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Title - Matters of Trust: A Comparison of Patient-Provider Trust in Colorectal Cancer Survivors Using the Trust in Oncologist Scale

Short Title - Matters of Trust: Patient-Provider Trust in CRC Survivors Using the TiOS

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Abstract

Objective: Trust is a vital component of the patient-provider relationship. Higher trust is associated with increased adherence to treatment and improved outcomes. The purpose of this study was to compare colorectal cancer (CRC) survivors' reported trust toward their primary care physician (PCP) and oncologist (ONC).

Methods: CRC survivors (n=62) were surveyed using the Trust in Oncologist (TiOS) instrument that assessed five domains (honesty, fidelity, caring, competence, and global/overall) using a 5-point Likert scale. Social and demographic variables were analyzed using nonparametric tests.

Results: Mean trust was higher toward the ONC compared to the PCP across all TiOS domains ($P=0.001-0.023$). Trust was lowest in the competence and caring domains for both ONC and PCP. Younger age was associated with lower trust compared to older age ($P=.0002$, $P=0.018$). Higher cancer stage was associated with significantly lower trust toward PCP ($P=0.074$).

Conclusion: Results confirm the importance of trust between cancer patients and physicians. Although CRC survivors report high overall trust toward their oncologist, they do not always believe their oncologist is competent to treat their disease. We propose the novel concept of Forced Attachment Theory to explain the phenomenon of an obligated sense of attachment from CRC patients toward their treating physicians.

Background

Colorectal cancer is the third leading cause of cancer-related deaths in men and in women, and the second leading cause of cancer deaths when men and women are combined (1). The American Cancer Society has estimated 104,270 new cases of colon cancer and 45,230 new cases of rectal cancer for 2021. Nebraska maintains a largely rural population, with the latest data from the Nebraska Cancer Registry reporting 4,527 residents diagnosed between 2011 and 2015, resulting in 1,692 deaths (2). Both rural and urban cancer populations face barriers in screening and access to care (3,4).

Patient trust in a physician has been defined as 'the belief that a doctor is working in the patients' best interests' (5) as well as the optimistic acceptance of the vulnerable situation in which patients believe that the physician cares for their interests (6). Although trust can be interchanged with confidence, trust can often involve higher emotions and is therefore less rational (7). Several degrees of trust and distrust occur within interpersonal relationships. The concept of distrust is the expectation of negative or harmful behaviors and is unique from low trust, which entails the absence of beneficial action. Considering the variations and degrees of trust, it is possible for patients to simultaneously hold a certain amount of trust and a certain amount of distrust toward a physician (8).

Previous research suggests that higher patient trust is associated with adherence to care plans, desirable treatment outcomes, increased patient satisfaction, and an increase in clinical trial participation (7,9-11). However, the complex dynamics affecting patient trust between colorectal cancer patients and their primary care physicians and oncologists have not previously been studied. There is a need to examine trust in the patient-provider relationship to provide a higher quality of care to cancer patients.

Previous studies have identified trends between levels of trust and a variety of variables. Specific populations have been identified to have abnormally higher or lower levels of provider trust. Compared with Non-Hispanic White patients, Non-Hispanic Black and Hispanic patients report a lower degree of trust with their healthcare providers (12-14). In studies assessing trust in prostate cancer patients, Non-Hispanic Black patients were found to have greater variability in self-reported levels of patient-provider trust when compared to Non-Hispanic White patients (15).

Distrust (the opposite of trust) has been found to have a negative and pervasive impact on health-seeking behavior (16). Distrust of the healthcare system has been found to be significantly correlated with age in breast cancer patients (16,17). Other studies have found that marital status has a measurable effect among Non-Hispanic White men, with mistrust greater in those that were married. Levels of low trust have also been found to be related to fewer quality interactions with providers (12).

There are discrepancies between earlier studies regarding gender and trust, with both positive and neutral relationships reported (18). Two studies of patients with rheumatic disease found female gender to be related with higher levels of trust (13,19). Older age has been associated with higher trust in five studies (20-23). Lower education was found to be correlated with higher trust (21,23).

Patients diagnosed with colorectal cancer often rely on a wide range of social support provided by family, friends, primary care providers, and oncology specialists (24). Colorectal cancer patients depend on their oncologist as a primary source of information but rely on family physicians to fill in gaps in understanding and provide additional support (24). Rural patients with high levels of trust in their physicians occasionally rely entirely on the recommendations made by their primary care physician concerning their treatment decisions as opposed to their other treating physicians (25). Previous studies have suggested a research gap due to potential differences in the levels of trust felt by patients for their primary care physicians versus their oncologists (8).

Considering this gap in patient trust toward primary care providers compared to their oncologist, we theorize that cancer patients may report varying levels of trust due to the unique nature of these relationships. Identifying properties and factors of trust for colorectal cancer patients is essential considering the severity of the disease and the associated dependence that is required from the patient to adhere to care guidance (8,26). Further research is warranted due to the life-threatening nature of this disease and combined essential need for trust from the patient toward the physician (8).

Based on the findings from current literature, there is a need for further research to examine levels of trust in colorectal cancer survivors. Previous research suggests that oncologists play a different role within the patient care relationship than primary care physicians, indicating the need to examine possible differences in patient-provider trust. This study is novel in that patient-reported levels of trust have not been assessed in this population to our knowledge, nor have levels of trust been compared between different types of providers. We hypothesize that there will be observable differences between measurable survey values in patient-provider trust between primary care physicians and oncologists as well as differences associated with demographic variables.

Methods

Data Source

This study utilized information that was available from an existing patient database maintained by the University of Nebraska Medical Center (UNMC). Participants (age 19+, n=62) were previously recruited into the iCaRe² database registry (IRB 253-13 EP) with a confirmed primary colon, rectal, or colorectal diagnosis in the state of Nebraska within the last ten years. Participants were characterized by rural or urban status based on their FIPS code of primary residence using the CDC Urban-Rural Classification Scheme by County published in 2013. For consistency, each patient was provided with two copies of the TiOS; 1) to be completed about their primary care physician, 2) to be completed about their oncologist.

The iCaRe² biorepository was developed and is governed by UNMC to maintain and track cancer patients, patients who are at a high risk of developing cancer, and healthy control individuals. The registry contains patient demographics such as age, gender, and place of residence, as well as medical data and socioeconomic characteristics, including education and income. The registry collects two baseline disease-specific questionnaires at the time of diagnosis to procure additional patient information.

Study Design

This is a cross-sectional, observational study utilizing survey data to examine levels of patient trust.

Study Population and Sampling

All participants with a confirmed primary diagnosis of colon or rectal cancer were eligible for this study. This included males and females of all races and ethnicities (aged 19+) with a primary colon or rectal diagnosis of any stage. No limitations were set regarding dates of diagnosis or medical history. Factors that could complicate the recruitment process included physician communication skills, number of comorbidities, having been in remission, number of visits to the physician in the last 12 months, recent metastasis, and age at diagnosis. These factors have been theorized as variables that may alter how patients feel about their physicians, and therefore their willingness to participate. Participants were emailed a copy of the TiOS questionnaire if a current email address was listed in the medical records.

For patients without listed email addresses, a paper version of the TiOS questionnaire was mailed to their residence or provided during a clinic visit. All eligible participants (n = 173) were invited to participate in this study (*Figure 1*). This study was approved by the University of Nebraska Medical Center Institutional Review Board (IRB Ref no: 010-18-EP) and written informed consent was obtained for all study participants.

Materials

Extensive demographic information had been previously recorded in the registry prior to the start of this study. The first iCaRe² core questionnaire contains socio-demographic factors (age, gender, race, ethnicity, chemical exposure, lifestyle factors), while the second extended module questionnaire collects disease-specific factors (symptoms, medical history, family medical history, validated quality of life survey - SF-36). Clinical data, such as primary cancer site, tumor histology, stage, dates of diagnosis, and dates of treatment, are collected by iCaRe² personnel from the medical records and logged into the database.

Numerous survey instruments have been developed to assess and explore the complex patient-provider relationship and the role that trust plays. The Trust in Physician Scale (27) was developed to measure patient trust in the primary care provider and predates the TiOS. The Patient Trust Scale (28) was constructed to incorporate changes in the healthcare system, specifically the transition to managed care (29). A recently developed instrument, the Physician Trust Scale (7), is currently the highest utilized instrument for measuring trust. All three of these instruments were developed in the primary care setting and measure reported levels of patient trust toward the primary care physician.

In contrast, the Trust in Oncologist Scale (TiOS) was created to assess cancer patient satisfaction and trust in health care (30). The instrument utilizes the four main domains from the previously validated 10-item Trust in Physician Scale (7) of "competence, fidelity, confidentiality, and honesty." During the development of the TiOS, an additional domain of "caring" was added based on patients' accounts of trust obtained from qualitative research (30). This additional domain is important because the existing dimensions did not fully capture patients' constructions of trust, nor did these domains capture the oncologist's expression of involvement, sympathy, and attention to the patient. Using the TiOS, an overall trust score can be obtained by averaging the responses, with higher scores indicating higher trust. Previous studies have found that patients are able to distinguish between the different aspects of trust (domains), allowing investigation within and between individual core trust domains (30).

The TiOS was validated in two studies (first in Dutch and then in English) using confirmatory factor analysis, exploratory factor analysis, measurement of internal consistencies, and calculation of Spearman's correlations between the instrument and known correlates. These correlates were satisfaction, trust in health care, and the number of previous consultations with the oncologist.

The TiOS employs 18 items to measure a cancer patient's trust in their oncologist along five domains: global, competence, fidelity, honesty, and caring. Internal consistency was assessed with a Cronbach's alpha of .94 (30). All 18 items of the scale consisted of questions using a 5-point Likert answering scale ('strongly disagree' (1) to 'strongly agree' (5) (30). For example, "Your doctor is very careful and precise" is a question item measuring the competence domain. Mean trust (range 1-5) is calculated by averaging the responses. Three items are phrased in a negative context to provide reverse-coded questions. In addition to the 18-items on the TiOS survey, an open-ended answer box was included on the survey for this study. Adding this qualitative measurement allowed patients the opportunity to express concerns not measured by the survey and provide additional information for analysis. *Table A (Supplemental)* shows an overview of all items and dimensions of the TiOS, including the breakdown of dimensions into the five primary domains.

Statistical Methods

Central tendency distributions and frequencies were used to examine the study population prior to analysis. Mean scores were analyzed from both the oncologist and PCP survey results. Internal reliability was assessed prior to statistical analysis and found to be strong with a Cronbach's alpha of 0.942 for the oncology instrument and 0.965 for the PCP instrument.

Descriptive statistics for categorical variables included frequencies and percentages. For continuous variables, descriptive statistics included the mean, quartiles, and minimum/maximum. The relationship of five demographic and background variables with the difference in each subscale score were examined. Nonparametric and ANOVA tests were used to examine differences in subscales for the variables age, gender, primary cancer type (colon/rectal), history

of secondary cancer (yes/no), and cancer stage (0, I, II, III, IV). Mean differences in each subscale (global, competence, honesty, fidelity, and caring) were calculated to compare differences in average trust scores between the oncologist and PCP survey instruments. SPSS version 26 and PC SAS version 9.4 were used for the analysis. The statistical level of significance was set to 0.05 for all analyses.

Results

Demographics (*Table 1*) for the study population were 87% Non-Hispanic White with 43% of the population aged 19-64 ($n=27$) and 57% of the population over the age of 65 ($n=36$). The majority of study participants were female ($n=35$), and 75% with a history of colon cancer ($n=48$) versus 24% with a history of rectal cancer ($n=15$). Interestingly, 37% of study participants ($n=24$) were also diagnosed with a second primary cancer other than colon or rectal. Study participants ranged in cancer stage from 0-IV and were stratified into three categories for this study 1) stages 0, I, II represented 43% of the total population ($n=27$), 2) stage III represented 32% of the total population ($n=21$), and 3) stage IV accounted for 24% of the study population ($n=15$). The mean length of time from date of CRC diagnosis to study participation was 2086 days (Range = 468-5658 days).

Patient-reported scores are shown in *Table 2* for the ONC and PCP survey instruments. Mean trust scores were consistently reported higher toward the oncologist than toward the primary care provider, and found to have a statistically significant difference. The global domain displayed the highest mean difference ($Md=0.298$, $P=0.001$) and suggests that CRC survivors feel stronger overall levels of trust toward their oncologist over their PCP. The second highest mean difference was found in the competence domain ($Md=0.238$, $P=0.007$), suggesting that CRC survivors may feel that their oncologist is more competent in their medical practice skills than their PCP.

Additional analyses using the overall global domain were conducted to determine if demographic variables of age, gender, primary cancer site, the presence of a secondary cancer, stage, or geographic area were associated with higher or lower levels of self-reported trust (*Table 3*). CRC survivors stratified into the higher age group of ≥ 65 reported higher levels of trust toward both their oncologist and PCP ($M=4.857$; $M=4.571$) when compared to CRC survivors stratified into the lower age group of ≤ 64 ($M=4.389$, $P=0.002$; $M=4.074$, $P=0.018$). Survivors were stratified into staging subgroups to determine if an earlier or later stage diagnosis was associated with levels of trust. CRC survivors with stage 0-II disease reported higher levels of trust toward both their oncologist and PCP ($M=4.704$; $M=4.574$), with self-reported trust scores decreasing as the survivor's cancer stage increased. Trust scores between these staging subgroups were found to be statistically significant, with trust being consistently reported higher toward the oncologist than the PCP.

Further extrapolation (*Table B Supplemental*) of all domains across the variables of interest found several domains associated with significant impact on self-reported trust. Confirming previously suggested results, the global domain of overall trust was associated with higher trust in survivors toward their oncologist under the age of 64 (ONC $M=4.388$, $P=0.001$), while survivors over the age of 65 ($M=4.388$, $P=0.001$) reported higher trust toward their PCP. Female CRC survivors reported higher scores in the honesty ($M=4.764$, $P=0.002$) and fidelity ($M=4.723$, $P=0.014$) domains toward their oncologist when compared to male CRC survivors. Survivors with colon cancer reported higher trust in the competence domain toward their PCP than rectal cancer survivors ($M=4.196$, $P=0.084$).

The presence of a secondary cancer diagnosis was associated with two separate domains of trust. Survivors with a secondary cancer reported lower levels of trust toward their oncologist in the honesty domain than survivors without a secondary cancer diagnosis ($M=4.478$, $P=0.062$). Survivors diagnosed with a secondary cancer also reported lower levels of trust in the fidelity domain toward their PCP than survivors without a second primary cancer diagnosis ($M=4.260$, $P=0.06$). Consistent with previous results, the association between a higher cancer stage and lower levels of trust was found in the global domain toward the oncologist ($M=4.703$, 4.650 , 4.566 , $P=0.009$).

Discussion

When comparing self-reported trust from CRC survivors toward their oncologist versus their primary care provider, we found that scores were consistently higher toward the oncologist across all domains of the Trust in Oncologist Scale. The global domain represents "the irreducible soul of trust, and includes aspects that combine elements from some or all of the separate dimensions" (8). The reported mean difference in trust in the global domain ($P=0.001$) suggests that cancer patients feel a deeper trust in their oncologist that includes a combination of aspects from the fidelity, honesty, caring, and competence domains.

The significant decrease in reported trust for the competence domain is an important result of this study ($P=0.007$). This suggests that CRC survivors do not feel confident in the medical and interpersonal skills of their PCP. Previous studies have found that competence is part of the necessary foundation of trust in the patient-provider relationship (8). The NCCN Guidelines for Survivorship provide recommendations for developing Survivorship Care Plans (SCPs) for cancer survivors that integrate care across care-disciplines (31). Primary Care Providers serve a key role in the multidisciplinary application of SCPs with the goal of facilitating care coordination and improving health outcomes of survivors. These results advocate for improved communication between PCPs and their patients to increase trust within these relationships.

The stratification of cancer stage in this study provided an opportunity to explore how survivors in varying stages of disease progression related to their physicians. As CRC stage increased, levels of self-reported trust decreased toward both the oncologist and PCP. We theorize several possibilities for this outcome. First, earlier studies have explored the theory of attachment as a model that attempts to describe the dynamics of interpersonal relationships between people. This model specifically focuses on the strong emotional and physical attachment that is formed between a patient and caregiver (or, in this circumstance, a physician caring for a patient). Insecurely attached patients trust their physicians less and are associated with a decreased satisfaction in their physician than patients who were securely attached (32). We theorize that CRC survivors may feel an obligated sense of attachment toward their treating physician during their cancer journey of diagnosis and treatment. We introduce *Forced Attachment Theory* as a novel theory to explain this phenomenon. This patient-physician attachment dynamic changes the longer that a patient receives care for ongoing cancer burden or progression of disease; resulting in a decrease in reported trust as cancer stage increases. Previous studies supporting this theory have proposed that the severity of cancer disease may play a role in how patients report trust (33).

Survivors diagnosed with late-stage (AJCC IV) and metastatic disease (AJCC IV) reported lower trust toward their oncologist and PCP, suggesting a possible correlation between length of treatment time and aggression of disease to a less trusting relationship between patient and physician. The average length of time for patients in this study from date of diagnosis to date of survey completion was 2086 days or 5.71 years. Although this study did not have a sufficient sample size to extrapolate data by length of survivorship, this preliminary data suggests a need for additional research to better understand this association.

Study Limitations

There were several limitations of this study, the first being the recruitment of a convenience sample that may not have fully represented the average population of CRC survivors in the state of Nebraska. The majority of study participants were Non-Hispanic White females with colon cancer. The minimal variation in demographic and social characteristics may reduce the generalizability of the results to other populations. A second limitation is that cancer survivors were only asked to self-report their feelings of trust toward their oncologist and not toward the rest of their oncology team. Third, the Trust in Oncologist instrument is relatively new when compared with older trust instruments; therefore, this research is limited in its comparability to other studies across a broader disease spectrum.

Clinical Implications

Results suggest that colorectal cancer patients are able to differentiate between multiple domains of trust, particularly in the competence of their oncologist (and corresponding larger physician team) to treat their disease. Multidisciplinary teams (MDT) in oncology are becoming standard in the treatment of colorectal cancer. Previous research has found that adequate MDT processes are associated with improved survival for patients with colorectal cancer (34). Future studies should explore the complex interpersonal relationships that form between these MDTs and patients, with a focus on how trust impacts these dynamics to better inform clinical practice.

Future research should seek to further understand the impact of trust in the patient-provider relationship as well as the various factors that influence trust. In this study, a small subgroup of survivors responded to the request for study participation with the sole purpose of declining due to a poor or lack of patient-provider relationship. For future discussion, the medical data for this subset of the population should be examined to draw possible inferences for this behavior and the consequences resulting from this negative relationship. Participant responses to the Trust in Oncologist Scale should be correlated with the length and quality of their provider relationship as these could significantly influence trust values. Additionally, there is a future opportunity to analyze qualitative data from similar cancer patient populations to gain a better understanding of trust perspectives.

Conclusion

The TiOS instrument has had minimal use on an international scale but has already proven to be a valuable addition to the collection of metrics available to examine trust. This study focused primarily on colon and rectal cancer; however, patients with other cancers (for example, breast, prostate, leukemia) may have differing levels of trust due to the unique aspects of their individual disease burden. Future research should build upon the foundation established here and continue to explore our theory of Forced Attachment in cancer patients. To our knowledge, the Trust in Oncologist Scale has never been utilized in the United States or within a CRC population that is primarily in the post-treatment and long-term phase of their survivorship journey. The results from this study should inform physicians and provider care teams on the importance of interpersonal skills and building quality relationships founded on trust with their patients.

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Conflicts of Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethics Statement

The protocol for this study was approved by the University of Nebraska Medical Center Institutional Review Board (IRB Ref no: 010-18-EP).

Data Availability Statement

The data (in de-identified format) that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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