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Cancer patients' trust in their physician – a review

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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-reaching, 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).

- Insert Figure 1 -

Results

Study characteristics

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

- Insert Table 1 & 2 -

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' 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.

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Reference List

- (1) Baier A. Trust and antitrust. *Ethics* 1986,**96**, 231-260.
- (2) Hall MA, Dugan E, Zheng BY, Mishra AK. Trust in physicians and medical institutions: What is it, can it be measured, and does it matter? *Milbank Quarterly* 2001,**79**(4), 613-639.
- (3) Gordon HS, Street RL, Jr., Sharf BF, Kelly PA, Soucek J. Racial differences in trust and lung cancer patients' perceptions of physician communication. *Journal of Clinical Oncology* 2006 Feb 20,**24**(6), 904-909.
- (4) Hall MA, Camacho F, Dugan E, Balkrishnan R. Trust in the medical profession: Conceptual and measurement issues. *Health Services Research* 2002,**37**(5), 1419-1439.
- (5) Mishra AK. Organizational responses to crisis: The centrality of trust. In Kramer RM, Tyler TR, eds. *Trust in organizations: Frontiers of theory and research*. Thousand Oaks, CA, Sage, 1996, 261-287.
- (6) Mayer RC, Davis JH, Schoorman FD. An integration model of organizational trust. *Academy of Management Review* 1995,**20**(3), 709-734.
- (7) Mechanic D, Meyer S. Concepts of trust among patients with serious illness. *Social Science & Medicine* 2000,**51**(5), 657-668.
- (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.
- (9) McKinstry B, Ashcroft RE, Car J, Freeman GK, Sheikh A. Interventions for improving patients' trust in doctors and groups of doctors. *Cochrane Database of Systematic Reviews* 2006, **3**, CD004134.
- (10) Goudge J, Gilson L. How can trust be investigated? Drawing lessons from past experience. *Social Science & Medicine* 2005,**61**, 1439-1451.
- (11) Pearson SD, Raeke LH. Patients' trust in physicians: Many theories, few measures, and little data. *Journal of General Internal Medicine* 2000,**15**(7), 509-513.
- (12) Ridd M, Shaw A, Lewis G, Salisbury C. The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *British Journal of Medical Practice* 2009,**59**(561), 116-133.
- (13) Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. *Public health reports* 2003,**118**, 358-365.
- (14) Fuertes J, Mislouack A, Bennett J, et al. The physician-patient working alliance. *Patient Education and Counseling* 2007,**66**(1), 29-36.
- (15) Balkrishnan R, Dugan E, Camacho FT, Hall MA. Trust and satisfaction with physicians, insurers, and the medical profession. *Medical Care* 2003,**41**(9), 1058-1064.

- (16) Hall MA, Zheng BY, Dugan E, et al. Measuring patients' trust in their primary care providers. *Medical Care Research and Review* 2002,**59**(3), 293-318.
- (17) Luhmann N. Familiarity, confidence, trust: problems and alternatives. In Gambetta D, ed. *Trust: making and breaking cooperative relations*. Electronic edition ed. Department of Sociology, University of Oxford, 2000, 94-107.
- (18) Mascarenhas OAJ, Cardozo LJ, Afonso N, et al. Hypothesized predictors of patient-physician trust and distrust in the elderly: implications for health and disease management. *Clinical Interventions in Aging* 2006,**1**(2), 175-188.
- (19) Luhmann N. *Trust and power*. Chichester, England, Wiley, 1979.
- (20) Lewicki RJ, McAllister DJ, Bies RJ. Trust and distrust: new relationships and realities. *The academy of management review* 1998,**23**(3), 438-458.
- (21) Fiscella K, Meldrum S, Franks P, et al. Patient trust - Is it related to patient-centered behavior of primary care physicians? *Medical Care* 2004,**42**(11), 1049-1055.
- (22) Jones IR, Ahmed N, Catty J, et al. Illness careers and continuity of care in mental health services: A qualitative study of service users and carers. *Social Science & Medicine* 2009,**69**, 632-639.
- (23) Kao AC, Green DC, Davis NA, Koplan JP, Cleary PD. Patients' trust in their physicians - Effects of choice, continuity, and payment method. *Journal of General Internal Medicine* 1998,**13**(10), 681-686.
- (24) Tarrant C, Colman AM, Stokes T. Past experience, 'shadow of the future', and patient trust: a cross-sectional survey. *British Journal of General Practice* 2008,**58**(556), 780-783.
- (25) Keating NL, Gandhi TK, Orav EJ, Bates DW, Ayanian JZ. Patient characteristics and experiences associated with trust in specialist physicians. *Archives of Internal Medicine* 2004,**164**(9), 1015-1020.
- (26) Berrios-Rivera JP, Street RL, Popa-Lisseanu MGG, et al. Trust in physicians and elements of the medical interaction in patients with rheumatoid arthritis and systemic lupus erythematosus. *Arthritis & Rheumatism-Arthritis Care & Research* 2006,**55**(3), 385-393.
- (27) Ommen O, Janssen C, Neugebauer E, et al. Trust, social support and patient type-Associations between patients perceived trust, supportive communication and patients preferences in regard to paternalism, clarification and participation of severely injured patients. *Patient Education and Counseling* 2008, **73**(2), 196-204.
- (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.
- (29) Ciechanowski P, Katon WJ. The interpersonal experience of health care through the eyes of patients with diabetes. *Social Science & Medicine* 2006,**63**(12), 3067-3079.

- (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.
- (31) Safran DG, Kosinski M, Tarlov AR, et al. The primary care assessment survey - Tests of data quality and measurement performance. *Medical Care* 1998,**36**(5), 728-739.
- (32) Trachtenberg F, Dugan E, Hall MA. How patients' trust relates to their involvement in medical care. *Journal of Family Practice* 2005,**54**(4), 344-352.
- (33) Nurgat ZA, Craig W, Campbell NC, Bissett JD, Cassidy J, Nicolson MC. Patient motivations surrounding participation in phase I and phase II clinical trials of cancer chemotherapy. *British Journal of Cancer* 2005,**92**(6), 1001-1005.
- (34) Seetharamu N, Iqbal U, Weiner JS. Determinants of trust in the patient-oncologist relationship. *Palliative Supportive Care* 2007,**5**(4), 405-409.
- (35) Salkeld G, Solomon M, Short L, Butow PN. A matter of trust--patient's views on decision-making in colorectal cancer. *Health Expectations* 2004 Jun,**7**(2), 104-114.
- (36) Mechanic D. Changing medical organization and the erosion of trust. *The Milbank Quarterly* 1996,**74**(2), 171-189.
- (37) Pollock K, Cox K, Howard P, Wilson E, Moghaddam N. Service user experiences of information delivery after diagnosis of cancer: a qualitative study. *Supportive Care in Cancer* 2008,**16**(8), 963-973.
- (38) Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision making? *Health Expectations* 2004,**7**(4), 317-326.
- (39) Mainous AG, Kern D, Hainer B, Kneuper-Hall R, Stephens J, Geesey ME. The relationship between continuity of care and trust with stage of cancer at diagnosis. *Relationship of the Process of Primary Care to Health Outcome* 2004,**36**(1), 35-39.
- (40) Spain P, Carpenter WR, Talcott JA, et al. Perceived family history risk and symptomatic diagnosis of prostate cancer: the North Carolina Prostate Cancer Outcomes study. *Cancer* 2008,**113**(8), 2180-2187.
- (41) Waljee JF, Hu ES, Newman LA, Alderman AK. Correlates of patient satisfaction and provider trust after breast-conserving surgery. *Cancer* 2008,**112**(8), 1679-1687.
- (42) Helmes AW, Bowen DJ, Bengel J. Patient preferences of decision-making in the context of genetic testing for breast cancer risk. *Genetics in Medicine* 2002,**4**(3), 150-157.
- (43) Bulsara C, Ward AM, Joske D. Patient perceptions of the GP role in cancer management. *Australian Family Physician* 2005 Apr,**34**(4), 299-300.
- (44) Geller G, Strauss M, Bernhardt BA, Holtzman NA. "Decoding" informed consent. Insights from women regarding breast cancer susceptibility testing. *Hastings Center Report* 1997,**27**(2), 28-33.

- (45) Davey HM, Armstrong BK, Butow PN. An exploratory study of cancer patients' views on doctor-provided and independent written prognostic information. *Patient Education and Counseling* 2005 Mar,**56**(3), 349-355.
- (46) Lasser KE, Ayanian JZ, Fletcher RH, Good MJ. Barriers to colorectal cancer screening in community health centers: a qualitative study. *BMC Family Practice* 2008,**9**, 15.
- (47) Henman MJ, Butow PN, Brown RF, Boyle F, Tattersall MHN. Lay constructions of decision making in cancer. *Psycho-oncology* 2002,**11**, 295-306.
- (48) Madsen SM, Holm S, Riis P. Participating in a cancer clinical trial? The balancing of options in the loneliness of autonomy: a grounded theory interview. *Acta Oncologica* 2007,**46**(1), 49-59.
- (49) Coyne CA, Demian-Popescu C, Brown P. Rural cancer patients' perspectives on clinical trials: a qualitative study. *Journal of Cancer Education* 2004,**19**(3), 165-169.
- (50) Knifed E, July J, Bernstein M. Neurosurgery patients' feelings about the role of residents in their care: a qualitative case study. *Journal of Neurosurgery* 2008 Feb,**108**(2), 287-291.
- (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.
- (52) Lansdown M, Martin L, Fallowfield L. Patient-physician interactions during early breast-cancer treatment: results from an international online survey. *Current Medical Research Opinion* 2008 Jul,**24**(7), 1891-1904.
- (53) Paltiel O, Avitzour M, Peretz T, et al. Determinants of the use of complementary therapies by patients with cancer. *Journal of Clinical Oncology* 2001 May 1,**19**(9), 2439-2448.
- (54) Heyland DK, Groll D, Rocker G, et al. End-of-life care in acute care hospitals in Canada: a quality finish? *Journal of Palliative Care* 2005,**21**(3), 142-150.
- (55) O'Malley AS, Sheppard VB, Schwartz M, Mandelblatt J. The role of trust in use of preventive services among low-income African-American women. *Preventive Medicine* 2004,**38**(6), 777-785.
- (56) Cline RJW, Haynes KM. Consumer health information seeking on the Internet: the state of the art. *Health Education Research* 2001,**16**(6), 671-692.
- (57) Newnham GM, Burns WI, Snyder RD, et al. Attitudes of oncology health professionals to information from the Internet and other media. *The Medical Journal of Australia* 2005 Aug 15,**183**(4), 197-200.
- (58) McKneally MF, Martin DK. An entrustment model of consent for surgical treatment of life-threatening illness: perspective of patients requiring esophagectomy. *The Journal of Thoracic and Cardiovascular Surgery* 2000 Aug,**120**(2), 264-269.

- (59) Bernstein M, Potvin D, Martin DK. A qualitative study of attitudes toward error in patients facing brain tumour surgery. *The Canadian Journal of Neurological Sciences* 2004,**31**(2), 208-212.
- (60) Wright EB, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *BMJ* 2004 Apr 10,**328**(7444), 864.
- (61) Oliffe J, Thorne S. Men, masculinities, and prostate cancer: Australian and Canadian patient perspectives of communication with male physicians. *Qualitative Health Research* 2007,**17**(2), 149-161.
- (62) Friedrichsen M, Milberg A. Concerns about losing control when breaking bad news to terminally ill patients with cancer: physicians' perspective. *Journal of Palliative Medicine* 2006,**9**(3), 673-682.
- (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.
- (65) Davey HM, Butow PN. Qualitative study of how women define and use information about breast symptoms and diagnostic tests. *The Breast* 2006,**15**(5), 659-665.
- (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.
- (67) Liang W, Kasman D, Wang JH, Yuan EH, Mandelblatt JS. Communication between older women and physicians: preliminary implications for satisfaction and intention to have mammography. *Patient Education and Counseling* 2006 Dec,**64**(1-3), 387-392.
- (68) Kirschning S, Von Kardoff E. The use of the Internet by women with breast cancer and men with prostate cancer--results of online research. *Journal of Public Health* 2008,**16**(2), 133-143.
- (69) Eggly S, Penner LA, Greene M, Harper FW, Ruckdeschel JC, Albrecht TL. Information seeking during "bad news" oncology interactions: Question asking by patients and their companions. *Social Science and Medicine* 2006 Dec,**63**(11), 2974-2985.
- (70) Charles C, Gafny A, Whelan T. Self-reported use of shared decision making among breast cancer specialists and perceived barriers and facilitators to implementing this approach. *Health Expectations* 2004,**7**, 338-348.
- (71) Shepherd HL, Tattersall MH, Butow PN. Physician-identified factors affecting patient participation in reaching treatment decisions. *Journal of Clinical Oncology* 2008,**26**(10), 1724-1731.

- (72) Katapodi MC, Facione NC, Humphreys JC, Dodd MJ. Perceived breast cancer risk: heuristic reasoning and search for a dominance structure. *Social Science & Medicine* 2005,**60**(2), 421-432.
- (73) Freedman TG. Prescriptions for health providers: from cancer patients. *Cancer Nursing* 2003,**26**(4), 323-330.
- (74) Reid CM, Gooberman-Hill R, Hanks GW. Opioid analgesics for cancer pain: symptom control for the living or comfort for the dying? A qualitative study to investigate the factors influencing the decision to accept morphine for pain caused by cancer. *Annals of Oncology* 2008 Jan,**19**(1), 44-48.
- (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.
- (76) Goldman RE, Risica PM. Perceptions of breast and cervical cancer risk and screening among Dominicans and Puerto Ricans in Rhode Island. *Ethnicity and Disease* 2004,**14**(1), 32-42.
- (77) Ling BS, Klein WM, Dang Q. Relationship of communication and information measures to colorectal cancer screening utilization: results from HINTS. *Journal of Health Communication* 2006,**11 Suppl 1**, 181-190.
- (78) Lacey MD. The experience of using decisional support aids by patients with breast cancer. *Oncology Nursing Forum* 2002 Nov,**29**(10), 1491-1497.
- (79) Daugherty C, Ratain MJ, Grochowski E, et al. Perceptions of cancer patients and their physicians involved in phase I trials. *Journal of Clinical Oncology* 1995,**13**(5), 1062-1072.
- (80) Thom DH. Physician behaviors that predict patient trust. *Journal of Family Practice* 2001,**50**(4), 323-328.
- (81) American heritage dictionary of the English language. 4 ed. Boston, Houghton Mifflin Company, 2000.
- (82) Kao AC, Green DC, Zaslavsky AM, Koplan JP, Cleary PD. The relationship between method of physician payment and patient trust. *Journal of the American Medical Association* 1998,**280**(19), 1708-1714.
- (83) Salmon P, Holcombe C, Clark L, Krespi R, Fisher J, Hill J. Relationships with clinical staff after a diagnosis of breast cancer are associated with patients' experience of care and abuse in childhood. *Journal of Psychosomatic Research* 2007,**63**(3), 255-262.
- (84) Goold SD. Trust, distrust and trustworthiness. *Journal of General Internal Medicine* 2002,**17**(1), 79-81.
- (85) Franssen SJ, Lagarde SM, van Werven JR, et al. Psychological factors and preferences for communicating prognosis in esophageal cancer patients. *Psycho-oncology* 2009,**18**, 1199-1207.

- (86) Maly RC, Stein JA, Umezawa Y, Leake B, Anglin MD. Racial/ethnic differences in breast cancer outcomes among older patients: effects of physician communication and patient empowerment. *Health Psychology* 2008,**27**(6), 728-736.

Table 1
Characteristics and results of included qualitative studies

First author, year, country	Aims of the study	Sample	Design and method	Role of trust	Findings regarding trust
1. Anvik, 2006, Norway	To describe the role of the GP during initial follow-up of patients with recently treated cancer	23 GP's, 91 cancer patients (heterogeneous) and their relatives	Cross-sectional; focus group, semi-structured face-to-face interviews and questionnaires	Deduced as outcome from data	Patients stated they trusted their GP's ability to take good care of them
2. Bernstein, 2004, Canada	To examine the perceptions and attitudes of patients undergoing neurosurgery regarding medical error	30 brain tumour patients within one week of undergoing a neurosurgical operation	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	Patients spontaneously mentioned trust in their surgeon as the most important factor mitigating fears of medical error
3. Bulsara, 2005, Australia	To investigate cancer patients' perceptions of the role of the general practitioner, particularly outside of the hospital setting	13 haematological cancer patients	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	Patients valued the long-term close relationship with their GP to promote trust
4. Butow, 2002, Australia	To obtain patient and health professional views on optimal ways of presenting prognosis to patients with metastatic breast cancer	13 health professionals in breast cancer care (both medical and non-medical), 17 breast cancer patients	Cross-sectional; structured face-to-face interviews	Deduced as outcome from data	Patients and professionals mentioned that prognosis was best communicated within a trusting relationship
5. Coyne, 2004, US	To gain a better understanding of low-income, rural cancer patients' attitudes, knowledge and beliefs regarding clinical trial participation	17 cancer patients (heterogeneous) living in a rural area	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	Patients' trust in their physician was generally high. Some patients relied solely on the oncologist's recommendations concerning treatment decisions
6. Davey, 2005, Australia	To systematically compare cancer patients' views on prognostic information provided by their doctor and written prognostic information obtained from a major cancer organisation	26 cancer patients (heterogeneous)	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	The amount of trust cancer patients had in their oncologist determined whether or not they would discuss independent information with him or her
7. Davey, 2006, Australia	To investigate how women explore and use information in the context of having diagnostic tests to investigate a breast symptom	14 women who had had a current breast symptom	Cross-sectional; unstructured telephone interviews	Deduced as outcome from data	Women expressed greater trust and confidence in healthcare professionals who provided information and answered questions

8. Freedman, 2003, US	To investigate medical encounters between women and their oncologic physicians throughout the breast cancer diagnostic and treatment process	12 physicians in oncology care and 25 female breast cancer patients	Cross-sectional; observations and semi-structured face-to-face interviews	Deduced as outcome from data	Patients who trusted their physician indicated to be more willing to adhere to and accept the physician's advice
9. Friedrichsen, 2006, Sweden	To study and explore problems perceived by physicians when breaking bad news to advanced cancer patients about discontinuing or not offering treatment	30 physicians in oncology care	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	Oncologists described that a lack of specific knowledge, e.g. of ongoing or published studies, resulted in being considered less trustworthy by patients
10. Geller, 1997, US	To learn what women would want to know, and how they would make a decision, if they were offered breast cancer susceptibility testing	80 females (random sample) from a range of ethnic and socioeconomic backgrounds	Cross-sectional; focus groups	Deduced as outcome from data	Women indicated that a trusting relationship with a physician facilitated their decision making about cancer susceptibility testing
11. Goldman, 2004, US	To explore the perceptions around breast and cervical cancer risk and screening among Dominicans and Puerto Ricans living in Rhode Island	147 adults (74 Dominicans, 73 Puerto Ricans)	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	A lack of trust was often mentioned as a barrier to getting screened
12. Henman, 2002, Australia	To examine why women with cancer want information, and what they believe to be the important factors influencing their decision making	20 female breast cancer patients	Cross-sectional; semi-structured telephone interviews	Deduced as outcome from data	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
13. Katapodi, 2005, US	To identify heuristics that influence perceived breast cancer risk	11 females who had had experiences with abnormal breast symptoms	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	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
14. Knifed, 2008, Canada	To explore the level of knowledge and anxiety in patients regarding the involvement of residents in their surgery	30 neurosurgery patients, most of whom underwent craniotomy for tumour	Cross-sectional; semi-structured face-to-face interviews	Deduced as outcome from data	Patients reported high trust in their surgeon, which removed most worries and anxiety about the involvement of residents during surgery

15. Lacey, 2002, US	To explore the lived experience of patients with breast cancer using decisional support aids during the prediagnosis, diagnosis, and treatment phases of their disease	12 female breast-cancer patients	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	Patients nominated their physician as an important decisional support throughout the treatment. Trusting their physician made seeking a second opinion unnecessary
16. Lasser, 2008, US	To describe barriers to and facilitators of colorectal cancer screening among diverse patients served by community health centers	10 primary care physicians, 23 patients eligible for colorectal cancer screening	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	Unscreened patients mentioned lack of trust in doctors as a barrier to screening whereas few physicians identified this barrier
17. Madsen, 2007, Denmark	To gain an understanding of the meanings assigned to patients' lived experiences during their treatment courses within or outside a trial setting	14 breast cancer and advanced ovarian cancer patients who participated in a clinical trial involving chemotherapy, and 15 who declined	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	Patients rated a trusting patient-physician relationship as very important for the decision to participate in a clinical trial. Trust decreased when women saw too many different physicians during the trials
18. McKneally, 2000, Canada	To describe the process of decision making and consent to surgical treatment from the patients' perspective, in the context of life-threatening illness	36 esophageal patients, recovered from esophagectomy	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	Repeated referral to their attending specialist would enhance patients' trust
19. Mechanic, 2000, US	To examine conceptions of trust among three groups of respondents diagnosed with either breast cancer, Lyme disease or mental illness	90 patients, of whom 30 with breast cancer, 30 with chronic Lyme disease, and 30 with mental illness	Cross-sectional; semi-structured face-to-face interviews	Trust included in design as main parameter; 2 questions about trust: 'What does trust mean to you?' and 'How do you decide that a person can be trusted?'	Physicians' interpersonal competence and honesty were identified as crucial aspects of trust by patients
20. Oliffe, 2007, Canada	To investigate what might be considered prostate cancer communication competencies in the male patient-physician dyad	59 male prostate cancer patients	Cross-sectional; secondary analysis of semi-structured face-to-face interviews	Deducted as outcome from data	Trust was built over time and led to feelings of mutual respect, which decreased feelings of awkwardness and vulnerability. Patients trusted their GPs to conduct all necessary examinations

21. Pollock, 2008, UK	To investigate service users' experiences of a patient information pathway after a diagnosis of cancer	27 cancer patients (15 lung cancer, 12 head and neck cancer) and 20 of their relatives	Longitudinal; semi-structured face-to-face interviews (1, 2, or 3 interviews per patient)	Deducted as outcome from data	Patients trusted their physician's professional expertise concerning treatment decisions. This trust allowed them to delegate responsibility for treatment and freed up time and energy
22. Reid, 2008, UK	To explore the factors influencing the decision to accept or reject morphine when first offered to patients with cancer	18 cancer patients (heterogeneous)	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	Trust was mentioned by patients as an important factor in their decision to accept opioids as medication for cancer pain
23. Sharf, 2005, US	To explore why patients refused recommendations for further diagnosis or treatment of lung cancer	9 lung cancer patients with documented refusal of doctors' recommendations	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	In all interviews patients expressed distrust in medical authority, such as motives of doctors or health information provided by doctors, as explanations for refusal
24. Torke, 2004, US	To describe the perspectives of older African American patients in a primary care clinic as they consider a medical decision	25 African American patients > 50 years old, who had discussed flexible sigmoidoscopy with their primary care provider	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	Patients indicated that trust was built by a health care provider's honesty, patience, kindness, interest, and continuity of care
25. Wright, 2004, UK	To determine how patients with breast cancer want their doctors to communicate with them	39 female breast-cancer patients	Cross-sectional; semi-structured face-to-face interviews	Deducted as outcome from data	Patients appreciated oncologists' display of efficiency, technical skills, reputation and honesty for building trust

Table 2
Characteristics and results of included quantitative studies

First author, year, country	Aims of the study	Sample	Design and method	Role of trust	Measurement of trust	Findings regarding trust
1. Charles, 2004, Canada	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	334 oncologists and surgeons in Ontario treating female early-stage breast cancer patients	Descriptive; cross-sectional; survey; structured questionnaire	Trust as secondary parameter	1 four-point Likert question	98% of oncologists and 99.5% of surgeons rated patient trust in the physician as a facilitator of treatment decision making with patients
2. Daugherty, 1995, US	To investigate the complex issues around participation in clinical trials, and patients' perceptions toward these trials	27 cancer patients who had agreed to participate in a phase I clinical trial.	Descriptive; cross-sectional; survey; structured questionnaire	Trust as secondary parameter	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	11% of all patients participated in the clinical trial because of trust in or advice from the physician. For 70%, resp. 63% of patients, trust in the referring physician or research oncologist was a major motivating factor to participate
3. Eggly, 2006, US	To investigate questions asked by cancer patients and their companions during stressful encounters in the oncology setting in the USA	28 cancer patients (heterogeneous) and their companions	Descriptive; cross-sectional; coding of video-recordings of oncology consultations	Trust as secondary parameter	1 seven-point Likert question	Companion trust in the physician correlated positively with the number of questions asked by companions ($r(24)=0.41$, $p<0.05$) and length of the interaction ($r(24)=0.51$, $p<0.01$). Trusting companions asked more questions relative to patients ($r(24)=0.44$, $p<0.05$)
4. Gordon, 2006, US	To examine whether racial differences in patient trust are associated with physician-patient communication about lung cancer treatment	103 patients (22% black, 78% white) visiting thoracic or oncology clinics	Descriptive; cross-sectional; survey; structured questionnaire	Pre- and post-visit trust as primary parameters	5 10-point Likert questions adopted verbatim or modified from previously published trust scales	Pre-visit trust in physician was statistically similar in black and white patients (mean score, 8.2 v 8.3, resp.; $p=0.80$), but black patients had lower post-visit trust in physician than white patients (8.0 v 9.3, resp.; $p=0.02$)
5. Helmes, 2002, VS	To investigate women's preferred physician involvement in the decision to obtain genetic testing for breast cancer risk	340 women (population based sample), between 18-64 years old, not ill.	Descriptive; cross-sectional; survey; structured telephone survey and written baseline questionnaire	Trust towards / satisfaction with primary care provider as secondary parameter	5 four-point Likert questions, constituting a subscale of an earlier developed scale (unpublished)	Trust in physician together with the believe in powerful others correlated with the decision to leave medical decisions to the provider ($\beta = 0.318$; $p<0.001$)

6. Heyland, 2005, Canada	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	440 patients with end-stage disease, 166 of which diagnosed with cancer and 160 of their family members	Observational; cross-sectional; survey; structured questionnaire	Trust as secondary parameter	1 five-point Likert item ('To in the doctors looking after you'), to be answered for satisfaction and importance	One of the aspects patients were least satisfied about was trust. The item about trust was one of the items rated most frequently by patients as 'extremely important' and not 'completely satisfied'
7. Jenkins, 2000, UK	To examine reasons for patients to accept or decline participation in cancer clinical trials	204 cancer patients (heterogeneous)	Descriptive; cross-sectional; survey; structured questionnaire	Trust as secondary parameter	1 item: 'I trusted the doctor treating me' (response options: 'yes' and 'no')	Almost all patients (97.3% of patients accepting, and 94.1% of patients denying trial entry) trusted their physician. Of all patients accepting trial entry, 21% declared doing so because they trusted the doctor treating them
8. Kirschning, 2008, Germany	To find out how far the traditional doctor-patient relationship is affected and changed by the Internet-informed patient	536 cancer patients (370 women with breast cancer, 193 men with prostate cancer) and 133 of their relatives	Descriptive; cross-sectional; online survey; structured questionnaire	Trust deduced as outcome from the data	Trust not measured	For men with prostate cancer, the second most important reason not to discuss information from the Internet with their physician was that they trusted their doctor (most important was lack of time)
9. Kraetschmer, 2004, Canada	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	606 breast cancer, prostate cancer and fracture patients	Observational; cross-sectional; survey; structured questionnaire	Trust as primary parameter	11 items on a 5-point Likert scale, constituting the 'Trust in Physician Scale' (Anderson & Dedrick, 1990)	Trust and preferred role were associated ($p < 0.0001$). Patients with low trust (9%) preferred an autonomous role in the decision making process. Patients with 'blind trust' (6,3%), favoured a passive role. Moderately (48,6%) and high (36,1%) trusting patients preferred shared decision making
10. Lansdown, 2008, UK	To examine, via an international survey, the impact of positive and negative interactions on the patient-physician relationship	462 breast-cancer physicians, 600 female postmenopausal breast-cancer patients	Observational; cross-sectional; online international survey	Trust as secondary parameter	1 five-point Likert question about trust for physicians, 3 five-point Likert questions about trust for patients	88% of physicians believed that patients trusted them. Of all patients, 83% were found to trust their physician's treatment plan. Many (81%) rated trust in their physician a vital element of their care
11. Liang, 2006, US	To explore the associations between physician communication styles and their older patients' intentions to get mammography and satisfaction with physician communication	7 general internists and 56 of their patients > 65 years	Mixed methods; observational; qualitative analysis of audiotaped conversations between patient and physician, quantitative analysis of survey	Trust as secondary parameter	1 item: 'Did you consider the visit with their physician as trusting?' (response options: 'yes' and 'no')	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, $p<0.001$)
13. Mainous III, 2004, US	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.)
15. O'Malley, 2004, US	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

18. Shepherd, 2008, Australia	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	604 physicians in oncology	Observational; cross-sectional; survey; structured questionnaire	Trust as secondary parameter	1 four-point Likert question: 'The patient trusts me' (response options: never, sometimes, often or always helpful to the treatment decision making process)	Having a trusting patient was considered 'always' or 'often' helpful to reaching a treatment decision by 88.2% of the respondents
19. Spain, 2008, US	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	555 newly diagnosed male prostate cancer patients, 348 Caucasian and 207 African American	Observational; cross-sectional; survey; structured questionnaire	Trust as secondary parameter	8 five-point Likert items, adopted from the 'Primary Care Assessment Survey' (Safran <i>et al.</i> , 1998)	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, $p < 0.05$), indicating that the racial differences in seeking prostate care may be mediated through physician trust
20. Waljee, 2008, US	To examine the effect of treatment-related factors on patient satisfaction with their healthcare experiences	714 breast-conserving therapy patients	Observational; cross-sectional; survey; structured questionnaire	Trust as secondary parameter	11 five-point Likert items, constituting the 'Trust in Physicians Scale' (Hall <i>et al.</i> , 2001)	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 ($p = 0.03$)