HOPE AS A DISCURSIVE PRACTICE IN CANCER RESEARCH DECISION-MAKING

by

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ABSTRACT

The purpose of this study was to examine hope both as a powerful discursive element in health-related literature and as a discursive practice in cancer research decision-making by patients, family caregivers, and physician researchers in a quaternary cancer research center. The practice of hope is an important activity for people diagnosed with cancer, but the unexamined, taken-for-granted practice of hope may exert undue influences on the decision-making/informed consent process for cancer research participation.

A genealogy (systematic analysis that illustrates the complex and often contradictory historical influences that culminate in the construction of a concept) of hope was created using philosophical, theological, and literary resources. From these analyses, major discourse practices of hope were identified. Then a focused discourse analysis of representative articles on hope published between 1999 and 2008 in the journal *Advances in Nursing Science* examined how influential articles reify hope as an object—with the result that hope becomes something that can be given or taken away from patients, thus limiting the scope of how hope can be enacted.

A secondary analysis of 109 transcripts from 25 cancer patients enrolled in Phase II clinical trials for hematopoietic stem cell transplants analyzed how patients, family caregivers *(n=20)*, and physician researchers *(n=10)* used metaphors to construct and represent cancer, medicine, science, and agency. Rhetorical analysis was utilized to indentify patterns of persuasion present in the transcripts that reinforced the hope imperative for patients to enroll in cancer research. Metaphors used by study participants were not neutral, but rather were dynamic forces that demonstrated the discursive power and hope's centrality to decision-making for cancer research participation.

Current discursive practices of the informed consent process allow researchers to meet federal and regulatory guidelines while ignoring a potential coerciveness in the underlying dynamics of hope-for-cure and the hope imperative. The implications of this work are significant for bioethics. This work will help cancer research professionals engage in informed consent processes that minimize the elements of coercion. The practice of hope may then be allowed to embrace outcomes beyond cure.

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Ubuntu: "I am what I am because of who we all are."
(From Bantu, a translation offered by Liberian peace activist Leymah Gbowee)

I am deeply indebted to the members of my committee for their consistent support, expertise, and scholarly commitment to me in the completion of this work. I also would like to recognize all the participants who agreed to tell their stories of decision-making. They have given us a gift in sharing their words. Finally, I offer my gratitude to Alex, Jennie, and Michael, whose steadfast support and love gave me courage to undertake and finish this endeavor.

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CHAPTER I

INTRODUCTION

Statement of the Problem

"This is my only hope." These words are spoken often by cancer patients trying to decide on their medical care and research options. For some, the decision to participate in a clinical trial comes after multiple courses of conventional chemotherapy or radiation have been unsuccessful in treating the disease. In such circumstances, the research associated with a clinical trial seems to offer the opportunity for hope. Hope is also invoked by investigators who believe that clinical trials may improve cancer care and outcomes for patients. Participation requires that patients give their consent to clinical trials under strict regulatory guidelines as set forth in the Code of Federal Registration (CFR) 45 § 16:124. These guidelines are established by the U. S. Department of Health and Human Services (DSHS) to protect human study subjects; the guidelines specifically mandate that decision to participate be autonomous, free of coercion, and adequately informed.

Quaternary cancer research centers most often offer interventions in Phase I/II clinical trials. The available information used to seek patient consent is preliminary at best and may be a component of a larger research program within the institution. Researchers are vested in finding new interventions that will decrease cancer morbidity and mortality and that will as a result further their professional careers. Patients in quaternary cancer research centers are there because care at the tertiary level has proven unsuccessful in the treatment of their cancer. They are now seeking the newest—and possibly the only—alternative for potential disease amelioration. Because people facing these life-threatening conditions are especially vulnerable to coercion, researchers must take extra efforts to assure that the informed consent process is free from coercion and is promising in terms of potential cure via research.

The guidelines governing informed consent are legal mandates. Those mandates dictate that informed consent must be a process that is autonomous, that is free of coercion, and that provides adequate information regarding relevant facts, risks, and potential benefits and alternatives (DSHS, 2010). In addition to legal mandates, there is also a moral obligation on the part of healthcare providers to facilitate decision-making for cancer patients in a way that educates and allows for independent decision-making. While important, legal mandates fall short in acknowledging the role hope plays in decision-making. Hope is actually practiced by both patients and researchers in a mostly taken-for-granted and unexamined manner. As legal mandates are used to protect human study subjects, those involved also need to acknowledge the powerful cultural and historical implications of hope in decision-making.

Purpose

This qualitative, exploratory study utilized a discursive examination of hope as articulated by patients, family members, and investigators as decisions were made to participate in cancer research. The broad, long-range goal of this study was to provide additional information about hope in decision-making for clinical research participation and to assist patients and providers in achieving autonomous, informed consent that was free of coercion. This close textual examination was meant to facilitate a full exploration and to provide clarity for researchers and patients regarding this most important yet taken-for-granted factor of hope in cancer decision-making.

Studies of hope in health care have been done primarily from an objectivist perspective—one that framed hope as a "thing" existing independent of social interactions. In the post-positivist theoretical model, hope was quantifiable and measurable; measurements were then used to inform providers how to assist patients in the pursuit of hope. If hope was assumed to be a single universal construct, that assumption clearly limited the analysis of the ways hope was operationalized in a larger population.

Hope as a practice should be acknowledged for the power it exerts in human relationships and particularly in decision-making processes. Hope is generally assumed to have only a positive effect in the lives of individuals, yet hope can be practiced in a coercive or exploitative manner, especially in a vulnerable population such as cancer patients. This study is intended to provide insight into how hope is practiced in a quaternary cancer research center by patients, family members, and researchers. Information gleaned from this study should generate new knowledge and provide a new perspective that will result in improved support of decision-making processes.

Research Questions

Previous research has evaluated hope as an objective entity and has even proposed ways to measure and quantify it. This study examined hope as it is used by cancer patients, family members, and researchers in the decision to participate in research at a quaternary cancer research center.

Informed consent is not only a legal, mandated process, it is an ethical imperative. Researchers need to fully comprehend the unexamined assumptions of hope as it is invoked by patients, family members, and themselves throughout the informed consent process. This study examined how hope influences the decision-making process for cancer research participation.

Hope can be used as a noun or a verb; in cancer care, it is often referred to as a verb or an action—something people do. Hope as action is a practice or activity in which people engage in the trajectory of a cancer diagnosis. In this study, hope was analyzed as a "practice" or an enactment coconstructed by patients, family members, and researchers. The choice of the term *practice* was purposeful, as it allowed the analysis of hope as an action and removed it from the usual category of a "thing" that can be possessed.

Specific Aims

Aim #1: To explore the historical discourses of hope.

RQ 1A. What are the discourses of hope that influence how people construct the practice of hope?

Aim #2: To examine how people with cancer practice hope in making decisions about their participation in cancer research.

RQ 2A. How, when, and why do patients, family members, and researchers employ the construct of hope?

RQ 2B. What words do patients, family members, and researchers use as metaphors for hope?

RQ 2C. How is hope practiced in a quaternary cancer research center?

Aim #3: To describe cultural, religious, political, and traditional words that frame hope and assumptions held by investigators relative to research participation.

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CHAPTER II

BACKGROUND AND SIGNIFICANCE

Cancer Research

More than 1,550 people die every day of cancer; the estimated death rate in America from cancer in 2007 was 559,650, rendering cancer the second most common cause of death after heart disease (American Cancer Society, 2007). Despite cancer ranking as the second most common cause of death, the National Cancer Institute (NCI) Cancer Trends Progress Report of 2007 stated that the United States death rate dropped for the first time since 1993. When adjusted for delayed reporting, the incidence of new cancers was found to be relatively stable since the mid-1990s. Clinical research is integral to improving the morbidity and mortality associated with cancer.

Hope and Cancer

Hope has been described as a construct that provides comfort, encouragement, and an ability to look toward a more positive future. Several studies have identified hope as a resource for coping with cancer, providing the patient with strategies for managing the disease and engaging valuable social support (DuFault & Benita, 1985; Ebright & Lyons 2002; Ersek, 1992; Rustoen & Wiklund 2000). In the present study, a theoretical model of hope was derived from the premise that hope is integral to how people clarify, prioritize, and affirm their choices regarding cancer care.

Hope has been identified as a key component in cancer patients' coping, resilience, empowered self-care, and perceived quality of life (Dickerson et al., 2006; DuFault & Benita, 1985; Eliott & Olver, 2002; Ersek, 1992; Saleh & Brockopp, 2001). Several studies have drawn direct links between patients' faith experiences and connection to God as correlative with the experience of hope (Dickerson et al., 2006; Eliott & Olver, 2002; Ersek, 1992; Herth, 1989, 1992, 2000; Rustoen & Wiklund, 2000; Saleh & Brockopp, 2001;).

The association of hope with religion and spirituality is a strong cultural theme in America; the relationship between hope and religion can be useful in determining how hope is practiced by people. This relationship between hope and religion can also be a hindrance in understanding the notion of hope as practiced outside the Western traditions of Judeo-Christian religions.

Hope as an Interpersonal Interaction

Communication is foundational for patients who are navigating the decision-making process following a diagnosis of cancer. Several studies have reported that communication between the patient and the provider significantly impacted how much influence hope had for the patient (Caocci et al., 2006; Eliott & Olver, 2002; Thorne, Hislop, Kuo, & Armstrong, 2006). Recognizing how much influence providers can exercise on patients established the need to investigate the nature and power of that influence on the practice of hope.

Dissemination of statistical information has been correlated with the increase of hope in cancer patients. The use of survival statistics in conferences between patients and providers was examined and found to be a complex issue, as patients both wanted the facts in numeric format and resented the implications contained in the numeric risk statements. Yet despite this resentment, some patients reported taking comfort in the statistics. This held true even when fewer than 5% of patients with that particular cancer survived. The tiniest chance of survival carried with it hope for the individual to be among those who would comprise the survival statistic (Thorne et al., 2006).

Communication in all its forms had recognized significance for patients engaged in decision-making and in the cocreation of hope. Consent conferences included verbal conversations accompanied by written documents. Beyond the one-on-one communication between the patient and the investigator, broader communication was an influence in the decision-making process. At one large cancer research center in the American southwest, researchers who surveyed patients about a recent media campaign for a new chemotherapeutic agent found that the media had an observable effect on patients' awareness of self-care options and provided opportunities to foster hope (Pentz et al., 2000). The Internet is another source of social support and information. The literature affirmed that decisions to participate in cancer research were influenced by patient hope and that hope was created in the context of shared communication in many forms (Dickerson et al., 1999).

Measuring Hope

Significant work in the investigation of hope and cancer patients has been done by Kaye Herth. Herth's postpositivist theory asserted that hope can be defined and measured. Her initial work in 1989 introduced the Herth Hope Scale (HHS) in a study whose purpose was to examine the relationship between a level of hope and a level of coping response in adult oncology patients receiving chemotherapy in the midwestern

United States. Herth found that individuals with strong religious faith had a higher level of hope and coping response than those without faith or those who reported "weak faith." Herth identified three factors of hope: 1) temporality and future; 2) positive readiness and expectancy; and 3) interconnectedness.

The HHS tool was abbreviated and became the Herth Hope Index (HHI), a name by which it is still called. Herth's work established the "four attributes of hope"—experiential, spiritual/transcendence, relational, and rational thought. Most significantly, Herth asserted that hope is an important component in the lives of people with cancer (Herth, 1989, 1992, 2000).

The HHI is still considered an exemplar when working with cancer patients and the construct of hope. It does have limitations, however, because it is built upon a premise of religious and cultural connotations of hope that are noninclusive and are not experienced by all people across various cultures.

Hope and Hopelessness

In Greek mythology, hope was one of the consignees of Pandora's Box. Hope—*elpis* in Greek—was the last of the contents of the box (or the jar, depending on the version of the myth). Pandora received the box from Zeus or Hermes with a warning to never open it. Curiosity got the best of her, however, and when she opened the box, Pandora unleashed evil and misfortunes on the entire world population. According to at least one version of the myth, Pandora closed the box and left the spirit Hope trapped inside. Another version of the myth allowed an intervening time of trials and tribulations for the world until Pandora returned to re-open the box; at that time, hope fluttered out (Athanassakis, 1983). One interpretation of the myth asserted that the final release of hope was symbolic of better times promised in the midst of hardships. Another interpretation was that *elpis*/hope was the worst of all evils, since it was a deception. In this view, Pandora saved the world by closing the lid and preventing the escape of hope. Two divergent conceptualizations of hope emerged from Greek mythology, depending on the version of the myth conveyed. The myth of Pandora's Box set the stage for the constructs of hope and hopelessness having interstitial and binary meanings. One does not exist without the intrinsic presence of the other.

Work in health care has mirrored this dualistic nature of hope. Viewing hope as an object that can be quantified and measured, researchers like Herth (2000) have designed tools that measure the individual's level of hope or, conversely, hopelessness. Beck created a tool in 1974 to assess hopelessness in psychiatric patients. Observing patients struggling with despair, Beck determined they stood in need of reframing their feelings of hopelessness in order to replace pessimism with optimism. In essence, they needed to replace helplessness with skills of adaptation and coping. To work with these very vulnerable people, it was important to predict and to prevent self-harm and suicide, so Beck formulated a tool that used 11 items drawn from a repository of pessimistic statements made by the physicians who had judged the patients to be hopeless. These were combined with nine items from a resource test of attitudes about the future structured in a semantic differential format (Beck, Weissman, Lester, & Trexler, 1974). Both tools measured the meaning of practicing hope in the presence of an enduring sense of hopelessness.

Snyder (1995) posited hope as a goal and directed thinking comprised in two separate domains. He defined hope as "a cognitive set that is based on a reciprocally derived sense of successful agency (goal directed determination) and pathways (planning to meet goals)" (p. 357). This theory has been applied to achieving academic success in college, to assessing aging in adults, to analyzing young people victimized in early adolescence by violence, and finally to assisting people coping with chronic illness (Basile et al., 2006; Kylma & Vehvilainen-Julkene, 1997; Snyder et al., 1991; Snyder et al., 2002; Valle, Huebner, & Suldo, 2006).

Various tools have been designed to measure hope in various populations. Snyder created a scale (Hope Scale—HS) to measure hope in a wide variety of people, not just cancer patients. Herth's Hope Index (HHI) was created to evaluate hope in cancer patients. Beck's Hopelessness Scale (BHS) was created to evaluate hope in psychiatric patients. Scales like the HS, HHI, and BHS tap certain dimensions of hope/hopelessness but at times only obfuscate understanding of what is constitutive in either the practice of hope or of hopelessness.

Decision-Making

Federal regulations offer a strict code for how consent for research participation should be offered and confirmed (CFR 45 § 16:124) (DSHS, 2010). The federally mandated elements required for decision-making include a statement of the research purpose; the identification of potential risks and benefits; an explanation of procedures, possible compensation, and limits to confidentiality; and a declaration of voluntariness. The decision must be based primarily on adequate information. It must be free of coercion and be made autonomously (or voluntarily) by the research participant. The concept of autonomy is based on the objectivist's perspective that people are able to be separate and distinct individuals free from the influence of others. New research needs to move beyond *autonomy* and substitute *agency* in its place. The concept of agency is further developed in a later section.

Nevertheless, there is still a gap in current literature and research on hope when addressing the concerns of provider influence on subsequent decision-making about enrollment in clinical trials. To begin to address this gap, analyses need to be undertaken to demonstrate how people with cancer construct hope and hopelessness.

Among cancer patients, the concept of hope is activated almost synchronously with the diagnosis. Hope for a cure—or at least for the chance of additional time—is a concept commonly employed not only by patients and their loved ones, but also by researchers. Extended survival is desired by researchers and those whose livelihood depends on continued research programs for possible improvement of morbidity and mortality associated with cancer care. Hope may represent a coercive influence in the decision-making process for people with cancer when it leads them to decide for the option of research, because that option represents the "only hope" for possible survival. When research is offered to patients, the very language used to facilitate informed consent sometimes uses words like *treatment, therapeutic benefit, hope,* and *cure.* This kind of communication may lead patients to perceive research as an intervention with certain outcomes—when in reality, research is designed to establish safety and possibly efficacy questions, but it has uncertain outcomes.

A construct integral to decision-making in clinical research trials is the notion of *therapeutic misconception* —a term that does not distinguish between medical treatment and research interventions. Therapeutic misconception may adversely affect informed consent if patients confuse the difference between research and treatment (Appelbaum, Lidz, & Grisso, 2004).

Informed consent is required by law to be a free and uncoerced process. Without such laws, patients may be coerced into considering research studies that hold little promise of ameliorating the disease.

Early Phases of Clinical Trials

Clinical trials are classified as Phase I, II, III, or IV, according to the research question under investigation (NCI, 2008). Phase I trials, the earliest trials, are comprised of the first research done in human subjects. They are performed on small populations ranging from 10 to 80 participants. The focus of Phase I trials is to identify a safe dose and any potential side effects.

Phase II trials are intended to further identify safety concerns in dosage and to ascertain a range of side effects. Populations for Phase II trials are larger, between 100 and 300 participants.

Phase III trials are done on larger populations of between 1,000 and 3,000 participants. They are undertaken to confirm effectiveness of the research intervention in comparison to established interventions, to monitor side effects, and to evaluate safety parameters in larger groups of people.

Phase IV studies are postmarketing studies done after a drug has been approved and is available on the market. These studies may be done by companies or investigators interested in examining additional information that has not yet been captured by the initial clinical trials.

In the area of oncology research, the Federal Drug Administration (FDA) added a policy allowing for earlier access to promising new research interventions through various mechanisms, referred to as “expanded access.” This means that “when no satisfactory alternative treatment exists, subjects are generally willing to accept greater risks from test articles that may treat life-threatening and debilitating illnesses” (NCI, 2008; FDA, 2008). While helping bring potentially beneficial drugs to market more quickly, this policy has had the unintended consequence that interventions are primarily approved in early Phase I–II trials. In other words, many people may face a research participation decision before much data have been accumulated. Cancer care at the quaternary level is most often entirely research-driven, so referred patients are choosing between early-phase clinical trials for disease intervention.

As one example, Victoria Wolfe is a woman who participated in several Phase I and Phase II clinical trials for her acute promyelocytic leukemia. An ethnographic presentation of Wolfe’s journey through decision-making was presented juxtaposed to a theoretical framework of the ethical decision-making process by Shannon–Dorcy (Shannon Dorcy & Wolfe, 2003). Nurses are often called on to help translate the information given to patients for decision-making relative to cancer research participation. Shannon Dorcy’s manuscript highlighted the need to acknowledge nurses’ role in the research consent process, and underscored the need for nurses to honor the fidelity of the relationship while practicing informed consent for research (Shannon Dorcy & Wolfe, 2003).

Significance

Currently there are many subtle and not-so-subtle ways in which hope is cocreated by and for people with cancer in the clinical care setting. Hope is a powerful activity in which researchers and patients engage while making decisions for cancer research participation. People employ hope as a result of their experiences, and hope continues to be inculcated throughout their lives. Hope is reinforced and employed in the discourses of providers, patients, and family members. The same language of hope is often used by researchers and care providers who explain the various treatment and research options open to people with cancer. The construct of hope even plays a significant role in scientific literature, verifying that the concept of hope is widely associated with cancer in scientific discourse. Literature searches of “Cancer & Hope” within ProQuest returned 45,084 articles, Pub Med returned 4,158 articles, and Web of Science returned 1,683 articles.

Given that providers and patients rely on the construct of hope in the clinical management of the illness and in options for treatment and research participation, greater knowledge is needed on how hope is practiced and perhaps at times exploited. Insight is needed into how human beings interpret and construct hope in specific linguistic, social, and historical contexts. Research is needed to understand when and how hope is included as an influence or an element of coercion in the informed consent process. These findings will enhance the process of informed consent and possibly eliminate unintended but nonetheless real elements of coercion, since avoiding coercion is both a federally mandated regulation and an ethical imperative. Additionally, the research will provide new insights into how hope is present in the patient/investigator dyad and will explore dimensions of the cocreation and dynamics of hope. Assumptions that hope is something that professional staff can engender in others may be erroneous. In fact, patients may be the primary creators of hope and investigators may be inspired to continue their research efforts by the patients' articulation of hope.

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CHAPTER III

THEORETICAL AND METHODOLOGICAL FRAMEWORK

Introduction

The research questions for this study explored historical discourses of hope; examined how people with cancer practice hope in decision-making for cancer research; and, finally, described the cultural, religious, political, and other assumptions that frame hope relative to decision-making. A constructivist epistemology was chosen. Constructionism provides the foundation for recognizing that truth or meaning exists in and because of our interactions with the realities of our world. Meaning is not waiting to be found, it is constructed (Crotty, 2003).

Constructionism provided a starting point that helped inform and shape how the study was designed. The methodology of discourse analysis stemming from the constructionist approach as discourse analysis was the study of language in use. Words were the textual focus of analysis in the transcripts and were analyzed relative to hope and informed consent. The work of Pierre Bourdieu helped in understanding hope as constructed in the texts under analysis. Bourdieu's concept of *habitus* and additional concepts of language—such as ontology, agency, and genealogy—were developed; each was useful to understanding hope relative to decision-making and cancer research participation.

Bourdieu

Pierre Bourdieu (1930–2002) was a French sociologist who created a theory of action around the concept of *habitus,* a theory that asserted people are the embodiment of their class and political positions within society. Bourdieu did not see the historical inculcation of an individual's class to be deterministic. *Habitus* has a strong component of personal agency that assures people have the capacity to make generative choices that express individual free will. Bourdieu identified this process of tastes or preference as constructs shaped by the home as it is referent to a larger community context or class. *Class* is a collective process organized historically with specific cultural and political influence. *Habitus* served as an expanded model for understanding personal autonomy and provided a historical and cultural context for how hope influenced the decision to participate in cancer research (Bourdieu, 1997, 1984, 1990).

Habitus

The word *habitus* is Latin for a pattern, characteristic, or condition of the body. For Bourdieu, the tapestry of human existence was a blend of personal agency greatly influenced by the culturally accessible experiences and choices available to individuals in the course of their lives. Bourdieu used *habitus* to reference socially acquired, embodied systems of dispositions or predispositions; he believed that personal choices or preferences are neither random nor linear components of an individual's life. *Habitus* is not only about moral socialization; it is about personal inclinations, tendencies, and propensities in opinions, habits, decorum, and practices in different historical and cultural settings. Bourdieu carefully avoided determinism or essentialism as philosophical notions, because those notions leave humans passive and powerless in reflexive responses to stimuli. He believed that change is not a possibility if one's responses are programmed by essentialist determinism and if there is no free will.

The ability to make choices while reflexively remaining engaged with the researchers and with the societal norms for what constitutes being a "good patient" constitutes *habitus;* it served as the theoretical foundation upon which the study of hope in decision-making for cancer patients was built. Hope is part of a social construction of reality, and this process is a cooperative one—it never happens in a vacuum. People are raised in a social milieu where they learn to comprehend by way of discourse and where they assume social practices such as "fitting in" or gaining political power. People diagnosed with cancer engage in a reflexive dialogue with cancer researchers and use language to produce meaning about what it means to be a patient or to be a researcher.

Language as Ontology

Bourdieu (1997) maintained that language was understanding and that language is a practice of the construction of meaning in which people reflexively share:

> The constitutive power which is granted to ordinary language lies not in the language itself, but in the group which authorizes it and invests it with authority. Official language, particularly the system of concepts by means of which the members of a given group provide themselves with a representation of their social relations (e.g. the lineage model or the vocabulary of honor), sanctions and imposes what it states, tacitly laying down the dividing line between the thinkable and the unthinkable, thereby contributing towards the maintenance of the symbolic order from which it draws its authority. (p. 21)

Bourdieu saw language as a mechanism of power within the sphere of one's space. He advocated for researchers' acute awareness of their own positions and recognition of their power and prejudices. Such awareness helps researchers understand how much power they have in relationship to the participants in the research. In the case of clinical research decision-making, researchers have a responsibility to assure freedom from coercion and to provide support for patients making decisions. For Bourdieu, the critique of the dominant symbolic order was an exhortation against oppression and invoked a responsibility for social justice and accountability on the part of all individuals. His philosophical framework is useful because it shares features with early theological and religious discourses on hope that advocate an objective reality and free will relative to decision-making.

A patient's expectation of what constitutes hope informs the process for choosing options for cancer interventions. The combination of influences by which people practice hope is knit together in the history of their experiences (the ordinary) and then is manifest in the ability to discern independent action in new situations (the extraordinary) (Bourdieu, 1990).

Agency

Agency is a term that signifies the capacity of individuals to discern, evaluate, and form independent motives for action or to implement practices. Overriding structure versus agency is the classic dilemma of free will versus determinism. Do individuals exercise agency (free will), or are choices and actions based on social inculcation?

Hope and optimism are expectations of society in general when dealing with illness and are practiced by patients as well as by researchers. There is a reflexive relationship between patients, family members, and researchers as the discourse around clinical research participation occurs.

Genealogy

This study will provide an overview of the notion of hope and show how a genealogy of hope influences the construction and general practice of hope today. To draw conclusions about how hope is enacted within the clinical context of cancer research decision-making, it is first necessary to explore the complex, often complicated, and even contradictory dialectic of hope. This contradictory dialectic is why the model of genealogy was chosen for this analysis. Michel Foucault's concept of "genealogy" was built on the work of Nietzsche to examine the relationship of power to the development of morals (Foucault, 1972; Nietzsche, 1996).

Foucault used genealogy as a valuable asset in the analysis of notions held as "truths" in both written and oral discourse. These notions include things like sexuality, hope, and other principles often seen as absolutes or as essences with an assumed single "truth" or representation. Foucault maintained that most "truth" comes to us in daily life not in a linear manner but via an irregular, often contradictory, dynamic process of power and influence.

Foucault studied *discourse* rather than language and asserted that discourse is a linguistic concept that creates meaning. Discourse, then, is the process of constructing the topic as it defines and produces our objects of knowledge. This is opposed to an objectivist epistemology, which says that the object is the source of definition and of knowledge itself. Foucault acknowledged discourse as a process, so discourse consists of more than the words of a single document, a single text, or an individual source. Discourse is a culturally enacted process that includes a broad range of sources that create shared meaning and shared knowledge. Foucault did not argue that physical things or actions do not exist; he merely pointed out that without discourse, there is no meaning (Foucault, 1972).

Brief Genealogy of Hope

One important discourse regarding hope—*elpis*—resides in Greek mythology. Hope was introduced as either a solace to the world or an instrument of torture, since it is ultimately inaccessible. Another contributing influence in the genealogy of hope is the work of Aristotle, who framed hope in a neutral manner. He also advocated the use of inductive reasoning to affirm knowledge in an empirical fashion. If it is objectified, hope becomes capable of being seen and measured as a phenomenon (Tredenick & Barnes, 1976).

Another set of historical milestones in this brief genealogy of hope are the writings in the New Testament and the Old Testament. Discourses of hope in the Bible generally drew on the promise of salvation from the forces of evil, sorrow, hunger, and eternal death: "This hope we have is an anchor of the soul, both sure and steadfast, and which enters the Presence behind the veil" (Hebrews 6:18). In 1 Corinthians 13:13, Paul wrote that "The greatest spiritual gifts are faith, love and hope." "Now may the God of hope fill you with all joy and peace in believing, that you may abound in hope by the power of the Holy Spirit" (Romans 15:12, 13)(New American Bible, 1999).

The Aristotlean notion of hope as a virtue was further developed by Thomas Aquinas in the thirteenth-century *Summa Theologica*. He sought to elucidate the role of the virtues within a Christian anthropology and explained them as qualities that enable participation in divine tranquility while progressing through one's status as *homo viator*. According to Aquinas, hope has God as its teleological object. Hope itself has two objects: one looking toward a future good of what one might expect to attain (building on the rationalist view of hope originally put forth by Aristotle), and the other providing assistance through which one attains what one expects or hopes to attain. Aquinas theorized that hope resides in the will and that its principal object is eternal happiness, which can only be attained with the assistance of God (Aquinas, 1920). Ultimately, hope attains God by leaning on God. Insofar as love may have united us with others, we may hope for others as well as for ourselves.

We can trace the historical creation of hope by using language. Discourses about hope allow for an examination of how hope has been transformed into a set of assumptions and reified. Tracing the historical and cultural discourses of hope helps in the analysis of the words spoken by cancer patients and their families.

Research Design and Methods

This study is an exploratory discursive analysis of existing transcribed interviews. A secondary analysis was done on 109 interviews utilizing HyperResearch® software for transcript coding. Participants were drawn from within a quaternary cancer research center and consisted of patients (*n*=25), family members (*n*=20), and researchers (*n*=10).

Demographic data were gathered to examine how this group of primarily White, upper-middle-class, Protestant Americans made decisions about participating in cancer research. Other demographic criteria needed for understanding the sample context were diagnoses, length of time since original diagnosis to current seeking of care at the quaternary center, age, gender, self-identified religious or spiritual affiliations, and racial/ethnic identifications. These components of demographic data were helpful in understanding how people exercised *habitus* in their practice of hope.

Content Analysis

Certain themes were identified from the genealogical analysis that were instrumental in the second part of the study, the content analysis of the 109 interviews. Content analysis is a general term for a variety of types of textual analysis; it involves comparing, contrasting, and categorizing data. The investigator performed content analysis in the following steps: 1) Creation of a set of codes; 2) Systematic application of those codes to the set of textual data; 3) Creation of a matrix of variables from the coded textual data; 4) Analysis of the matrix by interpretive methods (Schwandt, 2001).

A directed approach to content analysis was used because the categories for coding of the transcripts were pre-established. Those pre-established codes became the key categories for coding patient, family caregiver, and physician statements (Hsieh & Shannon, 2002).

Critical Discourse Analysis

Language is a major component of discourse because it serves to construct or create the context of whatever the signifier is engaged in signifying. Critical discourse analysis allows an examination of the distribution of power as it relates to the practice of hope. Discourse enables people to engage in the process of informed consent when making decisions about participating in research. Within the social setting of a quaternary cancer center, the key actors are patients, family caregivers, and individual researchers. Each has a specific role in the social milieu of the consent conference and each is invested in the process by virtue of his or her position as patient, family caregiver, or researcher.

Critical analysis can only be done when there is an adequate comprehension of social power and dominance. There are certain discourses of hope that are privileged by prevalence and dominance in social discourse. In the early Christian church, for example, priests had preferential access to written texts and scriptures, so discourse was shaped by a religious and theological set of actors whose agency and cultural context allowed them to use the concept of hope in a context of poverty and suffering. In addition to a larger global overview of dominant discourse, it is necessary to scrutinize the micro or unofficial uses of power conveyed in tone, word choice, hesitations, pronoun use, and rhetorical style (Fairclough, 2003).

Discourse analysis of hope was done on textual data, with intertextuality as a key concept. Fairclough (2003) summarized intertextuality in this way: “for any text there is a set of other texts and a set of voices which are potentially relevant and potentially incorporated into the text” (p. 47). Fairclough referred not only to the cited or attributed voices of others but also to the pervasive voice or even to the hegemonic presence of other texts that are knit into a re-contextualization in each text.

Shared meanings can and do create assumptions within texts. Fairclough (2003) identified three major assumptions: existential assumptions, propositional assumptions, and value assumptions. Explicit articulation of value is generally easy to assess. Implicit valuation, however, is more difficult to assess and must be culled out of the text for successful discourse analysis. The transcribed texts were reviewed for implicit as well as explicit assumptions. One prevailing implicit assumption held by participants was the notion that hope is a good thing and a value.

Methods and Measures

Sample for Secondary Analysis

Data were collected and secondary analysis was performed on an existing data set of 109 transcribed interviews with cancer research patients (*n*=25), family members (*n*=20), and investigators (*n*=10*)*. The interviews were conducted over 2 years, encompassing a period that spanned from 3 months before participating in the research to 1 year after participating. Physicians were interviewed only once; those interviews occurred at an independent time point.

Interviews

Participants ranged in age from 22 to 72, with 30 males and 25 females participating. Four patients died before the day-80 interview (*n*=21), 5 patients died before the day-365 interview, 1 patient withdrew before the final interview, 1 patient did not return to the center for his 1-year follow-up appointment, and 2 patients were too ill to be interviewed. Five patients did not have identified family caregivers, resulting in the *n*=20. Six caregivers were unable to be interviewed because they had returned to their homes prior to the patients' final interview 1 year following hematopoietic cell transplant (HCT). Questions for interviews are listed in Appendix A. Ten attending physicians were interviewed at a single time point. See demographic Table 1 at the end of this chapter. The interviews lasted between 45 minutes and 90 minutes. (See Table 2, Interview by Group.)

Limitations

The initial interviews identified what influenced patients' and family members' decisions to participate in early-phase clinical trials. The interviews also identified when the decisions were made to participate in early-phase clinical trials. Additionally, 10 physicians were interviewed for their perspective on the decision-making process for patients and family members. The current study is a secondary analysis of that primary data set.

Hope was not the focus of the primary study, but the notion of hope arose enough to warrant the secondary analysis. Future work will benefit from the opportunity to ask purposeful questions specifically related to hope. Even though specific questions about hope were not asked in this study, the spontaneous comments about hope justified further study of hope and its role in decision-making in cancer research.

The current study is also limited because the original sample had very little cultural and ethnic diversity. The data relative to hope and research came from a fairly singular perspective of White, upper-middle-class Americans.

Protection of Human Subjects

The study was reviewed by the University of Utah Institutional Review Board (IRB) as well as by the Fred Hutchinson Cancer Research Center (FHCRC) Institutional Review Board to assure regulatory compliance with research practices and the protection of human subjects involved in research. A full review was conducted by the FHCRC IRB, and an expedited review was done by the University of Utah. A waiver of consent was granted by the FHCRC.

Risks to the Subjects

A convenience sample of 25 patients, 20 family caregivers, and 10 physicians comprised the parent sample. To be eligible for the study, potential participants had to be English-speaking, 18 years of age or older, and legally able to make their own decisions regarding care. (Children were not included in the study, because the primary assessment was of adult decision-making rather than surrogate decision-making.) Patients who were intubated or unable to respond orally to questions were not eligible for the study. Patients deemed too ill for study participation by the attending outpatient physician were not eligible for the original study because the extra interviews would have represented unnecessary stress and burden. All other adult patients who arrived for allogeneic transplant for a Phase II protocol at the Seattle Cancer Care Alliance (SCCA) were eligible.

Patients' health status varied, depending on the status of their disease as they entered the FHCRC/SCCA. Generally, the Karnofsky score (a measure of health status) of the patients was 80% at the time they entered the study and at the day-80 interview. At 1 year, patients generally had a 90–100% Karnofsky score.

Sources of Data

Research data were collected from participant document reviews and from interviews conducted with subjects. In addition, demographic information—such as age, gender, race/ethnicity, diagnosis, stage of disease, and course of previous treatments—was collected. This information was garnered from the patients' existing medical records and from data sent from the patients' referring physicians.

Potential risks of the proposed study were minimal. Participants may have experienced some emotional discomfort as they described their experiences in the original interviews. Patients may also have been fatigued by the interviews. Patients were encouraged to defer the interview or request to withdraw from the study if the burden seemed too great. One patient did withdraw at day 360 and 1 withdrew the day after signing the consent form. The study used existing typed transcripts to avoid causing further fatigue or emotional distress to participants.

Recruitment for study participation began with contact in the outpatient setting (the SCCA) among patients coming to FHCRC/SCCA for allogeneic HCT for a Phase II study. The appropriate clinical team pulled the consent form for the study and one of the study investigators met with the patient and caregiver to obtain consent for participation in the study. The study was explained to potential participants; they were told that refusal to participate in the informed consent study did not preclude participation in other clinical trials. Patients who agreed to participate in this study were registered through the bio-statistics clinical office at the FHCRC. They signed a consent form that was kept on file in both their medical records and the researchers' records. All participants received a copy of the signed consent for their records.

Interviewers were trained in methods for assessing and dealing with discomfort, charged emotions, and undue fatigue. Research data were kept confidential in locked file cabinets in offices with access available only to the research team. Computers on which data were stored had restricted access codes. All study data were stripped of identifiers and were stored with only study-specific numbers.

Study Rigor

In a qualitative exploration, it is important that the data source be large enough to provide depth and richness to the constructs under examination. The current study used a large enough sample (interviews n=109) to compare and contrast discursive enactments of hope. The use of a secondary data set enabled the researcher to undertake a robust critical analysis of hope as a taken-for-granted concept in the informed consent process. The data set represented an opportunity to examine hope as practiced in the discussions of decision-making of patients enrolling in Phase II cancer research trials.

One goal of the study was to demonstrate that hope does not have to be limited to a post-positivist epistemology where it is evaluated in a decontextualized, empirical manner; rather, hope can be seen in a constructionist epistemology that acknowledges the cultural, historical, and political *habitus* of hope. The implications of this work are significant for bioethics and ultimately for the informed consent process. Additionally, new insight is provided into the applied philosophical and metaphysical discourses of hope and how hope is enacted in the care of cancer patients.

Summary

The purpose of this study was to examine the concept of hope as it is practiced in the quaternary cancer research setting. The literature generally supports the value of hope for those who are diagnosed with cancer. Much has been written that acknowledges the role of hope and its influence on human beings, especially when those people are coping with a cancer diagnosis. The majority of the literature on hope originates from a rationalistic empirical framework that reifies hope instead of inviting a comprehensive understanding of the practice of hope in a particular cultural context.

Cancer research is integral to discovering new methods of disease amelioration. Patients who are offered research are often those for whom there are few remaining options. To participate in research, patients and their families and researchers engage in a procedure called “informed consent.” Implementation of informed consent is mandated by the federal government and must include autonomous decision-making, adequate information offered by the researcher in a noncoercive manner, awareness of options, and voluntariness. These regulatory mandates are established to prohibit the exploitation of people participating in research. Intrinsic to the regulatory mandates is the ethical imperative not to exploit other human beings and to protect vulnerable participants.

Coercion or undue influence in consent is subtle and difficult to define. Guidance offered by the United States Department of Health and Human Services states that for informed consent to be adequate for those seeking enrollment in research, “known benefits should be stated accurately but not exaggerated, and potential or uncertain benefits should be stated as such, with clear language indicating how much is known about the uncertainty or likelihood of these potential benefits” (NIH, 2008, p. 284). Investigators must inform people clearly and avoid enhancing the likelihood of benefit by employing the concept of a hope-for-cure. Representing clinical research as the “only hope” frames the research option as life-saving and potentially beneficial. Thus, careful examination of what people report as significant in influencing their choices for research participation is important to help gain an understanding of if and how hope is articulated and implemented in the informed consent process.

Given the methodology of discourse analysis, the author acknowledges a position of inquiry that is informed by her twenty-five-year experience with oncology clinical research and cancer patients. This acknowledgment of her point of entry into formal inquiry manifests what Bourdieu classified as *habitus*. Her sense of distinction (perspective) is mediated through *habitus* (Bourdieu, 1987, p. 170). So it is artificial to claim a *tabula rasa*, or a blank slate, as she formulated her research questions and designed the study.

Overview of Specific Analyses

The three parts of this study are meant to triangulate the understanding of hope in the context of decision-making for cancer research participation. The first part of the study began at the most general level—the philosophical level—to identify how hope has been primarily objectified and reified in health care literature. A critique of the objectivist model of hope was completed as it was represented in published literature. Articles written about hope from the last 10 years (n=3) were critiqued and compared and contrasted within a constructivist framework. The articles were chosen from *Advances in Nursing Science* (1999–2010). Intertextuality, as described by Fairclough (2003), facilitated the analysis of inherent assumptions in the three articles. The implication of a singular approach to hope is that only certain things can be classified as hope, so the full understanding of the breadth of hope and its role in decision-making in cancer patients cannot be fully explored or understood.

The next two parts of the study utilized discourse analysis of a secondary data set of interviews. All 109 interviews used the following codes: Genealogy, Hope as Noun, Hope as Verb, Hope as Practiced, Active Voice, Passive Voice, and Metaphors. After the codes were applied, a parallel was drawn between discourse and *rhetoric*—the ancient art of argument or persuasion. The informed consent conference, though mandated by federal policies, also served as an encounter of patients and family members with the researcher. The elements of *logos* (logic of the argument), *pathos* (emotions of the audience), and *ethos* (trustworthiness or credibility of the researcher) were then used as further refinements in coding of the category "Hope Practiced." Analysis of the rhetorical elements confirmed how the enactment of the consent process was a persuasive encounter. (See Table 3, Philosophical Framework.)

The third part of the study was a review of metaphors used by participants in the 109 interviews. In-depth textual discourse analysis was used to identify metaphors invoked by participants. Five major categories of metaphor were identified across participant groups: *journey, time, hands, faith,* and *war*. The analysis provided a greater understanding how hope is cocreated by patients, caregivers, and researchers using metaphorical language. *Habitus* and the concept of agency in decision-making provided a framework for recognizing unacknowledged assumptions in metaphorical usage. Once made explicit, these assumptions enabled the authors to see how formal and informal language have created a powerful incentive for participation in cancer research trials with the practice of hope central to the election to participate in research. See Table 4 for identification of where specific aims are addressed.

The significance of this study is the uncovering of assumptions and examination of practices generally taken for granted when hope is invoked in the cancer research setting. The author anticipates further contributions to increase understanding of the practice of hope and the role hope plays in a patient's decision to participate in cancer research. There is a need for an examination not only of the language, but of the entire practice of the informed consent process. The goals of cancer researchers—to decrease the associated morbidity and mortality of cancer—are noble. The quest for improved outcomes must recognize that hope-for-cure may not be the only outcome hoped for by patients and families.

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Table 1

Participant Characteristics (*n*=55)

Characteristic	**Participants**
Age Range	22–72
Female No. (%)	30 (55%)
Race/Ethnicity No. (%)	
Black	2 (4%)
White	48 (87%)
Asian	2 (4%)
Hispanic	1 (2%)
Native American	2 (4%)
Patients' Diagnosis No. (%) (*N*=25)	
Acute myleogenous leukemia	6 (24%)
Acute promyleocytic leukemia	1 (4%)
Chronic lymphocytic leukemia	1 (4%)
Hodgkins Disease	1 (4%)
Multiple myeloma	5 (20%)
Non-hodgkins lymphoma	8 (32%)
Refractory Anemia/Myleodysplastic Syndrome	3 (12%)
Highest Level of Education Completed No. (%)	
Some high school	2 (4%)
High school/GED	12 (22%)
Some college	9 (16%)
College graduate	12 (22%)
Some graduate school	1 (2%)
Graduate degree (includes MDs)	18 (33%)
Missing variable	1 (2%)

Table 2

Interview by Group

	Pre	**3 mo**	**1 yr**	**Independent Time Point**
Patients	*n*=25	*n*=21	*n*=12	NA
Caregivers	*n*=20	*n*=15	*n*=6	NA
Physicians	NA	NA	NA	*n*=10

Table 3

Philosophical Framework

Constructionist-meaning is created via language, and textual review helps examine assumptions and taken-for-granted practices like hope (Chapters IV, V, VI).
Methods—a. Discourse analysis of language in use in nursing literature written about hope, examining assumptions of published authors in ANS from 1999–2008 (Chapter IV). b. Discourse analysis of language used by patients, family caregivers, and researchers in a quaternary cancer center as transcribed in existing data set of 109 interviews (Chapter V). 1. Coding—derived by researcher based on review of the literature on hope and her experiences in cancer research. 2. Refinement of coding—additional coding of participant statements was done applying *logos*, *ethos*, and *pathos* to demonstrate how hope is rendered an imperative via persuasion in clinical discussions about research.
Thematic coding was all transcribed for metaphors employed in discussions of decision-making about cancer research participation (Chapter VI).

Table 4

Specific Aims, Research Questions, Methods, and Where Addressed

AIM	**Research Questions**	**Methodology**	**Addressed**
#1 To explore the historical discourse of hope.	**1.** What are the discourses of hope that influence how people construct hope*?*	**1. Genealogy of hope**, built on a review of major historical discourses of hope as presented in published literature.	**1. Chapter IV**
#2 To examine how people with cancer practice hope relative to decision-making and cancer research participation.	**2. A.** How**,** when, and why do patients, family members, and researchers employ the construct of hope?	**2. A. Discourse Analysis of 109 interviews**	**2. A. Chapters V, VI**
	2. B. What words do patients, family members, and researchers use as metaphors for hope?	**2.B. Discourse Analysis of 109 interviews**	**2. B. Chapters V, VI**
	2.C. What words or phrases are co-located in discussions about hope?	**2.C. Discourse Analysis of 109 interviews**	**2. C. Chapters V, VI**
	2.D. How is hope practiced in a quaternary cancer research center?	**2. D. Discourse Analysis of 109 interviews**	**2. D. Chapters V, VI**
#3 To describe cultural, religious, political, and traditional words that frame hope and assumptions held by investigators relative to research participation	**NA**	**3. Discourse Analysis**	**3. Chapters V, VI**

CHAPTER IV

HEGEMONY, HERMENEUTICS, AND THE HEURISTIC OF HOPE

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Hegemony, Hermeneutics, and the Heuristic of Hope

Kathleen Shannon Dorcy, MN, RN

Hope has become a commodity, one that society expects those who suffer to invest in and one that healthcare providers are expected to promote as an outcome. In nursing research, a single hegemonic epistemology/ontology has been implemented through an exclusive hermeneutic (interpretation of data) and has resulted in hope being designated as an external objective heuristic for those who suffer. Evidence is articulated in this article for adopting a broader method of analysis and interpretation (genealogy) that can facilitate fuller apprehension of hope in the human experience of suffering and despair. **Key words:** *constructivism*, *discourse analysis*, *genealogy*, *hegemony*, *hermeneutics*, *heuristic*, *hope*, *objectivism*, *phenomenology*

MANY RESEARCHERS have studied the phenomenon of hope, the influence it bears on suffering, and the degree of despair or hopelessness experienced by patients in moments of illness and injury. From these formal inquiries into the phenomenon of hoping, a hegemonic theme has emerged, one that has dominated the published analyses of hope over time: hope is a positive *thing* and people *should* cultivate hope when coping with a constellation of physical, emotional, psychological, or spiritual suffering endured in episodes of loss, illness, or injury. Hope has become a commodity, one that society expects those who suffer to invest in and one that healthcare providers are expected to promote as an outcome.

In response to a call by the journal *Advances in Nursing Science* (*ANS*) for critique and replication of research previously published, 3 articles written specifically about hope in the years 1999 to 2009 were reviewed. These 3 articles were chosen because they are representative of the field of healthcare research on the concept of hope and so provide an opportunity to critique and understand the continuity of the published works dealing with hope. The articles' conclusions about hope were examined using textual analysis, so as to identify assumptions and articulate rhetorical strategies used by the *ANS* authors to legitimate their presentations and their interpretations of the concept of hope. The purpose of this critique is twofold, first to provide recognition of the hegemonic expectations that have established a mandate in discourse for how research and scientific inquiry of hope should be done and second to encourage a broadening of methodological frameworks employed in nursing science.

ANS STUDIES

In 1999, Forbes[1] published a study evaluating 2 different methods (phenomenological and postpositivist) for evaluation of results relative to building nursing theory. It was a qualitative study of older adults with chronic illness intended to evaluate methods employed for the purpose of expanding the conceptual development of hope.[1]

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In another study, an Australian researcher, Turner,[2] performed a secondary analysis of data from her 2002 study of hope in young people. The original work was a "hermeneutic phenomenological study" that was designed to explore the phenomenon of hope as perceived by 10 Australian youth. Gadamerian concepts of openness to meaning and fusion of the horizons as well as projection, prejudice, and fore projection were utilized in the interpretation of data. Stories of hope were recounted by the youths, recorded, transcribed, and then analyzed. The reexamination of the data allowed for the author to gain greater insight into how the very experience of despair and hopelessness were points where hope could be "embodied."[2]

The third article, by Lohne,[3] published in 2008, assumes an analytic framework similar to the others in employing concept analysis and a phenomenological foundation for the purpose of expanding the concept of hope. The study is qualitative and provides a synthesis of 3 empirical studies on hope within the context of spinal cord injuries. A conceptual model was developed and titled "The Battle Between Hoping and Suffering" and "The Road of Hope," illustrating the researcher's interpretation of the distinction between *being in hope* and *having hope.*[3] See Table 1 for overview of articles.

KEY CONCEPTS

The concepts of *hegemony, hermeneutic,* and *heuristic* are integral to the analysis of the chosen articles on hope. *Hegemony* is here defined as the set of processes by which a dominant cultural perspective maintains its dominance within a society. In the case of professional nursing, cultural dominance is maintained through research, publications, and pedagogical expectations. These provide a consistent and largely unchallenged perspective of what constitutes quality research.

Hermeneutics is here defined generally as the interpretation of meaning, not only in linguistic analysis but more broadly in cultural and ontological assignations of meaning. Nursing research has generally affirmed a hermeneutic stance that investigators can sufficiently "bracket" themselves as distant from the data and so assure an "objective" conclusion.

The final concept, *heuristic,* is used as a noun and describes a process/method wherein an individual solves a problem or resolves a situation. In the analysis that follows, a presentation will be made that demonstrates how a single hegemonic epistemology/ontology has been implemented through an exclusive hermeneutic (interpretation of data) and has resulted in hope being designated as an external objective heuristic for those who suffer.

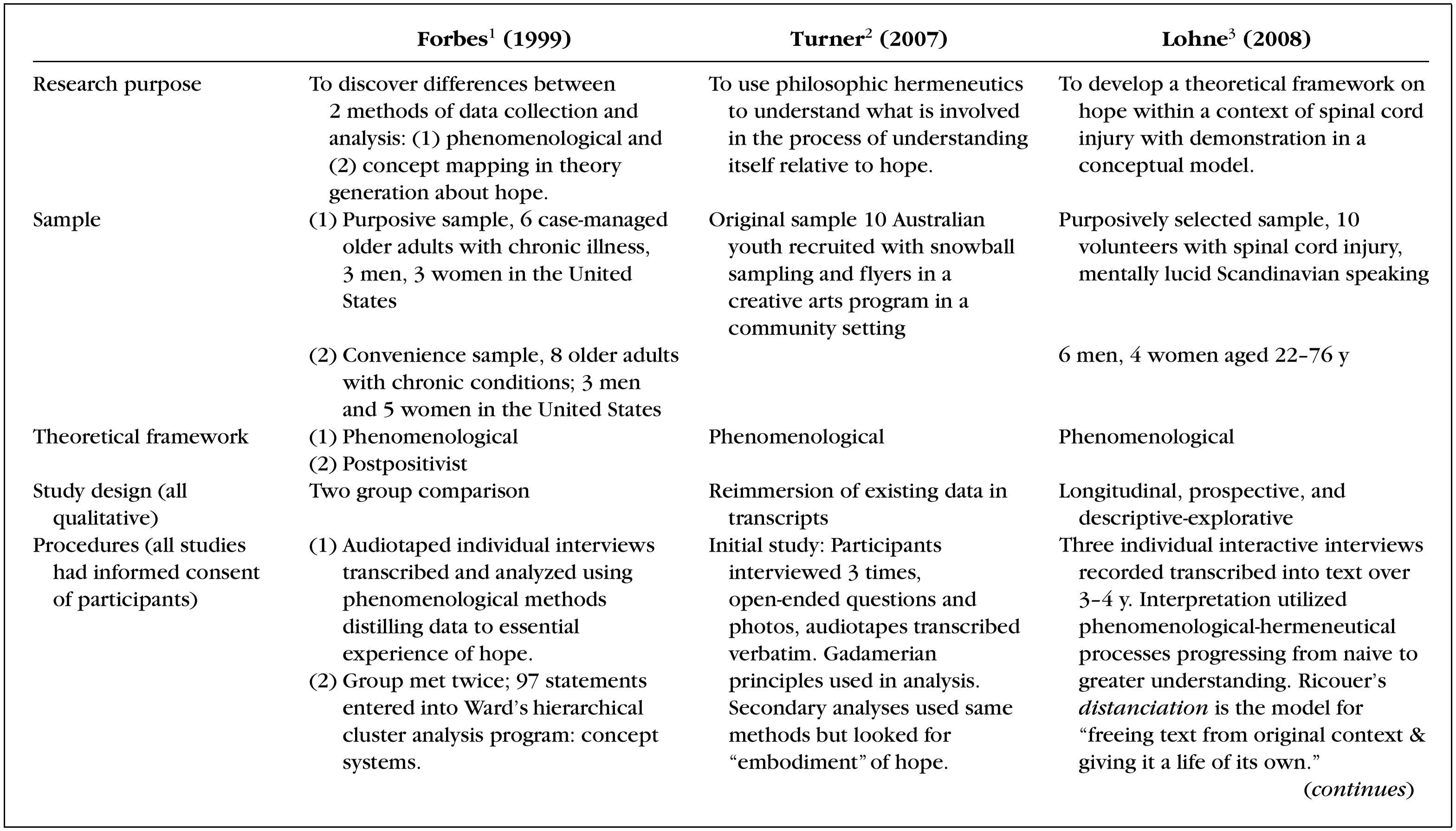
HOPE

Within an objectivist epistemology, hope becomes an artifact or an object. With hope as an external reality, power to access hope rests with those who "know the way" and grants those who know the truth of hope a kind of ultimate power. Thus, the researcher can assume a position of power to provide hope or guide others to hope. This is particularly true when the researcher is within a clinical setting. The objectivist framework of research is capable of reducing abundant and sometimes conflicted semiotic data into a single universal concept.

Some of the questions to consider in this review of *ANS* published discourses about hope are as follows: (1) How is hope conceptualized? (2) Are there existential, propositional, or value assumptions integral to the author's premise? (3) What is the explicit or implicit hermeneutics (interpretation of meaning) applied to the data? (4) Can hope be defined in a universal manner that reduces all hope to a singular truth? To aid this effort, a genealogical review will synthesize selected publications from the genre of healthcare providers' research efforts and some selective constructions of hope as viewed historically.

Genealogical here means the intensely comprehensive synthesis of the origins and

Table 1. Summary of articles



	Forbes[1] (1999)	Turner[2] (2007)	Lohne[3] (2008)
Research purpose	To discover differences between 2 methods of data collection and analysis: (1) phenomenological and (2) concept mapping in theory generation about hope.	To use philosophic hermeneutics to understand what is involved in the process of understanding itself relative to hope.	To develop a theoretical framework on hope within a context of spinal cord injury with demonstration in a conceptual model.
Sample	(1) Purposive sample, 6 case-managed older adults with chronic illness, 3 men, 3 women in the United States (2) Convenience sample, 8 older adults with chronic conditions; 3 men and 5 women in the United States	Original sample 10 Australian youth recruited with snowball sampling and flyers in a creative arts program in a community setting	Purposively selected sample, 10 volunteers with spinal cord injury, mentally lucid Scandinavian speaking 6 men, 4 women aged 22–76 y
Theoretical framework	(1) Phenomenological (2) Postpositivist	Phenomenological	Phenomenological
Study design (all qualitative)	Two group comparison	Reimmersion of existing data in transcripts	Longitudinal, prospective, and descriptive-explorative
Procedures (all studies had informed consent of participants)	(1) Audiotaped individual interviews transcribed and analyzed using phenomenological methods distilling data to essential experience of hope. (2) Group met twice; 97 statements entered into Ward's hierarchical cluster analysis program: concept systems.	Initial study: Participants interviewed 3 times, open-ended questions and photos, audiotapes transcribed verbatim. Gadamerian principles used in analysis. Secondary analyses used same methods but looked for "embodiment" of hope.	Three individual interactive interviews recorded transcribed into text over 3–4 y. Interpretation utilized phenomenological-hermeneutical processes progressing from naive to greater understanding. Ricouer's *distanciation* is the model for "freeing text from original context & giving it a life of its own."

(*continues*)

Table 1. Summary of articles (*Continued*)

	Forbes[1] (1999)	**Turner[2] (2007)**	**Lohne[3] (2008)**
Results	(1) Themes 8, with underlying theme clusters. Central task . . . making peace with situation. Transcendence over suffering, cyclic process. B. Clusters 8. “Illness changes hope. Gain awareness, mindfulness, focus & develop tools for hope.”(p80)	“In . . . reconstruction of the participants’ hope/no hope states, it was identified that hope was embodied & enabled participants to reclaim their hope in the grieving & loss situations of their lives.”(pE59)	“Findings revealed 9 themes: universal hope, uncertain hope, hope as a turning point, the power of hope boundless creative & flexible hope, enduring hope, despairing hope, body-related hope, & existential hope. Model ”. . . illustrated The Battle between Hoping & Suffering.”(p237)
Conclusions	Difference between methods in time, depth of data, “. . . determination of which method is better suited to building middle range theory depends on . . . researcher decisions . . . most importantly the typed of theory one wishes to build.”(p86)	“. . . hope as a confluence of having a driving force, being connected, having choices, & options & being-at-one-with.”(pE59)	“According to the conceptual model, experiences based on the participants” former life before the spinal cord injury, created new hopes.”(p246) Hoping changed from early stages of rehab to 4 y post, “hope to improve” changes to “being fine.”(p242)

evolutions of "truths" taken for granted and assumed to have a universally static value. Genealogy challenges the historical linear progression of how meaning is transported through time and acknowledges the complex mosaic from influences of politics, religion, theology, and economics on the construction of meaning. Genealogy, as distinct from a concept analysis, sees multiplicity in meaning as opposed to a single universally applicable definition necessary for the formulaic comprehension of a concept.[4]

SELECTED GENEALOGY OF HOPE

To draw conclusions about how hope is present within the clinical context of healthcare, it is first necessary to explore the complex and often-complicated aspects that the notion of hope carries through time and context, namely, *hope as a benefit* versus *hope as a curse*. A quest for origins suggests a dualistic, even a contradictory, nature of hope.[4,5]

Hope is an old term, richly imbued with mythological and theological associations. As recorded in accounts of the Greek mythology, hope was one of the consignees of *Pandora's box,* with hope*,* or *elpis, as* the last of the contents of the opened jar or box (depending on the version of the myth). Pandora had received the box from Zeus, or Hermes, with the warning to never open it. Curiosity got the best of Pandora, however, and upon her opening of the lid, evil and misfortunes were unleashed upon the world's population. Pandora then closed the box and left hope trapped inside. One version of the myth has an intervening time of trials and tribulations for the world before Pandora returned to reopen the box and "out fluttered hope." One interpretation of this action asserts that the final release of hope was symbolic of better times promised in the midst of hardships. Another interpretation, for instance that of Nietzsche, is that *elpis*, hope, should be the worst of all evils, something that is representative of terrifying foreknowledge. Pandora saved the world by preventing its earlier escape out of the box. Clearly, 2 divergent conceptualizations of hope emerge early on, dependent on the version of the myth conveyed.[6]

The discourse of hope in the Bible generally is distinct in its use whether in the Old or the New Testament.[7] The Hebrew word *Qoh* for hope implies a future orientation or expectation, and this expectation is closely linked with trust and confidence in the future. Also from the Hebrew, *piel* is a verb, meaning "quiet waiting" or "perseverance" or "to expect with tenseness." Yet another variation in Hebrew is *qwh pi*, which means "to hope," "to expect or to wait upon."[7,8] In the New Testament, there is a transition to the word *hope* that implies transformation and steadfast endurance. The New Testament employs hoping as a verb to represent redemption from suffering and the transcendence of evil and threats of persecution. Hope as a noun in the New Testament signifies a covenant, or a promise between the people and the God of salvation. This covenant has imbricated elements of waiting, trust, faith, confidence, expectation, and motivation.[9]

HOPE IN MODERN DISCOURSE

Hope has been described in more recent times as a construct that provides comfort, encouragement, and an ability to look toward a more positive future. In discussions regarding health, hope is derived from the premise that hoping is integral to how people clarify, prioritize, and affirm their choices within healthcare. Several studies have identified hope as a resource for coping with cancer, one that provides the patient with strategies for managing the disease and engaging in social support.[10-13]

Hope has been identified as a key activity in coping, resilience, empowered self-care, and perceived quality of life in patients with cancer.[14-19] Several studies have drawn direct links between patients' faith experiences and connections to God as correlative with the experience of hope.[17,20-24] The association of hope with spirituality and religion is a strong cultural and literary tradition within Western Judea-Christian cultural groups. This relationship between hope and spirituality can be useful in determining how hope is employed within a Judea-Christian context. This context, however, can provide a barrier to hope for those outside this Westernized linguistic tradition. Insight into how people have used hope through time and how cultures have, in some instances, reified hope into a positive attribute one should possess is a critical element of a comprehensive analysis.

HOPE AS AN INTERPERSONAL INTERACTION

The dialogue patients have with care providers about disease progression, the low likelihood of survival, and the possibility of impending death are often laced with numeric representations of chances for survival. The dissemination of statistical information has been correlated with the increase of hope in patients with cancer. The use of survival statistics in conferences between patients and providers has been examined and found to be a complex issue as patients both desire the facts in numeric format and resent the implications contained in the numeric risk statements. Despite feelings of resentment, some patients report taking comfort in the statistics, even when a 5% cure rate was predicted. The translation of this, the tiniest chance of survival, gives individuals an invitation for engaging in the practice of hoping so as to be among those who could comprise the small survival statistic.[20]

The literature affirms that decisions to participate in clinical research are influenced by patients' hope and hope is created in the context of shared communication in many forms.[15,20–24] In surveying patients about a recent media campaign for a new chemotherapeutic agent, researchers found that viewing media had an effect on patients' awareness of self-care options and provided opportunities to foster hope. The Internet has become another source of social support and information seeking.

MEASURING HOPE

The Herth Hope Scale, introduced in 1989 and later shortened to the Herth Hope Index, examined the relationship between levels of hope and levels of coping response in adult oncology patients receiving chemotherapy. Herth[17–19] found that individuals with self-identified strong religious faith had a higher level of hope and coping response than those without faith or who reported "weak faith." Most significantly, the author asserted that hope is important in the life of people with cancer. The HHI is built upon a premise of familiarity with religious and cultural representations of hope and demonstrates another example of inherent existential, propositional, and value assumptions. This integration with religious discourse is an element of intertextuality and continuity, which demonstrates how hope enactment is coauthorized by the social setting and the people who employ the notion of hope.[25]

CONTEXT OF METHODOLOGICAL REVIEW

Scientific publications, considered as texts, are genres that inculcate the continuity of current paradigms of scientific thought. The inclusion and attribution of other voices demonstrate the concept of intertextuality.[4] The claims made in texts are often founded on assumptions that, though not explicitly stated, represent strong components of meaning. A value assumption present throughout all the *ANS* texts is that hope is a good thing and that people should hope. The existential assumption in all the articles is that hope exists as a positive phenomenon. The propositional assumptions are that hope can serve as the heuristic to suffering and that interview data corresponds exactly with reality.[25] See Table 2 for more details.

Intertextuality involves the recognition of explicitly named and cited references as well as recognition of other references present implicitly, unstated, or not cited. In the 3 *ANS*

Table 2. Author assumptions

	Forbes[1] (1999)	**Turner[2] (2007)**	**Lohne[3] (2008)**
Existential assumptions	Hope exists as a positive phenomenon.	Hope exists as a positive phenomenon.	Hope exists as a positive phenomenon.
Propositional assumptions (what is, can, or will be the case)	Interview data correspond with reality. Hope and hopelessness are closely related. Hope is future oriented. Hope is helpful to chronically ill people.	Interview data correspond with reality. Hope and hopelessness are closely related. Hope is future oriented. Hope is helpful for young people confronted by loss and grief.	Interview data correspond with reality. Hope and hopelessness are closely related. Hope is future oriented. Hope is helpful and cyclic for people with spinal cord injury.
Value assumptions (what is good or desirable)	People should hope. Hope is important. Depth of data is good. Saving time is good.	People should hope. Hope is important. Reimmersion is a good method for new interpretation.	People should hope. Hope is important. Conceptual models are exemplars of research results.

articles, the texts referenced are constitutive of the context of a recognizable discourse on hope over time. Implicit intertextuality can be seen in the themes of hope as a heuristic to suffering, in the method of analysis, and in the hermeneutics utilized as grounded theory, objectifying or reifying hope. Each author employed phenomenology as the theoretical framework for the investigations into hope. Notably, none of the authors referenced the same philosophers. Frankl,[26] an existential psychiatrist, is cited by Turner[2] and Lohne[3] but not by Forbes.[1] A list of explicit shared references can be found in Table 3.

Legitimation is an analytic tool and can be useful in the examination of texts as it helps specify how authors legitimate their findings. The strategies for legitimation according to Fairclough's categorization are as follows: authorization, rationalization, moral evaluation, and mythopoeis. *Authorization* is the referencing of the authority of tradition by custom or law. *Rationalization* is referencing the utility of institutionalized actions and knowledge as constructed by cultures to recognize cognitive validity. *Moral evaluation* references legitimation by value systems, and *myothopoesi*s references legitmation conveyed through narratives of various kinds.[25(p98)]

Each of the *ANS* authors shared a tradition of implementing theory generation as a method that produces reliable authoritative truth, thus providing legitimation by

Table 3. Explicit shared references

	Forbes[1] (1999)	**Turner[2] (2007)**	**Lohne[3] (2008)**
Morse and Dobernick[27]	Yes	No	Yes
Dufault and Martocchio[10]	No	Yes	Yes
Erikson[28,29]	No	Yes	Yes
Lynch[30]	No	Yes	Yes
Frankl[26]	No	Yes	Yes

Table 4. Legitimization

	Forbes[1] (1999)	**Turner[2] (2007)**	**Lohne[3] (2008)**
Authorization (authority of traditional custom law)	Theory generation is important.	Theory generation is important.	Theory generation is important. Conceptual models validate findings.
Rationalization (legitimization is by institutionalized action constructed to endow cognitive validity)	"Similarity between these findings & . . . Morse & Doberneck's . . . supports strength of research between methods & among researchers."(p86)	"Reimmersion in the data added new dimensions to my understanding of hope & how it functions in peoples' lives."(pE50)	"The interpretations also revealed a distinction between *being in hope* & *having hope*. . . . According to Marcel, the concept of *being* must be understood as internal activity & is derived from the act of existence."(p246)
Moral evaluation (legitimization by reference to values)	"When current theory about a concept of interest is insufficient, the researcher may desire to build or expand theory."(p74)	Lost horizons of hope, ". . . is a dangerous time& all efforts must be made to connect the person to the core of . . . hope . . . a mandate of professional nursing care."(pE59)	"Pt.'s longing should be focused as important sources for maintaining & promoting hope when pts' filled with despair & fear."(p246)
Mythopoesis (legitimization conveyed through narrative)	Study used interviews and verbatim transcripts to legitimate meaning.	Study used interviews and verbatim transcripts to legitimate meaning.	Study used interviews and verbatim transcripts to legitimate meaning.

authorization. Rationalization was established with the formal citation of established experts in the field and the linking of those experts to cognitive validity. Moral evaluation was invoked by the explicit message that hope is good and people who suffer should hope. The use of narrative data and the author's masterful interpretation of those narratives as truth is one way that legitimation by mythopoesis was established by each author.[25] See Table 4 for more details.

The articles themselves are representative of culturally distinct voices. Forbes[1] is an American, Turner[2] is an Australian, and Lohne[3] is Norwegian. Forbes writes while she was an assistant professor at the University of Wisconsin-Milwaukee in 1999, where the prevalent hegemonic voice of academic research at the time was shifting from objectivism as a research epistemology to constructivism. Her research was about comparing the 2 epistemologies and methods to ascertain difference in theory generation for hope. The comparison of 2 methods in theory building was done with a phenomenological method of interview involving chronically ill, older people. The alternative method of concept mapping was accomplished by using a computer program to analyze the narratives of a group process.[1]

According to Forbes,[1] the differing methods delivered similar results and were found to be consistent with the findings in the pioneering work of Morse and Doberneck[27] who identified the themes of uncertainty, enduring, and suffering. The epistemological model in Forbes[1] is still objectivism, and the inquiry seeks to define hope as a unitary, universal truth that exists external to the individuals. In keeping with phenomenological ontology, it endeavors to reveal the "lived experience of hope" in older people with chronic illness (see Table 1).

Turner's study[2] engages in a "reimmersion in existing data" to gain greater insight into hope as seen through the eyes of 10 young Australians. In this work, the author makes a powerful point that the stories of hope from the youth were often articulated through experiences of intense suffering and loss. This poignant interplay between hope and suffering is in continuity with the historical genealogy of hope where hope is employed to transcend or transform situations of profound suffering and despair.[2] The youths in Turner's study construct hope from the core of their own beings, similar to what Frankl observes of hope, "rising above the suffering of the moment."[26(p29)] Concluding comments of the author suggest that hope is the actual process whereby suffering can be "apprehended." A crucial element in this author's work different from the other studies from *ANS* is the view of hope as internal to the individual, an experience that can be shared between people and not some *thing*, not an object of reified external reality with a single unitary meaning.[2] See Table 1 for full study summary.

The third author, Lohne,[3] is a widely published researcher and educator in Norway. Her work also focuses on understanding hope in the context of suffering after incidences of spinal cord injury. The findings from her longitudinal study are consistent with Danish researchers Kylmä and Vehviläinen-Julkunen.[31] Their meta-analysis of literature relative to hope in nursing concluded that most of the research on the topic of hope has been grounded in a positivist (objective) paradigm.[31]

Lohne's philosophical framework combines existential phenomenology and a use of a "hermeneutical circle" as the tool for interpretation. In this interpretative process, the author specifies that understanding of the data grows from the naive to a deeper comprehension of the whole text and its individual components. Lohne cites Ricoeur's concept of *distanciation* as a process whereby the interpreter approaches the text without consideration of the individual participant's intentions or intent.[32] "During this process of understanding, the text is freed from its original context and given a life of its own."[3(p242)] Lohne's formulation of hope is influenced by the philosophy of Gabriel Marcel for whom the concept of being should be understood as a internal activity, one derived from act of existence.[33(p246)] Lohne's conclusions clearly identify a distinction between *being in hope* and *having hope*. (See Table 1 for full study summary.)

DISCUSSION

In Forbes's study, the theoretical framework referenced is existential or phenomenological. The study employs 2 methods of assessing the development of hope with older adults: phenomenological individual interview analysis and a comparison with a group interview utilizing Ward's hierarchical cluster analysis. Fundamentally, theory generation regarding hope was the explicit goal of the study. Forbes's findings are an attempt to arrive at a universal definition of hope. Ultimately, hope is a heuristic for coping with the limitations of aging and chronic illness.[1]

In her 2002 study, Turner[2] found that hope was crucial in the lives of Australian youth who suffered traumatic life experiences. Hope was seen as something that facilitated coping with the pain, as well as allowing for the full "apprehension of the suffering." The existential assumptions in her work are also that hope fulfills a positive, good role in the lives of those who suffer. After reimmersion in her original research, Turner[2] stated that at this juncture she is abandoning her search for a universal definition of hope. Her theoretical framework is phenomenological.

The 2008 work by Lohne[3] is also rooted in a phenomenological and an existential theoretical framework. This work is concerned with theory generation and demonstrating concurrence with previous works on hope. The continuities evident in her article build exactly upon the premises and methodology of other grounded theorists and could be said to show fidelity with this shared method. *Being on the road to hope* is contrasted with *being on the road to death*. Hope is a signifier for life in this work and serves as heuristic to the process of suffering and the "vicious cycle" between despair and will and faith. The relationship of hope to matters of faith is clearly demonstrated as a continuity with Lohne's work.[3]

In schools of nursing, *concept analysis* is commonly taught as a step-by-step method for increasing the "maturity of a concept" to contribute to the generation of theory. Steps guiding concept analysis are concept delineation, concept comparison, concept clarification, concept correction, and concept identification. In the case of hope, this kind of analysis and hermeneutic includes the premise that in establishing the maturity of the concept, the researcher is "giving voice" to the patient's hope. Utilization of the metaphor of giving voice is an explicit example of how hope is seen as something that is able to be handed to another. *Hope as a thing* and *hope as experience* are themes imbricated within the general discourse on hope. Also, inherent in the objectivist's interpretation of hope is that the assumption that the words of interview data are a precise representation of objective reality. This assumption of objective reality in the interview data creates certitude relative to the researchers' interpretation. It is as if the final assessment, analysis, and conclusions of the data have a unitary meaning, one stated by the participants of the study and then precisely represented by the researcher.[33,34]

The works on hope in *ANS* have contributed significantly to the study of the phenomena of hope. Each embodies what Kuhn[35] has classified as "normal science," whereby a discipline creates a matrix of practices that are considered paradigms for replicating and proving mature science. Theory generation is what nursing has chosen as its exemplar for research in the social sciences, and the *ANS* authors are expert at this implementation of method and interpretation. But, as Kuhn[32] speaks of revolutionary science as totally distinct from normal science, perhaps it is time to move into a new paradigm of practice for future investigations into hope.

Current methods for understanding hope are hegemonic in academic analyses of hope within the genre of nursing literature. Hope is assumed to be a positive thing, and people should endeavor to have hope or to encourage others in it. The hermeneutics involved in deriving meaning from data also deserves a second look. Researchers now must acknowledge their own personal presence as it influences the posing of the research question, the collection of data, and the interpretation of data.

Nursing research has progressed from the early 1990s when qualitative methods argued for the investigator to bracket oneself and to strive for the goals of authenticity or fidelity to the spoken words of interviewees, essentially an objectivist version of interpretive studies. Most of the research on hope is interwoven with an objectivist epistemology/ontology that relegates meaning to the objective reality. More recently, Eliott and Olver[14] have studied hope, using discourse analysis as the method for analyzing the words of patients speaking about end-of-life decision making. This linguistic framework systematically allows for the analysis of hope both as a verb and as a noun and demonstrates how language is powerfully nuanced in the act of hoping. Eliott and Olver's[14] interpretive process allows for meaning to be explored in new ways rather than only in the paradigm of concept analysis and theory generation.

ALTERNATIVE TO CONCEPTUALIZING HOPE

Eliott and Olver[14] posit that hope is a phenomenon constructed in the words and shared dialogue of people, as opposed to a reality that exists independently, outside of the of the individual or the researcher. Their analytical premise is shaped by the notion that language is not a neutral, transparent description of the objective world. Rather, it is culturally contextual explication of the speaker's intentions. The authors assert several characteristics of hope. It is both objective and subjective; it is a burden and a resource. It may be a tool for evaluating situations, an inspiration for action, or a reason for inaction. It is present or future oriented and may be at once both vulnerable and enduring.[14]

Eliott and Olver[14] suggest that hope should be viewed as taxonomy rather than as an externally derived, unidimensional definition of an objective concept. They privilege the spoken word as the surest explication of the individual's notion of hope. They assert that the objective definitions and attempts to measure hope in various scales limit hope, decreasing hope's relevance for people. Finally, the authors conclude that patients do not differentiate between unrealistic hope and realistic hope, demonstrating a multiplicity of dimensions of hope and the need to have a broad range of meanings in order for hope to function.[14]

CONCLUSION

It is important to understand that what is critiqued here is not the findings of the authors in *ANS* but rather the unchallenged processes of professional research practices that assure the continuities of normal science alone. While normal science is valuable, nursing as a profession needs to broaden the methodological approaches employed in interpreting hope to allow for recognition of the vast implications hope has on individuals and professional practice. Providers are not separate or disengaged from the process by which hope is "created" in the lives of patients and their families.

The commodification of hope has played a significant role in the marketing of Western healthcare ordaining hope as a positive force in the face of suffering. The use of hope as a commodity reinforces how valuable hope is as concept for people in general. Hope sells everything from new inventions to cancer centers and the fund drives that support these endeavors. Hope as a commodity is an omnipresent but unexamined presence in the daily practice of healthcare. Providers are deeply invested in hope as it inspires providers and comforts providers who work with those who suffer and those who are in despair.

It is not the intention of this author either to diminish hope or to impede the hoping process for patients or for care providers. Instead, this is a call for recognition of the hegemonic expectation mandated for patients and family members by society and translated by care providers into daily practice. Hope is often a scripted performance that can in fact become coercive when an expectation exists for people with life-threatening illnesses or injuries to keep trying and to not give up hope. In this situation, hope can become merely a heuristic for suffering and despair, reduced to a coping mechanism. Moving beyond current approaches to a broader comprehension, hope may be seen as a potentially powerful and more varied opportunity for those who suffer and who are in despair.

Providers have dichotomized the context of hope in many situations as life or death. This operative dichotomy leaves those who suffer illness with a deeper sense of despair as they are labeled *noncompliant* or *dysfunctional* when the choices made do not agree with what providers judge to be the best or the most hopeful option for patients. In the words of Gabriel Marcel, ". . . there can strictly speaking be no hope except when the temptation to despair exists."[36(p36)] It is within profound suffering and despair that hope is enacted. We do not need a unitary definition of hope. In confronting the vagaries of human suffering and despair, the practice of hope must not be limited. Further explorations into the meaning and performance of hope must be open to the complexities existing within the experience of human hopelessness.

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CHAPTER V

THE *HABITUS* OF HOPE: THE HOPE IMPERATIVE

Abstract

Hope has been promoted as an integral component in the care of cancer patients. Within the nursing literature, hope has been reified as an objectified singular reality that can be measured and promoted for patients. Yet hope may be also be a constructed, coercive component in clinical decision-making in which providers are complicit in wielding hopeful influence. Patients, family members, and researchers share a *habitus* of hope defined contextually and reflexively by language.

Hope is a powerful multidimensional social practice, and nurses and researchers need to recognize how hope can be used to coerce people into opting to follow recommended courses of care or research. Discourse in cancer centers between patients, nurses, and researchers reinforces the *habitus* of hope, or the *hope imperative*. Examination of the discourse of cancer and hope reveal ethical implications for the support of patients and family members relative to cancer research and decision-making. As an expectation of cancer care providers and researchers, hope represents a political and social power differential. In choosing options for cancer care, patients may have no other choice than to subscribe to the *hope imperative*.

Introduction

The American Cancer Society reports a combined cancer incidence rate of 3,937, and a mortality rate of 1,684.5 per 100,000 in the United States (ACS, 2010). These numbers represent the statistical count of people who have had to face a diagnosis of cancer and who, together with their family members and physicians, have had to make decisions relative to treatment and research interventions. Cancer centers recognize the power of the word *hope* so well that it even appears in the name of some cancer centers (i.e., City of Hope in Duarte, California; Patrick Dempsey Center for Hope and Healing in Lewiston, Maine; and Florida Cancer Institute–New Hope in eight locations in Florida). Hope is even more widely employed in the branding effort attached to cancer treatment centers.

Hope is a word widely employed within the context of cancer care decision-making for patients and family members. "Hope is all I have left. . ." (A3) These words of one cancer patient, explaining why he opted to enroll in an early-phase cancer clinical trial, are not untypical of the discourse appealing to a shared understanding of hope heard within the clinical setting. This paper calls for an exploration of how cancer care discourses are linked inextricably to the discourses of hope. This overlapping of discourses may result in unintended consequences, including coercion for people who consent to participate in clinical research or interventions for prolonged aggressive disease.

Days after surgery for a malignant brain tumor, Senator Edward Kennedy greeted the press with a "thumbs up" gesture when asked how he was doing. At the same general time, his wife sent an email to friends and family saying that although the Senator was learning to deal with fatigue, “the news is all positive and encouraging” (Altman, 2008). Both Senator Kennedy and his wife demonstrated what might be called the *“hope imperative*,” a cultural expectation ingrained in Americans to “look at the bright side.”

Barbara Ehrenreich (2009) described this cultural phenomenon as *positivity*. “Positivity,” she writes, “is not so much our condition . . . as it is our ideology—the way we explain the world and think we ought to function within it” (p. 4). For her, the experience of being “recruited” into positivity happened when she was diagnosed with breast cancer. Everywhere she encountered messages that commanded she “accept her cancer” and “see it as a gift.” She vehemently disagreed with this command performance of positivity. She asserted that the social mandate of positive optimism and “fake cheer” requires a patient’s denial of feelings of anger and fear. Additionally, she felt the only benefit of positivity is that it provides a “great convenience for health workers” (Ehrenreich, 2009, p. 41).

These examples highlight the deep desire Americans have to be positive or to be perceived as being positive. Cancer patients are regularly confronted with the *hope imperative:* the expectation that to be successful in the medical system, they need to be willing to be positive and try to achieve a successful outcome—one defined as a cure or at least an amelioration of the cancer. Patients’ contributions to their own care and to the healthcare system are generally as cultivators of positivity, with “hope” as the talisman. Some recent literature has commented on “unrealistic optimism in early phase clinical trials” (Jansen et al., 2011) and associated this phenomenon with patients’ belief that “expressing hope and having an optimistic attitude would actually improve the likelihood that they would experience a therapeutic benefit” (Sulmassy, 2010, p. 3708).

Interestingly, within this work the researchers appeared to *blame* the patients themselves for harboring "unrealistic optimism" and offered little insight into the influence researchers and cancer care providers have on these expressions of optimism.

Decision-Making

Federal regulations have long offered a strict formula for how consent should be offered and confirmed for participation in research studies (CFR 45 § 16:124). Given that care providers have a federal mandate as well as an ethical obligation to assure all decision-making is free and not coerced, *informed consent* and the influence of hope in cancer care decision-making need to be more fully understood.

There is a gap in current literature regarding decision-making and the role hope plays for cancer patients who are trying to decide whether to enroll in clinical trials. The very paradigm of decision-making bears further research, as some investigators have shown that patients opting for surgery for advanced cancers saw the surgery more as a "next step" rather than a decision for or against something (Ferrell et al., 2003). In our efforts to assure ethically sound decision-making, perhaps we have been over-zealous in our determinations of how we should frame options for cancer care and research. We need to ascertain what best supports patients and families in choosing options of care. Early-phase research should be reevaluated to determine how mandatory regulatory decision-making guidelines are implemented.

Hope

Hope is a word quite commonly used as healthcare personnel dialogue with patients who have been diagnosed with cancer. As a concept, hope obviously helps people who are dealing with hardship, loss, fear, anxiety, and pain. As an operative concept in the lives of cancer patients, hope has been investigated by many and found to be significant for people living with cancer and undergoing cancer treatment (Caocci et al., 2006; Dickerson, Boehmke, Ogle, & Brown, 2006; Dufault & Martocchio, 1985; Ebright & Lyons, 2002; Eliott & Olver, 2002, 2006; Ersek, 1992; Herth, 1989, 1992, 2000; Huizinga, Sleijfer, van de Wiel, & van der Graff, 1999; Kylma & Vehvilainen-Julune, 1997; Nowotny, 1989; Pentz et al., 2002; Rusteon & Wiklund, 2000; Saleh & Brockopp, 2001; Schutta & Burnett, 2000; Thorne, Hislop, Kuo, & Armstrong, 2006). At an extreme end of the spectrum, an author critiqued nurses who seek to "engender hope in patients" as lacking evidence from randomized clinical trials (Lipscomb, 2007).

Hope has been presented as a method of coping (Dufault & Martocchio, 1985; Herth, 2000; Menninger, 1959; Lynch, 1965; Snyder et al., 2002, 2004); as a theological precept (Aquinas, 1920; Moltman, 1993; Luther, 2005); as a literary theme (Dickinson, 1993; Donne, 2001; Shakespeare, 1998); as a psychological component for coping with suffering (Frankl, 1963; Herth, 1989, 1992, 2000; Lynch, 1965; Menninger, 1959; Morse & Doberneck, 1995; Snyder et al., 2002); and as a philosophical framework (Aquinas, 1920; Athanassakis, 1983; Bloch, 1986; Nietzsche, 1996; Voltaire, 1924). Hope has also been considered a source of motivation associated with the successful achievement of life goals, such as winning at sporting events, being accepted into college, and finding success in school (Snyder, 2000; Snyder et al., 2002; Valle, 2006). This array of constructions of hope across time and genres has clearly had a profound effect in informing and shaping societal and individual concepts of hope.

"Hope" is understood in the broad variety of ways people talk about it (Eliott & Olver, 2002). Talking is *discourse*, and discourse analysis is defined as "an examination of language in use" (Schwandt, 2001, p. 57). Considering discourse as an element of *habitus* (Bourdieu, 1984) helps show how multiple meanings are created and how shared meanings are developed in usage.

Habitus

Pierre Bourdieu (1984) used the term *habitu*s to refer to the socially acquired, embodied systems of dispositions or predispositions that individuals share. Bourdieu borrowed the word *habitus* from the Latin, in which it means a pattern, a characteristic, a condition, or a quality of the individual. Bourdieu regarded personal choices or preferences as neither random nor linear components of an individual's life. For Bourdieu, the tapestry of human existence was a blend of personal agency greatly influenced by culturally accessible experiences and choices available to each person in the course of one's life.

Habitus is not only about moral socialization; it is about personal inclinations, tendencies, and propensities in opinions, behavior, decorum, and practices within different historical and cultural settings. Important for understanding how these social and cultural factors influence individual decision-making or consent process, Bourdieu carefully avoided determinism or essentialism as philosophical notions, because those notions leave humans passive and powerless in reflexive responses to stimuli. Change is not a possibility if one's responses are programmed by essentialist determinism (habits in the narrow sense), and there is no free will or authentic autonomous choice.

In the context of the current discussion, it is the ability to make choices while remaining engaged with the researchers and with societal norms that define what it means to be a "good patient." This constitutes the *habitus of hope.* The word *hope* is part of a shared cultural discourse, and as an idea it is part of a socially constructed reality—a cooperative process—not one that takes place in a vacuum. People are raised in a social milieu where they learn to comprehend within the give and take of discourse such social practices as "fitting in."

Both cancer patients and researchers engage in a reflexive dialogue. In addition to the community or global overview of dominant discourse, it is also necessary to scrutinize the micro or less official uses of power, such as those conveyed by tone, word choice, hesitation, pronoun use, and rhetorical style (Wetherell, Taylor, & Yates, 2001). Within these linguistic elements is a considerable bias of Westernized dominant culture that assumes what hope should look like.

Hope is most often an objectified thing, assumed to have a singular definition—a process that can be linked to Judeo-Christian theological-philosophical precepts. The discourse of cancer research for both patients and physicians is shaped by the desire to cure cancer. A *habitus* of hope—the cradle of the *hope imperative—*is reinforced by society's avoidance of speaking of death and a strong societal bias that cure is the ultimate goal of cancer care. Hope as a co-creation between cancer patients, their family members, and researchers can be seen in quotes from each of the patients, family members, and physician researchers involved in the study.

Methods

The present study relied on a discursive (or close textual) analysis of secondary interview data in which the influence of hope on decision-making for cancer research participation were explored. All participants were identified within a large quaternary center in the northwestern United States. The original sample included 25 people diagnosed with a hematologic malignancy, each of whom had consented to participate in a Phase II hematopoietic cell transplant (HCT). Twenty additional subjects included in the study were family caregivers designated by the patients to be interviewed. Ten more subjects were physicians who oversaw care of HCT patients and participated in consent conferences with patients and their family members (see Table 9). A waiver of consent was granted by the Institutional Review Board (IRB) to allow for the secondary analysis of transcripts. The original study was explained to all participants; each signed a written consent form and was given copies of the consent form.

The secondary analysis included 109 transcripts of semistructured interviews that were conducted at three time points during a year. The patients and designated caregivers were interviewed immediately after consenting to the Phase II HCT protocol, again at eighty days post-HCT, and finally at 1 year post-HCT. Hyperreseach© software was used to review and code transcripts. Interviews were examined using discourse analysis and the elements described above; researchers specifically looked for how the language of hope was articulated and nuanced. Quotes from participants were identified and coded to elucidate where and how the language of hope occurred in the dialogue of subjects relative to discussions of how patients and their families decided to participate in clinical research. The following codes were applied to statements in the transcribed interviews:

Genealogy, Hope as Noun, Hope as Verb, Hope as Practiced, Active Voice, Passive Voice, and Metaphors.

After the codes were applied, it became clear that the codes were too limited and static to fully capture the dynamics of the decision-making process. Though mandated by federal policies, the informed consent conference facilitates an encounter between the researcher and patients and their family members; it is a rhetorical event that socially and dynamically aligns speakers and hearers in a process of persuasion. The interactive process includes the components of reasoning, conveying value, and compassion. Although the informed consent process retains some of the aims of traditional rhetorical practice, such as teaching or instructing, this didactic aim can easily be subordinated to another rhetorical aim—that of moving or persuading. The elements of *logos* (logic of the argument), *ethos* (trustworthiness or credibility of the researcher), and *pathos* (emotions of the audience) have been used to further refine and integrate the data in order to capture the dynamic interplay of the decision-making performance. Use of *logos, ethos*, *and pathos* confirmed that the enactment of decision-making for participation in cancer research is a persuasive encounter.

Rhetorical Analysis

Rhetoric

The general framework of rhetoric was chosen in order to analyze the dynamics of discourse contained in the transcripts of the series of interviews. Rhetoric is reproduced and reinforced within the cultural milieu as a durable disposition. Living in a culture, learning the language, and experiencing life over time creates a recognized reality that is socially accessible to individuals as they negotiate daily life and engage with others in the community. Critical analysis of language use can only be done with an adequate comprehension of constitutive social power. In the study of discourses on hope, it is imperative to understand what privileged certain discourses and instilled them with power. For instance, in the early Christian church, priests had preferential access to written texts and scriptures; that access resulted in a discourse shaped by a religious and theological set of actors whose agency and cultural context allowed for the employment and interpretation of the concept of hope within a broad context of a class of people beset by poverty and suffering. For cancer patients today, the historic discourse of cancer and how it is to be treated has been transformed within the context of an intensely detailed medical model for intervention. The power, then, is within the hands of researchers and those who finance that research.

Rhetoric, defined as "as the faculty of observing in any given situation the available means of persuasion" (Rhys, 1961, p. 9), is not generally a concept applied to the analysis of patient decision-making. But rhetorical analyses can help illuminate the insinuation of coercion introduced by the *hope imperative* present in recruitment of patients for cancer clinical research participation.

Portrayal of Persuasion

The patients who were enrolled in the study had hematologic malignancies and had decided themselves or had been referred by their primary oncologists to seek an HCT. All the HCT protocols were Phase II research protocols; some had as few as 4 patients in the protocol prior to the study participants' enrollment. The research protocols represented early-stage research designed to evaluate safety.

Reasoning or *Logos*

The principle of informed consent uses *logos* as the key marker for a participant's cognitive awareness and understanding of implications of research participation. Within the sample, 92% of the patients and 75% of the family caregivers stated that they had decided that they would participate in any clinical trials that were offered before they arrived at the cancer center and before the consent conferences or reading of consent forms (Shannon Dorcy & Drevdahl, 2011). The decision to participate before the "consent conference" was held indicates the patients' *a priori* placing of hope in the center's research offerings.

Patients' comments made poignantly clear how well they had come to a cognitive understanding of the research process. The wife of patient who had traveled from another country for care at the center said, "No, it was not a decision. I mean, do you want to live or do you want to die? Well, I think we both vote that he live, and this is the only way that was a possibility. So there was no need for discussion" (Participant 19B). One patient reasoned, "If I relapse, I'm the same I would have been had I not gone through this. Somebody's got to be in the 20–30% range, and I am one of them" (Participant 5A). A female patient stated, "I couldn't leave myself with any regrets that there was something that I didn't try for a cure. . . . I couldn't have any regrets, even though the numbers didn't look that great" (Participant 9A).

Participants expressed some degree of clarity about the risks they were facing with the hematological diagnoses they had received and they understood the potential risks and possible benefits they might have if they decided to participate in clinical research trials. One physician summed up several of the patient/family experiences by saying, "[It's] a terminal disease, one they could have lived with for several months or a year or two before they would succumb to it. . . . .So they come here with the hope of being cured" (Participant MD 2).

Reputation or *Ethos*

Part of the equation for evaluating the success of the persuasion in the consent process is how well the hearers—the patients and families in this case—perceive the credibility or goodness of the speaker. Many of the patients (64%) and family members (50%) articulated how important it was to them to know of the national reputation and ranking of the research center (Shannon Dorcy & Drevdahl, 2011). Patients who had been diagnosed with aggressive diseases like acute myelogenous leukemia (AML) and who had been referred to the center within days of the diagnosis spoke of trusting the referring center and the credibility of their hometown physician. Other patients had done national searches in the literature and consulted with other agencies to seek out what could be termed "the best."

The notion of the "best" often carried with it a *hope* of cure and *hope* for survival, and these words were heard repeatedly in discussions as to why people decided to participate in research. The following comments are just a brief overview of how this *hope* in the center's "*ethos*" was expressed. One individual remarked, "This is the only place that I called because I knew you guys were number one in the world" (Participant 11A). One family member said, "We made it [a decision to come to the research center] right away. It just really felt like a no-brainer" (Participant 17B). A patient said, "…a few Nobel prizes, it's like why would you go anywhere else" (Participant 3A)? One patient summed up the decision to pursue research at the cancer center by saying, "I knew that this cancer center was the best in the world. . . . I felt very confident that this was what I needed to do if I expected to have any longevity in my life" (Participant 24A). Another patient remarked, "Once we knew what the options were and once we knew more about (the cancer center) and literally the worldwide reputation that is has and the depth of knowledge and the doctors that are here, that makes it pretty easy" (Participant 23A).

Emotions or *Pathos*

Pathos is associated with an appeal to the emotions. The root of the word p*atho*s means to "suffer," and rhetorically that sense of suffering is conveyed via the evocation of the imagination. The power of *pathos* exists in the artful use of language calculated to elicit a response in the listener. Words utilized situate the speaker and the hearer within a shared emotional resonance. Within this context, hope is coconstructed between researchers and patients/family members as they speak and listen to one another, and hope stands as a counter-balance to the *pathos*/suffering of cancer. In many of the interviews, patients said that the participation in research represented a *hope* for them to be freed from the angst and suffering of a terminal illness.

The resonance between researchers and patients can be heard in those statements where the power of suffering is illustrated. One mother described her young son encouraging her to participate in research. "It was so hard," she said. "I was so sick with high-dose chemo and he was right there, like my little cheerleader [telling me] 'you can't give up now, you've come this far,' [which makes me feel] I can't quit" (Participant 10A). A young woman relayed this as her experience: "I'm glad I made the right decision [to come to the cancer research center] . . . the body pain, the throwing up, seeing blood . . . the diarrhea, the uncontrolled urine . . . the hearing loss, the uncomfortableness, and now the numbness in my leg and arms, but nothing compared to the hospital, so I'm grateful, because I think now I am cured" (Participant 18A).

Dynamics of the Rhetorical Process

The individual coding of statements into the categories of *logos, ethos*, and *pathos* provides some insight into the decision-making process, yet it falls short of demonstrating the full dynamics of persuasion. In the discussions about what influenced participants' decisions to participate in clinical research, most cited all three categories of *logos, ethos*, and *pathos*. See Table 10 for a summary of these statements.

Participants generally had an intellectual or cognitive awareness of what the research participation entailed, which represents the *logos* or information about their disease. At the same time, the component of the researchers' reputations and the endorsement of the center's expertise by referring physicians confirmed the *ethos* or credibility for the participants. Finally, participants acknowledged the *pathos,* or emotional influence of facing possible death and decreased time with loved ones as a component in agreeing to enroll in clinical research.

It is clear that no single element determined the decision to participate in clinical research, but rather that the decision was the combination of considerations that resulted in an affirmation of research as the ultimate choice. Most participants held a strong conviction that the research offered by the specific researcher at this specific center would afford them the best hope of survival.

Discussion

Within discourse, there are multiple reflexive components, including speakers, hearers, and subjects. In recruiting for clinical trial participants, the previously discussed elements of rhetoric or persuasion provided a framework upon which to understand enrollment for cancer research participation and the power of the *hope imperative*. Given the theoretical foundation that language is not merely words but generative of ideas and meaning, the *habitus* of speakers and hearers is one way that the dynamics of persuasion can be understood.

Scientists and physicians engaged in investigation of new interventions to improve cancer outcomes are recognized and honored by society for their contributions. Social conventions like Nobel Prizes, the MacArthur Award, publication in scientific journals, and presentations at conferences generally provide the foundation upon which *ethos,* or credibility, is built. The option for a possible cure for cancer and relief from suffering evokes a strong emotional response in patients, family members, and the researchers engaged in clinical investigation, constituting the second category of rhetoric, or *pathos.*

Logos is the distillation of a "rational" body of evidence that appears to confirm the "truth" or hope science holds for the new cancer clinical trial. Offering of the trial to eligible patients and the patients' subsequent enrollment into the trial can be viewed as the reasoned and rational foundation of scientific process. It is not only the individual level of practitioner/institutional accomplishment (*ethos)*, the amelioration of the individual's suffering *(pathos*), or the scientific advancement of an intervention (*logos)* where *the habitus of hope* is found.

Habitus organizes practices and perceptions so that shared meanings are reflexively uttered and understood. Without *habitus,* the other three components—*ethos, pathos,* and *logos*—render persuasion only a vague invitation. When coupled with the social power of shared assumptions that confirm the value of research, its potential for cure, and the resulting possible amelioration of suffering, then there is an *imperative* to invest in *hope*.

This strong personal investment or hope for success in clinical research is manifest in many ways. For instance, publication bias is a phenomenon that latently determines which studies are published; generally, only those studies reporting positive findings are published (Walters, in press; Ioannidis, 2005). Publication bias prevents learning from trials in which patients do not show significant improvement or trials that do not support the initial hypothesis. Publication bias also may explain the titling of abstracts and study findings at international meetings. Estey and others (2006) have undertaken a review of all American Society of Hematology (ASH) abstracts presented from 1993 to 2001. Their findings show that “81% of all drugs reported as positive for acute myelogenous leukemia therapeutics remain, at least 5 years from date of ASH publication, either outside the scope of clinical practice or unevaluated in randomized trials” (Estey, Bedikian, Witter, Pierce, & Giles, 2006). This low rate of advancement of much-heralded agents into further trials or clinical practice is most likely due to the agent’s lack of efficacy or unsatisfactory level of toxicity. Estey and others call for this publication bias phenomenon to be explored, yet it still remains a common practice to see “promising results” published and touted while few new agents are making solid progress toward integration into clinical practice or advanced-phase clinical trials.

Most people who are treated on Phase I trials are only eligible for these trials because conventionally available treatments have become ineffective against their cancers. Research represents an opportunity to evaluate toxicity and possible efficacy of new agents. The primary goal of a Phase I trial is to determine safety in dosing of the agent. The research question is, "How safe is this medication?" Efficacy is evaluated at a later stage of research, yet the assumptions that are communicated in the discourse of informed consent for a Phase I trial convey an implicit hope-for-cure.

There are many subtle and not-so-subtle ways in which hope is cocreated for people with cancer in the realm of clinical care. The language of hope is often used by researchers and care providers to couch the various treatment and research options open to people with cancer. In scientific literature, the language of *hope* has a significant presence. Literature searches using "cancer and hope" in the title found an increase in articles using the word *hope* in the title. An example from the *Journal of the American Medical Association* brought up an article titled, "New screening methods offer hope for more accurate breast cancer detection" (Mita, 2008). Such a title demonstrates how science and cancer care are explicitly linked to articulations of hope, thus invoking a powerful societal response to the evidence-based work. Given that providers and patients rely on the construct of hope in the clinical management of the illness and in the options for treatment and research participation, further studies are needed to determine how the language of *hope* is used and perhaps at times misused.

Conclusions

This study set out to examine the *habitus* of hope and to explore the implications of hope in decision-making for cancer research participation. The discourses of cancer and hope have been so integrally linked in both the professional and personal domain that all players—patients, family members, and physicians—bring an expectation of hope to the decision-making processes. *Hope-for-cure* or *hope* for additional time are ideas expressed by cancer patients and their loved ones. The same outcomes of *hope-for-cure* or additional time are desired by researchers and those whose livelihood depends on continued research programs for improvement in morbidity and mortality associated with cancer care.

Hope may also represent a coercive influence in the decision-making process for people with cancer because it may lead them to decide on options of research that are represented as the "only hope" for possible survival. When research participation is offered to patients, the discussion and nuanced language used in informed consent conferences may lead the patient and family to understand that a particular clinical trial is the "best" for them. It is important to note that the researcher's utilization of *hope* is one articulated at a societal level, but the perception of research is often expressed as a *hope-for-cure* for cancer at the individual patient level (Jansen, 2011; Sulmassy, 2010).

The research presented here suggests that researchers and all care providers within the context of cancer care should be aware of the power of the *hope imperativ*e. Communication between patients and researchers may lead patients to perceive research as an intervention with certain outcomes as opposed to a process for answering safety and efficacy questions regarding a specific research question, a confusion known as the *therapeutic misconception* (Appelbaum, 2004*).*

The main conclusion of this study is that a *habitus of hope* posits a subtle yet powerful imperative for patients and family members within their personal life experiences and expectations as they are making decisions about possibly participating in cancer research. An overt *hope imperative* is posed for patients in the discourse of informed consent with general *hope* in scientific practice and specific *hope* for a successful or promising research trial. Researchers and nurses should strive for awareness of the power they wield in supporting patient and family decision-making. The ethical challenge is to respect the important work hope may do for people while maintaining distinct insight into how coercive a researcher's or practitioner's own *habitus of hope* may be for patients. Assumptions should also be examined about what is critically constitutive of *decision-making*. Do cancer patients feel as if there is a decision to be made to participate in research? Or does participation in clinical research exist primarily as the *hope imperative*?

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Table 9

Sample Characteristics

	Patients (*N*=25)	**Caregivers (*N*=20)**	**Physicians (*N*=10)**
Gender	*M*=14 *F*=11	*M*=7 *F*=13	*M*=9 *F*=1
Age	22–72	35–62	Not asked
Ethnicity	Native American=2 Asian=1 African-American=1 Hispanic/Latino=1 White=20	Asian=1 African-American=1 White=18	White=10
Years in Practice	NA	NA	6 years ***N***=2 11 years ***N***=3 18 years ***N***=1 20 years ***N***=2 27 years ***N***=1 36 years ***N***=1

Table 10

Demonstration of the Dynamics of the Rhetorical Process

Participant	*Logos*	*Ethos*	*Pathos*
1A	“My disease was unresponsive to all other therapies.”	“This place had the best reputation and my own doctor recommended it.”	“If I didn’t do this I would die in two or three years.”
5B	“We never once thought *no, we are not going to do anything.* That was not an option.”	“There was never any doubt we were going to the right place.”	“It was life or death.”
7A	“We never really were presented any other options after I relapsed.”	“My doctor said it was the only place to go for what I had.”	“I never really grasped that it was really bad that my cancer kept coming back really fast after chemo.”
9B	“Yes it’s her only chance; 30% is better than zero.”	“This place is the best in the world.”	“I tell her, I can replace anything I lose, but I cannot replace you.”
14A	“My doctor was very clear that this kind of disease is very aggressive and the only way to get rid of it is with a transplant.”	“This is the only option left for me.”	“I need to live another five or six years to take care of the children.”
17B	“He said . . . ‘will I kick myself two years down the line because I didn’t do it when the opportunity was there?’”	“We have always heard it was the best place to come for a transplant.”	“He really just wants to live longer.”
18B	“I want to know the best and I want to know the worst. . . . the more I get into it, the smarter I’ve gotten . . . about the whole process, including clinical trials.”	“[We came] because it’s a renowned facility . . . and certainly the number of transplants that are done every year far outweigh most facilities around the world.”	“The primary motivation was to be healthy again.”

CHAPTER VI

THE METAPHORICS OF HOPE-FOR-CURE

Abstract

The use of metaphorical language is commonplace and can provide concrete understanding of complex abstractions for patients with cancer, their family members, and their physicians. In discussions about treatment options, research recruitment, and prognosis of disease, evaluation is needed as to explore implications of metaphor employment.

The author did a secondary analysis of 109 transcripts of interviews of 55 people: 25 cancer patients enrolled in Phase 2 clinical trials for hematopoietic stem cell transplants (HCT), 20 family members, and 10 physicians. Textual analysis, specifically thematic analysis, was used to identify metaphors in the transcripts. Five dominant metaphors were identified as most commonly used across groups.

Metaphors were categorized into five major types across groups: *time, journey, hands, war,* and *faith.* All the metaphors were linked to the hope-for-cure of the underlying hematologic malignancy. *Journey* was the most commonly used metaphor (48–60%) and included the expectation that the destination of the journey was amelioration of the disease and survival. *Hands* and the concept of holding was next in usage across groups, ranging from 28 to 40%, and implied a sense of trust in whose hands the patients' life was held. *Faith* was the next most utilized metaphor (20–40%) and

referred to expectations of miracles and a cure. *Time,* at 20 to 30%, represented the concept of being given a longer time to live. *War* was the last major category, at 20 to 30%, and referred to treating the disease.

The high correlation between groups in usage of metaphors may indicate a shared understanding of meaning. Differences may indicate a significant disconnect between providers and patients/family member and may suggest ethical implications for the process of decision-making relative to cancer clinical research participation.

Introduction

Patients are referred to quaternary cancer centers by their community oncologists to receive care for aggressive and life-threatening illnesses. These patients are offered clinical trials for disease amelioration at these referral centers, where clinical research decision-making is a large part of their experience. Early-phase clinical trials are not intended to be treatment interventions; instead, they are meant to answer safety and dosing questions in order to advance clinical science (http://clinicaltrials.gov/ct2/info/glossary#phaseII). Research has established that patients often perceive early-phase trials as offering therapeutic benefit, and it is this perception of promise for cure that prompts their enrollment in those research trials (Kimmelman & Palmour, 2005; Moore, 2001; Schutta & Burnett, 2000; Yoder, O'Rourke, & Etyre, 1997). Decision-making done in the context of informed consent mandates that people are informed both in writing and in face-to-face conferences that early-phase research is not for therapeutic benefit—yet the perception of potential benefit persists. Some researchers have found that patients do not view research options as a decision to be made, but rather as the next logical step if they wish to continue living (Ferrell et al., 2003).

Optimism has been reported as one reason patients agree to participate in research (Horng & Grady, 2003; Jansen, 2006; Jansen, Appelbaum, & Klein, 2011; Sulmasy, Astrow, & He, 2010). Optimism, however, does not seem to represent the factual cognitive knowledge of the patients studied, but instead seems to stand in metaphorically as a hope-for-cure. Metaphors as important parts of everyday language and as components in discourse between cancer patients/family members and physicians have been examined closely. Some authors have encouraged the use of metaphorical language as a vehicle for increasing rapport with patients and families (Reisfield & Wilson, 2004).

Metaphors are not just words; they are ideas that map complex abstractions to other more familiar structures so that meaning is conveyed. By utilizing a cognitive linguistic model, metaphor is defined as coming to know or understand one conceptual domain in terms of another conceptual domain. The coming to know—or "understand"—is accomplished by drawing a relationship between two concepts (A, the source domain, and B, the target domain) and is further expanded by establishing "the set of systematic correspondences between the source and the target" (Lakoff & Johnson, 1980, p. 6). It is through the correspondences or mappings that meaning is made comprehensible in the use of metaphorical language. Conceptual metaphors are rooted in everyday experiences, and metaphorical thought is unconscious and inescapable. Metaphors are very often used to convey hope, an important concept for people with cancer. Hope has been defined as a "multidimensional" and dynamic process (Lakoff & Johnson, 1980). Hope has been described as a strategy for "coping" with cancer (Dufault & Martochicchio, 1985;

Menninger, 1959; Thorne, Hislop, & Kuo, 2006) and as a phenomenon worth "fostering" in cancer patients (Ebright & Lyons, 2002; Herth, 2000).

Since hope is expressed metaphorically, it is important to examine the implications of metaphorical language in cancer conversations and clinical research decision–making, where the employment of hope is commonplace. What metaphors are commonly used by patients/family members and physicians in relationship to cancer clinical trial enrollment? Are there differences in the metaphors employed by patients/family members and physicians? How do metaphors get used in decision-making? The purpose of this study is to explore the use of metaphors and to understand how metaphorical language constructs meaning for people with cancer, their family members, and cancer clinical researchers.

Material and Methods

Sample and Methods

The Seattle Cancer Care Alliance (SCCA) is a large cancer referral center where about 400 hematopoietic stem cell transplants (HCT) are performed each year (FHCRC, 2010). Participants for the study were a convenience sample of research patients enrolled in Phase 2 clinical HCT trials for hematologic malignancies. Family-member caregivers were designated by the patients, and physicians were identified from the allogeneic transplant service for participation. Those who agreed to be interviewed included 25 patients, 20 caregivers, and 10 physicians. A total of 109 semistructured interviews were conducted. Interviews were done before the HCT, at about 80 days after the HCT, and at the 1-year follow-up visit to the hematopoietic stem cell transplant (HCT) center. Three patients died before day 80, and 5 additional patients died before the 1-year follow-up interview. This sample size was purposefully large enough for qualitative analysis and to provide sufficient data for exploration of concepts pertinent to research participation for cancer patients and their family members (Sandelowski, 1995).

The original study and the secondary study were approved by the Fred Hutchinson Cancer Research Center Consortium Institutional Review Board (IRB). All participants signed consents for the original study, and the IRB granted a waiver of consent for the secondary analysis of the data. The transcripts were entered into HyperRESEARCH™, a computer software for qualitative data analysis created by Researchware of Randolph, MA.

Close textual analysis was done and participant utterances in the transcripts were coded for metaphor use. Metaphors were technically understood to be correspondences or mappings between the source domain and the target domain, with understanding moving from the concrete to the more abstract (Kovecses, 2002). Therefore, anywhere in the text where participants used concrete words like *next step* or *climbing a mountain* to describe the cancer treatment process and the related decision-making process for research clinical trial enrollment, the text was highlighted. After all 109 transcripts were coded, the highlighted texts were then grouped into one of five major metaphor categories. The five dominant categories of metaphors identified as most commonly used by participants were *time, journey, hands, war*, and *faith*.

Results

The patients all had hematologic malignancies, and in order to participate in the study, all had to have had a good ECOG performance status (< 2). As shown in Table 11, all participants ranged in age from 22 to 72 and were comprised of 25 men and 30 women. Participants were predominantly White and most had some college education. Interestingly, 26%—14 of the 55 participants—reported having only some high school or a high school diploma/graduate equivalency degree.

Five major categories of metaphors were identified in the textual analysis of the participants' interviews: *journey, hands, faith, time,* and *war*. *Journey* was the most commonly employed metaphor across groups, used by 48% of patients, 60% of family caregivers, and 50% of physicians/researchers. The full display of metaphors by category and usage by participant groups can be seen in Figure 1.

Across the three participant groups, patients and family caregivers used proportionally more metaphors more frequently than did the physicians/researchers. The rate of metaphors was 2.0 per person in the patient group, 2.6 in the caregiver group, and 1.6 in the physician/researcher group. Due to the small sample size, it is difficult to draw inferences about the differences between groups; however, there is a different rate of metaphor usage between females (1.48) and males (2.16). Regarding gender, 13 of the 20 caregivers were female, 11 of 25 patients were females, and 1 of 10 physicians/researchers were female.

Further exploration was done to assess associations among metaphor categories across participant groups. The only statistically significant association was between the use of *journey* and *time* (*P*=.017, Fisher's Exact Test, two-sided). All patients (6/6) and physicians (2/2) who used the metaphor *time* also used the metaphor *journey*; use of *time* and *journey* were unrelated within caregiver participants.

Journey

Twenty-nine of 55 participants used metaphors of *journey.* The starting point of the journey was the diagnosis, and the destination was the hoped-for cure of the hematologic malignancy that had necessitated the early-phase research HCT. For a synthesis of how metaphors of *journey* were mapped from the source to target, see Table 12.

People used words like *path* and *road* to describe the trajectory of cancer care and research treatments. The methods of travel varied from “steps” to “sailing” to “climbing.” Most often, patients and family caregivers referred to their referring physicians and the researchers at the center as navigators of the journey. Less frequently, reference was made to God as “guiding the course.” Generally, the destination was hope-for-cure and continued life. Participants used phrases like *steering* and *driving* to indicate how decision-making was done relative to care and research participation. Synthesized representational quotes from participants follow:

- Participant 1A: “I want to get to a place where you can say this is all over and I can get on with my life.”
- Participant 2B: “I believe God is a research scientist and he is guiding us down this path.”
- Participant 3A: “It’s just what’s happening, what’s coming down the road because it has been my philosophy since 1996 . . . the next thing that comes out is going to be a little bit better.”
- Participant 3B: “For the first time in 9 years I feel like there is a light at the end of the tunnel.”

- Participant 5A (describing the course envisioned after undergoing the HCT): “I am going to drive ahead day by day.”
- Participant 8A: “I believe in God . . . and I know that this is the direction he has led me to.”
- Participant 10A (speaking about how her young son had helped influence the decision to go for the HCT and to travel to the cancer center): “My husband said, ‘he is the best navigator.’”
- Participant MD 10 (describing a story of a patient he had referred to an early-phase research HCT); “He said, ‘I’ve reached the end of the road, I mean my leukemia . . . so I am going to take my chances here.’”

In their simplest expressions, the metaphors of *journey* used by the participants signified a sense of life as a trajectory. When participants discussed decisions about research participation, the metaphor of *journey* was most commonly understood as traversing a course clearly marked by the milestone of cancer diagnosis. Additional milestones were events such as remissions, relapses, and cycles of chemotherapy. The date of diagnosis marked a dramatic change in the previous directions of the individuals’ *journey*.

When people spoke of who was “steering,” who was “in the driver’s seat,” or who the “navigator” was, these metaphors contextually addressed the issues of control, choice, and range of available directional options. While the *journey* metaphor was not unexpected in the discussions of participants, it took on complex new dimensions when placed in the context of a life-threatening illness. While a *journey* can a be seen as a single “trip” or an excursion, most cancer patients and family members clearly saw the current “*journey*” as one starting from initial diagnosis and continuing to an eventual destination that was hope-for-cure.

Any journey has a temporal component that spans time and space. In these texts, people spoke of the *journey* as being “on the road,” “on a path,” “driving,” or “taking steps” toward a destination. Some spoke of “climbing” and taking “new roads or paths”; in those cases, the metaphor of *journey* communicated the unfamiliarity of the terrain, the obstacles encountered, the difficulty of summiting the terrain, and the very real option that this *journey* could mean “the end of the road”—death—for the individual patient.

Hands

Eighteen participants used the metaphor of *hands* in the discussions regarding their decision to participate in cancer research. A conventional understanding of the source domain of *hands* targets issues of control and trust. Patients and family caregivers spoke of “hands” they were in as they progressed through the HCT. Also, the image of the science and the cure going “hand in hand” connoted serendipity between the research and possible curative treatments. The metaphor of “hands” also offered a humanizing of the research process, bringing in a more accessible focus when compared to the complex language of human leukocyte antigens (HLA) and major histocompatibility complex (MHC) used to explain the early-phase research HCT. See Table 12 for metaphor mappings of the source and target domains. Selected representational quotes follow:

- Participant 11A (describing who he sees as being in control of his life and his choices regarding cancer research participation): “I have come to a point where it’s out of my hands.”

- Participant 13B (family caregiver discussing how the referring physician offered her and her husband reassurance about the decision to travel to the cancer referral center for an early-phase research HCT): “He said, I feel like you will be fine, you’ll be in good hands there.”
- Participant 17B (a family caregiver characterizing how he views embarking on the research HCT): “I definitely feel the fear . . . and I give it over into God’s hands and say, ‘OK, we are at the best hospitals, we have the best doctors, and we have the best nurses. And we have you there God, to help us and we are going to get through.’”
- Participant 23A (a patient articulating the vision of research and clinical treatment as almost synonymous actions): “I am a part of research, but in doing that . . . it’s a part of the treatment, being a part of the research. They kind of went hand in hand. I did not segregate it that much.”
- Participant 24B (using the image of hands as holding/carrying the patient through the research HCT): “They don’t have as much hands on as you do down here.”
- Interviewer: “Is that a good thing?”
- Participant 24B: “Yes, it’s real nice if you are doing it for the first time. . . . You kind of get carried through the process.”
- Participant MD3 (physician demonstrating how he addresses patients who consent for research HCT): “We will try our best to help you live, but we are limited in what we can offer, and what will happen will happen. You will either live or not. And it will be in God’s hands.”

The metaphor of *hands* was used as participants spoke about the issues of control. Many said that their arrival at the quaternary cancer center and enrollment in clinical research meant that the future was “out of my hands.” *Hands* were a way of embodying how patients and family members transferred control of their lives and care of the patient to the research center. When researchers acknowledged that patients and family members “put their lives in our hands,” they recognized the power held by the clinical research team and the trust placed in them. Another metaphorical use of *hands* was seen in how people discussed balancing the demands of being in cancer research treatment—treatment became just one more thing for patients to juggle. Support and assistance were also intertwined with the metaphor of *hands* when participants spoke of “being hand-in-hand” with the doctors and nurses in the center or when they stated how staff “held our hands” through the whole process of the transplant. A direct relationship to hope-for-cure was evidenced in the participants’ use of metaphors like “cure is just within our grasp now,” “we are holding on for a cure,” and “we are holding on to the words of doctors.”

Faith

Eighteen of the 55 participants used metaphors that could be categorized as *faith*. Most often the source metaphor of faith had as its target trust in the early-phase research HCT (see Table 12). Expressions of faith included references to faith in God, but also included faith in science and in the reputation of the cancer referral center.

The concept of *fate* guiding the process was heard from multiple participants. Representational quotes follow:

- Participant 2A: “We prayed for the best cure.”
- Participant 4A: “I . . . believe in . . . fate leading the way a little bit: . . . a thing is right when all the gates open. They just keep opening.”

- Participant 7B: “I wanted to give him the best chance to live. . . . This is the only chance that I think he’s going to have. . . . It’s a miracle.”
- Participant 12B (a family member relating how faith in the center drove the decision to participate in cancer research): “We just had incredible faith in [researchers at the referral cancer center].”
- Participant 21B (a family caregiver describing how faith in God and prayers complement the early-phase HCT): “It’s in God’s hands and He’s the only one can decide how it’s going to come out. We’ve got family all over the United States and we’ve got prayers going.”

The metaphor category of *faith* was primarily used to signify the participants’ trust in or reliance on someone beyond themselves. Some spoke of expecting “miracle cures” from God, science, or a combination of both. One participant believed that “God was a research scientist” who was going to cure his son. Some were less specific in whom their trust was directed, stating that they were waiting on “the big plan out there.” One participant spoke about the opportunity to come to the center as a moment when the “stars aligned” and all the “best researchers came down from Mecca” to see his loved one who was there for treatment of acute myelogenous leukemia. Others spoke of being “led by God” or “led by fate” to be treated at the research center. Several families spoke of coming for a transplant at the center because the center is “the best place to go,” signifying a substantial trust in science and trust in the reputation of the researchers. Participants also offered accounts of trusting in “the prayers of all the people back home” as a part of their faith in being cured of the hematologic malignancy that brought them to the center.

Time

Approximately 27% of participants (15/55) used the metaphor of *time* to explain how they decided to participate in an early-phase research HCT. The metaphor of time as source domain often had as the target domain the longevity of the patient's life. Time also framed the incremental hope that life would be saved or extended by the decision to participate in research. Expressions of time held a poignancy of urgency in the face of questionable odds. Time was also seen as the ultimate judge of success (see Table 12).

The metaphors of time are synthesized as follows with representational quotes:

- Participant 7B (a family caregiver acknowledging that timing of the research HCT had created the best chance at a successful outcome): "I think we have really been fortunate, really blessed on all our timing and doctors working with [the patient]."
- Participant 9A: "But my understanding right now is that there is really nothing else to try for a cure. . . . it might have worked this time. Time will tell."
- Participant 11A: "I understood it was all research . . . I just did it one day at a time. . . . I knew there was a chance it [HCT] was going to work and there was a chance it was not going to work."
- Participant 12A: "At least this [HCT] is a chance, although it's a small chance, but it is a chance . . . that I can be cured. And if not cured, maybe extend my life some."
- Participant 17A: "[The HCT might] hold it back . . . or at least . . . buy time and possibly . . . have long-term success."
- Participant 19B: "We did not question [HCT]. . . . we wanted to get on it too, his time was ticking already."

- Participant 21B: “We’ve calmed down . . . the crying, the screaming, and the yelling, all this is over with and we are just going to take it one day at time. Just stay relaxed, enjoy day by day.”

Time as metaphor was significant because in addition to being directional, it had a discrete point of beginning—the diagnosis of the hematologic malignancy. Included in this category of *time* was the recognition of looming finality—possible death. *Time* was at once a metric for measuring survival and ultimate cure, as well as a threat because “time is ticking away.” Participants talked of being “robbed of time,” of needing “more time to see the kids grow up,” and the “timeliness arrival” at the center. *Time* was also seen as the ultimate evaluation of successful attainment of cure—“time will tell,” “we are taking it a day at a time and we know that his time is not up yet,” and “the timing is right for us to get ahead of the disease.” Overall, *time* as an external measurement could be seen as a desired end point to extend the life of the patient enrolled in the research clinical trial, and also as a possible uncertainty of a time in the future with unknown outcomes. *Time* was both a comfort and a potential threat, as it was balanced against the aggressiveness of the patients’ cancer and the available days to live.

War

Twelve participants invoked metaphors of *war* or *battle* in the transcribed interviews. Proportionately, the physician group used words that were metaphors of *war* more than either the patients or the family caregivers.

War and cancer have long been linked historically. The most common source domain for war is cancer, and the target is victory over the disease. Many concepts are illustrative of correspondences or mappings with the metaphor of *war*. These include bullets—chemotherapy, radiation, or even the HCT—all of which are meant to "kill" the cancer cells. Other corresponding concepts can be seen in the use of words like *fight, beat, shoot,* and *pull the trigger* (see Table 12). Representational quotes follow:

- Participant 2A (a patient describing how he intended to have the HCT and his family's prayers "fight" the leukemia): "Leukemia is something that can be fought on every hand."
- Participant 12B (a family caregiver describing how she could agree to the HCT because of her husband's will to "fight" against the disease): "I draw my strength from him because he fights."
- Participant MD3: "They want to be alive for a long time. . . . They want to fight it and stave it off and they want to eliminate the disease . . . to be around for other family members. . . . They have other things they still want to do."

Surprisingly, given the predominance of the official war on cancer, metaphors of *war* were one of the least used by participants. Implications of "fighting" and "not giving up the fight" seem most often to address the motivation to defeat cancer and hope to attain a cure. *War* did not appreciably add to the understanding of decision-making relative to cancer research participation.

No Use of Metaphor

Seven participants—two patients, three family caregivers and two physician researchers—did not use any metaphors from the five major metaphor categories identified (*journey, hands, faith, time,* or *war)*. These same participants also did not use any metaphors as evaluated in the interview transcripts.

Discussion

Resonance between individuals due to life experiences and cultural discourses help reinforce common, conventional metaphors (Kovecses, 2002). The word *cancer* is a metaphorical expression believed to be first used in medical literature, employing the Greek word *karkinos* (crab), around 400 BC. Another metaphorical expression comes from the Greek word *onkos* (now the root of the word *oncology*), referring to the burden carried by the body of one afflicted with cancer (Muherjee, 2010).

In 1971, President Richard M. Nixon declared "war" on cancer and designated the Army's Fort Detrick, Maryland (a decommissioned biological warfare facility), as a cancer research center (NIH). Dominant metaphorical themes of "war" and "battle" relative to cancer research and treatment have been identified by researchers (Learner, 2001; Lupton, 2003; Mitchell, Ferguson-Pare, & Richards, 2003). The expectation that patients accept these militaristic metaphors has met with sharp criticism and even a call for a metaphor-neutral zone to be applied to cancer conversations (Sontag, 1990).

The use of metaphor in cancer conversations is neither good nor bad and always needs to be viewed contextually (Reisfeld & Wilson, 2004). The participants in this study used metaphors to structure the experience of deciding to participate in cancer research. In this structuring of experience, there is a strong element of hope-for-cure. The desire by patients and family members for research to be curative is well documented (Bierdrzycki, 2010; Jansen et al., 2011; Shannon Dorcy & Drevdahl, 2011).

Metaphor as a linguistic and intellectual device does not abandon one signification for another. Its power and usefulness is that it stands related to two significations at once. None of the metaphors used by participants as recorded in the transcripts achieved the level of high poetic art. Indeed, many were hackneyed and little more than clichés. Spent, worn, and tired as some of the participants may have been, they were nonetheless capable of communicating something of psychological and intellectual meaning and importance.

Both *journe*y and *time* as metaphors are deeply entrenched ways of thinking about and understanding life. The discourse of cancer research is replete with the use of metaphors (William-Camus, 2010), and so it is no surprise that most study participants used metaphors in the transcribed interviews. Perhaps *time* is linked to *journey* because *journey* has the implicit underlying structure of time and flow.

One of the inherent dangers of metaphors is that misleading assumptions may be made about what the speaker intended by invoking a specific metaphor. Communication between researchers, patients, and family caregivers plays a significant role in how patients predict the outcomes of clinical research participation (Thorne et al., 2007). How researchers tell the story of the research clinical trial and relate possible outcomes of clinical trial participation helps create the basis for the metaphorical hope-for-cure. Metaphors that target hope-for-cure are not attributable only to patients and family members, but to researchers as well.

Ethical Implications

This study adds to a body of literature that suggests that hope—specifically hope-for-cure—is the motivation for people participating in early-phase clinical trials. This hope-for-cure raises the ethical concern of coercion in the decision-making process. Could the use of metaphors actually structure the decision-making so as to relegate participation in clinical research to merely taking the “next step” in a long “journey”?

When the inaccurate estimation of risk is pervasive, are there standards by which the erroneous perceptions of risk can be corrected? The cultural expectation for “looking on the bright side” was critiqued and condemned as detrimental to patients and self-serving to cancer researchers and nurses, since hopeful patients are easier and more compliant (Ehrenreich, 2009).

The formulaic following of all the federal mandates for informed consent clearly still leaves room for consideration of how best to assure that vulnerable people are able to make decisions regarding research participation without the metaphorical presence of coercion. Time needs to be spent helping patients and family members clarify what they desire from their participation in the research study. Researchers and all cancer care providers need to be aware of the conventional metaphors used by they themselves as well as by patients and family members.

Limitations

This study is a secondary analysis, so no questions were posed to the participants to directly ascertain use of metaphors. The sample of 55 individuals does not allow for generalization to other larger groups of cancer patients, caregivers, and physicians. The sample also has little racial and ethnic diversity, limiting how much can be gleaned about how other more diverse cultures and populations might have used metaphors. Metaphors were generalized, but did have cultural variations.

The use of semistructured interview tools also may have limited the responses of participants and so resulted in fewer uses of metaphors. This was a qualitative study, so interpretation is relative to the researcher’s specific analysis. Literature supports that both qualitative and quantitative data need to be used to establish evidence-based standards for patient/family caregiver communications for cancer research decision-making (Thorne et al., 2011).

Conclusions

This study provides evidence of how patients, family caregivers, and physicians/researchers structure metaphors in the process of decision-making for cancer research. The findings indicate that hope-for-cure is the target domain of all five of the dominant structural conceptual metaphors that were used. Hope-for-cure is a powerful and sometimes overriding dynamic for participants in clinical trials. The answer is not to establish a metaphor-free or hope-free zone. Further research needs to be done to establish ways in which hope-for-cure can be realistically balanced with early-phase clinical trial participation.

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Table 11

Participant Characteristics (*N*=55)

Characteristic	Participants
Age range	22–72
Female No. (%)	30 (55%)
Race/Ethnicity No. (%)	
African-American	2 (4%)
White	48 (87%)
Asian	2 (4%)
Hispanic	1 (2%)
Native American	2 (4%)
Patients' Diagnosis No. (%) (*N*=25)	
Acute myleogenous leukemia	6 (24%)
Acute promyleocytic leukemia	1 (4%)
Chronic lymphocytic leukemia	1 (4%)
Hodgkins disease	1 (4%)
Multiple myeloma	5 (20%)
Non-Hodgkins lymphoma	8 (32%)
Refractory anemia/Myleodysplastic syndrome	3 (12%)
Highest level of education completed No. (%)	
Some high school	2 (4%)
High school/GED	12 (22%)
Some college	9 (16%)
College graduate	12 (22%)
Some graduate school	1 (2%)
Graduate degree (including MDs)	18 (33%)
Missing variable	1 (2%)

Metaphor Type by Group

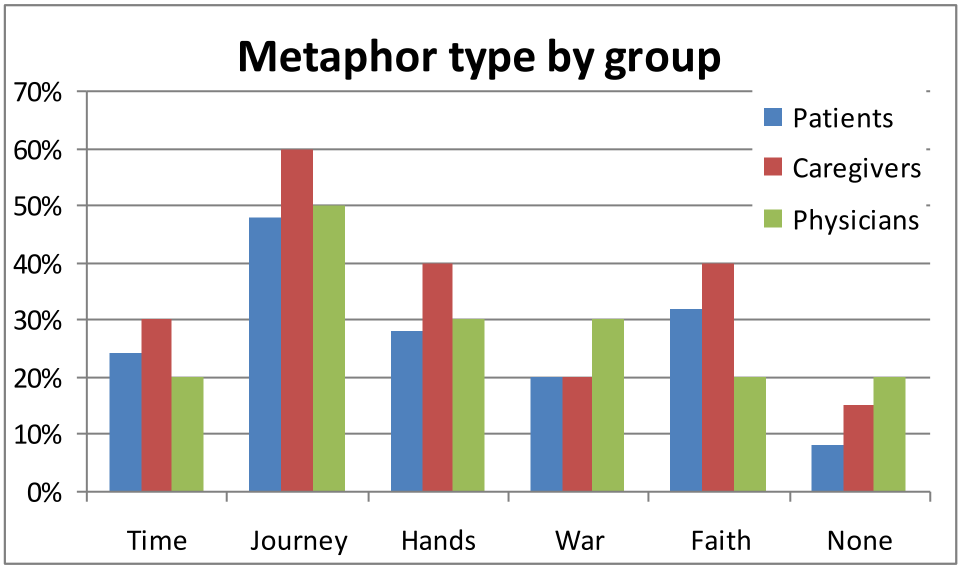

FIGURE 1. Use of metaphor by group of patients, caregivers, and physicians.

Table 12

Conceptual Metaphor Mappings

JOURNEY

Source	***Target***
JOURNEY	**CANCER DECISION- MAKING**
Travelers	Patients, family & physicians
The journey	Course of cancer
Distance traveled	Events like remissions, relapses since diagnosis
Obstacles encountered	Toxicities & adverse events related to therapies
Decisions about which way to go	Choices for cancer interventions
The destination	Cure
The navigator	Researchers and other health care providers, family members
Driving/steering	Who is in charge of the journey
Steps or walking	Incremental progress in the course of cancer treatment
Sailing	A course somewhat "uncomplicated" and assisted by forces beyond self
Path, road	Cancer treatment as a charted territory
Climbing	Ascent of difficult terrain
"Footwork"	Patients' part of the finding treatment options

TIME

Source	***Target***
TIME	**LIFE**
The increments of time	Days of survival
The judgment of "too late"	Uncontrollable disease progression
The judgment of "timeliness"	Arresting of disease process
Waiting on time	Potential of cure
Buying time	Extending life
"Time is up"	Death
Window of opportunity	Time right for possible cure
"A day at a time"	Guarded expectations of future
"Living from day to day"	Control the moment despite guarded expectations

HANDS

Source	***Target***
HANDS	**CONTROL**
Whose hands	Patients', families', physicians', or God's
What is being held	Life of the patient
"Holding on"	Continuing to hope in treatment or research process
"Letting go"	Trusting in the research/treatment process
"Held our hand"	Support for patient and family
"Trying to juggle"	Coping with demands of cancer treatment

FAITH

Source	***Target***
FAITH	**TRUST IN RESEARCH**
Led by God	Discernment about cancer research participation
Expecting a miracle	Research outcomes=cure
Trust in fate	Research team and interventions will bring positive outcomes
Trusting in the big plan	Trust in God, science, or forces beyond individual
“Ray of sunshine”	Option for research therapy
Light or “light at the end of the tunnel”	Relief from anxiety, pain, uncertainty
“Out on a limb,” “holding on to the outer branches”	Taking a risk

WAR

Source	***Target***
WAR	**ANTI-CANCER THERAPY**
Battles	Rounds of chemotherapy
Soldiers	Patients, families, physicians
Ammunition	Treatment or research process
Continue the fight	Stay in treatment or research process
Only shot at life	Research participation
Victory	Cancer is destroyed
“Fighter”	Do not acquiesce or “give up”

CHAPTER VII

CONCLUSION

The purpose of this discursive study was to explore hope as articulated by patients, family members, and investigators in the decision-making process for participation in cancer research at a quaternary cancer center. The conclusions from this study answered the research questions, and the findings addressed three areas: (a) the discourses of hope that influence how people construct hope; (b) the practice of hope relative to decision-making for cancer research participation; and (c) the assumptions held by investigators relative to cancer research participation. Following is a discussion of the major findings and conclusions drawn from this research, followed by a final reflection.

Discourses of Hope

The first major finding of this research was that most of the healthcare literature on hope originates from a singular philosophical approach, one that reifies hope as a positive *thing*. Hope is commodified in the daily practice of cancer care. Further, talk of hope is often a scripted performance that can be coercive when people with life-threatening illnesses are expected to "keep trying" and to "not give up hope." Patients are then labeled "noncompliant" or "dysfunctional" when the clinical choices made do not agree with what providers judge to be the best or the most hopeful option for patients.

Practice of Hope in Cancer Research Participation

The second major finding in this research was that patients, family caregivers, and researchers in the quaternary cancer center all are invested in hope relative to decision-making for research participation. An overt *hope imperative* is posed for patients in the discourse of informed consent, in scientific practice generally, and specifically in terms of discussions regarding successful or promising research trials. While the reputation of the cancer center, trust in the researchers, and the emotional context of a diagnosis of cancer structure the social space in which patients agree to research participation, that space is concurrently structured by the brokerage of the institution and participating physician researchers with those who promote research.

Assumptions of Investigators

The third major finding in this research was that the hope-imperative was operative in physician researchers as well as in patients and family caregivers. Although the physicians generally acknowledged that individual patients diagnosed with advance-stage hematologic malignancies may not be cured, there was an overriding *habitus* that their research was imbued with the hope-for-cure. While researchers all verbalized commitment to discharging the legal and moral obligations of the federally mandated elements of informed consent, some also recognized that patients had already made their decisions to participate in clinical research prior to arriving at the center.

Recommendations

Based on research findings, the author has recommendations for: (a) educational curriculums of nursing and medical schools; (b) the clinical practice of nurses and researchers in cancer centers; (c) policy formation at the national level; and (d) further research.

Recommendations for Educational Curriculum Development

These findings have implications for the education of all clinicians, researchers, and institutional review board (IRB) members. In order to assure that we are able to engage in research with patients, we need first to acknowledge that the vulnerability caused by suffering and illness seems to have created a societal imperative to "hope." Reflection on researcher motivation and values needs to be a part of graduate studies. The idea that researchers should "bracket" themselves and see the verbatim translation of patient interview data as something objective and free of interpretation is unrealistic. All research is interpreted by the researcher and the process of analyzing data.

The curriculums for research courses as well as for ethics courses need to include examinations of the role hope plays in decision-making. The practice of objectifying hope and allowing only the phenomenological philosophical framework to serve as the foundation for qualitative research limits the scope and inquiry that can be done. Faculty need to expand the repertoire of research models to include more than theory-generation and concept-analysis. Additionally, IRB members should be offered classes that broaden the awareness of the language of hope and how use of that language may possibly be coercive for patients.

Recommendations for Clinical Practice

Hope is a powerful cultural discourse. Cancer researchers and nurses must be careful not to coerce people into clinical trials by their personal investment in hope.

Enrollment in a cancer clinical trial is often couched in expressions that convey a sense of power to those offering participation, insuring the economic capital (for example, that of a drug company that has high stakes in the trial on human subjects) and promoting the social capital of the arbiters of admission (the researchers). In turn, these forces downplay the value of the role of potential participants, ignoring the social capital these individuals bring to the table in the classification of eligibility for the study. Absent these individuals consenting to research participation, there would be no enactment of the particular protocol, and participation—whatever its motive force on the part of the consenting participant—is essentially constitutive of its actuation.

The informed consent conference provides a special kind of *milieu* or social space where, among other elements, a set of power relations is established or at least maintained. Traditionally, *consent* has been used as both a noun and an intransitive verb. More recently, *consent* has become a transitive verb as seen in the following uses: “I need to consent the patient,” or “Has the patient been consented yet?” There are implications in the metamorphosis of the word *consent* into a transitive verb. As a noun, *consent* conveys the meaning of permission, approval, and agreement. As an intransitive verb, *consent* means “to agree to do something,” “to give permission, approval, or assent to something proposed.” *Consent* as an intransitive verb connotes agency and autonomy. To *consent someone*—using *consent* as a transitive verb—connotes an act of bringing into compliance or of establishing acquiescence. The patient in that usage is no longer an agent or a subject but an object—truly a patient, one acted upon. A complete moratorium on using *consent* as a transitive verb would not only delight the grammarian’s purist heart, but restore dignity and power to the person who enrolls in clinical research through the informed consent process.

Recommendations for National Policy

The complexity surrounding the language of hope means that ensuring the integrity of the process of informed consent requires more than simply imparting dispassionate, adequate information. In fact, consciousness-raising about the mandated expectation of hope needs to be discussed at forums such as Public Responsibility in Medicine and Research (PRIM&R) and at local institutional review boards. Our current regulatory processes are careful to avoid any semblance of promising "cure," yet that is what most people cite as the reason for consenting to participate in cancer clinical trials. We need to seriously evaluate how hope is firmly entrenched in the rhetoric and assumptions of the consent process. Clearly, the federal system has strengths, but the process of informed consent should not be seen as something static but rather as something in need of further and continuous refinement. Autonomous, coercion-free decision-making for vulnerable people with life-threatening illnesses cannot be a perfunctory process.

Recommendations for Further Research

Little research has been conducted that examines the influence that the language of hope has on decision-making for participants in cancer clinical trials, even though multiple studies have reported that patients decide to participate in clinical trials because these trials offer "hope" for survival. The next step in this current research program would be to do a prospective, multi-site study to examine how several centers who do early-phase cancer research handle informed consent. One of the most promising opportunities is to introduce palliative care into the consent process and research intervention. Palliation of symptoms and quality of life are elements that could broaden the discourse as it exists today and move early-phase research away from hope-for-cure to address issues of quality of life and amelioration of suffering.

Final Reflections

Pulitzer Prize-winning novelist N. Scott Momaday regularly told the story of the Kiowa Arrow Maker, a tale he described as being “superbly metaphorical.” Sitting one evening in his teepee with his wife, he straightened his newly made arrows; using his teeth as an anvil while bending the arrows with his hands; he tested their trueness in his bow. At one point, he nodded to his wife and drew her attention to a small chink in the wall of the teepee where the lacing had failed between two of the buffalo hides. His eyes spoke and told her that someone was lurking outside their home.

“Let us go on talking as if of ordinary things,” he whispered to her after a pause, all the while continuing to straighten and test his arrows. Finally he raised his voice slightly and carefully, deliberately spoke these words: “I know that you are out there. If you are my friend, you understand Kiowa and you will reveal yourself to me. But if you do not understand what I am saying, you will remain silent and I will know who you are.” Having spoken, he continued to test his newly made arrows. Flexing the bow high and low about the teepee until he drew it even with the chink, he let the arrow fly and killed his enemy (Momaday, 1997, pp. 9–10).

The arrow maker is quintessentially the word maker, as Momaday pointed out—in effect, the poet. In his shift from *ordinary* speech—“Let us talk as if of ordinary things”—to the words of carefully chosen deliberative speech, the arrow maker revealed the power of metaphor. He actually knew what he had not known before. Disadvantage became advantage as discourse became an extraordinary moment of discovery. The tables were turned. The threat of death became the promise of life.

In the spirit of the arrow maker tale, the ordinary speech of the informed consent conference ought to be allowed to become what it inchoately is: a moment of privileged communication—privileged not only in the sense of confidential, but under the more important aspect of open to opportunity. This opportunity could and should embrace a broader discussion of the meaning of hope, and should be seen as a mutual quest for enhanced quality of life and the amelioration of suffering.

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APPENDIX A

DEMOGRAPHICS QUESTIONNAIRE

Study ID#_____________ Insurance_____________________(Private, Public, Private Pay)

Date__________________ UMR#_________________ UPN______________

DOB__________________ Karnofsky_______________

Gender: Male Female

Ethnicity:

Hispanic

Non-Hispanic

Race:

American Indian or Alaska Native Asian

Black or African-American White

Native Hawaiian or Other Pacific Islander

Other (please specify)____

Annual Household Income:

$0-$10,000

$10,001-$20,000

$20,001-50,000

$50,001-70,000

$70,001-100,000

$100,001-150,000

Over $150,000/year

Family Makeup:

Number of dependents:_______

Number of individuals in your household:_______

Education: What is the highest level of education you have completed?____

Occupation: What type of work did you do in your most recent job?____

Please check the one phrase that best describes your level of activity during the past 2 weeks.

I can do my normal activity, and I have no complaints about my health.

I can do my normal activity, but I am not completely healthy.

I can do my normal activity, if I make an extra effort.

I can take care of all my personal needs, but I cannot do my normal activity or work.

I can take care of most personal needs, but I sometimes need help.

I can take care of some personal needs, but I often need help.

I need special care and help with my personal needs most of the time.

I need special care, sometimes in the hospital.

I am in the hospital most of the time.

APPENDIX B

INTERVIEW QUESTIONS/PROBES

Questions/probes for patients:

1. When did you make the decision to participate in this research? How were you asked to take part in this research?
2. Describe the information you used to help you make the decision. How was the information about the research given to you?
3. What and/or who influenced you most in making your decision?
4. Who do you see as the primary decision-maker?
5. Why did you make the decision that you did? What were you thinking about while you were making your decision?
6. Which relationships have been influential in helping you reach a decision? Are there any relationships that have hindered you reaching a decision?
7. Describe the relationship you have with the research team.
8. Describe factors in your personal life that helped or hindered your decision-making (e.g., prior experiences, beliefs, faith).
9. Describe the circumstances that lead to your coming to FHCRC (probe for relevant details about the referral process, e.g., resource availability, time from diagnosis, ability to obtain visa, insurance coverage)

10. Is there anything else you want to share?

Questions/probes for family caregivers/physicians: (physicians script italicized when different))

1. When and where (did your)(do) family member make the decision to participate in this research? How were they asked to take part in the research?

2. Describe the information(you provide to patients and family members) (your family member)used to help make the decision. How was the information about the research provided?

3. What and/or who (influences patients and family members) influenced (your family member) most in making your decision?

4. Who should be the primary decision-maker?

5. Why do you think (patients make the decisions they do) (your family member make the decision that he/she did)? What do you think (patients think when making the decision) he/she was thinking about when he/she made her/his decision?

6. What is your role in the decision-making? Did the two of you come to the same decision? Describe that process.

7. Which relationships (have been) influential in helping (patients and families) (you and your family member) reach a decision? Are there any relationships that hindered reaching a decision?

8. Describe the relationship you and (your family member) (the patient) have with the (research team) or (family).

9. Describe factors in (patient families) (your family member's) personal life that helped or hindered decision-making (e.g., prior experiences, beliefs, faith)

11. Describe the circumstances that lead to (patients and families) (your family member) coming to FHCRC (probe for relevant details about the referral process, e.g., resource availability, time from diagnosis, ability to obtain visa, insurance coverage).

10. Is there anything else you want to share?