Cancer patients' trust in their oncologist
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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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<tr>
<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,
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 unresponsive 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 patients’ 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?

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<th>Summary of main findings</th>
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<td>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.</td>
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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
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.
Summary and general discussion

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.
Summary and general discussion

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
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.