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Polar or Separate Constructs?

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Caroline A. Greenidge, M.D., M.A.

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Harry Perkins
Major Professor's Signature

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PATIENTS' TRUST AND DISTRUST OF PHYSICIANS: POLAR OR SEPARATE CONSTRUCTS?

By

Caroline A. Greenidge, M.D.

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ABSTRACT

PATIENTS' TRUST AND DISTRUST OF PHYSICIANS: POLAR OR SEPARATE CONSTRUCTS?

By

Caroline A. Greenidge. M.D.

Trust relations lay the foundation for the covenant between society and the profession of medicine and yet it remains an enigmatic concept although it has been studied in multiple disciplines. It is generally assumed that distrust is the absence of trust; and therefore, distrust has had very little systematic research on its own antecedents and effects (Cook, Kramer, Thom, Stepanikova, Mollborn and Cooper, 2004). Current research supports that the constructs of trust and distrust although related are distinct (Benamati, Serva, Fuller, 2006; Lewicki, McAllister and Bies, 1998). Subsequently, the antecedents and effects of distrust are different from the antecedents and effects of trust and should be studied independently.

DEDICATION

Dedicated to my faithful and loving husband Stephen, Sr.; our children: Stephen, Jr. "Tristan", Ariane, Ayodele, Jemila-Okera, our angel Gabriel; my parents by marriage Everton and Ianthe Coppin; my father Edward B. Thomas; and in loving memory of my mother, Jasmine K. Thomas.

The Lord is my rock, and my fortress, and my deliverer; my God, my strength, in whom I WILL TRUST…

Psalm 18:2

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INTRODUCTION

1.1 Statement of Problem

The patient-physician relationship serves as the Ark of the Covenant (a sacred container holding the tablets of stones containing the Ten Commandments) in that it holds a sacred interaction whose basis stems from a covenant of trust between society and the profession of medicine. This sacred interaction is grounded in the physician's fiduciary obligation to patient health and healing. The covenant of trust is therefore the foundation upon which the patient-physician relationship is built (Bailey, 1996; Brody, 1992; Caterinicchio, 1979; Mechanic and Schlesinger, 1996; Pearson and Raeke, 2000).

Our Western ideal of the physician healer predates Christianity and even Hippocrates, deemed to be the father of Western medicine. Asklepios, a revered mythical physician-god of ancient Greece was the physician role model for great physicians such as Hippocrates and Galen (Bailey, 1996). The Hipprocratic Oath, (circa 400 BC) which begins with: "I swear by Apollo the physician, and Aesculapius, and Hygeia , and Panacea and all the gods and goddesses, making them my witnesses, that I will fulfill, according to my ability and judgment, this Oath and covenant: ..." (Chadwick and Mann, 1950), underscores the ancient Greek influence upon current medical practice. Note that Greek mythology deemed Apollo to be the father of Asklepios (the god of healing), and Hygiea and Panacea the daughters of Asklepios (goddesses of health). Physician followers of the Asklepian tradition were "expected to practice their craft without

primary regard for the social status of their patients, personal risk or financial gain" (Bailey, 1996, p. 261). Medical ethics demands that a physician should serve the less fortunate and practice with integrity, compassion and even sacrifice. Recently health care reform, health disparities and economic pressures have greatly diminished the practice of Asklepiad traditions of selfless service by physicians.

The covenant of trust exists in medicine because patient vulnerability is primary and unavoidable (Clark, 2002; Hall, Dugan, Zheng, Mishra, 2001). Trust serves to establish social order (Miszal, 1996: Chapter 3) and the social basis of the trust covenant in medicine can be described as: "A contractual arrangement that tenders service in trust in exchange for the social largess of professional autonomy" (Clark, 2002). An awareness of this contractual agreement brings to light the self-interest of members of the medical profession in preserving a patient-physician relationship that is based on trust and not distrust. The preservation of trust and professional autonomy is difficult in a social matrix of distrust; but be as it may, patient fidelity is still the primary duty of the physician because, willing or not, the vulnerability of the patient necessitates trust in the physician. The medical profession must therefore hold unto its virtues of benevolence, integrity and competence, and its initial mandate of selfless service to mankind, forsaking gain and profit, and reining in self-interest.

Community perceptions, public opinion and the media fuel the deteriorating trust in the medical profession and medical research (Mechanic, 1998). Patient vulnerability is shrouded in a camouflage of an educated consumer and physicians have metamorphosed

into contracted technical advisors. This is exemplified by the malpractice crisis, and the focus on specialty care and not primary care (Pelligrino, 1999). Idealistically, a trusting patient and a trustworthy physician are necessary and sufficient for an effective therapeutic patient-physician relationship.

Conversely, a distrusting patient and an untrustworthy physician may be engaged in a formal contractual patient-physician relationship that may be perceived of lesser therapeutic value. Distrust promotes an atmosphere of societal caution and "wariness replaces trust" (Pelligrino, 1991, p.77). Should a covenant of distrust replace the covenant of trust that is the foundation upon which the profession of medicine was built, and if so will this be in the best interest of the autonomous yet still vulnerable patient? Those who doubt physicians' trustworthiness and believe that increased patient vulnerability would produce lower trust should consider the value of trust. "On balance, an ethic of trust is more realistic, conceptually sounder and phenomenologically more consistent than an ethic of distrust" (Pelligrino, 1991, p. 84). An ethic based on wariness and distrust is "really no ethic at all, but an illusory relationship of mutual self-defense" (Pelligrino, 1991, p. 84). Changing the covenant of trust to one of distrust diminishes the sacred responsibility of a virtuous physician as a healer, care provider, advocate for the sick and promoter of health.

An evaluation of the patient-physician interaction, a major component of the interpersonal aspect of health care reveals significant disparities in trust and mistrust. African Americans, Latinos and others when compared to Caucasians in the United

States reported a 13 to 18 percent less positive perceptions of physician in terms of satisfaction with style and trust (Cooper-Patrick, et al., 1999). The level of patient's trust is not only associated with ethnicity (LaVeist, Nickerson and Bowie, 2000) but other demographic factors as well, such as: patients' age, gender, education and occupation (Cook et al., 2004). The level of patient's distrust is associated with physician behaviors such as: negative non-verbal cues, lack of availability, a lack of time, lack of explanations, lack of respect and showing signs of distrust of the patient (Cook et al. 2004). The profession of medicine cannot afford to lose trust and a low level of trust can be improved upon. It's believed that trust reduces health disparities, improves access to health care and improves health outcomes (Thom, Hall and Pawlson, 2004).

A major contributor to the deterioration of trust in the medical profession and medical research is the extensive documentation of racial and ethnic disparities in health, health care and health outcomes. In the Institute of Medicine (IOM) reports: *Unequal Treatment – Confronting Racial and Ethnic Disparities in Healthcare* (Smedley, Stith, and Nelson, 2003) and *The Unequal Burden of Cancer – An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved* (Haynes and Smedley, 1999) differences in the interpersonal aspect of health care are felt to contribute to the documented disparities between Caucasian and ethnic minorities in health care and health care outcomes in the United States (Smedley, et al.); and cancer care and cancer outcomes (Haynes and Smedley). Both IOM committees recommended an increase in clinical research for improved understanding and elimination of the disparities and generalizability of research findings in minority populations (Smedley, et al.; Haynes and

Smedley); but minority population's distrust of medical research impedes successful clinical trial recruitment and retention.

The Senate hearings in the 1970s on human experimentation included poignant testimonies by survivors of The Tuskegee Study. In *Bad Blood – The Tuskeegee Syphilis Experiment* (Jones, 1993 p.214), James H. Jones recounted the loss of trust by study participants, exemplified by this statement by study survivors lawyer, Lester Scott, "They have no faith, trust, nor confidence that the Public Health Service will properly examine them and give them proper treatment" *("Quality of Health Care: Human Experimentation,"* 1973). There are many barriers to the successful recruitment and retention of minority patients in clinical trials; but a major divide is caused by previous betrayal of trust and the resultant distrust that minority populations holds for medical research and the medical community (Corbie-Smith, Thomas and St George, 2002, Corbie-Smith, Thomas, Williams and Moody-Ayers, 1999).

1.2 Research Significance

Trust plays a central role in the patient-physician relationship and this has long been acknowledged and well documented (Bailey, 1996; Barber, 1983; Brody, 1992; Caterinicchio, 1979; Mechanic and Schlesinger, 1996; Pearson and Raeke, 2000, Pellegrino, in Veatch, and Langan, Eds., 1991). In this climate of deteriorating trust, we possess limited knowledge on patients' trust and distrust in their physicians, and their effect on patients' attitudes, behaviors and health outcome. There is limited research on

the antecedents and consequences of trust and even more so distrust in the patient-physician relationship.

Trust has been hypothesized or shown to affect patient's behaviors and attitudes such as patients' continuity with the physician, self-reported adherence to medication, satisfaction with physician care (Thom, Ribisl, Stewart and Luke, 1999); loyalty and satisfaction with physician, self reported health improvement (Kao, Green, Davis, Koplan and Cleary, 1998; Kao, Green, Zaslavsky, Koplan and Cleary, 1998); willingness to seek care, share confidential information, (Hall, Dugan, Zheng, et al. 2001); accept and adhere to treatment (Altice et al., 2001; Hall, Dugan, Zheng, et al. 2001), following physician recommendations (Safran, Taira, Rogers, et al., 1998; Hall et al., 2001); remain with physician (Safran, Montgomery, Chang, Murphy, and Rogers, 2001; and changing physician (Keating, et al.,2002).

Patients in two managed care settings with a low level of trust reported less satisfaction with care, lower intention to follow doctors' advice, and lower reports of symptom improvement (Thom, Kravitz, Bell, Krupat and Azari, 2002). Low levels of trust in people of color, especially African Americans is associated with lower levels of care seeking, preventive service and surgical treatments when compared to Caucasians (LaVeist, et al., 2000). Lower trust and higher distrust in African Americans is also linked to: lower use of preventive services (O'Malley et al 2004); less satisfaction with care and unwillingness to share information (LaVeist et al, 2000); patient consent and adherence (Altice et al 2001). African American distrust of the medical profession is a long held attitude based on historical racial abuses and discrimination (Gamble, 1997 and

Gamble, 1993). This attitude of distrust also labeled as mistrust, is associated with lower levels of satisfaction with medical care (LaVeist et al., 2000). A focus group study reported that African American patient's distrust "inhibits care seeking, can result in a change in physician and may lead to non-adherence" (Jacobs, Rolle, Ferrans, Whitaker and Warnecke, 2006). African American distrust of the medical community is also a deterent to participation in medical research (Corbie-Smith, et al.,1999).

Researchers in medicine and related fields agree that trust, distrust and trustworthiness impact not only organization endpoints but the interpersonal also (Mechanic & Schlesinger 1996; Anderson and Dedrick, 1990; Safran, Kosinski, et al.,1998; Hall, Zheng et al., 2002 and Thom and Campbell, 1997). One aim of this research is to evaluate cancer patients' trust and distrust of their physician in the clinical trial research setting involving a behavioral intervention; and to document the impact of patients' trust and distrust on patient retention, attrition or death during the trial. Another aim of the study is to evaluate whether cancer patients' trust and distrust of their physician serve as predictors for patient retention, attrition or death during the trial.

Attrition occurs frequently in randomized controlled clinical trials (RCCT) due to its longitudinal design (Given, Keilman, Collins and Given, 1990) but few studies report analyses of attrition rates (Bottomley, Afficace, Thomas, Vanvoorden and Ahmedzai, 2003) including cancer longitudinal studies (Cooley, 2000) and studies utilizing behavioral interventions (case management, crisis counseling, cognitive-behavioral therapy) (Gilbar and Neuman, 2002). Behavioral intervention cancer longitudinal studies attrition rates range from 30 % in a multi-site RCCT study of cancer patients receiving

chemotherapy (Given, and Sherwood, 2005) to 61% (Gilbar and Neuman, 2002) and 84% (Chandra, et al., 1998) in prospective observational studies of newly diagnosed cancer patients receiving treatment. Reviews on attrition rates in cognitive-behavioral non-cancer longitudinal studies reported ranges from 10-59% (Davis and Addis, 1999), and 30 -60% (Garfield, 1994).

Reported attrition predictors include demographic variables such as: younger age, Canadian aboriginal status and involvement in manual labor (Murnaghan and Buckley, 2002); gender, education and socio-economic status (Marsh et al., 1989; Difranciso, et al., 1998; McMahon, Kelly and Kouzekanam, 1993; Mosher Ashley 1994; and Scogin, Hamblin, Beutler, 1986). Also reported are psychological and symptom severity variables such as: depression, mania, paranoia, anticipated weight loss or gain (Davis and Addis, 1999); asthma symptom severity (Bender, Ikle, DuHamel, and Tinkelman, 1997) as well as personal and other variables such as caretaker status, depression, hostility, and assignment to experimental group (Moser, Dracup and Doering, 2000). It is the aim of this research study to explore whether patients' trust in and distrust of physicians served as significant predictor variables for attrition.

Currently there is a lack of consistent/gold standard predictors for attrition from longitudinal behavioral intervention clinical trials (Gilbar and Neuman, 2002; Kendall and Sugarman 1997). In behavioral intervention trials attrition predictive factors covers a wide spectrum, researchers have reported: participation in the control group; perceived dietary compliance, symptom severity, and disease knowledge, (Given, Given and Coyle, 1985), age, race/ethnicity, cancer diagnosis, caregiver, and recruitment staff factors

(Neumark, Strommel, Given and Given, 2001). Other researchers have reported the status of being a single parent, ethnic minority and lower anxiety (Kendall and Sugarman 1998) and lower household income and negative treatment attitude (Grilo et al., 1998). Although potentially challenging, the identification of predictors of attrition can help to target and retain at risk populations in randomized controlled clinical trials (RCCT).

1.3 Purpose of Study

This study serves as an exploration of health behaviors of cancer patients (more specifically patients' retention, attrition and death during the trial) as influenced by a patient's level of trust and distrust in their physician in a clinical trial.

Objective: The objective of this research project is to examine Caucasian and African American cancer patients' trust and distrust in their physicians and its effect on patient participation in a randomized controlled clinical trial (RCCT) utilizing a behavioral intervention for symptom control.

Specific Aims:

1. To examine the Wake Forest Physician Trust Scales' factor structure internal consistency and construct validity in measuring both cancer patients' trust *and* distrust in their physicians.
2. To examine cancer patients' trust and distrust in their physicians, controlling for: race/ethnicity (Caucasian/African American), age, gender (male/female), education level (some college or more, high school graduate, less than high school graduate), trial group assignment (experimental or control), Center for

Epidemiological Studies Depression (CES-D) measure of depression, satisfaction with physician communication, patient mastery, and symptom severity mean score.

3. To examine the relationship between patients' trust and distrust in their physicians; and patients' retention, attrition or death during the clinical trial. Patients' race/ethnicity (Caucasian/African American), age, gender (male/female), education level (some college or more, high school graduate, less than high school graduate), trial group assignment (experimental or control), Center for Epidemiological Studies Depression (CES-D) measure of depression, satisfaction with physician communication, patient mastery, and symptom severity mean score; variables that may serve as determinants of patients' retention, attrition or death will be included in the model.

1.4 Study Null Hypothesis:

1. The Wake Forest Physician Trust Scale is not a reliable measure of Caucasian and African American cancer patients' trust and distrust in their physicians.
2. Cancer patients' trust and distrust will not vary by race/ethnicity (Caucasian/African American), age, gender (male/female), education level (some college or more, high school graduate, less than high school graduate), trial group assignment (experimental/control), CES-D measure of depression, patient satisfaction with physician communication, patient mastery, and patient symptom severity mean score.

3. Patients' trust and distrust will not significantly affect the outcomes of patients' retention in, attrition from and death during the clinical trial after adjusting for other significant variables.

1.5 Definition: Trust, Distrust and Trustworthiness

Trust as defined by Webster's Dictionary is "a firm belief or confidence in the honesty, integrity, reliability, justice etc., of another person or thing; faith; reliance" (Webster's New World Dictionary, 1964).Trust has also been defined as placing one's confidence in someone or an entity; the trustor is willing to be vulnerable without measures in place, to monitor or control the actions of the trustee (Mayer, Davis and Schoorman, 1995). A third definition of trust as an essential component in the patient-physician relationship (Mechanic, 1996; Mechanic and Schlesinger, 1996), is "the optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for the trustor's interest" (Hall, Dugan, et al., 2001). Current theories about patient trust in a physician describes it as a set of beliefs or expectations that a physician will behave in ways that protects the best interest of the patient (Anderson and Dedrick, 1990; Thom and Campbell, 1997); or as a feeling of confidence or reliance in a physician and the physician's intent (Caterinicchio, 1979).

The following describes four commonly proposed pre-conditions of trust. First, inter-relational trust emerges when there is a need by the trustor that only a trustee can fulfill; this creates dependency of the trustor on the trustee. Second, with trust, there is an optimistic assumption by the trustor that the trustee has his/her best interest at heart.

Third, the trustor also believes that the trustee is competent. However belief in competence is not usually all encompassing (i.e. A simply trust B). Belief in competence is usually limited, "trust is generally a three-part relation: A trusts B to do X" (Hardin 2002, 9). Fourth, trust involves risk of betrayal; the trustor can withdraw or lose what is entrusted to the trustee if the trustee fails to keep trust.

Trustworthiness has been proposed to be a predominant determinant of trust and has been defined as the beliefs about another party's ability, benevolence and integrity (Serva, Benamati and Fuller, 2005; Mayer, et al. 1995). Trustworthiness is believed to function as a second order antecedent, and represents beliefs which lead to the formation of a trusting attitude(Serva, Benamati and Fuller, 2005). Trustworthiness has been defined as a virtue/moral disposition, not as an attitude (Potter 2002, p25; Hardin 2002, p32). Virtue has been defined as, moral excellence; goodness; righteousness; conformity of one's life and conduct to moral and ethical principles; uprightness; rectitude (Random House Dictionary, 1987). Others have described trustworthiness not as a virtue but based on self-interest. External forces such as social norms or constraints; and shared interest or "encapsulation interest," which are both deemed to be based on self-interest drives trustworthiness (Hardin 2002, 53). The trustee is motivated by norms to be trustworthy; the trustor uses social constraints as a contract with the trustee. The trustee is interested in preserving a relationship with the trustor and therefore "encapsulates" the interests of the trustor as his/her interest; but trustworthiness based on a "social contract," or "encapsulated interest" does not capture the caring component of trustworthiness therefore a definition based on "goodwill" also exists (Baier, 1986, Jones, 1999).

Trustworthiness therefore encompasses motivation, caring, competence, and action and in its purest form, is a virtue (McLeod, 2006). The underlying motive of the trustee determines whether trustworthiness is based on self-interests such as social norms or shared interest; goodwill or a virtue. Trustworthiness as a virtue will be the definition of trustworthiness used in this thesis. Also in this thesis the measure of physician trustworthiness is defined based on technical competence, interpersonal competence and agency/ fiduciary responsibility.

For the purpose of measuring trust, researchers have focused on physician attributes that merits trust and in the medical profession, over the last decade, the work of multiple research teams have advanced our knowledge of the measurement of patient's trust: Thom, Hall, Pawlson, (2004); Zheng, Hall, Dugan, Kidd and Levine,(2002); Anderson and Dedrick, (1990); Safran, Taira et al., (1998); Kao, Green; Davis, et al.,(1998); Kao, Green, Zaslavsky, et al.,(1998). The theory of trust in medicine is based on general trust in physicians as well as trust in specific physicians. A brief summary of their conceptual framework of trust follows. They initially proposed five potentially overlapping domains/dimensions of physician attributes identified by patients, that engenders trust: (1) **fidelity** involves loyalty, caring, respect, advocating for patients interest and avoiding conflicts in interest; (2) **competence** involves good practice and interpersonal skills (communication which enhances the technical aspects of care), correct decision-making and the avoidance of mistakes (both technical and cognitive); (3) **honesty** involves telling the truth and avoiding intentional falsehood; (4) **confidentiality** involves the proper use of sensitive information; and (5) **global trust** is described as " the

soul of trust" which is a combination of some or all of the aspects of the separate dimensions (Hall, Dugan, et al., 2001; Hall, Zheng et al., 2002; Anderson and Dedrick, 1990; Safran, Taira et al., 1998; Kao, Green, Davis, et al.,1998; Kao, Green, Zaslavsky, et al.,1998; Mechanic, 1996). Note should be made, that to date, none withstanding the proposed trust domains, all trust is an unidimentional construct (Zheng, et al., 2002; Kao, Green, Zaslavsky, et al. 1998; Safran, Kosinski, et al., 1998) , suggesting that "these domains are all part of a single "global" concept" (Thom et al., 2004, p125-126).

Thom and Campbell (1997) have identified seven categories of physician behavior that increased patient's trust. Two were related to technical competence and the other five were related to interpersonal competence. **Technical competence**: (1) provide a thorough evaluation of problems; (2) provide appropriate and affective treatment; and **interpersonal competence**: (3) provide communication that is clear and complete; (4) encourage partnership building; (5) express caring; (6) and show respect and understanding of the patient's experience; and (7) demonstrate honesty. Thom, Bloch and Segal (1999) then focused on improving patients' trust by changing physician behavior based on their seven physician behavioral categories, however; they did not show a significant change in the outcomes measures of: patients' trust, patients' and physicians' satisfaction with the office visit, continuity in the patient physician relationship, adherence to treatment plan and the number of diagnostic tests and referrals, all measures that have been shown to be related to patient trust in physicians in the literature. The researchers proposed a possible explanation of the negative finding, arguing that the seven behavioral categories were determined from analysis of four focus

group data, and therefore did not allow for the determination of a predictive value of the individual behaviors.

Distrust as a polar construct of trust has been defined as a negative belief that the trustee will act in the best interest of the trustor; and the trustor has an unwillingness to be vulnerable or dependent upon the goodwill of the trustee (Hall, Dugan, et al., 2001). Simplistically, distrust describes a lack of trust and earlier research placed them as extremes of a single dimension (Rotter, 1967). However, it has been proposed that trust and distrust although related are distinct constructs (Benamati et al., 2006; Cho, 2006; Huang and Dastmalchian, 2006; McKnight, Kacmar and Choudhury, 2004; Kramer, 1999; Lewicki, et al. 1998; Sitkin & Roth, 1993).

Distrust as a separate construct from trust has been defined as "a positive expectation of an injurious action," (Luhmann, 1979). Distrust therefore is not simply an absence of trust but distrust is an active expectation that the trustee's behavior will be irresponsible, incompetent, or cause harm (Lewicki, et al. 1998). If trust and distrust function as separate constructs then theoretically a patient can be both trusting and distrusting of the physician who will be perceived as being both trustworthy and untrustworthy. The trustor therefore engages in behaviors balancing risk (trust) and sanctions (distrust). The patient and physician may then engage in the explicit negotiation of a formal contractual interaction that may or may not engender an effective therapeutic patient-physician relationship. Inter-relational distrust is based on risk of failure and reliance. Understanding the role that patients' trust and distrust play in the patient-physician interaction may allow improvement in the patient-physician

relationship, patient behaviors and health outcomes.

1.6 Conceptual Framework of Coexisting Trust and Distrust

In the past researchers have conceptualized the attitudes of trust and distrust along a bipolar continuum; but currently, models show co-existing trust and distrust as distinct constructs (Benamati, et al.2006; and Lewicki et al. 1998). A model of trust and distrust not as polar attitudes but as attitudes that possess positive and negative features, results in a conflicting attitude. Trust, distrust and trustworthiness was examined in the setting of consumer use of online banking services and commerce (Benamati, et al.2006; Cho, 2006; McKnight, et al., 2004; Lewicki, et al., 1998; Sitkin & Roth, 1993), and the researchers provided further evidence to support that trust and distrust exist as related yet separate constructs. This research was designed to show both trust and distrust independently exerting a positive or negative influence on consumer decisions and behaviors (Benamati, et al., 2006; Cho, 2006). Benamati et al. were not able to determine the relative contribution of both trust and mistrust on the intentions of the consumer to use of online banking services because in their study trust overwhelmed distrust. Trust and trustworthiness was found to have a positive impact on intention to use; but in the presence of trust, distrust became insignificant (Benamati, et al., 2006).

Cho (2006), however, reported that trust and distrust impacted different behavioral intentions, trust predicted a consumers' willingness to commit to a business-to-consumer internet exchange relationship and distrust predicted a consumers' self-disclosure of personal information. Data therefore exist to support that the attitude of trust

Figure 1. A Model of an Alternate Social Reality of Coexisting Trust and Distrust.
(Adapted from Benamati, et al., 2006 and Lewiciki, et al., 1998)

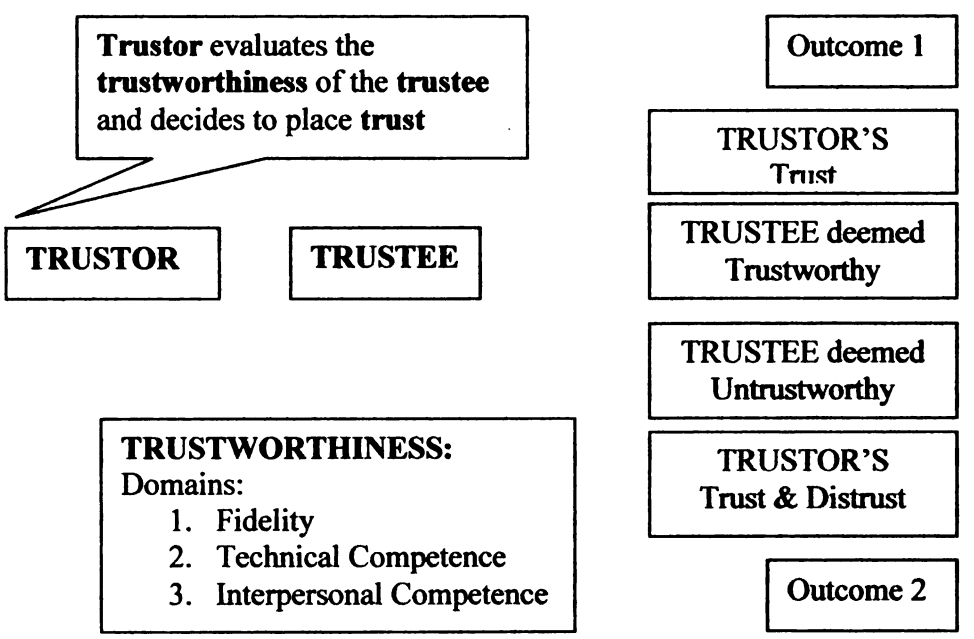
	Low or No DISTRUST (d) Absence of: Fear, skepticism, and monitoring.	**High DISTRUST (D)** Presence of: Fear, skepticism and monitoring.
Low or No TRUST (t) Absence of: Hope Faith Confidence	**DISENGAGED TRUST & DISTRUST** **("Detachment")** Low or No Trust (t) & Low or No Distrust (d) **td**	**UNBOUNDED DISTRUST** **("Blind Suspicion")** Low or No Trust (T) & High Distrust (D) **tD**
High TRUST (T) Presence of: Hope Faith Confidence	**UNBOUNDED TRUST** **("Blind Trust")** High Trust (T) & Low or No Distrust (d) **Td**	**BOUNDED TRUST** **("Trust but verify")** High Trust (T) & High Distrust (D) **TD**

and the attitude of distrust are based on separate positive and negative components (Cacioppo and Berston, 1994). Figure 1 is adapted from Benamati, et al., (2006) and Lewicki et al., (1998), and illustrates the concept of trust and distrust as separate positive and negative components. It also, delineates the coexistence of trust and distrust leading to four states described as unbounded trust, bounded trust, unbounded distrust, and disengaged trust and distrust. Trust and distrust exhibits positive and negative components; trust exudes the positive emotions of "hope, faith, and confidence;" while distrust on the other hand exudes the negative emotions of "fear skepticism and monitoring." Trust co-existing with low or no distrust is labeled unbounded trust, which leads to complete faith or "blind trust" in the trustee or by a trustor who then abdicates all responsibility. Distrust co-existing with low or no trust is labeled unbounded distrust, and described as "blind suspicion."

A distrusting trustor assumes harmful motives by the trustee and the trustor therefore engages in a bounded fashion with the trustee. The coexistence of low or no trust and low or no distrust is labeled a disengaged state; and is also described as detached. A disengaged state leads to minimal interdependence between trustor and trustee. Bounded trust has been described as the healthy temperance of trust with distrust, called "prudent paranoia" (Kramer, 2002). Blind trust may not be deemed as prudent because the patient is depending upon of the competence, compassion and character of the physician; who is after all, a fallible human being; but bounded trust which is trust bounded by distrust may impose upon the trustee the necessary mantle of fiduciary responsibility (Pelligrino, 1992).

Figure 2, depicts the trustor evaluating the trustworthiness of the trustee. It also illustrates trust and distrust co-existing in a nomological system that includes trustworthiness and behavioral intention. The attitudes of trust and distrust are formed based on the trustor's judgment of the trustee's trustworthiness which is based on a determination of competence and intention. This model utilizes an evaluation of competence and fidelity to determine trustworthiness. The trustor then decides to place trust in the trustee..

Figure 2. A Model of Coexisting Trust and Distrust.
(Adapted from Benamati, et. al., 2006)



In Figure 2, the following assumptions exist: (a) trust and distrust are related but distinct constructs; (b) trust and distrust are co-existing constructs and (c) trust and distrust exist within an interaction of a minimum of two parties, with a minimal willingness to be in

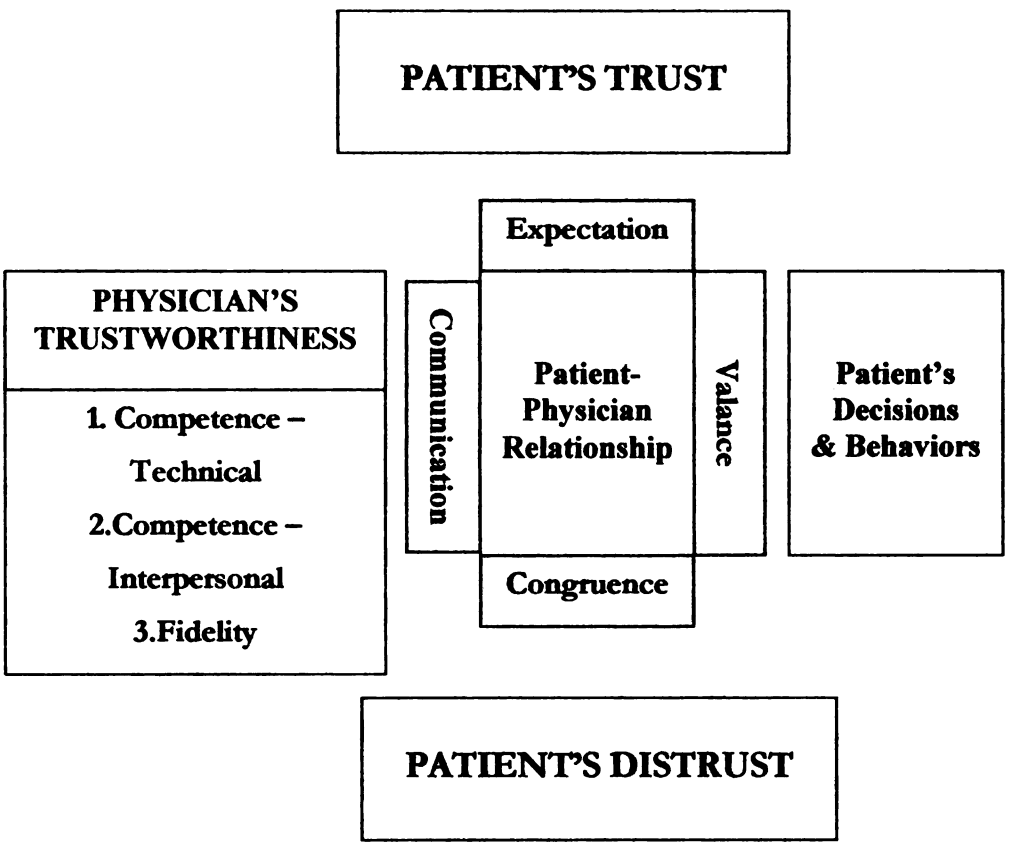
contact over a period of time and also involves a minimal ability and willingness to communicate. The patient physician relationship is bounded by both trust and distrust. The vulnerability of the patient necessitates trust but possible violation of trust may generate distrust. Both trust and distrust are learned attitudes, emotionsIn distrust, there is an assumption by the trustor that the trustee does or does not have his/her best interest at heart; and in trust it is the opposite. However, we cannot just will ourselves to trust; cause must exist in order for trust to develop. "Trust but verify," a rational trustor is open to evidence that contradicts his or her trust theory, therefore rational or bounded trust is partial trust. The rational trustor evaluates the trustworthiness of the trustee based on perceived evidence and past experience and is constantly up-dating whether or not to trust; therefore, the attitude of trust can be destroyed by rational justification of the attitude (McLeod, 2006). "Blind trust," the faith component of trust (...faith is the substance of things hoped for the evidence of things not seen) limits rational thinking on trust, because trust inherently involves risk (if verification was possible there would be no need for trust); attempts to rationalize away the risk also destroy trust.

Unbounded trust that is honored can be valuable because of the tangible and intangible "goods of trust," such as "opportunities for cooperative activity, knowledge, autonomy, self-respect and overall moral maturity;" unbounded trust as a virtue is valuable in and of itself (McLeod, 2006). Trust allows us to form relationships with others and to depend on others. Trust leads to cooperative work, and cooperative work provides goods. Trust minimizes monitoring, which complicates cooperative work. Trust is a form of "social capital" (Fukuyama 1995, Hardin 2002). "High-trust" societies have stronger economies

and stronger social networks in general than "low-trust" societies (Fukuyama 1995; Inglehart 1999). Philosophers argue that knowledge depends on trust in the testimony of others. St Augustine of Hippo, 345 –430 AD, wrote "*crede, ut intelligas* - believe in order that you may understand;" and St Anselm of Cantebury, 1133-1109 AD, wrote "For I do not seek to understand that I may believe but I believe in order to understand. For this I believe that unless I believe, I should not understand." Therefore some level of "blind trust" must exist in addition to rational belief, because an individual cannot verify the truth of all knowledge. In order to act on one's belief or to be autonomous one must "chose and act in accordance with our values, we need to trust ourselves to do so" (Grovier 1993; McLeod, 2002). Trust therefore is "the very basis of morality" (Baier, 1986).

The following brief discussion highlights four components contributing to the multiplicity of components within the patient-physician interaction. Figure 3, depicts a conceptual model of coexisting trust and distrust with the selected components of communication, expectations, valence and congruence. The attitudes determined by trust and distrust have been described as a positive and negative valence. Expectancy Violations Theory by M. Burgoon (1991) and JK Burgoon (1993), propose interacting individuals have pre-interaction expectancies about communication behaviors of another. An individual perceiving violation of expected communication behavior of another enters a cognitive-evaluative process wherein the violation is valenced as a positive confirmation of pre-interaction expectancies or a negative confirmation of pre-interaction expectancies.

Figure 3. A Conceptual Model of Coexisting Trust and Distrust.



Positive or negative valencing of the violation tends to have greater impact (whether positive or negative) than conformity to expectation. In health communication attitudinal and behavioral change occurs more frequently with positive violations of expectancies (Burgoon, M., 1991). The following relationship is hypothesized. The more the trustor perceives the trustee's communication as being congruent and the greater the meeting of the trustor's expectations by the trustee, then the greater the number of

positive expectancy violation the more positive the valence and the more likely the growth in trust. The more the trustor perceives the trustee's communication as being incongruent and the greater the lack in meeting of the trustor's expectations by the trustee, then, the number of negative expectancy violation is greater. The more negative the valence, then the more likely the growth in distrust. Research suggests that the human cognitive system reacts to a state of distrust by automatically inducing the consideration of incongruent associations or opposite associations to a given message (Schul, Mayo & Burnstein, 2004). It has been proposed that a state of distrust leads to a difference in processing information than a state of trust (Schul, et al., 2004). The extent to which message-incongruent associations are activated differs under the condition of trust and distrust. A state of distrust appears to generate the question "and what if the information were false" (Schul, et al., 2004, p678).

The constructs of expectation, congruence, valencing and communication can serve as theoretical building blocks for tackling the problem of whether trust and distrust are polar or distinct constructs. They can aid in determining what elements influences the ratio of coexistence of the trust and distrust within an interpersonal relationship. Variables define the way a construct is to be measured in a specific situation and it is necessary to match variables to constructs when identifying what needs to be assessed during the development of theoretical model. Intuitively we believe that trust and distrust are key constructs determining the behaviors and choices of individuals.The proposed conceptual or theoretical framework may be useful when applied to areas of concern such as the patient-physician interaction and patient participation in clinical trials because it

offers potential variables to consider patients' trust and distrust. The difficulty still remains in finding more variables that can serve as the operational forms of the two constructs.

1.7 Theories on Trust, and Distrust in the Interpersonal Interactions

In order to better understand the constructs of trust and distrust within the patient-physician relationship, this research drew from a number of theories on interpersonal interactions and trust and distrust that was generated by various disciplines, including communication, psychology, sociology, anthropology, consumer behavior, marketing, nursing and medicine. Some of the theories used may not be highly developed or rigorously tested, however, the utilization of knowledge stemming from the epidemiological and the biological sciences aided the adaptation and application of these theories to this clinical research issue.

It is a general belief that a therapeutic patient-physician relationship engenders not only healing but also influences health behaviors. The whys and wherefores on how this occurs, simplistically put, remains puzzling. Scientists in various disciplines have proposed many theories or systematic methods to help our understanding of events or situations within the patient-physician interaction. Previous research in this area narrowly focused on the setting within which the patient-physician interaction occurs and researchers often ignored the complexity of the system within which the interaction took place. A broad theory that may aid researchers in an approach to this problem is the ecological perspective of levels of influence (McLeroy, Bibeau, Steckler and Glanz, 1988).

The ecological perspective describes a multi-level interacting approach emphasizing multiple factors within and across various levels of influence: intrapersonal, interpersonal, institutional, community factors, and public policy. This research evaluates the intrapersonal constructs of patient's trust and distrust within the context of the interpersonal patient-physician relationship and their impact on cancer patients' behaviors as they relate to their retention, attrition and death during a clinical trial. In the discipline of nursing, (Hupcey and Penrod, 2003; Hupcey, Penrod and Morse, 2000; Hupcey, Penrod, Morse and Mitcham, 2001) has served to clarify varying discipline-specific (medicine, nursing, psychiatry and sociology) scientific concepts of trust and proposed a more mature interdisciplinary concept of the process of establishing trust. Their evaluation of hospitalized patients' trust in health care providers has led to further development of a model of the process of establishing trust in the patient-provider relationship with the following structural features: (1) Trust emerges when an identified health care need can only be met by an health care provider; (2) Trust involves assessment of risk when relying on another to meet this need; (3) Trust involves monitoring or testing behaviors that can be both overt and covert; (4) Trust involves a willing dependence on someone else's action; (5) Trust evolves with congruent expectations of actual behaviors of health care providers. Hupcey et al. (2001) identified "meeting expectations," as core in the process of developing trust.

Expectation as defined by Random House (2000) is the act of looking for with \ reason or justification. The construct of expectation, exemplifies the temporal, attitudinal and cognitive dimensions of trust. This theoretical model proposes a process of

meeting/rewarding expectations over time and the successes or failures in this endeavor leads to the building or the diminution of trust. Bell, Krazitz, Thom, Krupat and Azari, (2002) found statistically significant association between unmet expectations within the context of visit specific value expectations and low patient satisfaction with care, poor symptom improvement and weaker intention to adhere to physicians' advice. Unmet expectations occurred more frequently in younger patients, unmarried patients and patients with decreased level of trust in their physicians. Patients with a lower level of trust were more likely to communicate less, have more unmet expectations and subsequent diminution of trust and subsequent greater symptom severity.

Research in the field of addiction has shown that unmet expectations alter neural signals within the brain's reward circuitry, (Sutton, et al. 2003) and signify a physiological response (neuronal adaptation) to a psychological experience (an un-rewarded expectation) (Carlezon, Jr. and Wise, 2003). Behavioral changes occur with repeated un-rewarded expectations; in addiction medicine this process is called "extinction" (Carlezon, Jr. et al.,2003). Extinction in addiction medicine describes the decrease in drug seeking behavior by rats repeatedly denied drugs via a mechanism that previously supplied an addictive drug (an un-rewarded expectation) (Sutton et. al., 2003). This neuronal adaptation in the brain of rats is triggered by a memory of a rewarded expectation changing to an un-rewarded expectation (Carlezon, Jr., et al., 2003). Consider a parallel to "extinction," not of drug seeking behavior but of trust, repetitive un-rewarded or unmet expectations results in a decline or "extinction" of trust. Patient-physician expectations in the context of the clinical relationship carry both

psychological and communicative properties and shape the cognitive and affective aspects of the relationship (Cegela, Socha McGee and McNeilis, et al., 1996; Cegala,1997). Communication expectancies are functions of cultural and sociological norms and communication behaviors vary for individuals and groups, and O'Hair (1996) showed that patients' preferred certain styles of communication and these preferences were in actuality expectations. His relational expectancy model, describes both affective and cognitive processing impacted by previous experiences, expectations and relational knowledge. The individual subsequently develops goals/plans and a formulated expectation that is then carried into the interaction. A key feature of the relational expectancy model is that of expectancy violation, negative expectancy violations generates relational dissatisfaction in patient-provider communicators; and expectancy violations induces a level of arousal leading to cognitive and behavioral change.

Carl Rogers, a psychotherapist, proposed an influential theory on the therapeutic process within interpersonal relationships. Although from a psychotherapy point of view, this theory is also applicable to human relationships in general. He posited an "underlying orderliness" in all human relationships that either facilitated relational/personal growth and openness or inhibited relational/personal growth, facilitating defensiveness and blockage. Roger's primary element was labeled congruence and this concept of congruence was defined as "an accurate matching of experiencing and awareness" (Rogers, 1961, p339). Congruence was also extended by Rogers to include communication "an accurate matching of experiencing, awareness and communication" (Rogers, 1961, p339).

Rogers gave the example of a hungry infant, fully aware of his/her hunger and expressing this awareness verbally, and was deemed a "congruent" or genuine response. He then proceeded to give an example of a man exhibiting anger by his tone and gestures in a discussion with friends, but when his actions were labeled as angry he denied with apparent surprise and sincerity being angry and his friends responded by laughing in disbelief. This example was labeled as "incongruent." Rogers described the man's response as incongruent because of the mismatching of experience and awareness. The man's friends experience was his angry tones and gestures but the man's response described a lack of awareness of his angry tone and gestures. This lack of awareness was described as "defensiveness or denial." Roger's presented yet another example of a woman at a party exhibiting behaviors signaling boredom by yawning and looking at her watch. Upon her departure she stated her enjoyment and described the party as delightful. Rogers labeled this behavior as incongruence between awareness and communication and described it as "falseness or deceit," because the woman was aware of her experience of boredom but chose to label it otherwise.

An important corollary of the construct of congruence is if a person is fully congruent then all communication should be within the context of personal perception. To be fully congruent means all communication describes personal awareness of personal experience, for example instead of saying "he is stupid" one might say, "I believe he is stupid." Increased congruence at any or all level(s) (experience, awareness, communication) on one or both sides of an interpersonal interaction can lead to: clearer communication, improved clarity in response, lowered defenses, diminished facades,

genuine expressions, accurate listening, increased empathy, understanding, and a positive regard leading into a relationship with greater unity, integration, and lower conflict and increased energy for "effective living; change in a direction of greater maturity," in other words a highly therapeutic interaction. Incongruence at any or all level(s) can lead to the opposite.

Rogers, (1961,p344-345) "general law of interpersonal relationships," assumes that (a) two people possess a minimal level of willingness to be in contact (b) the ability and minimum level of willingness to communicate with each other, and (c) this occurs over a period of time. If the previously stated assumptions hold then the following relationship is proposed to be true. The higher the level of congruence of experience, awareness and communication of an individual in a relationship, the better the reciprocal communication which leads to improved psychological adjustment and functioning in both individuals and greater satisfaction in the relationship on both sides. The converse holds, in that the higher the level of incongruence of experience, awareness and communication of an individual in a relationship, the lesser the reciprocal communication which leads to lesser understanding, maladaptive psychological adjustment and functioning in both individuals and greater dissatisfaction in the relationship on both sides. Roger's "general law of interpersonal relationships" appears to be another potential crucial piece of the puzzle, which helps to clarify potential mechanism by which trust and distrust co-exists in an interpersonal relationship. The following definition of trust supports this. Trust is conceptualized to exist in an interaction wherein there is a perception of vulnerability by an individual, the trustor, who after evaluating certain

characteristics of another (trustworthiness); the trustor then becomes a willing dependent upon the goodwill of the trustee (Bair 1986; Jones, 1996 and 1999; Mayer, Davis, Schoorman, 1995).

1.8 Measurement of Trust and Distrust

Current available scales for measuring patients' trust in physicians differ in content, and suffer from limited testing and development (Pearson and Raeke, 2000). Previously developed scales include: the interpersonal trust measure of Trust in Physician Scale (Anderson and Dedrick, 1990); the Primary Care Assessment Survey, (PCAS) (Safran, Kosinski et al, 1998); the Kao-Green Patient Trust Scale (Kao, Green, Davis, et al., 1998) and the Wake Forest Physician Trust Scale (Hall, Dugan et al, 2001; Hall, Zheng et al., 2002). The Trust in Physician Scale, a validated 11- item interview-administered tool with a minimum reported Cronbach α of 0.85, was designed to measure an individual's trust in their own primary care physician and consisted of the 3 domains of dependability, confidence and confidentiality of information (Anderson and Dedrick, 1990). The Primary Care Assessment Survey (PCAS), a validated self-administered written questionnaire designed to measure primary care performance across different types of indemnity and managed care delivery systems and consisting of 11 unique summary scales, 51 questions and 7 distinct elements of primary care performance of which trust was one. The PCAS trust subscale consisted of 8-items, Cronbach α range of 0.81 - 0.95 with three trust domains of, integrity, agency and competence (Safran, Kosinski et al, 1998). The Kao-Green Patient Trust Scale is a validated 16–item, later

trimmed to 10-item modification of the Trust in Physician Scale designed to measure the effect of payment method and other elements of managed care on patient trust (Kao, Green, Davis, et al., 1998, and Kao, Green, Zaslavsky, et al., 1998). The subsequent 10-item Patient Trust Scale added items to evaluate patient trust, and patient evaluation of physician confidentiality and reliability in the setting of possible managed care cost and administrative restrictions and reported Cronbach α of 0.94. The Wake Forest Physician Trust Scale (Hall, Zheng et al., 2002) is a validated 10-item scale designed to measure patient trust in physicians in general and consist of four of the five trust domains: fidelity with two items, competence with three items, honesty with one item, and global with four items. It excludes the domain of confidentiality.

Thom and Campbell (1997) and Thom, Bloch and Segal (1999) identified seven behavioral categories of physician behavior that increased patient's trust from analysis of focus group data: (1) provide a thorough evaluation of problems; (2) provide appropriate and affective treatment; (3) provide communication that is clear and complete (4) encourage partnership building; (5) express caring; (6) show respect and understanding of the patient's experience and (7) demonstrate honesty. The seven behavioral categories were determined from analysis of four focus group data, and were not clearly defined, validated or tested for reliability and therefore this did not allow for the determination of a predictive value of the individual behaviors. In 2001, Thom, et al., reported that "caring and comfort, technical competency and communication are the physician behaviors most strongly associated with patient trust." It is of great interest to note that a Cochran Review (McKinstry, Ashcroft, Car, Freeman and Sheikh , 2007) reported not

finding any published reports of a successful intervention designed to positively impact patients' trust in physicians.

The Wake Forest Physician Trust Scale was chosen for this study because it was developed to measure interpersonal trust and not social trust; and may be more applicable to our proposed conceptual model. The Wake Forest Physician Trust Scale (Anderson and Dedrick, 1990; Safran, Taira et al., 1998; Kao, Green, Davis, et al.,1998; Kao, Green, Zaslavsky, et al., 1998) is more strongly correlated with patient satisfaction, patient desire to remain with a physician, patient willingness to recommend physician to friends and patient not seeking second opinions, but is less correlated with social trust measures such as insurer trust, membership in managed care and choice of physician; and equivalent correlation with lack of disputes with physician, length of patient-physician relationship and number of patient visits (Mark, Zheng, et. al., 2002) .

Furthermore, in medicine trust, distrust and trustworthiness have been examined in limited patient populations, and few clinical and organizational context (Cook, Kramer, Thom et al., 2004). The trustworthiness of medical organizations although an important research focus in the last decade (Mechanic & Schlesinger 1996; Anderson and Dedrick, 1990; Safran, Kosinski, et al, 1998), should not preclude vital research on patient trust and distrust in individual medical personnel (Hall, Zheng et al., 2002 and Thom and Campbell, 1997). Very few studies have simultaneously evaluated physician and patient's trust and distrust (Cook, et al. 2004). This study expands our knowledge on cancer patient's trust and distrust in their physician by the simultaneous measurement of and evaluation of both their effects.

Chapter 1

METHODS

2.1 Summary of Design.

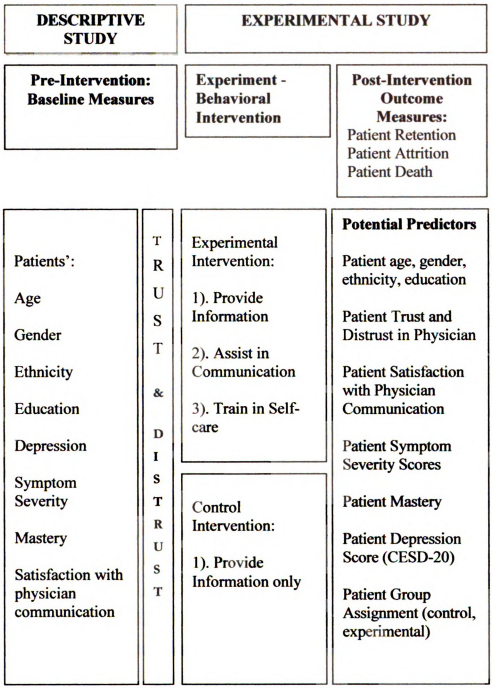
Secondary Analysis of a RCCT Data-set.

This study was a secondary analysis of a completed longitudinal randomized controlled clinical trial (RCCT). The institutional review board at Michigan State University and all the sites participating in the RCCT project approved this study. Following consent the enrollment and interview data was entered into a secure web-based data collecting system. The subsequent data was processed and all possible identifying data was removed from the data-set used in the secondary analysis.

This secondary analysis evaluated the relationships between the dependent variable of patient retention, attrition or death during the RCCT and the two independent variables of patients' trust and distrust, controlling for patients': age, ethnicity, gender, levels of satisfaction with physician communication, controlled and experimental grouping, symptom severity score, patient mastery and depression (CES-D-20 score). All data analyses were performed with SAS software, version 9.

The overall study design had two major components. As shown in Figure 4, the descriptive portion of our study delineated whether there was any relationship between age/ethnicity/gender etc. and patient trust, and distrust at baseline before entry into the RCCT.

Figure 4. A Schema of the Secondary Analysis and Measured Variables.



The experimental portion of the study tested the propositions that after adjusting for site of cancer; pre-intervention patients' trust and distrust controlled for previously proposed predictors for attrition, predicted the post-intervention measured outcome of: retention, attrition and death during the study.

The dependent or outcome variable of patient retention, attrition or death during the RCCT was determined as follows. Patients were classified as retained in the study if they completed all three interviews at baseline (prior to randomization), week 10 and week 20 of the trial. Patients were classified in the attrition group if they refused to continue in the study, to continue the experimental intervention, or to complete any one of three interviews. Patients were classified in the death group based on reports of patients' death and a review of medical records after participants signed consent forms.

The independent or predictor variables of patients' trust and distrust in the analyses were treated in three different ways: first as two separate continuous variables, second as two separate categorical variables with two levels of low or high trust (low trust [t] /high trust [T]) and low or high distrust (low distrust [d] /high distrust [D]), and third as two co-existing categorical variables with the four levels of co-existing low or high trust and low or high distrust: low trust [t]/low distrust[d] or [td]; high trust [T]/low distrust[d] or [Td]; low trust [t]/ high distrust[D] or [tD]; high trust [T]/high distrust[D)]or (TD).

The independent controlling variable of patients' depression was treated both as a continuous variable quantified as a mean score and as a categorical variable with two levels depressed or not depressed. A score $\geq$ 16 was labeled depressed and < 16 was

labeled not depressed. The independent controlling variables of patient mastery, patient satisfaction with physician communication and symptom severity in the analyses were always treated as continuous variables and quantified as mean scores. In the analyses the independent controlling variables of gender, race/ethnicity, education and intervention grouping were always treated as categorical variables. Gender had two levels, male or female; race/ethnicity had two levels, Caucasian or African American, education had 3 levels, some college or more, high school graduate, less than high school graduate; and intervention grouping had two levels, experimental or control.

The RCCT: Automated Telephone Symptom Management (ATSM)

The RCCT was designed to evaluate the impact of an automated telephone symptom management program as a behavioral intervention to aide patients' in the management of thirteen commonly occurring cancer treatment related symptoms. The study utilized the Homelink Service, an automated monitoring and triage system developed by the University of Michigan Health System. The automated monitoring and triage system served three main functions: 1) eligibility checking, 2) initial 6-week screening and event notification and 3) upon reaching threshold, preparation of data for delivery to either experimental or control arm of the trial. An Interactive/Automated Voice Response System (AVR) version of the M.D. Anderson Symptom Inventory (Paice, 2004), provided weekly monitoring of patients' symptom severity. Patients' reporting a predetermined symptom severity score threshold score of 2 or greater on a scale of 0-10 were selected to enter the RCCT. Patients were randomized to the two arms

of the trial, consisting of an automated telephone symptom management (ATSM) – experimental arm and a nurse-assisted symptom management (NASM) – control arm.

In ATSM, patients were referred by the AVR to the accompanying symptom management area in the symptom management guide (SMG) if they reported a symptom severity score or 4 or greater. ATSM provided information and education support by directing patients to printed information provided in the symptom management guide (SMG). SMG provided written instructions for the management the cancer treatment related symptoms. Referrals to tabs in the SMG were recorded by ATSM. Patients were also reminded to contact their oncologist when symptoms were urgent (deemed to be a score of 7 on a scale of 0 to 10). SMG was designed to complement the information and education provided by medical-caretakers. The symptom management approaches in SMG is based on National Comprehensive Cancer network (NCCN) guidelines, evidence-based efficacy provided by RCT, and information form quasi-experimental studies for the non-pharmacological management of the 17 prevalent

Figure 5. A Schema of the Randomized Controlled Clinical Trial (RCCT)

Patient Consent
SCREENING AND TRIAGE Twice weekly automated telephone calls for up to 6 weeks to monitor severity of 13 prevalent symptoms. 1 + symptom ≥ 2 on a severity scale of 0-10, patient enters trial
Baseline interview
Random Assignment
SMG sent
RANDOMIZED TRIAL **ATSM** 6 weekly automated calls (week 1-4,6 &8) Referral to SMG Oncologist – calls as needed 7 + symptom severity referred to oncologist Versus **NASM** **6 nurse calls** (week 1-4,6 &8) Individualized symptom management Use of SMG Oncologist – calls as needed 7 + symptom severity referred to oncologist
Interview week 10 and week 20
Medical record audit

cancer symptoms. SMG has been used in five previous studies and was well utilized by the study subjects.

The NASM is a cognitive behavioral problem-solving intervention delivered by telephone over a period of 8 weeks by a nurse specially trained to implement a multi-dimensional protocol for the management of 17 common cancer and chemotherapy related symptoms. Interventions are standardized protocols and computer software allows tracking of the number and severity of all symptoms during the course of the intervention. Each week all 17 symptoms are assessed, together the subject and the nurse select and individualize standardized strategies from the intervention themes to address symptoms at threshold. Components of the four intervention themes includes: 1) self-care; 2) information, decision-making and problem solving; 3) communication with providers and 4) counseling and support. The value of NASM as a control is based on proven efficacy of an oncology nurse utilizing a problem solving approach to symptom management that individualized to the patients' situation (Given et al., 2004).

The RCCT project was designed to facilitate patient communication with their providers, with a focus on the development of patients' communication skills, in order to improve the treatment and management of their illness. The reader is referred to Sikorskii, Given, Given, Jeon and McCorkle, (2007) for results on the RCCT study.

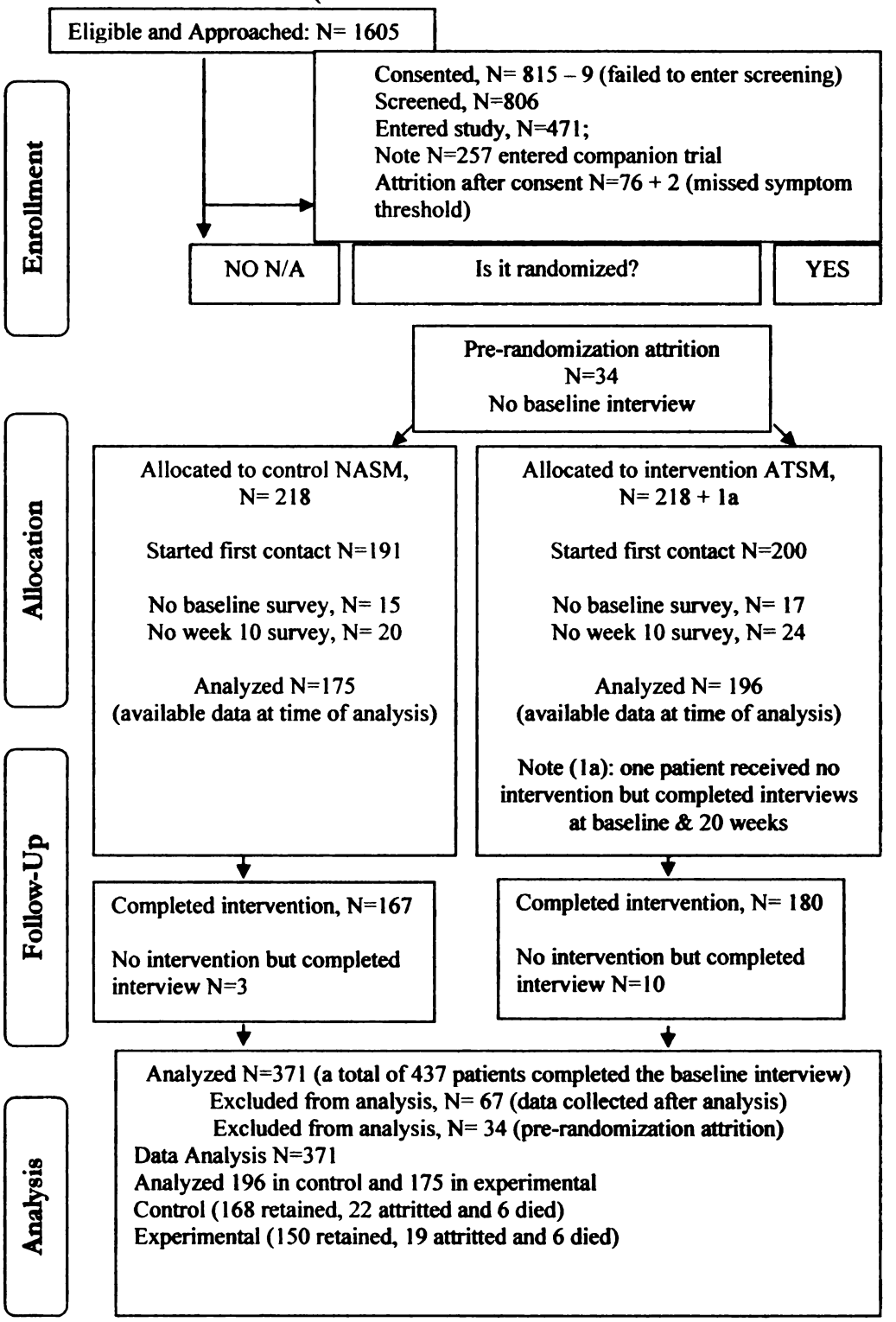
2.2 Participants and their Participation in the RCCT

The participants selected for this secondary analysis included all the research patients enrolled in the RCCT study at the time of the secondary analysis. Research study

participants were recruited to the RCCT study from two comprehensive cancer centers, a community cancer oncology program and six hospital-affiliated community oncology centers in the Mid-West. Patient eligibility for study participation was determined by patient's care providers and based on information in their medical record. Inclusion criteria included: age equal or over 21 years, cancer patients who were undergoing a course of chemotherapy for common solid tumor cancers, including breast, colorectal, lung and non-Hodgkin's lymphoma, cognitively intact, English speaking/reading, the ability to hear and speak via telephone and the possession of a touch-tone telephone. Patients were excluded if they had other hematological malignancy, treatment that includes bone marrow transplant or stem cell rescue, and any diagnosis of active (under treatment) emotional or psychological disorder.

Figure 6, delineates the flow of patient participation (recruitment, retention, attrition and death) during the entire RCCT (for RCCT details see, Sikorskii, 2007). Nurse recruiters approached 1,605 eligible cancer patients of which 815 signed informed consent forms. Nine patients failed to enter the screening and of the 806 patients screened, 76 patients attrited, two failed to meet the symptom threshold, and 257 entered a simultaneously run companion trial. Entering the ATSM, RCCT were 471 patients, 34 of which attrited prior to the baseline interview, therefore 437 completed the baseline interview. The patients were then randomized, 219 to ATSM or experimental arm and 218 to NASM or the control arm. Between the baseline interview and the second interview at week ten, a total of 41 patients either attrited or died in the ATSM group and 35 patients either attrited or died in the NASM group.

Figure 6. A Modified Consort E-Flowchart of Patients' Participation in the RCCT. (Modified data from Sikorskii et al. 2007 manuscript.)



Completing the second interview at 10 weeks, were 167 patients in the ATSM group and 180 patients in the NASM group. In the secondary the numbers differ because the analysis was conducted prior to the end of the data collection. The actual accrual number at time of analysis was 434 cancer patients. Note in the qualitative analysis, the sample size was, n=434; analyzed were n=48 for African Americans and n=368 for Caucasians. In the quantitative analysis the sample size was, n=371, with n=43 for African Americans and n=328 for Caucasians. In the secondary analysis control or NASM n=196 and experimental or ATSM n=175.

The RCCT research study was powered to detect a statistically significant difference in the primary outcome measure of the severity index of the 17 core cancer related symptoms between the experimental and conventional care control group. Power calculations projected the need for accrual of 175 subjects per group to detect a meaningful difference. Projected minority accrual of 10-15% of the total study sample was based on previous accrual rates.

In order to improve data collection and limit missing data points the instruments was administered via a telephone interview. Patients reported to an interviewer: gender, birth date, education level, ethnic background, current marital status and number and age range of household members. Each participant's medical record was audited following the end of the 8-week observation, and the status of the patient recorded as continuing in the study, withdrawal from the study or death.

Information also collected/extracted included: co-morbidities, symptoms, complications and treatment plans. Data regarding cancer stage, site, and recurrence was

collected from medical records after participants signed consent forms. Cancer stage was coded as *early* (stage 1 or 2) or *late* (stage 3 or 4), according to the TNM staging criteria of the American Joint Committee on Cancer (2003).

The study covered 6 contacts over a period of 8-weeks with data collected at baseline (after consent but before randomization), at 10-weeks and at 20-weeks. This timing was implemented in order to evaluate the randomization process, the initial impact of the measurement and probable drift, and deferred or sustained impact of the intervention. Prior to randomized assignment to control or experimental group, consented patients were screened over the telephone to assess the presence of one or more of the seventeen cancer-related symptoms. Patients scoring a two or higher on one or more of seventeen cancer-related symptoms were enrolled in the study and subsequently interviewed.

2.3 Materials

All patient reported data was collected via a telephone interview at baseline (after consent but before randomization), at 10-weeks and at 20-weeks.

Wake Forest Physician Trust Scale (WFPTS)

The Wake Forest Physician Trust Scale was developed for measuring patients' trust in their primary care providers (physicians as well as non-physician). The Wake Forest Physician Trust Scale was chosen for this study because it was developed to measure interpersonal trust and not social trust, and may be more applicable to our

proposed conceptual model. The original scale consists of 10-items with four response categories: (i) fidelity - 2 items, (ii) competence – 3 items, (iii) honesty – 1 item, and (iv) global – 4 items with an overall alpha of 0.93 (Hall et al., 2002). The 10-item questionnaire WFPTS utilizes a Likert 1-5 response categories (strongly agree, agree, neutral, disagree, and strongly disagree). Three items (#2, 3, and 8) are negatively worded. In previous reports, trust was measured by the sum of the 10 item scores, with a higher score indicating more trust. The Wake Forest Physician Trust Scale has previously established reliability and validity in a random national sample of HMO members asking about their primary care providers. At the time of the study no reports were found of the instrument being used among cancer patients. The coefficient alpha for the patients in the RCCT was 0.91 in Caucasians and 0.88 in African Americans.

Princess Margaret Hospital Patient Satisfaction with Doctor Questionnaire (PMH/PSQ-MD) (Loblaw, Bezjak and Bunston, 1999).

A modified version of the PMH/PSQ-MD was used to determine patients' satisfaction with physician communication in the study. The PMH/PSQ-MD was developed for use in the outpatient oncology setting, and is specific to patient-physician interaction. The original scale consists of 29-items asking patients about their satisfaction with information exchange, interpersonal skills, empathy, and quality of time. Our modified version consists of the 10 items evaluating information exchange, with an alpha of 0.92 and established convergent and divergent validity.

Symptom Experience Inventory

The cancer symptom inventory was developed by Given et al. (2004). The inventory measured 17 symptoms (fatigue, pain, dyspnea, insomnia, distress, nausea, fever, difficulty remembering, lack of appetite, dry mouth, vomiting, numbness and tingling, diarrhea, cough, constipation, weakness, and alopecia) and related concepts and includes the 7 most prevalent symptoms (fatigue, pain, dry mouth, insomnia, poor appetite, constipation and nausea) experienced by cancer patients undergoing chemotherapy. Patients were asked whether in a 1-2-week period they experienced a symptom, yes or no; if yes, they reported frequency, severity and limitation imposed upon daily activity on a scale of 0 (not present) to 10 (as severe as it possibly could be). For statistical analysis a sum score was calculated and a sum mean score across all seventeen symptoms was generated. Reliability coefficients of number of symptoms, severity of symptoms and limitations imposed upon daily activity are 0.71, 0.78 and 0.71 respectively

Depression – CES-D-20

The Center for Epidemiological Studies-Depression scale (CES-D) was used to evaluate patients' reports of depressive symptoms (Radloff 1977). The CES-D was developed to measure depression within non-psychiatric general population. The scale consists of 20-items with four specific response categories: depressed affect, positive affect, somatic/vegetative, and interpersonal, and one non-specific category. This 20-item scale assesses the depressive symptoms on a 4-point Likert-type scale ("almost all of the

time," "most of the time," "some of the time," and "rarely/none of the time"). The full version of the CES-D20 scale was utilized. A pre-determined score of ≤ 16 dichotomized the sample as depressed and > 16 as not depressed. The CES-D has a reliability range of 0.85 to 0.92.

Patient Mastery

The mastery scale is a modified seven-item measure which assesses patient psychological coping resources or self-care mastery on a 5-point Likert-type scale ("strongly disagree," "disagree," "no opinion," "agree" and "strongly agree"). The initial development of this instrument was done by Pearlin and Schooler, 1978. The original questions were modified to specifically address patients' mastery of cancer care. The alpha coefficients for this modified instrument were 0.73 among patients' in the RCCT.

Chapter 2

ANALYSIS AND RESULTS

3.1 Quantitative Analyses and Results.

Basic Descriptive Analyses

In the final tabulation, (see Sikorskii et al., 2007), the RCCT reported that a total of 437 patients completed the baseline interview and were randomized to the control (n=218) and experimental (219) groups. The data used for this secondary analysis comes from 328 Caucasians and 43 African American cancer patients. Note that for this research, which is a secondary analysis of the RCCT data, the variations in the number (n) are due to the conduction of the secondary analysis prior to final completion of the data collection and also some missing data points. Basic descriptive analyses of the socio-demographic characteristics of the research subjects included: percentage, mean, standard deviation, and range. The characteristics of the research participants are summarized in Tables 1, categorical variables reported as percentages and Table 2, continuous variables reported as mean, range, and standard deviation.

In Table 1, Caucasians were approximately seven and a half times more (n=328, 88.4%) than African Americans (n=43, 11.6%). There were three times as many women (n = 282, 76%) as men (n=89, 24%) in the study. Greater than two thirds the participants had some college education or higher (n = 255, 69%). Eighty percent of the participants were in the high trust group (T) (n=298) and eighty one percent of the participants were in the high distrust group (D) (n=301). Almost one third the participants were categorized

as depressed (n = 115, 31%). Approximately three quarters of the participants were in the high trust-distrust type (TD, n=270, 73%), eleven percent in the low trust-distrust type (td, n=42), and eight percent in both the high-trust-low-distrust type (Td, n=28) and low-trust-high-distrust type (tD, n=31).

In Table 2, the mean age of the participants was about 60 years old, with a range of 35-89 years old). The mean trust score of study participants was 26.2 out of a maximum of 30, while the mean distrust score was 17.4 out of a maximum of 20. The mean for depression score was 12.5 with a wide minimum and maximum score range of 0 - 39. The mean cancer related symptom severity score was 4.3 with a range of 0 – 8.63. The mean for patient mastery score was 25.9 with a minimum and maximum score range of 11 - 35. The mean for patient satisfaction with physician communication was 43.3, with a minimum and maximum score range of 27-50.

Other socio-demographic data not included in Tables 1 and 2 due to higher patient numbers in a later analysis (Caucasian, n=370 and African Americans, n=49) included: over half of the participants were married (n = 253, 60%); the most common site of cancer among participants was breast (n = 167, 40%), followed by lung (n = 70, 17%) then colon (n = 60, 14%); and the vast majority of participants had a diagnosis of late stage cancer (n = 339, 81%) with 21% of participants having had a recurrence in their cancer (n = 89).

Descriptive statistics comparing means of patients' trust by patients' characteristics are summarized in Tables 3. The level of patients trust was significantly related to patients' race/ethnicity, Caucasians were significantly more trusting

(mean=26.3) than African Americans (mean=24.8), p value 0.009. Second, the level of patients trust was also significantly related to patients' depression with a mean trust score of 26.1 and a p value of 0.052. Third, the level of patients trust was also significantly related to patients' mastery, with a mean trust score of 26.2 and a p value of < 0.0001. Finally, the level of patients trust was also significantly related to patients' satisfaction with physician communication, with a mean trust score of 26.2 and a p value of < 0.0001.

Descriptive statistics comparing means of patients' distrust by patients' characteristics are summarized in Tables 4. The level of patients distrust was significantly related to patients' race/ethnicity, Caucasians were significantly more distrusting (mean=17.5) than African Americans (mean=16.5), p value 0.009. Second, the level of patients distrust was also significantly related to patients' depression with a mean distrust score of 17.4 and a p value of 0.008. Third, the level of patients distrust was also significantly related to patients' mastery, with a mean distrust score of 17.4 and a p value of < 0.0001. Finally, the level of patients distrust was also significantly related to patients' satisfaction with physician communication, with a mean distrust score of 17.4 and a p value of < 0.0001.

Bivariate Analysis

Bivariate analyses of research subject characteristics by clinical trial participation grouping (retention, attrition and death) were also performed. The p values for the categorical variables were calculated using Fisher Exact Test (using Proc Freq in SAS) instead of the Chi square test due to the small sample size. The p values for the

continuous variables were calculated using multiple comparison procedures (MCPs) such as analysis of variance (ANOVA) using Proc ANOVA in SAS and Tukey's Studentized Range (HSD-honestly significant difference) test using Proc GLM in SAS. The following statistical associations between study participants characteristics and clinical trial participation grouping of retention, attrition, and death of study participants are summarized in Tables 5 and 6.

Retention, attrition, and death for study participants were n=318 (86%), n=41 (11%) and n=12 (3%), respectively. In Table 5, females were more likely to stay in the study when compared to male counterparts 87% versus 82%, with a p value of 0.024. Non-depressed participants were less likely to drop out of the study than depressed participants, 7% versus 19% with a p value of 0.002. Participants with a high level of distrust were less likely to drop out of the study than participants with a low level of distrust, 9% versus 20% with a p value of 0.002. There were also statistically significant differing percentages in retention, attrition, and death for study participants by distrust type (td=low-trust/low-distrust; Td=high-trust/low-distrust; tD=low-trust/high-distrust; TD=high-trust/high-distrust). Participants with high distrust and low or high trust were more likely to stay in RCCT when compared to participants with low distrust and high or low trust, p value 0.008. African Americans were more likely than Caucasians to leave the study, 33% versus 10 % with a borderline p value of 0.052. Trust category (both high and low), p value 0.131; ethnicity, p value, 0.052, education, p value 0.353 and intervention group, p value 1; were not statistically significantly associated with the clinical trial participation grouping of retention, attrition, and death.

In Table 6, the patients who stayed in the study when compared to patients who left the study were less likely to be depressed (mean score 12.03 versus 15.24, p value 0.032), and had a higher level of distrust (mean score 17.57 versus 16.27, p value <0.001). Also the patients who stayed in the study when compared to patients who died during the study had lower total symptom severity score (mean score 4.22 versus 4.80, p value 0.026), a higher level of mastery (mean score 26.21 versus 21.83, p value <0.001), and a higher level of trust (mean score 26.26 versus 23.58, p value 0.031).
A higher level of mastery was not associated with patients who stayed or left the trial (mean score 26.21 versus 24.47, CI 0.124, 3.354). Age was also not statistically associated with patient retention, attrition or death during the RCCT, p value 0.495.

Multinomial Logistic Regression

To address our research question we compared research patients who were retained in the trial (reference group) to patients who attrite from the trial and patients who died during the trial, utilizing multinomial logistic regression to control for potential confounders. Study participation (retention, attrition, death) was treated as the dependent variable in the following analyses. The results explain the odds ratios (OR) of retained subjects to subjects who attrite and subjects who die. Retained subjects were treated as the reference class. The exp $^{(\beta)}$ coefficients in multinomial logistic regression are interpreted in a similar fashion to odds ratios. Evaluation of patient trust and distrust controlled by gender, age, race/ethnicity, education, mean symptom severity score, group assignment (experimental/control), depression/CESD score), patient satisfaction with

physician communication and patient mastery were evaluated and included in the model based on literature support and/or statistical significance at the level of ≤ 0.25 in the bivariate analyses. Reliable income data was not available at time of the analysis. Cancer stage, cancer site, recruitment site and marital status were evaluated for any significant contribution to the attrition model; they were not significant predictors for patient retention, attrition or death, and were not included in our current attrition model. As supported in the literature, possible interactions between the independent variables (such as gender and education level or race, and education level) were tested for significant contribution to the attrition model and none was found. Variance inflation factors were used to test for collinearity, with a threshold value >5 used for exclusion of candidate variables from the model. The goodness of fit for the various models was assessed using the Akaike Information Criterion (AIC) statistic. All models were fitted with the use of the Proc logistic, link=glogit procedure in SAS (version 9.1.2).

The multinomial logistic regression results are summarized in Tables 7 and 8 and Figure 10. In Table 7, attrition was referenced to retention. Research subjects ethnicity (OR 2.890, CI 1.125, 7.427; p-value 0.028), trust (OR 1.270, CI 1.027, 1.597; p-value 0.039) and distrust (OR 0.685, CI 0.559, 0.846, p value 0.0003 were statistically associated with attrition referenced to retention. In other words: African American participants were 2.9 times more likely to leave the trial when compared to their Caucasian counterparts; participants with higher levels of trust were 1.2 times more likely to leave the trial when compared to their less trusting counterparts and participants with lower levels of distrust were 1.5 times more likely to leave the trial when compared to

their greater distrusting counterparts that stayed in the trial. Patients' age, gender, education, symptom severity mean score, intervention grouping (experimental or control), patients' satisfaction with physician communication and patients' mastery were not statistically associated with attrited referenced to retained participants.

In Table 8, death was referenced to retention. Research subjects female gender (OR 0.225, CI 0.059, 0.862, p-value 0.02); and mastery (OR 0.791, CI 0.656, 0.953, p value 0.014), were found to be statistically associated with death referenced to retained. In other words, female participants were 4.4 times less likely to die than their male counterparts and patients with higher levels of mastery were 1.3 less likely to die than their counterparts with lower levels of mastery during the RCCT.

3.2 Qualitative Analysis and Results

Validation of the Wake Forest Trust in Physician Scale (WFTPS) Principal Component and Common Factor Analyses

Principal component analysis and common factor analysis were used to determine the factor structure underlying the 10 questions/variables of the Wake Forest Physician Trust Scale (WFTPS). Principal component and common factor analysis are advanced statistical procedures which can be used in the social sciences to reduce the number of observed variables into a smaller number of artificial variables (called principal components or factors) that account for most of the variance in a data set. Principal component analysis is an orthogonal model and assumes no correlation between the principal components; this method is used for uncorrelated components. Common factor

analysis is an oblique model, assuming correlation between the factors; this method is used for correlated components. There is evidence to support that trust and distrust are correlated but distinct constructs and not two extremes of the same construct, (McKnight et al., 2004; Lewicki et al, 1998; Sitkin et al., 1993) Therefore in our validation analysis we used common factor analysis.

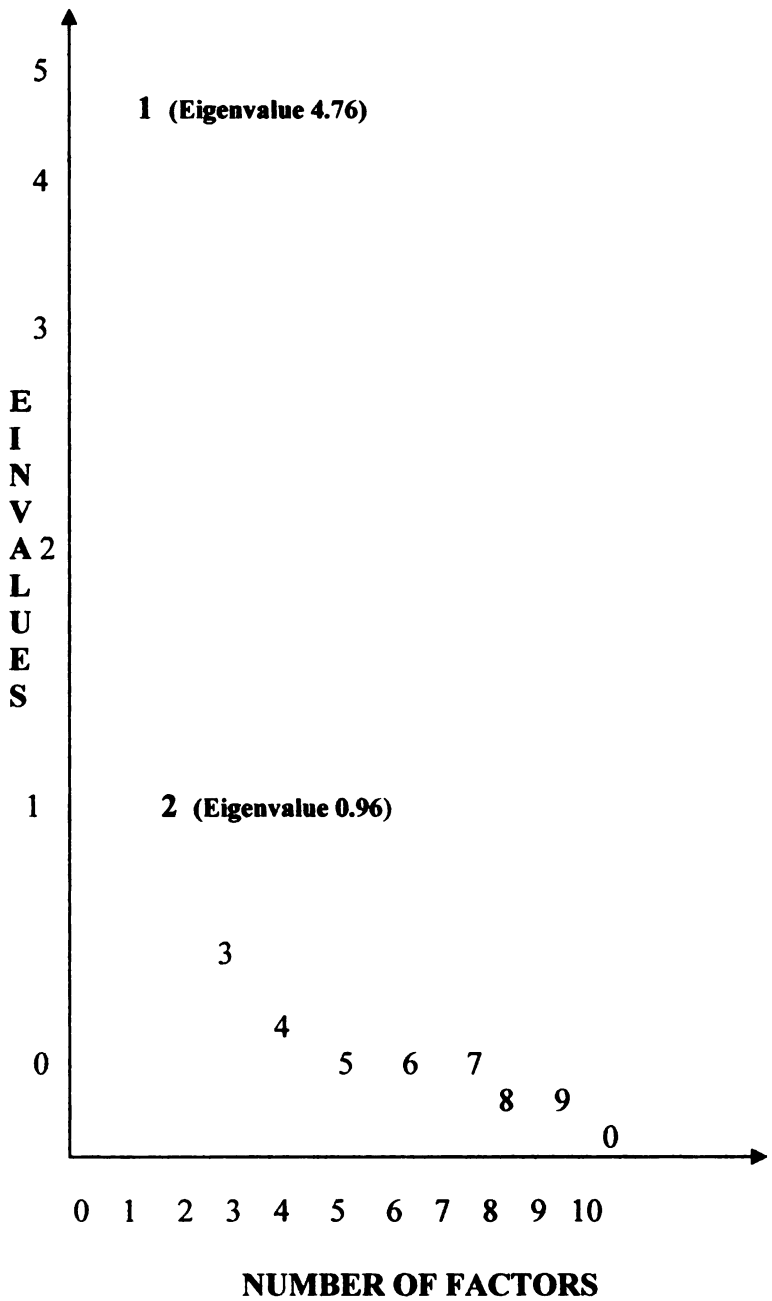
Common Factor Analysis Steps:

The initial extraction of the factors was undertaken and 10 factors were extracted and their Eigenvalues determined. The following procedure was followed in order to determine the number of "meaningful" factors to retain: (a) Eigenvalue-one criterion, (b) The scree test, (c) the proportion of variance accounted for. The interpretability criteria that were followed included: (i) minimum of 3 variables with significant loadings on each retained factor; (ii) determining whether the variables that loaded on a given factor shared the same conceptual meaning (iii) evaluating whether the variables that loaded on a different factor measured different constructs (iv) evaluating whether the rotated factor pattern demonstrated "simple structure," as defined by: (a) a variable loading high on one factor and low to zero on others and (b) demonstrating that the factors load high on some variables and low to zero on others.

Factor Analysis

An a priori criterion of 0.40 was used for inclusion of an item in a factor. Adequacy of sample size for performing factor analysis indicates about 5 times more

Figure 7. Wake Forest Trust Scale Scree Plot



observations than items are needed for analysis (McCallum, Widaman, Zhang, & Hong, 1999). In this analysis the sample size was 368 Caucasian and 48 African American cancer patients for 10 items indicating that the sample size was adequate for factor analysis (>5:1 ratio). Additionally, the Kaiser-Meyer-Olkin measure of sampling adequacy was .91 in the Caucasian group and .81 in the African American group. These measures of sampling adequacy are well above the .60 that is recommended by (Kaiser, 1974, see Hatcher, 1994).

Responses to the 10 item Wake Forest Trust Scale were evaluated using squared multiple correlations as prior communality estimates in common factor analysis. The principal factor method was used to extract the factors and this was followed by a promax (oblique) rotation. A scree test (see, Figure 6) suggested two meaningful factors, which were retained for the rotation. In interpreting the rotated factor pattern, an item was said to load on a given factor if the factor loading was 0.4 or greater, and was less than 0.4 for the other. Using these criteria, 6 items loaded on the first factor and 4 items loaded on the second factor. In reviewing the items that loaded on the two factors there appeared to be a sharing of some conceptual meaning. In other words the grouped items appeared to measure the same underlying construct and items for each factor appeared to be measuring different constructs. The rotated factor pattern did not demonstrate "simple structure" since most of the items had high factor loading on one factor and near-zero loadings on the other factor. Therefore we utilized a rotated factor structure matrix; which is based on standardized regression coefficients and this did demonstrate "simple structure." There were at least 3 variables with significant loading on each retained

factor; factor 1 consists of 6 variables and factor 2 consists of 4 variables. The variables loading on a retained factor appeared to have similar conceptual meaning. Factor 1 included, Questions 1,5,6,7,9,and 10 and factor 2 included Questions 2,3,4, and 8. The variables appeared to load on the different factors and appeared to support different constructs. Question 3, 4 and 5 asked the patient to evaluate, their doctor's medical skill, thoroughness and carefulness and his decisions about which medical treatment was best for the patient. The variables loading on the retained factor 2 had similar conceptual meaning. The inter-Factor Correlation was 0.52 for factor 1 and factor 2. Factor 1 was labeled trust and factor 2 was labeled distrust.

Chapter 3

CONCLUSION AND CONTRIBUTIONS

4.1 Substantive Contribution

These research findings support the novel use of the previously validated Wake Forest Trust in Physician Scale as a valid scale for measuring *both* patients' trust and distrust in their physicians. The assumptions of trust and distrust as opposite ends of a single continuum were not supported by common factor analysis. Subsequent in depth analyses and a more in-depth review of the literature supported discarding the initial assumption of trust and distrust as opposite ends of a single continuum and replacing it with the assumption that trust and distrust are related but distinct constructs. The use of the 10 item Wake Forest Trust in Physician Scale in the simultaneous measurement of both patients' trust and distrust in their physicians makes it a more versatile and efficient instrument; allowing a more expedient measurement of trust and distrust as related yet separate constructs.

The results of the factor analysis of the WFTPS support a two factor model in both Caucasians and African American patients in the RCCT. A comparison factor analysis was performed on a national dataset utilizing the WFTPS; n=903, with Caucasians, n=808 and African Americans, n=95. The coefficient alpha for the total

population was 0.92, for the Caucasian population 0.93 and for the African American population 0.88. The WFTPS therefore exhibits internal consistency, with good internal consistency reliability estimates. A two factor model was also supported by this analysis. Theoretically there may be two explanations for this result. First, this result may be due to a response pattern bias, wherein people tend to agree with the wording of the question, which can lead to a separation of the 10 items in the WFTPS into two factors. The second explanation could be that the scale is actually measuring both trust and distrust.

This study also contributes to the growing literature on patient trust by examining cancer patients' trust and distrust in their physician. The setting was that of a behavioral intervention randomized controlled clinical trial of cancer patients actively undergoing clinical treatment. The Wake Forest Trust in Physician Scale was developed in the general population and an HMO patient population (Hall et al., 2001 and 2002). In the setting of a cancer diagnosis, trust assumes an even greater significance due to the greater emotional dimension of the patient-provider interaction; (Arora, 2003) however, there has been limited reliable and valid measurement of patient's trust (Pearson and Raeke, 2000). It was quite reassuring to find that 80% of patients in the study reported a high level of trust in their physician but it was quite surprising to also find that 81% of patients reported a high level of distrust of their physician. However, only 73% of patients reported a co-existing high level of trust and distrust. It is therefore important to understand patients' trust in and distrust of physicians in the setting of cancer in order to delineate the impact of an interpersonal interaction on cancer patients' attitudes and behaviors.

An association exists between patients' trust, distrust and patients' satisfaction (Safran, Taira et al., 1998, Laveist, et al., 2000) but no one has simultaneously evaluated the three factors in the setting of cancer. This study supports a robust and significant association between patients' satisfaction with physician communication and both patients' trust and distrust. However, patients' satisfaction with their physicians' communication was not a significant predictor on patients' retention, attrition and death during the 8-week period of the behavioral intervention in the clinical trial. Previous research reports a disappearance of race/ethnic difference in patient satisfaction with adjustments for patients' trust and medical (hospital) distrust (Laveist, et al., 2000); however in this research patients' trust and distrust and patients' race/ethnicity were significant predictors for retention and attrition from the clinical trial after controlling for patients' satisfaction with physician communication. It is important to note that the effect of race/ethnicity as a significant factor impacting patients' retention/attrition from the trial withstood taking into consideration patients' trust and mistrust.

Finally, our data suggest that for cancer patients participating in a behavioral clinical trial the level of both trust and distrust was significantly higher in Caucasians compared to African Americans. Higher distrust and not higher trust was significantly associated with retention in the clinical trial, and higher trust was associated with attrition from the clinical trial. In seeking to explain the unexpected phenomena of distrust and not trust acting as the protective factor in clinical trial participation it may be helpful to consider that African Americans attrited more than their Caucasian counterparts and were also both significantly less distrustful and less trusting. Therefore, African American

patients were still more likely to leave the trial than Caucasian patients even when their level of trust and distrust was taken into account. This unexpected turn of event is revisited in the theoretical contribution section.

Researchers have reported medical mistrust as being independent of race (LaVeist et al, 2000) but past research also documents that trust differs by race/ethnicity (Boulware, et al, 2003; Doescher, et al., 2000).The conflicting data on race/ethnicity and patients' trust and distrust levels supports the importance of the continued and simultaneous measurement of trust and mistrust in heterogeneous populations.

4.2 Limitations to the study

We support the use of the Wake Forest Trust in Physician Scale in measuring cancer patients' trust and distrust in physicians based on our common factor and confirmatory analyses; but this is a single study with a relatively small dataset (N=419). Continued and repeated use of the Wake Forest Trust in Physician Scale in larger data sets will help to confirm these novel findings. Confirming and extending the trust and distrust constructs and indicators utilizing path analysis with trust and mistrust as latent variables should also be undertaken with a larger patient population in the future.

4.3 Future Study

A few studies have looked at patient's trust in their physicians over time (trust as a "state" versus a "trait") but have focused on primary care physicians (Thom et al.

1999; Hall et al., 2002). This study contributed to the growing literature on patient trust by examining cancer patients' trust and distrust in their physicians and has the future potential to examine cancer patients' trust in and distrust of their physicians over time. The development of trust is impacted by time; spanning minutes, hours, days, weeks, months, and years; and in times of crisis and critical illness the shorter time spans predominate. (Hupcey, et al., 2001) This investigation of trust is performed in the setting of patients undergoing chemotherapy, and typifies both a personal crisis and a critical illness; and an 8-week intervention study should represent a dynamic model in which to assess the flux of trust and distrust.

The RCCT study utilized a behavioral intervention that provided information and assistance in communication to randomized intervention and control groups. It is anticipated that the intervention should positively impact patient trust by improving the congruence between patient-physician expectations through improved communication. Increased understanding of the impact of the interpersonal interaction on trust and distrust over time, should aide in the shedding of light on the concept of patients' trust in and distrust of their physicians in the setting of cancer.

4.4 Theoretical Contribution

Supporting Literature

The patient-physician relationship is an interdependent relationship that is also categorized as a trust relationship. Some essential characteristics of trust are: 1) system

level integration; 2) reduction of complexity and 3) a lubricant for cooperation. The integrative and reductive function of trust benefits the social system but the cooperative function of trust benefits the individual. At the individual level it is assumed that the individual makes a rational choice to place trust. A proposed model of four elements that define a trust situation includes: first, a trustor places trust and this allows the trustee to honor or violate trust. The trustee cannot honor or violate trust without its placement by the trustor; second, if the trustee honors trust the trustor benefits but if trust is violated the trustor regrets the placement of trust; third, the trustor voluntarily places resources in the hands of the trustee without formal safeguards or sanctions; and fourth, a time delay occurs between the placement of trust by the trustor and the action of the trustee (Coleman, 1990:97-99).

Figure 8, seeks to summarize a proposed literature-based model of co-existing trust and distrust relations. It is assumed that trust and distrust are related but distinct constructs. Trust exists when an individual chooses to be dependent upon another for the fulfillment of a need and there is no guarantee that the individual will not be at risk for harm. For a trust relation to exist the trustor must place trust in the trustee. The trustor can enter the relationship with high trust and low or no distrust or the trustor can have both high trust and high distrust. Note only the Td and TD trust-distrust type was considered in this model. The trustee has the choice of honoring or violating the trust of the trustor. The trustor's choice of unbounded trust or trust bounded by distrust and the trustee's choice to honor or violate the trustor's trust determine the outcomes for the trustor and the trustee. The outcomes are labeled: benefits, sufferings and sanctions.

Figure 8. A Conceptual Model of Coexisting Trust and Distrust Relations.

Temporal Embeddedness:
Interaction over time provides opportunities for trustor's learning and control of trustee.

Pre-conditions

1. Trustor must be vulnerable &placing trust in trustee puts trustor at risk
2. Trustor has a need that only the trustee can fulfill.
3. Trustor is willing to be dependent upon the trustee.
4. A Guarantor or third party monitors & sanctions the trustee for trustor.
5. Trustor & trustee possess pre-existing expectations.
6. Trustor & trustee have a minimum level of willingness to be in contact with each other and possess the ability to communicate with each other
7. Trustor & trustee possess a level of congruence or incongruence of experience, awareness and communication

Trustor believes Trustee is Trustworthy Trust >Distrust (Td)		**Trustor believes Trustee is Trustworthy and Untrustworthy Trust=Distrust (TD)**	
UNBOUNDED TRUST (Td) Trustor Places Trust in Trustee Expectation= Good Outcome No Monitoring by Trustor No Sanctions in Place Monitoring by Guarantor Guarantor's Sanctions in Place		BOUNDED TRUST (TD) Trustor Places Trust in Trustee Expectation= Good & Bad Outcome Monitoring by Trustor Trustor's Sanctions in Place Monitoring by Guarantor Guarantor's Sanctions in Place	
The Trustee Honors Trust	**The Trustee Violates Trust**	**The Trustee Honors Trust**	**The Trustee Violates Trust**
Trustor &Trustee Experience Un-limited Benefits Very Limited Suffering	Trustor Experiences Great Suffering & Trustee Experiences Limited Benefits Sanctions	Trustor & Trustee Experience Limited Benefits &Very Limited Suffering	Trustor Experiences Limited Suffering & Trustee Experiences Greater suffering Sanctions

Network Embeddedness:
Social network linkage between the trustor, the trustee and Guarantor.

Benefits are greatest with unbounded trust and honored trust, but are the least with unbounded trust and violated trust. The mathematics is simple, in a state of unbounded trust more is invested therefore the potential for loss is greater. Suffering is greatest for the trustor when unbounded trust is violated; on the other hand the potential for trustee's greatest suffering can occur if sanctions are imposed by both the trustor and a third party acting as a guarantor.

Facilitators of trust within the social context rest upon sanctions for untrustworthy behavior. Trust emerges, and is established within the social context of an interdependent relationship and the behavior of the individuals is influenced by the social context within which the relationship exists. In "Social Networks and Trust," Buskens (2002) theorizes that the social context: can provide *information* to trustors so that they can *learn* whether the trustee is trustworthy or not; and also help trustors control an untrustworthy trustee through sanctions. Buskens, also describes an aspect of the social context labeled network embeddedness that describes the extent to which the trustor and the trustee are linked to a third party or guarantor in a social network.

Network embeddedness is weighted by whether the relationship extends past a business network into a personal network. Knowledge of the individual is also influenced by the frequency of the interaction. The trustor takes the risk when trust is placed but the trustee is open to sanctions when trust is violated. Sanctions if perceived as threatening by the trustee will lead to defensive behaviors that may interfere with the fiduciary responsibility of the trustee towards the trustor. Another aspect of the social context is labeled temporal, which describes the interaction over a period of time. Temporal

embeddedness influences the trustor's opportunities for learning about and controlling the trustee. The Trustor utilizes their network embeddedness and temporal embeddedness to gain knowledge of the trustee. Buskens, (2002) proposes that improved understanding of the precise effect of the social network on trust including the constructs of network and temporal embeddedness may serve to solve and control trust problems.

A trustee's trustworthiness is influenced by the short-term and long-term incentives to honor or violate trust. Figure 9, delineates a game theoretic representation of coexisting trust and distrust. In this scenario, all four trust-distrust types are represented: low-trust/low-distrust (td), low-trust/high-distrust (tD), high-trust/low-distrust (Td) and high-trust/high-distrust (TD). A patient with the td or trust-distrust type invests the least amount in the trust relation. As documented in figure 9, the payoff amount is minimal, but the loss to the patient is also minimal. A patient with the tD or low-trust/high-distrust invests more than the td type but still significantly less than the Td type who invests the most and therefore has the most to lose. Please note the simplistic mathematical modeling: suffering is modeled as loses to the patient and benefits modeled as payoff to both patient and physician. Sanctions are not overtly modeled but sanctions influence the physician's decision to honor or violate patient's trust and also influence the payoff to the physician.

In revisiting the unexpected result of distrust being a protective factor against attrition from the RCCT, if one places the patients in the trust-distrust game, then it may be logical for the Td type patient to be more likely to attrite compared to the tD type who may have less invested in the study. The expectation of the Td type will be different than

the expectation of the tD type; the Td type is more likely to be disappointed than the tD type and this could lead to attrition from the RCCT.

Figure 9. A Game Theoretic Representation of a Trust and Distrust Interaction

Patient with Low Trust & Low Distrust (td) Patient Places Trust in Physician Physician Honors Trust or Violates Trust Payoff ($5, $5) (-$5, $10) (Patient Benefits, Physician Benefits) (Patient Loss, Physician Benefits)	**Patient with Low Trust &High Distrust (tD)** Patient Places Trust in Physician Physician Honors Trust or Violates Trust Payoff ($10, $10) (-$5, $15) (Patient Benefits, Physician Benefits) (Patient Loss, Physician Benefits)
Patient with High Trust &Low Distrust (Td) Patient places Trust in Physician Physician Honors Trust or Violates Trust Payoff ($40, $40) (-$20, $60) (Patient Benefits, Physician Benefits) (Patient Loss, Physician Benefits)	**Patient with High Trust & High Distrust (TD)** Patient places Trust in Physician Physician Honors Trust or Violates Trust Payoff ($20, $20) (-$10, $30) (Patient Benefits, Physician Benefits) (Patient Loss, Physician Benefits)

The tD type is more likely to enter the trial with preconceived sanctions in place, which may engender a greater sense of control, and foster a greater likelihood of staying in the RCCT.

4.5. Concluding Statement

This is the first report on the use of the Wake Forest Trust in Physician Scale (WFTPS) in cancer patients in a RCCT. The WFTPS is a valid measure of patients' trust in physician. This research supports that the WFTPS is also a valid measure of both patients' trust *and* distrust in their physicians. In medicine researchers have not wholly embraced the concept of trust and distrust as related but unique constructs. This novel concept of the coexistence of trust and distrust in the patient physician relationship shows promise, and may increase our understanding of why interventions targeting patients' trust in physicians alone, have failed in the past (McKinstry et al., 2007; Thom, 2000; Thom, Bloch, et al., 1999) to improve patients' trust in physicians and subsequently alter measured outcomes.

Appendix A- Data Tables and Figures

Table 1 - Patients' Demographics (Categorical Variables)

Research Subject Characteristics		**Number (N)**	**Percentage (%)**
Gender			
	Female	N=282	76%
	Male	N=89	24%
Ethnicity			
	Caucasian	N=328	88.4%
	African American	N=43	11.6%
Education			
	Some College or more	N=255	69%
	High School Graduate	N=84	23%
	Not High School Graduate	N=32	8%
Intervention Group	Control	N=196	53%
	Experimental	N=175	47%
Depression (PCES-D score)	Greater than 16 – Depressed	N=115	31%
	Less than 16 – Not Depressed	N=256	69%
Trust Level			
	High Trust (T)	N= 298	80%
	Low Trust (t)	N= 73	20%
Distrust Level			
	High Distrust (D)	N= 301	81%
	Low Distrust (d)	N= 70	19%
Trust and Distrust Type	Low Trust/ Low Distrust (td)	N= 42	11%
	High Trust/ Low Distrust (Td)	N= 28	8%
	Low Trust/High Distrust (tD)	N= 31	8%
	High Trust/ High Distrust (TD)	N= 270	73%

Table 2 – Patients' Demographics (Continuous Variables)

Research Subject Characteristics	Number (N)	Mean and Range	Standard Deviation (SD)
Age	N=370	Mean=60.1 Range 35 – 89 years	SD= 12.4
Trust	N=370	Mean=26.2 Range 12 – 30	SD= 3.5
Distrust	N= 369	Mean= 17.4 Range 9 – 20	SD= 2.4
Depression Measure CES-D Score	N= 366	Mean=12.5 Range 0 - 39	SD= 8.5
Symptom Measure (Mean Sum Score)	N= 364	Mean= 4.3 Range 0 – 8.63	SD= 1.6
Patient Mastery	N= 365	Mean=25.9 Range 11 – 35	SD= 4.1
Patient Satisfaction With Physician Communication	N= 371	Mean= 43.3 Range 27 - 50	SD= 5.3

Table 3 – Patients' Characteristics Association with Patients' Trust

Characteristics	N	Mean	P- value(p) R – Square (R^2)
Gender:			
Female	281	26.101	0.889
Male	89	26.160	
Ethnicity:			
Caucasian	**328**	**26.314**	**0.009**
African American	**42**	**24.833**	
Education			
Some College or more	254	26.134	0.209
High School Graduate	84	26.524	
Not High School Graduate	32	25.250	
Intervention Group:			
Control	196	25.480	0.0496
Experimental	174	26.428	
Patient Age	369	26.136	0.086
Depression Measure:			
Total CES-D Score	**366**	**26.131**	**0.052**
Symptom Severity			
Mean Score	363	26.102	0.707
Patient Mastery	**365**	**26.161**	**< 0.0001 , R^2 = .147**
Patient Satisfaction with Physician Communication	**370**	**26.146**	**< 0.0001, R^2 = .690**

Table 4 – Patients' Characteristics Association with Patients' Distrust			
Characteristics	N	Mean	P- value(p) R – Square (R^2)
Gender: Female Male	280 89	17.303 17.414	0.707
Ethnicity: **Caucasian** **African American**	**327** **42**	**17.505** **16.476**	**0.009**
Education Some College or more High School Graduate Not High School Graduate	253 84 32	17.462 17.488 16.531	0.110
Intervention Group: Control Experimental	195 174	17.544 17.213	0.189
Patient Age	368	17.380	0.708
Depression Measure: **Total CES-D Score**	**365**	**17.389**	**0.008**
Symptom Severity Mean Score	362	17.367	0.784
Patient Mastery	**364**	**17.434**	**< 0.0001, R^2 = .090**
Patient Satisfaction with Physician Communication	**369**	**17.388**	**< 0.0001, R^2 = .445**

Table 5 – Patients' Characteristics Association with Clinical Trial Participation Grouping: Retention, Attrition and Death (Categorical Variables).

Characteristics	Retention N=318 N (%)	Attrition N=41 N (%)	Death N=12 N (%)	P- value (p)
Gender:				
Female	245 (87%)	32 (10%)	5 (8%)	0.024***
Male	73 824%)	9 (10%)	7 (8%)	
Ethnicity:				
Caucasian	286 (87%)	32 (10%)	10 (3%)	0.052***
African American	32 (44%)	9 (33%)	2 (5%)	
Education				
Some College or more	221 (87%)	27 (10%)	7 (3%)	0.353***
High School Graduate	72 (86%)	10 (12%)	2 (2%)	
Not High School Graduate	25 (78%)	4 (13%)	3 (19%)	
Intervention Group:				
Control	168 (74%)	22 (11%)	6 (3%)	<.999***
Experimental	150 (65%)	19 (11%)	6 (3%)	
Depression Measure:				
CES-D Score ≥ 16	88 (77%)	22 (19%)	5 (4%)	0.002***
CES-D Score < 16	230 (90%)	19 (7%)	7 (3%)	
Trust Category				
High Trust ≥ 24 (T)	259 (87%)	32 (11%)	7 (2%)	0.131***
Low Trust <24 (t)	59 (81%)	9 (12%)	5 (7%)	
Distrust Category				
High Distrust ≥ 16 (D)	267 (89%)	27 (9%)	7 (2%)	0.002***
Low Distrust < 16 (d)	51 (73%)	14 (20%)	5 (7%)	
Trust Distrust Type				
Low Trust / Low Distrust (td)	32 (76%)	7 (17%)	3 (7%)	
High Trust / Low Distrust (Td)	19 (68%)	7 (25%)	2 (7%)	0.008***
High Distrust / Low Trust (tD)	27 (87%)	2 (6.5%)	2 (6.5%)	
High Trust /High Distrust (TD)	240 (89%)	25 (9%)	5 (1%)	

*** P values obtained by Fisher Exact Test, using Proc Freq in SAS

Table 6 – Patients' Characteristics Association with Clinical Trial Participation Grouping: Retention, Attrition and Death (Continuous Variables)

Characteristics	Retention N=318 Mean Standard Deviation	Attrition N=41 Mean Standard Deviation	Death N=12 Mean Standard Deviation	P- value (p)
Age: Mean (Std Deviation)	57.01(11.78)	57.51 (14.05)	61.17(11.54)	0.495*
Depression Measure: Total CES-D Score Mean (Std Deviation)	12.03(7.56)	15.24 (8.23)	14.17(9.45)	0.032** Retain-Attrite (CI 0.205, 6.225)
Total Symptom Severity Score Mean (Std Deviation)	4.22 (1.56)	4.26 (1.32)	4.80 (1.63)	0.026** Retain-Death (CI)
Patient Mastery	26.21 (3.90)	24.47 (3.90)	21.83 (6.36)	<0.001** Retain-Attrite (CI 0.124, 3.354) Retain-Death (CI 1.614, 7.145)
Trust	26.26 (3.42)	26.02 (3.61%) 12 (50%)	23.58 (3.70%) 4 (17%)	0.031** Retain-Death (CI 0.289, 5.062)
Distrust	17.57 (2.34)	16.27 (2.73)	16.33 (3.90)	<0.001** Retain-Attrite (CI 0.375, 2.234)

* P values obtained by … using Proc ANOVA in SAS

** P values obtained by Tukey's Studentized Range (HSD) test using Proc GLM in SAS

Table 7 - Multinomial Logistic Regression Model of Patients' Attrition Referenced to Retained.

Covariates	Odds Ratio	95% CI	p - value
Age	0.994	0.964, 1.026	0.728
Gender:			
Male	1.070	0.419, 2.731	0.888
Female	1.000		
Ethnicity:			
African American	**2.890**	**1.125, 7.427**	**0.028***
Caucasian	**1.000**		
Education:			
Some College or more	1.000		
High School Graduate	1.105	0.461, 2.649	0.982
Not High School Graduate	1.248	0.352, 4.425	0.788
Symptom Severity Mean Score	1.182	0.895, 1.561	0.240
Intervention Group:			
Experimental	0.951	0.456, 1.983	0.893
Control	1.0		
Depression	1.017	0.961, 1.076	0.563
Trust	**1.270**	**1.012, 1.594**	**0.039***
Distrust	**0.685**	**0.559, 0.846**	**0.0003***
Patient Satisfaction with Physician Communication	0.991	0.872, 1.126	0.888
Patient Mastery	0.936	0.834, 1.049	0.254

*statistically significant

Table 8 - Multinomial Logistic Regression Model of Patients' Death Referenced to Retained.

Covariates	Odds Ratio	95% CI	p-value
Age	1.013	0.959, 1.071	0.638
Gender:			
Female	**0.225**	**0.059, 0.862**	**0.030***
Male	**1.000**		
Ethnicity:			
African American	2.405	0.450, 12.857	0.305
Caucasian	1.000		
Education:			
Some College or more	1.000		
High School Graduate	0.957	0.175, 5.240	0.151
Not High School Graduate	3.141	0.662, 14.903	0.477
Symptom Severity Mean Score	1.024	0.646, 1.622	0.921
Intervention Group:			
Experimental	0.751	0.198, 2.850	0.674
Control	1.0		
Depression	0.966	0.873, 1.068	0.501
Trust	0.978	0.705, 1.356	0.893
Distrust	0.978	0.666, 1.435	0.908
Patient Satisfaction with Physician Communication	0.976	0.787, 1.210	0.823
Patient Mastery	**0.791**	**0.656, 0.953**	**0.014***

*statistically significant

Figure 10. Clinical Trial Retention, Attrition, Death & Patients' Levels of Trust & Distrust

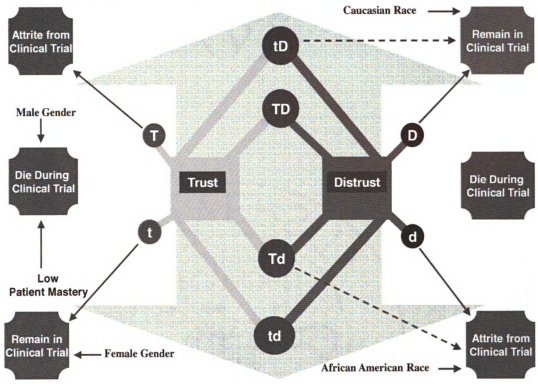
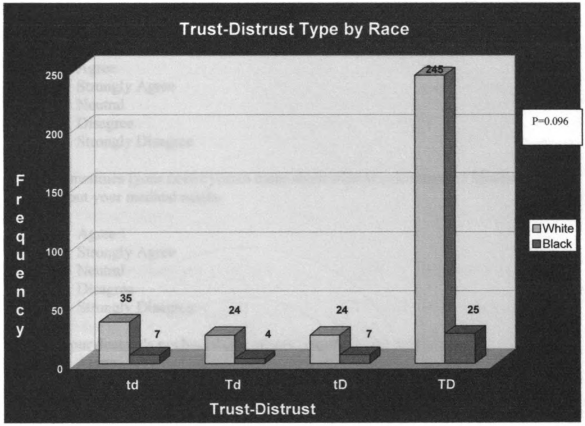


Figure 11. Trust-Distrust Type by Race.



Appendix B – WFTPS

Wake Forest Trust in Physician Scale (10 item scale)

1. [Your doctor] will do whatever it takes to get you all the care you need.
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

2. Sometimes [your doctor] cares more about what is convenient to him/her than about your medical needs.

   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

3. [Your doctor]'s medical skills are not as good as they should be
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

4. [Your doctor] is extremely thorough and careful.
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

5. You completely trust your doctor's decisions about which medical treatments are best ***for you.***
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

Wake Forest Trust in Physician Scale (10 item scale, continued).

6. [Your doctor] is totally honest in telling you about all the different treatment options available for your condition.
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

7. [Your doctor] only thinks about what is best for you
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

8. Sometimes [your doctor] does not pay full attention to what you are trying to tell him or her
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

9. You have no worries about putting your life in [your doctor]'s hands
   - ❑ Agree
   - ❑ Strongly Agree
   - ❑ Neutral
   - ❑ Disagree
   - ❑ Strongly Disagree

10. All in all, you have complete trust in [your doctor]
    - ❑ Agree
    - ❑ Strongly Agree
    - ❑ Neutral
    - ❑ Disagree
    - ❑ Strongly Disagree

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