does not actually, or additionally, predict trust, and vice versa.

Finally, it is striking that non-significant findings were rarely encountered in this review. We consider it very unlikely that these have never occurred, as illustrated by the fact that in a recent study we found no significant effect of trust on cancer patients’ prognostic information preferences [136]. The lack of non-significant findings may result from a publication bias, possibly enhanced by the fact that trust was often a side issue, since secondary variables might more likely be left unreported than are primary variables.

**Future directions**

The fact that in qualitative studies trust was often spontaneously put forward by patients supports our idea that trust is a key phenomenon in cancer care. For the present, however, a thorough comprehension of cancer patients’ trust in their physician is lacking, because of the scarcity of high quality studies specifically aimed at trust. Our knowledge of trust in this population could benefit from evidence from the broader literature of physician-patient trust. However, both the specific oncologic population and the particular process of trust might be distinct from other patient populations and related concepts, and therefore deserve separate research attention. We suggest that future research should first of all explore some conceptual issues of trust in cancer care, building on
existent knowledge of trust among other patient populations and interpersonal trust in non-medical settings. Specific attention should be directed to the identification of properties and processes of trust specific for this population: what is cancer patients’ understanding of trust, and how do they construct it? Second, more attention should be devoted to excess, or ‘blind’, trust. Especially in the oncology population, very strong trust might be frequent, resulting from the severity of the disease and patients’ associated dependence [13]. While in much of the literature, the premise appears to be that the more trust, the better, a surplus of trust could prove to have negative effects, such as physicians shirking their responsibility, or patient passivity. In this review, results with regard to decision making indeed suggest diminished patient involvement associated with high trust, which may not necessarily be beneficial. Although some authors acknowledge the possible drawbacks of excess trust [42,97,112], we believe that the possible hazards of blind trust need more empirical investigation. Third, although trust seems strong overall, more substantial research could establish whether trust among cancer patients is eroding, as feared, and whether specific groups are more vulnerable to lose trust. Fourth, we encountered two lacunas in current knowledge, i.e., the effect of increased access to online information on trust, and physician characteristics associated with trust. Finally, we focused our search on cancer patients’ interpersonal trust, thus excluding the broader literature on trust in the healthcare system. Although a spillover effect of public (mis)trust on interpersonal trust is possible [13,137], interpersonal trust has been proven to be distinct from public trust. The relation between interpersonal and public trust among cancer patients deserves future research attention.

The results of this review highlight that cancer patients’ trust in physicians requires further conceptualization. The scarcity of systematic empirical research results in a lack of knowledge about characteristics and processes of trust among cancer patients, despite the relevance of such trust for these patients. More elaborate research will increase our understanding of what trust in physicians encompasses to cancer patients, and how physicians can contribute to such trust. This is important because a more trusting relation between cancer patient and physician may ultimately improve the quality of care, as well as treatment outcomes.
Disentangling cancer patients’ trust in their oncologist: a qualitative study

Marij Hillen, Astrid Onderwater, Myra van Zwieten, Hanneke de Haes, and Ellen Smets

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ABSTRACT

Objective
Patients' trust in their physician is crucial for optimal treatment. Yet, among oncology patients, for whom trust might be especially important, research into trust is limited. A qualitative interview study was carried out to investigate 1) to what extent aspects of trust important to cancer patients reflect the aspects described in other patient populations, and 2) which additional themes emerge.

Methods
In-depth, semi-structured interviews were performed with a purposefully selected heterogeneous sample of 29 cancer patients. Transcribed interviews were analyzed using MAXqda. Data were clustered across interviews to derive common themes related to trust.

Results
Three commonly described aspects, i.e., Fidelity, Competence, and Honesty, were strongly reflected in patients' accounts of trust in their oncologist. Confidentiality was irrelevant to many. An additional aspect, labeled Caring, was distinguished. Central to the accounts of these patients was their need to trust the oncologist, arising from the severe and life-threatening nature of their disease. This necessity to trust led to the quick establishment of a competence-based trust alliance. A deeper, more emotional sense of trust was developed only after repeated interaction, and seemed primarily based on the oncologist's interpersonal skills.

Conclusions
The need for trust encountered in this study underscores the power imbalance between cancer patients and their oncologist. Additionally, these results imply that, when aiming to measure cancer patients' trust, what we might actually be assessing is patients' intention and determination to trust their oncologist.
INTRODUCTION

There is general consensus about the relevance of patients’ trust in their physician for establishing a strong and well-functioning medical relationship. The concept of physician-patient trust, however, remains difficult to grasp. Several attempts have been made to comprehensively conceptualize patients’ trust in their physician. A recurring element in the resulting definitions is patients’ confidence that the physician acts in their best interest [e.g.,14,25,77]. Other elements, less consistently included in these definitions, are patients’ beliefs about their physician’s honesty, medical competence, caring, and respect. Some state more generally that to trust is to optimistically accept one’s vulnerable situation [10]. Trust is considered forward-looking, and can as such be distinguished from satisfaction with the physician, which is more evaluative [10].

Empirical research lagged behind theory of patients’ trust for a long time [39], but has recently received more attention. Three questionnaires have been developed, aiming to capture patients’ trust in their physician [17,61,62]. The Physician Trust Scale, by Hall et al. [17], is the most widely used and well developed instrument. Hall et al. distinguish four specific dimensions of trust: 1) Fidelity, which refers to patients’ belief that the physician acts in their best interest, 2) Competence, referring to the physician’s perceived medical and interpersonal skills, 3) Honesty, which is patients’ conviction that the physician tells the truth and avoids intentional falsehoods, and 4) Confidentiality, which is the adequate use of privacy-sensitive information [6]. A fifth dimension, labeled Global trust, should capture all ‘holistic’ aspects of trust, which go beyond the separate dimensions. The Physician Trust Scale and other existing trust scales were developed in primary care or general internal medicine mainly.

Unknown is whether these same aspects of trust are relevant to cancer patients. The specific nature of oncology care might set cancer patients’ trust in physicians apart from interpersonal trust in other medical settings. The diagnosis of cancer is generally perceived as life-threatening, often involving intense treatment with uncertain outcomes. Patients have to make drastic medical decisions together with an oncologist, with whom no previous therapeutic relationship exists. The oncology setting is therefore characterized by a strong vulnerability of the patient.

Despite the obvious importance of trust to cancer patients, a recent review revealed that surprisingly little is known about the nature, predictors, and consequences of cancer patients’ trust in their physician [138]. Not one study exclusively addressed cancer patients’ understanding or explanation of trust. Insight into cancer patients’ trust
would be valuable, as it could provide indications to oncologists about how trust could be improved or lost. As such, it could be used to improve physician education and training.

Therefore, in the present study we aim to elucidate cancer patients’ trust in their oncologist, originating from the following research questions: 1) To what extent are the four aspects of trust as discerned by Hall et al. [17], i.e., Fidelity, Competence, Honesty, and Confidentiality, reflected in cancer patients’ constructions and explanations of trust? and 2) Which additional themes emerge?

**METHODS**

**Participants**

A heterogeneous sample of cancer patients was assembled, in order to capture the most relevant variation in the population. Inclusion criteria were 1) age >18 years, 2) fluent command of Dutch and 3) no serious mental disorder. Diversity of the sample was ensured by purposeful selection based on patient characteristics assumed to relate to trust levels and experiences. Information on these socio-demographic (i.e., age, gender, educational background, cultural background), and medical (i.e., curative or palliative aim of treatment, phase of treatment) characteristics were provided by patients’ oncologist or nurse. Additionally, oncologists specifically identified patients dissatisfied with health care. Patients were selected from the departments of Internal Medicine and Gynaecology of the Academic Medical Centre (AMC). An information letter was provided to selected patients by their oncologist or nurse. Patients agreeing were telephoned by the researchers one week later for an appointment. Oncologists and nurses reported patients’ reason for declining to the researchers. Sample size was based on data saturation: data acquisition stopped when three consecutive interviews did not provide any relevant new information.

**Data collection**

In-depth, semi-structured interviews were conducted at patients’ home or in the hospital, depending on patients’ preference. The interview protocol is displayed in Box 1. The first part of the interview was relatively open-ended, exploring patients’ own ideas about, and experiences with trust in the different oncology specialists presently and previously involved in their care. In the subsequent, more structured, part of the interview participants were asked to rank the separate aspects of trust according to perceived
personal relevance. Interviews took approximately one hour. Interviews were conducted between February and September 2009 by two of the authors (M.H. and A.O.), both with a background in psychology and trained in qualitative interviewing. The hospital’s Medical Ethics Committee provided an exemption for the study to seek formal approval.

**Box 1. Topic list for the in-depth interviews**

<table>
<thead>
<tr>
<th>A Introduction by researcher</th>
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</thead>
<tbody>
<tr>
<td>◦ Emphasis on voluntary participation</td>
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<tr>
<td>◦ Explanation of confidentiality and anonymity</td>
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<tr>
<td>◦ Short explanation of the goal of the interview</td>
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<tr>
<th>B Open-ended part</th>
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<tbody>
<tr>
<td>1. Patient’s course of disease</td>
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<tr>
<td>◦ Disease history</td>
</tr>
<tr>
<td>◦ Present state and prognosis</td>
</tr>
<tr>
<td>◦ Experience of care in general until now</td>
</tr>
<tr>
<td>2. Patient’s interpersonal trust in oncologist</td>
</tr>
<tr>
<td>◦ Role of different oncologists in care</td>
</tr>
<tr>
<td>◦ Amount of trust in oncologists</td>
</tr>
<tr>
<td>◦ Aspects facilitating and inhibiting trust in oncologist</td>
</tr>
<tr>
<td>◦ Importance and consequences of trust in oncologist</td>
</tr>
</tbody>
</table>

| 3. Possible consequences of trust |
| ◦ Information preferences |
| ◦ Medical decision-making preferences |
| ◦ Disclosure of personal information |
| ◦ Use of, and disclosure of, complementary and/or alternative medication |
| ◦ Treatment adherence |
| ◦ Requesting a second opinion/filing a complaint |

<table>
<thead>
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<th>C Structured part</th>
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<tbody>
<tr>
<td>Ordering of different aspects of trust (as proposed by Hall et al. [17])</td>
</tr>
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</table>

<table>
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<tr>
<th>D Conclusion of the interview</th>
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</thead>
<tbody>
<tr>
<td>◦ Explanation of further procedure</td>
</tr>
<tr>
<td>◦ Patient’s general impression of the interview</td>
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</tbody>
</table>

**Analysis**

Interviews were transcribed verbatim. Analysis was performed in parallel with the interviewing, following guidelines for qualitative research [139] and using MAXQDA2 software [140]. First, two authors (M.H. and A.O.) familiarized themselves with the material. Subsequently, the same authors coded the interviews independently. After each interview, they compared and discussed codes until consensus was reached. Analysis for
the first, unstructured, part of the interview was inductive, aimed at identifying the most relevant themes. For the second, structured part of the interview we used a more deductive approach, based on the aspects of trust described by Hall et al. [17]. Initial codes were grouped thematically and then arranged hierarchically. The coding scheme was continuously revised based on the analysis outcomes. Gradually, open coding (summarizing and categorizing the data) was replaced with axial coding (confirmation of codes and the identification of broader relationships) [141]. Eventually, data were clustered across interviews to derive common themes related to trust, which were compared to aspects of trust as identified in the literature. Deviant case analysis was performed to reduce bias from preconceived ideas. At two different times, two senior researchers (E.S. and M.v.Z.) with a background in medical psychology and medical ethics, respectively, critically reviewed primary documents, coding schemes, and interpretations, as a quality check on the data.

RESULTS

Of all 45 patients who were asked to participate, 29 (64%) consented. Reasons for patients to decline participation were: insufficient health ($n = 8$), no time or willingness to participate in research ($n = 3$), having little to say except that trust was strong ($n = 3$), or not further specified ($n = 2$). The sample included patients of varying age, gender, educational background, country of origin, cancer site, time since diagnosis, and treatment aim (see Table I).

Reflection of the four specific aspects of trust in cancer patients’ accounts

Fidelity

Most oncologist attributes and behaviors that patients related to interpersonal trust concerned fidelity. The belief that the oncologist acts in their best interests was deduced from his or her behavior, such as making an effort and being reliable. A lack of such behaviors would reduce trust:

I felt like they were only thinking about themselves. Not providing an explanation to the patient as to why. (...) I felt like it was his scoreboard and not my scoreboard. And it should be about my scoreboard, not his. (44-year-old woman)
### Table 1. Demographic and medical characteristics of patients

<table>
<thead>
<tr>
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<th>Number of patients (N = 29)</th>
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<tbody>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
</tr>
<tr>
<td>18–40</td>
<td>5</td>
</tr>
<tr>
<td>41–65</td>
<td>15</td>
</tr>
<tr>
<td>&gt;65</td>
<td>9</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
</tr>
<tr>
<td>Low (secondary school or lower)</td>
<td>18</td>
</tr>
<tr>
<td>High (college or university)</td>
<td>11</td>
</tr>
<tr>
<td><strong>Country of origin</strong></td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>20</td>
</tr>
<tr>
<td>Other Western country</td>
<td>2</td>
</tr>
<tr>
<td>Surinam</td>
<td>2</td>
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<tr>
<td>Morocco</td>
<td>2</td>
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<tr>
<td>The Netherlands Antilles</td>
<td>1</td>
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<tr>
<td>Ukraine</td>
<td>1</td>
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<tr>
<td>Egypt</td>
<td>1</td>
</tr>
<tr>
<td><strong>Cancer site</strong></td>
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</tr>
<tr>
<td>Bone</td>
<td>1</td>
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<tr>
<td>Brain</td>
<td>1</td>
</tr>
<tr>
<td>Breast</td>
<td>6</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>12</td>
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<tr>
<td>Genitourinary</td>
<td>4</td>
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<tr>
<td>Gynecologic</td>
<td>4</td>
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<tr>
<td>Muscle</td>
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<td><strong>Time since diagnosis in years</strong></td>
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<td>&lt;1</td>
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<td><strong>Aim of treatment</strong></td>
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<td>Curative</td>
<td>11</td>
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<td>Palliative</td>
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Chapter 3

Competence

Patients rarely spontaneously mentioned medical skills as an important attribute of trust. In contrast, when they were asked to rank specific aspects of trust in order of priority, Competence was frequently ranked the most important.

But I think that eventually it... this is the most important [aspect of trust]... that is what it’s all about, whether a physician can help you or not... whether she is expertly. If she were not an expert, she would never be able to help you. She can be very loyal and put your interest first, and be honest, but if she is not expertly then it all stops. (39-year-old man)

Honesty

Many patients considered honesty crucial for, and sometimes even the most important aspect of trust. Some patients referred to honesty as telling the truth about the disease and prognosis.

Well, I think, for me honesty is by far the most important for trust. And that they honestly tell me what is the matter with me and... Because obviously it is no use for me if they paint me a prettier picture than the reality. (39-year-old man)

Other patients interpreted honesty as whether oncologists admitted their misjudgments.

And it is also true that when a physician... we are all human, physicians too. If he has misjudged a situation, and later returns to the topic, that also creates some trust. (57-year-old woman)

Confidentiality

To most patients, confidentiality was not an important consideration or determinant of trust.

Well, I think that the privacy, it is unpleasant when something happens with that, that can be very unpleasant, but it's not that terribly bad for my trust. (39-year-old man)
**Themes specific to cancer patients**

*Caring*

Many of patients’ explanations of trust in their oncologist were not captured by the foregoing aspects. Such explanations related to patients’ perceptions of the oncologist’s involvement in their personal well-being, derived from caring behaviors, such as showing sympathy.

Interviewer: And what else could a physician do to damage trust?
Patient: Well, not showing any interest, I guess. I think that is the most important. That the physician shows at least a bit of interest in the patient, and not only in the disease, if you know what I mean. (46-year-old woman)

For me… um… let me think… for trust it is important that the doctor has to be close for such severely ill patients, for those people. That is important… that doesn’t concern career, but the physician. Well, for other diseases it may be enough. But for such a disease the physicians have to give a little extra. (46-year-old-woman)

Other oncologist behaviors adding to patients’ trust, indicating genuine sympathy, were the devotion of time and individual attention to patients.

It does matter for trust that the oncologist has time and attention for us. If you have the feeling that people are very hasty or don’t take the time for you, then that makes you insecure. Then perhaps you’re afraid to ask questions, then you will think: never mind. Yes, that is part of it. (35-year-old woman)

Patients indicated that the perceived involvement of the oncologist created a feeling of ‘not being treated as merely a number’.

Well, the involvement mostly, and the humanity, which creates the feeling that you are a human being and not a number, a patient number. Yes, to me that makes a vast difference. (57-year-old woman)
Chapter 3

The need to trust

A phenomenon central to patients’ accounts was their need to trust their oncologist. In their narratives, almost without exception, these cancer patients referred to this necessity, expressing the need to ‘surrender’ and ‘leave their lives in the hands of their oncologist’.

To what extent do I trust my oncologists... Well, my life is in their hands, of course. So yeah, you need to have that much trust at a certain moment. It is like: I surrender to this. What they do must be right. (46-year-old woman)

Yes, you have to trust. You have to, because you are entirely at their mercy. (60-year-old woman)

Patients indicated that this necessity to trust sets trust in their oncology specialist apart from trust in other people.

Well, it is very strange, an oncologist... Well, when you have known him for maybe one or two minutes you already start to trust him. I have to trust him. Because, after all, you place your life in his hands. And I have to trust him more than, for example, that lady at the corner of the street. I would trust her too, but not with my life, let me put it that way. But I just need to trust him, because I need him. (44-year-old woman)

So yeah, I think the process is not that much different, except that trust in a friend is voluntary, and you can break it up whenever you want. And trust in the oncologist is a must, you don’t have a choice. (59-year-old man)

Patients’ need to trust seems to emerge from the severe, sometimes life-threatening, nature of cancer.

And what’s more, because it is life-threatening you need even more trust than with other diseases. With other diseases, if something goes wrong, well: bad luck! But if you have bad luck with this disease, you will die... (71-year-old man)

Especially during the acute phase shortly after diagnosis, when time matters, patients indicated they needed to trust their oncologist almost unlimitedly.
It all went so fast. You were suddenly at their mercy, you suddenly had cancer and the tumor needed to be removed. So yeah, you barely had time to think. And it has never occurred to me to go to another hospital first, no. (46-year-old woman)

Well, in the beginning you blindly trust the oncologist, you have to. Because time is running out, you cannot just say: let's first wait and get to know him. (44-year-old man)

**Trust on the short versus long term**

Patients report that their need to trust forces them to determine as soon as possible whether they can trust their oncologist, arguing that without a substantial amount of trust they could not be involved in a treatment relation with their oncologist.

If trust is not there after a first consultation, then I think you should discuss right at the end of the conversation whether that trust will develop at all. If not, you have to find another oncologist right away, I think. (39-year-old man)

That is very important, a first impression is very important. Yes, if you get a negative impression from the first meeting it can… it can still eventually turn into a positive relation, but then you have to fight… then you have to somewhat put yourself aside and think: what happens here is good for me, and then perhaps you’ll think differently. But to me personally, during a first meeting it is very important to make contact. (81-year-old man)

You'll figure out soon enough whether you can trust someone or not. (43-year-old man)

This 'immediate' trust is quickly established and strong. Patients report to base it mainly on characteristics related to perceived medical competence, such as the oncologist’s reputation and experience. In addition to this ‘short track’, a slower process seems to take place alongside, which is less enforced upon patients. Many patients indicate that to build a deeper, trusting, relationship with the oncologist takes time and repeated interaction. Whether such a profound and slowly evolving bond of trust is stronger
compared with immediate trust is difficult to determine. However, factors mentioned by patients as important to such ‘long-term trust’ seem to relate more to interpersonal skills of the oncologist. Examples of such skills are caring behaviors and showing interest in the patient.

But what I mean, of course, is that at a certain moment, when the right doctor is there… then your trust increases. And why is that? He gets to know you better. Then, like I said, that knowledge becomes clearer. This doctor sees me more often and knows me well. Well, then he knows immediately what I say and what I mean, and trust naturally increases. Because if someone has seen you once or twice, that is different from someone who has seen you ten times. (64-year-old man)

The contrast between such immediate trust based on medical competence, and more voluntary, slowly evolving, trust is illustrated by a patient who seems determined to trust the oncologist he recently started visiting:

Yeah, actually I am sure that I trust him. (…) Well, of course, I think that when you have a medical result… last time the tumor had increased, but well, then he says that it’s a matter of millimetres, and that it has happened more often. And at that moment, then you will need to trust him, and I do. I do not have any reason to think that he is wrong. No… (58-year-old man)

However, the same patient’s trust in the oncologist he has been seeing since four years seems more fundamental, and rather based on interpersonal factors.

Because I am also being treated by doctor C (…) for my intestine, and I really trust her completely. I think it’s great what she does. (…) Well, it’s also trust, that she gives you, and putting you at ease, and also… I only see her once a year (…). She says: I want to keep in touch with you. So call me whenever something’s up, I can always call her, and she always properly returns my call. And I’m always attended by her. For me that creates a lot of trust. (58-year-old man)
Determination to trust

Patients’ need to trust their oncologist seems to result in a determination, either conscious or unconscious, to preserve this trust. Trust appears not easily affected by oncologists’ medical shortcomings such as overlooking symptoms or unsatisfactory surgery results, or communication failure such as conveying diagnosis in a public place or not displaying empathy. Some patients even defended their oncologist’s inadequacy, such as the failure to react to symptoms of relapse.

Well, I absolutely feel like he has my best interest at heart and I think: he is only human, and he sees so many patients, he’s always so incredibly busy, so I think: well, then sometimes something can… can slip through, he is only human. So I absolutely do not blame him for that. (57-year-old woman)

This determination to trust might prevent patients from requesting a second opinion. Almost all patients believe that in the absence of trust, they would readily find a second opinion or another oncologist.

(…) and if you have a doctor you can’t trust, then you walk away, don’t you? Then you take someone else, because there are plenty of doctors. If I cannot trust them, I walk away. (76-year-old woman)

If I would not trust my oncologist, I would go to another hospital… I will look for another oncologist. (46-year-old woman)

In reality, however, few of the interviewed patients actually changed oncologists or asked for second opinions, even when the relation with their oncologist was not optimal.

DISCUSSION

Main findings

We examined how cancer patients construct and explain trust in their oncologist. Three of the commonly described aspects of trust, i.e., Fidelity, Competence, and Honesty, were central to patients’ accounts of trust in their oncologist. Cancer patients, like other
patients, report to trust physicians who they feel act in their best interest, and sincerely provide information about the patient's prospects and their own performance. Few patients spontaneously mentioned competence, even though they considered it crucial to trust. Patients often presupposed that their oncologist's medical skills were sufficient. Confidentiality was hardly relevant to most, in line with findings in different patient populations [13,17,25,142]. We distinguished Caring as another aspect in these patients' accounts, referring to the time, attention, and sympathy the oncologist devoted to the patient. Patients especially appreciated ‘not to be treated as a number’, which reflects findings of another qualitative study among cancer patients [101].

The primary purpose of this study was to examine and clarify the concept of trust among cancer patients. However, because of the strong foundation in the conceptual model by Hall et al. [17], our findings might additionally serve to assess content validity of that model in the oncology population. Such validation would be especially relevant for the purpose of developing trust measurement instruments for cancer patients. Our results suggest that the model of Hall et al. is largely applicable in this population. However, Caring should be considered as an additional dimension of cancer patients' trust.

A connecting thread through patients' accounts was their need to trust their oncologist, arising from the life-threatening nature of cancer. During acute phases of the disease patients required even stronger trust. Patients' need to trust often led to the immediate establishment of competency-based trust. A deeper, more slowly evolving, sense of trust was established after repeated interaction. To some patients, their need to trust seemed to induce a hesitation to question their oncologist's behavior and performance.

**Vulnerability and the need to trust**

The need to trust encountered in this study, especially during acute phases, seems related to the vulnerability associated with severe disease and treatment. Such vulnerability is argued to create remarkably strong trust [10]. Several authors suggested that the life-threatening nature of cancer creates a vulnerability that forces particularly strong trust upon patients [13,60,77]. Our results empirically support this assumption. Patients might be strongly inclined to preserve this trust in their oncologist. A lack of it would imply that they feel they are not in good hands, even though they are at the mercy of this person. Remaining with such an oncologist could create cognitive dissonance. Patients might even reason that the fact that they remain with their oncologist must mean that they trust them.
(... and because I indeed, if you ask me so directly: do you trust that man? If I had not trusted him, I would not have stayed with him. So I trust that man. (57-year-old woman)

The need to trust might result in a positive bias in patients’ perceptions, preventing them from being needlessly critical of their oncologist. Yet, patients’ trust and evolving hesitation to search for an alternative opinion could also keep them from holding their physicians responsible for their actions. As Thom et al. [143] argue, “in some circumstances, patient trust in the physician could actually lead to poorer care, as patients would be less likely to seek a second opinion or question inappropriate medical advice” (p.128). Indeed, high trust levels could negatively impact patient’s autonomy. Several studies indicate that highly trusting patients are less inclined to show involvement in medical decision making [42,91,95].

Two distinct types of trust

Almost all patients reported fairly strong initial trust in their oncologist, which is apparently the ‘default’ level. Indeed, Meyerson et al. [144] suggest that interpersonal trust generally begins at moderate or high levels, and is enabled by role-based behaviors: people can be counted on to perform actions consistent with the training and experience in their role. Rousseau et al. [9], in a cross-disciplinary theory of trust, label such initial trust ‘calculus-based’. It involves a rational choice to trust, based on reliable information regarding the trustee’s intentions and competence. As a result of repeated interaction, calculus-based trust is gradually replaced by ‘relational trust’. Such relational trust corresponds to the deeper trusting relation reported by patients, which might be less competence-based but rather arising from the oncologist’s interpersonal skills.

In sociology, coercive and voluntary trust are distinguished [145]. The former involves an enforced dependency on the expertise of the other, evolving from an unequal power balance. Voluntary trust, like relational trust, involves frequent communicative interactions. In oncology, patients’ initial trust levels might arise from both rational role-based expectations (calculus-based), and a dependency on the oncologist (coercive). Such trust might be so automatic that patients do not consciously reflect on it [2,76]. A shift towards relational or voluntary trust involves repeated interaction, during which the oncologist’s interpersonal skills gain importance, reducing the power imbalance. In other patient populations, such a deepening of trust through a continuous relationship with the physician has been found repeatedly also [52,108,133]. At present, conclusions about
factors contributing to such long-term trust would be premature, since other factors than interpersonal skills might come into play over time.

**Implications**

The findings of this study have important consequences for oncology specialists. They underscore the magnitude of the power imbalance between oncologists and their patients, demanding much of the oncologists’ communicative skills. However, recent increases in time pressure and efficiency in health care may result in a stronger emphasis on technical knowledge and skills, as a result of which communicative skills are liable to suffer. The ‘automatic’ establishment of patients’ urgency-based trust might create a situation where patients make lower demands upon their oncologists’ communication than they would in less severe situations. Even, or especially, when they are not always judged on it by patients, oncologists will have to continue assuming responsibility for good interpersonal communication for the establishment of a more solid and balanced trust alliance.

The need to trust encountered in this study also has important consequences for the assessment of trust. Efforts are presently being made to develop scales to adequately assess patients’ trust in their oncologists. Such scales are a prerequisite for the development and implementation of trust-targeted interventions. The present findings suggest that strong overall trust levels will be reported, resulting in a skewed distribution of trust among cancer patients. To patients, consciously reflecting on trust might give room for the possibility that trust is not evident. This might be threatening to patients who are dependent on their oncologist for their recovery or extension of their life. Therefore, what we might actually be assessing in this specific population is patients’ intention or determination to trust their oncologist, rather than their actual interpersonal trust.

This study is, to the best of our knowledge, the first to exclusively address cancer patients’ views of trust in their oncologist. Its first, most important limitation is related to the sampling method. We only sampled patients from a large-city academic hospital. As a result, some variation in the population might have been missed. The purposeful sampling of patients, however, may have partly removed this objection. This allowed us to specifically sample patients who had been referred from other, non-academic, hospitals, and could thus reflect on their other experiences and oncologists. Moreover, this allowed us to specifically sample dissatisfied patients. Secondly, the fact that this study was performed in a Dutch population might have impacted the outcomes. The Netherlands have been described as a culture characterized by an emphasis on authority of, and trust in, the medical profession [146]. In contrast, Anglo-Saxon countries, such as the USA, are
focused more on performance, accountability, and monitoring. Even though The Netherlands appear to be undergoing a shift towards a more Anglo-Saxon culture, Dutch patients might traditionally be more inclined to trust physicians than patients from, e.g., the USA [147]. Therefore, it would be preliminary to generalize the present results to other cultures.

CONCLUSION

In this qualitative study we provided insight into cancer patients’ construction and explanation of interpersonal trust in their oncologist. Our most salient finding was a strong need to trust, leading to the fast establishment of a competence-based trust alliance. A deeper, more emotional trust bond was developed only after repeated interaction, and was rather based on the oncologist’s interpersonal skills. These findings call upon oncologists to maintain their responsibility for good interpersonal communication. For future research of the assessment of trust among cancer patients, our findings raise the question what one is assessing: patients’ actual trust, or their determination to trust their oncologist.
Trust of Turkish and Arabic ethnic minority patients in their Dutch oncologist

Published in Dutch as:
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Marij Hillen, Shaima el Temna, Jane van der Vloodt, Hanneke de Haes and Ellen Smets
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ABSTRACT

Objective
To examine the nature of the trust that Turkish and Arabic (ethnic minority) patients suffering from cancer have in their oncologist and explore how this trust is established.

Design
Semi-structured qualitative interviews.

Method
Nine cancer patients of Turkish and Arabic origin were interviewed about the trust they have in their oncologist.

Results
The trust that these patients have in their oncologist appears to gradually evolve over time. According to the patients, three specific elements tend to promote trust. Firstly, patients attached importance to a strongly proactive physician approach, even in the palliative phase when treatment was no longer indicated; a wait-and-see attitude was perceived as a lack of willingness to help and was detrimental to their trust. Secondly, patients indicated that they needed their oncologist to reassure them and avoid discussing depressing topics, so that they would not give up hope. Finally, the oncologist’s non-verbal communication - particularly, facial expression - contributed to patients’ trust.

Conclusion
Among this group of Turkish and Arabic cancer patients, trust in the physician was not self-evident and, to some extent, might need to be ‘earned’ by oncologists. Because of the great need of these patients for a proactive attitude, oncologists need to clearly explain their motivation when choosing for a possibly less active approach. To preserve hope, oncologists need to unravel exactly what their patients’ information needs are. The results of this explorative small-scale study may help physicians to optimize the trust that Turkish and Arabic ethnic minority patients have in them.
“Trust in great things comes slowly.”
Ovid, Roman poet (43 B.C. to 17 A.D.)

INTRODUCTION

Improved oncologic treatments have led to an increased chance of surviving cancer, so that the number of people living with cancer is increasing [148]. However, because a life-threatening diagnosis and uncertain prognosis make cancer patients vulnerable, it is crucial that these patients can trust their oncologist [60]. Patients who have trust in their oncologist are less anxious, more likely to participate in decision making and to adhere to medical advice [138]. In general, cancer patients have a strong trust in their oncologist [138]. This results, in part, from how the oncologist communicates with the patient. Cancer patients have indicated that trust is strengthened in particular by the oncologist’s honest and open communication, caring and involved behavior, and acting in the patient’s best interest [149]. In addition, the oncologist’s medical expertise is important for trust, but is presupposed by most patients.

In the oncology setting, research on trust is scarce and mostly based on native Dutch patients; little information is available on the trust of patients from other cultural backgrounds. Although cancer is less prevalent among ethnic minority patients, the percentage of these patients is expected to rapidly increase in the coming years [150]. Within Dutch health care, ethnic minority patients form a particularly vulnerable group, resulting from language barriers, cultural differences, and (often) a lower socio-economic status. Moreover, physicians have indicated that they sometimes find communication with these patients difficult [151].

Recently, there has been increased interest in the experiences of, and communication with, ethnic minority cancer patients in the Netherlands. This is apparent from the reports ‘Allochtonen en kanker’ [Ethnic Minorities and Cancer] from the Dutch Cancer Society and ‘Palliatieve zorg aan mensen met een niet-westerse achtergrond’ [Palliative Care to Persons with non-Western backgrounds] from the NIVEL, Comprehensive Cancer Centre the Netherlands (Integraal Kankercentrum Nederland) and Pharos (Advisory Center) [152-154]. Despite the limited amount of empirical research among ethnic minority cancer patients, it is suggested that their trust is less solid than that of native patients [155]. Moreover, it is unknown whether ethnic minority patients attach the same importance to the behaviors of oncologists as do native patients. In the Netherlands, the non-Western ethnic minorities originate mostly from Islamic countries such as Turkey, Morocco and Egypt.
To gain insight into how Turkish and Arabic ethnic minority cancer patients experience trust in their oncologist, an explorative study was performed. Patients were individually interviewed about how they perceive the establishment of trust. Based on these findings, we provide some practical recommendations to help oncologists improve their communication with this vulnerable patient group.

METHOD

Sample

Semi-structured qualitative interviews were conducted with cancer patients of Arabic and Turkish origin. With the aim to achieve sufficient variation, we purposefully selected patients on age, gender, ethnic origin and education. Patients were approached through two hospitals - the Academic Medical Center in Amsterdam and the Zaans Medical Center in Zaandam - and via an Egyptian cultural organization in the Netherlands.

Data collection

An investigator with a Dutch-Egyptian background (S.e.T.) interviewed patients in the Dutch and/or Arabic language. They were asked about the meaning, strength, importance, development, predictors and consequences of trust in their oncology specialist(s). During data acquisition, the interview protocol was adapted as and when deemed necessary. We aimed for data saturation, as indicated by the lack of new information/themes during three consecutive interviews.

Analysis

All interviews were audio-recorded, transcribed and, where necessary, translated into Dutch by the interviewer. These translations were checked for accuracy by a professional translator. According to guidelines for qualitative research, data analysis was performed in parallel with data acquisition [139]. Using the MAXQDA 2007 software for qualitative analysis [140], all interviews were independently coded by at least two of three researchers (S.e.T., M.H. and/or J.v.d.V.). Subsequently, the codings were compared and discussed until consensus was reached. The nature of the analysis was inductive; elements of trust previously identified among native patients were not compared or tested. The analysis proceeded from open coding (summarizing and categorizing data) to axial coding.
(confirming codes and identifying broader relations). Eventually, the data were clustered to reveal the main themes.

RESULTS

Sample characteristics
Data collection took place between April 1 and October 1 2011. During that period, of the 16 eligible patients, two refused participation, two were too sick to participate, and later on three could not be reached. Finally, nine patients (age range 20–73 years) participated who were being treated in four different hospitals by 7 different physicians. Of these, five were female, six had a low education level, and four were minimally or not proficient in Dutch (an interpreter was present during three interviews). The patients had the following background: Moroccan (n = 1), Turkish (n = 5), Egyptian (n = 2) and Lebanese (n = 1). All patients were Muslim, and seven of the nine were first-generation immigrants. Due to difficulty in recruiting sufficient patients, full data saturation was not reached.

Primary tumor locations were breast (n = 2), colon (n = 1), pancreas (n = 1), uterus (n = 1), lungs (n = 1), thymus gland (n = 1), bone (n = 1), and sarcoma (n = 1). Three patients were treated with curative intention, five received palliative care, and one patient no longer received active treatment.

When does trust develop?
All patients reported that they trusted their current oncologist, which appeared to result from the severity of their disease. For example, a 65-year-old woman of Turkish origin said:

Look, if you have a serious illness, for the most part you just have to trust your doctor, because he’s going to treat you. You’re dependent on him, he’s the doctor.

However, this strong sense of trust was not necessarily present at the start of the treatment relationship. Patients often indicated that, initially, they critically observed their
oncologist’s behaviors and actions. Only after the oncologist had repeatedly acted to their satisfaction, did the trust slowly develop. The following quotes illustrate this process:

The first trust grew over the course of the years. Because we’re satisfied with the doctor, we have grown to be more trusting. (51-year-old man, Turkey)

Yes, trust actually came after a year. He [the oncologist] has of course observed me for a year - and I have observed him. Back and forth, listening to what he says, and should I believe him? And checking what he tells you. (31-year-old woman, Turkey)

Only one patient reported that she had a strong trust in her oncologist from the start of the treatment relationship:

Yes, trust was present from the beginning - since the first time I entered his office. That man was good, his manners were right.’ (36-year-old woman, Egypt)

**Proactive behavior**

For patients, one of the most important factors for the development of trust was that the oncologist provided fast and maximal care. According to these patients, fast care meant that the physician rapidly reached a diagnosis and directly proceeded to treatment (or referred if necessary). They believed that this proactive behavior led to better cure, stabilization and/or improvement of their disease:

What matters to trust for me is that she [the oncologist] just goes for it. And, for example, I had planned an MRI, but my back started to ache again. And she just did her best to do the MRI sooner - but another oncologist wouldn’t have done that. So yes, she stays on the safe side rather than waiting. Another doctor would say: ‘Yes, we will wait until you are in pain and then we will do the scan.’ No, that’s not how it works. (20-year-old man, Morocco)

The doctors said: ‘Well, mister X., we are incredibly busy, we don’t have time, we have to wait for three months.’ So then I lost my trust. Because when I’ve seen the tumor sitting there on the monitor, I’ve lost my trust because I’m very ill
and people should take action as quickly as possible. Then I became a bit angry and I didn’t trust them anymore. So that’s important. (64-year-old man, Turkey)

Some patients related a lack of oncologists’ proactiveness to the Dutch healthcare system. Compared to experiences in their own country of origin, they perceived their Dutch doctors to be somewhat reticent:

They wait until a situation happens, and only then they start to think about what could be done. They don’t try to prevent the damage before it occurs. No, they wait until the damage occurs and then they search for a solution for it. While with us in Egypt, if something like this happens the doctor tries to help you in every way possible.’ (37-year-old woman, Egypt)

**Palliative phase**

Even patients in the palliative phase (for whom active treatment was no longer indicated) had the idea that something could always be done. If not for cure, then to improve their health or stabilize their disease. Similarly for these patients, the oncologist’s proactive behavior determined their trust.

When the oncologist says: ‘We cannot do anything for you here, but you could go to another hospital for a second opinion - there they may be able to see what they can do for you, even if there is nothing more to do.’ If a doctor says that, that’s a reason for me to trust him. That creates trust, like: hey, yes, they really want to help me. (70-year-old man, Turkey)

If the doctor says: ‘There is nothing more I can do for you.’ Then I would never trust him again, never again.’ (31-year-old woman, Turkey)

The examples of the behavior of proactive oncologists reported by patients in the palliative phase appear to border on the phenomenon of oncologist’s preserving hope.

**Preserving hope**

Patients indicated that preserving hope for curaion, improvement of their health, and/or disease stabilization, kept them going ‘mentally’. For trust in their oncologist it was important that the oncologist delivered positive messages. Ways in which the oncologist
could preserve hope were by continuing treatment, reassuring, and by not too openly discussing somber topics.

The radiotherapist delivers the message a little… not pleasantly, but at least better than the surgeon does. He delivers bad news, but, for example, he adds something positive. (…) Therefore, I trust him more than that surgeon, who will only say 'just go home.' He immediately gives up. (20-year-old man, Morocco)

Trust is that if I visit him, I'm not scared…and I feel spiritually reassured. Reassured in what way? (…) The conversation, the words that reassure me. For example, that he tells me there are many people with this disease who've been cured, giving me hope. Hope means that he reassures me. (36-year-old woman, Egypt)

Then they stand next to the MRI-scan and say: ‘Yes, three months, four months, that's how much time you still have. And here, and here…’ [patient points to an imaginary MRI-scan]. You see, I would deliver this news like: Look, this is what we'll do and then maybe you will improve. Using that sort of phrasing. But I wouldn’t say: ‘Oh, in a few months it will be over.’ He should say it more positively. Because, you see, you're already at rock bottom - you’re already a cancer patient. You know it's very likely that you will die…you know - that feeling is with you all the time. On the other hand, there's hope… and you should never let go of that. (31-year-old woman, Turkey)

Only one patient emphasized that, in addition to optimism, realistic and open information giving by the oncologist contributed to his trust.

He needs to be honest, even if it's painful, but…it is important. (20-year-old man, Morocco)

**Non-verbal communication**

Striking was that patients explicitly mentioned that the oncologist’s facial expression contributed to their trust.
He was very sweet and he laughed, and that face created trust in me. Facial gesticulation is important. (64-year-old man, Turkey)

His contact with me is important for my trust. Like, for example, if someone has one child, his only child - he treats it with tenderness and attention…exactly like that. Tenderness, that is…the smile, his smile. (36-year-old woman, Egypt)

**DISCUSSION**

The results of this explorative study suggest that, among Turkish and Arabic ethnic minority cancer patients, trust evolves over time. According to these patients, the most outstanding elements contributing to trust were the oncologist's proactive behavior, supporting the preservation of hope, and their facial expression. However, because of the small patient sample, these results should be considered as being preliminary.

Based on this explorative qualitative study we are unable to draw any definite conclusions about the strength of trust among Turkish and Arabic patients; for this, additional quantitative investigations are needed to collect more evidence. However, we can cautiously posit that for this group of patients, trust grows only after repeated interaction with the oncologist. Patients may often adopt a critical stance because they are unfamiliar with the Dutch healthcare system, resulting in initially low expectations with regard to their oncologist. Only when patients have found that their oncologist acts in their interest, does trust increase. Oncologists may realize that trust is not self-evident among these patients and that they may have to work harder to win their trust.

The strong emphasis of these patients on fast and maximal treatment, and their concerns about disease progression resulting from a less active approach, may be culturally driven. In these patients' countries of origin, e.g., Turkey, Morocco and Egypt, treatment often starts early and is continued at considerable length, so that the palliative phase is often not distinguished as such [156]. As a result, patients may expect Dutch physicians to have a similar attitude [157]. Apparently, these patients derive their opinion about their physicians' medical skill from their degree of proactiveness. However, oncologists will not always be willing or able to change their medical policy - simply because the Dutch healthcare system deviates from policy elsewhere. Instead, oncologists could attempt to explain even more clearly to this patient group why (in some situations) treatment is not advisable or may even be harmful. In this way they might avoid loss of
trust and the search for a second opinion – which is often made in the patient’s country of origin.

Patients preserved a strong need for hope, even when there was no prospect of cure or prolonging life. The extent to which the oncologist supported this hope had a strong effect on patients’ trust. This need for hope qualifies the desire for honesty that was earlier detected as an element of trust among native Dutch cancer patients. For ethnic minority patients, although being realistically and honestly informed was considered important, they did not wish that only the negative aspects be emphasized. Patients clearly indicated that they were aware of the severity of their situation, but also indicated that receiving a positive message helped them to keep going. This corresponds with previous findings among ethnic minority patients [158,159], but appears to apply (to some extent) to native patients as well [149,160]. For oncologists, this does not mean that they have to outline the situation more positively than it actually is, but they can meet a need for hope by emphasizing their continued availability for their patient. This allows the patient to at least preserve the hope that they are not being abandoned.

Patients emphasized the importance of their oncologist’s non-verbal communication. Especially facial expression seemed to determine how caring they perceived their oncologist to be. However, because the present study was not a comparative one, we cannot assess whether ethnic minority patients set more value on non-verbal communication than native Dutch patients in constructing trust. It is possible that Turkish and Arabic ethnic minority patients placed particular emphasis on these aspects in their narratives. However, we do know that among native Dutch patients, non-verbal communication is not spontaneously mentioned in relation to trust. Increased attention paid to non-verbal communication may be explained in several ways. Patients in the present study originated from cultures with a stronger emphasis on non-verbal communication (‘high context cultures’) than others, such as the Netherlands (‘low context cultures’) [161]. Another explanation may be that these patients pay more attention to non-verbal signals because of their limited proficiency in the Dutch language. For oncologists, it is important to realize that the non-verbal aspects of their message may be more important for this group of patients than they are accustomed to.

Our results may not reflect all possible variations in attitudes and experiences. Because of the difficulty in recruiting sufficient patients for this study, we interviewed fewer patients than planned and did not reach data saturation. Therefore, the results of this study need to be interpreted with caution. Moreover, we cannot conclude whether trust is established in different ways between sub-groups, e.g., depending on age, gender or education level. Additional qualitative and quantitative studies are required to
corroborate these preliminary findings. Also, it is important to note that all interviewed patients had an Islamic background, so that their experiences and opinions do not reflect those of ‘the’ ethnic minority patient. Similar to native Dutch patients, there is considerable variation in the evaluation of oncologists’ behavior between ethnic minority patients.

**PRACTICE IMPLICATIONS**

It is important that the physician assesses the patient’s preferences and level of understanding. If the patient expresses a strong need for hope, the physician may provide less detailed information and place more emphasis on positive aspects. If the patient does not appear to understand or accept the medical policy, it may help if the physician explains his/her motives in much more detail, preferably corresponding with the patient’s worries. By consciously and explicitly applying their communication skills, physicians can discover and hopefully fulfill the individual preferences of ethnic minority patients, in order to gain and preserve optimal trust among this patient group.

**CONCLUSION**

The results of this explorative small-scale study indicate that Turkish and Moroccan ethnic minority cancer patients do not automatically trust their oncologist, but that winning trust is a process that takes time. Physicians can enhance these patients’ trust by clearly explaining their medical policy, by emphasizing more positive aspects when necessary, and by being aware of the importance of their non-verbal communication.
PART II

Can we reliably and validly measure cancer patients’ trust in their oncologist?
Assessing cancer patients’ trust in their oncologist: development and validation of the Trust in Oncologist Scale (TiOS)

Marij Hillen, Caro Koning, Hanneke Wilmink, Jean Klinkenbijl, Eric Hans Eddes, Bellinda Kallimanis-King, Hanneke de Haes, and Ellen Smets
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Chapter 5

ABSTRACT

Purpose
The aim of this study was to develop and validate the Trust in Oncologist Scale (TiOS), which aims to measure cancer patients’ trust in their oncologist. Structure, reliability, and validity were examined.

Methods
Construction of the TiOS was based on a multidimensional theoretical framework. Cancer patients were surveyed within a week after their consultation. Trust in their oncologist, satisfaction, trust in health care, self-reported health, and background variables were assessed. Dimensionality, internal consistency, test-retest reliability, and construct validity were investigated.

Results
Data of 423 patients were included (response rate = 65%). After item reduction, the TiOS included 18 items. Trust scores were high. Exploratory factor analysis suggested one-dimensionality. Confirmatory factor analysis nevertheless indicated a reasonable fit of our four-dimensional theoretical model, distinguishing Competence, Fidelity, Honesty, and Caring. Internal consistency and test-retest reliabilities were high. Good construct validity was indicated by moderate correlations of trust (TiOS) with satisfaction, trust in health care, willingness to recommend, and number of consultations with the oncologist. Exploratory analyses suggested significant correlations of trust with ethnicity and age.

Conclusions
The TiOS reliably and validly assesses cancer patients’ trust in their oncologist. The questionnaire can be employed in both clinical practice and future research of cancer patients’ trust.
INTRODUCTION

Patients’ trust in their physician is considered essential for good quality and effective medical care [13]. Several definitions of trust exist, but they invariably include the aspect of patients’ vulnerability [6,77]. Hall et al. [10] contend that to trust, patients have to optimistically accept their vulnerable situation and believe that the physician will care for their interests. The significance of trust is reflected in an abundance of analytical essays published on the topic [e.g., 3,24,39,60]. Yet, empirical research has long lagged behind in both quantity and quality [39]. Over the past decade, increased empirical attention has resulted in more knowledge on patients’ trust. Evidence suggests that trusting patients are more satisfied [17,25], more adherent [87,108,162], more involved in decision making [87], and less inclined to request a second opinion [15,17]. Research papers reporting that trust is not associated with presumed beneficial effects, or that strong trust is associated with harmful outcomes, are very scarce. This might, however, be the result of a publication bias [138]. Most of the present evidence on patients’ trust originates from correlational research performed in primary care. Within this setting, three different questionnaires have been developed to assess patients’ interpersonal trust in their physician [17,61,62].

The Trust in Physician Scale [62] was developed first, and measures patients’ trust in their primary care provider. It assesses patients’ perception of the physician’s 1) ‘dependability’, i.e., looking out for the patient’s best interest, 2) skills and knowledge, and 3) provision of reliable information. The Patient Trust Scale [61] was constructed subsequently to incorporate changes in the health care system, specifically the transition to managed care. Although based on the Trust in Physician Scale, the scale additionally took into account cost restraints faced by the physician.

The Physician Trust Scale [17] was developed most recently and is currently the most widely used instrument to assess patients’ trust [6]. The original theoretical model of Hall et al. encompassed five trust dimensions: 1) Fidelity, the physician’s pursuit of the patients’ interests, 2) Competence, the physician’s medical and interpersonal skills, 3) Honesty, telling the truth and avoiding intentional falsehoods, 4) Confidentiality, the physician’s adequate handling of sensitive information, and 5) Global trust, “(…) the irreducible soul of trust, or aspects that combine elements from some or all of the separate dimensions” [17, p. 298]. The Confidentiality dimension was removed after pilot testing, because it lacked relevance to patients. Moreover, empirical data did not support the multidimensional model, but rather suggested that patients’ trust was best regarded as one-dimensional.
As all three existing scales were developed in the primary care setting, it is unclear to what extent they accurately assess trust in specific patient populations. Aspects of trust irrelevant to primary care patients could be significant to patients with specific diseases or vice versa [17]. Confidentiality, for example, might become more significant for trust in more severe or sensitive circumstances, such as HIV/AIDS or genetics.

For cancer patients, different elements might be relevant for trust than for primary care patients. When confronted with a cancer diagnosis, trust in the oncologist appears to be essential [60,149]. This necessity may be stronger than in most other conditions, because of the life-threatening nature of cancer. Patients need to cope with a severe diagnosis and intensive treatment which strongly impacts on their daily lives and future. Moreover, they need to grasp complex information and make difficult medical decisions. Consequently, cancer patients’ constructions and explanations of trust might differ from trust in other patient populations.

Presently, no measure of trust for oncology patients exists, preventing advances in systematic research of predictors and correlates of cancer patients’ trust. Therefore, the aim of this study was to develop a questionnaire which reliably captures cancer patients’ trust in their oncologist, the Trust in Oncologist Scale (TiOS), and to assess its psychometric properties, i.e., dimensionality, reliability and validity.

**MATERIALS AND METHODS**

**Construction**

In open-ended qualitative interviews with cancer patients [149], we identified aspects defining patients’ trust in their oncologist. This resulted in the development of an initial conceptual five-dimensional model of cancer patients’ trust, reflecting four of the dimensions of Hall et al. [17], i.e., Competence, Fidelity, Confidentiality, and Honesty. In addition, patients’ accounts of trust obtained in our qualitative study resulted in the construction of a fifth dimension, which we labeled ‘Caring’. This dimension, added because the existing dimensions did not fully capture patients’ constructions of trust, refers to the oncologist’s conveyance of involvement, sympathy, and attention to the patient [149].

Item collection and development were performed by two of the authors (M.H. and E.S., both researchers), based on the five-dimensional model. In addition to all ten items of the original Physician Trust Scale, appropriate items were selected from other trust
measures [17,62,86,163] so that at least three items per dimension were included. When not enough items were available, new items were constructed by the first author, based on the results of our qualitative study. Where possible, patients' original wording was used. Newly constructed items were discussed among two of the authors (M.H. and E.S.), following guidelines for item construction [164]. Existing items phrased in English were translated into Dutch following a forward-backward procedure, involving two forward and two backward translators. The two most general items of the Global Trust dimension by Hall et al. [17] were added to the new scale, as overall trust assessments. To allow for variation in responses to the two items, they were modeled as single indicator variables.

Item collection resulted in 33 candidate items.

Wording, relevance and difficulty of items were tested in a pilot sample of 12 patients visiting the Department of Medical Oncology of an academic hospital, using guidelines for cognitive interviewing [165]. Patients commented upon the wording and relevance for trust (content validity) of each item, and on possible relevant additions to the questionnaire. Consequently, minor adjustments were made. No items were removed or added.

**Patients and procedure**

Cancer patients were recruited from three departments of an academic hospital: Medical Oncology (MO), Radiation Oncology (RO), and Surgery (SG), and from the department of Surgery at a regional hospital (SR). Inclusion criteria were 1) >18 years of age, 2) a diagnosis of malignant disease, and 3) sufficient mastery of the Dutch language. Patients were either in treatment or received regular checkups. According to rules of thumb, a sample size of 10–15 participants per variable is required to perform Confirmatory Factor Analysis (CFA) [166]. After item reduction, we expected to include approximately 20 items in the definitive scale. Because of our intention to split the data into a training and test set, a minimum of 400 patients (200 for each data set) was required. Two different recruitment procedures were adopted, depending on department policies and preferences: the researcher approached patients either directly by mail within three days after their consultation with the oncologist (RO and SG), or after consent was obtained by their attending oncologist (SR and MO). All patients received an introductory letter and the questionnaire, along with a form to indicate refusal to participate. Reminders were sent to non-responders after three to four weeks if possible (RO and SR). A subset of 77 patients was asked to complete the questionnaire again three to four weeks after the first time, to assess test-retest reliability. This time interval was expected to be long enough to
avoid memory bias and short enough to prevent changes in patients' levels of trust (e.g., as a result of new consultations with their oncologist).

Materials

Trust in Oncologist Scale (TiOS)

The initial version of the TiOS contained 33 candidate items. All items consisted of a proposition in the third-person singular, to be answered on a five-point Likert scale (strongly disagree = 1 to strongly agree = 5). Ten items were negatively phrased. An example of a question is ‘Your doctor strongly cares about your health’. An overall trust score (range 1–5), was obtained by averaging the responses, with higher scores indicating higher trust.

Background characteristics

Socio-demographics assessed were patients' age, gender, marital status, education level, ethnicity, and religion (‘Do you consider yourself religious?’). Disease characteristics included time since diagnosis, cancer site, and treatments undergone. Questions about the relationship with the caregivers included the number of different oncologists patients had seen, and the number of consultations with their present oncologist.

Satisfaction with Physician

Satisfaction with the previous three consultations with the oncologist was measured by the five-item Patient Satisfaction Questionnaire (PSQ) [167]. Responses were marked on a visual analogue scale (not at all satisfied = 1 to extremely satisfied = 100). Internal consistency for the PSQ was strong (Cronbach’s $\alpha = .89$). Additionally, one question assessed whether patients would recommend their oncologist to others, rated on a five-point Likert scale (strongly disagree = 1, to strongly agree = 5).

Trust in Dutch health care system

Patients' general trust in the Dutch health care system was assessed with one item, adapted from a trust in Dutch health care questionnaire [19]. Patients were asked: ‘How much trust do you have in the current Dutch health-care system?’ to be rated on a five-point Likert scale (very little trust = 1, to a great deal of trust = 5).

Self-reported Health Status (SF-12)

Self-reported physical and mental health status were measured using a Dutch translation [168] of the 12-item short-form (SF-12) of the Medical Outcomes Study [169]. Internal
consistency was strong for both the physical (α = .89) and the mental (α = .89) component.

Analyses

Unless otherwise indicated, all analyses were performed using SPSS 16 (SPSS Inc., Chicago, IL, USA). Data of participants with more than 25% missing overall or on the TiOS specifically were completely removed. Remaining missing values on the TiOS were replaced using expectation maximization (EM) [170]. Regression analysis was performed to check whether the different acquisition procedures, i.e., via the researcher or via the oncologist, might have induced bias.

To analyze dimensionality, the data was randomly split in two halves: a training set, and a test set. First, the original 33-item five-factor model was tested on the training set with confirmatory factor analysis (CFA), using Lisrel 8.5 (Scientific Software International, Lincolnwood, IL, USA). We calculated χ², Root Mean Square Error of Approximation (RMSEA), and Comparative Fit Index (CFI) to test the fit of the model, using Robust Maximum Likelihood estimation. An acceptable model fit would be indicated by χ² of >.05, RMSEA of <.06, and CFI of >.95. Second, in case of unsatisfactory fit of the initial model and item set, item reduction would be performed, based on preliminary descriptive characteristics of all items. Items deemed inadequate because of high rates of non-response, low item-scale and test-retest correlations, and high skewness, were removed. If two similar items had equivalent content and psychometric properties, two authors (M.H. and E.S.) selected the most appropriate alternative based on additional criteria, i.e., avoiding confusing or lengthy wording, and patients’ additional comments indicating an item’s relevance for trust. Third, to examine alternative models of dimensionality, exploratory factor analysis (EFA) was performed on the training set, using the definitive item selection. Outcomes were used to adapt the theoretical dimensional model. Based on the EFA findings, CFA was performed to test the final model, using the test set. Fourth, internal consistency of the TiOS overall and its subscales was calculated using Cronbach’s α, within-item-variance, and between-items-covariance. Inter-item correlations between .10 and .50 were considered acceptable. Item-scale correlations should be >.20. Correlations between test and retest scores were calculated to assess test-retest reliability. Both internal consistency and test-retest reliability were expected to be high.

Construct validity was assessed by calculating Spearman’s correlations between trust (TiOS) and satisfaction (PSQ), trust in health care, willingness to recommend the oncologist to others, and number of previous consultations with the oncologist.
Moderately positive associations between trust and these correlates would indicate good construct validity [10,17,25,44]. Exploratory analyses were performed to assess Spearman’s correlations between trust, and patients’ age, gender, education, ethnicity, religion, time since diagnosis, and physical and mental health.

RESULTS

Descriptives and missing data

Of all 675 patients who received the questionnaires, 506 (75%) responded, 70 (10%) of whom declined participation, resulting in a response rate of 65% (N = 436). Most frequent reasons to decline were 1) too much of a burden (n = 28), 2) not enough contact with the oncologist (n = 12), and 3) poor health (n = 10). Data of 13 participants with high rates of missing data were completely excluded. For the remaining 0.74% of missing data on the TiOS, EM was performed. Patients’ socio-demographic data are displayed in Table 1. The distribution was left-skewed, with high Kurtosis. Most patients had one (45%) or two (36%) oncologists presently involved in their cancer care. Regression analysis indicated that the type of recruitment, i.e., by the researcher or the oncologist, explained no variation in trust scores (0.8%, F(1, 421) = 3.26, p = .07).

Dimensionality and item reduction

Step 1  Confirmatory factor analysis (CFA) of initial model

To address problems of under-identification due to empty cells, response categories 1 (completely disagree) and 2 (disagree) were collapsed, leaving four Likert response categories. Our original theoretically driven five-factor model did not result in a satisfactory model fit: Satorra-Bentler Scaled $\chi^2$ ($476, n = 211$) = 1283.81 ($p < .001$), RMSEA = .09, and CFI = .94.
Table 1. Demographic, health, and relationship characteristics of the sample (N = 423)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mdn (Range)</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (n = 413)</td>
<td>63 (19–90)</td>
<td>13</td>
</tr>
</tbody>
</table>

### Gender (n = 423)
- Male: 239 (57%)
- Female: 184 (43%)

### Educational level (n = 420)
- None/primary school: 47 (11%)
- Secondary/lower level vocational school: 248 (59%)
- College/university: 125 (30%)

### Ethnicity (n = 421)
- Dutch: 400 (95%)
- Other, Europe or USA: 7 (2%)
- Surinamese: 4 (1%)
- Turkish: 5 (1%)
- Moroccan: 3 (1%)
- Other, non-Western country: 2 (0%)

### Religious (n = 421)
- Yes: 209 (50%)
- No: 212 (50%)

### Time since diagnosis in months (n = 422)
- <1: 5 (1%)
- 1–6: 77 (18%)
- 6–24: 148 (35%)
- >24: 192 (46%)

### Specialist about whom reported (n = 423)
- Radiation oncologist: 148 (35%)
- Medical oncologist: 133 (31%)
- Surgeon/urologist: 142 (34%)

### Self-reported cancer site (n = 419)
- Gastrointestinal: 182 (43%)
- Genitourinary: 85 (20%)
- Breast: 84 (20%)
- Gynecologic: 15 (4%)

**Table 1. Continued**

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>Head/neck</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>Lung</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>4</td>
</tr>
</tbody>
</table>

Number of consultations with present oncologist ($n = 419$)

<table>
<thead>
<tr>
<th>Interval</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3</td>
<td>40</td>
<td>10</td>
</tr>
<tr>
<td>3–5</td>
<td>112</td>
<td>27</td>
</tr>
<tr>
<td>6–10</td>
<td>123</td>
<td>29</td>
</tr>
<tr>
<td>11–15</td>
<td>57</td>
<td>14</td>
</tr>
<tr>
<td>&gt;15</td>
<td>87</td>
<td>21</td>
</tr>
</tbody>
</table>

*Step 2  Item reduction and model adjustment*

In total, 15 items were removed, resulting in a definitive sample of 18 items, displayed in Table 2 along with their origin and psychometric properties. All three items of the Confidentiality dimension were removed because of insufficient psychometric quality, and because patients, in their additional comments to the questionnaire, indicated these items to be irrelevant to trust. Consequently, we re-specified our final model to be four-dimensional (see Figure 2). The mean overall trust score for the definitive item set ($TiOS$) was 4.56 ($SD = 0.51$, range 2.44–5.00).

*Step 3  Exploratory factor analysis (EFA)*

EFA with direct oblimin rotation ($\Delta = 0$) was conducted for the definitive set of items. Three components were extracted with eigenvalues >1, jointly explaining 62% of the variance. Item loadings suggested that component 1, on which all items loaded strongly, represented a general measure of ‘trust’ (eigenvalue = 8.42). Component 2 comprehended negatively phrased items (eigenvalue = 1.48), and component 3 was the least coherent, containing a variety of items (eigenvalue = 1.18). These results suggest that meaningful dimensions of trust could not be distinguished, and that a one-dimensional model of trust might be the most appropriate.
Step 4  Testing of definitive model

Based on the EFA outcomes, CFA was used to test a one-dimensional model. This model did not fit the data satisfactorily (Satorra-Bentler Scaled $\chi^2 (134, n = 212) = 210.64 (p < .001)$, RMSEA = .05, and CFI = .93). Additionally, we tested our definitive, theoretically-driven four-factor model (see Figure 2). This model fit the data reasonably well (Satorra-Bentler Scaled $\chi^2 (122, n = 212) = 154.58 (p = .03)$, RMSEA = .04, and CFI = .95). Standardized factor loadings of the items were adequate (see Table 3). However, correlations between common factors were extremely strong (see Table 4). This, and issues indicating persistent multi-collinearity encountered when running the model, suggest that, conceptually, a one-dimensional model best explains our findings.

Reliability

Reliability of the TiOS overall was high ($\alpha = .92$), and ranged from acceptable to good for the subscales: Competence ($\alpha = .65$), Fidelity ($\alpha = .87$), Honesty ($\alpha = .75$), and Caring ($\alpha = .73$). Correlations between all four dimensions and the two global validation items ranged from .48 to .67. Item-scale correlations ranged from .51 to .71. Inter-item correlations were acceptable, ranging between .20 and .60, mostly. Test-retest reliability for the total score was high, $r_s = .93$, and ranged between .43 and .92 for individual items. We found equally high test-retest reliability, ranging between .77 and .82, for all four dimensions of the TiOS.

Validity

Good construct validity was indicated by significant Spearman’s correlations between overall trust and satisfaction ($r_s(420) = .63, p < .001$), willingness to recommend the oncologist to others ($r_s(408) = .62, p < .001$), trust in health care ($r_s(423) = .24, p < .001$), and number of consultations ($r_s(419) = .16, p < .001$) (see Table 5).
**Figure 1.** Final measurement model of the definitive four-dimensional theoretical model tested in confirmatory factor analysis.

Note: Items 17 and 18 are modeled as single indicator exogenous variables. Asterisk Represents all possible correlations between item 17 and item 18 and the common factors.
Table 2. Overview of all items included in the TiOS: their source, dimension, mean, standard deviation, skewness, and item-scale correlation

<table>
<thead>
<tr>
<th>Item</th>
<th>Content</th>
<th>Source (^b)</th>
<th>Dimension</th>
<th>(M)</th>
<th>SD</th>
<th>Skewness</th>
<th>Item-scale correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Your doctor is very careful and precise(^a)</td>
<td>PTS</td>
<td>Competence</td>
<td>4.65</td>
<td>0.67</td>
<td>-2.65</td>
<td>.53</td>
</tr>
<tr>
<td>2</td>
<td>Your doctor is totally honest in telling you about all the different treatment options available for your condition</td>
<td>PTS</td>
<td>Honesty</td>
<td>4.68</td>
<td>0.63</td>
<td>-2.31</td>
<td>.63</td>
</tr>
<tr>
<td>3</td>
<td>Your doctor always gives you honest information about your prospects</td>
<td>New</td>
<td>Honesty</td>
<td>4.58</td>
<td>0.77</td>
<td>-2.28</td>
<td>.56</td>
</tr>
<tr>
<td>4</td>
<td>Your doctor strongly cares about your health(^a)</td>
<td>IP PTS</td>
<td>Fidelity</td>
<td>4.51</td>
<td>0.79</td>
<td>-1.97</td>
<td>.69</td>
</tr>
<tr>
<td>5</td>
<td>Your doctor always tells you everything you want to know about your illness</td>
<td>MISS</td>
<td>Fidelity</td>
<td>4.63</td>
<td>0.72</td>
<td>-2.33</td>
<td>.64</td>
</tr>
<tr>
<td>6</td>
<td>You think your doctor can handle any medical situation, even a very serious one(^a)</td>
<td>IP PTS</td>
<td>Competence</td>
<td>4.53</td>
<td>0.76</td>
<td>-1.77</td>
<td>.65</td>
</tr>
<tr>
<td>7</td>
<td>Your doctor always takes his/her time with you</td>
<td>New</td>
<td>Caring</td>
<td>4.61</td>
<td>0.70</td>
<td>-2.24</td>
<td>.58</td>
</tr>
<tr>
<td>8</td>
<td>Your doctor explains everything so that you can consent to medical decisions</td>
<td>New</td>
<td>Fidelity</td>
<td>4.64</td>
<td>0.64</td>
<td>-2.64</td>
<td>.71</td>
</tr>
<tr>
<td>9</td>
<td>Sometimes you worry that your doctor's medical decisions are wrong(^c)</td>
<td>IP PTS</td>
<td>Competence</td>
<td>4.37</td>
<td>1.09</td>
<td>-1.87</td>
<td>.54</td>
</tr>
<tr>
<td>10</td>
<td>Your doctor only thinks about what is best for you</td>
<td>PTS</td>
<td>Fidelity</td>
<td>4.62</td>
<td>0.69</td>
<td>-2.35</td>
<td>.63</td>
</tr>
<tr>
<td>11</td>
<td>Sometimes your doctor does not pay full attention to what you are trying to tell him/her(^c)</td>
<td>PTS</td>
<td>Competence</td>
<td>4.24</td>
<td>1.10</td>
<td>-1.48</td>
<td>.61</td>
</tr>
<tr>
<td>12</td>
<td>Your doctor would always tell you the truth about your health, even if there was bad news(^c)</td>
<td>PCAS</td>
<td>Honesty</td>
<td>4.67</td>
<td>0.65</td>
<td>-2.65</td>
<td>.51</td>
</tr>
<tr>
<td>13</td>
<td>You have doubts whether your doctor really cares about you as a person(^m)</td>
<td>TiPS</td>
<td>Caring</td>
<td>4.47</td>
<td>0.98</td>
<td>-2.03</td>
<td>.61</td>
</tr>
<tr>
<td>14</td>
<td>Your doctor listens with care and concerns to all the problems you have(^a)</td>
<td>IP PTS</td>
<td>Caring</td>
<td>4.57</td>
<td>0.72</td>
<td>-1.94</td>
<td>.63</td>
</tr>
<tr>
<td>15</td>
<td>Your doctor will do whatever it takes to get you all the care you need</td>
<td>PTS</td>
<td>Fidelity</td>
<td>4.70</td>
<td>0.56</td>
<td>-1.87</td>
<td>.75</td>
</tr>
<tr>
<td>16</td>
<td>Your doctor is available for you whenever you need him/her</td>
<td>New</td>
<td>Caring</td>
<td>4.46</td>
<td>0.78</td>
<td>-1.37</td>
<td>.62</td>
</tr>
<tr>
<td>17</td>
<td>You have no worries about putting your life in your doctor's hands</td>
<td>PTS</td>
<td>Global item</td>
<td>4.39</td>
<td>0.99</td>
<td>-1.91</td>
<td>.51</td>
</tr>
<tr>
<td>18</td>
<td>All in all, you have complete trust in your doctor</td>
<td>PTS</td>
<td>Global item</td>
<td>4.39</td>
<td>0.60</td>
<td>-2.21</td>
<td>.72</td>
</tr>
</tbody>
</table>

\(^a\)Minor modifications to original wording.  
\(^b\)PTS = Patient Trust Scale [61]; IP PTS = Item Pool for PTS [17]; MISS = Medical Interview Satisfaction Scale [163]; PCAS = Primary Care Assessment Survey [86]; TiPS = Trust in Physician Scale [62].  
\(^c\)Reverse-scored items.  
\(^m\)Five-point Likert scale: 1 = totally disagree, 2 = disagree, 3 = as much agree as disagree, 4 = agree, 5 = strongly agree.
### Table 3. Confirmatory factor analysis of the four-dimensional conceptual model for the TiOS: standardized factor loadings

<table>
<thead>
<tr>
<th>Item</th>
<th>Standardized factor loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your doctor is very careful and precise (item 1)</td>
<td>.77</td>
</tr>
<tr>
<td>You think your doctor can handle any medical situation, even a very serious one (item 6)</td>
<td>.80</td>
</tr>
<tr>
<td>Sometimes you worry that your doctor’s medical decisions are wrong (item 9)</td>
<td>.65</td>
</tr>
<tr>
<td>Sometimes your doctor does not pay full attention to what you are trying to tell him/her (item 11)</td>
<td>.69</td>
</tr>
<tr>
<td>Your doctor strongly cares about your health (item 4)</td>
<td>.85</td>
</tr>
<tr>
<td>Your doctor always tells you everything you want to know about your illness (item 5)</td>
<td>.80</td>
</tr>
<tr>
<td>Your doctor explains everything so that you can consent to medical decisions (item 8)</td>
<td>.87</td>
</tr>
<tr>
<td>Your doctor only thinks about what is best for you (item 10)</td>
<td>.83</td>
</tr>
<tr>
<td>Your doctor will do whatever it takes to get you all the care you need (item 15)</td>
<td>.93</td>
</tr>
<tr>
<td>Your doctor is totally honest in telling you about all the different treatment options available for your condition (item 2)</td>
<td>.87</td>
</tr>
<tr>
<td>Your doctor always gives you honest information about your prospects (item 3)</td>
<td>.87</td>
</tr>
<tr>
<td>Your doctor would always tell you the truth about your health, even if there was bad news (item 12)</td>
<td>.72</td>
</tr>
<tr>
<td>Your doctor always takes his/her time with you (item 7)</td>
<td>.83</td>
</tr>
<tr>
<td>You have doubts whether your doctor really cares about you as a person (item 13)</td>
<td>.66</td>
</tr>
<tr>
<td>Your doctor listens with care and concerns to all the problems you have (item 14)</td>
<td>.86</td>
</tr>
<tr>
<td>Your doctor is available for you whenever you need him/her (item 16)</td>
<td>.84</td>
</tr>
</tbody>
</table>

*Factor 1 = Competence, factor 2 = Fidelity, factor 3 = Honesty, factor 4 = Caring.*
Table 4. Confirmatory factor analysis of the four-dimensional conceptual model for the TiOS: common factor loadings

<table>
<thead>
<tr>
<th>Factor</th>
<th>Competence</th>
<th>Fidelity</th>
<th>Honesty</th>
<th>Caring</th>
<th>Global 1 (item 17)</th>
<th>Global 2 (item 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competence</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fidelity</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Honesty</td>
<td>.96</td>
<td>.88</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring</td>
<td>.91</td>
<td>.98</td>
<td>.76</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global 1 (item 17)</td>
<td>.86</td>
<td>.78</td>
<td>.80</td>
<td>.74</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Global 2 (item 18)</td>
<td>.93</td>
<td>.92</td>
<td>.82</td>
<td>.92</td>
<td>.85</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 5. Construct validity of the TiOS: means, standard deviations, and Spearman’s correlation of TiOS score with related measures

<table>
<thead>
<tr>
<th>Measure (possible range)</th>
<th>M</th>
<th>SD</th>
<th>r_s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trust in Oncologist (1-5)</td>
<td>4.56</td>
<td>0.51</td>
<td>.63***</td>
</tr>
<tr>
<td>Satisfaction with oncologist (0-500)</td>
<td>407</td>
<td>74</td>
<td>.63***</td>
</tr>
<tr>
<td>Trust in health care (1-5)</td>
<td>3.93</td>
<td>0.77</td>
<td>.24***</td>
</tr>
<tr>
<td>Willingness to recommend oncologist (1-5)</td>
<td>4.64</td>
<td>0.67</td>
<td>.62***</td>
</tr>
<tr>
<td>Number of physician consultations</td>
<td>3.09</td>
<td>1.27</td>
<td>.16***</td>
</tr>
</tbody>
</table>

***Significant at α <0.001.

Exploratory analyses

Trust was significantly stronger among older patients (r_s(413) = .10, p <0.05), and patients with better mental health (r_s(287)= .17, p <0.01). Dutch patients (M = 4.57, SD = 0.51) reported stronger trust than non-Dutch patients (M = 4.34, SD = 0.49), F(421) = 0.90, p <0.05. Correlations between trust and all other exploratory variables were non-significant (p >0.05).

DISCUSSION

In this study, the TiOS, an 18-item questionnaire assessing cancer patients’ trust in their oncologist, was developed and empirically validated. Our findings suggest that the TiOS reliably and validly assesses cancer patients’ trust in their oncologist. In addition to the
dimensions distinguished previously, i.e., Fidelity, Competence, and Honesty, a new dimension of cancer patients' trust, labeled 'Caring', was distinguished and empirically validated in this study. Internal consistency, test-retest reliability, and construct validity of the TiOS were good, as indicated by moderate correlations between trust and satisfaction, willingness to recommend the oncologist to others, trust in the health care system, and the number of consultations with the oncologist. Exploratory analyses indicated higher trust among older, Dutch patients with better mental health.

Dimensionality analyses lead us to conclude that, at least in this heterogeneous sample of cancer patients, trust is very coherent and can therefore be regarded as one-dimensional. At the same time, testing of our theoretical model suggests that patients do distinguish between different aspects contributing to trust, i.e., Competence, Fidelity, Honesty, and Caring. This distinction allows for the separate use or investigation of one of these four specific aspects of trust. Depending on researchers' aims, trust can therefore be represented and used both as a broad, general construct, and as combination of separate dimensions each representing an aspect of trust [171]. Possibly, multidimensionality is more pronounced among cancer patients with stronger variations in trust levels, e.g., in palliative care.

The skewed distribution of trust scores is in line with findings in other populations [17,25,61,62]. Indeed, the high trust levels among cancer patients reported here possibly even exceed trust levels reported in the primary care setting [15,17,172]. Possibly, such strong trust is induced by the life-threatening nature of cancer. Previous qualitative findings [149] indeed suggest that for these patients, the need to trust their oncologist is strong. Even in a sub-optimal relation with the oncologist, patients might refrain from questioning their trust, thus preventing them from experiencing cognitive dissonance that could arise when they remained with an oncologist they do not trust completely. Salmon and Young [173] suggest that patients with more threatening diseases, such as cancer, might create more positive images of their physicians, reasoning that “(...) patients subjectively construct their image of the practitioner to meet their own safety and dependency needs and in line with their own mental models of self and other” (p. 33). However, this theory is not completely in line with our exploratory finding of stronger trust among patients with better mental health. Research would need to confirm whether trust levels are indeed higher for patients with severe conditions like cancer by comparing different patient populations and with varying health status.

The finding that trust is less strong among patients with non-Dutch ethnicities has been reported previously, both in primary care and in the oncology setting [44,46,73,79,172]. Previous studies were mostly performed in the USA, and report lower
trust among African American than among Caucasian patients. In the present study, trust was lower among non-Dutch patients from both Western and non-Western countries. However, the relative scarcity of non-Dutch patients in our sample and the exploratory nature of this analysis warrant further investigation of the relationship between trust and ethnicity. Such research should preferably not only focus on trust levels, but also on differences in constructions and explanations of trust.

The skewed distribution of trust scores raises the question whether these high scores accurately reflect very strong levels of trust, or result from a measurement limitation. It would be worthwhile to first investigate whether, among specific groups of cancer patients, TiOS scores are less skewed. Such research could be conducted in samples where lower trust might reasonably be expected, e.g., immigrants or patients requesting second opinions. A lack of more variability in TiOS scores among such samples would warrant further explorations of more sensitive research methods. More variability in trust levels could possibly be registered with different item wordings or other response formats (e.g., asymmetric answer formats). Alternatively, researchers might resort to different methods, such as unobtrusive measures, in order to avoid patients’ conscious processes and cognitions [174]. Presently, the quantitative, self-report, nature of the TiOS prohibits conclusions about patients’ underlying processes during questionnaire completion. As such, the TiOS might be assessing patients’ determination to trust the oncologist, rather than their actual basic trust.

In addition to these considerations about skewness, this study has some limitations. First, although construct validity of the TiOS was addressed, more research would be needed to assess how TiOS scores relate to relevant clinical and/or patient reported outcomes, thus establishing predictive validity. Second, the TiOS was presently only validated in a sample of Dutch cancer patients. Further validation should include administration of the scale among patients in other countries. A final important consideration is the scope of the questionnaire. As the oncology setting is becoming increasingly multidisciplinary, patients are confronted with treatment by an interdisciplinary team of healthcare professionals. The oncologist is no longer by definition the central carer. Indeed, in patients’ perceptions, there might not be a central care provider at all [29]. Patients’ additional comments in the survey suggest that, consequently, some patients find it easier to report on the care delivered by the entire team, than by the oncologist specifically. It is worth investigating whether and how increased multi-disciplinarity in oncology care impacts on patients’ interpersonal and more general trust.

In conclusion, the current study has contributed to research of cancer patients’ trust in their oncologist by enabling the accurate assessment of trust in the cancer patient
population. We think that the TiOS improves further expansion of this field of study, resulting in better insight into the nature, predictors, and consequences of these patients’ trust, which could ultimately improve patient care.
Validation of the English version of the Trust in Oncologist Scale (TiOS)

Marij Hillen, Phyllis Butow, Martin Tattersall, George Hruby, Frances Boyle, Janette Vardy, Bellinda Kallimanis-King, Hanneke de Haes, and Ellen Smets
Patient Education and Counseling, 2013. DOI: 10.1016/j.pec.2012.11.004
Chapter 6

ABSTRACT

Objective
The Trust in Oncologist Scale (TiOS) was recently developed and validated in The Netherlands to assess cancer patients’ trust in their oncologist. In this study, we translated and further validated the scale among English-speaking Australian cancer patients, to establish cross-cultural validity.

Methods
The translated 18-item scale was administered to cancer patients (N = 175) from three Sydney hospitals. In addition to trust, we assessed patients’ satisfaction, trust in health care, and background characteristics. Dimensionality, internal consistency, and construct validity of the translated scale were assessed.

Results
Psychometric properties of all items were acceptable. Trust scores were very high. Factor analyses indicated one-dimensionality of the scale. Internal consistency was strong. Moderate to high correlations were found between trust (TiOS) and its known correlates, i.e., satisfaction, number of previous consultations with the oncologist, and trust in health care, indicating good construct validity.

Conclusion
Trust is highly coherent, suggesting that cancer patients do not distinguish between separate dimensions of trust. Future research could clarify if trust is equally strong and one-dimensional among specific groups of cancer patients.

Practice implications
Both the English and the Dutch Trust in Oncologist Scales appear suitable for assessing cancer patients’ trust reliably and validly.
INTRODUCTION

Cancer patients are confronted with a life-threatening diagnosis and face difficult and life-altering treatment decisions. Many patients experience distress, uncertainty, and vulnerability [60]. A trusting relationship with the oncologist can alleviate patients’ burden, increase involvement in decision making and reduce the inclination to request a second opinion [15,17,25,87]. Hence, trust in the oncologist is important. However, since not much empirical research has shed light on why and how cancer patients trust their oncologist [138], we know little about the realization, strength, predictors, and consequences of cancer patients’ trust.

To gain a better understanding of patients’ trust, one first needs to be able to assess it. The only instruments available to date were developed in the primary care setting [17,61,62]. The most recent of these, the Physician Trust Scale by Hall et al. [17], has been validated most extensively [6]. However, this scale might not be fully applicable to cancer patients because of the specific nature of the oncology setting.

We therefore recently developed an oncology-specific trust measuring instrument in Dutch, the Trust in Oncologist Scale (TiOS), and established its reliability and validity among Dutch cancer patients [175]. The suitability of the TiOS for English-speaking cancer patients has not yet been confirmed. To allow for cross-cultural comparison, we validated an English translation of the TiOS among English-speaking Australian cancer patients. Dimensionality, construct validity, and reliability were assessed.

METHODS

Construction of the TiOS in Dutch

The TiOS was based on the ten-item Physician Trust Scale by Hall et al. [17], and on qualitative data regarding cancer patients’ explanations of trust [149]. A five-dimensional model of cancer patients’ trust was constructed, encompassing Competence, Fidelity, Confidentiality, Honesty, and Caring. Appropriate items for all dimensions were collected from the Physician Trust Scale and related scales [17,62,86,163], or newly constructed. The resulting 33 candidate-items were pilot-tested. During questionnaire validation, the Confidentiality dimension was removed. The final 18-item scale comprised four dimensions, i.e., 1) Fidelity, the oncologist’s pursuing the patients’ interests, 2) Competence, the
oncologist’s medical skills, 3) Honesty, telling the truth and avoiding intentional falsehoods, and 4) Caring, the oncologist’s involvement, sympathy and devotion of attention to the patient. For a full description of the construction of the TiOS, see Hillen et al. [175]. The TiOS was translated into English following a forward-backward procedure [176].

Validity testing

Patients and procedure

Adult, English-speaking cancer patients in treatment or follow-up were recruited from four Medical Oncology and Radiation Oncology departments of three hospitals in the Sydney area. Depending on department policies, patients were either approached face-to-face by a researcher (location 1), approached by their physician (locations 2 and 4) or directly mailed the questionnaire (location 3). All patients received an introductory letter and the questionnaire, leaving open the possibility to refuse participation. Ethics approval was obtained from the University of Sydney and Area Health Service Ethics Committees linked to the participating cancer centres.

Instruments

All 18 items of the TiOS consist of a proposition in the third person singular, with a five-point Likert answering scale (strongly disagree = 1 to strongly agree = 5). Three items are negatively phrased. Mean trust (range 1–5) is calculated by averaging the responses. Socio-demographic (i.e., gender, age, marital status, education level, ethnicity, mother tongue and religion) and disease characteristics (i.e., time since diagnosis, cancer site, treatments undergone, and number of previous consultations with the present oncologist) were assessed. Satisfaction with the oncologist was assessed with the five-item Patient Satisfaction Questionnaire (PSQ) [177]. An additional item asked whether patients would recommend their oncologist to others. Physical and mental Health Related Quality of Life (HRQOL) were measured with the 12-item short form health survey (SF-12) [169]. Finally, one item asked patients how much trust they had in the Australian health care system.

Analyses

For missing values, we used Expectation Maximization [170]. Using confirmatory factor analysis (CFA), we tested our four-dimensional model first, then a uni-dimensional representation of trust. A good model fit would be indicated by non-significant $\chi^2$, and Root Mean Square Error of Approximation (RMSEA) <.06 [178]. As in the Dutch sample, we expected uni-dimensionality, but also a reasonably good fit of our four-dimensional
Development of the English Trust in Oncologist Scale

model. We calculated internal consistencies (Cronbach’s α), inter-item correlations and item-scale correlations for the TiOS. Construct validity was assessed by calculating Spearman’s correlations between trust (TiOS) and its known correlates: satisfaction, trust in health care, and number of previous consultations with the oncologist. We expected that high trust levels would be strongly associated with high satisfaction, and moderately with strong trust in health care and a larger number of previous consultations [10,17,25,44]. Exploratory, we assessed correlations between trust and patients’ HRQOL, socio-demographics and disease characteristics. Analyses were performed using SPSS 16 [179], and Lisrel 8.5 [180].

RESULTS

In total, 177 questionnaires were returned (response rate 70%, range 56–84% for the different locations). Data from two participants were excluded because of more than 25% missing data. Socio-demographic characteristics of the sample are shown in Table 1. All items, including their psychometric properties, are displayed in Table 2. Skewness was below 2 for all items, and item-scale correlations were >.3. Mean trust over all 18 items was 4.47 (SD = 0.50, range 2.50–5.00). The theoretically driven four-factor model failed to converge in CFA. This was probably due to collinearity, as indicated by between-item correlations as strong as .8. Moreover, even when collapsing response categories 1 and 2, the distribution of trust scores over response categories remained uneven, including empty or near-empty cells. A one-dimensional model resulted in an acceptable model fit (SBχ² (137) = 200.73, p <.01, and RMSEA = .05) [181]. Standardized item loadings on this factor were strong (M = .80, range .58–.91) [181]. Post-hoc exploratory factor analysis, to check if a one-dimensional model fit would be confirmed when no assumptions were made about the data, confirmed the one-dimensionality of the TiOS.

Very strong internal consistency of the TiOS was suggested by Cronbach’s α of .94 [182]. Item-scale correlations were acceptable (range .43–.81) [183]. Inter-item correlations ranged between .2 and .8. As expected, mean scores on the TiOS correlated significantly with known correlates of trust, i.e., satisfaction with the oncologist (PSQ: r₁ = .62), willingness to recommend the oncologist to others (r₁ = .59), number of previous visits with the oncologist (r₁ = .21) and trust in health care (r₁ = .33). All correlations in the exploratory analyses were non-significant.
Table 1. Demographic, health and relationship characteristics of the sample (N = 175)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (n = 174)</strong></td>
<td>62</td>
<td>21–88</td>
</tr>
<tr>
<td><strong>n %</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender (n = 175)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>76</td>
<td>43</td>
</tr>
<tr>
<td>Female</td>
<td>99</td>
<td>57</td>
</tr>
<tr>
<td><strong>Educational level (n = 175)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/Primary school</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Secondary/Lower level vocational school</td>
<td>103</td>
<td>59</td>
</tr>
<tr>
<td>College/University</td>
<td>58</td>
<td>33</td>
</tr>
<tr>
<td><strong>Ethnicity (n = 175)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australian</td>
<td>144</td>
<td>82</td>
</tr>
<tr>
<td>Other</td>
<td>31</td>
<td>18</td>
</tr>
<tr>
<td><strong>Religious (n = 173)</strong></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>146</td>
<td>84</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>16</td>
</tr>
<tr>
<td><strong>Time since diagnosis in months (n = 173)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>1–6</td>
<td>18</td>
<td>10</td>
</tr>
<tr>
<td>6–24</td>
<td>49</td>
<td>28</td>
</tr>
<tr>
<td>&gt;24</td>
<td>105</td>
<td>61</td>
</tr>
<tr>
<td><strong>Specialist about whom reported (n = 175)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation Oncologist</td>
<td>38</td>
<td>22</td>
</tr>
<tr>
<td>Medical Oncologist</td>
<td>137</td>
<td>78</td>
</tr>
<tr>
<td><strong>Self-reported cancer site (n = 175)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>60</td>
<td>34</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>49</td>
<td>28</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>26</td>
<td>15</td>
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<td>Gynecologic</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>Lung</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Bone</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Skin</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 1. Continued

<table>
<thead>
<tr>
<th>Number of consultations with present oncologist (n = 175)</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;3</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>3–5</td>
<td>26</td>
<td>15</td>
</tr>
<tr>
<td>6–10</td>
<td>43</td>
<td>25</td>
</tr>
<tr>
<td>11–15</td>
<td>35</td>
<td>20</td>
</tr>
<tr>
<td>&gt;15</td>
<td>56</td>
<td>32</td>
</tr>
</tbody>
</table>

DISCUSSION AND CONCLUSION

Discussion

In this study, the English version of the 18-item Trust in Oncologist Scale (TiOS) was validated. Mean trust scores were invariably high. Strong internal consistency, inter-item correlations and item-scale correlations suggest sufficient reliability. Construct validity was confirmed by strong correlations of TiOS scores with satisfaction and moderate correlations with number of previous visits with the oncologist and with trust in health care. Importantly, we found TiOS scores to be one-dimensional, indicating that these patients do not distinguish between different aspects of trust, i.e., Competence, Fidelity, Honesty, and Caring. Although this distinction was slightly stronger among Dutch patients, we still concluded that trust was best considered as a one-dimensional construct. The present findings confirm this suggestion of one-dimensionality. The even weaker distinction between dimensions of trust by Australian patients could reflect a more homogeneous composition of this sample. Even though mean trust was equally high in both samples, the Australian data lack sufficient variation in trust scores. Very few patients reported weak trust in their oncologist. This lack of variation may be due to Medical Ethical Committee regulations, prohibiting the random and direct approach of patients by mail as employed in the Dutch sample. Recruitment via the participating oncologists may have resulted in selection bias towards including only strongly trusting patients.
<table>
<thead>
<tr>
<th>Item</th>
<th>Content</th>
<th>Dimension</th>
<th>$M$</th>
<th>$SD$</th>
<th>Skewness</th>
<th>Item-scale correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Your doctor is very careful and precise</td>
<td>Competence</td>
<td>4.58</td>
<td>0.60</td>
<td>-1.4</td>
<td>.73</td>
</tr>
<tr>
<td>2</td>
<td>Your doctor is totally honest in telling you about all the different treatment options available for your condition</td>
<td>Honesty</td>
<td>4.61</td>
<td>0.60</td>
<td>-1.6</td>
<td>.71</td>
</tr>
<tr>
<td>3</td>
<td>Your doctor always gives you honest information about your prospects</td>
<td>Honesty</td>
<td>4.58</td>
<td>0.56</td>
<td>-1.1</td>
<td>.67</td>
</tr>
<tr>
<td>4</td>
<td>Your doctor strongly cares about your health</td>
<td>Fidelity</td>
<td>4.58</td>
<td>0.59</td>
<td>-1.1</td>
<td>.77</td>
</tr>
<tr>
<td>5</td>
<td>Your doctor always tells you everything you want to know about your illness</td>
<td>Fidelity</td>
<td>4.50</td>
<td>0.65</td>
<td>-1.5</td>
<td>.65</td>
</tr>
<tr>
<td>6</td>
<td>You think your doctor can handle any medical situation, even a very serious one</td>
<td>Competence</td>
<td>4.50</td>
<td>0.68</td>
<td>-1.2</td>
<td>.69</td>
</tr>
<tr>
<td>7</td>
<td>Your doctor always takes his/her time with you</td>
<td>Caring</td>
<td>4.57</td>
<td>0.67</td>
<td>-1.8</td>
<td>.68</td>
</tr>
<tr>
<td>8</td>
<td>Your doctor explains everything so that you can consent to medical decisions</td>
<td>Fidelity</td>
<td>4.58</td>
<td>0.56</td>
<td>-0.9</td>
<td>.69</td>
</tr>
<tr>
<td>9</td>
<td>Sometimes you worry that your doctor's medical decisions are wronga</td>
<td>Competence</td>
<td>4.32</td>
<td>0.90</td>
<td>-1.5</td>
<td>.57</td>
</tr>
<tr>
<td>10</td>
<td>Your doctor only thinks about what is best for you</td>
<td>Fidelity</td>
<td>4.50</td>
<td>0.65</td>
<td>-1.2</td>
<td>.79</td>
</tr>
<tr>
<td>11</td>
<td>Sometimes your doctor does not pay full attention to what you are trying to tell him/hera</td>
<td>Competence</td>
<td>4.33</td>
<td>0.89</td>
<td>-1.5</td>
<td>.58</td>
</tr>
<tr>
<td>12</td>
<td>Your doctor would always tell you the truth about your health, even if there was bad news</td>
<td>Honesty</td>
<td>4.50</td>
<td>0.67</td>
<td>-1.9</td>
<td>.56</td>
</tr>
<tr>
<td>13</td>
<td>You have doubts whether your doctor really cares about you as a personb</td>
<td>Caring</td>
<td>4.32</td>
<td>1.02</td>
<td>-1.9</td>
<td>.43</td>
</tr>
<tr>
<td>14</td>
<td>Your doctor listens with care and concerns to all the problems you have</td>
<td>Caring</td>
<td>4.47</td>
<td>0.66</td>
<td>-1.2</td>
<td>.79</td>
</tr>
<tr>
<td>15</td>
<td>Your doctor will do whatever it takes to get you all the care you need</td>
<td>Fidelity</td>
<td>4.49</td>
<td>0.70</td>
<td>-1.4</td>
<td>.81</td>
</tr>
<tr>
<td>16</td>
<td>Your doctor is available for you whenever you need him/her</td>
<td>Caring</td>
<td>4.03</td>
<td>0.96</td>
<td>-1.1</td>
<td>.59</td>
</tr>
<tr>
<td>17</td>
<td>You have no worries about putting your life in your doctor's hands</td>
<td>Global item</td>
<td>4.40</td>
<td>0.80</td>
<td>-1.4</td>
<td>.66</td>
</tr>
<tr>
<td>18</td>
<td>All in all, you have complete trust in your doctor</td>
<td>Global item</td>
<td>4.57</td>
<td>0.63</td>
<td>-1.3</td>
<td>.76</td>
</tr>
</tbody>
</table>

aReverse-scored items.

bFive-point Likert scale: totally disagree = 1, disagree = 2, as much agree as disagree = 3, agree = 4, strongly agree = 5.
Our repeated finding of one-dimensionality of patients’ trust confirms earlier quantitative findings [17,25,62]. However, it contradicts qualitative findings suggesting that cancer patients do distinguish between dimensions of trust [13,149]. This apparent discrepancy deserves further research attention. As yet, it appears difficult to quantitatively expose patients’ possible distinction between trust dimensions. Further validation among specific groups of cancer patients with likely more varying levels of trust should be conducted, e.g., among second opinion patients, immigrants, or patients in palliative care, to investigate if the TiOS is responsive to more pronounced dimensionality and varying trust levels.

**Conclusion**

The current results contribute to research on cancer patients’ trust in their oncologist. Use of the TiOS allows further expansion of this field of study, resulting in better insight into the nature, predictors, and consequences of cancer patients’ trust. Confidence in the cross-cultural validity of the TiOS enables its use in different countries, allowing direct comparisons between patients’ trust levels internationally. Ultimately, this could contribute to improved patient care.

**Practice implications**

Our findings suggest that the English translation of the Trust in Oncologist Scale is suitable for use among English-speaking cancer patients in Australia and other countries with similarly organized health care systems. For the present, we suggest that when applying the TiOS, a single score can be used. However, for a more refined understanding of patients’ trust, one might test whether patients in a specific sample distinguish different dimensions of trust.
PART III

Is cancer patients’ trust influenced by how the oncologist communicates?
Developing and administering scripted video vignettes for experimental research of patient-provider communication

Marij Hillen, Liesbeth van Vliet, Hanneke de Haes, and Ellen Smets
Patient Education and Counseling, 2013. DOI: 10.1016/j.pec.2013.01.020
ABSTRACT

Objective
Scripted video-vignette studies enable experimental investigation of specific elements of patient-provider communication, separating cause and effect. However, scripted video vignettes have been infrequently used to this end. Resultantly, few guidelines are available for their design, development and administration. We aim to provide guidelines enabling researchers to make more informed decisions.

Methods
Based on the available methodological literature, we discuss methodological considerations when developing and administering scripted video vignettes.

Results
Developing and using valid video vignettes requires: I) deciding if using video vignettes is appropriate, II) developing a valid script, III) designing valid manipulations, IV) converting the scripted consultation to video, and V) administering the videos. We provide a first checklist of the methodological considerations in each phase. Advantages and pitfalls of possible approaches are discussed.

Conclusions
No ‘gold standard’ can be identified for most methodological issues, as literature testing the consequences of different approaches is lacking. The best approach when developing and implementing video vignettes depends upon the aims and practical limitations of a particular study.

Practice implications
Our checklist may serve as a starting point for further study of scripted video vignettes methodology. More detailed methodological reporting would yield new knowledge, thus allowing the research field to progress.
BACKGROUND

Observational research has been frequently used to investigate the effects of care providers’ communication on relevant patient outcomes [184]. Such research aims to identify, categorize and quantify communication behavior [167]. Although observational research allows registering actual clinical behavior in a non-invasive manner, an important drawback is that it does not permit definitive conclusions about cause and effect [63]. Experimental methods are therefore needed. Experimentally manipulating care providers’ communication behavior in clinical practice is problematic because the manipulations may expose patients to sub-optimal communication. Alternatively, the impact of communication can be investigated in lab settings, by experimentally varying behavior in a hypothetical patient-provider interaction. A specific type of such experimental lab research involves scripted video vignettes.

In patient-provider communication research, scripted video vignettes have been introduced to systematically study the effects of specific communication on patient outcomes. Scripted video vignettes are short visual depictions of pre-written (hypothetical) events. Generally, multiple variations of a scripted vignette are created, depicting a consultation between care provider(s) and patient(s). Except for varying specific elements of communication, all other content of the vignettes is held constant. The role-played video vignettes are viewed by ‘analogue patients’ (APs), who are either (former) patients, or healthy people instructed to imagine themselves in the place of the patient observed in the video [72]. After watching the video vignette(s), APs’ perceptions or evaluations of specific aspects of the videotaped consultation can be assessed. Several outcome measures can be employed: 1) evaluative outcomes, such as perception of the physician [66,185-191] or preference for a consultation style [190,192-194]; 2) affective outcomes, such as (self-reported and/or physiological) anxiety and distress [67,195,196]; 3) behavioral outcomes, such as intended treatment decision [192], self-disclosure [189], and compliance [66,191]; and 4) cognitive outcomes, such as recall [67,196].

The research field using scripted video vignettes of patient-provider communication is still in development. A review of the empirical literature revealed that only 18 experimental video-vignette studies testing the effects of physician communication have been published thus far [197] (see Table 1 for an overview). Results of these studies indicate that video vignettes allow effective manipulation of communication [26,66,187,198,199], are perceived as realistic [66,67,195,199,200], and that observers are well able to immerse themselves in the situation depicted [67,196,200]. Thus, they can yield valid and informative results. Significant effects were indeed established thus far for
evaluative, affective and behavioral outcomes, and in some but not all cases for cognitive outcomes. Thus, the relative scarcity of literature seems not due to a lack of feasibility or validity of this methodology for studying patient-provider communication. An alternative explanation for the limited use of video vignettes is that researchers shy away at, or get lost in, the daunting task of creating and implementing video vignettes. Presently, no clear instructions or guidelines exist on how to deal with the many methodological issues encountered. Very little empirical evidence is available to support one approach over the other.

We aim to advance the field by providing an overview of the methodological considerations encountered in each phase of developing and implementing scripted video vignettes, and possible approaches to address these considerations. This is a first attempt at providing guidelines, to prepare researchers for making the most appropriate choices for their specific situation. It may serve as a starting point for further study of the methodology itself, to enable the development of more specific guidelines and recommendations in the future.

**METHODS**

For our overview, we based ourselves on three sources. First, the method sections of the 18 available studies previously identified were inventoried for methodological issues, possible approaches and their rationales when developing and administering scripted video vignettes in physician-patient communication research. Second, we sought methodological literature on developing vignettes in related fields and using different designs. To that end, literature databases PubMed, Embase, CINAHL and PsychINFO were searched using all variants of the keywords ‘Vignettes’, ‘Methodology’ and ‘Development’. This search yielded three papers exclusively focused on the challenges in the development of vignettes [68,71] or on methodological difficulties [65]. Moreover, four papers presented exceptionally elaborate, stepwise, accounts of their methodological choices during vignette development [69,70,201,202]. All seven methodological articles identified in our literature search are displayed in Table 2. Third, the first and second authors (M.H. and L.v.V.) supplemented the overview based on their experience with developing vignettes.

Through informal discussion between all authors, the methodological issues were formalized and categorized into five phases. These phases are: 1) Deciding if using video vignettes is appropriate (Phase I), 2) Developing a valid script (Phase II), 3) Designing valid manipulations (Phase III), 4) Converting the scripted consultation to video (Phase IV), and
5) Administering the videos (Phase V). All methodological considerations encountered during each of these stages are displayed in Figure 1. Moreover, Table 1 provides an overview of the different approaches used in the 18 empirical studies published thus far, to direct readers to relevant empirical examples.

**Figure 1.** Visual display of the methodological issues encountered in all phases of conducting experimental research using video vignettes

<table>
<thead>
<tr>
<th>Research phase</th>
<th>Methodological dilemmas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase I: Deciding if using video vignettes is appropriate</td>
<td>1. The background of the script based on literature or real interactions</td>
</tr>
<tr>
<td>Phase II: Developing a valid script</td>
<td>2. The proportion of the consultation scripted whole or bridged consultation</td>
</tr>
<tr>
<td>Phase III: Designing valid manipulations</td>
<td>3. Establishing realism which expert to consult at which stage</td>
</tr>
<tr>
<td>Phase IV: Converting the scripted consultation to video</td>
<td>4. Developing an introductory video, written or audio introduction</td>
</tr>
<tr>
<td>Phase V: Administering the videos</td>
<td>1. Operationalizing manipulations: consulting experts determining levels per manipulation</td>
</tr>
</tbody>
</table>

**RESULTS**

**Phase I: Deciding if using video vignettes is appropriate**

Scripted video vignettes are a suitable methodology to answer some questions, but not others. Frequently, researchers using this method have failed to justify their choice (see Table 1). Methodologically, scripted video vignettes may be most appropriate if causal relations between specific elements of communication and particular outcomes are of interest [186,189,194,196,200]. In clinical practice, specific communication elements cannot be isolated as not all behavior can be standardized [65].
### Table 1. Overview of experimental studies of communication in health care using video vignettes and their methodological approach

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Communication variables manipulated</th>
<th>Outcome variable (effects established?)*</th>
<th>Motivation for using vignettes</th>
<th>Phase I</th>
<th>Phase II: Script</th>
<th>Phase III: Manipulations</th>
<th>Phase IV: Videos</th>
<th>Phase V: Administering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aruguete and Roberts, 2002, USA [199]</td>
<td>Non-verbal behavior</td>
<td>- Satisfaction + - Trust + - Self-disclosure + - Willingness to recommend + - Compliance + - Recall = Increased internal validity can be achieved</td>
<td>1. Not reported 2. Videos lasted seven minutes. Each video covered history taking, diagnosis, prescribing medication, prognosis, complications, and follow-up 3. Not reported 4. Not reported</td>
<td>1. Non-verbal behavior (expressing concern or distance). Manipulation involved differences on 5 behavioral dimensions, e.g., eye contact, distance to the patient. No report of operationalization or manipulation basis 2. Only non-verbal 3. Not reported</td>
<td>1. Actors played the patient and physicians 2. The camera was positioned over the patient's shoulder and focused at the physician 3. Not reported</td>
<td>1. Contact style (affiliative vs. controlling). Operationalization included differences on 5 behavioral dimensions. No report of operationalization or manipulation basis 2. Both verbal and non-verbal 3. Not reported</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bradley et al., 2001, Australia [200]</td>
<td>Authoritative and consultative communication styles</td>
<td>- Satisfaction + - Adherence = - Recall =</td>
<td>Ratings can be made independently of confounding factors (e.g., previous exposure to the doctor)</td>
<td>1. Scripts based on informal focus groups and advice from a medical practitioner 2. Videos lasted three minutes. No report of content 3. University students, lay people and health professionals commented on script similarity, credibility, manipulation success, medical content 4. Written introduction of the scenario</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Dowsett et al., 2000, Australia [192]</td>
<td>Patient-centered and doctor-centered communication</td>
<td>- Preference + - Satisfaction +/- - Less skewed satisfaction scores - APs can compare and contrast different styles directly</td>
<td>1. Not reported 2. No report of duration. Each video covered diagnosis, treatment, and prognosis. 3. Not reported 4. Not reported</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1. Professional actors played the patient and physician roles 2. Not reported 3. Pilot-testing conducted only on the scripts (see Phase II.3)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>1. Healthy adults ranging from 17-84 years. Not motivated 2. Observation in groups (up to 30 subjects), participants were instructed not to converse. Setting not described 3. One video per participant 4. Participants were debriefed after participation, not further specified</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>1. Communication style (doctor-centered vs. patient-centered). Operationalizations involved differences on 11 behavioral dimensions. Manipulations based on literature review, observations, interviews with patients 2. Both verbal and non-verbal 3. Not reported</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1. Professional actors played the patient and physician roles 2. Not reported 3. Not reported</td>
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<tr>
<td></td>
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<td></td>
<td>1. Breast cancer survivors and their healthy relatives and friends. Not motivated 2. Not reported 3. Two videos (patient-centered and doctor-centered) per participant. Each participant first saw both versions of the diagnosis, then of the treatment, and finally of the prognosis 4. Not reported</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Author, year, country</td>
<td>Communication variables manipulated</td>
<td>Outcome variable (effects established?)*</td>
<td>Motivation for using vignettes</td>
<td>Phase I</td>
<td>Phase II: Script</td>
<td>Phase III: Manipulations</td>
<td>Phase IV: Videos</td>
<td>Phase V: Administering</td>
</tr>
<tr>
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</tr>
<tr>
<td>Study</td>
<td>Type of Study</td>
<td>Level of comfort</td>
<td>Description</td>
<td></td>
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</tr>
</tbody>
</table>
| Floyd et al., 1999, USA [193] | Physician's interview approach to assess HIV risk | None             | 1. Not reported  
2. No report of duration or content  
3. Not reported  
4. Not reported  
1. Interview technique. Operationalization included five areas of the interview, encompassing two or three possible recommended techniques for each area. No further report of operationalization and manipulation bias  
2. Not reported  
3. Not reported  
4. Not reported  
1. Healthy students and seniors. Not motivated  
2. Observation in groups. Setting not described  
3. All videos were observed by all participants  
4. Not reported |
| Gerbert et al., 2003, USA [190] | Physician gender and ethnicity | Preference + Perception of physician + | APs can compare and contrast different physicians directly  
1. Scripts based on literature on the effectiveness of short health advice interventions  
2. Videos lasted 45 seconds, and included a short health advice message  
3. Not reported  
4. Physicians introduced themselves briefly to the camera  
1. Gender (male vs. female) and ethnicity (African American, Latino, or European American). Operationalization established by using different actors  
2. Only non-verbal  
3. No duration differences  
1. Actors played the physicians. They were similar in age and attractiveness  
2. The physician gazed directly into the camera. No patient was visible or audible  
3. Not reported  
1. Healthy people visiting a shopping mall. Not motivated  
2. Not reported  
3. All five videos observed by all participants  
4. Not reported |
<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Communication variables manipulated</th>
<th>Outcome variable (effects established?)*</th>
<th>Motivation for using vignettes</th>
<th>Phase I</th>
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<th>Phase III: Manipulations</th>
<th>Phase IV: Videos</th>
<th>Phase V: Administering</th>
</tr>
</thead>
</table>

1. Not reported 2. Videos lasted 12 minutes (consisting of 24 fragments of 30 seconds). No report of content 3. Not reported 4. No introduction, but four 'practice trials' to acquaint participants with the procedure

1. Non-verbal behaviors: trunk angle (forward, straight, or backward), arm position (open vs. folded), leg position (open vs. crossed). No report of operationalization and manipulation basis 2. Only non-verbal; all verbal content filtered out 3. Not reported

1. Four family medicine residents played the physicians 2. Actors were recorded at an angle of 45° orientation toward the camera, facing the simulated patient. Only the patient's legs and feet were visible so that patient was unrecognizable 3. Not reported
<table>
<thead>
<tr>
<th>Study</th>
<th>Outcome Measure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Satisfaction</td>
<td>Full disclosure, an existing positive relationship, offering to waive costs, and severity of clinical outcomes of a medical error - Changing physicians + - Seeking legal advice +/- - Satisfaction + - Trust + - Emotional response +/-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Outcome Measure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mazor et al., 2006, USA</td>
<td>Full disclosure</td>
<td>None 1. Not reported 2. Not reported 3. Not reported 4. Not reported 1. Medication error type (missed allergy vs. inadequate monitoring), outcome (life threatening vs. less serious), physician disclosure (full vs. non-disclosure), costs handling (waive costs vs. no reference to costs), prior positive relationship (yes vs. no). Operationalization by variations in physician communication and information through voice-over. No report of manipulation basis 2. Not reported 3. Not reported 4. Not reported</td>
</tr>
</tbody>
</table>

1. Not reported 2. Not reported 3. One video per participant 4. Not reported 1. Patients awaiting their appointment in a medical clinic. Not motivated 2. Not reported 3. Observation in private. Setting not described 4. Beforehand, the study was described as focusing on doctor-patient communication about medical errors. Debriefing afterward not reported 1. Health plan members. Not motivated 2. Observation in private. Setting not described 3. One video per participant 4. Beforehand, the study was described as focusing on doctor-patient communication about medical errors. Debriefing afterward not reported
Table 1. Continued

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Communication variables manipulated</th>
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<th>Phase IV: Videos</th>
<th>Phase V: Administering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Porensky, 2010, USA (PhD Thesis)</td>
<td>Forecasting bad news and framing prognostic information</td>
<td>Psychological distress +/- Recall = Prognosis interpretation + Hopefulness +</td>
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<td>- One aspect of the interaction can be isolated and manipulated</td>
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<tr>
<td>- Patient outcomes can be assessed directly after the bad news conversation</td>
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<tr>
<td>1. Information provided in script was based on oncologic literature, and in accordance with recommendations for delivering bad news</td>
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<tr>
<td>2. Each video covered only the diagnosis (two minutes) and prognosis (two minutes) parts of a consultation</td>
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<td>3. Not reported</td>
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<td>4. Written introduction of the situation and medical history</td>
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<tr>
<td>1. Warning before diagnosis (yes vs. no), framing of prognosis (positive vs. negative). Operationalization of the warning condition included the addition of one extra statement. Prognosis framing manipulated in two sentences with reversed framing. No report of manipulation basis</td>
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<td>2. Mostly verbal, but slight non-verbal aspects (i.e., eye contact in warning condition)</td>
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<td>3. Approximately same length</td>
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<tr>
<td>1. A physician played the physician</td>
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<td>2. The physician directly faced the camera as if talking to the observer directly, to enhance realism. No patient participated in the video. Recording in physician's own office</td>
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<td>3. Individual pilot-testing (with ten older adults (50-87 years)) to test manipulation success, setting, and ability to imagine oneself in the situation described</td>
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<tr>
<td>4. Participants were debriefed afterward. Not further specified</td>
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<tr>
<td>1. Healthy adults ranging from 50-87 years, to resemble colon cancer patients' age range</td>
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<tr>
<td>2. Observation in private. Videos were viewed in an experiment room, on a desktop computer screen</td>
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<tr>
<td>3. One diagnosis and one prognosis segment per participant</td>
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<tr>
<td>4. Participants were debriefed afterward. Not further specified</td>
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</tbody>
</table>
### Table 1. Continued

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Communication variables manipulated</th>
<th>Outcome variable (effects established?)*</th>
<th>Motivation for using vignettes</th>
<th>Phase I</th>
<th>Phase II: Script</th>
<th>Phase III: Manipulations</th>
<th>Phase IV: Videos</th>
<th>Phase V: Administering</th>
</tr>
</thead>
</table>
| Roberts and Aruguete, 2000A, USA [189] | Task- and socioemotional behavior | - Satisfaction +/-  
- Trust +/-  
- Self-disclosure +/-  
- Willingness to recommend +/-  
- Compliance =  
- Recall of information = | One aspect of the interaction can be isolated and manipulated | 1. Not reported  
2. Videos lasted seven minutes. Each video covered diagnosis, prognosis, medication prescription, and life style recommendation | 1. Operationalization  
2. Verbal/non-verbal  
3. Compensating duration differences | 1. Actors  
2. Camera perspective  
3. Pilot-testing | 1. Viewing  
2. Setting  
3. Number of videos per viewer  
4. Informing/debriefing | 1. An actor played the physician. The actor was a white, 60-year-old, male  
2. The appearance and dialogue of the patient was minimal and the physician appeared to directly to the observer, to facilitate participant imagination  
3. Not reported | 1. Patients awaiting their appointment in a student health clinic. Not motivated  
2. Observation in private. Videos were viewed in a room free of distraction  
3. One video per participant  
4. Beforehand, the study was described as investigating physician-patient communication. Debriefing afterward not reported |
<table>
<thead>
<tr>
<th>Saha and Beach, 2011, USA [191]</th>
<th><strong>Patient-centered communication (PCC) behaviors</strong></th>
<th><strong>None</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Trust +</td>
<td>1. Not reported</td>
<td>1. Patient-centered communication (high vs. low). Operationalization of high PCC based on two core elements: biopsychosocial orientation and partnered approach, and specific associated behaviors. Manipulations based on aspects mentioned in literature</td>
</tr>
<tr>
<td>- Liking +</td>
<td>2. Videos lasted between four minutes and five minutes and 20 seconds. No report on content</td>
<td>2. Both verbal and non-verbal: non-verbal behaviors reinforced verbal behaviors</td>
</tr>
<tr>
<td>- Competence +</td>
<td>3. Experts (patients, healthcare professionals, and a researcher) consulted on accuracy of script content and realism of dialogue, in multiple iterations</td>
<td>3. High PCC version was longer. No compensation; altering dialogue pace to compensate for the difference resulted in less realistic takes</td>
</tr>
<tr>
<td>- Overall evaluation +</td>
<td>4. Written introduction covering brief description of the history, displayed on introductory screen</td>
<td>4. Beforehand, the study was described as investigating patients’ decision making about heart disease. Debriefing afterward not reported</td>
</tr>
<tr>
<td>- Necessity of treatment +</td>
<td>1. Patient with a cardiac disease diagnosis or at risk, to ensure that the videos were of relevance to them</td>
<td>1. Professional actors played the patients (male and female) and physicians. The physicians wore scrubs, white coats and stethoscope. A professional director ensured standardization of behaviors between actors</td>
</tr>
<tr>
<td>- Treatment decision +</td>
<td>2. Observation in private. Setting not described</td>
<td>2. The videos were recorded using the patient's point-of-view angle facing the physician. The patient was not seen, to facilitate participants’ identification.</td>
</tr>
<tr>
<td></td>
<td>3. One video per participant</td>
<td>3. Not reported</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Communication variables manipulated</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>4. Introduction</td>
<td></td>
<td></td>
<td>4. Informing/debriefing</td>
</tr>
</tbody>
</table>

1. Consultation style (patient-, disease-, or emotion-centered). Operationalization involved providing information and emotional support according to the patient's needs (patient-centered), providing medical information to the physician's standard (disease-centered) or dealing explicitly with sadness and anxiety (emotion-centered). Script examples provided in the paper. No report of manipulation basis.


3. Coding of the communication in the vignettes with RIAS codes (by the researchers) to assess manipulation success.


2. Observation in groups of 2-23 people, participants were instructed not to converse. Setting not described.

3. One video per participant.

4. Not reported.
<table>
<thead>
<tr>
<th>Study</th>
<th>Communication style</th>
<th>Avoiding ethical problems that would arise when varying communication in clinical care</th>
<th>Operationalization of patient-centered communication style involved developing an understanding of the patient as a person, conveying empathy and finding common ground. Manipulations based on interviews with physicians and empirical literature.</th>
<th>1. Information provided in script based on oncology literature 2. Videos lasted four minutes. No report of content 3. Not reported 4. Read-aloud introduction describing the situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shapiro et al., 1992, USA [67]</td>
<td>Worried or non-worried communication style</td>
<td>- Anxiety + - Recall + - Perceived severity of situation +</td>
<td>1. Presentation of ambiguous mammography results (worried vs. nonworried). Operationalization involved either tense and anxious or calm and relaxed appearance of physicians. No report of manipulation basis 2. Both verbal and non-verbal 3. Not reported</td>
<td>1. Not reported 2. Not reported 3. Individual pilot-testing (with 22 women) to assess manipulation success, realism, and ability to imagine oneself in the situation described</td>
</tr>
<tr>
<td>Swenson et al., 2004, 2006, USA [194]</td>
<td>Patient-centered (PC) or doctor-centered (DC) communication</td>
<td>- Less skewed distributions - One aspect of the interaction can be isolated and manipulated</td>
<td>1. Scripts based on interviews with physicians and a working group of communication experts 2. Videos lasted two to three minutes. No report of content 3. Not reported 4. Not reported</td>
<td>1. Professional actors played the patients and physicians 2. Not reported 3. Individual pilot-testing (with ten physicians in general internal medicine) to assess face validity of the videos</td>
</tr>
</tbody>
</table>

1. Women at risk for breast cancer. Not motivated 2. Observation occurred in private, in a laboratory. Videos were watched on a large television monitor 3. One video per participant 4. Not reported
**Table 1.** Continued

<table>
<thead>
<tr>
<th>Author, year, country</th>
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<th>Outcome variable (effects established?)*</th>
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<th>Phase IV: Administering</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>- Compliance +/-</td>
<td>1. Not reported 2. No report of duration or content 3. Not reported 4. No introduction of situation, but role-induction (including description of the nature of the video)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>1. Courtesy (highly courteous vs. relatively inconsiderate) and competence (highly vs. less competent). Operationalization of courtesy involved 18 behaviors identified in previous research. Operationalization of competence involved showing all vs. a selection of 18 guideline behaviors. Manipulations based on previous study and physician guidelines 2. Both verbal and non-verbal 3. Not reported</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>1. Actors played the patient, physician and nurse 2. Not reported 3. Individual pilot-testing (with 28 students) to assess manipulation success and realism</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>1. Healthy psychology students. Not motivated 2. Observation in small groups (8-15 participants). Setting not described 3. One video per participant 4. Beforehand, the study was described as focusing on ‘consumer perceptions’. Debriefing afterward not reported</td>
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</table>

This selection of literature was based on a systematic review by Van Vliet et al. about the use of analogue patients in clinical and scripted video-vignette studies [197]. We excluded all clinical studies identified in this review, leaving 16 published video-vignette studies. Two studies not included in the review were added, one of which is a non-peer-reviewed PhD thesis published online [188,196]. We included both studies in the overview as they report in detail about their methodology, and could therefore be illustrative to the reader. For a more elaborate study description and review of the studies, we refer to Van Vliet et al. [197].

* '+' indicates significant effects, '=' indicates no significant effects, '+/-' indicates significant effects for part of the manipulations.

** Studies not included in the review by Van Vliet et al.
In scripted video vignettes, all elements (communication as well as context) except for the intended manipulation can, and must, be kept constant [186], allowing definitive conclusions about cause and effect. For example, specific variations in the phrasing of a diagnosis can be contrasted while the remainder of the consultation is standardized [196]. Moreover, analogue patients may provide less skewed outcome ratings than are often found in clinical practice [192,194]. This may be because social desirability is reduced. Especially when assessing evaluative outcomes such as satisfaction and trust, patients are often hesitant to be critical of their own healthcare provider. In video-vignette studies, APs may be able to provide more autonomous ratings [197]. Ethically, for studies that investigate the effect of potentially harmful communication, scripted video vignettes provide an alternative to manipulating communication in real-life situations, especially when participants are from a vulnerable patient group [66,67]. For example, in a study manipulating physicians’ information giving behavior, it may be expected that a lower amount of information could negatively impact on real patients, making a lab setting more appropriate [66].

Scripted video vignettes also have their disadvantages, the most important one being their possible limited ecological validity. Even maximally realistic vignettes will differ from communication as it naturally unfolds. For example, viewers cannot ask questions and care providers cannot tailor their communication [67]. Consequently, not all conversational elements can be tested using video vignettes. Additionally, isolating specific communication elements means employing a reductive approach, which may oversimplify the rich and complex reality of communication [68]. For a more elaborate overview of advantages and disadvantages of using scripted video vignettes, see Van Vliet et al. [197].

**Phase II: developing a valid script**

*The background of the script*

A script can be written based either on literature guidelines and experience [67,190,194,196,200] or on real interactions [195] (see Table 1). Drawing from one’s own experience or that of experts allows shaping of the consultation content completely according to the researcher’s wishes. It could, however, result in a less realistic script. When using real audio- or videotaped consultations as a basis, precise phrasings can be integrated verbatim into the script. This does require that the original consultations are representative of the situation aimed to be depicted.
The proportion of the consultation scripted

The script can reflect a whole consultation or, alternatively, encompass part(s) or an abridged version of the consultation [see e.g., 194,196]. Abridged scripts may come at the expense of ecological validity. They will, however, reduce the time and effort needed to create and administer the videos. Moreover, if manipulations are subtle and small, their impact may be larger when using shorter videos, as participants are allowed to focus more closely [65]. For example, in a study investigating the impact of oncologist communication on patients’ trust, the planned manipulations were small, encompassing only a few sentences. Therefore, the script was cut down to last only five minutes, while the researchers made sure that essential elements of the consultation were preserved (Hillen et al., submitted). In the studies published thus far (see Table 1), vignettes were usually shorter than real consultations (lasting on average approximately seven minutes, range 2–19 minutes), but included at least their basic elements, e.g., diagnosis, treatment, and prognosis [189,192,195,199]. Others focused on one or two segments of the consultation only [26,196].

Establishing realism

Realism of the script can be evaluated by consulting various experts, such as healthcare professionals, patients, and/or researchers from the same field. These experts can comment on the script’s realism, regarding both communicative behavior and context [191,200]. Additionally, professional film makers can advise on script fluidity [69]. As Table 1 shows, consultation of experts at this stage is not commonly performed. In some studies, however, experts consulted at other development stages may have been involved during script development as well.

Developing an introduction

An introduction to familiarize participants with the observed situation can be presented in several ways: face to face by the researcher [67], written on paper [196,200] or on the video screen [191], read aloud by voice-over (Hillen et al., submitted), or enacted by the characters from the video consultation [190] (see Table 1). In the latter case, the patient and/or care provider might introduce themselves to the camera, as if interviewed in documentary-style.

An advantage of using a video introduction is that it allows participants to grow accustomed to multiple facets of the subsequent video. They can process basic elements, such as the setting or characters’ appearance, allowing them to focus more on the communication elements of the subsequent experimental video. A video introduction in
documentary-style may have a relatively strong emotion-inductive effect [203-205], creating empathy and emotional involvement with the patient depicted, which may or may not be desirable depending on study aims. A disadvantage of emotion-induction is that it is difficult to assess how and to what extent the introductory video influences participants’ subsequent perception. Therefore, if the introduction is intended to be purely informative, a written introduction or audio introduction by voice-over is preferred.

Phase III: designing valid manipulations

Operationalizing manipulations

When a basic script is ready, variations of the script need to be created, requiring careful consideration of both the operationalization of the independent variable(s) and the ideal number of manipulation levels [65]. Elementary factors, such as ‘warning before diagnosis’ [196], or ‘arm position’ [185] allow for straightforward operationalization. Many studies, however, aim to manipulate less clearly defined concepts (see Table 1), e.g., ‘patient-centered communication’ [191,192,194] or ‘the expression of compassion’ [195]. Operationalizing such concepts requires more elaborate motivation. To ensure internal validity, a possible effect should be attributable only to a manipulation of the variable of interest. Resultantly, studies manipulating very specific, isolated, behaviors are more powerful than those combining several behaviors into one manipulation. Experts can be consulted at this stage to ensure that the proposed manipulations are distinguishable, yet not caricatures of normal practice [65]. Researchers have based the translation of elusive concepts in manipulations on (empirical) literature [66,116,191,192,200], and/or qualitative exploration among the target group [66,192] (see Table 1).

A final consideration is how many levels of the variable of interest are to be presented: two (e.g., standard vs. enhanced expression of empathy [195]), or three or more (e.g., patient-, vs. disease- vs. emotion-centered consultation style [187]). More levels allow the identification of optimal levels of performance, in case of a non-linear (e.g., curvilinear) relationship. However, including more than two levels requires a larger sample size to demonstrate effects with sufficient power. Moreover, if more than one variable is manipulated, a sufficient number of vignette versions should be created to encompass all possible combinations of the manipulations [65].
Table 2. Overview of the methodological literature on the development and use of vignettes

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Field of study</th>
<th>Types of vignettes</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heverly et al., 1984, USA [65]</td>
<td>Medicine; clinical judgment</td>
<td>Written</td>
<td>Stepwise description of methodological problems encountered when developing case vignettes. Focus on developing multiple (non-communication) manipulations</td>
</tr>
<tr>
<td>Hughes, 2002, UK [68]</td>
<td>Social and nursing research</td>
<td>All types (both written and video)</td>
<td>Consideration of both the advantages and the pitfalls of using vignettes, most importantly external validity</td>
</tr>
<tr>
<td>Poulou and Brahm, 2001, Greece [71]</td>
<td>Education; teachers' perceptions and decisions</td>
<td>Written</td>
<td>Comparison of vignettes with other techniques. Consideration of advantages and limitations.</td>
</tr>
<tr>
<td>Kim et al., 2011, USA [201]</td>
<td>Medicine; medical communication assessment</td>
<td>Video</td>
<td>Stepwise elaborate description of vignettes development</td>
</tr>
<tr>
<td>Lapatin et al., 2012, USA [202]</td>
<td>Medicine; health disparities research</td>
<td>Written</td>
<td>Stepwise elaborate description of vignettes development</td>
</tr>
<tr>
<td>Schoenberg and Ravdal, 2000, USA [70]</td>
<td>Social research; attitudes and awareness</td>
<td>Written</td>
<td>Elaborate description of vignettes development, focus on advantages and difficulties</td>
</tr>
<tr>
<td>Johnson, 2000, Australia [69]</td>
<td>Education; children's safety knowledge</td>
<td>Video</td>
<td>Elaborate description of vignettes development, discussion of methodological and ethical difficulties</td>
</tr>
</tbody>
</table>

The verbal and/or non-verbal nature of the manipulations

Manipulations may encompass verbal or non-verbal elements, or both. It may be difficult and even artificial to distinguish verbal from non-verbal communication in manipulations, because they are so tightly linked [206]. Including both verbal and non-verbal elements in manipulations could thus enhance realism and ensure ecological validity. For example, in one study varying patient-centered communication, the manipulation encompassed both verbal and non-verbal behaviors, as the authors argued that patient-centered communication behaviors would unlikely occur in isolation [191]. Most frequently, verbal and non-verbal behaviors are manipulated simultaneously (see Table 1).

The downside of this approach, however, is that it reduces the possibility of causal attribution. If both verbal and non-verbal aspects are varied, one cannot be sure whether a possible effect was caused by what someone said or how the person said it. To disentangle verbal from non-verbal effects, in a study manipulating only non-verbal
behavior, video vignettes were presented to participants without sound [185]. Ideally, all combinations (i.e., verbal and non-verbal, only verbal, only non-verbal, and neither verbal nor non-verbal) would be included into the design as separate conditions. In reality, however, this may not always be feasible, since it requires more video versions as well as a larger sample size. Therefore, researchers will have to weigh ecological validity against causal attribution.

Compensating for duration differences

Including manipulations into the basic script will almost invariably result in duration differences between different versions. Time may then account for a possible effect instead of the manipulation. Duration differences can either be compensated for, or accepted. Compensation may include adding ‘fillers’ to the script, i.e., segments of communication not containing significant content. Alternatively, the actors can alter dialogue pace. Both options, however, have similar drawbacks. First, it may be more difficult to keep the script realistic when using fillers or altering dialogue pace, and second, one can never rule out that the ‘filler’ produces its own effect, thus becoming a manipulation in itself. Moreover, it may be argued that duration differences are characteristic of real consultations. For example, in practice, a consultation with a more empathic physician might last longer [207]. This rationale has previously motivated researchers to retain small duration differences between different conditions [e.g., see 191]. No studies reported compensating for duration differences between vignette versions (see Table 1).

Phase IV: converting the scripted consultation to video

Choosing appropriate actors

To play the script characters, either real care providers [185,187,195,196] or professional actors [66,189-192,194,198-200] can be recruited (see Table 1). Real care providers are chosen because they may portray their roles most realistically. Moreover, they are likely to have a natural way of expressing and using medical language. On the other hand, the design of a vignette study requires actors to precisely adhere to the script, and to repeatedly play several slightly different versions of the same script. This may be impossible for care providers. They may be inclined to stick to their usual consultation style. Both for adhering to a script, and for replicating and portraying different styles, professional actors may be better equipped.

An additional consideration is the appearance of the care provider or patient to be portrayed. Their age, gender and ethnicity, as well as their attire and the room
furnishing will inevitably impact on participants’ perception. For the care provider role, researchers might select an actor with prototypical age and gender, to enhance viewers’ perception of reality. For the patient role, identification by as many participants as possible optimizes external validity. If, for example, APs are sampled from a large age range, a middle-aged video patient may enable maximal identification by most participants. Considerations regarding appearance of the characters may also depend on the precise research question. Previous studies have provided no or limited information on characteristics of the actors or professionals who played their vignettes, with some exceptions [189-191] (see Table 1).

Determining the camera perspective

The camera perspective impacts on viewers’ perception of a video [208], and could thus contribute to the vignettes’ external validity. The camera may either show only what the patient views (i.e., facing the care provider), or alternate between the patient’s and the care provider’s point-of-view (POV). Using only the patient's POV [189,191], the patient is not visible, or only over the back of the shoulder (see Figure 2A). The care provider faces the camera, gazing into it directly (if the patient is not visible), or slightly right or left of it (if the patient is viewed over the shoulder). When both viewpoints are used, the patient’s POV alternates with the care provider’s POV, possibly using overview shots of the setting additionally (see Figure 2B). Using this approach, the patient is clearly identifiable, unlike when only the patient’s POV is used.

It has been argued that if the patient is not visualized, viewers will instead infer the patient’s feelings themselves, invoking empathic involvement [209]. Others argue that the two approaches invoke different types of empathy: alternating views create ‘embodied empathy’, i.e., experiencing the bodily and affective feelings of the observed patient, whereas using only the patient’s POV is thought to create ‘imaginative empathy’ in viewers [185,189-191,196,199] (see Table 1). Such imagination is used to enact the patient’s mental experience [208]. This distinction has also been labeled differently, as ‘perspective taking’, i.e., imagining experiencing the emotions of the video character, versus ‘empathy’, i.e., imagining what the video character feels like [210]. A disadvantage of hearing but not or barely seeing the patient is that it may feel alienating to viewers. Moreover, to achieve emotion induction and ‘embodied empathy’ among participants, alternating views may be most appropriate, as they allow close-ups of the patient and care provider at crucial (emotional) moments.

Finally, the choice of camera viewpoint has practical consequences for editing. Alternating viewpoints allows flexible cutting between different takes. The patient’s POV,
on the other hand, dictates either very long takes or a very fluent transition of one shot into the other.

**Pilot-testing the videos**

Pilot-testing of the videos is not restricted to one specific development phase; it can be used to test the basic script, the manipulations, and/or the eventual video-recordings. Thus, pilot-testing may serve several purposes: it can enhance internal validity, by establishing manipulation success, and external validity, by investigating realism and participants’ involvement in the videos. Peer researchers, potential participants, and experts may be involved. The extent and focus of pilot-testing varies strongly between published studies, and is often not clearly reported (see Table 1).

To test realism, questions used are ‘I think these films are realistic’ [67], or ‘As a portrayal of a doctor-patient relationship, this videotape is believable’ [66]. To assess manipulation success, pilot participants can be asked to score the script or video characters on the manipulated variable, using a variety of adjectives. For example, in a study manipulating a directive versus a shared decision making style, pilot participants were asked to score both versions on power, authority, directing, sharing, cooperation, negotiation, and one-sidedness [26]. Involvement has been tested by asking how well participants were able to put themselves in the scene or imagine what the video-patient is going through [66,67]. Alternatively, a validated scale assessing ‘transportation skill’, i.e., viewers’ absorption into a story, might be used [211].

The more extensively and the further on in the development process the pilot-testing is performed, the more informative results it will produce, yet, the more expensive and time-consuming it will be to adjust the video vignettes. Similarly, using a variety of pilot participants, e.g., both clinicians and patients, will more likely ensure that realism, involvement and successful manipulation are accomplished. Because of budget or time constraints, researchers may need to adopt a middle course between optimizing the quality and effectiveness of their vignettes, and remaining within the range of what is practically possible.
Figure 2. Schematic display of two alternative approaches to camera perspectives

A. Only point-of-view angle facing care provider.

Point-of-view angle facing care provider, and patient only visible over the shoulder

B. Alternating viewpoints

1. Point-of-view angle facing care provider

2. Point-of-view angle facing patient

3. Overview shot showing both care provider and patient
Phase V: administering the videos

Choosing viewers

Viewers in video-vignette studies, i.e., analogue patients (APs), can be actual or former patients [26,186,189,191,194,199], healthy participants [66,67,187,188,190,193,196,198,200,212], or all three [192,195] [see also 197]. Sampling choices have seldom been motivated by researchers (see Table 1). Proponents of involving actual or former patients as APs believe this will enhance external validity [191]. Healthy participants may be recruited out of convenience, because it is considered more ethical, or because researchers are interested in their perceptions specifically [187]. Evidence thus far indicates that there is little difference between perceptions and evaluations of patients and healthy participants, justifying the use of the latter [192,195]. When involving healthy participants, matching them with the patient population of interest, e.g., in age and gender, has been suggested to improve external validity [68].

The choice of participants will also affect issues regarding the vignettes development. For example, healthy participants may be less familiar with the situation depicted in the video, requiring a different introduction than patients.

Arrangement of the setting

The viewing location and its arrangement may impact on APs’ ability to immerse themselves in the observed consultation. It can be argued that the more the setting resembles the observed consultation, the better observers will be able to identify with the situation. This may motivate researchers to equip a (medical) consultation room as viewing location. Alternatively, maximal ‘absorption’ into the story might be achieved by creating a more cinematic setting, including an obscured room. The video and audio equipment should be of good enough quality to allow participants to immerse, including a monitor that depicts the video character at a size comparable to real life. Whether and how these context factors actually impact on patients’ perception has, to the best of our knowledge, not been empirically tested. Detailed reports of viewing location or equipment are lacking in the current studies (see Table 1).

Participants can view the vignettes either in private [67,188,189,191,196,199] or in groups [26,66,187,193,195,200]. If researchers aim to create viewing conditions similar to the observed consultation, viewing in private may be preferable. Viewing the vignettes in groups can hamper participants’ ability to immerse in the observed consultation. When in groups, people may use certain emotion regulation strategies, such as distraction, which
are not used when alone [213]. This is undesirable when assessing an affective outcome measure, such as anxiety. For evaluative outcomes as well, group processes may impact on patients' personal ratings. Such emotion regulation might be reduced by creating ‘cinematic’ viewing conditions (including a large screen and darkness) during group viewings. Advantages of group viewings are that they are more efficient. Moreover, they enable organized group discussions after viewing.

Determining the number of videos per viewer

APs can be shown one vignette version [66,67,186-189,191,195,196,198-200], or several versions [26,185,190,192-194]. Showing more than one video to each viewer yields more observations, which will increase statistical power. Second, it induces contrast, thus allowing participants to compare videos [214]. A drawback is that showing several vignettes to the same participant will introduce a second level of analysis, as observations are correlated, thereby complicating statistical analyses. Moreover, possible order effects need to be accounted for in the design and analysis phase. Third, participants may lose their ability to distinguish between versions after seeing too many similar vignettes. Also, information from previous observations may interfere with subsequent ones. Using cognitive outcomes, such as recall, may not be feasible with multiple viewings. To reduce ‘blurring’ of the different videos and potential learning effects, a distraction task can be provided to APs between viewings. Alternatively, the time period between the videos can be elongated. Neither of these strategies against blurring effects was reported thus far (see Table 1).

Informing and/or debriefing viewers

Well-constructed video vignettes should not be distinguishable from video recordings of real medical consultations. This poses a dilemma for researchers: to what extent are APs informed about the fact that the vignettes are simulated? If viewers expect to be watching a real consultation, they may more easily identify with the patient. APs can be debriefed after their participation. However, researchers or medical ethical committees may object to deceiving participants in this respect, especially since some medical consultations can have a strong emotional impact on patients. Moreover, viewers may understand that the consultations are not real when viewing a second, similar, video. As a consequence, they will view the second video less unbiased than the first. In this case, viewers may rather be informed in advance to ensure that the different observations remain comparable. Alternatively, researchers may clarify that the vignettes represent actual situations, but are enacted without the actual patients for privacy reasons. None of the published studies
thus far reported the extent to which APs were informed about the nature of the videos (see Table 1).

To assess how biased participants view the vignettes, it may be relevant to assess, directly after each vignette, how well they could immerse themselves in the video consultation, and how realistic they thought the videos were. Ratings of perceived realism may be used as potential confounders in analysis [198], although no empirical studies reported doing so (see Table 1).

**DISCUSSION AND CONCLUSION**

**Discussion**

We have provided an overview of the various methodological considerations when conducting experimental research using scripted video vignettes to study patient-provider communication. For each phase of development and implementation, we discussed limitations and advantages of possible approaches. Our overview can be helpful for making more informed methodological decisions and writing more standardized and detailed methods sections in future articles.

Overall, no gold standard exists for how best to tackle many of the methodological issues. Many of the 18 published studies failed to report or justify a number of their choices. There is little empirical evidence for the exact effects of the various possible approaches. Consequently, it is generally not possible to provide evidence-based recommendations. Instead, we described the advantages and disadvantages of possible approaches, based on the existing literature and our own experience.

In the present paper, our focus was on the use of video vignettes within the healthcare setting, testing the effects of communication on patients. However, vignettes have been employed in a wider range of research topics and study designs, both within and outside of the medical setting [65,68]. The literature identified in our broader search of methodological literature on vignettes development describes partly similar methodological difficulties. Therefore, researchers may refer to the wider field of vignette development for inspiration.

However, guidelines for how to develop vignettes appear virtually nonexistent, not only in the doctor-patient communication research field, but over the entire range of vignettes research; its methodology has not been standardized. Therefore, studies that
empirically investigate and compare the consequences of different methodological approaches are needed, to enable more evidence-based design choices in future research. For applying video vignettes in experimental research of doctor-patient communication, we suggest that methodological investigation first focuses on maximizing participant identification with the video character. To that end, the relative impact of the choice of viewers, the type and content of an introduction, and different camera perspectives should be examined first. Such methodological evidence will increase the validity of eventual findings, and might lead to the creation of a guideline for optimal methodological choices.

Such research is even more relevant since making substantiated choices can prevent unnecessary investments of money and time. The whole process of developing scripted video vignettes, depending on the size of the research team and availability of resources, takes at least a couple of months, and can be very expensive. If video recording (including actors, film equipment, and crew) has to be repeated after unsatisfactory pilot-testing results, this will add significantly to time and money investments. Unnecessary other costs can be avoided if well-informed methodological decisions are made well in advance. Elaborate accounts of the proposed methodology will also facilitate the process of receiving ethical approval. Because of their unfamiliarity with video vignette methodology, ethical committees may be hesitant or overly critical in granting consent. This process will be facilitated if methodological decisions are well founded.

Methodological choices eventually made should be strongly guided by the study aims and outcome measure(s). A study assessing patients’ trust in a physician requires a different methodological approach than one assessing recall accuracy or signs of distress. If, for example, emotions are the main outcome, one needs to realize that particular content beyond manipulation can unintentionally evoke emotions.

This paper has some limitations. First, our overview of different possible methodological approaches was based on a limited body of literature. This was unavoidable, as methodological literature on video vignette development is scarce. Second, although we elaborately searched the broader range of literature of vignette development, this paper was not intended as a systematic review but as a practical tool. Therefore, our broader literature overview may not be fully exhaustive. Concluding, our paper should be viewed as a starting point rather than a definitive overview, upon which future research can build.

**Conclusion**

Development and administration of scripted video vignettes for experimental research on patient-provider communication is a research area still in development. No ‘gold standard’
exists for most methodological issues encountered when conducting this type of research, as literature testing the consequences of different approaches is lacking. Methodological literature from related research fields can be consulted, but equally lacks standardization. The best approach when developing and implementing video vignettes depends upon the aims and practical limitations of a particular study.

**Practice implications**

Our overview will hopefully enable researchers to make informed decisions that best fit their research aims while keeping in mind practical limitations. Figure 1 can be used as a checklist for researchers to make sure that all relevant issues are considered. Moreover, the checklist provides an opportunity for standardizing methods sections of future papers. We suggest that in future scripted video-vignette studies, researchers provide detailed descriptions of their methodological choices. In an aligned publication, we describe a video-vignette study's methodology in detail [215]. Such descriptions can guide future researchers, will ultimately enhance the quality of future studies using video vignettes, and thus advance the evidence in the field.
How can oncologist communication enhance patients’ trust? An experimental study

Marij Hillen, Hanneke de Haes, Lukas Stalpers, Jean Klinkenbijl, Eric Hans Eddes, Phyllis Butow, Jane van der Vloodt, and Ellen Smets

Submitted
ABSTRACT

Background
Cancer patients need to trust their oncologist to embark in the process of oncologic treatment. Yet, it is unclear how oncologist communication contributes to such trust. The aim of this study was to investigate the effect of three elements of oncologists’ communication on cancer patients’ trust: conferring competence, honesty, and caring.

Methods
Eight videotaped consultations, 'vignettes', were created, reflecting an encounter between an oncologist and a patient with colorectal cancer. All vignettes were identical, except for small variations in the oncologist’s verbal communication. Cancer patients (N = 345) were randomly assigned to viewing two vignettes, asked to identify with the patient and afterwards to rate their trust in the observed oncologist. The effects of competence, honesty, and caring on trust were established with multilevel analysis.

Results
Oncologist’s enhanced expression of competence (β = .17, 95% CI .08, .27; p <.001), honesty (β = .30, 95% CI .20, .40; p <.001), as well as caring (β = .36, 95% CI .26, .46; p <.001) resulted in significantly increased trust. Communication of honesty and caring also increased patients’ expectation of operation success and reported willingness to recommend the oncologist.

Conclusions
As hypothesized, oncologists can influence their patients’ trust by enhanced conveyance of their level of competence, honesty and caring. Caring behavior has the strongest impact on trust. These findings can be translated directly into daily clinical practice as well as in communication skills training.
How can oncologist communication enhance patients’ trust?

INTRODUCTION

Communication is a prerequisite for treatment of oncologic patients. For communication to be effective, it should evoke patients’ trust [55]. Trust was found to lead to improved information exchange and decision making, better adherence to medical advice, less second opinion seeking, and higher satisfaction with the physician [138].

To optimize cancer patients’ trust, we need to know how it is established. In previous studies, trust was higher among older [42], higher educated [42,108] and non-minority cancer patients [73,93]. These characteristics, however, cannot be influenced to improve patients’ trust levels. Care providers’ communication, on the other hand, can be modified [216]. Insight into the elements of oncologist communication that affect trust is therefore of great relevance. A recent review [138] and qualitative study [149] indicated that cancer patients might trust oncologists whom they perceive as medically competent [13,111,112], honest in their information provision [13,113,116], and communicating in a patient-centered way [13,73,100].

Yet, the available evidence so far suffers from important shortcomings [138]. Trust was not the primary subject of interest in most studies and was often assessed using unvalidated scales. Moreover, all published studies employed correlational designs, prohibiting conclusions about cause and effect. Finally, in these studies no distinction was made between immediate trust, developing within the very first consultation, and longer-term ‘relational’ trust which evolves more slowly, after repeated interaction [149]. As oncologic care is increasingly multi-disciplinarily organized, involving short-term relations with multiple caregivers [29,173], immediate trust is gaining increasingly more importance. Therefore, we experimentally investigated the hypothesized effect of oncologists’ enhanced communication of competence, honesty and caring on stronger immediate trust among cancer patients.

METHODS

Design

Video vignettes, i.e., videotaped medical consultations based on scripts, were created. These enable variation in isolated elements of communication while the remainder of the conversation is kept constant. This is unfeasible in clinical practice and unethical:
manipulating behavior in real clinical practice might expose cancer patients to inferior communication [217,218]. Video vignettes form an ethically acceptable and feasible alternative, with findings being translatable to clinical practice [197].

After composing a basic vignette, multiple variations were created. The three relevant elements of oncologist communication were systematically varied on two levels (standard vs. enhanced): Competence, Honesty, and Caring. These variations were combined in an experimental 2 x 2 x 2 factorial design resulting in eight different video vignettes (see Figure 1). To increase statistical power, cancer patients were randomly allocated to view and evaluate two different vignettes. Vignette version and order were balanced. Patients were blinded to video conditions. The primary outcome was patients’ trust in the observed oncologist. Secondary outcomes were expectation of operation success and likelihood to recommend the oncologist to others. The hospital’s Medical Ethics Committee provided an exemption for the study to seek formal approval.

**Subjects and procedure**

Patients (≥18 years), presently or previously suffering from cancer, were approached through cancer patient organizations and four outpatient clinics of one academic and one non-academic, regional, hospital. Members of patient organizations were recruited through printed and website announcements, while follow-up clinic patients received an invitation letter from their surgeon, radiotherapy or medical oncologist.

If patients signed up for participation, an individual appointment was made at a medical consultation room to stimulate their identification with the situation. They first filled in a baseline questionnaire (T0). Next, they were shown two videos, separated by a 10-minute distraction task. Patients were invited to identify with the observed patient. Each video viewing was followed by the completion of a questionnaire (T1 and T2) assessing their evaluation of the observed oncologist. Videos were shown on a screen placed opposite the patients.

**Development of experimental conditions**

A basic script was created, displaying a male surgeon and a colon cancer patient discussing upcoming surgery (for a more elaborate description of the video vignettes development, see Appendix A). The script was based on six audio-recorded consultations of three oncologic surgeons and their patients. Next, variations of the basic script were created in Competence, Honesty, and Caring. Therefore, two or three verbal communication alterations were added to the basic version (see Box 1 and Appendix A).
Trained actors played the roles of (male) oncologist and patient. For all versions, identical variants with a male and a female patient were created to stimulate patient identification. Pilot-testing of the scripts indicated that the variations were identifiable, and that the scripts were perceived as realistic (Appendix A). Next, the scripts were video-recorded in a medical consultation room setting. We used the patient's point of view: at all times, the camera was directed at the physician [219]. Mean video duration was 6 minutes and 25 seconds. Manipulated versions were on average 40 seconds longer than standard versions.

**Box 1. Overview of script additions for manipulations for three elements**

<table>
<thead>
<tr>
<th>Competence:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>The scientific literature clearly demonstrates that [this operation] offers the best chance at survival. I recently attended a scientific conference, where it was confirmed once more that this operation is the best possible treatment.</td>
</tr>
<tr>
<td>2.</td>
<td>We perform [this surgery] very often. In our center we all have our specialization, so that we perform certain procedures much more often to become even more skilled in them. So I perform this operation a lot.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Honesty:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>[The risk of a colostomy] is something I really want to discuss with you, even though the chances of it are slight. Because I believe that you as a patient have the right to be informed about such small risks, to avoid that you will be taken unaware by this afterwards.</td>
</tr>
<tr>
<td>2.</td>
<td>All these [complications] will not necessarily occur, but I do want to discuss them with you. Because, even though we do our very best, it remains hard to predict: we can never rule out that you will experience complications. This way at least you are well informed.</td>
</tr>
<tr>
<td>3.</td>
<td>I should add that we can never be 100% sure [that the cancer will be completely removed]. So I can never give you an absolute guarantee. There is always a slight chance that we run into an abnormality during surgery. But for now all signs suggest that you will be cancer-free after the operation.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caring:</th>
<th></th>
</tr>
</thead>
</table>
| 1.          | **Oncologist:** Were you very worried about it [the result of the scan]?
**Patient:** Yes, in a way… After all, it is your biggest fear in such a moment. But it seems to have turned out well, hasn’t it?  
**Oncologist:** Yes, it seems so. So that is good, and one less thing to worry about. |
| 2.          | **Oncologist:** Do you particularly dread the thought of a colostomy?  
**Patient:** Yes, it seems horrible, this bag attached to your stomach which may open at any moment, with all that filth… And you can’t show yourself anywhere anymore…  
**Oncologist:** Yes, I understand what you mean. |
| 3.          | But I will talk to you before the operation in any case. And it is important to know that I am always available for you in case of questions. This is our phone number. I may not always answer the phone myself, but if necessary I will return your call when I do have the time. |
Chapter 8

Measures

Operationalization check (T1 and T2)

We tested to what extent patients perceived the oncologist communication as competent, honest, and caring using three items (five-point Likert scale, completely disagree = 1 to completely agree = 5).

Background characteristics (T0)

Patients’ socio-demographics included age, gender, educational level, and ethnic background. Medical characteristics assessed were time since diagnosis, treatment status, and primary tumor site. Patients’ trust in their own oncologist was assessed with the validated, 18-item Trust in Oncologist Scale (TiOS) (five-point Likert scale, completely disagree = 1 to completely agree = 5), capturing cancer patients’ trust [175,220]. Reliability of the scale was good (α = .82).

Outcome assessment (T1 and T2)

The primary outcome, Trust in the observed oncologist, was assessed with the 18-item Trust in Oncologist Scale (TiOS) [175]. For this purpose, phrasing of the items was adapted to refer to the observed oncologist rather than the patient’s own oncologist.

Secondary outcomes were possible distal effects of communication: 1) Likelihood of recommending the oncologist to others (five-point Likert scale, not at all likely = 1 to very likely = 5), and 2) Confidence that the proposed surgery would succeed (not at all confident = 1 to very confident = 5).

Statistical analysis

All analyses were performed using SPSS 16.0 (SPSS Inc., Chicago, IL, USA). Power analysis using G*Power version 3.1.5 [221] was performed. We aimed to test 8 effects. Using an alpha of .05, for a 95% power to detect effects with a medium effect size of Cohen’s $F^2 = .15$, at least 160 observations would be required [222]. To account for the fact that two observations were nested within each patient, the number of independent observations was calculated. Therefore, the required sample size was multiplied by $1 + r_1 = .70$ [223]. This yielded a minimum sample size of 272 observations.

Missing values on the TiOS were replaced using expectation maximization (EM) [170]. Manipulation success was assessed using random intercepts multilevel analyses, to
account for the multilevel structure of observations (level 1) nested within patients (level 2). We compared evaluations of the observed oncologist as competent, honest, and caring between standard and varied conditions. Main and interaction effects of socio-demographic characteristics and the three communication variables on trust in the observed oncologist were also examined using random intercepts multilevel analyses. Analyses were performed stepwise, to examine whether entering variables significantly improved model fit [224]. First, we assessed the need for multilevel modeling, by assessing variation in reported trust between and within participants without including any explanatory variables. Next, in Model 1, socio-demographic characteristics, patients' trust in their own oncologist and the observation order (first or second oncologist observed) were entered. In Model 2, the communication variations (Competence, Honesty, and Caring) were added. To that end, we contrasted all four video versions in which a specific communication element was enhanced with the four versions in which it was kept standard. Exploratorily, all two-way interactions between socio-demographic characteristics and communication manipulations were tested (Model 3A), as well as interactions between the different communication manipulations (Model 3B).

The main effects stepwise multilevel model was then repeated, replacing 'trust in observed oncologist' with the secondary outcome variables: likelihood of recommending and expectation of surgery success.

RESULTS

Data check

Trust scores from two patients were excluded from analyses because of high rates (>50%) of missing data. Missing values for trust were replaced at T0 (1.5%), T1 (3.6%), and T2 (1.8%).

Operationalization of all three communication elements was successful: the enhanced Competence ($M = 4.08$ vs. $M = 3.94$, $\beta = .12$, 95% CI .01, .23; $p < .05$), enhanced Honesty ($M = 4.05$ vs. $M = 3.89$, $\beta = .19$, 95% CI .08, .30; $p < .01$), and enhanced Caring ($M = 3.35$ vs. $M = 2.94$, $\beta = .45$, 95% CI .31, .58; $p < .001$) conditions were perceived as such.
Patients

Socio-demographic and medical characteristics of the study sample (N = 345) are provided in Table 1. Of all patients, 52% were female and the median age was 63 (SD = 11, range 29–89). Patients’ mean trust in their own oncologist was 4.21 (SD = 0.60). Mean trust in the observed oncologist was 3.65 (SD = 0.73). Mean likelihood of recommend the oncologist was 3.39 (SD = 1.18), and mean expectation of surgery success was 2.26 (SD = 0.74).

Association between background characteristics and trust

Participants strongly differed in their reported trust (var($\mu_0$) = .63, $\chi^2 = .06$, $p < .001$) (Model 0). Stronger trust in the observed oncologist was associated with patients' older age, lower education, and stronger trust in their own oncologist. Finally, trust reported after the second observation was stronger than after the first (Table 2). These effects were observed even when variations in communication were taken into account.

Effect of communication on trust

Trust in the observed oncologist ranged between 3.44 (SD = 0.71) when all communication elements were standard, and 3.90 (SD = 0.69) when all elements were enhanced (Figure 1). Enhanced competence, honesty and caring each resulted in stronger trust (Model 2; Table 2 and Figure 2). An interaction between age and Caring ($\beta = -.15$, 95% CI - .25, - .05; $p < .01$) indicated that the effect of Caring on trust diminished with increasing age (Model 3A). All other interactions were non-significant (Models 3A and 3B). Fit indices for each model are provided in Table 3.

Effect of communication on likelihood of recommending and expectation of operation success

Patients were significantly more likely to recommend the oncologist when expressing enhanced Competence, Honesty, and Caring (Table 4). Also, patients were more confident of operation success after observing the oncologist expressing enhanced honesty or caring. However, expression of enhanced competence did not strengthen patients' expectations of operation success (Table 4).
| Table 1. Sociodemographic, and medical characteristics of the sample (N = 345) |
|---|---|---|
| **Age (n = 344)** | Median (Range) | SD |
| | 63 (29–89) | 11 |
| **n** | 344 |
| **Gender (n = 345)** |  |  |
| Male | 167 | 48 |
| Female | 178 | 52 |
| **Educational level (n = 345)** |  |  |
| None/Primary school | 11 | 3 |
| Secondary/Lower level vocational school | 168 | 49 |
| College/University | 166 | 48 |
| **Population (n = 344)** |  |  |
| Dutch | 339 | 99 |
| Other | 5 | 1 |
| **Recruitment origin (n = 345)** |  |  |
| Patient organization | 197 | 57 |
| Academic hospital in urban area | 114 | 33 |
| Non-academic hospital in rural area | 34 | 10 |
| **Time since diagnosis in years (n = 341)** |  |  |
| 0–1 | 42 | 12 |
| 1–2 | 61 | 18 |
| 2–5 | 105 | 31 |
| >5 | 133 | 39 |
| **Treatment status (n = 345)** |  |  |
| In active treatment | 88 | 26 |
| Undergoing regular follow-up care | 236 | 68 |
| No treatment or follow-up care | 21 | 6 |
| **Primary tumor site (n = 344)** |  |  |
| Colon | 80 | 23 |
| Other gastrointestinal | 26 | 8 |
| Breast | 79 | 23 |
| Genitourinary | 66 | 19 |
| Gynecologic | 26 | 8 |
| Lymph nodes/bone marrow | 42 | 12 |
| Other | 25 | 7 |
Chapter 8

Table 2. Main effects of background variables, communication manipulations and observation order on trust (TiOS) in multilevel analysis (Model 2)

<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>SE b</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age</td>
<td>.20</td>
<td>.05</td>
<td>.11, .30</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Patient gender</td>
<td>.06</td>
<td>.10</td>
<td>-.13, .25</td>
<td>ns</td>
</tr>
<tr>
<td>Patient education</td>
<td>-.09</td>
<td>.03</td>
<td>-.14, -.04</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Trust in own oncologist</td>
<td>.41</td>
<td>.08</td>
<td>.27, .56</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Competence</td>
<td>.17</td>
<td>.04</td>
<td>.08, .27</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Honesty</td>
<td>.30</td>
<td>.05</td>
<td>.20, .40</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Caring</td>
<td>.36</td>
<td>.05</td>
<td>.26, .46</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Observation order</td>
<td>.18</td>
<td>.04</td>
<td>.10, .26</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Figure 1. Means and standard errors of trust for eight video versions

Note: ‘+’ indicates manipulation (enhancement) of a communication element in a video version
**Figure 2.** Mean and standard errors of trust for standard versus enhanced conditions of *Competence, Honesty* and *Caring*, and for first versus second observation

**Table 3.** Fit indices of multilevel models including trust as the dependent variable

<table>
<thead>
<tr>
<th></th>
<th>AIC</th>
<th>-2LL</th>
<th>df</th>
<th>Sig (p &lt;.05)</th>
<th>Sig (p &lt;.01)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empty model</td>
<td>1779.46</td>
<td>1773.46</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model 1</td>
<td>1713.03</td>
<td>1697.03</td>
<td>8</td>
<td>*</td>
<td>**</td>
</tr>
<tr>
<td>Model 2</td>
<td>1628.36</td>
<td>1606.36</td>
<td>11</td>
<td>*</td>
<td>**</td>
</tr>
<tr>
<td>Model 3A</td>
<td>1629.23</td>
<td>1595.23</td>
<td>17</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Model 3B</td>
<td>1628.64</td>
<td>1600.64</td>
<td>14</td>
<td>ns</td>
<td>ns</td>
</tr>
</tbody>
</table>

Note: Lower values of the LRT and AIC indicate closer fit. Model 1 included patients’ age, gender and education, trust in own oncologist and observation order. Model 2 additionally included manipulation of Competence, Honesty and Caring. Model 3A additionally included interactions between socio-demographic characteristics and communication manipulations, whereas Model 3B included interactions between the different communication manipulations.
Table 4. Main effects of communication manipulations on likelihood of recommending and expectation of operation success in multilevel analysis (Model 2)

<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>SE b</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Likelihood of Recommending</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competence</td>
<td>.19</td>
<td>.05</td>
<td>.08, .29</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Honesty</td>
<td>.24</td>
<td>.05</td>
<td>.13, .34</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Caring</td>
<td>.36</td>
<td>.05</td>
<td>.25, .46</td>
<td>&lt;.001</td>
</tr>
<tr>
<td><strong>Expectation of operation success</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competence</td>
<td>.05</td>
<td>.06</td>
<td>-.06, .16</td>
<td>.38</td>
</tr>
<tr>
<td>Honesty</td>
<td>.20</td>
<td>.06</td>
<td>.08, .31</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Caring</td>
<td>.16</td>
<td>.06</td>
<td>.04, .27</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

Note: In addition to the effects of the three communication manipulations, Model 2 included the effects of observation order, age, gender, education, and trust in patient’s own oncologist.

**DISCUSSION**

This is the first experimental study showing that oncologist’s enhanced expression of specific communication behaviors results in higher trust compared to standard communication. Moreover, we showed that such trust strengthens patients’ expectations of operation success and their reported willingness to recommend the oncologist.

Our results provide specific directions for which types of communication are beneficial, viz. conveying medical competence, honesty, and caring. Even though our communication variations were small, effect sizes were moderate. Thus, oncologists can directly enlarge their patients’ trust and expectations by means of even small alterations in their way of communicating. As such, these findings can be directly implemented in clinical practice as well as oncologist communication skills training.

Oncologist’s caring behavior, for example, by briefly addressing patients’ cues, led to the strongest increase in trust. Such emotionally supporting statements may be even more effective in gaining patients’ confidence than providing factual information [225]. Additionally, stressing medical competence, for example, by mentioning experience with the surgery concerned, was generally beneficial for trust. Such statements, which oncologists might avoid for fear of seeming boastful or defensive may, in fact, be reassuring to patients. Similarly, expressing honesty by stressing the limitations of medical procedures and one’s capacities was perceived by patients as trustworthy. This is comforting to oncologists who may be concerned that such openness is interpreted by patients as indicating insecurity. Although being realistic should be carefully balanced with maintaining
hope [226], our results suggest that patients overall do appreciate oncologists’ openness. Indeed, such openness even augments patients’ expectation of operation success.

Previous correlational findings indicated that oncologists’ behavior is an important determinant of patients’ trust [138]. This impact of communication on trust is now confirmed experimentally, thus enabling the conclusion of a causal relationship [186]. Because identical video footage was used throughout all our video versions, effects on trust can only be explained by the inserted manipulations. Moreover, the extremely skewed trust ratings traditionally found in patient-reported trust were successfully avoided using a video-vignettes design [192,194]. Patients rating their own oncologist usually appear hesitant to be critical, possibly originating from their strong dependence upon the oncologist [143,149]. In the present study, trust ratings were less extreme.

Our results showed that, despite a clear overall effect of communication, observing an identical oncologist can still yield varying levels of trust: the same oncologist was perceived as more trustworthy by some patients than by others. Such variations in how patients perceive oncologist communication can partly be explained by patients’ background. Our results show that elderly patients’ trust benefits less from caring communication by the oncologist. Similarly, patients’ personality was suggested to determine how they evaluate oncologist communication and trustworthiness [227]. An anxious disposition, avoidant attachment style and internal locus of control may predispose patients to trust their physician less [48,95,228]. The identification of other patient characteristics that influence their evaluation of communication and consequent trust will allow oncologists to employ flexible communication approaches, tailored to patients’ individual preferences.

This study has some limitations. First, manipulated video versions were unavoidably longer; on average 40 seconds. Designing videos of equal length would involve including neutral ‘filler segments’ to standard conditions. These fillers, however, exert effects of their own as any communication is by definition meaningful. It is in itself interesting to note that, if used adequately, as few as 40 seconds may be needed to improve communication.

Second, using an experimental study design required instructing patients to observe an unfamiliar oncologist. Use of this design has previously invoked the question to what extent analogue patients’ perceptions are comparable to perceptions of a real oncologist [189,194,195]. Yet, accumulating evidence indicates that analogue patient designs provide valid results [197,229]. We have maximized patients’ identification, and thus external validity, by recruiting real oncologic patients and adjusting the camera perspective and setting of the observation [219].
In conclusion, this study contributes to clinical practice and training. It demonstrates that oncologists can strengthen their patients’ trust by adapting their communication behavior. This finding should encourage oncologists to express their competence, honesty, and caring behavior and should be addressed in oncologist communication skills training. Enhancing patients’ trust requires only a few seconds.
How attachment style and locus of control influence patients’ trust in their oncologist

Marij Hillen, Hanneke de Haes, Lukas Stalpers, Jean Klinkenbijl, Eric Hans Eddes, Mathilde Verdam, and Ellen Smets

Submitted
Chapter 9

ABSTRACT

Objective
Cancer patients need to trust their oncologist. How the oncologist communicates probably contributes to patients’ trust. Yet, patient characteristics such as their attachment style and health locus of control may influence how such communication is perceived. We examined how these personality characteristics influence trust as well as moderate the relation between oncologist communication and trust.

Methods
Eight videotaped scenarios of an oncologic consultation were created. Oncologist communication was systematically varied regarding their expressed competence, honesty and caring. Cancer patients (N = 345) were randomly assigned to view the videos and report their trust in the observed oncologist. Patients’ self-reported attachment style, health locus of control and trust in their own oncologist were assessed.

Results
Patients with a stronger external health locus of control trusted the observed oncologist more (p <.001). Attachment avoidance nor attachment anxiety were related to trust in the observed oncologist. However, attachment avoidance moderated the positive effect of oncologist communication of caring and honesty on trust: avoidant attachment significantly diminished the effect (p <.011 and p <.044, respectively). High attachment avoidance (p =.003) and attachment anxiety (p <.001) were related to weaker trust in patients’ own oncologist.

Discussion
Patients’ attachment avoidance may hamper their trust in their own, but not necessarily in a newly observed, oncologist. As expected, patients’ attachment style influences how oncologist communication influences trust, underscoring the importance of oncologists tailoring their communication to individual patients. We confirmed observational findings that patients convinced that others control their health trust their oncologist more than others.
INTRODUCTION

Cancer patients need to be able to trust their oncologists, since they depend on their medical knowledge and skills for either cure or extension of life [13]. When so much is at stake, strong interpersonal trust is even more crucial than in many other medical situations. To help oncologists create optimal trust, we need evidence on how it is established.

Trust may be defined as the optimistic acceptance of a vulnerable situation, in which patients believe their physician to act in their best interests [10]. It is in part caused by the oncologist’s behavior. Three communication elements appear to especially foster cancer patients’ trust. Trust is enhanced if the oncologist 1) explicitly conveys medical competence, 2) informs the patient honestly and in sufficient detail, and 3) is caring and compassionate towards the patient [138 and Hillen et al., submitted].

Trust is also presumed to be dependent on patient characteristics. Women, elderly, and more highly educated cancer patients were more trusting of their oncologist [42, 73, 93, 108]. Additionally, particular personality traits, i.e., patients’ attachment style and their locus of control, have been frequently linked to cancer patients’ ability to trust their oncologist. Moreover, these traits may influence how oncologist communication is perceived [227], thus moderating the effect of communication on trust. However, solid evidence for the direct and indirect associations between cancer patients’ personality characteristics and trust is rare. Such associations should be established, as reduced trust is associated with more patient worry [112, 123], reduced treatment adherence [121, 126, 230], and reduced loyalty to oncologists [231]. Therefore, this study sought to estimate how attachment anxiety, attachment avoidance, and health locus of control (HLOC) predict cancer patients’ trust in the oncologist (research question 1), and moderate the effect of communication on trust (research question 2) (see Figure 1). Results can help oncologists adapt their communication to individual patients.

Attachment style

Attachment style is a consistent and enduring pattern of how an individual relates to people when in a dependent relationship [173]. According to Bowlby's attachment theory, people form mental representations of themselves and others during childhood by interacting with attachment figures [232]. The attachment styles observed in childhood are thought to persist throughout adulthood, and influence cognitions, affect, and behavior in close relationships [233, 234]. People have traditionally been categorized into ‘attachment
styles’, i.e., anxious, avoidant or secure. Consequently, initial attachment self-report measures comprised three categorical descriptions, whereby people indicated which best described their predominant feelings in close relationships. More recently, evidence has accumulated that two dimensions of insecurity underlie such self-report measures of adult attachment style [235]. Thus, presently, adult attachment is predominantly assessed by combining scores on two, largely independent, continuous dimensions: attachment anxiety and attachment avoidance [236]. This dimensional approach allows uncovering nonlinear relationships with other variables and may provide more nuanced estimates of empirical relationships [237].

Attachment anxiety involves a fear of interpersonal rejection or abandonment, an excessive need for approval from others, and distress when the other is unavailable or unresponsive. Attachment avoidance involves fear of dependence and interpersonal intimacy, an excessive need for self-reliance, and reluctance to self-disclose [238]. High scores on either or both dimensions are indicative of insecure attachment, whereas securely attached individuals score low on both attachment avoidance and anxiety [235].

At times of stress and vulnerability, e.g., in illness, attachment behaviors are thought to be particularly activated. Insecure attachment could then hamper patients’ willingness or ability to form a trusting relation with their physician [48,239]. The vulnerability induced by diagnosis and treatment of cancer might cause cancer patients to rely on attachment mechanisms even more [239]. Thus, cancer patients with insecure attachment styles may trust their oncologist less than securely attached patients [240].

Patients’ attachment style may also moderate how they perceive their oncologist’s communication, and how such communication impacts trust [239]. More specifically, avoidantly attached people are known to seek control, and might therefore require more information. As a result, they might appreciate an oncologist who elaborately and honestly provides information more than others. Attachment avoidance has also been associated with refusing empathy [241,242]. Consequently, for highly avoidant patients, caring behavior of the oncologist may negatively impact on trust. Reversely, anxiously attached patients were suggested to have a strong need for proximity [241], which may lead to a particularly strong beneficial effect of the oncologist’s caring behavior on trust.

To summarize, it is hypothesized that cancer patients who score high on either attachment avoidance, attachment anxiety, or both, will report lower trust in the oncologist. The higher patients’ attachment avoidance, the stronger the expected positive effect of honest information provision by the oncologist. Moreover, the positive effect of
caring behavior on trust is expected to be stronger than average for patients with high attachment anxiety and weaker for patients with high attachment avoidance (see Figure 1).

**Figure 1.** Visual representation of research hypotheses

![Visual representation of research hypotheses](image)

**Powerful others health locus of control**

Health locus of control (HLOC) has additionally been related to patients’ trust. Moreover, it may determine how the oncologist’s communication influences their trust. HLOC is defined as the extent to which individuals attribute their health to their own actions or to external agents. Patients with an internal HLOC believe that positive health results from their own doing, willpower, or efforts [228]. In contrast, external locus of control may lie either with ‘chance’ or ‘fate’, or with ‘powerful others’. Powerful others HLOC is the belief that powerful individuals other than one-self, e.g., healthcare providers, control one’s health [243]. HLOC is thought to remain relatively stable throughout people’s lives [244,245].

Both people’s belief of whether others control their health and trust concern interpersonal relations. Thus, the two constructs have been repeatedly associated
Patients’ beliefs about the power of others over their health may determine their orientation toward, and evaluation of, their healthcare provider. When confronted with cancer, most patients have to undergo drastic procedures or treatments with limited guarantees and several associated risks. A belief that the physician carrying out this procedure or treatment strongly impacts one’s health could predispose someone to trust. Previous research in primary care \cite{95,246} and among HIV patients \cite{228} suggests that patients who believe others exert a strong control over their health are more trusting of their physician than those having an internal locus of control. Likewise, the effect of communication on trust may differ depending on patients’ health locus of control. Specifically, patients with a strong belief in powerful others may feel little need for personal control. Consequently, they might attach relatively less importance to detailed and honest information provision by their oncologist \cite{247}.

Summarizing, patients with strong powerful others HLOC were hypothesized to have more trust. Moreover, the stronger patients’ belief in powerful others in controlling their health, the weaker the expected positive effect of an oncologist’s honest information-provision on trust (see Figure 1). No hypotheses were formed regarding the interaction between caring and competent communication and HLOC on trust.

**METHODS**

**Design**

This investigation is part of an experimental study in which the effects of specific characteristics of oncologist communication on patients’ trust were investigated (Hillen et al., submitted). Videotaped medical consultations (‘video vignettes’) were used, in which three elements of oncologist communication were systematically varied on two levels (standard vs. enhanced): Competence, Honesty, and Caring. Combining the three manipulations in an experimental 2 x 2 x 2 factorial design resulted in eight different video vignettes. Cancer patients were randomly assigned to view two different video variants, to increase statistical power. Video version and order were balanced, i.e., all 28 possible combinations of two out of eight videos occurred equally often. The primary outcome was patients’ reported level of trust in the observed oncologist. The hospital’s Medical Ethics Committee provided an exemption for the study to seek formal approval.
Subjects and procedure

People who currently or previously had cancer (≥18 years) were recruited. Members of patient organizations were recruited through printed and website announcements. Clinic patients from four outpatient clinics of one urban, and one rural hospital received an invitation letter from their oncologist (surgeon, radiotherapy or medical oncologist). During an individual appointment at a medical consultation room, participants first completed a baseline questionnaire assessing socio-demographic, medical, and personality characteristics (T0). Next, they successively viewed two videos on a flat screen monitor placed opposite them, while imagining themselves in the place of the observed patient. The two videos were separated by a ten-minute distraction task to avoid possible blurring. After each video viewing, patients evaluated the observed oncologist on a questionnaire (T1 and T2, respectively).

Development of experimental conditions

Video vignettes development is described in detail in Appendix A. The videos illustrated an encounter between a surgeon and a patient with colorectal cancer discussing upcoming surgery. First, we developed a basic script based on six audio-recorded consultations of three oncologic surgeons and their patients. Second, variations of the basic script were created for communication of Competence, Honesty, and Caring, by adding two or three verbal communication alterations. For enhanced competence, the oncologist emphasized experience with the operation and being up-to-date on the recent research. To demonstration enhanced honesty, the oncologist emphasized wanting to honestly and exhaustively inform the patient about possible complications and the limitations of his abilities. For enhanced caring, the oncologist twice addressed a concern raised by the patient, and emphasized his continued availability (Appendix A).

After pilot-testing (Appendix A), scripts were video-recorded with actors playing the roles of oncologist (male) and patient. For all eight versions, identical variants with a male and a female patient were created, to stimulate patient identification. Mean video duration was six minutes and 25 seconds. Manipulated versions were on average 40 seconds longer than standard versions.
Chapter 9

Measures

Socio-demographic and medical characteristics

Patients’ socio-demographics included age, gender, educational level, and ethnic background. Medical characteristics assessed were time since diagnosis, treatment status, and cancer site.

Personality characteristics

We assessed attachment using the extensively validated Experiences in Close Relationships short form (ECR-sf) [238]. The ECR-sf measures attachment anxiety (six items) and attachment avoidance (six items) (seven-point Likert scale, completely disagree = 1 to completely agree = 7). We translated the scale into Dutch using a forward-backward translation procedure. Internal consistency was acceptable ($\alpha = .74$ for attachment avoidance and $\alpha = .60$ for attachment anxiety). Health locus of control was assessed using the Dutch version of the Powerful Others subscale of the Multidimensional Health Locus of Control (HLOC) scales, (six-point Likert scale, completely disagree = 1 to completely agree = 6) [243,248]. Reliability in this study was good ($\alpha = .83$).

Outcome variables

The primary outcome was trust in the observed oncologist, assessed with the validated 18-item Trust in Oncologist Scale (TiOS) (five-point Likert scale, completely disagree = 1 to completely agree = 5) [175,220]. We adapted item phrasing to refer to the observed oncologist, rather than the patient’s own oncologist. An example of a question is ‘This doctor strongly cares about your health’. An overall score is obtained by averaging the responses. Reliability of the scale was good in this sample ($\alpha = .82$). Exploratorily, patients’ trust in their own oncologist was assessed using the same, unadapted, TiOS.

Analyses

Power analysis using G*Power version 3.1.5 [221] was performed. We aimed to test 11 effects. Using an alpha of .05, for a 95% power to detect effects with a medium effect size of Cohen’s $F^2 = .15$, at least 178 observations would be required [222]. To account for the fact that two observations were nested within each patient, the number of independent observations was calculated. Therefore, the required sample size was multiplied by $1 + the presumed correlation between TiOS scores of observations 1 and 2 (r, = .70) [223]. This yielded a minimum sample size of 303 observations.
All other analyses were performed using SPSS 16.0 [179]. Missing TiOS values were replaced using expectation maximization (EM) [170]. We used random intercepts multilevel analyses, to account for the multilevel structure of the two observations (level 1) nested within each patient (level 2). All non-dichotomous variables were standardized in multilevel analysis to improve interpretation of beta values. First, we tested the appropriateness of using multilevel analysis with an empty model including only within and between subject variation in trust (Model 0). Note that, in multilevel models 1 through 4, we controlled for the observation order, by including it into the model as a fixed factor. This allowed us to control for any effects related to the observation order rather than the communication styles or patients characteristics (see Hillen et al., submitted). In Model 1, we added socio-demographic characteristics (i.e., age, gender, and education) to control for their effects. Next, we additionally included the main effects of the three communication variations on trust, i.e., Competence, Honesty, and Caring (Model 2). For research question 1, the main effects of attachment avoidance, attachment anxiety, and locus of control on trust were tested by including them in Model 3. Finally, we tested research question 2 by including the hypothesized interactions between communication and personality characteristics (Model 4). These were the interactions between 1) Caring and attachment avoidance, 2) Honesty and attachment avoidance, 3) Honesty and attachment anxiety, and 4) Honesty and locus of control. Exploratorily, we assessed the association between personality characteristics and patients’ trust in their own oncologist in stepwise linear regression analysis. We tested main effects of attachment anxiety, attachment avoidance and powerful others HLOC while controlling for socio-demographic characteristics. To account for multiple testing, findings were considered significant if $p < .01$, and marginally significant if $p < .05$.

RESULTS

Data check
Two patients were excluded from analyses because of high rates (>50%) of missing data. We replaced missing values on TiOS at T0 (1.5%), T1 (3.6%), and T2 (1.8%). Variation of all three communication characteristics was successful: the enhanced Competence ($M = 4.08$ vs. $M = 3.94$, $\beta = .12$, 95% CI .01, .23; $p < .033$), enhanced Honesty ($M = 4.05$ vs. $M = 3.89$, $p < .01$).
\( \beta = .19, \ 95\% \text{ CI} \ (.08, .30; p < .001) \), and enhanced Caring \( (M = 3.35 \text{ vs. } M = 2.94, \ \beta = .45, 95\% \text{ CI} \ .31, .58; p < .001) \) conditions were perceived as such.

Sample

Table 1 displays socio-demographic and medical characteristics of the sample \( (N = 345) \). Patients’ median age was 63 years \( (SD = 11, \text{ range} 29–89) \), and 52% were female (see Table 1). Mean trust in the observed oncologist was 3.65 \( (SD = 0.73, \text{ range} 1.28–5.00, \text{ skewness} = -.35) \). Patients’ mean trust in their own oncologist was 4.21 \( (SD = 0.60, \text{ range} 1.78–5.00, \text{ skewness} = -.92) \). Average score for attachment anxiety \( (ECR-sf) \) was 2.72 \( (SD = 0.95, \text{ range} 1.00–6.67) \), and for attachment avoidance was 2.86 \( (SD = 1.10, \text{ range} 1.00–6.00) \). Mean score for powerful others locus of control \( (PO-MHLC) \) was 3.27 \( (SD = 1.05, \text{ range} 1.00–6.00) \).

The relation between personality characteristics and trust in the observed oncologist

Table 2 displays the fit indices and explained variance in trust scores \( (TiOS) \) for the different models tested in multilevel modeling. There was strong variation in trust between patients \( \text{var}(u0j) = .63, \chi^2 = .03, p < .001 \), indicating appropriateness of using multilevel modeling (Model 0). As previously established (see Hillen et al., submitted), elderly, lower educated patients were more trusting (Model 1), and enhanced communication of Competence, Honesty, and Caring by the oncologist enhanced trust (Model 2). High scores on powerful others HLOC correlated with higher trust in the observed oncologist \( (\beta = .19, 95\% \text{ CI} \ .10, .29; p < .001) \), even when accounting for socio-demographic characteristics and communication variations (Model 3). Lower attachment avoidance was marginally associated with lower trust \( (\beta = -.10, 95\% \text{ CI} \ -.19, -.23; p < .036) \). Attachment anxiety did not predict patients’ trust in the observed oncologist.
Table 1. Sample characteristics (N = 345)

<table>
<thead>
<tr>
<th></th>
<th>Mdn (Range)</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (n = 344)</td>
<td>63 (29–89)</td>
<td>11</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (n = 345)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>167</td>
<td>48</td>
</tr>
<tr>
<td>Female</td>
<td>178</td>
<td>52</td>
</tr>
<tr>
<td>Educational level (n = 345)</td>
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<td></td>
</tr>
<tr>
<td>None/Primary school</td>
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<td>3</td>
</tr>
<tr>
<td>Secondary/Lower level vocational school</td>
<td>168</td>
<td>49</td>
</tr>
<tr>
<td>College/University</td>
<td>166</td>
<td>48</td>
</tr>
<tr>
<td>Population (n = 344)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>339</td>
<td>99</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Recruitment origin (n = 345)</td>
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<td></td>
</tr>
<tr>
<td>Patient organization</td>
<td>197</td>
<td>57</td>
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<td>Academic hospital in urban area</td>
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<td>33</td>
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<tr>
<td>Non-academic hospital in rural area</td>
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<td>10</td>
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<tr>
<td>Time since diagnosis in years (n = 341)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-1</td>
<td>42</td>
<td>12</td>
</tr>
<tr>
<td>1-2</td>
<td>61</td>
<td>18</td>
</tr>
<tr>
<td>2-5</td>
<td>105</td>
<td>31</td>
</tr>
<tr>
<td>&gt;5</td>
<td>133</td>
<td>39</td>
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<tr>
<td>Treatment status (n = 345)</td>
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<tr>
<td>In active treatment</td>
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<tr>
<td>Undergoing regular check ups</td>
<td>236</td>
<td>68</td>
</tr>
<tr>
<td>No treatment or check ups</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>Primary tumor site (n = 344)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon</td>
<td>80</td>
<td>23</td>
</tr>
<tr>
<td>Other gastrointestinal</td>
<td>26</td>
<td>8</td>
</tr>
<tr>
<td>Breast</td>
<td>79</td>
<td>23</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>66</td>
<td>19</td>
</tr>
<tr>
<td>Gynecologic</td>
<td>26</td>
<td>8</td>
</tr>
<tr>
<td>Lymph nodes / bone marrow</td>
<td>42</td>
<td>12</td>
</tr>
<tr>
<td>Other</td>
<td>25</td>
<td>7</td>
</tr>
</tbody>
</table>
The moderating effect of personality characteristics on the relation between communication and trust in the observed oncologist

As predicted, attachment avoidance moderated the effects of oncologist communication on trust (Model 4). These moderation effects explained the direct association between attachment avoidance and trust, which was no longer statistically significant. The higher patients' attachment avoidance, the weaker was the positive effect of oncologist's honest communication on trust ($\beta = -0.11, 95\% CI -0.21, -0.00; p < 0.044$) (see Figure 2). Similarly, the effect of oncologist's caring communication on patients' trust was weaker among more avoidantly attached patients ($\beta = -0.13, 95\% CI -0.23, -0.03; p < 0.011$) (see Figure 3). The other predicted interactions were non-significant. Main and interaction effects of all variables are displayed in Table 3. Model 4 explained 19.5% of the total variance in trust scores (see Table 2).

The relation between personality characteristics and trust in one's own oncologist

Patients' trust in their own oncologist was not significantly associated with patients' gender, age or education. Patients with higher attachment anxiety and higher attachment avoidance reported less trust in their own oncologist (see Table 4). Conversely, high powerful others HLOC was associated with stronger trust in patients’ own oncologist.

Table 2. Fit indices of multilevel models, including trust as the dependent variable

<table>
<thead>
<tr>
<th>Model</th>
<th>AIC</th>
<th>-2LL</th>
<th>df</th>
<th>Model fit improvement</th>
<th>Explained variance in trust scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 0</td>
<td>1779.46</td>
<td>1773.46</td>
<td>3</td>
<td></td>
<td>8.3%</td>
</tr>
<tr>
<td>Model 1</td>
<td>1740.25</td>
<td>1726.25</td>
<td>7</td>
<td>**</td>
<td>12.9%</td>
</tr>
<tr>
<td>Model 2</td>
<td>1655.72</td>
<td>1635.72</td>
<td>10</td>
<td>**</td>
<td>18.2%</td>
</tr>
<tr>
<td>Model 3</td>
<td>1610.58</td>
<td>1584.58</td>
<td>13</td>
<td>**</td>
<td>19.5%</td>
</tr>
<tr>
<td>Model 4</td>
<td>1604.94</td>
<td>1570.94</td>
<td>17</td>
<td>**</td>
<td></td>
</tr>
</tbody>
</table>

Note: Lower values of the AIC and -2LL indicate closer fit. ** indicates significance at p<.01. Explained variance of each model was calculated by comparing its residual variance with the residual variances of the null-model [249]. Model 0: empty model; Model 1: socio-demographics; Model 2: socio-demographics and personality characteristics; Model 3: socio-demographics, personality characteristics and communication manipulations; Model 4: socio-demographics, personality characteristics, communication manipulations, interactions between personality characteristics and communication manipulations.
Figure 2. Visual display of the interaction between Attachment Avoidance (ECR-sf) and oncologist Honesty on Trust (TiOS)

![Figure 2](image)

Figure 3. Visual display of the interaction between Attachment Avoidance (ECR-sf) and oncologist Caring on Trust (TiOS)

![Figure 3](image)
Chapter 9

DISCUSSION

We examined whether cancer patients’ attachment style and locus of control predicted their trust in an oncologist observed in a videotaped consultation. Moreover, we investigated whether the impact of oncologist communication on trust was moderated by these personality characteristics. Results indicated that the belief that powerful others exert a strong influence over one’s health predicted stronger trust in an observed as well as patients’ own oncologist, irrespective of patients’ age, gender or education level. Neither attachment anxiety, nor attachment avoidance were independently predictive of trust in the observed oncologist. Patients’ attachment avoidance did, however, moderate how the oncologist’s communication of caring and honesty influenced patients’ trust. Finally, exploratory analyses revealed that more attachment anxiety and more attachment avoidance were associated with stronger trust in patients’ own oncologist.

Table 3. Main and interaction effects of socio-demographic characteristics, personality characteristics and communication manipulations on trust (TiOS) in multilevel Model 4

<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>SE</th>
<th>p</th>
<th>95% CI</th>
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<tr>
<td><strong>Level 1 model</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>-.77</td>
<td>.18</td>
<td>-.11</td>
<td>-.42</td>
</tr>
<tr>
<td>Observation order</td>
<td>.18</td>
<td>.04</td>
<td>&lt;.001</td>
<td>.10, .26</td>
</tr>
<tr>
<td>Age</td>
<td>.16</td>
<td>.05</td>
<td>.001</td>
<td>.06, .26</td>
</tr>
<tr>
<td>Gender</td>
<td>.06</td>
<td>.10</td>
<td>.570</td>
<td>-.14, .26</td>
</tr>
<tr>
<td>Education</td>
<td>-.11</td>
<td>.05</td>
<td>.017</td>
<td>-.21, -.02</td>
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<tr>
<td>Competence</td>
<td>.16</td>
<td>.05</td>
<td>.001</td>
<td>.06, .26</td>
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<tr>
<td>Honesty</td>
<td>.31</td>
<td>.05</td>
<td>&lt;.001</td>
<td>.21, .40</td>
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<tr>
<td>Caring</td>
<td>.36</td>
<td>.05</td>
<td>&lt;.001</td>
<td>.27, .46</td>
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<tr>
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<td>.06</td>
<td>.750</td>
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<td>.05</td>
<td>.110</td>
<td>-.19, .02</td>
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<tr>
<td>Powerful others HLOC</td>
<td>.15</td>
<td>.06</td>
<td>.008</td>
<td>.04, .25</td>
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<tr>
<td>Attachment avoidance x Honesty</td>
<td>-.11</td>
<td>.05</td>
<td>.044</td>
<td>-.21, -.00</td>
</tr>
<tr>
<td>Attachment avoidance x Caring</td>
<td>-.13</td>
<td>.05</td>
<td>.011</td>
<td>-.23, -.03</td>
</tr>
<tr>
<td>Attachment anxiety x Caring</td>
<td>.07</td>
<td>.05</td>
<td>.200</td>
<td>-.03, .17</td>
</tr>
<tr>
<td>LoC belief in powerful others x Honesty</td>
<td>.08</td>
<td>.05</td>
<td>.098</td>
<td>-.02, .18</td>
</tr>
<tr>
<td><strong>Level 2 model</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant (intercept)</td>
<td>.55</td>
<td>.05</td>
<td>&lt;.001</td>
<td>.45, .66</td>
</tr>
</tbody>
</table>

Note: the smallest level of analysis (level 1) is an observation. Two observations are nested within a participant (level 2)
How patients’ attachment style and locus of control influence trust

**Table 4. Regression model for the association between socio-demographic and personality characteristics and patients’ trust in their own oncologist (TiOS)**

<table>
<thead>
<tr>
<th>Step 1</th>
<th>b</th>
<th>SE b</th>
<th>β</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>-.01</td>
<td>.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.00</td>
<td>.07</td>
<td>00</td>
<td>.99</td>
</tr>
<tr>
<td>Age</td>
<td>.00</td>
<td>.00</td>
<td>.03</td>
<td>.63</td>
</tr>
<tr>
<td>Education</td>
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<td>.02</td>
<td>.06</td>
<td>.30</td>
</tr>
</tbody>
</table>

**Step 2**

<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>SE b</th>
<th>β</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
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<td>.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.04</td>
<td>.07</td>
<td>04</td>
<td>.54</td>
</tr>
<tr>
<td>Age</td>
<td>.00</td>
<td>.00</td>
<td>02</td>
<td>.75</td>
</tr>
<tr>
<td>Education</td>
<td>.01</td>
<td>.02</td>
<td>.03</td>
<td>.63</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-.17</td>
<td>.03</td>
<td>-.26*** &lt;.001</td>
<td></td>
</tr>
<tr>
<td>Avoidance</td>
<td>-.09</td>
<td>.03</td>
<td>-.16** .003</td>
<td></td>
</tr>
<tr>
<td>Powerful others HLOC</td>
<td>.08</td>
<td>.03</td>
<td>.15** .009</td>
<td></td>
</tr>
</tbody>
</table>

Note: $R^2$ = .00 for Step 1, $\Delta R^2$ = .12 for Step 2 ($p < .001$)

Based on the available theory and empirical evidence, an insecure attachment style (i.e., high scores for attachment avoidance, attachment anxiety, or both) was expected to predict less trust in the observed oncologist. The unexpected absence of these effects could be explained by the lab setting used in this experiment, allowing only the establishment of an initial relationship. As patients observed the videotaped oncologist only twice, and in similar consultations, the current study did not simulate a long-term relationship. Attachment style may play only a limited role in the initial establishment of a relation, gaining significance during further development of an interpersonal relationship [173]. Consistent with this explanation, both attachment anxiety and attachment avoidance were found to be associated with weaker trust in patients’ own oncologists. Patients had continuous relationships with their own oncologist: 61% had seen their oncologist more than ten times, while only 4% had had less than three contacts. In a previous qualitative study on trust, two types of trust were identified among cancer patients [149]. The first type was immediate, whereas the second evolved more slowly, after repeated interaction. Possibly, the current experimental design allows only the manipulation of the former, short-term type of trust. Trust in patients’ own oncologist may reflect the second, slowly established, type. Consistently, trust in the observed and in patients’ own oncologist correlated only moderately ($r_p = .24$). This does not automatically disqualify the results of this study, as short-term relations with multiple oncologists are
becoming more and more standard in cancer care [29], prohibiting the opportunity to form long-term relationships [173].

Our findings suggest that avoidantly attached patients interpret caring behaviors of the oncologist less positively than others. Among extremely avoidantly attached patients, caring behavior did not increase trust at all. This finding is consistent with the idea that avoidantly attached individuals deal with insecure situations by striving for autonomy and control, and distancing themselves from attachment figures [241].

Oncologists, accustomed to patients who appreciate caring, compassionate communication [13,98,100], may be inclined to approach avoidantly attached patients by communicating even more caringly, to reduce interpersonal distance. Our results might help them realize that such caring behavior may be counterproductive for these patients. Out of a reluctance to form a relationship with their oncologist, these patients may reject proximity-seeking behavior, which they perceive as threatening [242]. Oncologists can attempt to be responsive to such specific attachment needs by showing clear respect for patients’ sense of autonomy and independence [239,242]. Thus, they may support insecurely attached patients form a collaborative therapeutic relationship [250].

We expected that avoidantly attached patients would perceive an honestly communicating oncologist as more trustworthy than others: receiving more honest and detailed information would increase their sense of personal control [242]. Our results, however, suggest an opposite association: Honest information provision did not enhance trust for avoidantly attached patients. Although this relation should be further confirmed, we might speculate that the specific type of information provided by the ‘honest’ oncologist reduced, rather than enhanced, patients’ sense of personal control. The fragments added to the script to enhance honesty mostly involved the oncologist attempting to be realistic and nuanced, e.g., stressing that metastases could not be ruled out. Such information might impair a sense of personal control among avoidantly attached patients, and thus damage their trust.

Our results confirmed the presumption that patients with cancer who believe that powerful others impact strongly on their health were more trusting of the oncologist. This relation is consistent with previous empirical findings [95,228,246], and intuitively makes sense: Patients who feel they have little control over their cancer will feel comfortable delegating power to their oncologist. For these patients to be forced into a more autonomous position regarding, for example, their treatment choices would be stressful [95]. To them, fully trusting their oncologist may be most beneficial. Indeed, cancer patients who have an external locus of control experience experienced less stress and negative affect [251]. However, when taken to its extreme, patients who feel they...
have no control over their medical situation may blindly trust their oncologist and assume a passive role [246]. For such patients, the oncologist may need to actively encourage reflecting on, and voicing, their personal preferences.

This study has some strengths, most important of which is the experimental design which allows for conclusions about cause and effect. However, some limitations of the study also need to be mentioned. Most important is the reduction in ecological validity that the use of a lab setting may have entailed. Even when significant efforts were invested into maximizing realism and patients’ identification, results may not be fully translatable to clinical practice. Second, this study relied on quantitative measurement of attachment styles. As a result, it was not possible to unravel the possibly complex nature of the relation between attachment and patients’ trust in their own oncologist. Previous empirical findings suggest that avoidantly attached patients focused on maintaining control whereas anxiously attached patients primarily sought safety [241]. Their different respective focuses led to different trust-related goals, different ways of dealing with trust-violation, and interpretations of trust-related experiences. In future research, such intermediate processes may be exposed through qualitative assessments of attachment.

Concluding, this study is the first to experimentally test the influence of personality characteristics on how cancer patients perceive oncologist communication and how it, consequently, determines their trust in an oncologist. Results indicate that communication perceived positively by some may strike other patients as disagreeable. Thus, these findings underline how oncologists should continuously attempt to tailor their communication style to their individual patients [252]. This will enable them to achieve and preserve trust, which will benefit cancer patients.
How patient accrual can impact on outcomes: the difference between patient organization members and other patients in healthcare communication research

Marij Hillen, Hanneke de Haes, Mathilde Verdam, and Ellen Smets

Submitted
ABSTRACT

Objectives
To investigate how comparable outcomes of medical communication research are when using different patient accrual methods by comparing cancer patients organization members with outpatient clinic patients.

Methods
In an experimental video-vignettes study, the impact of oncologist communication on trust was tested. Background characteristics (socio-demographics, trait anxiety, health locus of control, and attachment style), reported trust, and the impact of communication on trust were compared between the two groups.

Results
Cancer patient organization members (n = 196) were younger and higher educated than clinical patients (n = 148). Members felt more personal control over their health (p <.01), but were also more anxious (p <.05). They reported lower trust in general health care (p <.05), in their own oncologist (p <.001), and in the oncologist in the videos (p <.05). The impact of oncologist communication on trust was similar for both groups.

Conclusions
Despite considerable differences in trust levels, both groups appear equally affected by oncologist communication. Thus, although including cancer patient organization members may impact the generalizability of some findings, using these participants to investigate communication appears justified.

Practice implications
Cancer patient organization members may regard their oncologist more critically. Nonetheless, communicating competence, honesty, and caring may benefit the relation with these patients similarly as with other patients.
INTRODUCTION

Approaching real patients for participation in medical communication research is sometimes difficult [253]. To facilitate patient recruitment, researchers frequently refer to patient associations, self-help groups or advocacy groups [see for example 13,195,254,255,256,257,258]. Members of such groups are known to be willing and motivated to participate in research. However, they may not always be representative of the average patient. Indeed, researchers who sampled patient support group members have frequently discussed a potential lack of representativeness as a limitation of their studies [e.g., 256,258].

Only a small percentage of all patients are represented in patient organizations. For example, on average 5% of Dutch cancer patients is a member of a patient organization [261]. Members of support groups have been found to be more likely highly educated, female, white, and middle class than others [262-264]. Moreover, they were more agreeable, employed more active coping strategies, and felt more control over their disease, but on the other hand they were found to feel more anxious and distressed [264].

If such socio-demographic and personality characteristics influence patients’ perception and evaluation of communication, selection bias might occur when participants for research of medical communication are recruited through patient organizations.

Empirical research on such selection bias is surprisingly scarce. To date, literature has mostly focused on comparing between research participants (volunteers, members of patient support groups) and non-participants, allowing only a comparison of general background characteristics [265,266]. Investigating whether patient selection influences relevant outcome measures is only possible when both patient organization members and non-members participate in research. This was the case in a (non-communication) study investigating selection bias, comparing quality of life outcomes of members from a patient organization for sarcoidosis with a random sample of non-member sarcoidosis patients [267]. Results indicated that the patient organization members reported lower quality of life and more physical symptoms than non-members. Comparable studies in the field of physician-patient communication, however, appear nonexistent.

\[1\] The terms ‘patient support group’, ‘patient organization’ and ‘patient advocacy groups’ are often used interchangeably. In essence, however, the term ‘support group’ refers to active interventions aimed at individual patients [259]. The terms patient organizations and advocacy groups refer to the organizations that primarily promote patients’ collective interests [260]. Thus, a patient organization may organize support groups as one of their activities. We will refer to patient organizations throughout this article, adapting our phrasing when quoted literature explicitly refers to patient support groups.
We performed a study on the effect of oncologist communication on patients’ trust (Hillen et al., submitted). In this study, we experimentally investigated whether oncologist’s enhanced expression of medical competence, honesty, and caring communication induced higher trust in the oncologist. After viewing a video of an enacted medical consultation, patients’ trust in the observed oncologist was assessed (see Appendix A for a detailed description of the study methodology). Participants were accrued through various Dutch cancer patient organizations as well as oncology outpatient clinics. Including both members and non-members created a unique opportunity to compare the two groups. The aim of this study was therefore methodological: to estimate if cancer patients accrued through patient organizations differ from patients accrued through hospital outpatient clinics on 1) socio-demographic and personality characteristics, 2) trust levels, and 3) the impact of oncologist communication on trust. As such, this study provides insight into the impact of patient accrual choices patient accrual on patient-reported outcomes.

METHODS

Video vignettes, i.e., videotaped scripted medical consultations, were created (see below). After composing a basic vignette, three elements of oncologist communication were systematically varied on two levels (standard vs. enhanced): conveyance of Competence, Honesty, and Caring (2 x 2 x 2 factorial design). Participants were randomly assigned to view two out of eight versions of the video vignette. Study design, video-vignettes development and procedure have been described in detail in Hillen et al. (submitted) and in Appendix A.

Sampling

All participants had to be at least 18 years old, have acceptable proficiency of Dutch, and being in treatment or follow-up with an oncology specialist presently or previously. Patients were informed that the study concerned the relation between patient and oncologist.
Cancer patient organization members (CPO members)

Members of 15 different cancer patient organizations were invited to participate through printed and online advertisements of the organizations’ journals and websites. Interested members could self-apply through telephone, e-mail or regular post.

Clinical patients

Patients who had been treated or were currently being treated for cancer were approached through four oncology departments of one academic and one non-academic hospital. Patients from the academic hospital (surgery and radiotherapy) received an invitation letter from the researchers, asking them to self-apply through an enclosed reply card, by phone, or by e-mail. Non-respondents were reminded three weeks later. Patients could also indicate their reasons for refusal on a reply card. Patients at the non-academic, rural hospital (surgery and medical oncology) were approached by their nurse-practitioner. The researchers received contact details of possibly interested patients and contacted them by phone.

Measures

Socio-demographic characteristics were assessed using open-ended (age) and multiple-choice (gender, education) questions. Patients were asked to indicate the time since diagnosis in months, cancer site, and whether they were still in active treatment. Trust in health care in general was assessed by asking: ‘How much trust do you have in the current Dutch health-care system?’ (very little trust = 1 to a great deal of trust = 5) [268]. Patients’ trust in their own oncologist was assessed using the well-validated Trust in Oncologist Scale (TiOS) [175,220]. The TiOS consists of 18 statements (completely disagree = 1 to completely agree = 5). An example of a question is ‘Your doctor strongly cares about your health’. An overall score is obtained by averaging the responses. Reliability of the scale was good in this sample (α = .94). Trust in the observed oncologist was also assessed with the TiOS, adapting the phrasing to refer to the observed oncologist, instead of patients’ own oncologist (α = .82). Attachment was assessed using the ECR short form [269], which measures attachment avoidance (six items) and attachment anxiety (six items) (completely disagree = 1 to completely agree = 7). Reliability was acceptable (α = .74 for attachment avoidance and α = .60 for attachment anxiety). Patients’ external health locus of control was assessed using the Dutch version of the Powerful Others subscale of the Medical Health Locus of Control scales (PO-MHLC) (completely disagree = 1 to completely agree = 6) [243,248]. Reliability was good (α = .83). State anxiety was assessed on the 20-item Trait
subscale of the State-Trait Anxiety Inventory (STAI) (almost never = 1 to almost always = 7) [270]. Reliability was high (α = .92).

**Analysis**

Handling of missing data and manipulation checks are described in Hillen et al. (submitted). Comparisons between the two groups (CPO members vs. clinical patients) were made with regard to socio-demographic, disease and personality characteristics using χ² tests and independent t-tests (Question 1). Effect sizes for t-tests are reported as $r^2$, ($r^2 = .01$ small, $r^2 = .09$ medium, $r^2 = .25$ large [222,271]). The main effect of patient group (CPO members vs. clinical patients) on trust in the observed oncologist (Question 2), as well as the moderating effects of patient group on the relation between communication manipulations and trust (Question 3) were examined using stepwise random intercepts multilevel analyses. This analysis accounts for the multilevel structure of observations (level 1) nested within patients (level 2), as all patients viewed two different videos.

Our baseline model, Model 1, included all previously tested (Hillen et al., submitted) main effects of socio-demographic characteristics (age, gender, and education) and variations of oncologist communication (enhanced vs. standard Competence, Honesty and Caring) on trust. In Model 2, we tested whether recruitment group predicted trust while accounting for socio-demographic characteristics and communication manipulations. Finally, in Model 3, we tested whether recruitment group influenced the impact of variations in oncologist communication on trust, by adding interactions between communication manipulations and recruitment group to the model. In multilevel analysis, all dichotomous variables were standardized as 0 vs. 1, and all non-dichotomous variables were standardized, to allow interpretation of beta values as giving an indication of effect sizes.

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²In all multilevel modeling, we controlled for the observation order, by including it into the model as a fixed factor. This allowed us to control for the effect of the order of the two observations; whether trust in first or the second observed oncologist was stronger irrespective of communication manipulation (see Hillen et al., submitted).
RESULTS

Sample descriptives

Of all participants (\(N = 345\)), 196 were cancer patient organization members and 148 were clinical patients (see Table 1). Median age was 63 years (\(SD = 11\), range 29–89) and 52% were female. Most frequently occurring primary cancer sites were colon (23%), breast (23%), genitourinary system (19%) and lymphoma (12%). Mean time since diagnosis was 5.5 years (\(SD = 61\) months, range 2–320 months), and 26% were currently in active treatment.

Comparison between CPO members and clinical patients

Socio-demographic and clinical characteristics

CPO members were not significantly more likely to be female (55%) than clinical patients (47%) (\(\chi^2(1) = 1.91, \text{ ns}\)). CPO members were younger (\(M = 60\) years, \(SE = 0.76\)) than clinical patients (\(M = 63\) years, \(SE = 0.83\)) (\(t(342) = -3.34, p < .001, r^2 = .03\)). Of all CPO members, 57% were highly educated (college or university), compared to 37% of clinical patients (\(t(343) = 4.26, p < .001, r^2 = .05\)). Mean time since initial diagnosis was longer among CPO members (\(M = 84\) months) than among clinical patients (\(M = 40\) months) (\(t(339) = 6.99, p < .001, r^2 = .13\)). CPO members differed from clinical patients with respect to their self-reported treatment status, i.e., whether they were still in active treatment (30% vs. 20%, respectively), underwent only check-ups (61% vs. 78%), or neither (9% vs. 2%) (\(\chi^2(2) = 14.34, p < .001\)).

Personality characteristics

CPO members scored higher for trait anxiety (\(M = 1.69, SE = 0.04\)) than clinical patients (\(M = 1.58, SE = 0.03\)) (\(t(327) = 2.12, p < .05, r^2 = .01\)). CPO members scored lower on Powerful Others locus of control (\(M = 3.11, SE = 0.07\)) than clinical patients (\(M = 3.47, SE = 0.09\)) (\(t(337) = -3.15, p < .01, r^2 = .03\)), suggesting they felt more personal control than clinical patients. The two groups did not differ on attachment anxiety nor attachment avoidance.
Table 1. Demographic, health and relationship characteristics of the sample (N = 345)

<table>
<thead>
<tr>
<th></th>
<th>CPO members (n = 197)</th>
<th>Clinical patients (n = 148)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mdn (Range)</td>
<td>SD</td>
</tr>
<tr>
<td>Age (n = 344)</td>
<td>60 (29–89)</td>
<td>11</td>
</tr>
<tr>
<td>Gender (n = 345)</td>
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<tr>
<td>Male</td>
<td>89</td>
<td>45</td>
</tr>
<tr>
<td>Female</td>
<td>108</td>
<td>55</td>
</tr>
<tr>
<td>Educational level (n = 345)</td>
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<td></td>
</tr>
<tr>
<td>None/Primary school</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Secondary/Lower level vocational school</td>
<td>82</td>
<td>42</td>
</tr>
<tr>
<td>College/University</td>
<td>112</td>
<td>56</td>
</tr>
<tr>
<td>Cancer site (n = 344)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon</td>
<td>22</td>
<td>11</td>
</tr>
<tr>
<td>Other gastrointestinal</td>
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<td>4</td>
</tr>
<tr>
<td>Breast</td>
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<td>20</td>
</tr>
<tr>
<td>Genitourinary</td>
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</tr>
<tr>
<td>Gynecologic</td>
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<td>12</td>
</tr>
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<td>Other</td>
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<td>Treatment status (n = 345)</td>
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</tr>
<tr>
<td>In active treatment</td>
<td>59</td>
<td>30</td>
</tr>
<tr>
<td>Undergoing regular check ups</td>
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<td>61</td>
</tr>
<tr>
<td>No treatment or check ups</td>
<td>18</td>
<td>9</td>
</tr>
<tr>
<td>Number of months since diagnosis (n = 341)</td>
<td>84</td>
<td>67</td>
</tr>
<tr>
<td>Trust in own oncologist (n = 345)</td>
<td>4.12</td>
<td>0.66</td>
</tr>
</tbody>
</table>

Trust

Trust in health care was slightly lower among CPO members (M = 3.84, SE = 0.06) than among clinical patients (M = 4.05, SE = 0.06) (t(343) = -2.27, p < .05, r^2 = .01). Mean trust in patients’ own oncologist was lower among CPO members (M = 4.11, SE = 0.05) than among clinical patients (M = 4.32, SE = 0.04) (t(343) = -3.21, p < .001, r^2 = .03). Mean trust in the observed oncologist was lower among CPO members than among clinical patients (F(1, 344.27) = 5.91, p = .01) (Model 2, see Table 3). Taking into account recruitment
The impact of patient accrual

origin (in Model 2) significantly improved the model fit compared to Model 1 (see Table 2). All interactions between recruitment group and the communication manipulations (Competence, Honesty and Caring) were non-significant, indicating that the strength of the effect of oncologist communication on trust was not dependent on patients’ recruitment group (all three interactions non-significant). Adding the interactions (in Model 3) did not improve model fit compared to Model 2 (see Table 2). Therefore, in Table 3 we report only the main effects of Model 2.

Table 2. Fit indices of multilevel models, including trust as the dependent variable

<table>
<thead>
<tr>
<th>Model</th>
<th>AIC</th>
<th>-2LL</th>
<th>df</th>
<th>Model fit improvement</th>
</tr>
</thead>
<tbody>
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<td>1635.72</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Model 2</td>
<td>1651.86</td>
<td>1629.86</td>
<td>11</td>
<td>*</td>
</tr>
<tr>
<td>Model 3</td>
<td>1653.85</td>
<td>1625.85</td>
<td>14</td>
<td>ns</td>
</tr>
</tbody>
</table>

Note: Lower values of the AIC and -2LL indicate closer fit. * indicates significance at \( p <.05 \). Model 1: observation order, socio-demographics (age, gender and, education) and communication manipulations (Competence, Honesty, and Caring). Model 2: observation order, socio-demographics, communication manipulations, and recruitment group. Model 3: observation order, socio-demographics, communication manipulations, recruitment group, and interactions recruitment group x communication manipulations.

Table 3. Effects of patient socio-demographic characteristics (age, gender and education), oncologist communication manipulations (Competence, Honesty, and Caring) and recruitment group (CPO members vs. clinical patients) on trust (TiOS) in multilevel analysis Model 2.

<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>SE b</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age***</td>
<td>.19</td>
<td>.05</td>
<td>.09, .29</td>
</tr>
<tr>
<td>Patient education</td>
<td>-.12</td>
<td>.05</td>
<td>-.21, -.02</td>
</tr>
<tr>
<td>Patient gender***</td>
<td>.06</td>
<td>.10</td>
<td>-.14, .26</td>
</tr>
<tr>
<td>Oncologist Competence***</td>
<td>.17</td>
<td>.05</td>
<td>.08, .27</td>
</tr>
<tr>
<td>Oncologist Honesty***</td>
<td>.30</td>
<td>.05</td>
<td>.20, .40</td>
</tr>
<tr>
<td>Oncologist Caring***</td>
<td>.36</td>
<td>.05</td>
<td>.27, .46</td>
</tr>
<tr>
<td>Recruitment Group**</td>
<td>.24</td>
<td>.10</td>
<td>.05, .43</td>
</tr>
</tbody>
</table>

*Significant at \( p <.05 \). **Significant at \( p <.01 \), ***Significant at \( p <.001 \). Note: patient age and patient education were standardized. All other variables were dichotomous, and scored as 0 vs. 1.
DISCUSSION AND CONCLUSION

Discussion

We examined whether cancer patient organization members yield different patient-reported outcomes than patients recruited through oncology outpatient clinics when studying physician-patient communication. We compared outcomes between both groups for background characteristics, reported trust and the impact of oncologist communication on reported trust.

Our findings provide some relevant methodological insights into how patient accrual routes may influence study results. We confirmed previous findings indicating that patient organization members differ from patients accrued through hospital clinics on socio-demographic and personality characteristics [262-264]: members were younger, higher educated, more anxious, and felt more personal control over their disease. Additionally, we established how patient organization members may perceive and judge physicians more critically, not only their own care provider but also a newly observed oncologist. Effect sizes were moderate, indicating that differences in trust scores should be acknowledged, yet did not differ dramatically between the two groups. CPO members’ more critical stance may stem from a more autonomous view on their health [264], inducing a lower need to fully trust their oncologist [228]. Indeed, we found a lower perceived external locus of control among these patients, indicating a higher sense of personal control over their health. Alternatively, some patients may have joined patient organizations out of discontent or distrust of their care providers [259]. A final explanation for lower trust among CPO members is that they received their diagnosis longer ago. As a result, they may be able to reflect on their oncologist with some more emotional distance.

Importantly, only the level of the patient reported outcome, i.e., trust, differed between CPO members and clinical patients. The strength and direction of the earlier established effects of oncologist communication on trust were comparable between the two groups. This suggests that the mechanism for how communication impacts on trust is similar for both groups. This finding has important consequences for the question whether accruing patient organization members for studies on medical communication is justifiable or not. Had the main purpose of our study been to establish an absolute value of our outcome variable, i.e., the strength of trust, then the results for CPO members would not have been generalizable to the cancer patient population. However, to investigate
processes, e.g., how variations in communication impact on trust, sampling patient organization members appears to yield similar results to sampling patients through hospital clinics. Future research should indicate whether this finding is generalizable to other evaluative outcome measures, such as satisfaction.

For the specific topic of trust in the oncologist, recruiting cancer patient organization members may have an additional advantage, on top of their practical accessibility. Trust scores have been repeatedly found to be extremely high, clustering around the upper end of measurement scales [17,25,61,62]. Our results show that including cancer patient organization members may create less skewed outcome values. This allows for more variation and may, consequently, lead to a better ability to detect effects of communication.

A limitation of our study was the fact that recruitment was not completely random. First, although patients were randomly approached, their self-application may have resulted in a selection bias in both groups. As we have no data on non-responders, we cannot assess in what respects participants differed from non-responders. Second, we have no information about whether clinical patients were members of a CPO. If a proportion of clinical patients were CPO member, it is plausible that in reality, differences between CPO members and clinical patients are even more pronounced than established in the present study. Third, even within the group of clinical patients, we used different patient accrual methods in the non-academic compared to the academic hospital due to different hospital regulations. Patients were either approached directly or through their own nurse-practitioner. This may have induced selection bias: patients critical of their care providers may be less likely to participate when approached through their nurse-practitioner. Because of the small subsample of clinical patients from the non-academic hospital, we were unable to examine differences between patients recruited in the different hospitals. Such investigation may, however, provide even more insight in how patient accrual methods impact on patient-reported outcomes.

Finally, the effect sizes of the individual predictors in our multilevel analysis may have been somewhat underestimated. When several predictors are included into the model at the same time, beta's represent only the unique effect of an individual predictor.

**Conclusion**

These results provide insight into how including cancer patient organization members versus clinical patients may impact on study outcomes in research on communication in health care. Future communication researchers using only patient organization members as participants should consider that their results may not be representative of the entire
patient group under focus. However, when investigating processes, e.g., how communication impacts trust, patient accrual methods may be less impactful than when researching absolute values of patient-reported outcomes. Research including both members and patients recruited through hospital clinics may take group membership into account as a possible confounder.

**Practice implications**

For oncology practice, it may be useful to be aware of the more critical stance generally taken by cancer patient organization members towards their oncologist. Nevertheless, communication strategies that enhance cancer patients’ trust overall, i.e., conveying competence, honesty and caring, may be similarly beneficial to the relation with these patients.
Summary and general discussion
We set out to investigate cancer patients’ trust in their oncologist. Empirical evidence about the meaning of trust is meant to make the subject more tangible for clinicians, teachers and policy makers. Evidence on how trust is established provides useful suggestions to oncologists (in training) for how they can contribute to a well-functioning treatment relation with their patients. Empirical evidence on the relation between oncologist communication and trust is scarce, especially in the oncology setting. As a result, we know little about the meaning and level of cancer patients’ trust, or which oncologist communication behavior contributes to trust.

In our investigation of cancer patients’ trust in their oncologist, we followed the stepwise approach proposed by Goudge and Gilson [6], introduced in Chapter 1. All chapters were organized around three consecutive 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 oncologist communication?

In this chapter, our main findings will be summarized and discussed in relation to the existing literature on trust. Subsequently, applicability of these findings and future research perspectives will be discussed for all three questions.

PART 1: HOW DO CANCER PATIENTS CONSTRUCT AND EXPLAIN TRUST IN THEIR ONCOLOGIST?

<table>
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<th>Summary of main findings</th>
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<td>Patients’ trust in their physician is crucial for optimal treatment. In oncology, the importance of trust is assumed to be even greater, because of the life-threatening nature of cancer. In Chapter 2 we reviewed the available empirical literature on cancer patients’ trust in their oncologist. Of 45 relevant papers, only a few were primarily focused on trust. Trust was frequently not defined, and existing conceptualizations varied strongly. Patients’ trust in their oncologist was found to be strong overall. The physician’s technical competence, honesty and patient-centered behavior appeared to contribute to trust. Strong trust led to easier communication and medical decision making, less patient fear and improved treatment adherence. However, few studies primarily focused on trust and</td>
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methods to assess trust were inadequate or unvalidated. Therefore, we concluded that
systematic, theoretically based research attention is needed to gain a more thorough
understanding of cancer patients’ trust in their oncologist.

To further our insight into what patients mean when they discuss trust, we
qualitatively investigated patients’ constructions and explanations of trust in their
oncologist in Chapter 3. A diverse sample of cancer patients was interviewed in-depth.
Results indicated that patients had difficulty verbalizing a topic as abstract as trust. Many
patients felt they had no choice but to trust their oncologist. From the onset of the
treatment relationship, a strong but superficial, necessity-based trust emerged in patients.
Only after time and repeated interaction did a deeper and relational sense of trust
develop. Using a framework of trust developed in the primary care setting, we investigated
whether cancer patients distinguished separate dimensions of trust and, if so, which
dimensions. We concluded that patients distinguished four dimensions of trust. These
were the oncologist’s fidelity (acting in the patient’s best interest), medical competence,
honest and open information provision, and a caring and compassionate attitude. The
latter aspect, labeled ‘Caring’ was added to dimensions of trust earlier identified in the
literature.

For ethnic minority patients, trust in the oncologist may be different than for
others. Therefore, in Chapter 4, we separately interviewed a small sample of Turkish and
Arabic ethnic minority cancer patients to investigate how their constructions and
explanations of trust may differ from other cancer patients’ trust. As opposed to most
native patients, these patients described that trust was not initially strong but, rather,
needed to evolve gradually over time. They emphasized three important elements which
promoted trust. First, they attached much importance to the oncologist’s proactive
approach to treatment in any phase of their disease. Patients perceived a wait-and-see
attitude as a lack of willingness to help, which was detrimental to their trust. Second, the
oncologist’s reassurance and avoiding discussing depressing topics were important to
these patients to allow them to maintain hope. Finally, these ethnic minority patients
appeared to rely heavily on the oncologist’s non-verbal behavior, specifically his or her
facial expression. Although these three elements are to some extent relevant for all
cancer patients, they might be more explicitly valued by ethnic minority patients.
Discussion of the most important themes

Cancer patients have difficulty conceptualizing trust

In our literature review, we established that little empirical research to date specifically addressed cancer patients’ trust, and trust was rarely conceptualized. This hinders interpretation of findings: if we do not know exactly what researchers, patients or physicians mean when discussing trust, then how meaningful or comparable are research findings? Our interviews were aimed at addressing this shortcoming. We found, however, that patients struggled to put into words their experiences of trust. Especially when still undergoing active treatment, patients had difficulties verbalizing and conceptualizing trust, as illustrated by this quote of a patient:

Well, I think it’s a difficult topic, to speak about trust in an oncologist. (…) I cannot answer that, I wouldn’t know.

This finding appears to reflect the ambiguous and hard-to-define nature of trust in general [6]. Trust might function so automatically that it cannot be easily put into words [76]. As Möllering [2] contends: “It would be a contradiction in terms to expect people to tell us (in an interview for example) what they do not know.” (p. 416). Luhmann [8] even argued that patients’ accounts of their trust are merely retrospective constructions of their own feeling: “Although the one who trusts is never at a loss for reasons and is quite capable of giving an account of why he shows trust in this or that case, the point of such reasons is really to uphold his self-respect and justify him socially.” (p. 26). Especially for cancer patients, who might feel they need to fully rely on their oncologist, trust could remain automatic and unconscious. Only if it is damaged might patients consciously reflect on their trust in their oncologist [76]. Such accounts of damaged trust might provide us with more insight into how trust works when it is still strong and undamaged. Indeed, we found that patients who had had both trustful and distrustful experiences were well able to reflect on the realization of their trust. Alternatively, reflecting on trust might be facilitated if patients are followed-up over time by researchers, from the onset of the treatment relation. Reflecting on trust throughout the treatment process possibly enhances patients’ ability to identify behaviors and processes impacting their trust.

A need to trust is present among many patients

Patients’ felt need to trust their oncologist resulted in strong trust at the onset of the treatment relation. As discussed in Chapter 3, the vulnerability associated with a cancer
diagnosis might force exceptionally strong trust upon patients [13,60,77]. Hall et al. [10] propose that high trust levels might arise as a coping mechanism, to deal with the emotional distress associated with severe disease. They suggest that patients confronted with a life-threatening illness often need to believe that physicians have more power than they have in actuality. Indeed, we found that questioning their trust felt almost threatening to some patients. Thus, from a coping perspective, exceptionally strong levels of trust might be functional to patients in managing the emotions associated with their disease. Strong trust may be beneficial to patients’ well-being. On the other hand, too strong levels of trust might have harmful consequences. First, unquestioned trust may diminish patients’ confidence to act as autonomous patients [272]. Overly trusting patients may fail to recognize the importance of their own contributions to their medical care [273], possibly resulting in more passivity in the medical consultation, e.g., less active involvement in medical decision making [42,62,97] Second, extremely strong trust levels may result in feelings of betrayal when patients’ high expectations of the oncologist are not met [274].

As initial, necessity-based trust is not based on careful consideration and testing of the oncologist, it may at times involve unrealistic images of the oncologist. As a result, it may be less resilient than gradually evolving relational trust and, thus, more easily threatened. The risks of both passivity and feelings of betrayal suggest that the optimum level of trust does not lay at the extremity of the continuum between trust and distrust. Instead, some sense of prudence might be functional for cancer patients in their relation with the oncologist.

Relational trust evolves gradually

During some disease stages, patients’ need to trust appeared less pronounced. Especially when entering a less acute or life-threatening phase of their disease, patients seemed better able to form a substantiated sense of trust. This form of trust appeared to be more strongly based on continuous interaction with the oncologist than necessity-based trust. As discussed in Chapter 3, the contrast between an initial necessity-based and a slowly evolving, more deliberately formed trust is consistent with theories on trust outside the oncology setting [144]. In situations of high dependence, people are thought to initially evaluate the benefits, costs and associated vulnerability of trust versus distrust [12]. Based on this rational evaluation, they swiftly form a ‘calculus-based’ sense of trust [145]. Only after repeated interaction does initial trust evolve into a more relational and voluntary sense of trust. Relational trust is thought to involve a sense of interpersonal attachment, whereby the patient believes that the doctor responds to his needs in a caring manner [275]. Whereas patients base initial calculus-based trust mostly on commonly available
information or reputation, relational trust is influenced by information from within the consultation [9].

Mere calculus cannot, however, fully account for cancer patients’ initial trust. The extreme strength of initial trust may be specific for oncology. In other settings, e.g., primary care, patients’ initial trust was found to remain conditional to some extent [53,276]. Cancer patients, however, may not all be able to approach trust so rationally. The extreme vulnerability that comes with a cancer diagnosis, may induce, according to Greener [145] “a situation of enforced dependency, where we are effectively forced to trust someone because we have no alternative”. Gilson [20] contends that, when patients have no choice but to trust, its voluntary nature is threatened. She suggests that, because of its involuntary character, consequent trust might not even be considered as actual ‘trust’, but rather as a form of ‘dependency’. However, even in such involuntary situations, a trusting intention may or may not be present: seriously ill patients who feel forced to enter a treatment relation still make the choice to trust or not to trust [10]. Consequently, their trusting behavior, i.e., undergoing the oncologist’s treatment, may or may not be accompanied by a trusting intention, i.e., an attitude of optimistic acceptance of dependence on the oncologist’s treatment.

Turkish and Arabic ethnic minority cancer patients similarly reported feeling the need to trust their oncologist. For them, however, it was more difficult to immediately start trusting. Instead, these patients reported that trust evolved slowly, after repeated interaction and a critical review of their oncologist’s behavior. This slow establishment of trust corresponds to a more relational sense of trust. The necessity-based trust initially present in other patients might not necessarily be established in these ethnic minority patients. This hesitance to trust initially could result from an unfamiliarity with, and possibly even distrust in, the Dutch healthcare system [73]. If trust is not present from the start but rather emerges slowly, ethnic minority patients may encounter extra difficulty to cope with the initial, most acute, phase of their disease.

Patients distinguish several aspects of trust

We added Caring to the dimensions of trust described by Hall et al. [10], as it might be particularly important for cancer patients’ trust. Accordingly, Mechanic and Meyer [13] found the physician’s caring behavior to be of central importance to seriously ill patients’ trust. Caring might reflect a more emotional element of trust, in line with the assumption that trust takes on a more emotional form for patients confronted with a life-threatening disease [10]. Alternatively, it may be argued that caring is important to any patients’ trust. Accordingly, in qualitative research on the construction of primary care patients’ trust,
Chapter 11

caring was identified as an important aspect [277]. Interestingly, however, this element was subsequently not included in the questionnaire based on this qualitative work [278].

Whereas we found that honesty was important to patients' trust, many stressed their need for a sense of optimism in their oncologist's communication as well. Ethnic minority patients especially emphasized they needed their oncologist to allow them to preserve hope. Wanting to maintain optimism may result in patients wanting to know less than complete information [279]. The oncologist's ability and willingness to meet this need for hope or optimism may be an important element of patient-centered cancer care to other patients as well [280]. Honestly communicating with patients about prognosis, risks and uncertainties while at the same time sustaining hope or optimism may at first sight appear contradictory, but can be feasible. Several authors have described strategies to maintain some form of optimism without violating the truth [281,282]. Others provided elaborate, in-depth analyses of the balance between realism and optimism in oncology care [283,284].

How can our findings be used?

Central to our findings were patients' need to trust, and an initial high level of trust. Both point to a strong emotional component in trust establishment of cancer patients, which may be less present in other patient populations. This emotional need contrasts with the contemporary image of the autonomous patient, who critically observes and tests physicians before trusting them [285]. Patients are increasingly expected to assume an active and autonomous role, demanding information from their doctor and involvement in their own medical decisions[286]. Grimen [22], however, posits that patients and doctors cannot truly become equals - because of the continuous persistence of a power difference “[patients] may be forced to trust what they get” (p.18). For severely ill cancer patients, taking a critical stance and carefully weighing their trust may simply not be possible or even beneficial. Physicians, but policy makers and other healthcare professionals alike, should be aware of seriously ill patients' vulnerable position, and the role of 'autonomous patient' should not be forced upon them [252]. Salmon [173] has argued that, even outside of the oncology setting, the asymmetry of the relation between physician and patient should be acknowledged, viewing the patient as vulnerable and dependent, and the practitioner as expert and caring. Preferably, physicians may carefully, yet explicitly, explore to what degree each individual patient wishes and is able to take on an active and autonomous role, instead of relying on their intuition. This could imply that with some patients, oncologists will resume their traditional, paternalistic, role to establish optimal trust. Patients may in these cases make lower demands upon their oncologist's behavior.
Consequently, the responsibility for good interpersonal communication lies more with the oncologist than when patients request a more autonomous role.

For Turkish and Arabic ethnic minority cancer patients, the starting point for trust may be lower than for others. Trust for these patients may be less evident and automatic. For oncologists, this may mean that they have to go to greater pains to ‘win over’ their patients’ trust. Once trust is established, many ethnic minority patients may wish to take on a somewhat passive role in medical decision making. Their preference may result from cultural values, as in their countries of origin, i.e., Turkey and Arabic countries, healthcare organization is still more paternalistic [158]. Additionally, ethnic minority patients may not feel up to the task of weighing difficult medical information, as they are sometimes poorly educated and a language barrier may exist [287, 288]. Consequently, the power difference between oncologists and these patients may be even greater than usual [289, 290]. To some patients, maintaining this power difference may be necessary to preserve trust. Nevertheless, patients’ cultural background should not be viewed as proof of their preferred role. Hence, careful exploration of ethnic minority patients’ preferences is warranted just as with native patients.

Future perspectives

Blind trust

An important issue to address in future research is the double-faced nature of trust. Most empirical studies thus far consider trust only as something favourable; the more trust, the better [138]. However, especially in oncology care, where many patients feel they need to trust their oncologist, an extreme form of trust, i.e., ‘blind trust’, may frequently occur. Such blind trust may in some cases be harmful to patients and their treatment [10, 42, 62]. Blind trust could discourage patients from taking an active part in their own treatment, by reducing their inclination to seek information and participate in decision making. Moreover, blindly trusting patients may be hesitant to come forward when care is suboptimal [273]. On the other hand, blind trust could serve an important psychological function for severely ill patients, allowing them to cope with their disease. As established in Chapter 2, the various possible consequences of blind trust have rarely been the focus of empirical research. Moreover, the topic raises an ethical dilemma: is blind trust, if it indeed leads to patient passivity, wrong, and should patients be stimulated towards more reserve towards their oncologist [8]? Or might such unsolicited empowerment induce uncertainty, doubt and fear in patients? These are complex questions, which nevertheless deserve to be translated into empirical research questions.
A shortage of trust

Nearly all patients in both our native and ethnic minority cancer patient samples reported strong trust. We therefore mainly gained insight in how trust is constructed in well-functioning relations. Despite our explicit efforts, it was difficult to specifically include less trustful, or even distrusting, cancer patients, whereas they could have different constructions and explanations of trust. Therefore, we may have missed variation that exists within the patient population. Future qualitative studies could sample distrustful patients, e.g., by focusing on second opinion seekers. Their accounts may shed more light on the construction of both distrust and well-functioning trust.

PART 2: CAN WE RELIABLY AND VALIDLY MEASURE CANCER PATIENTS’ TRUST IN THEIR ONCOLOGIST?

Summary of main findings

Our review of the empirical literature (Chapter 2) revealed that, until now, cancer patients’ trust was assessed with either non-validated or single-item measurements, or with scales developed in the primary care setting. Unclear was to what extent these measures were apt to accurately capture cancer patients’ trust. Accordingly, Lewicki et al. [12] ascertained that many studies have used measurements of trust inconsistent with their definition of trust. We therefore aimed to develop a measurement scale to assess cancer patients’ trust, consistent with patients’ conceptualization of trust. We constructed a multidimensional questionnaire based on the Physician Trust Scale by Hall et al. [17] and our qualitative interviews with patients. The newly developed 18-item Trust in Oncologist Scale was validated among Dutch cancer patients. The development and validation results are described in Chapter 5. Subsequently, the TiOS was translated into English and cross-culturally validated among an Australian sample of cancer patients (Chapter 6). Based on our qualitative findings, the questionnaire included the dimension of Caring, in addition to the dimensions proposed by Hall et al. [10], i.e., Fidelity, Competence, and Honesty. The TiOS proved reliable and valid in assessing cancer patients’ trust. Trust was found to be strong overall. The proposed multidimensionality was reflected in patient ratings only to a limited degree. In both the Dutch and the Australian sample, overall, trust was ultimately best regarded as one-dimensional.
Discussion of the most important themes

Is trust one- or multidimensional?

The one-dimensionality of patients’ trust in quantitative measurement is in contrast with how patients distinguished multiple dimensions of trust when qualitatively assessed. Similar one-dimensional reflections of trust were reported in quantitative measurements of trust in other patient populations [17,25,52], whereas multidimensional accounts of trust were reported in several qualitative studies [13,277]. This raises the question which type of measurement, qualitative or quantitative, more accurately reflects cancer patients’ trust. Do patients ultimately experience trust holistically or multidimensionally?

A first possibility is that patients do distinguish between dimensions of trust, but that in our validation samples, dimensionality was obscured by the generally high trust scores and limited variation. Perhaps in specific subsamples with more variation in trust scores, dimensionality would be more present. This explanation is supported by the more pronounced dimensionality in our Dutch than in our Australian patient sample. Dutch patients were more randomly sampled, resulting in more varying trust scores, as discussed in Chapter 6. Possibly, including patients with even more diverse trust scores would result in clearer distinctions between trust dimensions. Examples of patient sub-groups that may be less trusting are immigrants, second opinion seekers or highly educated patients. A second possibility is that the apparent lack of dimensionality resulted from a limitation inherent to our measurement scale, or from patients’ inability to reflect on unconscious processes. The TiOS is a self-report scale relying on conscious reflection. As a result, patients’ highly coherent trust scores might result from a determination to trust their oncologist or from social desirability. In that sense, a fast and quantitative measurement might be less capable than qualitative measures to tap into patients’ underlying, less superficial, trust constructions.

Hall et al. [10] provide an alternative explanation, arguing that both qualitative and quantitative findings are accurate. They contend that, although trust does consist of all these separate dimensions, they are all so tightly interconnected that patients do not distinguish between them. As a result, if an oncologist is trusted in one respect, this influences all dimensions of patients’ trust, and vice versa. At present, it would be premature to conclude that cancer patients do not distinguish between dimensions of trust. It is plausible that a patient trusts in an oncologist’s medical competence, while at the same time being more hesitant about that same oncologist’s honesty. On the other hand, it is conceivable that trust needs to be strong in every respect for a general sense of trust to arise.
(How) should we distinguish what trust is from what causes it?

A conceptual issue in the assessment of trust is how to distinguish aspects, predictors and consequences of trust. This, in other words, entails the distinction between what trust is, what causes trust, and what follows from trust. Hall et al. [33] explain this issue as follows: “(…) some things that cause us to trust or not trust, or some things we might do or not do based on trust, might themselves be seen as measures or indications of trust. Therefore, there is sometimes disagreement about whether a particular attribute should be on one side or the other of this line” (p. 458).

These conceptual issues are inherent to the assessment of most attitudes and beliefs, and concern the distinction between formative and reflective measurement [291,292]. In formative measurement, a latent construct is caused by a number of ‘causal indicators’, whereas in reflective measurement, the latent construct itself causes so-called ‘effect indicators’. It is often not straightforward to distinguish formative from reflective measurement. In our trust scale, this issue first of all becomes apparent at the item level: the individual items forming a trust dimension are conceptually considered reflective indicators, but may alternatively be conceptualized as formative. Consider for example the item ‘Your doctor would always tell you the truth about your health, even if there was bad news’, as an indicator of the trust dimension Honesty. If interpreted as hypothetical, as intended, then it should be regarded a reflective indicator: patients’ belief in their oncologist’s honesty causes them to answer the item affirmatively. However, we cannot rule out that patients relate the item to their actual experience of this specific oncologist behavior. If so, then the item should be considered formative, as it causes the patient’s general believe in the oncologist’s honesty.

A similar issue occurs at the dimensional level. Within formative measurement, methodologists further distinguish between causal and composite indicators [292]. Whereas causal indicators are the variables that together cause (changes in) the latent construct, composite indicators are the elements that together constitute the latent construct. Conceptually, we considered the dimensions of trust, i.e., Competence, Honesty, Fidelity and Caring, as composites of the latent construct of trust: based on theory we hypothesized that trust is an exact linear combination of the dimensions. Empirically, however, these trust dimensions might serve as causal indicators of trust: instead of what trust constitutes of, they might together cause trust.

The specific trust definition employed for our scale, involving various dimensions or trusting beliefs distinguished by patients, may have partly caused these conceptual issues. Originating from a more general trust definition might have been more straight-forward. For example, the two ‘global trust’ items included in the TiOS (e.g., ‘All in all, you have
complete trust in your doctor") can unambiguously be viewed as composites of trust. Nevertheless, assessing patients’ trust using only global items entails other challenges. After all, distinguishing possibly existing independent aspects of trust is impossible using such short and general scales. Moreover, items tapping into patients’ trust as a whole almost unavoidably include the word ‘trust’. Thus, they may be even more susceptible to patients’ conscious processes and intentions than items that are less obviously about trust.

How can our findings be used?

The Trust in Oncologist Scale can be used as a patient-reported outcome (PRO), to indicate the quality of oncology care. Presently, satisfaction with care is regularly employed as a PRO to assess patients’ experiences with oncology care [293]. Trust as a PRO in clinical research may be of added value, as it taps more into interpersonal and emotional aspects of care than satisfaction. On the other hand, as with satisfaction, the consistent skewness of trust scores may limit usefulness of trust as a PRO. Indeed, patients’ trust in their radiation oncologist was found to be irresponsible to changes in the oncologist’s information giving behavior [294]. Unclear is whether this lack of effect is due to the generic trust measure used in this particular study, or to limitations of trust as an informative PRO.

The TiOS can moreover be employed to register on a population level how cancer patients’ trust develops over time. This may, for example, allow assessment of whether and how changes in healthcare organization impact on the quality of medical relationships in oncology. Additionally, the TiOS is a useful tool for future research specifically aimed at cancer patients’ trust. It can be employed to identify and test the importance of a wide variety of trust predictors, at the physician, patient and healthcare organizational level. Moreover, it may serve to identify what follows from patients’ trust in their oncologist.

Future perspectives

Assessing trust

If cancer patients’ trust is fundamentally multidimensional, then our present quantitative trust measures apparently do not accurately capture it. Several solutions for this measurement difficulty have been proposed. More variation in the higher end of the continuum could be generated to reduce skewness, using asymmetrical response formats [295]. Reversed item phrasing provides an alternative approach to increasing variation in
scores. However, reduced skewness due to reversed phrasing might result from patients’ misunderstanding rather than from more nuanced answering of the items [296]. If reducing skewness does not result in the presumed increased multidimensionality, even among specific patient sub-samples, the TiOS may be shortened for future research purposes. A shorter scale may in that case be more convenient in use, while yielding the same amount of information. Alternative measurement methods should at the same time be considered. Lewicki et al. [12] contend that the use of Likert scales does not do justice to the complexity of all components that jointly constitute patients’ trust. They propose that other, mostly qualitative, measures be used in addition to questionnaire data. Such methods, e.g., diary accounts, narratives or critical incident techniques, could be triangulated with survey data. For example, in a study among general practitioners, patients were asked to reflect in-depth on video-recordings of their own consultations [276]. Thus, observable behavior could be related to patients’ subjective experiences. A possible problem when triangulating different methods, however, became apparent in our study: what should researchers do if qualitative data are not in accordance with survey data of the same patient? Which of the two measurements should be considered the most adequate reflection of patients’ trust? This question may prove challenging to answer.

Alternatively, methods might be developed that rely less on patients’ conscious processes, and could thus be less biased by patients’ social desirability or intentions to trust. Unobtrusive or implicit measures may be used as a starting point [174]. In several psychology sub-disciplines, unobtrusive measures were found to register the automatic impact of people’s attributes or attitudes on behavior, thus measuring their spontaneous reactions, thoughts or feelings [see 174 for an overview]. Careful adaptation and translation of these principles to trust research may improve assessment of both rational and emotional elements of patient’s trust [2].

Alternative methods to assess cancer patients’ trust could address an additional challenge. Based on patients’ trust scores on the present questionnaire, we cannot distinguish between the two types of trust identified in our qualitative work, i.e., initial ‘necessity’-based vs. slowly evolving relationship-based. Thus, trust scores generated with the TiOS do not tell us whether patients a priori fully entrusted themselves to their oncologist, or whether the apparent same level of trust was based on careful consideration of the oncologist’s behavior and performance. This problem may hinder use of the TiOS for the purpose of discriminating between doctors. Unobtrusive measures may prove useful to validate or distinguish between different types of trust. Additionally, longitudinal assessment of trust might be considered in future research, to map how trust is established over time [12].
Considering the methodological and conceptual problems above, should we continue to investigate trust? Several arguments lead to the conclusion that trust is a subject worth further clarification. Trust has repeatedly, and often spontaneously, been mentioned by cancer patients as crucial for their treatment and ability to cope with their disease. This leads us to believe, along with many other researchers and clinicians [10,13,55,297,298], that trust is one of the most important indicators of the medical relationship. Indeed, longitudinal research suggests that trust is more predictive of outcomes such as adherence and continuity with physicians than a related concept such as satisfaction, because of its emotional component [10,25]. Thus, investigating and optimizing trust when considering severe illness and/or interpersonal relationships may prove more relevant than addressing satisfaction.

The measurement challenges we encountered should not be underestimated, but may be overcome in time. Only in the last decades has interpersonal trust become the focus of empirical research in health care. Clearly then, its conceptualization and measurement have not yet been thoroughly unravelled. Goold [24] argues that it is imperative to further investigate trust, stressing that “it is vital that the challenging task of defining and measuring trust and related concepts – distrust, scepticism, trustworthiness, confidence, vulnerability, and satisfaction, for instance – be approached rigorously” (p. 79).

PART 3: IS CANCER PATIENTS’ TRUST INFLUENCED BY HOW THE ONCOLOGIST COMMUNICATES?

Summary of main findings
To allow optimal trust levels, it is important to know how patients’ trust is established. Oncologist communication may be an important focus for research on predictors of trust, as interpersonal trust is by definition, at least in part, established through communication. Moreover, communication is more modifiable than fixed characteristics of health care, patients or oncologists. In Chapter 2, we established in our literature review that no experimental research on the predictors of cancer patients’ trust was thus far conducted. Moreover, based on the available evidence, it is difficult to ascertain which precise oncologist behaviors contribute to trust.

We addressed this shortcoming by designing a laboratory-style experimental study, to investigate whether and how oncologist communication influences patients’ trust.
We used a scripted video-vignettes design, creating variants of a video recording depicting an enacted oncologist-patient consultation. We manipulated three characteristics of oncologist communication which patients identified as important in our qualitative study. For each of these three characteristics, i.e., oncologist conveyance of medical competence, honest information provision and caring communication, we created a standard and an enhanced variant. Combining all standard and enhanced variants in every possible way resulted in eight different video vignettes. Except from these manipulations, the consultations were kept identical across all video variants. Cancer patients and survivors each viewed two of these eight vignettes and reported their trust in the observed oncologist on the Trust in Oncologist Scale. In Chapter 7, we described methodological choices and dilemmas encountered during the development and administration of the video vignettes. This overview may be useful to future researchers conducting video-vignettes research.

In Chapter 8, we tested how the three elements of oncologist communication influenced trust. The results indicated that even small variations in the communication of an observed oncologist influenced cancer patients’ trust. Specifically, trust increased when the oncologist expressed more caring behavior, communicated openly and honestly, and emphasized his medical competence. Patients trusted the oncologist in the second video they viewed more than the oncologist in the first video. Overall, older patients and lower educated patients reported higher trust, whereas patient gender did not predict trust. In Chapter 9, we sought to investigate whether trust depends on two of patients’ personality characteristics, i.e., their locus of control and their attachment style. Moreover, we examined whether the effects of oncologist communication on trust would differ depending on these personality characteristics. We found that patients with a strong belief that others controlled their health (strong external locus of control) reported higher trust in the observed oncologist. Neither patients’ attachment anxiety, nor their attachment avoidance was related to trust in the observed oncologist. The higher patients’ attachment avoidance, however, the weaker the positive effect of oncologist’s communication of caring on trust. Patients’ trust in their own oncologist, rather than in the observed oncologist, was weaker for patients with higher attachment anxiety and higher attachment avoidance. We concluded that these personal differences underscore the importance of oncologists’ tailoring of their communication to individual patients. Finally, in Chapter 10, we looked at the impact of different patient accrual methods on our study results, i.e., through hospital outpatient clinics, and through cancer patient associations. Many studies in healthcare communication rely on cancer patient association members only, whereas it is not clear whether results for these patients can be
Summary and general discussion

generalized to the broader patient population. Therefore, we tested whether study results of cancer patient organization members were similar to those of clinical patients. Overall, cancer patient organization members were younger and more highly educated than clinical patients. Members felt more personal control over their health, but were also more anxious. They reported less trust in general health care, in their own oncologist and in the observed oncologist. However, the impact of oncologist communication on trust was similar for both groups. We concluded that future studies should take into account that selecting patient organization members may impact on the generalizability of their findings. However, to investigate processes, e.g., how communication impacts on trust, this group may yield results that are similar to ‘average patients’.

Discussion of the most important themes

Experimental and specific evidence for the importance of communication behavior

We provided new and firm evidence for the importance of oncologists’ communication behavior to cancer patients’ trust when treating seriously ill patients. Adequate communication is nowadays considered essential for good clinical practice [55]. Consequently, communication skills training forms an integral part of both medical education and physician training [299,300]. However, causal evidence supporting the relevance of communication for patient-reported outcomes, such as trust, is rare. Such evidence is difficult to acquire, as it requires experimentally manipulating communication behavior. In clinical practice, this would entail both methodological and ethical challenges. Thus far, only a few experimental studies using video vignettes have been conducted. These provided some evidence for the impact of physician communication on trust in other settings than oncology [188,189,191,198,199]. Our study was the first to establish this connection for cancer patients. Moreover, we demonstrated that variations in communication, as small as adding three sentences, can have an impact on cancer patients’ trust. Apparently, improving the relation requires only small time-investments for oncologists.

Moreover, the results of our study provide specific clues for which communication behaviors are of relevance. We demonstrated that communicating medical competence, honest information provision and conveying care all individually contribute to trust. Until recently, evidence was often inconclusive, and opinions varied, about what precisely ‘good communication’ should entail [301]. Whereas observational evidence provides mostly unspecific indications in this regard [63], video-vignettes studies allow
researchers to isolate and test specific communication behaviors. Nevertheless, until presently, most video-vignettes studies manipulated unspecific communication characteristics, e.g., ‘patient-centered communication’, ‘socio-emotional behavior’ or ‘affiliative versus controlling consultation styles’, all of which involve multiple behaviors [189,191,198]. Although clinically relevant, manipulating a variety of behaviors at once prohibits conclusions about which behavior caused an effect. We avoided this ambiguity by varying three specific communication behaviors in isolation. This approach generated direct evidence about the relevance of oncologists’ expression of care, honesty, and competence for cancer patients’ trust.

Methodologically, we demonstrated how an experimental design using scripted video vignettes is feasible and can provide valuable evidence. Future researchers using similar designs can benefit from our checklist of methodological issues encountered in the development and administration of such vignettes. Moreover, we have shown that to investigate processes, e.g., how behavior influences trust, cancer patient organization members may be recruited to represent the cancer patient population. Thus, for this type of research, including a sample that is completely representative of the population may not be absolutely necessary.

**Caring communication strengthens trust**

Oncologists’ expression of caring had the most pronounced positive effect on patients’ trust. Apparently, addressing patients’ cues and emphasizing sustained involvement is strongly appreciated by patients. This finding is in line with cross-sectional findings in oncology [13,73,100,117,118]. Moreover, it makes sense intuitively that expressing caring behavior, which is more relationship-oriented than the display of honesty or competence, impacts trust the most, as trust is fundamentally a relational characteristic. Specifically, the degree to which oncologists address patients’ cues may be crucial for their trust. Indeed, in other patient populations, physicians’ elicitation of patient concerns, and addressing patient cues was specifically found to enhance trust [83,133]. By addressing patients’ cues, physicians allow patients to share their emotional experiences [302]. For patients who have cancer, expressing emotions might be even more important, as the severity of illness and treatment often induce fear, depression and distress [303]. If oncologists allow patients the opportunity to share these concerns and worries, patients’ perception of the oncologist’s involvement may strengthen, thus enhancing trust.
Honest communication strengthens trust

We found that honest and nuanced information giving by the oncologist contributed to trust. This confirms De Zulueta’s [16] conviction that “(...) truthfulness is a necessary, albeit insufficient, ingredient of trust”, and that doctors should "strive to be accurate and sincere if they truly respect their patients and value their own authenticity” (p.20). Indeed, both within and outside of the oncology setting, patients reported that physician honesty was beneficial to their trust [10,13,113,116]. However, what patients’ perception of ‘honesty’ entails is frequently not specified. Patients may derive oncologists' honesty from the duration of information-giving, an emphasis on realism, understandability, or a combination of these characteristics. Therefore, we modeled our manipulation of honesty after patients’ descriptions of oncologist communication on which they based their perception of honesty. In our qualitative interviews, patients most often mentioned oncologists’ being realistic and indicating the limits of their abilities and predictive power as conveying honesty. Thus, in our honesty manipulation, the oncologist mainly emphasized his wish to inform realistically and completely. Our results confirmed that this form of honest communication may strengthen trust. Nevertheless, oncologists may fear that too great an emphasis on the limitations of their skills and treatment comes at the expense of patients’ trust, rather than enhancing it. Will overly realistic information not make it impossible to fulfil patients’ need for hope and, as a consequence, reduce their trust? Balancing hope and realism in life-threatening illness remains a delicate matter for oncologists [282,304-307]. Nevertheless, preliminary evidence suggests that honest and realistic information giving is beneficial to trust as long as it does not come at the expense of preserving a sense of hope, e.g., in the form of emphasizing a continued availability to the patient [308].

Communicating medical competence enhances trust

Oncologists’ communication of their medical competence enhanced trust, albeit to a weaker extent than the other communication behaviors studied. The modesty of this effect may be explained by patients’ a priori assumption that oncologists are medically qualified and experienced. This assumption indeed became apparent in our qualitative interviews. In the Netherlands, where the quality of medical (oncology) care is high overall, patients’ trust in their oncologist’s medical competence and expertise may already be high, leaving little space for improvement. Moreover, it may be difficult for patients to assess their oncologist’s medical skills [13]. Thus, patients need to derive competence indirectly from observable characteristics such as status, reputation, or keeping up-to-date [138]. We demonstrated how oncologists may enhance trust by emphasizing experience...
and being up-to-date. Nevertheless, some patients explained they perceived oncologists’ emphasis on their medical competence as defensive, and sometimes even destructive to trust. Thus, strong individual differences in the evaluation of oncologists’ expression of competence may have weakened its effect.

**Individual differences**

We observed large individual differences in how patients perceived oncologist behaviors. Thus, although overall effects of expressing caring, honesty and competence were present, not all patients appreciated these behaviors to a similar extent. Specifically, for patients with avoidant attachment styles, who have a strong need for independence and often deny needing close relationships, caring and honest communication had less positive effects on trust, and sometimes even reduced it. These results may confirm oncologists’ feeling that with some patients, establishing a trustful relationship is particularly difficult [309]. These patients’ avoidant attachment styles can impair their ability or willingness to form a relationship with their physician. Among such patients with a tendency to distrust, or low dispositional trust, otherwise effective strategies to win trust may prove ineffective. In these cases, oncologists may need to resort to alternative strategies for trust enhancement. Patients’ attachment orientation may be merely one of many personality traits that are of influence in trust-building. This notion underscores that the same communication behaviors cannot be blindly advised for all patients. It remains crucial that oncologists adapt their consultation style to an individual patient. Such ‘tailoring’ may be achieved by carefully exploring patient preferences [252].

**How can our findings be used?**

Our findings contribute to both research and to clinical practice; they provide useful suggestions to both oncologists (in training) and teachers of medical communication. Increasing cancer patients’ trust, and thus reinforcing the therapeutic relationship, may be achieved in less than a minute. Moreover, the behaviors manipulated in our study, i.e., expressing caring, honesty, and medical competence, were not complicated, and can be simply learned and employed by oncologists (in training).

First, expressing care towards patients by shortly addressing their cues and concerns and emphasizing continuous availability is beneficial to patients’ trust. Thus, relational statements may prove a powerful tool for oncologists to strengthen the therapeutic relation. Second, oncologists may enhance trust overall by providing honest and realistic information. Nevertheless, they need to examine individual patients’ information preferences, so as not to overload patients who do not want overly specific
information. For all patients, care needs to be invested to simultaneously preserve a sense of optimism or hope. Especially migrant patients from Turkey and Arabic countries appreciate if the oncologist allows them to maintain some hope. Hope need not necessarily be directed at being cured. It may also refer to maintaining a good quality of life, or to not being abandoned by the oncologist. Third, oncologists may improve on their patients’ trust by emphasizing their medical competence. Patients generally seem to appreciate knowing that oncologists are experienced and up-to-date. Oncologists could employ these behaviors carefully in practice. Emphasizing medical competence may be particularly relevant if oncologists suspect that their medical expertise is of crucial importance to patients. On the other hand, information about the competence of the healthcare team surrounding the oncologist may prove to be equally beneficial to patients’ trust. Similarly, the oncologist’s competence may be conveyed through reputation or affiliation.

Lastly, patients’ personality characteristics may determine both their level of trust and how oncologist communication impacts on it. Oncologists may especially be aware of avoidantly attached patients, for whom caring communication may be harmful, rather than beneficial, to trust [241]. Moreover, providing overly nuanced information with an emphasis on limits and uncertainties may diminish these patients’ sense of personal control, resulting in weaker trust. When oncologists suspect a patient to be avoidantly attached, they may communicate respect for the patient’s personal distance and emphasize the patient’s independent and autonomous status [242]. Continuously involving the patient in the medical process may prevent resistance to treatment.

Future perspectives

The use of scripted video-vignettes designs

We investigated the effect of communication on trust in an experimental laboratory setting. This allowed several advantages, most important of which was the ability to distinguish cause from effect. An additional advantage of this design was that skewed distributions in trust scores could be successfully avoided when assessing patients’ trust in a hypothetical, rather than their own oncologist. Indeed, trust scores in our study were significantly less strong, and more variable, than in observational studies. Moreover, patients reported lower trust in the observed oncologist than in their own treating physician. The hypothetical setting we used may have reduced social desirability bias or dependency, thus increasing power to detect the impact of communication [192,194]. This particular advantage, however, simultaneously entails a limitation. We cannot ascertain to
what extent our findings would translate to real clinical practice. Reporting trust in an observed oncologist while imagining yourself as a patient may be fundamentally different to actually being that patient and depending on your oncologist. We aimed to increase external validity by including cancer patients and survivors as study participants, who could identify with the situation depicted. Nevertheless, the dependency so central to cancer patients’ trust in their own oncologist may have been absent.

Moreover, the laboratory setting used in this study may prove less than ideal for assessing a slowly evolving characteristic such as trust. In our qualitative interviews, we found a distinction between patients’ immediate, urgency-based trust, and a more slowly evolving relationship-based trust. For assessing the former, swiftly established, trust, an experimental setting appears well suitable. For assessment of a more slowly evolving relational trust, repeatedly assessing trust would be necessary. Whether establishing a true interpersonal relation in an analogue laboratory setting remains to be established.

These limitations do not make the use of experimental video vignettes designs inadvisable. As long as two important considerations are taken into account, we will argue that these analogue designs can provide valuable empirical evidence. First, such studies should mainly focus on relations between predictors and outcome variables, instead of the absolute value of the patient-reported outcomes. For our own study, we can only draw conclusions about what causes trust, not about the level of trust. Second, findings from video vignettes should be viewed as a starting point, and need to be corroborated through more externally valid study designs. Comparing the results of fieldwork and laboratory methods examining the same relationships strengthens validity [12]. For example, the relation between oncologist communication and trust established in this thesis might be confirmed in observational studies in real clinical practice. A first attempt at this was made using observational data of radiotherapy consultations [294]. This allowed us to relate objectively observable oncologist behaviors with patient ratings of trust after the consultation. Only a short trust scale, unspecific to the oncology setting, was available and few significant predictors of trust were identified. Nevertheless, in future trust research, similar data from clinical practice would be valuable in parallel with experimental studies, while taking care that data are scored in precise conformity with the experimental manipulations. Triangulating experimental data with observational data would moreover allow investigating whether patients’ trusting beliefs about their oncologist correspond to their trusting behaviors in actual clinical practice [7]. Eventually, randomized clinical trials contrasting standard with ‘enhanced’ communication styles might be designed to provide more ecological validation for video-vignettes findings.
Summary and general discussion

The strength of effects

Effect sizes of the three communication characteristics in our study were relatively moderate. Skeptics may conclude that the communication characteristics investigated are of limited clinical relevance. However, these communication characteristics were not randomly selected. We first carefully investigated how cancer patients reported oncologists contributed to their trust. Our resulting manipulations of oncologist’s communication of care, honesty and competence were closely based on patients’ descriptions of beneficial communication. Our results supported our hypotheses that the behaviors described by these patients indeed matter. The moderate size of effects is likely due to the wide range of additional factors that influence patients’ trust. As we have argued before, trust is thought to result from a complex interplay of several patient, oncologist, organizational and communication factors. In the present study, we have examined merely a few of these. Aside from the manipulated oncologist communication characteristics, we found that patients’ age and education level, as well as familiarity with the observed oncologist, attachment avoidance and health locus of control were associated with trust. Conceivably, other characteristics are of importance. These may be identified in both observational and experimental studies.

Future experimental video-vignettes research could assess the impact of other specific communication on trust. Non-verbal behaviors are a first and important focus, as they are thought to strongly impact on patients’ perception and evaluation of physicians [206,310,311]. Non-verbal behaviors that have been consistently linked to patients’ trust are, for example, the amount of eye contact and the physician’s posture. Behaviors as subtle as leaning backward or forward, or looking towards the patient or the computer screen may impact on patients’ perception of the oncologist and, consequently, on the medical relationship. Experimental video-vignettes studies could corroborate these observational findings and thus provide evidence for how oncologists may contribute to trust non-verbally.

OTHER DIRECTIONS FOR FUTURE RESEARCH

Three relevant topics for future trust research fall outside the scope of our research questions.
The consequences of trust

What follows from trust, i.e., its consequences, is a reasonable focus, now that we have endeavoured to clarify what trust is and how it is established. Trust may induce both attitudinal and behavioral effects [10]. Studies in oncology reviewed in Chapter 2 indicate that, on the attitudinal level, increased trust may lead to more satisfaction with treatment [120], a reduction in fear [103,112] and a lower risk-perception [123]. On the behavioral level, trusting cancer patients were found more likely to discuss important information with their oncologist [98], more accepting of treatment decisions or recommendations [89,100,105], more adherent [93,98,99,121,122,125,126,131], and more likely to remain with their oncologist [124]. Finally, patients' trust was associated with an earlier disease stage at diagnosis, suggesting that trusting patients may sooner revert to a doctor [92]. These findings are roughly in accordance with studies among other patient populations [10]. Trust has even been suggested to lead to better physical health, by facilitating placebo effects [312]. Existing studies, however, almost all employ cross-sectional study designs. Moreover, they mostly rely on patients' self-reports of the outcomes under study. Therefore, neither the accuracy of these findings, nor the direction of the effects, can be established unless more objective, experimental or longitudinal, study designs are used. Such studies could moreover aim to unravel through which mechanisms trust exerts its effects. For example, a possible effect of trust on cancer patients' physical well-being would probably be indirect: trust might encourage patients to attach more importance to the oncologist's medical advice, improving adherence, which ultimately causes health benefits. Possible pathways through which trust influences treatment outcomes have only sporadically been investigated within [313] and outside [314,315] the oncology setting.

How trust evolves over time

The evolving of trust between patient and oncologist over time could be investigated using longitudinal study designs with repeated measurement of trust [12]. This would allow first, empirically testing what cancer patients' starting point of trust is. Initial trust levels have been suggested to range from absence [316] through distrust [11,317] to high trust [318]. Second, it would enable detecting changes in the nature of cancer patients' trust over time. Thus, our hypothesis that trust evolves from an initial necessity-based to an eventual deep and relationship-based form could be examined [12]. This would require measurement techniques capable of distinguishing between different types of strong trust, e.g., a combination of qualitative methods and Likert scales such as the TiOS.
How recent healthcare developments impact on trust

Finally, the impact of recent developments in (oncology) care on trust deserves to be examined. First, patients are increasingly expected to be openly informed by their oncologist, to enable involvement in medical decision making. At the same time, along with increased access to the internet, an abundance of information and opinions has become available to cancer patients. Information provided by the oncologist does not always correspond with the patient’s other information sources. If such a lack of agreement is not adequately addressed by the oncologist, it may result in diminished trust and increased second opinion seeking by patients [319,320]. Second, oncology care is becoming increasingly multidisciplinary. To enable fast and optimal care, multidisciplinary teams have been established which are collectively responsible for cancer patients’ treatment. For patients, this means they see more different oncology specialists, which may come at the expense of continuity of medical relationships. Research indicates that it is nowadays not always clear to patients who their primary oncologist is [29]. As continuity of the relation was found to be important for trust [13], and relational trust is thought to grow over time, it is conceivable that increased multidisciplinarity impacts on trust. Third, recent times have seen elaborate media coverage of malpractice incidences. These scandals may affect patients’ general views on health care in general as well as physicians specifically, which might spill over to interpersonal trust relations in oncology.

Increased access to information, multidisciplinary oncology care and negative media exposure may separately or jointly exert their effects on cancer patients’ trust. These influences should be investigated by thoroughly monitoring the strength of cancer patients’ trust over time. Especially at the moment changes are implemented, e.g., when multidisciplinary departments are set up, in-depth investigations should be conducted to assess whether trust is impacted. Research on the impact of healthcare developments on interpersonal trust could be inspired by drawing parallels with trust research in other settings. For example, the recent decline of public trust in government and its causes have been widely discussed by sociologists [321]. Identifying analogue underlying causes, as well as using similar methodologies might advance this field of research.

CONCLUSION

In this thesis we aimed to unravel cancer patients’ trust in their oncologist. We investigated patients’ explanations of trust in-depth, and developed an oncology-specific questionnaire to assess trust. Using the resulting Trust in Oncologist Scale, we
Chapter 11

experimentally established the influence of oncologist communication on trust. Specifically, patients report stronger trust if the oncologist expresses medical competence, communicates in an open and honest manner, and conveys involvement and care. The results provide firm evidence for the importance of oncologist communication for the establishment of trust. The work described in this thesis provides methodological leads for researchers of physician-patient communication. Moreover, our findings provide specific practical handles for use in oncology practice and physician training, which may eventually contribute to better patient care.
Samenvatting
(summary in Dutch)
Voor een optimale behandeling is het van belang dat patiënten vertrouwen hebben in hun arts. In de oncologie is vertrouwen mogelijk nog essentieler, vanwege de levensbedreigende aard van kanker. Sinds enkele decennia groeit de zorg dat het vertrouwen van patiënten afneemt. Een dergelijke afname van vertrouwen zou voortkomen uit veranderingen in de organisatie van de gezondheidszorg en toegenomen autonomie bij patiënten. Onderzoek tot nu toe laat zien dat vertrouwen in de gezondheidszorg inderdaad is afgenomen. Vertrouwen binnen de behandelrelatie is echter nog onveranderd sterk. Toch is nog te weinig wezenlijk onderzoek naar vertrouwen tussen arts en patiënt uitgevoerd voor stevige conclusies. Er is weinig bekend over wat patiënten precies verstaan onder vertrouwen of hoe het tot stand komt. Het meeste beschikbare onderzoek is uitgevoerd binnen de eerstelijnszorg. Resultaten uit deze context zijn niet zomaar naar de oncologie te vertalen. Immers, vertrouwen komt voor patiënten met kanker mogelijk anders tot stand en is anders van aard, door de ernst en ingrijpendheid van het ziekteproces. Er zijn aanwijzingen dat de oncoloog in zijn of haar communicatie bij kan dragen aan vertrouwen. Welke concrete gedragingen van belang zijn weten we niet. Meer inzicht in hoe communicatie bijdraagt aan vertrouwen kan oncolozen helpen in het verbeteren van hun gespreksvoering met patiënten. Uiteindelijk kunnen zulke verbeteringen bijdragen aan verbeterde oncologische zorg.

In dit proefschrift wordt het vertrouwen van patiënten met kanker in hun oncoloog onder de loep genomen. Het beschreven onderzoek richtte zich achtereenvolgens op de betekenis, de meting en voorspellers van vertrouwen van patiënten met kanker. Het uiteindelijke doel was bewijs te vergaren over hoe de oncoloog via communicatie kan bijdragen aan vertrouwen. Daartoe werd uitgegaan van drie onderzoeksvragen:

1) Hoe beschrijven en verklaren patiënten met kanker vertrouwen in hun oncoloog?
2) Kunnen we het vertrouwen van patiënten met kanker in hun oncoloog op betrouwbare en valide wijze meten?
3) Wordt het vertrouwen van patiënten met kanker beïnvloed door hoe de oncoloog communiceert?

Deze vragen worden achtereenvolgens behandeld in de drie delen van dit proefschrift, waarna de resultaten worden geïntegreerd in een algemene discussie.
DEEL 1: HOE BESCHRIJVEN EN VERKLAREN PATIËNTEN MET KANKER VERTROUWEN IN HUN ONCOLOGOOG?

In Hoofdstuk 2 gaven we een overzicht van de beschikbare empirische literatuur over vertrouwen van kankerpatiënten in hun oncoloog. Van de 45 beschikbare artikelen over dit onderwerp waren er slechts enkele primair gericht op vertrouwen. Een begripsbepaling van vertrouwen werd vaak niet gegeven en er bestond veel variatie tussen de weinige beschikbare definities. Het vertrouwen van patiënten in hun oncoloog was over het algemeen genomen sterk. Diens technische vaardigheid, eerlijkheid en patiëntgerichte gedragingen vergrootten het vertrouwen van patiënten. Sterk vertrouwen leek te leiden tot soepeler communicatie en medische besluitvorming, minder angst bij patiënten en verbeterde therapietrouw. Echter, weinig studies waren primair op vertrouwen gericht en methoden om vertrouwen te meten lieten vaak te wensen over. Daarom concludeerden wij dat meer systematisch, theoretisch onderbouwd onderzoek nodig is om een meer fundamenteel begrip te krijgen van het vertrouwen van kankerpatiënten in hun oncoloog.

Om meer zicht te krijgen op wat patiënten bedoelen wanneer ze spreken over ‘vertrouwen’, onderzochten we in Hoofdstuk 3 hoe patiënten vertrouwen in hun oncoloog beschrijven en verklaren. Individuele diepe-interviews werden uitgevoerd binnen een diverse steekproef van patiënten met kanker. Patiënten bleken veel moeite te hebben om een abstract onderwerp als vertrouwen onder woorden te brengen. Veel patiënten hadden voor hun gevoel geen andere keuze dan de oncoloog te vertrouwen. Daardoor ontstond al bij de start van de behandelrelatie een sterk maar oppervlakkig vertrouwen, voortkomend uit de ervaren noodzaak te vertrouwen. Pas na verloop van tijd en herhaaldelijk contact met de arts ontstond een dieper, meer relationeel, vertrouwen. Met behulp van een raamwerk voor vertrouwen, afkomstig uit de eerstelijnszorg, onderzochten we ook of mensen met kanker onderscheid maakten tussen verschillende dimensies van vertrouwen en, zo ja, welke dimensies. Patiënten bleken vier dimensies te onderscheiden, namelijk: loyaliteit (het belang van de patiënt voorop stellen), medische deskundigheid, eerlijk en open informatie geven, en een zorgzame en meelevende houding van de oncoloog. De laatstgenoemde dimensie, die we als Zorgzaamheid bestempelden, werd toegevoegd aan eerder in de literatuur geïdentificeerde dimensies van vertrouwen.

Allochtone patiënten ervaren vertrouwen in hun oncoloog mogelijk anders dan anderen. Daarom namen we in Hoofdstuk 4 afzonderlijk interviews af met een kleine groep allochtone patiënten van Turkse en Arabische afkomst. Het doel was te onderzoeken hoe deze patiënten vertrouwen beschrijven en verklaren. Patiënten beschreven hoe vertrouwen niet al bij aanvang sterk was, maar langzamerhand groeide. Ze
benadrukten drie belangrijke elementen die bijdroegen aan vertrouwen. Allereerst hechtten ze veel belang aan een actiegerichte benadering van de oncoloog, in alle verschillende fases van hun ziekte. Een afwachtende houding werd door patiënten geinterpreteerd als een gebrek aan hulpvaardigheid, wat hun vertrouwen ondermijnde. Ten tweede vertelden patiënten dat zij er behoefte aan hadden dat de oncoloog hen geruststelde en zwaarmoedige onderwerpen vermeed, met als doel hoop te kunnen behouden. Ten slotte droeg de non-verbale communicatie door de oncoloog, met name diens gezichtsuitdrukking, bij aan het vertrouwen van patiënten. Ook al zijn deze drie elementen tot op zekere hoogte van belang voor alle patiënten met kanker, toch worden ze mogelijk meer expliciet gewaardeerd door allochtone patiënten met een Turkse en Arabische achtergrond.

De noodzaak tot vertrouwen die patiënten bleken te ervaren onderstreept de kwetsbare positie en afhankelijkheid van kankerpatiënten ten opzichte van hun oncoloog. Het beeld van de hedendaagse mondige, autonome en kritische patiënt behoeft bij mensen met kanker klaarblijkelijk nuancering. Het is van belang dat oncoloog een actieve en autonome rol wensen of dat juist een traditionele, paternalistische rolverdeling zorgt voor optimaal vertrouwen. In dat laatste geval ligt de verantwoordelijkheid voor goede communicatie meer bij de oncoloog. Bij allochtone patiënten zal het oncoloog soms meer moeite kosten om vertrouwen te ‘winnen’. Bovendien is het bij deze patiënten zaak om helder toe te lichten waarom soms voor afwachtend beleid wordt gekozen.

DEEL 2: KUNNEN WE HET VERTROUWEN VAN PATIËNTEN MET KANKER IN HUN ONCOLOOG OP BETROUWBAAR EN VALIDE WIJZE METEN?

In ons overzicht van de empirische literatuur (Hoofdstuk 2) stelden we vast dat het vertrouwen van mensen met kanker tot op heden werd gemeten met ofwel ongevalideerde losse vragen, dan wel met vragenlijsten die in de eerstelijnszorg werden ontwikkeld. Het was onduidelijk hoe geschikt deze meetinstrumenten waren om adequaat het vertrouwen van kankerpatiënten in hun oncoloog te meten. Daarom ontwikkelden wij een meetinstrument met dat doel, uitgaande van definities van vertrouwen die patiënten zelf gaven. We ontwikkelden een multidimensionale vragenlijst, gebaseerd op de bestaande Physician Trust Scale en onze kwalitatieve interviews met patiënten. De daaruit
voortkomende, uit 18 stellingen bestaande, Trust in Oncologist Scale (TiOS) werd gevalideerd onder Nederlandse kankerpatiënten. De resultaten daarvan zijn te vinden in Hoofdstuk 5. Vervolgens werd de TiOS vertaald in het Engels en intercultureel gevalideerd bij Australische kankerpatiënten (Hoofdstuk 6). In aansluiting op onze kwalitatieve bevindingen bevatte de vragenlijst de dimensie Zorgzaamheid, als aanvulling op eerder onderscheiden dimensies Loyaliteit, Deskundigheid en Eerlijkheid. De TiOS bleek op betrouwbare en valide wijze het vertrouwen van kankerpatiënten in hun oncoloog te kunnen meten. Het vertrouwen van deze patiënten bleek over het algemeen sterk te zijn. De verwachte multidimensionaliteit was in beperkte mate terug te zien in de resultaten. Zowel bij de Nederlandse als bij de Australische patiënten kon vertrouwen het beste als eendimensionaal beschouwd worden. Deze bevinding staat in contrast met het onderscheid tussen dimensies dat patiënten maakten in ons kwalitatieve onderzoek. De gevonden eendimensionaliteit komt mogelijk voort uit de sterkte van, en het gebrek aan, variatie in vertrouwen dat patiënten in de vragenlijsten rapporteerden. Daardoor ontstond een scheve verdeling van scores. We bespraken dat het uiteindelijk mogelijk problematisch is om met vragenlijsten de processen bloot te leggen die ten grondslag liggen aan vertrouwen.

DEEL 3: WORDT HET VERTROUWEN VAN PATIËNTEN MET KANKER BEÏNVLOED DOOR HOE DE ONCOLOGO COMMUNICEERT?

Voor optimaal vertrouwen is het belangrijk om te weten hoe het tot stand komt. Communicatie door de oncoloog is een belangrijke focus voor onderzoek naar voorspellers van vertrouwen. Interpersoonlijk vertrouwen ontstaat immers, ten minste deels, via communicatie. Bovendien is communicatie beter beïnvloedbaar dan vaststaande kenmerken van de gezondheidszorg, patiënten of de oncoloog. In ons literatuuroverzicht van Hoofdstuk 2 stelden we vast dat tot dusverre geen experimenteel onderzoek naar voorspellers van vertrouwen van kankerpatiënten was uitgevoerd. Met behulp van experimentele studies zou onderscheid kunnen worden gemaakt tussen oorzaak en gevolg. Bovendien was het op grond van de beschikbare kennis moeilijk vast te stellen welke concrete gedragingen door de oncoloog bijdragen aan vertrouwen.

Daarom ontwierpen wij een experimentele studie om te onderzoeken of en hoe communicatie door de oncoloog invloed heeft op het vertrouwen van patiënten. We maakten gebruik van zogenaamde ‘videovignetten’, waarbij verschillende variaties van een
video-opname werden gemaakt die een nagespeeld consult tussen een oncoloog en een patiënt toonden. We manipuleerden drie kenmerken van hoe de oncoloog communiceerde, die in onze kwalitatieve studie (Hoofdstuk 3) door patiënten waren genoemd als belangrijk voor vertrouwen. Voor elk van deze kenmerken, namelijk 1) blijk geven van medische deskundigheid, 2) het geven van eerlijke informatie, en 3) blijk geven van zorgzaamheid, creëerden we een standaard en een ‘verbeterde’ variant. Door de standaard en de verbeterde varianten op alle mogelijke manieren te combineren ontstonden acht verschillende video-vignetten. Afgezien van deze manipulaties van enkele seconden was het getoonde consult in alle varianten van de video identiek wat betreft beeld en inhoud. Patiënten met kanker en mensen genezen van kanker bekeken allen twee van de acht vignetten en rapporteerden na ieder van de observaties hun vertrouwen in de geobserveerde oncoloog, gebruikmakend van de Trust in Oncologist Scale. In Hoofdstuk 7 beschreven wij de methodologische keuzes en dilemma’s die men kan ondervinden bij het ontwikkelen en gebruiken van video-vignetten. Dit overzicht kan bruikbaar zijn voor onderzoekers die in de toekomst onderzoek met video-vignetten uitvoeren.

In Hoofdstuk 8 testten wij hoe de drie gemanipuleerde kenmerken van communicatie door de oncoloog het vertrouwen van patiënten beïnvloedden. De resultaten lieten zien dat zelfs kleine variaties in de communicatie door de geobserveerde oncoloog invloed hadden op het vertrouwen van kankerpatiënten. Vertrouwen was sterker wanneer de oncoloog zich meer zorgzaam gedroeg, open en eerlijk communiceerde en zijn medische deskundigheid benadrukte. Er was ook sprake van een volgorde-effect: Patiënten hadden meer vertrouwen in de oncoloog die zij in de tweede video zagen dan in de oncoloog uit de eerste video. Over het algemeen rapporteerden oudere, lager opgeleide patiënten sterker vertrouwen, terwijl het geslacht van patiënten geen invloed had op vertrouwen. In Hoofdstuk 9 onderzochten we of de mate van vertrouwen afhankelijk is van persoonlijkheidskenmerken van patiënten, in het bijzonder hun beheersingsoriëntatie (‘locus of control’), en hechtingsstijl. Bovendien onderzochten we of de invloed van communicatie door de oncoloog op vertrouwen afhankelijk was van deze persoonlijkheidskenmerken. We vonden dat patiënten met een sterke overtuiging dat anderen hun gezondheid bepaalden (sterke externe locus of control) meer vertrouwen rapporteerden in de geobserveerde oncoloog. Een angstige, noch een vermijdende hechting hing samen met vertrouwen in de geobserveerde oncoloog. Wel had zorgzame communicatie door de oncoloog een minder positief effect op vertrouwen bij patiënten die meer vermijdend gehecht waren. Bovendien rapporteerden zowel patiënten met een meer vermijdende als die met een meer angstige hechtingsstijl minder vertrouwen in hun eigen behandelend arts.
In Hoofdstuk 10 onderzochten we de invloed van verschillende methoden om patiënten te werven op onderzoekresultaten. Voor ons onderzoek beschreven in hoofdstukken 8 en 9 wierven wij patiënten zowel via de oncologische poliklinieken van ziekenhuizen als via verenigingen voor kankerpatiënten. Aan veel studies naar communicatie in de gezondheidszorg nemen alleen leden van kankerpatiëntenverenigingen deel, terwijl niet duidelijk is of resultaten van deze patiënten kunnen worden gegaan en gezien naar de bredere patiëntenpopulatie. Daarom testten we of de onderzoekresultaten vergelijkbaar waren tussen leden van kankerpatiëntenverenigingen en patiënten geworven via poliklinieken. De resultaten lieten zien dat leden van kankerpatiëntenverenigingen jonger en hoger opgeleid waren dan patiënten uit de poliklinieken. Leden ervoeren meer persoonlijke controle over hun gezondheid, maar waren ook angstiger. Ze rapporteerden een minder sterk vertrouwen in de algemene gezondheidszorg, in hun eigen behandelend oncoloog én in de geobserveerde oncoloog dan patiënten uit de poliklinieken. Het effect van communicatie door de oncoloog op vertrouwen was echter vergelijkbaar tussen de twee groepen. We concludeerden dat toekomstige studies er rekening mee moeten houden dat het werven via patiëntenverenigingen consequenties heeft voor de generaliseerbaarheid van resultaten. Echter, voor het onderzoeken van processen, bijvoorbeeld hoe communicatie het vertrouwen beïnvloedt, zijn resultaten van deze groep mogelijk vergelijkbaar met die van gemiddelde patiënten.

De belangrijkste conclusie van het derde deel van dit proefschrift is dat oncologen via kleine aanpassingen in hun communicatie direct aan het vertrouwen van patiënten met kanker kunnen bijdragen. Door blijk te geven van medische competentie, eerlijkheid en zorgzaamheid kan vertrouwen in korte tijd worden versterkt. Echter, sterke persoonlijke verschillen tussen patiënten onderstrepen hoe belangrijk het blijft dat de oncoloog zijn communicatie aanpast aan individuele patiënten. Vooral voor vermijdend gehechte patiënten lijkt open en zorgzame communicatie vertrouwen eerder te schaden dan te bevorderen.

ALGEMENE DISCUSSIE EN CONCLUSIE

Tot slot worden in Hoofdstuk 11 de belangrijkste resultaten uit de verschillende hoofdstukken besproken en worden aanbevelingen voor de klinische praktijk gegeven. Daarnaast bespreken we mogelijke richtingen voor toekomstig onderzoek naar vertrouwen. We concluderen dat het zinnig is om onderzoek naar vertrouwen te blijven
vervolgen, zeker in de oncologische context. Vertrouwen heeft toegevoegde waarde ten opzichte van soortgelijke graadmeters als tevredenheid, omdat het ook emotionele en relationele aspecten omvat. In vervolgonderzoek is het zinnig om naast onze vragenlijst naar vertrouwen in de oncoloog ook andere meetmethoden voor vertrouwen te ontwikkelen. Te denken valt aan kwalitatieve zelfrapportage of aan impliciete maten, waarmee automatische reacties en gevoelens van mensen kunnen worden geregistreerd. Video-vignetten bleken in ons onderzoek bruikbaar te zijn om specifieke invloeden op vertrouwen te onderzoeken. Echter, dergelijke studies zouden zo veel mogelijk gekoppeld moeten worden aan observationele gegevens, zodat de generaliseerbaarheid naar de klinische praktijk gewaarborgd blijft.

In toekomstig onderzoek naar vertrouwen zou allereerst meer aandacht moeten zijn voor de mogelijke negatieve gevolgen van extreem sterk vertrouwen. Patiënten met blind vertrouwen in hun oncoloog stellen zich mogelijk passief op in hun behandeling en durven niet kritisch te zijn op hun arts. Ten tweede zou kunnen worden onderzocht waar vertrouwen in de oncoloog toe leidt. Brengt sterk vertrouwen inderdaad betere besluitvorming, minder angst en meer therapietrouw met zich mee, zoals is gesuggereerd? Een laatste belangrijke vraag is hoe vertrouwen zich ontwikkelt over de tijd. Daarbij kan ook de impact van recente ontwikkelingen binnen de gezondheidszorg op vertrouwen in ogenschouw worden genomen. Oncologische zorg is in toenemende mate multidisciplinair georganiseerd, waardoor patiënten mogelijk minder in staat zijn een band op te bouwen met specifieke behandelaars. Daarnaast hebben patiënten steeds betere toegang tot (conflicterende) medische informatie en neemt de media-aandacht voor medische fouten toe. Al deze ontwikkelingen hebben mogelijk hun weerslag op het vertrouwen dat patiënten met kanker in hun oncoloog stellen.

Concluderend is in dit proefschrift het belang van communicatie door de oncoloog voor het vertrouwen dat patiënten in hun oncoloog stellen solide onderbouwd. Behalve methodologische aanknopingspunten biedt het onderzoek ook praktische handvatten voor het verbeteren van communicatietrainings aan artsen en medische studenten. Uiteindelijk kunnen deze resultaten daarmee bijdragen aan betere zorg aan patiënten met kanker.
Appendix A
Development and content of video vignettes
RATIONALE FOR USING SCRIPTED VIDEO-VIGNETTES DESIGN

The purpose of this study was to investigate the effect of oncologist communication behaviors on patients’ trust in them. Using scripted video vignettes in an experimental design was deemed most appropriate for several reasons. First, using an experimental design allowed standardization of all elements (communication, oncologist, and visit characteristics) except for the intended manipulations. Second, manipulating oncologists’ behavior in real practice was considered unethical as it might expose patients to sub-optimal communication. Finally, not being dependent on patient flows enabled recruitment of a large patient sample in reasonable time.

CONSTRUCTION OF SCRIPTED VIDEO VIGNETTES

Developing a basic script

Three oncologic surgeons from different Dutch hospitals each audio-recorded two of their consultations with recently diagnosed patients concerning upcoming surgery for colorectal cancer. Patients were asked for informed consent to tape the consultation. All recordings were transcribed verbatim. These transcripts were used to create a basic script of a standard consultation by one of the authors (M.H.).

The recorded consultations lasted 20-30 minutes. The script was cut down to last only five minutes, to ensure that our relatively small manipulations would be noticeable. Care was invested to preserve all essential elements of the consultations in the abridged script. Eventually, the basic script encompassed approximately six written pages of text. Where possible, text segments of the audio-recordings were incorporated in the script verbatim to ensure realism. Some segments were slightly adapted, to enhance fluency of the script, and small text fragments were newly added.

The basic script involved a consultation between a middle-aged patient and a middle-aged male oncologic surgeon, two weeks after the patient had been diagnosed with colorectal cancer. A male instead of a female surgeon was chosen, as a middle-aged male is still the stereotypical image many patients hold of surgeons. Colorectal cancer was chosen as this is a gender neutral disease, relevant to both male and female observers. The script depicts a consultation in which colorectal surgery is discussed in detail, involving the following elements: 1) recapitulation of the diagnosis and test results, 2) explanation of
what the operation encompasses, 3) discussion of possible side-effects (in particular the possibility of a colostomy), and 4) time for the patient's questions. In a previous consultation, the patient and oncologist had decided to opt for surgery instead of other possible treatments and the patient had subsequently undergone extra medical tests, to rule out the possibility of metastases.

Two oncologic surgeons commented upon the basic script to ensure realism and medical soundness. A professional script writer commented upon script fluidity and structure. Patients were not consulted in this phase, as they might have had difficulty extrapolating to a consultation that was different from their own exact experiences.

A voice-over neutrally introduced the situation, while muted images were shown of the oncologist and patient conversing (see Box 1 for the introductory text). This introduction was added to 1) explain the situation and setting to the analogue patients, and 2) allow analogue patients to become visually accustomed to the main characters and setting. The introduction was kept maximally neutral, to avoid invoking strong emotions among analogue patients before experiment onset.

**Box 1. Introductory text read aloud by voice-over before video onset**

You will now see a consultation between a surgeon and a patient. The patient was informed two weeks ago that he/she has colorectal cancer. After this diagnosis, he/she underwent a number of medical tests to determine whether the tumor has spread. The patient has been referred to a surgeon, with whom he/she has already had a first consultation about the possible treatment options. Together with the surgeon he/she has then decided to have colorectal surgery. You are about to see the second consultation between the patient and the surgeon, in which they discuss the specifics of the operation.

When you look at the consultation, please try to imagine that you are holding the conversation with the surgeon.

**Designing manipulations**

In a qualitative study of cancer patients' trust in their oncologist, the following elements of patients' trust were identified: perception of the oncologist's competence, honesty, fidelity, and caring behavior [149]. In the subsequently constructed Trust in Oncologist Scale (TiOS), these elements were validated as dimensions of trust [175,220]. Our proposed research design allowed us to manipulate only three variables while maintaining a feasible sample size. Therefore, we manipulated the three most 'tangible' elements, i.e., which allowed for the most straightforward operationalization: 1) Competence, i.e., the
Appendix A: Video-vignettes development

oncologist's medical skills, 2) **Honesty**, i.e., telling the truth and avoiding intentional falsehoods, and 3) **Caring**, i.e., the oncologist's involvement, sympathy and devotion of attention to the patient. Next, the qualitative data were re-examined to investigate from what communicative behaviors patients most often inferred oncologists' competence, honesty, and caring. Based on these data, two or three small verbal additions were made to the basic script for each of the three elements of trust. Although any verbal addition to the script is by definition accompanied by non-verbal expression, the manipulations were intended to be essentially verbal. To that end, the oncologist's non-verbal behavior was kept maximally constant in the added segments.

Demonstration of **Competence** was manipulated by two segments in which the oncologist 1) demonstrated to be up-to-date on the recent research literature, and 2) emphasized his specialization in, and extensive experience with, this particular operation. Demonstration of **Honesty** was manipulated by the oncologist 1) emphasizing his wish to exhaustively inform the patient, 2) indicating his wish to honestly inform the patient about all possible complications, and 3) stressing his inability to rule out metastases with 100% certainty. Finally, demonstration of **Caring** behavior was manipulated by the oncologist 1) exploring a patient cue regarding worry about possible metastases, 2) exploring the patient's concern about a possible colostomy, and 3) indicating his availability to the patient in case of further questions. See Box 2 for a verbatim overview of the manipulations, and Box 3 for two excerpts from the standard compared to the enhanced scripts.

Including the three additions in the script resulted in 'enhanced' script versions for all three characteristics, in addition to the 'standard' version. Next, the standard and enhanced versions of the script were combined in every possible way, following a 2 x 2 x 2 factorial design, resulting in eight scripts (see Figure 1). To ensure internal validity, we asked an expert group to comment upon the scripts regarding effectiveness of the manipulations. The expert group consisted of two researchers of physician-patient communication, an oncologic surgeon, and a coach in medical communication. Small adjustments were made to the scripts according to their comments.

The scripts differed in length; for all three manipulated characteristics, the enhanced version of the script was longer than the standard condition. As a result, the 'basic script' was shortest (5 minutes and 25 seconds) whereas the script in which all three characteristics were manipulated was the longest (7 minutes and 26 seconds). Mean duration was 6 minutes and 25 seconds. Duration differences were not compensated for, because compensating elements (e.g., using 'filler segments' or altering dialogue pace) could produce their own effects.

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Box 2. Overview of script additions for manipulations for three elements

Competence:

3. The scientific literature clearly demonstrates that [this operation] offers the best chance at survival. I recently attended a scientific conference, where it was confirmed once more that this operation is the best possible treatment.

4. We perform [this surgery] very often. In our center we all have our specialization, so that we perform certain procedures much more often to become even more skilled in them. So I perform this operation a lot.

Honesty:

4. [The risk of a colostomy] is something I really want to discuss with you, even though the chances of it are slight. Because I believe that you as a patient have the right to be informed about such small risks, to avoid that you will be taken unaware by this afterwards.

5. All these [complications] will not necessarily occur, but I do want to discuss them with you. Because, even though we do our very best, it remains hard to predict: we can never rule out that you will experience complications. This way at least you are well informed.

6. I should add that we can never be 100% sure [that the cancer will be completely removed]. So I can never give you an absolute guarantee. There is always a slight chance that we run into an abnormality during surgery. But for now all signs suggest that you will be cancer-free after the operation.

Caring:

4. Oncologist: Were you very worried about it [the result of the scan]?
   Patient: Yes, in a way… After all, it is your biggest fear in such a moment. But it seems to have turned out well, hasn’t it?
   Oncologist: Yes, it seems so. So that is good, and at least one thing we don’t have to worry about anymore.

5. Oncologist: Do you particularly dread the thought of a colostomy?
   Patient: Yes, it seems horrible, this bag attached to your stomach which may open at any moment, with all that filth… And you aren’t fit to be seen anymore…
   Oncologist: Yes, I understand what you mean.

6. But I will talk to you before the operation in any case. And it is important to know that I am always available for you in case of questions. This is our phone number. I may not always answer the phone myself, but if necessary I will return your call when I do have the time.

CONVERTING THE SCRIPTED CONSULTATION TO VIDEO

For all eight video versions, a variant with a male and one with a female patient were created to maximize participants’ identification with the video character. Three actors were recruited to play the roles of oncologist, male patient, and female patient, respectively. Actors were chosen over real patients and oncologist because of their experience adhering to a script. Moreover, the actors would be required to repeatedly play multiple nearly identical versions of the same script, which might be problematic to a real healthcare professional, who might lapse into his or her personal consultation style. A casting was organized to select the best actor from at least two candidates for each role.
Because of budget restraints, pilot-testing was performed on audio-recordings of the actors (oncologist and male patient) acting out the scripts and not on video-recordings. Audio-recordings were made of the basic vignette, and the vignettes with only manipulated Competence, manipulated Honesty, and manipulated Caring. A pilot group consisting of 20 researchers of medical communication, and seven lay people judged all four audio recordings on manipulation success and realism. Participants were randomly assigned to listening orders. For each vignette version we asked: ‘How competent / honest / caring did you perceive the oncologist to be?’, to be answered on a ten-point Likert scale ranging from very competent/honest/caring = 1 to not at all competent/honest/caring = 10. Additionally, participants were asked which of the four doctors they perceived as most competent/honest/caring. To test realism, participants were asked as how realistic they perceived the conversations overall (six-point Likert scale, range very unrealistic = 1 to very realistic = 6). Moreover, they were asked for suggestions to increase realism.

Figure 1: Graphic display of the creation of eight versions of the video vignettes, based on three manipulated dimensions with two levels each.
**Box 3. Excerpts from the standard compared with the enhanced scripts**

<table>
<thead>
<tr>
<th>Standard competence</th>
<th>Enhanced competence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient</strong></td>
<td><strong>Patient</strong></td>
</tr>
<tr>
<td>But is this operation performed often?</td>
<td>But is this operation performed often?</td>
</tr>
<tr>
<td><strong>Oncologist</strong></td>
<td><strong>Oncologist</strong></td>
</tr>
<tr>
<td>Yeah, it is pretty much a standard operation</td>
<td>Yeah, it is pretty much a standard operation</td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td><strong>Patient</strong></td>
</tr>
<tr>
<td>Yeah, okay</td>
<td>Okay, em..., let me see (…)</td>
</tr>
<tr>
<td><strong>Oncologist</strong></td>
<td><strong>Oncologist</strong></td>
</tr>
<tr>
<td>Okay, em..., let me see (…)</td>
<td>Okay, em..., let me see (…)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Standard Caring</th>
<th>Enhanced Caring</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oncologist</strong></td>
<td><strong>Oncologist</strong></td>
</tr>
<tr>
<td>Very good. Then this is how we will arrange everything with the nurses. They are the ones who will attend to you in preparation of the operation. You will mostly be in contact with the nurses in the coming weeks.</td>
<td>Very good. Then this is how we will arrange everything with the nurses. They are the ones who will attend to you in preparation of the operation. You will mostly be in contact with the nurses in the coming weeks. <strong>But I will talk to you before the operation in any case. And it is important to know that I am always available for you in case of questions.</strong></td>
</tr>
<tr>
<td>Alright, could you walk along with me to the reception then?</td>
<td>Alright, could you walk along with me to the reception then?</td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td><strong>Patient</strong></td>
</tr>
<tr>
<td>Mmm..</td>
<td>Okay</td>
</tr>
<tr>
<td><strong>Oncologist</strong></td>
<td><strong>Oncologist</strong></td>
</tr>
<tr>
<td>This is our phone number. I may not always answer the phone myself, but if necessary I will return your call when I do have the time.</td>
<td>This is our phone number. I may not always answer the phone myself, but if necessary I will return your call when I do have the time.</td>
</tr>
</tbody>
</table>

Pilot participants accurately identified the enhanced Honesty (M = 8.33 vs. 7.54 for the other versions) and enhanced Caring versions (M = 8.35 vs. 5.65 for the other versions). However, the oncologist in the enhanced Competence condition was not judged as more competent compared to the other versions (M = 7.90 vs. 7.87 for the other versions). Results regarding which oncologist was perceived as most competent/honest/caring did confirm all three intended manipulations, i.e., the enhanced competent/honest/caring
oncologist was perceived as most competent/honest/caring by more than half of all pilot participants. Participants judged the consultations as realistic (M = 4.65 (possible range: 1–6)). Suggestions were used to make slight adaptations to the script, particularly to intensify the enhanced Competence manipulation.

Videos were recorded in a studio simulating a simple outpatient consultation room. The oncologist, wearing a white coat, sat behind a desk. The patient’s ‘Point of View (POV)’ was employed throughout all video versions, i.e., the camera was directed at the oncologist, and the patient was visible vaguely over the shoulder (see Figure 2). Two cameras were used: one with a ‘medium wide’ shot, the other with a ‘zoom’ shot. In the wide shot, the contours of the patient’s shoulder were visible in the left corner of the screen (see Figure 2A). The zoom shot showed only the oncologist’s head and neck in close-up (see Figure 2B). The oncologist gazed slightly left of the camera, directly at the patient.

**Figure 2.** Graphic display of the patient ‘Point of View’ (POV) angle used in the recording of the video vignettes

- **A:** ‘Medium wide’ shot, with the contours of the patient’s shoulder visible in the left corner of the screen.
- **B:** ‘Zoom’ shot, showing only the oncologist’s head and neck in close-up.
Reference list
References


Dugan E, Trachtenberg F, Hall MA. Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. BMC Health Serv Res 2005;5.


[85] Robb N, Greenhalgh T. "You have to cover up the words of the doctor": the mediation of trust in interpreted consultations in primary care. J Health Organ Manag 2006;20:434-55.


[119] Anvik T, Holtedahl KA, Mikalsen H. "When patients have cancer, they stop seeing me"–the role of the general practitioner in early follow-up of patients with cancer–a qualitative study. BMC Fam Pract 2006;7:19-27.


[227] Ferguson E. Personality is of central concern to understand health: towards a theoretical model for health psychology. Health Psychol Rev 2013;7:s32-s70.


List of publications
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DOI: 10.1002/pon.1910

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Curriculum Vitae
Marij Hillen was born on 17 April 1983 in Leuven (Belgium). She studied psychology at the University of Amsterdam. In 2007, she completed a research master in Psychology (with merit) at the same university, specializing in psychonomics and methodology. Her research internship was focused on structural connectivity in synesthesia. Her research master thesis was on the impact of background music on cognitive performance, and the mediating effect of brain arousal. In 2008, she started her PhD project at the Department of Medical Psychology of the AMC in Amsterdam, supervised by dr. Ellen Smets and prof. dr. Hanneke de Haes and funded by the Dutch Cancer Society (KWF).

In 2010, as part of her thesis, she visited the Centre for Medical Psychology & Evidence-based Decision-making (CeMPED) at the University of Sydney, Australia. In 2011, she was selected to attend the Summer Course of the European Association for Communication in Healthcare (EACH). She has been teaching communication skills to medical students and supervising master theses of psychology and medical students. In 2012, she acquired her Basic Teaching Qualification at the University of Amsterdam. Between 2009 and 2011, she organized and chaired meetings of the AMC Network for Qualitative Research in Healthcare. Since 2011, she is actively involved in the Dutch Society for Psychosocial Oncology (NVPO): she is a member of the working committee for scientific research and editor of the NVPO journal ‘Psychosocial Oncology’.

In 2012, she acquired funding from Pink Ribbon to perform further research, focused on the impact of oncologist non-verbal behavior on breast cancer patients' trust. Since January 2013, she has been working as a postdoctoral researcher on this project.
Cancer patients' trust in their oncologist

Marij Hillen

Uitnodiging
voor de openbare verdediging van mijn proefschrift

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