Psycho-Oncology
Psycho-Oncology **21**: 392–399 (2012)
Published online 30 January 2011 in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.1910

Disentangling cancer patients' trust in their oncologist: a qualitative study

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Received: 30 June 2010
Revised: 2 December 2010
Accepted: 7 December 2010

Abstract

***Objective*: Patients' trust in their physician is crucial for an 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 bond 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.**

Keywords: qualitative research; cancer; communication; doctor–patient relationships; oncology

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. [1–3]). 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 [4]. Trust is considered forward-looking and can as such be distinguished from satisfaction with the physician, which is more evaluative [4].

Empirical research lagged behind theory of patients' trust for a long time [5], but has recently received more attention. Three questionnaires have been developed, aiming to capture patients' trust in their physician [6–8]. The 'Physician Trust Scale', by Hall *et al.* [7], is the most widely used and well-developed instrument. Hall *et al.* distinguish four specific dimensions of trust: (i) fidelity, which refers to patients' belief that the physician acts in their best interest, (ii) competence, referring to the physician's perceived medical and interpersonal skills, (iii) honesty, which is patients' conviction that the physician tells the truth and avoids intentional falsehoods, and (iv) confidentiality, which is the adequate use of privacy-sensitive information [9]. 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 [10] revealed that surprisingly little is known about the nature, predictors, and consequences of cancer patients' trust in their physician. Not one study exclusively addressed cancer patients' understanding or explanation of trust. Insight into cancer patients' trust would be valuable, as it provides 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*. [7], 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 (i) age >18 years, (ii) fluent command of Dutch, and (iii) 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 who were 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 phoned by the researchers 1 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.

Box 1. Topic list for the in-depth interviews

- A Introduction by researcher
  - Emphasis on voluntary participation
  - Explanation of confidentiality and anonymity
  - Short explanation of the goal of the interview
- B Open-ended part
  - Patient's course of disease
    - Disease history
    - Present state and prognosis
    - Experience of care in general until now
  - Patient's interpersonal trust in oncologist
    - Role of different oncologists in care
    - Amount of trust in oncologists
    - Aspects facilitating and diminishing trust in oncologist
    - Importance and consequences of trust in oncologist
  - 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
- C Structured part
  - Ordering of different aspects of trust (as proposed by Hall *et al*. [7])
- D Conclusion of the interview
  - General patient information
  - Explanation of further procedure
  - Patient's general impression of the interview

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 1 h. 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.

Analysis

Interviews were transcribed verbatim. Analysis was performed in parallel with the interviewing, following guidelines for qualitative research [11] and using MAXqda2 software [12]. 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,

DOI: 10.1002/pon

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*. [7]. 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) [13]. Eventually, data were clustered across interviews to derive common themes related to trust, which were compared with 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. vZ.) 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 1).

Table 1. Demographics and medical characteristics of patients

	No. of patients ($n = 29$)
Age (years)	
18–40	5
41–65	15
>65	9
Sex	
Male	13
Female	16
Education level	
Low (secondary school or lower)	18
High (college or university)	11
Country of origin	
The Netherlands	20
Other Western country	2
Surinam	2
Morocco	2
The Netherlands Antilles	1
Ukraine	1
Egypt	1
Cancer site	
Bone	1
Brain	1
Breast	6
Gastrointestinal	12
Genitourinary	4
Gynecologic	4
Muscle	1
Time since diagnosis (years)	
<1	6
1–3	9
3–5	7
>5	7
Aim of treatment	
Curative	11
Palliative	18

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 acted in their best interests was deduced from his/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 is about my scoreboard, not his. (F-44y)

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's 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's not expertly then it all stops. (M-39y)

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's the matter with me and… Because obviously it's no use for me if they paint me a prettier picture than the reality. (M-39y)

Other patients interpreted honesty as whether oncologists admitted their misjudgments.

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> And it is also true that when a physician…we're all human, physicians too. If he has misjudged a situation, and later comes back to it, that also provides a piece of trust. (F-57y)

Confidentiality

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

> Well, I think that the privacy, it's unpleasant when something happens with that, that can be very unpleasant, but it's not that terribly bad for my trust. (M-39y)

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 wellbeing, 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's 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. (F-46y)

> For me…ehm…let me think…for trust it's important that the doctor has to be close for such severely ill patients, for those people. That's 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. (F-46y)

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'll think: never mind. Yes, that is part of it. (F-35y)

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. (F-57y)

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's like: I surrender to this. What they do must be right. (F-46y)

> Yes, you have to trust. You have to, because you are entirely at their mercy. (F-60y)

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

> Well, it's very strange, an oncologist… well, when you've 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. (F-44y)

> 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. (M-59y)

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'll die… (M-71y)

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. (F-46y)

> Well, in the beginning you blindly trust the oncologist, you have to. Because time is running out, you can't just say: let's first wait and get to know him. (F-44y)

Trust on the short vs long term

Patients report that their need to trust forces them to determine as soon as possible whether they can

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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. (M-39)

> That's 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's very important to make contact. (M-81y)

> You'll figure out soon enough whether you can trust someone or not. (M-43)

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's different from someone who has seen you ten times. (M-64)

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

> Yeah, actually I'm sure that I trust him. (…) Well, of course, I think that when you have a medical result… last time the tumour 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'll need to trust him, and I do. I don't have any reason to think that he's wrong. No… (M-58y)

However, his trust in the oncologist he has been seeing since 4 years seems more fundamental, and rather based on interpersonal factors.

> Because I'm 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, which 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. (M-58y)

Determination to trust

Patients' need to trust their oncologist seems to result in a determination, either conscious or unconscious, to retain 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 interests at heart and I think: he's 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's only human. So I absolutely do not blame him for that. (F-57)

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 treating 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 can't trust them, I walk away. (F-76)

> If I wouldn't trust my oncologist, I would go to another hospital… I will look for another oncologist. (F-46y)

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

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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 [3,7,14,15]. 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 [16].

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 of trust by Hall *et al.* [7] 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 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 [4]. Several authors suggested that the life-threatening nature of cancer creates a vulnerability that forces particularly strong trust upon patients [1,15,17]. 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 hadn't trusted him, I wouldn't have stayed with him. So I trust that man. (F-57y)

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.* [18] 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 [19–21].

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.* [22] 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.* [23], 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 [24] are distinguished. 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 [25,26]. 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

DOI: 10.1002/pon

trust through a continuous relationship with the physician has been found repeatedly also [27–29]. 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. The 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 sampling strategy allowed us to specifically include 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 [30]. In contrast, Anglo-Saxon countries, such as the US, 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 US [31]. 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 retain 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.

Acknowledgements

We are very grateful to Mariëtte Weterman and to Sandra Diergaarde and her colleagues for their help in the recruitment of patients. Additionally, we thank Dr Van den Velden and all the oncologists at the Internal Medicine Department for their kind cooperation in approaching patients. Finally, we are grateful to Prof. Mark Hall for his feedback on our preliminary findings. This study was financially supported by the Dutch Cancer Society (Grant Number: UVA 2008-4015).

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