Cancer patients' trust in their physician-a review
Hillen, M.A.; de Haes, J.C.J.M.; Smets, E.M.A.

Published in:
Psycho-Oncology

DOI:
10.1002/pon.1745

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Cancer patients’ trust in their physician – a review

Marij A. Hillen, Hanneke C.J.M. de Haes, Ellen M.A. Smets

Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands (E-mail: M.A.Hillen@amc.uva.nl).

Corresponding author: Marij A. Hillen, Academic Medical Center, University of Amsterdam, Department of Medical Psychology. P.O. Box 22700, 1100 DE Amsterdam, The Netherlands. E-mail: M.A.Hillen@amc.uva.nl. Tel: +31.20.566.4631. Fax: +31.20.566.9104

Funded by: Dutch Cancer Society; Grant number: UVA 2008-4015

The authors declare no potential conflicts of interest

This research project was approved of by the Medical Ethical Committee of the Academic Medical Center of the University of Amsterdam.

Number of words
Abstract: 236
Body: 4355
Body + tables: 7833
The article includes 1 figure and 2 tables
Abstract

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

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

RESULTS The search identified 45 relevant papers, only 11 of which drew attention to the conceptualization of trust, and 5 of which focused on trust as the primary subject of interest. Trust in physicians was strong overall. Patients’ trust appeared to be enhanced by the physician’s perceived technical competence, honesty, and patient-centred behaviour. A trusting relationship between patient and physician resulted in facilitated communication and medical decision making, a decrease of patient fear, and better treatment adherence.

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

Keywords: cancer, oncology, trust, physician-patient relations, review,
Introduction

Trust in another person is essential for human co-existence. It is simply impossible to keep every important thing safe without sometimes leaving it to the care of others (1). If so, we have to believe in the goodwill of these others and make ourselves vulnerable to the violation of our trust (2). To trust someone, therefore, implies being vulnerable and dependent on others. We often expose ourselves to such a situation, either voluntarily or because we are forced to. Such interpersonal trust has been conceptualized in multiple ways within several disciplines. Generally, interpersonal trust has been found to be stronger than trust in public institutions, and more dependent on actual experiences and individual characteristics, instead of reflecting a person’s global attitudes, values and preferences (3, 4). Although opinions about what interpersonal trust does or does not entail vary, four characteristics recur in definitions of trust. First, trust between two people involves a prediction about the future behaviour of the other (5). Second, someone who trusts holds the positive expectation that the trustee will perform a valued behaviour (6). Third, to trust involves taking a risk, thus creating vulnerability to the actions of the trustee (6). Finally, when the consequences of breaking trust are more far-stretching, trust is generally stronger. Therefore, trust is usually strongest in close relationships, such as between family members (7).

In the physician-patient relationship, patients have to trust a person with whom no close relationship exists, because of their inability to take care of their own health (7). The relationship is characterized by a knowledge and power imbalance, whereby the patient often has no choice but to trust the physician. As such, patients’ trust could be considered ‘taken for granted’ or implicit, contrasting with explicit trust, which refers to a more deliberate choice to trust (8). Patients’ trust in physicians has been defined both broadly as ‘The belief that a doctor is working in the patients’ best interests’ ((9), p.2), and more specifically as the optimistic acceptance of a vulnerable situation in which the patient believes the physician to care for his interests (2). The complexity and ambiguity of physician-patient trust complicates its definition. This has resulted in a wide variety of conceptualizations (10), only a few of which were backed up empirically (11). Much of the literature consists of theoretical analyses aimed at clarifying the concept of physician-patient trust. Such analyses are useful for positioning it within the literature of communication in healthcare.

Trust can be viewed as a characteristic of the depth of the physician-patient relation (12). It is generally considered an important component of therapeutic or working alliance (13, 14). Yet, it should not be considered equivalent because the latter concepts comprise, in addition to trust, an element of mutual agreement about goals and tasks. Furthermore, trust has been distinguished from related concepts, such as satisfaction, confidence, and distrust. Trust is argued to refer to the patient’s future expectation about an ongoing relationship, whereas satisfaction is more backward looking (15, 16). Whereas trust is sometimes used interchangeably with confidence, some consider it to be more emotive, and less rational than the latter concept (16). Others argue that the distinguishing feature is the risk, which is associated with trust, but not with confidence (17). In trust, the risk can either be taken or avoided, whereas confidence is the normal state of being and does not involve considering alternatives. In a situation of confidence, it is less likely that one will be disappointed than in a situation of trust. Finally, trust and distrust are often viewed as two ends of a continuum, whereas others contend that trust and distrust are separable, not opposites (18-20). In this view, both trust and distrust involve expectations about another person’s behaviour. Whereas in trust the expected behaviour is beneficial, distrust entails the expectation of harmful behaviours. As such, high distrust is also distinguished from low trust, which is the absence of an expectation of beneficial behaviours. A patient may thus at the same time hold a certain amount of trust and a certain amount of distrust of a physician.
Empirical literature of physician-patient trust has been lagging behind theoretical discussion, consisting mostly of cross-sectional research that depends on patients’ self-reports, and rarely assessing objective measures of physician or patient behaviour in relation to trust (21). Correlates of patients’ trust have been identified mainly. Overall, patients seem to trust physicians with whom a continuous relationship exists (22-24), who take ample time in the consultation (21, 25), who are informative (25-27) and who display caring behaviours, such as intent listening and expressing empathy (25, 27, 28). Patient characteristics most consistently associated with trust are attachment style (securely attached patients are more trusting than patients with avoidant or anxious attachment styles) (29) and ethnicity (white patients report more trust than non-white patients) (25, 26). Trust in physicians has also been found to be associated with desirable treatment outcomes, such as more patient satisfaction (16, 30), better treatment adherence (31, 32), and more willingness to participate in clinical trials (33).

The relevance of trust is assumed to be even greater in oncology care. Cancer patients have to deal with complex medical information, make difficult medical decisions, and cope with uncertain prognosis and radical treatment, with sometimes limited guarantees for improvement (34). Patients therefore find themselves in an extremely vulnerable situation. As described by Baier (1), they have to leave what they usually value most, i.e. their lives, to the care of their physician. It has been suggested that the life-threatening nature of cancer and the severity of the treatment might force patients to trust almost unconditionally (7, 35).

Although patients’ trust in their physician is generally reported to be strong (2), there is concern that this solid trust is eroding, due to changes in health care organization that might pave the way to less continuity of care and less personal attention for the patient (7, 9, 11). Other developments, such as increased patient autonomy and improved access to (conflicting) medical information, e.g. from the Internet, may also negatively affect the physician-patient relationship (36).

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

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

Study characteristics
Study characteristics and results are summarized in Table 1 and 2 for qualitative and quantitative studies, respectively.

Thirty-three papers addressed cancer patients’ perspectives on trust in their physician, five of which additionally included their relatives, and six of which additionally included physicians. Four others included only physicians’ perspectives on cancer patients’ trust. Eight papers addressed non-patients’ risk of developing cancer. Over half of the selected papers (25 out of 45) used qualitative methods, mostly consisting of in-depth semi-structured face-to-face interviews. All studies were cross-sectional, except for one qualitative longitudinal study (37). All quantitative studies were descriptive. In most qualitative studies trust was not incorporated in the study design, but rather deduced post hoc from the data as moderating the oncologist-patient relation. Only one study specifically aimed at gaining a better understanding of cancer patients’ trust (7). Although almost all quantitative studies incorporated trust in the design as a separate parameter, it was a primary outcome in only five studies.

Methods to assess trust differed widely. A complete questionnaire or a subscale thereof was used in only six studies. Four of these made use of questionnaires developed in the primary care setting (38-41). Two others used self-constructed questionnaires (35, 42). Other quantitative studies included just one, or a few, items, either adopted from one or several different trust scales or developed on an ad hoc basis by the authors. Psychometric properties were rarely mentioned.

Conceptualization of trust
In 16 qualitative and 18 quantitative studies, the term ‘trust’ was used without any clarification: the investigators did not report what trust encompassed to them, nor to the participants. In the other 11 papers, trust was conceptualized in various ways. Kraetschmer et al. (38) mainly emphasized the complexity of the concept, highlighting both its ‘technical (expertise) and interpersonal (e.g. communication, respect) elements’ (p. 318). In several studies, both investigators (39, 43, 44) and patients (45, 46) defined trust as the physician acting as an advocate of the patient’s interest. Elsewhere, patients mostly conceptualized trust as the physician’s genuine concern and ‘being treated like a person’ (47, 48). In Mechanic and Meyer (7), most common in patients’ accounts were honesty, openness, responsiveness, having their best interests at heart, and willingness to be vulnerable without fear of being harmed.

Level of trust
Eleven studies reported patients’ trust levels. In qualitative studies, patients reported high levels of trust in their oncologists (49) and surgeons (50), respectively. Results of quantitative studies likewise suggest high levels of trust (3, 39, 40, 51). Moderate-to-high trust scores were
reported in two other studies (38, 52). In contrast, lower trust was reported in three studies including specific subsets of patients: patients who had made use of complementary medicine (53), women who underwent breast-conserving therapy (41), and patients in end-of-life care (54).

Correlates of trust

**Patient characteristics**
Six studies were focused on cancer patient characteristics associated with trust in their physician. Non-significant results were reported in one of these. Women were found to have stronger trust than men (38). Results also indicate that older patients are more trusting (3, 38, 55). Education level was positively associated with trust (38, 55), whereas it did not predict trust in another (3). Patients of African American ethnicity were found to have less trust than Caucasians overall (40), while elsewhere this was the case only after their visit (3). Patients with German nationality were more likely to trust than patients from other European countries (52). Finally, despite worries that patients’ increased access to health-related information, e.g. from the Internet, might impact their trust in physicians (56), we did not encounter any study establishing such an association. Oncology professionals did not believe that patients’ access to health-related information from the Internet and other media would harm their trust in their physician (57).

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

*Physicians’ perceived technical competence*
A limited ability to assess the technical skills of the specialist might force patients to rely on characteristics that plausibly relate to competence, such as status, references and the outcomes of treatment (7). Accordingly, having been referred several times to their attending specialist led to high expectations of competence, thus enhancing patients’ trust (58). Physicians’ communication of expertise, e.g. displaying efficiency and technical skills or reputation, was associated with patients’ trust (7, 59-61). Post-operative complications were strongly correlated with patients’ distrust of surgeons (41). Finally, physicians felt that in bad news conversations their inability to keep their knowledge of new research up to date caused patients to consider them less trustworthy (62).

*Physicians’ perceived honesty*
Breast cancer patients reported trusting honest physicians most (7, 60) and suggested that physicians’ honest and straightforward information disclosure promoted trust when presenting bad prognosis (63). Finally, African American patients nominated physicians’ truth telling as one of the most important aspects for building and maintaining trust (64).

*Physicians’ patient-centred communication*
Patients suggested that physicians’ behaviours, such as listening and caring, providing information and answering questions, which reveal ‘interpersonal competence’, enhanced
trust (7). Behaviours indicating genuine concern, such as intent listening, patience, and caring behaviour, promoted trust among women with breast cancer (47, 65) and older African American patients (64). African American patients, who reported lower post-visit trust, perceived their physician’s communication as less patient-centred than Caucasian patients (3).

Organization in the clinical setting
Four studies underscore the importance of time and continuity of care for the establishment of trust. A long-term relation with their GP promoted cancer patients’ trust (43, 66). Having experienced frequent changes of physician predicted African American patients’ distrust (64). Finally, among a general population sample, visit continuity with a specific provider and longer duration relationships were both associated with higher levels of trust (55).

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

Interpersonal communication
Both breast cancer patients and health professionals emphasized the importance of a trusting relationship as a prerequisite for and facilitator of communicating prognosis (63). Similarly, among older patients, those who described the relationship with their physician as ‘trusting’ were more satisfied with their physician’s communication than those with a less trusting relation (67). Patients’ trust in their oncologist enhanced the probability that they would discuss independent written prognostic information with him or her (45), while elsewhere the opposite was reported (68). Patients’ companions who were more trusting asked the oncologist more questions in bad news interactions (69).

Decision making
Patients considered a trusting relationship with a physician facilitative for decision making about cancer screening (44). Cancer patients indicated that trust in their physician encouraged them to accept the physician’s treatment decisions and recommendations (35, 47). Indeed, in an international survey, breast cancer patients trusted their physician in recommending the best available medical treatment (52). Trusting patients seem to feel confident to delegate responsibility about medical decisions to their physician (37, 42). Rural low-income cancer patients with very strong trust in their physicians sometimes even indicated to fully rely on their doctor’s recommendations concerning treatment decisions (49). Consistent with this trend of decreased patient involvement when trust is stronger, patients with extremely high trust, ‘blind trust’, favoured a more passive role in medical decision making than those with moderate or high trust (38). Clinicians experienced trusting patients as very helpful to the treatment decision-making process (70, 71). However, whether trusting patients were considered helpful because they assumed a more active or a more passive role does not become clear, and might even vary across physicians.

Patients’ emotional distress
Patients facing brain tumour surgery emphasized the great importance of trust in their surgeon in reducing their fear of the occurrence of medical error (59). Likewise, neurosurgery patients’ worries about the involvement of physicians in training (residents) in their care were
greatly reduced by trust in their surgeon (50). Patients’ trust in their health care providers was associated with a decrease of their perceived risk (72).

**Adherence to medical advice**

A sense of trust in the physician was related to patients’ willingness to accept, and adhere to the physician’s advice throughout the diagnosis and treatment (73). Elsewhere, trust in physicians was mentioned as an important factor in patients’ decision to accept opioids as medication for cancer pain (74). Consistently, distrust of physicians’ motives and health information was an important consideration for lung cancer patients to refuse recommendations for further diagnosis or treatment. (75)

Patients with high levels of trust in their physician made more use of cancer screening (40, 46, 55, 76, 77). Consistently, the greater colorectal and breast cancer patients’ trust was, the earlier the cancer stage at diagnosis (39).

The willingness to participate in a clinical trial, not seeking a second opinion and not using complementary medicine, also expresses the intention to act on the physician’s advice. Indeed, trust was found to reduce the inclination to seek a second opinion (78) and promote the acceptance of the physician’s advice to participate in a clinical trial (48, 51, 79), while distrust increased the likelihood of complementary therapy usage (53).
Discussion

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

Relation to findings in other medical fields
The main themes emerging from this review resemble findings of patients’ trust in physicians in other patient populations. Like cancer patients, other patients trust physicians who display facilitative behaviours and who are perceived as competent (25, 26, 80). Such medical skills cannot always be accurately assessed by patients. Their judgement will therefore be strongly influenced by the physician’s reputation, status, and interpersonal communication, such as explanation skills (2, 59). Subtle differences between patient groups also emerge. This review found an emphasis on physicians’ perceived honesty as a correlate of trust, while literature of other patient groups emphasizes physicians’ informativeness (25, 26, 80). Honesty appears to extend beyond mere information giving. It involves a more profound, general attribute of the physician’s character, perhaps even referring to the physician’s integrity (81). Such a need for honesty about crucial health prospects and developments might arise from the life-threatening nature of cancer. The correlates of trust identified in this review largely overlap with the aspects of trust that have been frequently described in the non-oncology literature: (i) fidelity, which is pursuing the patient’s best interests, (ii) competence, referring to the physician’s presumed medical and interpersonal skills, (iii) honesty, which is telling the truth and avoiding intentional falsehoods, and (iv) confidentiality, which entails the adequate use of privacy-sensitive information (2).

Consequences of trust in physicians in cancer care also largely resemble those found in other medical fields: among other patient groups trust appeared to facilitate communication (82), improve treatment adherence (32, 83) and reduce the inclination to seek a second opinion (15, 16). Affective correlates of trust, however, might slightly differ between patient groups. Cancer patients attached much importance to the effect of trust on (a reduction of) fear, worries, and perceived risk, while in studies in other medical fields patients’ satisfaction with care was mainly emphasized (84). The severe treatment associated with cancer care might cause fear about what could go wrong, leaving less room for considerations regarding satisfaction. However, whether observed differences between cancer patients and other patient groups are a reflection of differences in research focus, rather than in the experience of trust, cannot be concluded at present.
Limitations of the studies reviewed

Our findings may suggest substantial knowledge of cancer patients’ trust in their physician. However, several shortcomings of the studies hamper such a conclusion. First, few researchers addressed cancer patients’ trust in a systematic way. In almost all qualitative studies, trust was not the initial subject of interest, but an outcome deduced from the data. In quantitative studies, trust was often incorporated in the design as just one of many variables. As a result, little attention was paid to the conceptualization of trust. Even if discussed, definitions vary between studies (2). Consequently, different researchers, and even different participants within studies, might be referring to dissimilar matters. Authors might have paid little attention to a definition of the concept because trust was an accidental outcome and not their main or initial research interest. Often they appear to assume that a ubiquitous concept like trust does not require additional clarification: patients will automatically understand what it means. Alternatively, they may not want to venture upon the definition of such an ambiguous concept.

The second, related, limitation is that measures of trust varied between quantitative studies. Most studies employed subscales or even single items for which validation commonly lacked. A few studies used validated scales developed in the primary care context mainly. The use of pre-existing questionnaires in a new setting without assessing its reliability and validity has been shown to be problematic (10). Therefore, it is unclear whether these scales can be employed to validly capture cancer patients’ trust. Moreover, these questionnaires have been developed assuming a multi-dimensional view of trust, consistent with theoretical and qualitative literature, which both suggest that patients’ trust has various dimensions (11). However, in practice these scales have consistently behaved one dimensional, suggesting that patients have a holistic view of trust in their physician (16, 23). This discrepancy between quantitative and qualitative findings could suggest that, although several dimensions do exist and do influence trust, patients do not distinguish among them (2). As yet, we cannot determine whether cancer patients view trust similarly one-dimensional, or whether they distinguish separate dimensions.

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

Finally, it is striking that non-significant findings were rarely encountered in this review. We consider it very unlikely that these have never occurred, as illustrated by the fact that in a recent study we found no significant effect of trust on cancer patients’ prognostic information preferences (85). The lack of non-significant findings may result from a publication bias, possibly enhanced by the fact that trust was often a side issue, since secondary variables might more likely be left unreported than primary variables.

Future directions

The fact that in qualitative studies trust was often spontaneously put forward by patients supports our idea that trust is a key phenomenon in cancer care. For the present, however, a thorough comprehension of cancer patients’ trust in their physician is lacking, because of the scarcity of high quality studies specifically aimed at trust. Our knowledge of trust in this population could benefit from evidence from the broader literature of physician-patient trust. However, both the specific oncologic population and the particular process of trust might be distinct from other patient populations and related concepts, and therefore deserve separate research attention. We suggest that future research should first of all explore some conceptual
issues of trust in cancer care, building on existent knowledge of trust among other patient populations and interpersonal trust in non-medical settings. Specific attention should be directed to the identification of properties and processes of trust specific for this population: what is cancer patients’ understanding of trust, and how do they construct trust? Second, more attention should be devoted to excess, or ‘blind’, trust. Especially in the oncology population very strong trust might be frequent, resulting from the severity of the disease and patients’ associated dependence (7). While in much of the literature the premise appears to be that the more trust, the better, a surplus of trust could prove to have negative effects, such as physicians shirking their responsibility, or patient passivity. In this review, results with regard to decision making indeed suggest diminished patient involvement associated with high trust, which may not necessarily be positive. Although some authors acknowledge the possible drawbacks of excess trust (38, 44, 59), we believe that the possible hazards of blind trust need more empirical investigation. Third, although overall trust seems strong, more substantial research could establish whether trust among cancer patients is eroding, as feared, and whether specific groups are more vulnerable to lose trust. Fourth, we encountered two lacunas in current knowledge, i.e. the effect of increased Internet access on trust, and physician characteristics associated with trust. Finally, we focussed our search on cancer patients’ interpersonal trust, thus excluding the broader literature on trust in the health-care system. Although a spill-over effect of public (mis)trust on interpersonal trust is possible (7, 86), interpersonal trust has been proven to be distinct from public trust. The relation between interpersonal and public trust among cancer patients deserves future research attention.

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

Acknowledgements
This study was financially supported by the Dutch Cancer Society. We thank Pythia Nieuwkerk for her valuable comments and contributions. This work was funded by the Dutch Cancer Society; Grant number: UVA 2008-4015. The authors declare no potential conflicts of interest. This research project was approved of by the Medical Ethical Committee of the Academic Medical Center of the University of Amsterdam.


(8) Skirbekk H. Negotiated or taken-for-granted trust? Explicit and implicit interpretations of trust in a medical setting. *Medicine, Health care and Philosophy* 2009, 12, 3-7.


(28) Robb N, Greenhalgh T. "You have to cover up the words of the doctor": the mediation of trust in interpreted consultations in primary care. *Journal of Health Organization and Management* 2006,20(5), 434-455.

(30) Dugan E, Trachtenberg F, Hall MA. Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. *BMC Health Services Research* 2005,5, 64-70.


(51) Jenkins V, Fallowfield L. Reasons for accepting or declining to participate in randomized clinical trials for cancer therapy. British Journal of Cancer 2000,82(11), 1783-1788.


(63) Butow PN, Dowsett S, Hagerty R, Tattersall MH. Communicating prognosis to patients with metastatic disease: what do they really want to know? *Supportive Care in Cancer* 2002 Mar,10(2), 161-168.

(64) Torke AM, Corbie-Smith GM, Branch WT, Jr. African American patients' perspectives on medical decision making. *Archives of Internal Medicine* 2004 Mar 8,164(5), 525-530.


(66) Anvik T, Holtedahl KA, Mikalsen H. "When patients have cancer, they stop seeing me" -- the role of the general practitioner in early follow-up of patients with cancer--a qualitative study. *BMC Family Practice* 2006,7, 19.


(75) Sharf BF, Stelljes LA, Gordon HS. 'A little bitty spot and I'm a big man': patients' perspectives on refusing diagnosis or treatment for lung cancer. *Psycho-oncology* 2005 Aug, 14(8), 636-646.


<table>
<thead>
<tr>
<th>First author, year, country</th>
<th>Aims of the study</th>
<th>Sample</th>
<th>Design and method</th>
<th>Role of trust</th>
<th>Findings regarding trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Anvik, 2006, Norway</td>
<td>To describe the role of the GP during initial follow-up of patients with recently treated cancer</td>
<td>23 GP's, 91 cancer patients (heterogeneous) and their relatives</td>
<td>Cross-sectional; focus group, semi-structured face-to-face interviews and questionnaires</td>
<td>Deduced as outcome from data</td>
<td>Patients stated they trusted their GP’s ability to take good care of them</td>
</tr>
<tr>
<td>2. Bernstein, 2004, Canada</td>
<td>To examine the perceptions and attitudes of patients undergoing neurosurgery regarding medical error</td>
<td>30 brain tumour patients within one week of undergoing a neurosurgical operation</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients spontaneously mentioned trust in their surgeon as the most important factor mitigating fears of medical error</td>
</tr>
<tr>
<td>3. Bulsara, 2005, Australia</td>
<td>To investigate cancer patients’ perceptions of the role of the general practitioner, particularly outside of the hospital setting</td>
<td>13 haematological cancer patients</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients valued the long-term close relationship with their GP to promote trust</td>
</tr>
<tr>
<td>4. Butow, 2002, Australia</td>
<td>To obtain patient and health professional views on optimal ways of presenting prognosis to patients with metastatic breast cancer</td>
<td>13 health professionals in breast cancer care (both medical and non-medical), 17 breast cancer patients</td>
<td>Cross-sectional; structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients and professionals mentioned that prognosis was best communicated within a trusting relationship</td>
</tr>
<tr>
<td>5. Coyne, 2004, US</td>
<td>To gain a better understanding of low-income, rural cancer patients’ attitudes, knowledge and beliefs regarding clinical trial participation</td>
<td>17 cancer patients (heterogeneous) living in a rural area</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients' trust in their physician was generally high. Some patients relied solely on the oncologist's recommendations concerning treatment decisions</td>
</tr>
<tr>
<td>6. Davey, 2005, Australia</td>
<td>To systematically compare cancer patients’ views on prognostic information provided by their doctor and written prognostic information obtained from a major cancer organisation</td>
<td>26 cancer patients (heterogeneous)</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>The amount of trust cancer patients had in their oncologist determined whether or not they would discuss independent information with him or her</td>
</tr>
<tr>
<td>7. Davey, 2006, Australia</td>
<td>To investigate how women explore and use information in the context of having diagnostic tests to investigate a breast symptom</td>
<td>14 women who had had a current breast symptom</td>
<td>Cross-sectional; unstructured telephone interviews</td>
<td>Deduced as outcome from data</td>
<td>Women expressed greater trust and confidence in healthcare professionals who provided information and answered questions</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Title</td>
<td>Study Design</td>
<td>Data Collection</td>
<td>Findings</td>
</tr>
<tr>
<td>-------</td>
<td>---------</td>
<td>-------</td>
<td>--------------</td>
<td>----------------</td>
<td>----------</td>
</tr>
<tr>
<td>8. Freedman, 2003, US</td>
<td>To investigate medical encounters between women and their oncologic physicians throughout the breast cancer diagnostic and treatment process</td>
<td>Cross-sectional; observations and semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients who trusted their physician indicated to be more willing to adhere to and accept the physician's advice</td>
<td></td>
</tr>
<tr>
<td>9. Friedrichsen, 2006, Sweden</td>
<td>To study and explore problems perceived by physicians when breaking bad news to advanced cancer patients about discontinuing or not offering treatment</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Oncologists described that a lack of specific knowledge, e.g. of ongoing or published studies, resulted in being considered less trustworthy by patients</td>
<td></td>
</tr>
<tr>
<td>10. Geller, 1997, US</td>
<td>To learn what women would want to know, and how they would make a decision, if they were offered breast cancer susceptibility testing</td>
<td>Cross-sectional; focus groups</td>
<td>Deduced as outcome from data</td>
<td>Women indicated that a trusting relationship with a physician facilitated their decision making about cancer susceptibility testing</td>
<td></td>
</tr>
<tr>
<td>11. Goldman, 2004, US</td>
<td>To explore the perceptions around breast and cervical cancer risk and screening among Dominicans and Puerto Ricans living in Rhode Island</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>A lack of trust was often mentioned as a barrier to getting screened</td>
<td></td>
</tr>
<tr>
<td>12. Henman, 2002, Australia</td>
<td>To examine why women with cancer want information, and what they believe to be the important factors influencing their decision making</td>
<td>Cross-sectional; semi-structured telephone interviews</td>
<td>Deduced as outcome from data</td>
<td>Physicians' genuine concern, good reputation, and providing patients with sufficient information contributed to solid trust. Trust facilitated decision making and encouraged patients to accept the physician's recommendations</td>
<td></td>
</tr>
<tr>
<td>13. Katapodi, 2005, US</td>
<td>To identify heuristics that influence perceived breast cancer risk</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients who trusted their health providers had a more reasonable sense of personal control over the disease than distrusting patients. Trust also minimized perceived risk of breast cancer</td>
<td></td>
</tr>
<tr>
<td>14. Knifed, 2008, Canada</td>
<td>To explore the level of knowledge and anxiety in patients regarding the involvement of residents in their surgery</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deduced as outcome from data</td>
<td>Patients reported high trust in their surgeon, which removed most worries and anxiety about the involvement of residents during surgery</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
<td>Objective</td>
<td>Sample Size</td>
<td>Study Design</td>
</tr>
<tr>
<td>-------</td>
<td>------</td>
<td>---------</td>
<td>-----------</td>
<td>-------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Lacey, 2002, US</td>
<td>2002</td>
<td>US</td>
<td>To explore the lived experience of patients with breast cancer using decisional support aids during the prediagnosis, diagnosis, and treatment phases of their disease</td>
<td>12 female breast-cancer patients</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
</tr>
<tr>
<td>Lasser, 2008, US</td>
<td>2008</td>
<td>US</td>
<td>To describe barriers to and facilitators of colorectal cancer screening among diverse patients served by community health centers</td>
<td>10 primary care physicians, 23 patients eligible for colorectal cancer screening</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
</tr>
<tr>
<td>Madsen, 2007, Denmark</td>
<td>2007</td>
<td>Denmark</td>
<td>To gain an understanding of the meanings assigned to patients' lived experiences during their treatment courses within or outside a clinical trial setting</td>
<td>14 breast cancer and advanced ovarian cancer patients who participated in a clinical trial involving chemotherapy, and 15 who declined</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
</tr>
<tr>
<td>McKneally, 2000, Canada</td>
<td>2000</td>
<td>Canada</td>
<td>To describe the process of decision making and consent to surgical treatment from the patients' perspective, in the context of life-threatening illness</td>
<td>36 esophageal patients, recovered from esophagectomy</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
</tr>
<tr>
<td>Mechanic, 2000, US</td>
<td>2000</td>
<td>US</td>
<td>To examine conceptions of trust among three groups of respondents diagnosed with either breast cancer, Lyme disease or mental illness</td>
<td>90 patients, of whom 30 with breast cancer, 30 with chronic Lyme disease, and 30 with mental illness</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
</tr>
<tr>
<td>Oliffe, 2007, Canada</td>
<td>2007</td>
<td>Canada</td>
<td>To investigate what might be considered prostate cancer communication competencies in the male patient-physician dyad</td>
<td>59 male prostate cancer patients</td>
<td>Cross-sectional; secondary analysis of semi-structured face-to-face interviews</td>
</tr>
<tr>
<td>Study</td>
<td>Authors</td>
<td>Objective</td>
<td>Participants</td>
<td>Study Design</td>
<td>Data Collection</td>
</tr>
<tr>
<td>-------</td>
<td>---------</td>
<td>-----------</td>
<td>--------------</td>
<td>--------------</td>
<td>----------------</td>
</tr>
<tr>
<td>21.</td>
<td>Pollock, 2008, UK</td>
<td>To investigate service users' experiences of a patient information pathway after a diagnosis of cancer</td>
<td>27 cancer patients (15 lung cancer, 12 head and neck cancer) and 20 of their relatives</td>
<td>Longitudinal; semi-structured face-to-face interviews (1, 2, or 3 interviews per patient)</td>
<td>Deducted as outcome from data</td>
</tr>
<tr>
<td>22.</td>
<td>Reid, 2008, UK</td>
<td>To explore the factors influencing the decision to accept or reject morphine when first offered to patients with cancer</td>
<td>18 cancer patients (heterogeneous)</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deducted as outcome from data</td>
</tr>
<tr>
<td>23.</td>
<td>Sharf, 2005, US</td>
<td>To explore why patients refused recommendations for further diagnosis or treatment of lung cancer</td>
<td>9 lung cancer patients with documented refusal of doctors' recommendations</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deducted as outcome from data</td>
</tr>
<tr>
<td>24.</td>
<td>Torke, 2004, US</td>
<td>To describe the perspectives of older African American patients in a primary care clinic as they consider a medical decision</td>
<td>25 African American patients &gt; 50 years old, who had discussed flexible sigmoidoscopy with their primary care provider</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deducted as outcome from data</td>
</tr>
<tr>
<td>25.</td>
<td>Wright, 2004, UK</td>
<td>To determine how patients with breast cancer want their doctors to communicate with them</td>
<td>39 female breast-cancer patients</td>
<td>Cross-sectional; semi-structured face-to-face interviews</td>
<td>Deducted as outcome from data</td>
</tr>
<tr>
<td>First author, year, country</td>
<td>Aims of the study</td>
<td>Sample</td>
<td>Design and method</td>
<td>Role of trust</td>
<td>Measurement of trust</td>
</tr>
<tr>
<td>----------------------------</td>
<td>------------------</td>
<td>--------</td>
<td>-------------------</td>
<td>--------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>1. Charles, 2004, Canada</td>
<td>To explore the extent to which breast cancer specialists report practising shared decision making with their patients, their comfort level with this approach, and perceived barriers and facilitators to implementation</td>
<td>334 oncologists and surgeons in Ontario treating female early-stage breast cancer patients</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>1 four-point Likert question</td>
</tr>
<tr>
<td>2. Daugherty, 1995, US</td>
<td>To investigate the complex issues around participation in clinical trials, and patients’ perceptions toward these trials</td>
<td>27 cancer patients who had agreed to participate in a phase I clinical trial.</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>1 item about motivators for participation in clinical trials, with 9 nominal response options, two options of which regarded trust in the referring physician or the research oncologist</td>
</tr>
<tr>
<td>3. Eggly, 2006, US</td>
<td>To investigate questions asked by cancer patients and their companions during stressful encounters in the oncology setting in the USA</td>
<td>28 cancer patients (heterogeneous) and their companions</td>
<td>Descriptive; cross-sectional; coding of video-recordings of oncology consultations</td>
<td>Trust as secondary parameter</td>
<td>1 seven-point Likert question</td>
</tr>
<tr>
<td>4. Gordon, 2006, US</td>
<td>To examine whether racial differences in patient trust are associated with physician-patient communication about lung cancer treatment</td>
<td>103 patients (22% black, 78% white) visiting thoracic or oncology clinics</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Pre- and post-visit trust as primary parameters</td>
<td>5 10-point Likert questions adopted verbatim or modified from previously published trust scales</td>
</tr>
<tr>
<td>5. Helmes, 2002, VS</td>
<td>To investigate women’s preferred physician involvement in the decision to obtain genetic testing for breast cancer risk</td>
<td>340 women (population based sample), between 18-64 years old, not ill.</td>
<td>Descriptive; cross-sectional; survey; structured telephone survey and written baseline questionnaire</td>
<td>Trust towards / satisfaction with primary care provider as secondary parameter</td>
<td>5 four-point Likert questions, constituting a subscale of an earlier developed scale (unpublished)</td>
</tr>
<tr>
<td></td>
<td>Authors, Year, Country</td>
<td>Objective</td>
<td>Sample</td>
<td>Methodology</td>
<td>Trust Measurement</td>
</tr>
<tr>
<td>---</td>
<td>------------------------</td>
<td>-----------</td>
<td>--------</td>
<td>-------------</td>
<td>------------------</td>
</tr>
<tr>
<td>6.</td>
<td>Heyland, 2005, Canada</td>
<td>To investigate satisfaction with, and key elements of quality of end-of-life care that are important to Canadian hospitalized patients with end-stage medical disease and their family members</td>
<td>440 patients with end-stage disease, 166 of which diagnosed with cancer and 160 of their family members</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
</tr>
<tr>
<td>7.</td>
<td>Jenkins, 2000, UK</td>
<td>To examine reasons for patients to accept or decline participation in cancer clinical trials</td>
<td>204 cancer patients (heterogeneous)</td>
<td>Descriptive; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
</tr>
<tr>
<td>8.</td>
<td>Kirschning, 2008, Germany</td>
<td>To find out how far the traditional doctor-patient relationship is affected and changed by the Internet-informed patient</td>
<td>536 cancer patients (370 women with breast cancer, 193 men with prostate cancer) and 133 of their relatives</td>
<td>Descriptive; cross-sectional; online survey; structured questionnaire</td>
<td>Trust deduced as outcome from the data</td>
</tr>
<tr>
<td>9.</td>
<td>Kraetschmer, 2004, Canada</td>
<td>To better understand the relationship between people's trust in their physician and their desire for a participative role in decisions about their medical treatment</td>
<td>606 breast cancer, prostate cancer and fracture patients</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as primary parameter</td>
</tr>
<tr>
<td>10.</td>
<td>Lansdown, 2008, UK</td>
<td>To examine, via an international survey, the impact of positive and negative interactions on the patient-physician relationship</td>
<td>462 breast-cancer physicians, 600 female postmenopausal breast-cancer patients</td>
<td>Observational; cross-sectional; online international survey</td>
<td>Trust as secondary parameter</td>
</tr>
<tr>
<td>11.</td>
<td>Liang, 2006, US</td>
<td>To explore the associations between physician communication styles and their older patients' intentions to get mammography and satisfaction with physician communication</td>
<td>7 general internists and 56 of their patients &gt; 65 years</td>
<td>Mixed methods; observational; qualitative analysis of audiotaped conversations between patient and physician, quantitative analysis of survey</td>
<td>Trust as secondary parameter</td>
</tr>
</tbody>
</table>

Patients who described communication with their physician as 'trusting' were more satisfied with communication than women who rated physician communication as less trusting ($p=0.02$).
12. Ling, 2006, US
To assess the association between provider-patient interaction with colorectal cancer screening utilization
2570 randomly sampled respondents, > 50 years
Observational; cross-sectional; telephone survey
Trust as secondary parameter
1 item: 'Do you trust cancer information from a doctor or other health care professional' (response options: 'yes' and 'no')
Having trust in cancer information from the doctor or other health care professionals was most predictive of having undergone colorectal cancer screening (OR 2.08, p<0.001)

To examine the relationship between continuity of care and trust in one’s physician with stage of cancer among newly diagnosed colorectal and breast cancer patients
119 cancer patients (97 breast cancer, 22 colorectal cancer)
Observational; cross-sectional; survey; structured face-to-face interviews
Trust as primary parameter
11 5-point Likert items, constituting the 'Trust in Physician Scale' (Anderson & Dedrick, 1990)
Mean trust in primary care physician was 43.5 (scale 0-55). Trust was related to earlier detection among the entire sample of patients (p=0.02) and among a subsample of women with breast cancer (p=0.006)

14. Newnham, 2005, Australia
To investigate attitudes of Australian health professionals working in oncology to health-related information in the media and on the Internet and to patients who search for this information
226 oncology health professionals (physicians, nurses and researchers)
Observational; cross-sectional; survey; structured questionnaire
Perceived patient trust as secondary parameter
1 item: 'Do information-seekers have greater or less trust in their doctors?' (response options: 'greater trust', 'no difference' and 'lesser trust')
Most respondents believed that information from the Internet and other media would not harm patients' trust in, and relationship with, their physician (69% and 67%, resp.)

To explore factors that predict higher trust in primary care providers, and examine the role of patient trust on the use of preventive services for low-income African-American women
961 African-American females, > 40 years
Observational; cross-sectional; telephone survey
Trust as primary parameter
1 five-point Likert question ('My doctor cares more about holding down costs than about doing what is needed for my health') and 1 10-point Likert question ('All things considered, how much do you trust your doctor?')
Higher trust was significantly associated with greater use of recommended preventive services (OR: 2.3, 95% CI: 1.3, 4.0), controlling for the effects of insurance status, primary care, and patient characteristics

16. Paltiel, 2001, Israel
To examine the use of complementary therapies (CT) by Israeli oncology patients and to compare sociodemographic, psychologic, and medical characteristics, attitudes, and quality of life of users and nonusers of CT
1,027 cancer patients (heterogeneous)
Observational; cross-sectional; survey; structured questionnaire
Trust as secondary parameter
1 question: 'I trust my doctor... (response options: 'completely' and 'incompletely')
Patients expressing a lack of trust in their doctors (42.4%) were more likely to be recent users of complementary therapy than patients who trusted their doctor completely (30.1%, p<0.001)

17. Salkeld, 2004, Australia
To determine which aspects of the treatment decision process, therapy and outcomes are most important to patients with colorectal cancer (CRC)
175 colorectal cancer patients (102 men, 73 women) who had completed primary treatment
Observational; cross-sectional; survey; structured questionnaire
Trust as one of primary parameters
6 four-point Likert questions about the importance of different aspects of trust in the surgeon when choosing treatment, constituting 1 factor ('trust in surgeon')
Trust in surgeon was found to be the most important factor (accounting for 14.8% of the total variation in the 22 variables) for colorectal cancer patients in accepting that the right treatment decisions were being made
<table>
<thead>
<tr>
<th>18. Shepherd, 2008, Australia</th>
<th>To investigate barriers and facilitators for cancer physicians to care reaching treatment decisions with their patients and their support of strategies to encourage patient involvement and reflection on treatment options</th>
<th>604 physicians in oncology</th>
<th>Observational; cross-sectional; survey; structured questionnaire</th>
<th>Trust as secondary parameter</th>
<th>1 four-point Likert question: 'The patient trusts me' (response options: never, sometimes, often or always helpful to the treatment decision making process)</th>
<th>Having a trusting patient was considered ‘always’ or ‘often’ helpful to reaching a treatment decision by 88.2% of the respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Spain, 2008, US</td>
<td>To describe racial differences in perceived risk of prostate cancer and to examine whether (1) perceived high risk predicts greater personal responsibility for prostate care; and (2) greater personal responsibility for prostate care predicts earlier, pre-symptomatic diagnosis</td>
<td>555 newly diagnosed male prostate cancer patients, 348 Caucasian and 207 African American</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>8 five-point Likert items, adopted from the 'Primary Care Assessment Survey' (Safran et al., 1998)</td>
<td>Mean trust score was 88.4% (scale 10-100%). Higher physician trust predicted increased likelihood to have regular prostate exams and screening (OR 1.12, p&lt;0.05), indicating that the racial differences in seeking prostate care may be mediated through physician trust</td>
</tr>
<tr>
<td>20. Wajee, 2008, US</td>
<td>To examine the effect of treatment-related factors on patient satisfaction with their healthcare experiences</td>
<td>714 breast-conserving therapy patients</td>
<td>Observational; cross-sectional; survey; structured questionnaire</td>
<td>Trust as secondary parameter</td>
<td>11 five-point Likert items, constituting the 'Trust in Physicians Scale' (Hall et al., 2001)</td>
<td>Mean trust in surgeon was 2.24 (scale 1-5). Increasing breast asymmetry was associated with higher surgeon distrust scores (p =0.04) and with the occurrence of postoperative complications (p = 0.03)</td>
</tr>
</tbody>
</table>