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Matters of Trust: Examination of the Patient-Provider Relationship in Cancer Care

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Project Title: Matters of Trust: Examination of the Patient-Provider Relationship in Cancer Care

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Abstract

Background: The intangible concept of trust is critical in the patient-provider relationship. Cancer patients may experience positive and negative impacts of trust in this relationship to a higher degree due to the inherently serious nature of their disease and the level of dependence upon treatment providers.

Objective: The goal of this study was to compare colorectal cancer patients' levels of trust in their primary care physician and oncologist, along with examining trust differences associated with demographics and other characteristics.

*Methods: C*olorectal cancer patients (n=158) treated at Nebraska Medicine and consented into the Integrated Cancer Repository for Cancer Research IRB 253-13-EP (iCaRe^2) database were surveyed. The TiOS instrument measures five domains of trust using a 5-point Likert scale. Possible rural and urban differences, as well as other data characteristic patterns, were examined using descriptive statistics, frequency analysis, and t-tests.

Results: There was a measurable difference observed between oncologist and primary care provider (PCP) trust levels for all domains (except Competence), with trust in the oncologist reported higher. The overall Global domain measured a higher level of patient trust in the oncologist (3.65) compared to the PCP (2.96) with a P-value of 0.003. Due to the small sample size, statistical tests were not conducted comparing mean trust between oncologist and PCP within the sociodemographic and geographic variables.

Conclusion: The higher levels of trust reported for four out of five domains suggest that cancer patients feel more trust toward their oncologist than toward their PCP. The difference in trust in the Global domain suggests that cancer patients feel a deeper trust in their oncologist that includes aspects of Fidelity, Honesty, and Caring. Future studies should seek to further understand the impact of trust in the patient-provider relationship as well as the factors that influence trust. The findings from this study contribute to the current knowledge of patient-provider trust in the cancer patient population and provide valuable information for future studies.

Introduction

Service Learning Organization Site: Nebraska Medicine, Fred and Pamela Buffett Cancer Center

The mission of the Fred and Pamela Buffett Cancer Center is to coordinate basic and clinical cancer research, provide patient care and educational programs, and facilitate the application of new knowledge about the etiology, diagnosis, treatment, and prevention of cancer while improving overall health and quality of life.

Problem Statement

Colorectal cancer is the third leading cause of cancer-related deaths in women and the second leading cause in men (American Cancer Society, 2018). The American Cancer Society has estimated 97,220 new cases of colon cancer and 43,030 new cases of rectal cancer for 2018. Nebraska maintains a large rural population with the latest data from the Nebraska Cancer Registry reporting 917 diagnoses of colon and rectal cancer for the entire state in 2014 (Nebraska Health and Human Services, 2017). Previous research suggests that patient trust is associated with adherence to care plans, desirable treatment outcomes, increased patient satisfaction, and an increase in clinical trial participation (Hall et al., 2002; Dugan et al., 2005; Trachtenberg et al., 2005; Nurgat et al., 2005). However, patient trust in primary care physicians and oncologists of the colorectal cancer rural population within Nebraska has not previously been studied in this way. The patient-provider trust relationship should be examined to provide a higher quality of care to cancer patients.

Importance of Proposed Project

Patient trust is an important concept within many areas of healthcare but is especially critical in the cancer patient population. This is believed to be due to the extreme vulnerability of these patients as well as the severity of their disease (Salkeld et al., 2004). Cancer patients are often required to place all their trust in their physicians due to the inability to provide adequate care for themselves. Trust in the patient-provider relationship is fragile due to the power inequity between the patient and the provider (Delmar, 2012). It is important to study this relationship because patients with higher trust are more likely to report a better quality of health and more effective treatment results (Hall et al., 2001). Both rural and urban cancer populations face barriers in screening and receiving care, with Nebraska consisting of a large rural population (Jones et al., 2010; Hughes et al., 2015). Colorectal cancer patients have several stages of surgery, treatment, and care after diagnosis and require attention from an oncologist on a regular basis. Colorectal patients may seek medical or surgical treatment for cancer-related symptoms from their local primary care provider prior to pursuing care with an oncologist.

Literature Review

Trust is the belief or confidence placed in another person and involves a prediction regarding his or her future behavior. Patients are often required to place all of their trust in their physician, a person with whom no close relationship exists, due to their inability to care for their own health (Mechanic et al., 2000). Patient's trust in their physicians has been defined as 'the belief that a doctor is working in the patient's' best interests' (McKinstry et al., 2006) as well as the optimistic acceptance of the vulnerable situation in which patients believe that the physician cares for their interests (Hall et al., 2001). Although trust can be interchanged with confidence, trust can often involve higher emotions and is therefore less rational (Hall et al., 2002). 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 a 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 (Hillen et al., 2011).

Cancer patients are exceptionally vulnerable due to the inherently life-threatening nature of their disease. The severity of the treatment, and frequent low survival rates, may force cancer patients to trust their physicians almost unconditionally (Salkeld et al., 2004). Some researchers have proposed that the level of trust that patients place in their physicians has a profound effect on care seeking and completion of preventative, diagnostic, treatment, and behavioral recommendations (Hall et al., 2001; Berry et al., 2008). In recent studies on patients with colorectal cancer (CRC), many have focused on outcomes, side effects, quality of life, and survival (Salkeld et al., 2004; Hillen et al., 2011). This suggests that trust plays a role in the interpersonal relationship between cancer patients and their providers.

Recent studies have been initiated to examine the factors relating to and the impact of trust within cancer patient populations. One of the theories applied was the attachment theory, 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. From an attachment theory perspective, levels of trust and distrust do not significantly change over time between three months and nine months after diagnosis (Holwerda et al., 2012). Insecurely attached patients trust their physicians less and are associated with a decreased satisfaction in their physician than patients who were securely attached (Holwerda et al., 2012).

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 (Halbert et al., 2006; Berrios-Rivera et al., 2006; Bova et al., 2012). In studies examining prostate cancer patients, Non-Hispanic Black were found to have greater variability in the levels of patient-provider trust when compared to Non-Hispanic White patients (Do et al., 2010).

Distrust (the opposite of trust) has been found to have a negative and pervasive impact on health seeking behavior (Katapodi et al., 2010). Distrust of the healthcare system has been found to be significantly correlated with age in breast cancer patients (Katapodi et al., 2010). Halbert et al., (2009) found that marital status had a measurable effect on trust levels 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 (Halbert et al., 2006).

There are discrepancies between several studies regarding gender and trust, with both positive and neutral relationships reported (Murray et al., 2014). Two studies of patients with rheumatic disease found female gender to be related with higher levels of trust (Freburger et al., 2003; Berrios-Rivera et al., 2006). Older age has been associated with higher trust in five studies (Weng et al., 2011; O'Mally et al., 2004; Cunningham et al., 2007; Kayaniyil et al., 2009) while lower education was also found to be correlated with higher trust (O'Mally et al., 2004; Kayaniyil et al., 2009).

Patients with colorectal cancer often rely on a wide range of social support provided by family, friends, primary care providers, and cancer specialists (Sahay et al., 2000). Colorectal cancer patients depend upon cancer specialists as their primary source of information but rely on family physicians to fill in gaps in understanding and provide additional support (Sahay et al., 2000). 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 (Coyne et al., 2004). Previous studies suggest that differences in the levels of trust felt by patients for their primary care physicians versus their oncologists may vary (Hillen et al., 2011).

In many qualitative studies, trust was not the initial subject of interest but instead an outcome deduced from the data (Hillen et al., 2010). In quantitative studies, trust was incorporated in the research design as one of many variables and as a result has received little conceptual attention (Hillen et al., 2010). Cancer patients may feel trust in a different way toward their oncologist than toward their primary care physician due to the unique nature of the relationship. Additional research attention is warranted because of the necessity of trust from the patient toward the physician due to the life threatening nature of their disease (Hillen et al., 2010). Identifying properties and factors of trust for colorectal cancer patients is important considering the severity of the disease and the associated dependence that is required from the patient (Hillen et al., 2010; Mechanic et al., 2000).

Goals and Objectives

Based on the findings from current literature, there is a need for further research to examine levels of trust in cancer patients in Nebraska. Previous studies suggest that oncologists play a different role in patient care than primary care physicians, indicating the need to examine possible differences in patient-provider trust. Variations in levels of trust between rural patients and urban patients have also been found in other states, indicating that the highly rural state of Nebraska may exhibit similar trends. We hypothesize that there will be observable differences between survey values in patient-provider trust between primary care physicians and oncologists as well as differences across geographic areas.

The first goal of this study was to measure levels of colorectal cancer patient trust toward both their primary care physician and their oncologist. The second goal of this study was to examine characteristics of this population and variables that may be associated with trust. These variables and sociodemographic characteristics may exert an influence on the patient-provider relationship.

Research Hypothesis

I. Examine the relationship of trust within the colorectal cancer patient population in Nebraska.
    A. Compare levels of trust that colorectal cancer patients feel toward their primary care providers

and oncologists.

B. Identify characteristics of this population of cancer patients by demographics and geographic area.
    1. Conduct survey of colorectal cancer patients consented into the iCaRe^2 database registry using the Trust in Oncologist (TiOS) survey instrument. Examine sociodemographic factors of the respondents.

Research Methods

Data Source

This study utilized information that was available from an existing UNMC patient database. Participants (age 19+, n=153) were previously recruited into the iCaRe^2 database registry (IRB 253-13 EP) with a confirmed primary colon, rectal or colorectal diagnosis in the state of Nebraska over the last 10 years. Participants were recruited in a prospective fashion (n=5) from the oncology clinic at Nebraska Medicine, resulting in a combined retrospective and prospective population. Participants were identified by rural or urban status based on their zip 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 regarding their primary care physician, 2) to be completed regarding their oncologist. (See attached TiOS survey instrument in *Appendix*).

The iCaRe^2 registry database was developed and is governed by the University of Nebraska Medical Center 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 assess 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. Several participants (n=7) were removed from the data set due to ineligibility for a deceased status (n=5) and a decline status (n=1). One patient was removed from the study due to an ethical conflict of interest (n=1). Data that could complicate the analytical process may include 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 previously identified to impact levels of trust and may alter how patients feel about their physicians. 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 address, a paper version of the TiOS questionnaire was mailed to their residence or provided during a clinic visit. All eligible participants (n = 158) were invited to participate in this study.

Data Collection

The iCaRe^2 department sent an initial point of contact letter (either email or mail) to participants on behalf of the Fred and Pamela Buffett Cancer Center and this study. The Trust in Oncologist Scale (TiOS) was then distributed either in-person, via email, or by mail to all eligible patients. Participants visiting the oncology clinic at the Fred and Pamela Buffett Cancer Center during routine standard care visits were provided with the TiOS after consenting into the iCaRe^2 registry. Participants consenting in person were provided with the option of a paper or online version of the questionnaire for this study, in addition to the iCaRe^2 baseline questionnaires at time of iCaRe^2 consent. The online version of the questionnaire was created using the REDCap software platform hosted by Nebraska Medicine. One reminder notice was sent if no response was received within three weeks for mail, and two weeks for email. For emailed participants, if no response was received after one email reminder notice, a hard-copy survey was mailed to their residence.

Measures

Extensive demographic information has been previously recorded in the registry prior to the start of this study. The first iCaRe^2 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). (See attached iCaRe^2 questionnaires in *Appendix*). Clinical information has previously been collected from the medical records and recorded to include primary cancer site, tumor histology, stage, dates of diagnosis and dates of treatment.

To better understand the goals of this study, it is important to be aware of other trust-measuring survey instruments. The Trust in Physician Scale (Anderson et al., 1990) was developed to measure patient trust in the primary care provider and predates the TiOS. The Patient Trust Scale (Kao et al., 1998) was constructed to incorporate changes in the healthcare system, specifically the transition to managed care (Hillen et al., 2013). The most recently developed instrument, the Physician Trust Scale (Hall et al., 2002), is currently the most used instrument for measuring trust. All three of these instruments were developed in the primary care setting and measure reported levels of patient trust toward their primary care physician.

In contrast, the Trust in Oncologist Scale (TiOS) was created to assess cancer patient satisfaction and trust in health care (Hillen et al., 2012). The instrument utilizes the four main domains from the previously validated 10-item Trust in Physician Scale (Hall et al., 2002) 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 (Hill et al., 2012). This additional domain is important because the existing dimensions did not fully capture patients' constructions of trust, referring to 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); this allows for the separate use or investigation of one of the specific trust components (Hillen et al., 2012).

An abbreviated version of the TiOS, the Trust in Oncologist Scale-SF was developed as an effective short form version of the scale (Hillen et al., 2017). 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 number of previous consultations with the oncologist.

The long-version TiOS uses 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 Chronbach's alpha of .94 (Hillen et al., 2012). All 18 items of the scale consist of a questions using a 5-point Likert answering scale ('strongly disagree' (1) to 'strongly agree' (5) (Hillen et al., 2012). 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 1 shows an overview of all items and dimensions of the TiOS including the means and standard deviations of each test item. *Table 2* shows the Chronbach's alpha for each domain within the Trust in Oncologist Scale, with an overall (Global) alpha of 0.824. This is considered a good alpha score for the reliability test.

Table 1: Overview of all items and dimensions of the Trust in Oncologist Scale (Hillen et al., 2013) with reliability test results.

Dimension	**Item**	**Content**	**M**	**SD**
Competence	1	Your doctor is very careful and precise	3.81	0.402
Competence	6	You think your doctor can handle any medical situation, even a very serious one	3.65	0.562
Competence	9	Sometimes you worry that your doctor's medical decisions are wrong*	0.54	0.859
Competence	11	Sometimes your doctor does not pay full attention to what you are trying to tell him/her*	0.69	1.123
Honesty	2	Your doctor is totally honest in telling you about all the different treatment options available for your condition	3.69	0.549
Honesty	3	Your doctor always gives you honest information about your prospects	3.62	0.852
Honesty	12	Your doctor would always tell you the truth about your health, even if there was bad news	3.62	0.637
Fidelity	4	Your doctor strongly cares for your health	3.85	0.368
Fidelity	5	Your doctor always tells you everything you want to know about your illness	3.69	0.471
Fidelity	8	Your doctor explains everything so that you can consent to medical decisions	3.73	0.533
Fidelity	10	Your doctor only thinks about what is best for you	3.42	0.857
Fidelity	15	Your doctor will do whatever it takes to get you all the care you need	3.62	0.496
Caring	7	Your doctor always takes his/her time with you	3.65	0.629
Caring	13	You have doubts whether your doctor really cares about you as a person*	0.62	1.169
Caring	14	Your doctor listens with care and concern to all the problems you have	3.69	0.471
Caring	16	Your doctor is available for you whenever you need him/her	3.31	0.788
Global Item	17	You have no worries about putting your life in your doctor's hands	3.58	0.902
Global Item	18	All in all, you have complete trust in your doctor	3.73	0.533

*Reverse-scored items. Likert scale: 1= totally disagree, 2= disagree, 3= as much agree as disagree, 4= agree, 5= strongly agree

Table 2: Cronbach's alpha for each domain, including the mean, for the reliability test.

Domain	**Mean**	**Cronbach's Alpha**
Honesty	11.5019	0.79
Competency	12.8689	0.905
Fidelity	11.5353	0.762
Caring	12.3112	0.788
Global	11.6622	0.824

Statistical Analysis

Central tendency distributions and frequencies were used to examine the study population prior to analysis. Survey data was analyzed to study the means of each of the five domains for the survey and compare mean trust scores between oncologist and primary care physician groups. Demographics were considered during the analysis to identify potential patterns between groups based on age, gender, and geographic location. This is an exploratory study specifically examining patient feelings of trust toward their providers and therefore statistical analysis was limited. A larger sample would be necessary to conduct extensive statistical analysis comparing geographic regions or levels of trust between population groups. T-tests were used to examine the domains and possible differences in the trust scale as well as between demographic and geographic variables. SPSS version 25 was used for the analysis.

Results

An internal reliability test was conducted in SPSS prior to statistical analysis. Internal consistency was found to be strong with a Chronbach's alpha of 0.824. The per-patient status for the initial data collection is represented in *Table 3*. This includes 26 complete responses, 6 partial/incomplete responses, 1 declined response, 5 deceased after data query, and 1 removed due to a conflict of interest. *Table 4* shows variable information for complete survey responses. *Table 5* represents the statistical values for each domain including the N Statistic (number of times the response was answered), the minimum and maximum values present in the survey results, the mean statistic with standard error, and standard deviation. P-values are included to compare mean levels of trust between the oncologist and primary care provider groups. T-tests were used to compare differences in trust between oncologist and PCP groups. *Table 6* shows the average trust score by demographic group including gender, age range, residence origin, cancer site, and cancer stage.

Table 3: Participant participation and survey completion

Survey Status	Measure (n) (%)
Contacted	158
Declined	1
Deceased	5
Removed (COI)	1
Completed	26
Incomplete/Partial	6
% Response	20.89%
% Survey Completion	16.46%

Table 4: Variables for complete survey responses; patient characteristics and demographics

Variable		(n)	(%)
Race/ethnicity	Non-Hispanic White	**24**	**93%**
	American Indian/Alaska Native	**1**	**4%**
	White/Other*	**1**	**4%**
Marital Status			
	Single/Never Married	**1**	**4%**
	Married	**17**	**65%**
	Widow(er)	**1**	**4%**
	Missing	**7**	**27%**
Age (years)			
	≤64	**16**	**62%**
	≥65	**12**	**46%**
Gender			
	Male	**9**	**35%**
	Female	**17**	**65%**
Primary Cancer Site			
	Colon	**20**	**77%**
	Rectal	**6**	**23%**
Origin			
	Urban	**18**	**69%**
	Rural	**8**	**31%**
Qualitative Response			
	Yes	**9**	**35%**
	No	**17**	**65%**
Cancer Stage			
	0, I, II	**7**	**27%**
	III, IV	**19**	**73%**
Alcohol Consumption (current)			

	Yes	**7**	**27%**
	No	**8**	**31%**
	Missing**	**11**	**42%**
Smoking History (current)			
	Yes	**1**	**4%**
	No	**8**	**31%**
	Missing**	**17**	**65%**

*Available survey response for participants who did not fit into any other racial categories
**Missing values were removed from the analysis

Table 5: TiOS competency domains for the oncologist and primary care provider survey questions including means, medians, ranges, and P-values comparing domains

	Oncologist					**PCP**					**P =**
Domain	N	Mean	SD	Median	Min – Max	N	Mean	SD	Median	Min – Max	
Global	26	3.65	0.60	4.00	2.00-4.00	26	2.96	0.97	3.00	1.00-4.00	0.003**
Honesty	26	3.64	0.61	4.00	1.67-4.00	26	3.29	0.69	3.29	2.00-4.00	0.062*
Competence	26	2.17	0.44	2.00	1.75-3.75	26	2.03	0.49	2.00	1.50-4.00	0.270
Fidelity	26	3.66	0.40	3.80	2.80-4.00	26	3.21	0.72	3.10	2.00-4.00	0.007**
Caring	26	2.82	0.42	2.75	2.25-4.00	26	2.50	0.54	2.38	1.50-4.00	0.022**

*P< 0.1, ** P< 0.05 *** P< 0.01

0-4 Range Scale

Table 6: Mean trust score and P-values for Oncologists and Primary Care Providers by variable.

Mean (SD)			
Demographic Group		**Oncologist**	**PCPs**
Age (years)			
	≤64	3.65 (.65)	3.06 (.95)
	≥65	3.65 (.53)	2.80 (1.03)
Gender			
	Male	3.89 (.33)	3.06 (1.01)
	Female	3.53 (.67)	2.9 (.97)
Primary Cancer Site			
	Colon	3.73 (.53)	2.93 (1.03)
	Rectal	3.42 (.80)	3.08 (.80)
Residence Status			
	Urban	3.69 (.60)	2.97 (1.06)
	Rural	3.56 (.62)	2.94 (.78)
Cancer Stage			
	0, I, II	3.57 (.61)	3.29 (.95)
	III, IV	3.68(.61)	2.84 (.97)
Alcohol Consumption (current)			
	Yes	4 (.00)	3.71 (.49)
	No	3.44 (.68)	2.19 (.65)

There was a difference observed between oncologist and primary care provider (PCP) trust levels for all domains (except Competence) with trust in the oncologist reported higher. The Global domain (P= 0.003) suggests that cancer patient in this population feel stronger overall levels of trust in their oncologist than their PCP. The Honesty domain (P= 0.062) suggests that patients feel that their oncologist is more likely to tell the truth and avoid intentional falsehoods than their PCP. The Fidelity domain (P= 0.007) suggests that patients feel that their oncologist has a stronger investment in the pursuit of their interests. The Caring domain (P= 0.022) suggests that cancer patients feel that their oncologist has more involvement in their care and is more sympathetic and devoted to them. Although no significant difference was observed in the Competence domain, it is interesting to note that the mean scores of trust for both the oncologist and PCP are neutral-to-low compared to the other domain results. This may suggest that patients feel doubt in the medical skills of both their oncologist and PCP. Further studies should focus on understanding why patients feel these low levels of competence.

Mean differences in the trust scores by patients' demographic and clinical subgroups were observed within the oncologist group and the PCP group. For example, both in the oncologist and the PCP group, mean trust scores were higher among male than female patients, urban residents than rural residents, and patients who were diagnosed at later stages than those who were diagnosed at earlier stages Patients who stated that they currently consume alcohol reported higher trust in their oncologist (4.0) than those who do not currently consume alcohol (3.44). However, due to the small sample size, statistical tests were not conducted.

Discussion & Future Recommendations

The results from this study showed a measurable difference in levels of trust between oncologist and primary care provider for colorectal cancer patients. The higher levels of trust reported for four out of five domains suggest that cancer patients feel more trust overall toward their oncologist than toward their PCP. The Global domain represents "the irreducible soul of trust, and includes aspects that combine elements from some or all of the separate dimensions" (Hillen et al., 2011). The difference in trust in the Global domain (P= 0.003) suggests that cancer patients feel a deeper trust in their oncologist that includes the aspects of Fidelity, Honesty, and Caring. The lack of trust felt toward both the oncologist and the PCP in the construct of Competence is an important result from this study. This suggests that although cancer patients feel higher levels of trust in their oncologist, they may not feel confident in the medical and interpersonal skills of their oncologist. Previous studies have found that Competence is part of the necessary foundation of trust in the patient-provider relationship (Hillen et al., 2011). It is also possible that severity of their disease may play a role in how cancer patients report trust (Salkeld et al., 2004).

Future studies should seek to further understand the impact of trust in the patient-provider relationship as well as the factors that influence trust. There was a group of individuals who refuse to respond to the survey instrument for this study. For future discussion, the medical data for this subset of the population should be examined to draw possible inferences for this behavior. A comparison of trust levels between patients with similar disease burden should be assessed to determine how much of an impact disease severity exerts on trust. Participant responses to the Trust in Oncologist Scale should be correlated with the length and quality of their provider relationship; this could also 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 in the patient-provider relationship.

One limitation of this study was that the study population displayed many of the same characteristics (for example: race and ethnicity) and was relatively small which constrained the analytical process. A larger study population would be required for a more thorough analysis. The lack of measurable difference between the variables could be due to the small sample size. Although this study collected the type of oncologist (medical or surgical), we did not compare trust results between these subgroups. A larger sample size and further research would be necessary to determine if there is a difference in trust reported within these oncology specialist subgroups. Due to the minimal use of the Trust in Oncologist Scale survey instrument, future studies should focus on cancer patients of all primary diagnoses. This study focused primarily on colon and rectal cancer, however, patients with other disease (for example: breast, prostate, leukemia) may have differing levels of trust due to the unique aspects of their individual disease burdens.

The results from this study contribute to the growing body of knowledge regarding trust in the patient-provider relationship. Previous studies have proposed that one way to promote trust in the patient-provider relationship is for the provider to demonstrate interpersonal and technical competence, moral comportment, and vigilance to support positive patient outcomes (Murray et al., 2014). We recommend a future focus on policies that could be incorporated in the clinic setting to increase trust in the patient-provider relationship. These policies should place an emphasis on interpersonal competence for physicians as well as the importance that trust has on patient outcomes. Practice implications should also include an emphasis on creating higher-quality interactions between patients and their providers. A greater number of high-quality interactions in the clinic has previously been linked to higher levels of patient trust. To address the complications that population barriers may exert on this relationship, future studies should focus on measuring levels of trust in patient populations facing sociodemographic and geographic disparities.

Limitations

Limitations for this study included a small sample size that constrained data analysis. This limitation was addressed by submitting an IRB that allows ongoing recruitment of participants from the iCaRe^2 database so that the study will not be limited to the current number of eligible participants. During analysis, it was important to remember the impact which diagnosis at a higher stage may have on patient-provider trust. This is an exploratory study to examine levels of trust between patients and their providers; therefore, statistical analysis was limited.

Conclusions

There is a need for this research in the state of Nebraska, as the levels of patient trust have not yet been studied within this oncology population. The Trust in Oncologist Scale has had minimal use since it was developed, despite its validated accuracy in cancer patient populations. Future studies should focus on conducting trust-based studies in cancer patients to better address the unique needs of this specific patient population. Higher levels of patient-provider trust are related to patient adherence of physician advice regarding treatment recommendations, increased behavioral changes, higher levels of screening practices, and avoidance of complementary medicine. The information gained from this study should further research among cancer patient populations and contribute to the greater body of knowledge regarding the impact of trust in patient care.

Administrative Resources

It was necessary to have access to encrypted, file-protected computers on the UNMC campus for data collection and analysis. Basic office supplies such as envelopes, return envelopes, stamps, and printing supplies were required to mail out questionnaires. Fees for REDCap, SPSS software, and UNMC print shop and mailing services were also incurred.

Ethics

There are two risks for participants associated with this study: breach of privacy and psychosocial. It is possible that other people could learn the identity of participants. This risk was minimized by accessing personal health information (PHI) only on encrypted, UNMC secured network computers. There is a psychosocial risk as some participants may find talking about their cancer distressing. This risk was minimized by not requiring participants to answer survey questions that they may have found distressing. There was also a risk of conflict of interest as this study utilizes the iCaRe^2 database that falls under portions of my employment responsibilities. This risk was mitigated as this study is outside of the scope of my job requirements and was conducted outside of working hours.

References

Anderson, L. A., & Dedrick, R. F. (1990). Development of the trust in physician scale: A measure to assess interpersonal trust in patient-physician relationships. *Psychological Reports, 67*(3_suppl), 1091-1100.

Bain, N. S., & Campbell, N. C. (2000). Treating patients with colorectal cancer in rural and urban areas: A qualitative study of the patients' perspective. *Family Practice, 17*(6), 475-479.

Bain, N. S., Campbell, N. C., Ritchie, L. D., & Cassidy, J. (2002). Striking the right balance in colorectal cancer care—a qualitative study of rural and urban patients. *Family Practice, 19*(4), 369-374.

Berrios-rivera, J. P., Street, R. L., Garcia Popa-lisseanu, M. G., Kallen, M. A., Richardson, M. N., Janssen, N. M., et al. (2006). Trust in physicians and elements of the medical interaction in patients with rheumatoid arthritis and systemic lupus erythematosus. *Arthritis Care & Research, 55*(3), 385-393.

Berry, L. L., Parish, J. T., Janakiraman, R., Ogburn-Russell, L., Couchman, G. R., Rayburn, W. L., et al. (2008). Patients' commitment to their primary physician and why it matters. *Annals of Family Medicine, 6*(1), 6-13.

Bova, C., Route, P. S., Fennie, K., Ettinger, W., Manchester, G. W., & Weinstein, B. (2012). Measuring patient–provider trust in a primary care population: Refinement of the health care relationship trust scale. *Research in Nursing & Health, 35*(4), 397-408.

Brennan, N., Barnes, R., Calnan, M., Corrigan, O., Dieppe, P., & Entwistle, V. (2013). Trust in the health-care provider–patient relationship: A systematic mapping review of the evidence base. *International Journal for Quality in Health Care, 25*(6), 682-688.

Colorectal Cancer. American Cancer Society. https://www.cancer.org/cancer/colon-rectal-cancer/about/key-statistics.html. February 21, 2018.

Coyne, C. A., Demian-Popescu, C., & Brown, P. (2004). Rural cancer patients' perspectives on clinical trials: A qualitative study. *Journal of Cancer Education, 19*(3), 165-169.

Cunningham, C. O., Sohler, N. L., Korin, L., Gao, W., & Anastos, K. (2007). HIV status, trust in health care providers, and distrust in the health care system among bronx women. *AIDS Care, 19*(2), 226-234.

Delmar, C. (2012). The excesses of care: A matter of understanding the asymmetry of power. *Nursing Philosophy, 13*(4), 236-243.

Do, Y. K., Carpenter, W. R., Spain, P., Clark, J. A., Hamilton, R. J., Galanko, J. A., et al. (2010). Race, healthcare access and physician trust among prostate cancer patients. *Cancer Causes & Control, 21*(1), 31-40.

Dugan, E., Trachtenberg, F., & Hall, M. A. (2005). Development of abbreviated measures to assess patient trust in a physician, a health insurer, and the medical profession. *BMC Health Services Research, 5*(1), 64.

Freburger, J. K., Callahan, L. F., Currey, S. S., & Anderson, L. A. (2003). Use of the trust in physician scale in patients with rheumatic disease: Psychometric properties and correlates of trust in the rheumatologist. *Arthritis Care & Research, 49*(1), 51-58.

Fred & Pamela Buffett Cancer Center | Nebraska Medicine Omaha, NE. (n.d.). Retrieved April 04, 2018, from https://www.nebraskamed.com/nebraska-medical-center/fred-pamela-buffett-cancer-center

Halbert, C. H., Armstrong, K., Gandy, O. H., & Shaker, L. (2006). Racial differences in trust in health care providers. *Archives of Internal Medicine, 166*(8), 896-901.

Halbert, C. H., Weathers, B., Delmoor, E., Mahler, B., Coyne, J., Thompson, H. S., et al. (2009). Racial differences in medical mistrust among men diagnosed with prostate cancer. *Cancer, 115*(11), 2553-2561.

Hall, M. A., Dugan, E., Zheng, B., & Mishra, A. K. (2001). Trust in physicians and medical institutions: What is it, can it be measured, and does it matter? *The Milbank Quarterly, 79*(4), 613-639.

Hall, M. A., Zheng, B., Dugan, E., Camacho, F., Kidd, K. E., Mishra, A., et al. (2002). Measuring patients' trust in their primary care providers. *Medical Care Research and Review, 59*(3), 293-318.

Hao, Y., Landrine, H., Jemal, A., Ward, K. C., Bayakly, A. R., Young, J. L.,Jr, et al. (2011). Race, neighbourhood characteristics and disparities in chemotherapy for colorectal cancer. *Journal of Epidemiology and Community Health, 65*(3), 211-217.

Hillen, M., Koning, C., Wilmink, J., Klinkenbijl, J., Eddes, E., Kallimanis-King, B., et al. (2012). Assessing cancer patients' trust in their oncologist: Development and validation of the trust in oncologist scale (TiOS). *Supportive Care in Cancer, 20*(8), 1787-1795.

Hillen, M. A., de Haes, H. C., & Smets, E. (2011). Cancer patients' trust in their physician—a review. *Psycho-oncology, 20*(3), 227-241.

Hillen, M. A., Butow, P. N., Tattersall, M. H., Hruby, G., Boyle, F. M., Vardy, J., et al. (2013). Validation of the english version of the trust in oncologist scale (TiOS). *Patient Education and Counseling, 91*(1), 25-28.

HIPEC Surgery - Cancer Treatment. (n.d.). Retrieved April 05, 2018, from http://www.mountsinai.org/patient-care/service-areas/surgery/divisions/surgical-oncology/hipec

Holwerda, N., Sanderman, R., Pool, G., Hinnen, C., Langendijk, J. A., Bemelman, W. A., et al. (2013). Do patients trust their physician? the role of attachment style in the patient-physician relationship within one year after a cancer diagnosis. *Acta Oncologica, 52*(1), 110-117.

Hughes, A. G., Watanabe-Galloway, S., Schnell, P., & Soliman, A. S. (2015). Rural–urban differences in colorectal cancer screening barriers in nebraska. *Journal of Community Health, 40*(6), 1065-1074.

Ingram, D. D., & Franco, S. J. (2014). 2013 NCHS urban-rural classification scheme for counties.

Jason M. Foster, M.D. | Surgery | University of Nebraska Medical Center. (n.d.). Retrieved March 19, 2018, from https://www.unmc.edu/surgery/divisions/surgical-oncology/faculty/foster.html

Jones, R. M., Devers, K. J., Kuzel, A. J., & Woolf, S. H. (2010). Patient-reported barriers to colorectal cancer screening: A mixed-methods analysis. *American Journal of Preventive Medicine, 38*(5), 508-516.

Kao, A. C., Green, D. C., Zaslavsky, A. M., Koplan, J. P., & Cleary, P. D. (1998). The relationship between method of physician payment and patient trust. *Jama, 280*(19), 1708-1714.

Katapodi, M. C., Pierce, P. F., & Facione, N. C. (2010). Distrust, predisposition to use health services and breast cancer screening: Results from a multicultural community-based survey. *International Journal of Nursing Studies, 47*(8), 975-983.

Katz, M. L., James, A. S., Pignone, M. P., Hudson, M. A., Jackson, E., Oates, V., et al. (2004). Colorectal cancer screening among african american church members: A qualitative and quantitative study of patient-provider communication. *BMC Public Health, 4*(1), 62.

Kayaniyil, S., Gravely-Witte, S., Stewart, D. E., Higginson , L., Suskin, N., Alter, D., et al. (2009). Degree and correlates of patient trust in their cardiologist. *Journal of Evaluation in Clinical Practice, 15*(4), 634-640.

Lee, Y. Y., & Lin, J. L. (2011). How much does trust really matter? A study of the longitudinal effects of trust and decision-making preferences on diabetic patient outcomes. *Patient Education and Counseling, 85*(3), 406-412.

McKinstry, B., Ashcroft, R., Car, J., Freeman, G. K., & Sheikh, A. (2006). Interventions for improving patients' trust in doctors and groups of doctors. *Cochrane Database Syst Rev, 3*

Mechanic, D., & Meyer, S. (2000). Concepts of trust among patients with serious illness. *Social Science & Medicine, 51*(5), 657-668.

Murray, B., & McCrone, S. (2015). An integrative review of promoting trust in the patient–primary care provider relationship. *Journal of Advanced Nursing, 71*(1), 3-23.

Nebraska Cancer Registry Latest Cancer Data. Nebraska Department of Health and Human Services. August 10, 2017. Retrieved from http://dhhs.ne.gov/publichealth/Pages/ced_cancer_data.aspx.

Nurgat, Z., Craig, W., Campbell, N., Bissett, J., Cassidy, J., & Nicolson, M. (2005). Patient motivations surrounding participation in phase I and phase II clinical trials of cancer chemotherapy. *British Journal of Cancer, 92*(6), 1001.

O'Malley, A. S., Sheppard, V. B., Schwartz, M., & Mandelblatt, J. (2004). The role of trust in use of preventive services among low-income african-american women. *Preventive Medicine, 38*(6), 777-785.

Sahay, T. B., Gray, R. E., & Fitch, M. (2000). A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice, 8*(1), 38-44.

Salkeld, G., Solomon, M., Short, L., & Butow, P. N. (2004). A matter of trust–patient's views on decision-making in colorectal cancer. *Health Expectations, 7*(2), 104-114.

Sankaranarayanan, J., Watanabe-Galloway, S., Sun, J., Qiu, F., Boilesen, E. C., & Thorson, A. G. (2010). Age and rural residence effects on accessing colorectal cancer treatments: A registry study. *The American Journal of Managed Care, 16*(4), 265-273.

Siegel, R., DeSantis, C., & Jemal, A. (2014). Colorectal cancer statistics, 2014. *CA: A Cancer Journal for Clinicians, 64*(2), 104-117.

Trachtenberg, F., Dugan, E., & Hall, M. A. (2005). How patients' trust relates to their involvement in medical care: Trust in the medical profession is associated with greater willingness to seek care and follow recommendations. *Journal of Family Practice, 54*(4), 344-353.

Waters, E. A., Arora, N. K., Klein, W. M., & Han, P. K. (2010). Perceived risk, trust and health-related quality of life among cancer survivors. *Annals of Behavioral Medicine, 39*(1), 91-97.

Weng, H., Chen, Y., Lin, C., Tu, Y., Lin, H., & Yu, S. (2011). Specialty differences in the association between health care climate and patient trust. *Medical Education, 45*(9), 905-912.

Service Learning/Capstone Experience Reflection

Service Learning Activities:

1. Provide support for colorectal cancer related projects developed by Dr. Foster and collaborators
2. Conduct chart reviews for study-related medical data
3. Expand the study populations by consenting patients or adding posthumously
4. Place orders for genetic mutation analysis and track patients through the process
5. Build a master patient list for all patients who have received Cytoreductive Surgery (CRS).

Service Learning Research Goals

Contribute to the research projects currently being conducted by Jason Foster, M.D. in the department of Surgical Oncology. His clinical areas of expertise include management of peritoneal surface malignancies (PSMs) that spread in the abdominal cavity from an ovarian, colon, appendix, or mesothelioma primary. Treatment for these malignancies can involve cytoreductive surgery (CRS) - removal of visible tumor and intra-peritoneal hypothermic chemotherapy (HIPEC or IPHC) administered at the time of surgery (UNMC, 2018). Dr. Jason Foster is one of a very small number of surgical oncologists in the United States practicing HIPEC, which is used to treat these types of cancers.

I have learned that UNMC functions as a trickle-down society with moderate (and occasionally non-transparent) contact from senior leadership. Knowledge is disseminated through many channels of department leadership down through the employees and shared throughout. The organization as a University is quite large and includes over 40 academic departments and 6 colleges. This size lends itself toward the formation of “silo” environments within each department. I am aware of several action plans in the process of being implemented to address this issue and break down these silos. As of 2016, there were over 5000 students and 4000 students with a multitude of new buildings and clinics in construction or newly built. Working in both the College of Public Health and the Fred and Pamela Buffett Cancer Center (as a student and as an employee) has allowed me to observe the differences in how these departments function.

During my time with this organization, I had the opportunity to observe several different types of leadership strategies and how these styles function. It was an important learning experience and allowed me to reflect on my own growing leadership style. Important leadership skills that I have observed include: 1) promoting a team-based atmosphere and 2) investing in the members of your team. Leaders who employ these skills are able to unify their departments and work toward shared goals. Those who do not possess these skills end up with employees who feel unappreciated or abandoned in their work efforts. Observing examples of both good and bad leadership styles throughout this experience has encouraged me to reflect upon my own abilities. In the future, this will enhance my ability to lead teams in a variety of disciplines.

One specific type of leadership that I have observed recently is the ‘silent’ leader. This type of leadership is a more introverted approach to management in which power is exercised through actions rather than words. Leaders who possess this skill solve problems through collaboration, logical thought, and encouragement instead of through aggression or dominance. I have observed several silent leaders in the recent months and all have the same ability: they lead their teams through earned respect rather than force of character. This has affected how I think about my own leadership style in several ways. First, I have recognized that this style of leadership will not work well in every setting and with all types of employees. I also realize there are two major skills that silent leaders must develop to put this style into practice: 1) improved listening skills to encourage and consider multiple viewpoints of an issue and 2) leading by example without cutting corners.

SL/CE activities that were performed for this project focused mainly on cancers of gastro-abdominal origin, which merged well with the study goals examining a colorectal cancer patient population. One of the main goals was to create a master database of all patients who had undergone CRS HIPEC procedures with Dr. Foster. The purpose of creating this database was to provide a comprehensive foundation for both current and future research projects. Several current projects were discussed including:

1. An assessment of the use of central lines in patients admitted for CRS HIPEC, specifically looking at outcome status, infection information, and dates of insertion/extraction. Results from this study will be used to establish surgical guidelines and policy changes within Nebraska Medicine.
2. Publish a previously developed survey instrument into the REDCap software system to better capture responses for an ongoing study. This study is examining views of surgeons across the United States regarding their opinions on mortality rates for GI surgeries, including CRS HIPEC.
3. Build the master database of CRS HIPEC patients. This was completed by creating a series of EPIC OneChart data reports for surgeries conducted by Dr. Foster during a period of time at Nebraska Medicine. The list was merged with a previous surgery list and is in the process of being updated for the following patient information:
    a. Patient demographics
    b. Surgery dates (accounting for the possibility of more than one CRS HIPEC
    c. Tumor type
    d. iCaRe2 enrollment status
    e. Dates of diagnosis, progression, recurrence, and events
    f. Therapies
    g. Outcome status
    h. Central line data

   Data for this list is being collected from the EPIC OneChart system through individual chart reviews. The master list, once complete, will require occasional updates as more patients are treated with the CRS HIPEC procedure.

4. Consenting patients into the iCaRe2 database registry for future research projects. Participants recruited into the registry were seen during routine standard of care visits with Dr. Foster.

One of my greatest contributions during this SL/CE project period was the work for the master database. Completing this goal will allow Dr. Foster and his collaborators to pursue a multitude of future studies. A strength that I brought to this project was my previous knowledge and extensive training in chart review. I was able to immediately assist Dr. Foster with his projects due to my previous knowledge and experience in basic cancer etiology. These skills were due mainly to my on-the-job training as a clinical research coordinator with the Fred and Pamela Buffett Cancer Center, but also due in part to courses completed to fulfill the CEESP fellowship requirements. Another skill was my previous training and credentialing for patient study enrollment, which meant that only IRB regulatory change requirements were needed to begin work with his patient population.

My views of public health research have been greatly changed by this experience. I recognize this opportunity to develop a working relationship with Dr. Foster that I would like to continue considering our shared research interests. I have learned a great deal about public health practice and how difficult it can be to conduct research with living participants, particularly those coping with a cancer diagnosis. I value this entire experience, all that I have learned, and everyone with whom I have had the pleasure of working.

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Appendices

*iCaRe2 Core Data Questionnaire *See separate document*

*iCaRe2 GACCare Extended Module Questionnaire *See separate document*

*TiOS Survey Instrument *See separate document*

Qualitative Data

An interesting component to this study was the qualitative data produced by the open-ended question at the end of the survey allowing patients to comment with any additional information pertinent to their opinions. The initial data collection produced seven qualitative responses, of which four commented on the relationship between the patient and receiving care from multiple doctors. Three of the seven had positive interactions with their providers and received coordinated care between their oncologists and primary care physicians; others reported coordinated care between multiple oncology providers.

> "My primary doctor is in Missouri, as does my oncologist. He [PCP] found Dr. [***] to treat me, have surgery, and now I have two oncologists conferring back and forth. They all have been excellent."
>
> "I am very thankful for having both doctors. The combination of care they provided saved my life."
>
> "Dr. Armitage sent me to see [***] as soon as he found out I had colon cancer. They both saved my life!"

These comments relate to the previously established relationship between the quality of care interactions and levels of patient-provider trust. It suggests a possible relationship between trust and the multidisciplinary approach to cancer care. Further qualitative analysis would be necessary.

IRB Statement of Approval

Research for this study was approved by the Institutional Review Board (IRB) at the University of Nebraska Medical Center under IRB # 010-18-EP.

Application of Public Health Competencies

**See separate document*