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**EDUCATING NEWLY DIAGNOSED CANCER PATIENTS
WHO ARE UNDERGOING RADIATION THERAPY**

by
Michael Mimms

A Dissertation

Submitted to the
Department of Educational Leadership
In partial fulfillment of the requirement
For the degree of
Doctor of Education
at
Rowan University
October, 2011

Dissertation Chair: MaryBeth Walpole, Ph.D.

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Dedication

This dissertation is dedicated to the memory of my brother Joseph Dennis Cucinotta and of Jonathan Edward Rothschild, an extended family member and friend. Both are gone far too soon, but they will never be forgotten.

Acknowledgments

I am extremely grateful to my Committee Chairperson Dr. MaryBeth Walpole for her advice, guidance, patience, and commitment to excellence! To my wife Deborah Mimms, through her love, encouragement, dedication, loyalty, friendship, and artistic ability to make any project I tackle a piece of cake, I am most thankful.

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education is the key! I give my highest regards to my Lord and Savior Jesus Christ, just another example of His finding the “best” in me!

Abstract

Michael Mimms
EDUCATING NEWLY DIAGNOSED CANCER PATIENTS
WHO ARE UNDERGOING RADIATION THERAPY
2010/2011
MaryBeth Walpole, Ph.D.
Educational Leadership

The purpose of this research study was to examine the various levels of understanding that patients had about cancer when they had been diagnosed with the illness, and to improve their understanding of the radiation treatment process through the presentation of an educational video (Bogdan & Biklen, 2007). Patients often remained confused and thereby missed vital information, regardless of how many explanations or how much information they had been given to explain cancer and the options they had for treatment (Eiser, Davies, Jenny, & Glaser, 2005; Kodish et al., 2004). The goal of this study was to satisfy the need for cancer patients to be able to understand the treatment process and the terms and jargon used by the medical community.

The study utilized both quantitative and qualitative strategies to enrich the quality of the research. This study incorporated pre/post survey instruments, informal observations, and journaling. This study took place from January 2009-May 2011. Cancer patients were provided with information through a DVD, an ordinary, concise, three-dimensional visual medium. The fifty participants enrolled in the study were required to respond to a pre-survey and a post-survey, each consisting of 10 true/false/don't know questions. The survey questions used for the assessment were taken from the DVD they were asked to view entitled, "Cancer Treatment: Radiation Therapy and Interactive

Approach to Cancer Treatment.” In 8 of the 10 questions, the percentage of correct answers increased from pre-survey to post-survey, even though on 5 of the post-survey questions, more respondents answered incorrectly than answered correctly.

The pre/post survey data were analyzed to determine the impact of the video presentations on cancer patients by using the *Statistical Package for the Social Sciences* (SPSS). The study analyzed the pre/post survey comparison citing educational gains and areas requiring improvement to determine the effort needed to improve the patients’ experiences during the radiation period.

When a t-test was performed comparing the means of the pre-survey and the post-survey questions, using a t-test paired samples, only one question was found to be statistically significant at the 0.05 level ($p \leq .05$). The patients were surveyed, and they were required to rate their knowledge/understanding of radiation in several areas. The data suggested that the patients overwhelmingly felt that they understood the process.

This study produced a substantial increase from pre-to-post survey results on a majority of the questions. Patients were asked to participate in a study and demonstrate their knowledge about the treatment of their illness during a very traumatic period in their lives. Although other research suggested that patients were often confused and unclear about the medical information, this was not the response in this study (Butow et al., 1998).

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Chapter 1

Problem Statement

Introduction: Educating Cancer Patients

Daily, thousands of people in the United States are given the devastating news that they have been diagnosed with cancer. Often without noticeable prior warning, these families suddenly face this life-threatening dilemma. Families are typically faced with trying to interpret the medical information with no medical background. Even for families with professional backgrounds in other fields, the medical information is often emotionally beyond their understanding or ability to interpret. Many of these families have few, or no, members who can read and interpret the instructions presented to them by the medical community (Gibson, 1995).

Having seen first-hand the onset of symptoms that signaled something was wrong, I was involved in a traumatic event. As the husband of a two-time cancer survivor, I first watched as my wife struggled to medically understand her illness. I felt there was a need for a viable interpretation for the overwhelming medical terminology and information that was presented to us and other patients (Gibson, 1995). These patients needed the necessary information presented in a form that enabled them to understand and thereby manage their life-changing illness. The printed medical information and the oral treatment instructions were often beyond the patients' comprehension. Informed decision-making concerning the choice of available treatments for the disease was difficult, if not impossible, under these circumstances.

Cancer patients have often been unclear about the information related to their illness. As a result of a lack of access to information or incomplete information, informed

decision-making has often been absent. To provide a more thorough understanding of the treatment information that was critical to patients who have been diagnosed with cancer, this study focused on two areas. First, patients needed educational information that was easily understood. For patients to be able to understand the terms used by the medical community and to make informed decisions, they had to be presented with choices in clear, precise, and simplistic language. After making choices about treatments such as radiation, patients needed to be able to understand what the treatment was and what the possible side effects were. They also needed strategies for simplifying medical jargon and for making the jargon more patient-friendly in order to comply with treatment (Gibson, 1995). In working with Thomas Jefferson Hospital through this action research project, my intent was to provide the patients with this information.

The second focus of the study was my leadership. In this action research project, my goal as a leader was to enhance adult cancer patient education in the area of radiation treatment. The study that I conducted at Jefferson University Hospital's Bodine Cancer Treatment Center consisted of three cycles. In Cycle 1 from January-June 2009, I applied for permission to conduct research at a teaching and research university hospital, Thomas Jefferson University Hospital, a very structured and regulated institution. I was an outside researcher and not part of the Thomas Jefferson University Hospital staff. As a result, I was strictly bound by the hospital guidelines promulgated by them. I had definite ideas about the sequence and the content of each of my three cycles, but I clearly understood that when, where, and how I conducted the research required significant collaboration and negotiation. With that scenario in mind, I anticipated, based on conversations with my two hospital mentors and a lot of preliminary work that I conducted in Cycle 1, that

my sequence process followed the hospital's process. Continuing to follow the hospital's process, Cycle 2 included the development, implementation, and analysis of a clinician's questionnaire survey instrument. The purpose of the questionnaire was to enable the clinician staff to lend their professional expertise to the design of the pre/post patient surveys. Cycle 3 concentrated on lessons learned throughout the study and, by adhering to the hospital's recommendations, my gaining of IRB approval. Additionally, Cycle 3 focused on constructing the patient's surveys and conducting the study, including giving out the DVDs. My last chapter reviewed how I applied my leadership toward the successful completion of this study.

The context of the study area, Thomas Jefferson University Hospital's Bodine Cancer Treatment Center, was a quality medical facility. The site of this study was located midtown in the city of Philadelphia, Pennsylvania. It was renowned for its treatment of cancer patients. The Bodine Cancer Treatment Center as part of the Kimmel Cancer Center at Jefferson Hospital was one of the region's largest and busiest radiation oncology centers. The Center was accredited by the National Cancer Institute, with cancer specialists among the most outstanding in the nation. One of the world's leading cancer experts was heading the fight against cancer at Jefferson Hospital. Richard Pestell, M.D., Ph.D. was the Director of the NCI-designated cancer center. The Bodine Center afforded me the opportunity to gain personal access to the treatment center since my wife was a patient there. I was given the same courteous attention and individual consideration that the rest of the family members who accompanied their loved ones during the treatment process were given. I was allowed to observe the technicians at work as they administered the radiation treatments to my wife. I sat in with her when she was in

consultation with the doctors. I moved freely through the hallways to experience the atmosphere of a hospital at work. I began to take notes after I determined that Thomas Jefferson University Hospital would be the place I wanted to work on my research project. Such an open and obviously caring institution was ideal for the purpose of my study, which included three cycles spanning from January 2009-May 2011.

Purpose of the Study

The purpose of this action research study was to first examine the various levels of understanding that patients had about radiation treatment after they had been diagnosed with the cancer, and to improve their understanding of the radiation treatment process through presenting an educational video (Bogdan & Biklen, 2007). Because I led this improvement, a second purpose was to study my own leadership during the project. The thematic concerns that defined the importance of this study were based on prior research and personal observation. Patients often remained confused and thereby missed vital information, regardless of how many explanations or how much information they had been given to explain cancer and the options they had for treatment (Eiser, Davies, Jenny, & Glaser, 2005; Kodish et al., 2004). The goal of this study was to satisfy the need for cancer patients to be able to understand the radiation treatment process and the terms and jargon used by the medical community as I led that effort.

At the time of the study, cancer was the second leading cause of death in the United States (Aetna IntelliHealth, Inc., 2008). One in four Americans died from cancer every year. Cancer was the leading cause of death for women aged 40 to 79 and men aged 60 to 79. About 1.4 million new cases of cancer were diagnosed each year in the United States, and about 570,000 died from cancer.

The reasons for conducting this research project were numerous, but the main impetus for this study lay primarily with the patients since they needed the necessary information to be presented in a form that enabled them to understand their treatment (Mumford, 1997). The printed medical information and the oral treatment instructions were often beyond their comprehension. Informed decision-making was difficult, if not impossible, under these circumstances (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999).

Context/Reconnaissance

An educator of nearly 20 years and a doctoral student at Rowan University in Glassboro, New Jersey, I had been researching cancer patient education for the previous three years. When I began this study, my interest had been piqued when my wife was treated successfully for cancer a second time by Dr. Frederick Laucius and Dr. Maria Werner-Wasik at Jefferson University Hospital and the Bodine Cancer Center. After I had transported my wife for daily chemotherapy and radiation treatments, I had determined to focus my research at Thomas Jefferson University Hospital. I chose Thomas Jefferson Hospital as a major cancer treatment center located in a metropolitan area convenient for patients with parking provided directly at the hospital entrance. The staff members, professionals, and volunteers were friendly and open. The waiting areas were hospitable, comfortable facilities. Access to the doctors was only an elevator ride to another floor. During the times that I had been there, patients carried on conversations about their illnesses and about the treatments they had undergone. That gave me reason to believe that they would be open to specific questions for my study. In an earlier class project, the subjects for a research project had been my wife and friends who had been

diagnosed with cancer and required treatment at Jefferson Hospital. However, I had been able to include, with their written permission, a few patients who became friendly and talkative during the wait in the radiation reception area at Jefferson. After endless discussions with friends and colleagues, and after examining the literature on cancer patient education, I had been convinced that an action research study at the Bodine Center radiation department would produce educational benefits for the patients that would be extraordinary.

Research Questions

This study was designed to answer the following questions:

- 1) How did patients make sense of the medical information presented to them in the diagnosis and treatment of cancer?
- 2) How did the development of a cancer radiation educational videotape/DVD enhance the learning process for patients and increase their understanding of the effects and results of the radiation treatments?
- 3) How has my leadership shaped this research project?
- 4) To what extent did I utilize servant and transformational leadership during this study to improve patients' education?

A major issue was that research overwhelmingly suggested that patients were often unable to understand the cancer treatment process (Fouk, Carrol, & Wood, 2001). Research suggested that patients remained confused and thereby missed vital information, regardless of how many explanations or how much information they had, or were given, to explain cancer and their options for treatment (Gibson, 1995).

Conceptual Framework for Change

Jefferson Hospital was one of the leading centers in the tri-state area of Pennsylvania, New Jersey, and Delaware for treating cancer using radiation and chemotherapy. Based on numerous hours of previously conducted qualitative project observations for a research class, the services provided by Thomas Jefferson University Hospital were highly rated by staff and patients alike. On a daily basis the hospital staff provided an uninterrupted flow of treatments to patients from 7:00 a.m. to 5:00 p.m., Monday through Friday. Based on data and information gathered through personal experience and observation from January through April of 2008 at the Bodine Cancer Center and subsequent conversations with hospital personnel and radiation patients, the education of the patients awaiting radiation treatment was an area that I believed should be upgraded. My motivation was to provide better cancer information to patients. Increased knowledge and awareness undoubtedly resulted in better outcomes for the patients undergoing treatment, as well as for their family members.

To lead this change project at Jefferson, I chose to use Heifetz's (1998) seven-step change cycle. I realized that working in a regulated medical facility, accuracy was essential. Utilizing Heifetz's seven-step change cycle afforded me with the familiarity, sequential structure, and accuracy, which I needed to complete this study. The steps were: Step 1, planning the change (often referred to as choosing the target). Jefferson University Hospital was an institution with which I had grown very familiar during the last several years. As the hospital that provided not only radiation therapy but also chemo-therapy to my wife, I felt confident that this facility would be an excellent focal point from which to conduct my study. Understanding why the change was needed and

why the change was important were two of the keys to the initial step. Step 2, setting change goals, was the area of the process in which I formulated an assessment of the hospital in terms of policy, resistance, and obstacles, as well as an informal assessment of my own capabilities and ability to complete the study. This step was also when and where I engaged in articulating clear and measurable goals to Jefferson hospital administration. Step 3, initiating the action, was the part of the change process in which my basic planning ended and the action or beginnings of the change actually started. One of the ways I initiated the action of change was to constantly reinforce the importance of the change and the patient benefits of the change. Step 4, making connections, afforded me the impetus to move forward with the project since I had established connections with many of the hospital administrators. Without the positive attitudes of the administrators and their basic orientation for me as an outsider about hospital protocol, procedures, and policy, completing this study would have been even more difficult, if not impossible. Step 5, rebalancing to accommodate the change, was the area that forced me to become open and flexible to changes as well as to accept the realization of the importance of having secondary and tertiary plans as each inevitable change dictated. Step 6, consolidating the learning, was definitely a most critical step in this study. Understanding the hospital's medical procedures and processes was not, originally, an area of strength for me. Thus, it was absolutely imperative that I consolidated all new knowledge and learning to be able to apply lessons learned to subsequent steps throughout the study. Step 7 enabled me to begin to plan for the next steps in the change process.

Data Collection/Methodology/Analysis

This action research study used a mixed method design (Bogdan & Biklen, 2007). I utilized both quantitative and qualitative strategies to enrich the quality of the research. This study incorporated three survey instruments, informal observations, and journaling. This study took place from January 2009-May 2011. It included three cycles, with each of the three cycles consisting of a planning component, an action component, an observation component, and a reflection component (Kemmis & McTaggart, 1998). The last chapter addressed my leadership.

The action research project I led at Jefferson was fairly simple. I provided cancer patients with information through a DVD, an ordinary, concise, three-dimensional visual medium. My intent was that, through this vehicle, cancer patients would obtain clearer understandings of the treatments offered for their particular cancers. Through a clinician questionnaire, pre-post survey design, and informal observations, I assessed the impact of the video presentations on cancer patients and put forth every effort to improve their experiences. I also collected data on my leadership as I progressed through all action research cycles.

I analyzed the pre/post survey data to determine the impact of the video presentations on cancer patients by using the *Statistical Package for the Social Sciences* (SPSS). I analyzed the pre/post surveys in order to compare patients' levels of knowledge prior to and after watching the DVD in an effort to improve the patients' experiences during the radiation period. Based on the results and findings from this study, and in consultation with my hospital mentors, I offered several recommendations to the medical staff at Thomas Jefferson Hospital. I also determined the extent of my use of servant and

transformational leadership styles (Bass, 1990; Greenleaf, 1991) to improve patients' education. My goal was to enhance adult cancer patient education in the area of radiation treatments.

Summary and Proposal Overview

As the leader of this action research project, in Chapter 2, I reflected upon my leadership platform and upon my leadership theory in use. In Chapter 3, I discussed my literature review since pertinent literature was critical to the success of the study. In Chapter 4, I outlined the methodology of this mixed research project. In Chapter 5, I discussed how I gained access to Thomas Jefferson University Hospital. In Chapter 6, I examined the development, implementation, and analysis of a clinician (questionnaire) survey instrument. In Chapter 7, I discussed the distribution of the patient surveys, analyzed the survey results, examined the change process at Jefferson Hospital, and discussed the organizational culture at Jefferson. My leadership platform in this action research project reflected my experiences from both personal and professional vantage points. This platform chronicled my work experience as an officer in the United States Marine Corps, as a supervisor of manufacturing at Johnson & Johnson Baby Products, as an elementary school administrator in a local urban school district, and as an entrepreneur who started an educational firm to provide supplemental educational services to students in underachieving school districts. Throughout Chapter 2, I discussed my leadership qualities, challenges to my leadership theory, and finally the gradual shift in my leadership theory during the course of my doctoral program. Through the progression of my successive career changes, my leadership style changed to meet the expectations of the various positions. In Chapter 2, I described those changes.

Chapter 2

Leadership Platform

Introduction

After reflecting on experiences, personally and professionally, which had influenced and defined me as a leader, I evaluated various models of leadership theories to determine just where I fit. From this course of study, I determined that at various times and in various situations in my life, I had most often identified with the theories of transformational and transactional leadership (Doherty & Danylchuk, 1996).

I found that my leadership style had been affected by my experiences and by my environment throughout my lifetime. I had experienced a full range and an exciting number of events that had offered me opportunities to develop as an effective leader. Gardner (1984) writes, "Leadership is the process or example by which an individual (or leadership team) induces a group to pursue objectives held and shared by the leader and his or her followers" who will carry out the necessary work to obtain the objectives (p. 17). This was never more evident than in the United States Marine Corps where lives, both the leaders' and the followers', depended on everyone having the same objective.

According to the experts in the field of leadership development, transformational leadership theory could be described by using four distinct leadership components: (a) Intellectual stimulation, (b) Individualized consideration, (c) Inspirational motivation, and (d) Charisma with communication essential to the vision of the leader (Doherty & Danylchuk, 1996). Intellectual stimulation, as defined by Doherty and Danylchuk, was the ability to stimulate and motivate followers to be more curious and creative in thinking and problem solving. Often, as a school administrator I had attempted to utilize this

component of transformational leadership to enhance and empower the members of my teaching staff. Intellectual stimulation used the leader's ability to engage his subordinates by getting the subordinates to challenge their assumptions and to think about old problems in new ways (Kelloway & Barling, 2000). I planned to engage the radiation patients at Jefferson University Hospital in the area of patient education. I also planned to challenge the administrators at Jefferson to think about education in a new way. Intellectual stimulation involved questioning assumptions and finding new ways of doing things (Bass, 1990). Through my research with cancer patient education, I hoped to have patients question the assumptions that they already understood the information they had received about their illness and their prescribed treatments and to think about new ways of receiving valid information through supplemental means, specifically through a video/DVD. I examined a different method of providing these patients with additional information about their illness through media technology.

Another of the four essential components of transformational leadership was individualized consideration, a key element for me when I was a principal attempting to transform my school. Individualized consideration referred to the perception of a given follower that the leader had provided support, encouragement, or had somehow recognized the individual at a personal level (Murphy & Drodge, 2004). It had been my experience in business, in the military service, and in the field of education that followers had to have assignments that challenged, extended, and, in turn, enhanced their abilities as they increased their value to the leader and to the organization. Jobs done well by members of an organization provided immediate sources of motivation and meaningful rewards. Additionally, to achieve the desired goal-oriented results for most

transformational leaders, communication was essential to the vision of the leader (Deluga, 1990). It was important that I inspired and encouraged the stakeholders in my school when I was a principal to want to commit to the organization. The greater the sense of commitment and attachment to me, or to the organization, the easier it was to achieve the goals and objectives (Doherty & Danylchuk, 1996). I used individual consideration as a school administrator, production supervisor, and business owner. Within each of these previous professions, my goal was to improve the working relationship with each of my subordinates by providing tasks that motivated them as well as enhanced their potential for improved performance. It was my premise to enhance the procedure of providing cancer radiation information to patients of Thomas Jefferson University Hospital. Through a technological presentation, specifically on radiation therapy, my goal was to relate to these patients on a personal level. By providing easily understood information without excessive amounts of technical and confusing jargon, this study provided the patients with additional educational information to enhance their abilities to make sense of the radiation process.

Inspirational motivation was perhaps one of the most important components of transformational leadership that addressed the emotional ties of subordinates to an organization (Doherty & Danylchuk, 1996). Leaders subscribed to the notion that the greater the emotional attachment an employee developed with an organization, the greater the chance that the employee had of identifying with the leader's vision and goals of that organization (Doherty & Danylchuk). Particularly, as a school leader, I was able to create reasons for the employees to become emotionally connected to the organization through their pride in providing for the children's education. It was exciting for me as the

leader of this project to actually have had patients informed and positively affected by additional knowledge.

Finally, idealized influence (charisma) was the leadership component I used most often as an officer in the Marine Corps (Murphy & Drodge, 2004). I found very early in my military career that I easily commanded my men to follow me by using the autocratic techniques of force or threats. However, I found that I could capture the true potential, cooperation, and commitment of the Marines if my orders or instructions were based on the idealized influential elements of leadership. Idealized influence was best defined by the leader's ability to display conviction, trust, personal values, purpose, commitment, and ethics (Webb, 2007). From the inception of the cancer patient project, I had fostered and exhibited these qualities and attributes. I truly believed that without my sense of commitment, purpose, trust, and conviction for this project, I would never have gained access to Thomas Jefferson University Hospital. The sense of dedication, conviction, and purpose, which I used to create interest by hospital personnel in the project, was the same that I used to complete my study in such a heavily regulated institution.

Early Leadership Role

Early in the evolution of my careers, I was a leader of United States Marines. A common contemporary slogan that epitomized the leadership ethic in the Marine Corps was "the few, the proud, the Marines" (Simmons & Moskin, 1998). The Marine Corps had forged leaders for more than 200 years. As an officer in the Marine Corps, I found that leadership encompassed more than just convincing, or inducing, others to pursue the objectives we shared. There were other facets of leadership such as the aesthetic and the physical attributes of endurance and physical prowess that were also very important in

becoming a leader in the Marines. It was not by accident that during that era of my life, I traditionally utilized more of an autocratic style of leadership. I was required to retain as much power as possible. I quite naturally had to retain as much decision-making authority as possible (Tannenbaum & Schmidt, 1973).

However, experiences during my years as a Marine Corps officer taught me that accomplishments using the traditional power-over autocratic style of leadership would more easily be achieved using transactional leadership components (Doherty & Danylchuk, 1996; Simmons & Moskin, 1998). My Marines valued time away from the base. They cherished, like most of us, being with their families. Most importantly, Marines loved weekend passes or liberty. It did not take long for me to learn to use these individual areas or preferences of my troops to complete the assigned tasks I needed to have completed. Quite often, I practiced transactional leadership in its purest form (Doherty & Danylchuk). Transactional leadership involved leader-subordinate exchange relations in which the subordinate received some reward in return for compliance with the leader's expectations (Doherty & Danylchuk, 1996).

When my Marines did well on a specific military exercise, I rewarded them with additional time for family or liberty. If they were unable to comply with my expectations, we would stay with the task until the assignment was completed to my satisfaction. I used a similar method of transactional leadership as a supervisor in the management of my subordinates at Johnson & Johnson within the business sector (Doherty & Danylchuk, 1996).

Leadership in the Business Sector

Leadership within the business sector did not operate on physical attributes, nor on aesthetic attributes. As a production manufacturing supervisor for nearly 10 years leading employees toward the completion of more and better products for Johnson & Johnson Company, Inc., I incorporated a new dynamic in my style of leadership. No longer was the commanding appearance of the individual, nor his athletic prowess, the barometer of leadership. In business the objective was productivity through people. Peters and Waterman (1984) wrote, “Productivity through people [is] creating in all employees the awareness that their best efforts are essential and that they will share in the rewards of the company’s success” (p. 150).

The objective of the productivity model was fairly simple. The supervisors who were best able to convince or lead their group of workers to produce the most healthcare products over the course of a month, a quarter, or throughout the year were considered leaders within the organization, incorporating the definition of leadership stated by Gardner (1984). As a young supervisor I induced a group of people, or led them, to pursue objectives that they and I shared. All of us had a vision of success for the company. Prior to the introduction of a new incentive program, our efforts were primarily transformational in leadership design (Leithwood, 2004). Prior to the incentives, very simply, the monetary reward for the effort each employee would have to exert was not worth the energy. Through the introduction of numerous lucrative employee production incentive programs and using a strict system of transactional rewards, we as supervisors were able to lead our employees to produce at very high levels. In the classical transactional leadership theory when the company succeeded, the workers were rewarded

with lucrative incentive pay rates, and there were promotional opportunities for me (Doherty & Danylchuk, 1996). However, if the workers did not produce, they were monetarily punished in the classic transactional leadership sense of taking home considerably less in their weekly paychecks.

Educational Leadership

Unlike my experiences in the military and in the business world, I found that the education sector was a unique hybrid of the previous two positions. Just as quantitative productivity drove the business sector, leaders in our educational organizations were all too often evaluated only on their school's increase or decrease on the state-wide assessment scores. As a new school administrator in an urban district, I found it was necessary to use each of the leadership styles and lessons learned from both of my previous positions. In the No Child Left Behind era, productivity meant that schools were meeting or exceeding the adequate yearly progress (AYP) standards set by the federal government (Paige, 2008). Productivity and a professionally healthy appearance were not the only traits that a leader had to possess.

Educational leaders had to have, unlike in the Marine Corps or at Johnson & Johnson, Inc., the ability to heal wounds, but not the physical kind. Healing was a large part of the entire educational scheme for leaders (Deal & Peterson, 1999). "They [leaders] deal directly and openly with critical, difficult, challenging events in the lives of staff and students, and should always be aware of the message they are sending" (Deal & Peterson, p. 207). In practice, educational leaders were like parents in the home. If problems arose with staff or students, those problems were dealt with individually and immediately or the effects would be felt by the entire school, just as one member's

problems in the home could affect the entire family. The message of the educational leader had to be that each and every member was important to the function and production of the school, just as the parents let every member of the household know that each was vital to the family. To heal those wounds, especially in the midst of changes made as a new school administrator, I learned to become skilled in the art of leading my teaching staff. Initially, I relied primarily on a transformational approach to leading and accomplishing the objectives of the school (Murphy & Drodge, 2004). However, as I became more trusting and familiar with the talents and behavior of my staff, I more frequently utilized a transactional style of leadership (Doherty & Danylchuk, 1996). Often as an interesting and refreshing change of pace, I, as the leader, chose to use additional leadership styles. It was not uncommon that I offered simple incentives (Doherty & Danylchuk, 1996) or privileges to staff members for compliance with meeting the goals and vision of the organization.

Personal Leadership Perspective

Quite often when change or the transformation of schools was a facet of moving a school toward the desired objectives, we ran the risk of stepping on the toes of a few or many individuals (Deal & Peterson, 1999). It was of paramount importance for me to successfully move forward with the vision that I had of transforming a failing school into a successful school as the school's leader. If I hoped to successfully move forward, I had to summon the ability to heal those stakeholders, the naysayers, the obstructionists, the people who said that it had never been done that way before, and those who may have felt injured. Undoubtedly, I needed all of these workers to complete the mission (Deal & Peterson, 1999).

I found that over the years I have a propensity to gravitate toward a single school of educational leadership theory. I have become most comfortable with a transformational leadership theory since it lends itself to vision-led objectives, innovation, motivation, and new directions (Holmes, 1993). Occasionally, not unlike many effective leaders, I found that I changed and adapted to various other styles of leadership theory as a situation and specific challenges dictated. Moreover, as needed or required, I utilized several transactional (Friedman, 2004) elements of good planning, goal setting, design, resources, personnel management, and a concern for outcomes.

As an administrator in the urban school system, I characterized and identified my educational leadership theory as that of a transformational style of leadership because I used vision-led objectives, innovation, motivation, and new directions (Leithwood, 2004). When I first accepted the position of principal at my school location, the school system was definitely operating under the transactional leadership theory (Doherty & Danylchuk, 1996). The transactional theory was firmly in place at the school and had been for a number of years prior to my accepting the position of principal. It was not surprising since transactional leadership was the form used most in leadership organizations (Weese, 1994).

A transactional leader strived to develop a relationship of exchange with the subordinates and co-workers in which the subordinates received some reward in return for compliance with the leader's expectations (Doherty & Danylchuk, 1996). The subordinates received rewards relative to the low-order needs of the subordinates, sometimes as little as recognition for their accomplishments. In return, the subordinates complied with the expectations of the leader. In the district in which I was working,

compliance with the needs of the leader (superintendent) was something as simple as agreeing to try the implementation of a new program such as *Roots and Wings*, *Success for All*, or the latest program, the *100 Book Challenge* initiatives. There were few, if any, follow-ups to determine the success of the programs with the students. This type of lower-order thinking, programming, and low expectations for students created a system of low morale for staff and even lower achievement for students throughout our school system.

In my position as principal I was well-organized, a skill I learned early in life and practiced throughout my service with the Marine Corps. I was not and am not, though, an advocate of following tradition or of maintaining the status quo in any school setting which is failing to educate the students. I have always felt that it was my educational obligation to examine and implement a strategy that transformed the tradition of academic failure (Deal & Peterson, 1999).

I believe that I was born into a transformational theory of leadership, if not at that moment then certainly soon afterwards, in my childhood days (Holmes, 1993). “Some truly transformational leaders are clearly identifiable very early in their careers, indeed in their lives. Certain leadership skills such as influencing and motivating others in positive directions are discernible in childhood” (Holmes, p. 50). At an early age I was introduced by my parents to the concept of visualizing goals, being committed, motivating others, my siblings at the time, and maintaining loyalty to an organization, at the time my family.

As a school leader assigned to a failing school, I felt that the school organization was destined to become successful if only I induced the stakeholders (teachers and staff) to accept the changes necessary that brought about success (Deal & Peterson, 1999). I

have always faced the challenges in my life with a full-throttled vigor. Occasionally, that approach has been my undoing; however, more often than not, a “pedal-to-the-metal” approach has been a key to my success.

I have often referred to a few organizations that took an aggressive approach to achieving their goals as ones with a “ready-and-shoot” mindset. In the traditional sense, many companies and organizations spent inordinate amounts of time, research, and money in the development of promotions of new ideas or in advertising new products when an organization was in trouble (Peters & Waterman, 1984). I felt that this was exactly what was being done with our school system. I preferred to approach transforming, or changing, an organization in trouble by using a method of calculated risks, coupled with a full-speed-ahead system, similar to those advocated by Peters and Waterman.

As the leader of the hospital project, I had to take a different approach in my leadership theory. My leadership perspective had evolved to better understand the importance of observing an organization, not just for the intrinsic issues or concerns, but through all four conceptual frames (Bolman & Deal, 2003). Following three years of study, I gained a more thorough foundation and a clearer understanding of the culture of the hospital’s organizational structure. For the success of this project and to gain access to the hospital, I examined this organization using Bolman and Deal’s four perspectives: symbolic, human resource, political, and structural frameworks. According to Bolman and Deal, the symbolic frame examined how organization members utilized rituals, stories, and symbols to find meaning in the organization’s events and activities. From the

outset I realized that Thomas Jefferson University Hospital was a symbol of medical excellence in the Philadelphia tri-state area.

The focus of the human resource frame was on the commitment, energy, and skills that the employees brought to the organization (Bolman & Deal, 2003). From the very moment of parking at Thomas Jefferson University Hospital, patients and visitors felt the energy and commitment of each employee. From the hearty greetings in the mornings or in the afternoons from the parking attendants to the care and consideration shown by each and every member of the medical staff, it was clearly evident that the staff was committed to the patients and their overall medical welfare. Bolman and Deal (2003) referred to Maslow's hierarchy of human needs. After numerous personal conversations and hours of observing the staff at Jefferson Hospital, I noted that the staff exhibited high levels of employee satisfaction, belongingness, and self-actualization as they provided care and treatment for their cancer patients.

The political frame saw organizations as political arenas in which ongoing battles for scarce resources and time were prevalent, and power was the most important asset, with organizations seen as coalitions of diverse individuals and groups (Bolman & Deal, 2003). It was problematic for me in trying to understand the political structure of Jefferson Hospital as an outsider. I attempted to implement a change with many political hurdles in place. Having the director of the radiation oncology clinic, a hospital administrator, involved in the project almost from its inception and one of the professors at the Jefferson University Hospital assigned as my mentors for this project eliminated many of the political pitfalls that could have easily derailed this study.

I struggled with identifying and understanding the structural framework of Thomas Jefferson University Hospital. With the structural frame, I examined the social architecture of the organization and the design of roles and relationships of the members to achieve the organization's goals (Bolman & Deal, 2003). Initially, I had difficulty trying to understand the organizational goals, the structure of the organization, and the hierarchy of authority, roles, and how people worked together to coordinate services. However, I gained a firmer grasp of these concepts as I conducted my research within the radiation clinic.

What Leadership Qualities Do I Possess?

Deeds are more important than dialogue in effective leadership, and the leader had to show genuine respect for all people in all walks of life. These were lessons I learned from my parents early in my childhood. They were reinforced for me during my stint in the Marine Corps. The theme, "Semper Fidelis," meaning "Always Faithful," has served me well, to date. It was very important for me to be a man who was faithful to my word. In a leadership position, my staff and co-workers wanted to follow a good example, but they would only follow the leaders who could be trusted. A leader who could not be trusted to keep his word weakened the very essence of the organization (Tschannen, 2004). According to Tschannen, "The five facets of trust-benevolence, honesty, openness, reliability, and competence-relate directly to the five constituencies of schools (administrators, teachers, students, parents, and the general public). These considerations demonstrate the importance of trust in building successful schools" (p. 99).

Additionally, an educational leader had to possess vital characteristics in order to make a difference in the lives of staff members and co-workers. These characteristics included compassion, flexibility, and a sincere interest in the well-being of others. An ideal leader was rarely afraid to take on a challenge, attempted to complete most assigned and implied duties with accuracy, and continually exhibited the initiative and desire to excel while maintaining a positive attitude.

Since my leadership was vital to this study, I felt fortunate to have had the opportunity to examine leadership tendencies from several different perspectives. All four of my previous professions had shaped and helped me to expand my leadership strategies, specifically as they related to this project. The United States Marine Corps and its authoritarian style of leadership had given me the personal and mental toughness and the attitude that I needed to complete this study (Simmons & Moskin, 1998). At Johnson & Johnson I used a transactional style that subscribed to the rewards of hard work (Leithwood, 2004). This project required a lot of hard work that led to rewards for cancer patients at Jefferson Hospital and a personal reward for me as the leader of the project: the completion of my doctorate. As a principal in a large urban school district assigned to a school with many problems to solve, I led my people through many highs and possibly just as many lows; but I maintained an even keel in both situations. As I discussed in the final chapter in this dissertation process, I combined my previous use of leadership theories with my concern for cancer patients into a servant style of leadership to complete this study.

As a result of my transformation into becoming a servant leader through this project, my personal goals were very much like the goals of healthcare professionals

across the country; that is, the enhancement of the quality of healthcare through education. The need for major improvement in American healthcare had been well documented throughout several Institute of Medicine (IOM) reports. Additional follow-up reports have corroborated, supported, and even expanded the shortcomings that had been identified in the IOM reports. One of the major themes that surfaced from one of the latest IOM reports, *Health Professions Education: A Bridge to Quality* (Greiner & Knebel, 2003) specifically suggested that quality of healthcare in the United States could only be achieved through reforming education and professional development across the health professions. With this project I served cancer treatment patients in improving the educational quality of their healthcare awareness.

What Types of Leadership Theories Do I Tend To Practice?

As a principal in a fast-paced urban district, I realized very early the importance of being able to retrieve accurate information quickly. My staff and teachers, through my leadership, were able to do the same. I inspired and encouraged them toward loyalty to me and, therefore, to the organization. This built a pathway to achieve our goals and objectives (Doherty & Danylchuk, 1996). One of the more interesting aspects of transforming schools was the way leaders labored to achieve a delicate balance to their methods of using power. “In the traditional use of power in schools, the leader primarily uses his/her power to dominate the subordinates” (Fromm, 1947, p. 91).

One of the more daunting tasks that I faced as a leader was to try to transform my failing school while not using my power counter-productively. I never again wanted to use the concept of “power-over” or to dominate the stakeholders (Fromm, 1947). To successfully transform my school, I felt that my ability to induce the members of my

school to perform, to commit, and to subscribe to creative, higher-order thinking was best served by using a “power-with” style, rather than a “power-over” (Fromm, 1947). Based on years of experience in the business sector and even in the military, utilizing a system of shared power had more often than not given me my greatest sense of accomplishment and attainment of goals that I had set. On those rare occasions when I used my influence or power to forcefully gain accomplishments, this process rarely gave me the overall results I wanted. Building relationships that characterize and resemble action-together was my approach to transforming my school (Fromm, 1947). This approach served my needs as a leader and met the standards of the organization.

I developed a level of comfort that had allowed me to utilize multiple leadership styles/theories within this study. As I studied the nature of several leadership theories, I was able to find parts of other styles to adopt. When I began my own business enterprise, I examined several additional leadership styles. Each of these attempts to depict my leadership style brought me a tremendous amount of satisfaction in knowing that I had accomplished my goal by adjusting to situations that I could not possibly have predicted.

Because of my studies in this doctoral program, I believe that I could label myself as one who employed multiple leadership styles rather than describing my style with only one major style of leadership. I had, during the course of these classes, researched experts and examined their findings on how effective leaders projected a vision that would lead to the accomplishment of the educational objectives. I was much more aware of the traits, characteristics, and styles of an effective leader. I had been able to read and write about my own thoughts, feelings, and beliefs concerning teaching and learning.

Managing my own business had given me the comfort level and confidence to examine other styles or approaches to my leadership as well as to relinquish most, if not all, of my control during certain points in this process. One such examination I made was that of the various tests Greenleaf (1991) had for servant leadership, I recognized similarities and characteristics from those tests in my own leadership style. I thought about the numerous events in my life that depicted Greenleaf's findings. Even as a youngster caring for my siblings I portrayed a servant style of leadership by always having a concern for their well-being, by serving their needs at the time, by listening, by empathizing, etc. I was aware of this type of leadership in the Marines and at school but rarely used it.

Transformation to Servant Leadership

My leadership over time gradually moved from a position of autocratic leadership in the Marine Corps (Simmons & Moskin, 1998) to transactional as a Johnson & Johnson supervisor (Murphy & Drodge, 2004). From the transactional approach at Johnson & Johnson, I moved to transformational leadership as a principal (Murphy & Drodge). While I relied most heavily on these theories, in reading about servant leadership, I realized I had also used it somewhat in the Marines and as a principal. Servant leadership emphasized increased service to others, a holistic approach to work, promoting a sense of community, and the sharing of power in decision-making (Spears, 2004). Spears also discussed a number of servant leader characteristics, which I had utilized including listening, empathy, awareness, healing, conceptualization, and a commitment to the growth of people. As a husband whose wife had undergone radiation treatment on

numerous occasions, I definitely understood the importance of healing and empathy. The empathy I had for these patients was one of the major reasons that I began this project.

Healing was another important strength of leaders. Many patients who had been diagnosed with cancer required healing in a multitude of ways, from the emotional and psychological to the physical. This project provided the kind of educational healing and awareness that came from having patients feel secure through an enhanced and expanded knowledge base of their illness and treatment.

Conceptualization was the servant leader's ability to dream great dreams (Spears, 2004). I dreamed that the radiation cancer patients' understanding levels relative to this illness were raised as a result of this project. I envisioned the patients as they left the radiation treatment waiting area after viewing the DVD as more knowledgeable about cancer and the radiation process than when they arrived. Although I did not begin this process thinking solely about servant leadership, I felt that it was important that I used my leadership development as an opportunity to improve and to enhance the quality of the educational healthcare program at Thomas Jefferson University Hospital.

In keeping with the concept of servant leaders and their commitment to the growth of people, the patients' education, their more informed decision-making, and their feelings of empowerment were testaments to their growth (Braddock et al., 1999). I described this project from the point of view that patients deserved to be completely and thoroughly informed. They were entitled to more easily understood information relative to the decisions they made.

A problem for me was how to best assist or serve these patients (Braddock et al., 1999). The patients' decisions ultimately affected their present lives, their medical care,

and their futures. They needed, and should have had, opportunities for greater access to all medical information which was available in the hospital. I saw myself evolving and becoming a voice and an advocate on behalf of cancer patients at Thomas Jefferson Hospital. My latest strategy or approach of servant leadership was a complete reversal from anything I had previously written in my leadership platform (Spears, 2004).

Conclusion

As a former principal who operated as a transformational leader, it was important for me that the employees in my school shared the vision of the district as well as that of my school in increased student achievement and professional development goals that led to even greater student achievement (Deal & Peterson, 1999). It was important that I motivated my staff through daily words of encouragement for jobs well done, provided individual and group recognition for meeting goals and benchmarks, maintained an open-door policy for every member of the school and its surrounding community. I had always been a champion for the less fortunate in schools and in institutions of all kinds.

Clearly, those who had been diagnosed with cancer and needed assistance to better understand their illness needed someone to enhance their ability to comprehend the information. In this study, I intended to assist the patients in any capacity that I could. Giving these patients an additional form of supplemental education was an ideal opportunity for me to utilize my servant leadership role. The literature and research described in the next chapter further highlighted the need for additional cancer patient education.

Chapter 3

Literature Review

Need for Understanding Medical Terminology

My wife was a survivor of cancer, not once but twice. Twice I had commiserated with her and worried with her about the diagnosis and prognosis of the disease. Both of us were professionals in the field of education. That fact did not help us in understanding and interpreting the medical terminology used by the medical staff to convey information about the cancer. We felt an overwhelming desire for information in our language, that of the novice with emotional baggage, that needed to be taken into consideration by the doctors and nurses. I had found that other patients and their families felt the same way. The printed medical information and the oral instructions were above our understanding during that emotional period of time. We heard the words and we read the words, but we did not fully absorb the information.

I focused this literature review on two areas. First, I focused on cancer patients' educational development, or more specifically on their need to be able to understand medical terminology relative to the particular care and treatment they needed. Patients needed concise and specific language so that their treatment decisions would be made based on understanding and not on partial information picked up during the emotionally-charged critical time of the cancer announcement. The medical community also needed to understand patients' perspectives during the presentations of the devastating announcement that cancer was present. Scientific terminology was not to be used to present choices to the patients and their families. Patients and their families needed to

make truly informed decisions about their choices of care and treatment. Medical facilities needed to work to provide patient services that led to better relationships between themselves and their patients. Other areas, such as costs, schedules, procedures, possible side effects of different procedures, results that are expected from different procedures, and a whole host of other questions needed to be probed as well.

The second focus of this literature review was examining cancer patient audio-visual materials. It was well-documented that a wide variety of media was used to deliver cancer patient information (Chelf et al., 2001). This literature review specifically outlined the importance of having patient information that was clear, concise, at compatible reading levels, with some educational development classes needed to enhance the disbursement of information, and, finally, the importance of the use of audio-visual aids. The literature suggested that one of the greatest benefits derived from the use of audio-visuals aids was in the preparation of patients for medical procedures and for treatment processes which were, or could have been, life-threatening. Developing audio-visual materials was a resource-intensive and complex task that required some basic guidelines that ensured the achievement of a high-quality, effective product (Carey, Schofield, Jefford, Krishnasamy, & Aranda, 2007). I described the guidelines, which were categorized into four distinct areas, to achieve audio-visual materials that best prepared cancer patients for possible life-threatening procedures.

Patient Education

Patients needed educational development, but, more specifically, they needed patient education classes. Patients who had been diagnosed with cancer faced a host of new challenges. Patients needed to develop expertise in a wide range of technical skills

and knowledge of complex healthcare issues while also coming to terms with the uncertainty of a condition with an unpredictable trajectory (Swallow & Jacoby, 2001).

Fully involving the patients in clinical decisions was a challenging task for clinicians, but little training existed on the practice of assisting patients toward effective, informed decision-making (Braddock et al., 1999). To make informed consent more effective, future research had to seek to improve communications during this critical interchange (Kodish et al., 2004). The development of basic patient information classes to assist patients with making informed decisions, primarily about critical matters or other issues, went a long way toward improving both trust and communication among the various members of the hospital staff and parents/patients. The hospitals that explored the limitless possibilities of providing formal or informal training to the hospital staff about the importance of informed decision-making by patients built a framework for developing skills and behaviors that improved communication and trust. Improving patient and physician relationships was a key to increasing the potential for the beneficial outcomes that followed (Braddock et al.). Inadequate efforts to foster patients' involvement in decision-making impaired the doctor/patient relationship. Inadequate involvement interfered with the patients' acceptance of treatment and with their adherence to medical advice (Braddock et al.).

The first step in determining the needs and preferences of the patient was to assess, plan, implement, and evaluate the current patient education process. Assessment, the first and most crucial part of the process, led to a description of learning needs and characteristics and was the foundation for education planning and implementation (Almquist & Bookbinder, 1990; Giloth, 1993; Lorig, 1996; Rankin & Stallings, 1990;

Redman, 1993; Volker, 1991). The literature suggested that the amount, quality, and patient preferences regarding information varied widely across the course of the cancer illness and treatment (Butow, Brindle, McConnell, Boakes, & Tattersall, 1998). That which remained constant was that cancer patients gave their highest priority to obtaining information about their cancer diagnosis and treatment plan (Brandt, 1991; Carlsson & Strang, 1996, 1998; Fallowfield, 1995). Moreover, a significant number of cancer patients had large gaps of knowledge about the disease process and the effects the treatment could have on patients (Chelf et al., 2002). Studies suggested that patients had difficulty recalling information given near to, or at, the time of the initial consultation and the beginning of treatment (Butow et al., 1998). Patients' secondary response was to try to find out as much information as they could about the disease (Carlsson & Strang, 1998). Active problem-solving and coping were methods that patients used to seek more information and to get additional guidance (Weisman, 1979).

Additionally, various patients' needs and preferred methods of learning had been reported and the learning needs of individuals or groups of patients could be determined quickly and easily utilizing a variety of methods. One method was a simple one-on-one interview commonly used in an inpatient setting. While staff personnel were conducting an admission assessment, members of the radiation oncology staff could elicit the necessary information. Exploratory questions about the patients' knowledge of their illness and treatment, how they preferred to learn, what level of formal education they had completed, and if they had any immediate concerns were assessment strategies that medical institutions could implement to identify patients' needs (Volker, 1991). The information published about cancer and its diagnosis and treatment stated that patients

wanted information that was clear, concise, and accurate (Chelf et al., 2002). The authors suggested that the time and economic constraints on healthcare providers resulted in insurmountable challenges in their attempts to provide patients with individualized and preferred methods of learning about their illness. Patients benefited greatly from well-designed and well-controlled studies to define clearly patients' preferred learning styles. The information derived from the closely monitored educational processes helped to better determine "which learning methods are preferred and most effective for specific populations" (Chelf et al., p. 867). Knowing cancer patients' preferred learning methods was closely tied to providing educational materials that patients read and understood.

Patient Engagement in Learning

Presenting complex information to cancer patients was a challenge that most medical practices faced (Harrison-Woermke & Graydon, 1993). The need for information among cancer patients undergoing radiation therapy was high (Harrison-Woermke & Graydon), especially regarding the disease itself, the prognosis, tests, and treatments, as well as information regarding physical care and how to deal with their feelings and concerns (Bilodeau & Degner, 1996; Graydon et al., 1997; Harrison-Woermke & Graydon). Harrison-Woermke and Graydon suggested that structuring information led to greater recall and that a videotape conveyed complex information better than a brochure. The effect of information from videos was clear.

The first principle or guideline for developing satisfactory audio-visual materials for cancer patients required stakeholder engagement (Carey et al., 2007). Stakeholder engagement was defined as the provision that all information in the video/DVD met the needs of the audience that it served. In this instance the audience was made up of cancer

patients and their families. When the videos/DVDs were evaluated, they met the perceived criteria of acceptability and usefulness with both the consumers who were cancer patients and the healthcare professionals and caregivers. Developing new educational materials took a significant amount of time and financial investment (Carey et al.). Thus the goal or strategy of stakeholder engagement was two-fold. The first strategy was to engage the patient to want to use or view the newly-developed video materials. The second and most important goal or strategy was to make certain that the patient engaged the new resource sufficiently to facilitate learning.

When creating or providing audio-visual materials for cancer patients, medical facilities often provided information that depicted a threatening or frightening procedure. Audio-visual materials for cancer patients included modeling for the patient to be able to learn exactly how the treatment would actually be conducted. Many medical procedures relative to radiation treatments such as tattooing of the body, the making of a mold for the affected body part, some burns that occurred from the radiation, and strapping down of the body onto the table were distressing for patients even when the objective level of medical threat associated with a particular procedure was extremely low (Horne, Vatmanidis, & Cereri, 1994).

Any new resource materials should promote or relay a sense of confidence and enhance the patient's ability to cope with the treatment procedures. One simple method that promoted patient confidence was through actually modeling or role playing that showed how the patient received treatment (Gagliano, 1998). Since modeling was virtually impossible for medical personnel to do for each patient, this was done through audio-visual procedures. Individual self-care strategies also promoted information

through the use of audio-visual materials. Indeed, audio-visual media were very well-suited to modeling coping and other behaviors. Video role modeling in patient education had been linked to reductions in anxiety, to reductions in sympathetic arousal and pain, and to increased knowledge and coping ability.

Video Modeling as a Valid Educational Format for Cancer Patients

Many cancer patients and their families lacked understanding of the information presented to them. Yet, patients with cancer and their families needed information about their cancer diagnosis and their treatment plans (Butow et al., 1998). Additionally, patients needed more detailed information on the side effects of radiation, when the effects would occur, and how long they would last (Brandt, 1991; Carlsson & Strang, 1996, 1998; Fallowfield, 1995). Although some patients actively sought information about the cancer treatment, it was clear that a significant number of cancer patients would benefit from additional formal education pertaining to cancer treatment. Patients' most favored methods for learning about cancer topics were personal discussions and communications with doctors and nurses (Chelf et al., 2002). When personal interactions were not possible, video presentations with modeling behaviors were a valid secondary source of formal education in cancer information and treatment. Dr. Greg Orloff's DVD produced for the American Cancer Society (n.d.) demonstrated modeling behaviors for cancer patients receiving radiation treatments.

Current Thoughts about Patient Education

The current practices used to educate cancer patients about cancer treatments and possible choices for that treatment needed further development. The research suggested that there was no concrete structure in place that assessed learning needs and preferential

learning methods (Chelf et al., 2002). Further research was necessary to address the current educational treatment needs. Conflicting conclusions regarding the purpose of cancer patients' educational needs were evident.

One researcher questioned whether the world was ready for completely informing patients and completely sharing the decision-making process with their patients (Holmes-Rovner, 2007). The results of informing patients and their subsequent decision-making suggested that professionals were under the impression that the primary purpose of written information was to increase the patients' compliance with the medical professionals' orders. Compliance basically referred to the extent to which the patients used the information they received from their medical experts to help decide whether or not to take a prescribed medication or to receive a prescribed treatment. Along with the readability of information, the language used and, more importantly to this study, visual presentation was very important to patients (Holmes-Rovner). To reduce patient anxiety, to enhance coping mechanisms, to reduce conflicts over decisions made, to promote autonomy of patients, and to create an improved experience for patients and their families, patients needed to be educated about their disease, about the implications of having the disease, about the side effects and the management of the side effects, and about techniques for improving their own quality-of-life (Chelf et al., 2002). The ongoing evaluations of patients' learning needs, their preferred methods of obtaining the learning, and the outcomes from the learning contributed to more efficient teaching and learning (Chelf et al.).

Contemporary Education

With patients' continuing need for appropriate and understandable education about their illness, there were no limits as far as advancing patient education using technology. In addition to the three-dimensional animations and illustrations of the video, which I used in my study, there were uses for numerous other video technology and contemporary patient education devices. Medical personnel spent considerable time trying to assist patients and families to reach logical and comfortable decisions and to attempt to remove the shroud of mystery surrounding aspects of treatment that they were unable to witness (Abreu, Tamura, Sipp, Kearny, & Eavey, 2008). Yet even the most informative verbal description of a procedure was only an abstract concept to someone who had never seen such a procedure. A simple method that allowed a "visual demonstration" of an operation or procedure was very helpful. The time patients spent face-to-face with medical personnel to better assist patients with their treatment decisions optimized their overall healthcare outlook. Providing patients with additional supplemental educational materials that were accurate, informative, and easily accessible was also a definite benefit. However, the information provided must be appropriately crafted, since medical jargon was not easily understood by patients.

Intervention Strategies to Simplify and to Lower Reading Levels

Intervention strategies were needed to simplify medical jargon and to make the jargon more patient-friendly in patient education. The readability level of information presented to the patients with diagnosed cancer from medical doctors, nurses, and other healthcare workers was often written at a university or post-graduate level (Mumford, 1997). Information disseminated to patients that was above their aptitudes or was written

in a manner that caused problems in translations, which was frustrating and often useless to patients. To further illustrate this problem, my co-worker gave some educational literature to an associate who was a prominent lawyer to try to determine his understanding of unfamiliar terms. Some of the terms in the literature that were reviewed were taken from guided reading, cooperative learning, differentiated instruction, unified curriculum, and No Child Left Behind (NCLB, 2001). Although the attorney was not expected to be aware of all of the acronyms and specialized jargon associated with education, he easily read the words in the article. The problem was his inability to comprehend and to find a useful purpose for the information that was read. Many patients had the same kind of problem translating words into meaningful statements.

Many nurses were very cooperative with patients, but fewer doctors were cooperative with patients since their time and abilities to teach patients were limited (Woznick & Goodheart, 2001). Discussions and conversations held with hospital staff seemed at times like talking to a person from another culture. Although a similar language was being used, not all words or phrases translated exactly the same (Woznick & Goodheart). Doctors and nurses tended to use hospital terminology. They needed patient educational documentation based on specific reading levels, hand-manipulated materials, consumables, and other types of teachable materials such as videos and DVDs when they were handing out, or explaining, vital information to patients.

However, even when hospital medical personnel deliberately attempted to design leaflets and brochures to lower the readability levels of the documents, the levels of the completed documents were still much above the patients' understanding, dropping only to a mean of 11.3 years—comparable to a third-year high school student, with a range of

readability levels of 8.9 to 14.8 years—comparable to a third-year college student (Mumford, 1997). This was important since many patients read approximately five years below their last grade completed in school. Thus some intervention strategies for pre-testing hospital information and materials should have been implemented (Rice & Valdiva, 1991). This pre-testing did not have to consist of complicated field research. It was possible to develop and implement low-cost pre-test materials through random interviews or focus group discussions in which individuals and groups were asked to judge and comment upon a set of materials.

Statistics in Health Care

When conducting research on medical education, older adults and senior citizens should be included in the interviews and focus groups since a high rate of illiteracy disproportionately affected older adults. Many older adults were also unduly affected by high rates of cancer. Some 90 million people had problems reading and understanding their healthcare information, with 47% of those being adults (Billek-Sawbney & Reicherter, 2005). To further illustrate this dilemma, even as early as 1988, national statistics suggested that more than 27 million Americans over 17 years of age were functionally illiterate and that an additional 45 million Americans were marginally literate (Wong, 1992). Almost half of the adults in the United States did not understand what healthcare professionals told them about their medical care and treatment options (Schulte, 2007). It was simply not feasible, nor was there enough time or enough financial resources, to measure the reading comprehension of patients and to provide them with the literature that was educationally applicable. Many hospitals suggested that patients be given literature written at a level of three-to-five grades below their levels of

education as a better practice than just indiscriminately handing out medical materials (Wong). Furthermore, highly readable documents were those documents that were written at, or below, the fifth grade level. In the recent study people age 65 and older who could not read well enough to comprehend basic healthcare information were more likely to die within six years than were those who could read and understand their healthcare information (Schulte). Illiteracy was therefore linked to earlier death.

Even if the results were not catastrophic as in the case of older adults, all medical documents and information distributed to patients who had difficulty reading them were useless (Wong, 1992). Increasing the readability of medical materials was a basic and simple process. Only relevant essential information with an emphasis on clear and concise content was included. The information with the most important points was presented first, not lost in the body of the document. Highly readable documents also began with a statement of purpose, and they ended with a summary. The documents presented basic vocabulary to convey the diagnosis, treatment, or the conditions of treatment. Commonly used non-technical words were confusing to a marginally literate patient; for example, an injection was stated as a shot. Medical documents that were printed in large type and generously spaced made text appear less intimidating and easier for less able readers. However, it was not in the job descriptions of doctors, nurses, and attending staff to teach reading to their clientele. It was clear, though, that hospitals needed to disseminate medical information to patients that gave them an above-average hope of understanding the literature. The whole notion of providing highly readable documents was a fairly new idea. In a perfect world all pamphlets or sets of instructions were coded with the reading grade level needed to understand them. People with limited

reading skills were less adept at formulating questions than more proficient readers because they lacked the necessary vocabularies, and they lacked the ability to analyze printed materials.

Medical jargon needed to be simplified for correct interpretation by the patients. Despite patients' inability to read healthcare information, guidelines, and health-related information materials, health information leaflets were still being produced with high reading levels despite an increase in their usage (Mumford, 1997). Mumford not only examined some of the problems with the readability of the information, but he also examined other aspects of communicating hospital information to patients. The study suggested several recommendations to alleviate this situation, although there was very little information that suggested that the medical facilities followed through with the recommendations.

Another recommendation was that hospital information and materials needed to be pre-tested by focus groups, and even by individuals, to determine if the information presented was clear. Hospital personnel then determined the usefulness of the materials that had been distributed to patients who had been diagnosed with cancer (Rice & Valdiva, 1991). Upon further examination I surmised that there were no quick fixes to alleviate this problem. The solution was both time-consuming and expensive. To use the time, manpower, and funds to revise the hospital patient information was not a top priority for hospitals. Regardless of its importance to patients, it was an area that was not of a high priority for most medical organizations.

By creating a more cohesive education-based or knowledge/information-based working relationship between families and the medical community with clear, concise,

and understandable medical information, cancer patients received an important boost to their treatment. During their illness cancer patients and their families often lacked an understanding of the information presented to them by members of the medical community (Wong, 1992). The medical community consisted of doctors, nurses, health insurers, and others concerned with the patients' care and welfare. To adequately adapt to critical situations brought on by a cancer diagnosis, the patients developed a sense of control through adequate medical treatment and understandable information during the treatment process.

Control in this critical care situation was best categorized as patient empowerment or personal feelings that they had enough valuable information that led them to good health. Empowerment was the patients' ability to recognize, promote, and meet their own needs; to solve their own problems; and to put together the necessary resources to feel in control of their own lives (Gibson, 1995). Through empowerment and the feeling of being in control of their own lives after the diagnosis of cancer, patients discovered reality, were able to reflect critically about their personal situations, took charge of themselves and their situations, and developed and employed the necessary knowledge, competence, and confidence for making themselves heard and recognized by the medical profession. The devastating diagnosis of cancer left patients feeling isolated and alone. It took a tremendous amount of training for patients to feel that sense of control of their own lives again. To enhance patients' sense of control they required educating in at least two different areas. For cancer patients to gain a measure of control they needed to better understand their illness and treatment as well as to gain an improved educational awareness through visual presentation.

Chapter 4

Methodology

Purpose

The purpose of this action research study was two-fold. The first was to examine and improve the various levels of understanding that patients had about cancer and their treatment when they had been diagnosed with the illness. The second was to explore my leadership of this project.

I led the effort to improve patients' understanding and awareness. The thematic concerns that defined the importance of this study were based on prior research. Research had shown that patients often remained confused and thereby missed vital information, regardless of how many explanations or how much information they had been given to explain cancer and the options they had for treatment (Eiser et al., 2005; Kodish et al., 2004).

Action research was utilized to attempt to improve the specific problem of inadequate patient information (McMillan, 2004). Action research was a process of systematic inquiry, usually cyclical, conducted by those inside an organization rather than by outside experts. Its goal was to identify an action or series of actions that generated some improvement the researchers believed important (Hinchey, 2008). Since action research involved systematic inquiry, it included data gathering, analysis, and reflection. Finally, action research led to a plan of action, which frequently generated a new cycle of the process (Hinchey). Action research allowed people to understand themselves better, increased their awareness of problems, and raised commitment (Bogdan & Biklen, 2007).

Additionally, action research strengthened one's commitment and encouraged progress toward a particular goal. One component of action research was to examine the present practice in order to change it. In the current study, my goal was to bring attention to a process that would be improved by examining the understanding patients had about cancer when they had been diagnosed and by improving their understanding of the radiation treatment process. This study examined the knowledge base of patients diagnosed with cancer using field observations, my personal journal writings, and surveys in a pre and post design (Glesne, 2006; Patten, 2001). Action research was applicable to this study because my intent, through having the patients view the video, was to improve patients' knowledge regarding the treatment of their illness. Furthermore, I led this action research and thus reflected on and gathered data on my leadership to examine and then improve my leadership skills.

Research Questions

The research questions arising from the study were related to that purpose and included:

1. How did patients make sense of the medical information presented to them in the diagnosis and treatment of cancer?
2. How did the development of a cancer radiation educational videotape/DVD enhance the learning process for patients and increase their understanding of the effects and results of the radiation treatments?

The leadership questions that were considered are:

3. How has my leadership shaped this research project?

4. To what extent did I utilize servant and transformational leadership during this study to improve patients' education?

Location/Context/My Role

The setting for this action research project took place at Thomas Jefferson University Hospital's Bodine Cancer Treatment Center within the Kimmel Cancer Center at Jefferson University Hospital, located in Philadelphia, Pennsylvania. As described in much of the hospital's literature, the Bodine Center of Cancer Treatment was one of the region's largest and busiest radiation oncology centers. Jefferson's Cancer Center was accredited by the National Cancer Institute (NCI). Unlike many cancer treatment centers in other hospitals, Bodine had the capacity for treating hundreds of patients on a weekly basis for innumerable types of cancer using the latest and most up-to-date technology. Jefferson had centers for radiation, chemotherapy, x-rays, MRIs, and many other kinds of tests and treatments on site. Patients never left the hospital to receive various kinds of treatment, including surgery. Serving as the center of activities for the Department of Radiation Oncology, the center combined the collaborative efforts of highly accomplished radiation oncologists, surgeons, medical oncologists, and other specialists.

Population/Subjects

The patients involved in the study were adult men and women of varying ages, some with less severe diagnoses and prognoses of cancer and some with more severe diagnoses and prognoses of cancer. My subject population consisted only of cancer patients who were undergoing radiation treatments at Thomas Jefferson University Hospital in Philadelphia, Pennsylvania. The sample study included a mix of men and women from diverse populations. The study population was selected randomly from

those patients who were in the waiting area and were scheduled to receive radiation treatments at the Thomas Jefferson Bodine Cancer Center. Patients received varying amounts of radiation for various types of cancer. There was no set time schedule to which all patients adhered. Each patient was individually scheduled for radiation treatments. The process included the recruitment of 50 cancer patients who were willing to complete the pre-survey, watch the video, and complete the post-survey to ascertain the information they learned about radiation treatment from the video.

Data Collection

With assistance and input from the medical staff from Thomas Jefferson University Hospital, I developed a clinician questionnaire (Appendix A). The purpose of the clinician questionnaire was to select or highlight the most important educational aspects of the video as determined by the radiation oncology doctors, nurses, technicians, clinicians, and other related staff personnel. The clinician questionnaire that I developed asked the clinicians to rank the educational elements from the video in order of importance for their input into the patient surveys. I used their medical expertise for the development and implementation of my patient pre/post survey instruments (Appendices B & C).

I used mixed methods to collect the data including journaling, a questionnaire, and I designed a pre/post survey design (Clandinin & Connelly, 2000; Patten, 2001). The qualitative data included my journal writings. The journal entries I made throughout this process were reflective in nature (Bogdan & Biklen, 2007). Bogdan and Biklen contend that a researcher's journal writing may emphasize feelings, problems, ideas, impressions, and mistakes. With the changing landscape at Jefferson, I found that making

notations in my journal after many frustrating, and yet often exhilarating days, a cathartic experience.

To collect quantitative data, I used pre and post surveys that patients easily completed within a few minutes. The pre-survey consisted of basic instructions for the completion of the instrument, 10 true/false statements, several questions about marital status, racial background, levels of education, and medical history questions (Patten, 2001). The post surveys adhered to the guidelines established for presenting cancer and treatment information with clear, concise, and relevant information. The surveys were administered in a pre and post intervention design, with watching the video consisting of the intervention (Patten, 2001). My goal was to collect information from the cancer patients who were undergoing radiation treatments, and I used this information to enhance the educational process of the patients (Creswell, 2009).

The surveys were designed to gather vital information about patients' understanding of radiation, pre-and post-DVD. With patient approval and informed consent, I sampled a total of 50 patients prior to or after their radiation treatment sessions. Both the clinician questionnaire and the patient pre/post surveys were appropriate tools to give the kind of tangible numerical, statistical, and descriptive information which I needed to explore patients' understanding and the effectiveness of the video (Patten, 2001).

Data Analysis

I analyzed the clinician questionnaire data using survey-monkey to track frequency calculations. I used *Statistical Package for the Social Sciences* (SPSS) to analyze the pre- and post-test data. I first examined descriptive statistics including

question mean scores and a comparison of pre/post surveys, correct, incorrect, and “don’t know” responses. T-tests were performed of the individual pre-survey and post-survey questions. T-tests were appropriate since they assessed whether the mean score on the pre-survey significantly differed from the mean score on the post-survey (Cronk, 2008). I reviewed all of the participant’s correct responses.

I analyzed my journal data by allowing themes to emerge, consistent with qualitative techniques (Cronk, 2008). All themes that emerged were supported by the data, excerpts, and quotes from my journal writing.

Limitations

The study had some limitations. Fifty patients was a relatively small sample and not representative of the population of hospital patients. All patients were from the same city and the same hospital, which may not be a representative sample of a more general population. Also, the DVD is a relatively brief intervention. Because patients took the DVD home, there was no monitoring to ensure how long they watched it or that they actually watched it at all. An additional limitation was that there were no American Indians and no Pacific Islanders in the study.

Cycle Description

The completion of all three cycles took nearly 18 months. Designing and implementing the survey instruments that satisfied all parties concerned was a difficult process. Getting all stakeholders to agree that all necessary paperwork had been submitted and completed correctly took more time than I expected.

Cycle 1 used narrative inquiry to document the facts associated with this study.

Throughout this process, I viewed and then recorded my experiences through journaling. I collected the data and described the experiences to help tell my story and to construct what Clandinin and Connelly (2000) labeled archaeology of meaning and memory.

Cycle 1 took place from January-August 2009 and was a two-fold process. First, I decided on an audio-visual concept. My decision to gravitate toward a DVD was born from a video I viewed at my ophthalmologist's office. I discuss the decision-making process further, in Chapter 5. The second part of this cycle consisted of my contacting and working with hospital personnel to gain access and approval for the project. Prior to discussion with hospital personnel about the specifics of my project, I had to go through a number of circuitous channels to receive permission to move forward with the project. The initial step in this research study involved creating a liaison with Dr. Greg Orloff, who is my point-of-contact at Emory University in Atlanta, Georgia. Dr. Orloff led the Educational Cancer Research Department at Emory University and was near the completion of a DVD for cancer patients and their radiation treatments sponsored by the American Cancer Society. While he was in the final stages of completing the project, he granted permission for my use of his DVD on a limited basis for my study. The next phase of the initial cycle required that I make a formal presentation to the hospital administrator in charge of Bodine's Radiation Treatment Center. The presentation specifically outlined, in a half-hour presentation, the basic and background information of my personal educational expertise, the focus of my project, the research questions I examined, how I came to select Thomas Jefferson University for my study, my proposed research methods, and an explanation of my plan of action. Next, I was asked to provide the hospital's Administrative Review Body (CCRRC) with an initial protocol, which was

10 pages in length. This process was required by the hospital before any research could begin. The steps in Cycle 1 led to tentative approval by Jefferson Hospital administrators for my study to begin after I was trained as a hospital volunteer. All data in this cycle I recorded as journal entries and analyzed the entries according to themes that emerged (Bogdan & Biklen, 2007).

Cycle 2 from September-December 2009 consisted of Dr. Orloff's completion of the video for my personal use and of designing and implementing a hospital staff (clinician) educational questionnaire. In late August 2009, I received a long awaited call from Dr. Orloff that the final edited version of the DVD was completed and ready for viewing. I received the website information from him and began to produce copies of the video for the purpose of designing the clinician questionnaire. The clinician questionnaire was designed in collaboration with several of the Jefferson University Hospital doctors, nurses, clinicians, and radiation technicians who watched Dr. Orloff's video and judged the relative importance of each segment for the cancer patients' educational needs.

The goal for the design of the questionnaire was to select 10 or more major educational elements from the video to include in the final design of a pre/post survey. Examples of questions in the clinician questionnaire included: (1.) How important is it for cancer patients to understand that fatigue may be a side effect of radiation? (2.) How important is it for cancer patients to understand that radiation therapy is good at shrinking and destroying tumors without causing much damage to normal tissues? After receiving their submissions, I extracted, compiled, listed, and ranked the educational elements from the video that were deemed most important by the clinicians to use in the patient surveys. Although there was a large sample of clinicians to choose from, a hospital administrator

suggested that between five and eight clinicians would be more than sufficient. We had eight volunteer participants who completed the questionnaires, including four registered nurses, one radiation therapist, two general nurse practitioners, and a medical student (all of whom worked in the radiation/oncology unit at the Bodine Center of Thomas Jefferson University Hospital). From an educational vantage point it was important that I incorporate input from hospital stakeholders into the design of the questionnaire. To obtain valid information for the questionnaire, I gave the hospital staff an opportunity to view the video and rank the educational elements from most important to least important. I used input from hospital researchers, clinicians, technicians, administrators, doctors, and nurses. After collecting and analyzing the feedback from staff using survey monkey, I utilized the information I obtained to construct a patient pre-and post-educational radiation therapy survey instrument, a beginning and end-point knowledge assessment (Patten, 2001).

In Cycle 3 from January 2010 - May 2011 with the use of the DVD, cancer patients were enrolled in the study. As each potential participant entered the center for treatment, a nurse approached the patient to determine interest in participating in the study. If the patient indicated interest, the person was given consent forms, a pre-survey, instructions for watching the DVD, and a gift card. The participant completed and returned the pre-survey to the investigator. At that time the participant received a copy of the DVD to view and to keep. At the time of a future treatment, the participant was identified and given the post-survey to complete, which was collected by the investigator. The effectiveness of the video was evaluated through an analysis of the participants' results, which allowed a clearer picture of the patients' knowledge, awareness, and the

effectiveness of the video. I analyzed and evaluated the data I collected from the surveys using the *Statistical Package for the Social Sciences* (SPSS). In the following chapters I have presented the results of each cycle, and made recommendations for Thomas Jefferson University Hospital's Bodine Cancer Treatment Center for the improvement of cancer patient education.

In the final chapter of the study, I have used my collected journal data to explore and to better understand my leadership. This section consisted of an analysis of my gradual acknowledgement and progression toward becoming a servant leader. This chapter contained my views on my leadership plan of action, the organizational procedures and protocol at Jefferson, how I learned to use servant leadership to complete this project, how this project reshaped my leadership theory, and my thoughts through reflective journaling.

I looked forward to assisting cancer patients as they experienced the radiation treatment process. I was confident that this action research project not only enhanced my leadership and change philosophy, but was beneficial to people at a very difficult time in their lives. I was confident that my relationship with Thomas Jefferson Hospital's Bodine Cancer Treatment Center and my connection with Rowan University yielded a useful quality research study.

Chapter 5

Cycle 1

Narrative Inquiry: Deciding on an Audio-visual Concept

The collection of data during Cycle 1 followed the tenets of narrative inquiry. Narrative inquiry was described by Clandinin and Connelly (2000) as collaboration between the researcher and the participants in a specified time and place. The researcher's goal was to obtain a better understanding of the participants' experiences. Through the use of narrative inquiry, I described my leadership as I gained access to the facility and as I gained an understanding of the stringent regulatory procedures that had to be adhered to prior to the inception of research at Thomas Jefferson University Hospital. The implementation of a new process in a regulated facility such as Thomas Jefferson University Hospital was a difficult task. At best, stringent regulations coupled with confidentiality issues limited access to patients, a flawed study design, and an overall concern for the patients were just a few of the challenges I detailed throughout this narrative inquiry process.

I chronicled in my previous chapters the need for a simple educational process that allowed cancer radiation therapy patients to better understand their treatment (Gibson, 1995). The method I described to assist cancer radiation therapy patients became apparent to me during a visit to my eye surgeon. As a result of a near fatal car accident in February of 2005, my eye surgeon suggested that I definitely needed to have surgery performed in not just one eye, but in both of them. Similar to concerns that cancer patients have, I wanted no part of the explanation or the medical jargon that the

doctor gave to me as he explained exactly how he would proceed to perform the eye surgery. When the doctor suggested that he was going to put a needle in my eye and surgically remove some of the lens to implant a foreign object in my eye, I found the subject of eye surgery very distasteful. I literally was unable to comprehend or retain a word of anything he mentioned to me about the surgery after he said he would put a needle in the lens or retina area of my eye and implant something there. As I noted in my journal,

Just thinking about a needle in my eye was enough to stop my powers of concentration. Implanting something in my eye sounded horrible, too. I did not comprehend anything else after the doctor said that until I was in the examination room.

As good fortune would have it, following his consultation as I was waiting in the examination room, I noticed a very simple 3-D animation of a similar eye surgery. As I viewed the eye surgery video, I mentally noted that it ran very briefly, it was medically jargon free, it was patient friendly, and it was very concise. I thought, having watched the video on eye surgery, that it was extremely easy to comprehend the process. I basically thought, “Eureka!” I felt, after having seen this eye surgery video, that it was much easier for me to make an informed decision about my eye operation (Kodish et al., 2004).

The research suggested that excellent benefits were derived from audio-visual aids especially in the preparation of patients for medical procedures (Chelf et al., 2001). Immediately after watching the video, I felt a complete sense of empowerment. I felt that a visual representation of this process allowed me to easily accept and understand the surgery. I believed cancer radiation patients would definitely benefit from a similar type of medium. From that point forward, my research was tailored to finding and providing a medium that visually depicted a process that enhanced cancer radiation treatment

patients' awareness. After watching that 3-D video in my eye surgeon's office, I spent endless hours exploring the internet and reading innumerable documents for the sole purpose of finding a related visual representation suitable for cancer patients during the radiation therapy treatment process.

Starting in September 2008 during my Leadership Project Proposal class, I turned my complete attention to finding and providing a 3-D visual for the radiation cancer patients at Jefferson University Hospital. During a class in September 2008 the study became clear and marked the beginning of my complete understanding, the direction, and the sequence my project needed. With the sole premise of finding a visual 3-D video as the foundation for my project, the project really developed on November 11, 2008. I vividly remembered sitting in the Rowan University library frantically searching the web for anything that could visually bring the radiation process to life. I spent many hours searching journal articles. I spent numerous hours in the library reading the research and online articles for anything having to do with 3-D animation and cancer research. I even researched the company where I viewed the 3-D video initially in my eye surgeon's office, but there was nothing there of any consequence to my project. I talked with many of the people in the hospital for leads. I called Wills Eye Hospital in Philadelphia and the local branch of the American Cancer Society but met with little success. I surmised that if I found a medium that was noteworthy, medically-speaking, it would definitely improve the relationships between the patients and healthcare personnel (Braddock et al., 1999). I explored a number of avenues to find something that vividly depicted the whole cancer patient radiation treatment process for me, but I found nothing of value. As stated previously, this project did not begin to take shape until November 11, 2008. I was in the

Rowan University library searching the web for anything that would assist with the radiation treatment process for cancer patients. I knew what I wanted and what I wanted to accomplish, but until that point there was nothing at all that I thought could help me with my project.

Learning of the Video's Development

After much searching, I came upon the site www.cancerquest.org launched by Dr. Greg Orloff who was on staff with Emory University in Atlanta, Georgia. Dr. Orloff's site was specifically dedicated to cancer research and radiation. Dr. Orloff's site showcased concise, clear 3-D animations or representations of the whole cancer cell division process, cancer treatment, chemo-therapy, interviews with patients who were given the diagnosis of cancer, and a whole host of additional useful information. I immediately looked more thoroughly at his website, got his phone number, and during the early afternoon on Veteran's Day of 2008, I telephoned him at his office. He answered. I introduced myself, telling him that I was a doctoral student at Rowan University and that my research was geared toward cancer patients, specifically having to do with radiation therapy. I took some time to tell him that my wife was a two-time cancer survivor. He shared with me a similar story about his wife and her bout with cancer. At the end of that conversation, he said, "Michael, you're in luck. My department here at Emory University in Atlanta is in the process of developing exactly what you are looking for, a DVD, a video that has to do with cancer patient radiation treatment."

I thought, "What the heck are the chances of somebody's being involved in that type of research, with somebody else looking for something like that (me), and here is somebody simultaneously in the process of developing the visual aid?" I was aware that

developing any audio-visual materials, especially of the quality to meet the standards of the American Cancer Society, was resource intensive and difficult at best (Carey et al., 2007).

I thought about how fantastic it was that I had contacted him. My leadership abilities of persistence and reliance on goal-related hard work were rewarded (Simmons & Moskins, 1998). Obviously, if he produced the video in conjunction with the American Cancer Society, there was a need and a market for this type of research. I surmised that a video such as this that was well-produced would make ample strides toward filling the lack of knowledge among cancer radiation treatment patients. As I noted in my journal on the evening of November 11, 2008, "I feel very fortunate to have figuratively stumbled upon Dr. Orloff's project site in my tireless web-searches. What are the chances of this happening at this point in my life?" I answered, "Maybe one in a million!" The chances of my discovering such a useful site with my usual poor luck were less than finding the proverbial needle in a haystack. Actually, I privately took credit for my leadership in refusing to give up the search until I was satisfied that my vision and project could be realized (Kouzes & Posner, 1996). One of the many qualities I acquired during my years in the United States Marine Corps was a belief in never giving up without giving it a 100 percent total effort (Simmons & Moskins, 1998). This "never-say-die and never-give-up" mentality had served me well in my approach to every leadership position I ever held. This project proved to be no different, and only my persistence and leadership made this study a success. I maintained a persistent search for an appropriate and useful medium for my project. Dr. Orloff was not a figment of my imagination. He was a professional, a gentleman, and he was always very cordial to me on the telephone. And he was

knowledgeable. Looking at his web-site, I saw that there was an inordinate amount of quality information available. I clearly remembered that I just felt like, “Oh, my God, I hit the cancer patient research lottery” and recorded that statement in my journal on that same day.

Unlike many other strokes of my newly acquired good luck, this whole process had one small caveat. The caveat was that he had not actually started production yet, but Dr. Orloff assured me that he was scheduled to begin the project soon. He informed me that he would start shooting the video in a month or two, and it would only take a month or two to get it done. As this was November and he was going to start it in December or early January, I thought and recorded in my journal, “Surely, he will be finished with the video in January, February, or, at the latest, in March.” Little did I know that the one-and-two-month time frame would become seven or eight months. I did not care. All I knew was that 90 million people have problems understanding and reading their healthcare information (Billek-Sawbney & Reicherter, 2005), and that which I needed and had searched for during several months was being developed. I was leading this project, my vision was gaining momentum, and I was providing a much needed service to the patients at Jefferson Hospital (Kouzes & Posner, 1996). I felt it could not get much better than this, my leadership (servant leadership) at its best. The funding was available according to Dr. Orloff. All I needed to know to move forward with my project was that the video would be developed.

Gaining Access to Thomas Jefferson University Hospital

Much of that which I noted throughout my journal dealt specifically with gaining access to Thomas Jefferson University Hospital. I realized that I was less than a novice

researcher. So, I prepared myself to go through any and all gatekeepers to gain access to the hospital (Pope, 2005). The hospital administrative organization at Jefferson was very complex and scattered within several buildings throughout center city Philadelphia. I used hard work and persistence as my primary tools and my keys for successfully leading this project (Simmons & Moskins, 1998). Truly, attempting to decode the organizational framework of a completely different institution such as Jefferson Hospital was a difficult and time-consuming undertaking. Trying to analyze and unravel the organizational structure of this massive medical facility was an extremely involved process. However, as outlined in Mintzberg's (2005) five basic organizational elements structure diagram, each of the organizational levels is evident: middle management, an operating core, the strategic apex, support staff, and a techno structure. Understanding such a large institution was difficult at my level and with my limited access to the various areas of the hospital. It was also difficult to identify which individuals or groups of individuals within the hospital had the power (Bolman & Deal, 2003). Yet, even with an organizational healthcare giant such as Thomas Jefferson University Hospital, I felt comfortable attempting to gain access. I felt confident since I had tangible evidence after discovering Dr. Orloff's development of a cancer patient radiation treatment video. I felt more confident in attempting to convince Thomas Jefferson University Hospital personnel of the validity of my project since I had a clearer picture about the study. My goal or objective since securing, at least in concept, the kind of audio-visual medium that I would use for cancer radiation patients at Thomas Jefferson University Hospital was to convince Jefferson to allow me the use of their facility as a laboratory in which to conduct my research. I called Thomas Jefferson Hospital to set up an appointment with an appropriate

person. From there, it became very interesting. My initial contact with Jefferson Hospital had just one purpose and design: To gain access and to find that one person who would sanction me to begin my research at the Bodine Center which housed the Cancer Radiation Department at Thomas Jefferson University Hospital (Pope, 2005). In my first contact with the hospital, I spoke with a lady in personnel who put me in contact with a social worker housed in the Bodine Center. As I wrote in my journal, “Sometimes it pays to take a chance. Although I had no idea if a social worker could help me, I made the appointment.” After securing the appointment, the social worker and I sat down together while I spoke with her briefly about my project. I noted in my journal after meeting with her, “I felt it was important as the leader of this project to display a sense of conviction, trust, purpose, and a commitment” to the completion of the study to anyone whom I met in the hospital (Webb, 2007). She stated that she was impressed with the scope of the project but that this was really beyond her job description. She suggested that I speak with her supervisor who is the clinical administrator for the Kimmel Cancer Center at Jefferson. The social worker gave me the supervisor’s name as Ms. Joy Soleiman. She also stated that Ms. Soleiman was definitely the person I needed to see, but she was housed in another building several blocks away on Tenth Street. I politely asked her, the social worker, if she would contact her boss, Ms. Soleiman, to find out if I could meet with her today since I was already at Jefferson. One of the qualities I discussed in my leadership platform was my propensity for having a “pedal-to-the metal” mentality to accomplish my desired results as quickly as possible (Peters & Waterman, 1984). I entered the hospital and felt at the time that I would do whatever was needed to ensure that I would see someone that day to explain the scope of my project. After thinking

about this project for nearly two years, I felt that I would persuade the hospital administrators to help me carry-out my objectives of this study by any means necessary (Deal & Peterson, 1999). With that mental attitude set in my mind and since I was already there, I did not want to go home with no assurances. I asked for an immediate appointment. The social worker was kind enough to telephone her supervisor, Ms. Soleiman. She reached Ms. Soleiman immediately and explained my situation to her. Ms. Soleiman graciously told the social worker that she would see me within the next half hour, but she could not hold a lengthy meeting. The meeting with her and the process of explaining my project could not take a very long time.

After a brief walk to the other Jefferson building, I presented my project to one of the administrative heads of the hospital, Ms. Joy Soleiman. After exchanging a few polite pleasantries and profusely thanking her for her time, I began my project presentation. It took me approximately 15 or 20 minutes to present my study. She asked me a few questions, specifically about Emory University, Dr. Orloff, and the anticipated time frame for the completion of the video. After we exchanged a little more relevant information, I answered a few more of her questions and concluded my presentation. To my surprise, she immediately seemed to take interest in my project. Ms. Soleiman shared with me a project she had just completed. It was a booklet on the radiation treatment process. It had pictures, some portraits, and hospital-related artifacts, things of that nature. Her booklet encompassed the registration process at the radiation treatment office, check-in, and some information about the staff and personnel. It was basically a how-to and welcome booklet for patients as they arrived for radiation treatment at the Thomas Jefferson Bodine Cancer Treatment Center. She remarked that my DVD would be a great

addition to her booklet, and, with that response, I quickly gathered my materials to leave. I thanked her again for her time and assured her that I would await her call. From that experience I knew immediately that initiating any type of change in a large university hospital similar to Jefferson would not be an easy proposition. I remembered thinking that I was glad that I used Heifetz's (1998) seven-step change cycle. I realized from the moment I met Ms. Soleiman and through many subsequent conversations with hospital personnel that any change project needed structure and organization to succeed. It was also apparent in my conversations with Ms. Soleiman that to build and maintain acceptance of my project, I needed to reinforce the importance of the change to any and all of the hospital personnel I met on a regular and continual basis (Heifetz, 1998). However, I discussed in my journal that this was "a fantastic start." I felt as though I had literally just walked off the street, and an hour later I stood in front of, interacting with, and presenting my study to one of the leaders of the Thomas Jefferson University Hospital administration.

Submitting the Research Protocol for Jefferson's Review

To my surprise, the next day I heard from Ms. Joy Soleiman. She told me that she had to find someone within the hospital to mentor me since it was hospital policy. She first needed me to send her a protocol so she could present it to the hospital board for their review. The hospital board of review was Jefferson's version of an Internal Review Board (IRB). Their purpose was to prescreen research projects and studies prior to their offering official IRB approval. Their board of review was a formal screening process that examined potential studies. As soon as I heard of the screening pre-review process, I felt that having my research study approved would be a difficult process. I correctly reasoned

that what might be satisfactory at Rowan University might not pass as easily at a medical institution such as Thomas Jefferson University Hospital.

I quickly submitted a protocol or executive summary of my project as requested and sent it to Thomas Jefferson via e-mail the next day. After sending the e-mail, I waited for about a week for a response. After almost two weeks, I called to follow up. I was told, when I finally reached Ms. Joy Soleiman, that she had never received my e-mail. Clear communication was essential to the successful completion of this project (Deluga, 1990). In retrospect, I felt it was my fault for not following up or communicating with Ms. Soleiman sooner rather than waiting nearly two weeks only to be told she had never received my documents. Thoroughly disgusted and thinking or feeling that she thought I was not being truthful, I e-mailed her my proposal protocol again after verifying her e-mail address with her personally. I did, in fact, resend it to her. She still did not receive it. Totally upset and worried, I hand delivered my protocol for the proposal to her in Philadelphia. I physically went to her office and handed her my 10-page protocol. Ms. Soleiman assured me at this time that she would find someone to become my sponsor and move my protocol and my project through the hospital approval process. Ms. Soleiman reiterated, after I submitted the executive summary, that my project had to go before a formal review board prior to even gaining IRB approval from the hospital. I worried that my project might not be approved. Waiting for the outcome of the review of my project was very stressful. Ironically, several days later Ms. Suleiman told me, as she apologized, that she found a glitch in her computer system. Much of her e-mail was being diverted to spam mail. My first two submissions were received, but they were sent to her spam mail.

While I waited to hear from Thomas Jefferson University Hospital about the protocol that I had submitted, I followed up with Dr. Orloff in Atlanta to check on his progress in the development of the DVD for the American Cancer Society. On different dates throughout my journal during that period, I wrote statements concerning my apprehension. One day I wrote, "I feel very uncertain about the Jefferson Review Board process. What if they like one part and do not like another? What can I do to improve my chances with the board?" I did not think there was much of a chance that my protocol would be approved. I understood the institutional bureaucracy, policies, and procedures of a large organization and braced myself for the review board results regardless of their findings (Bolman & Deal, 2003). One thing I knew about myself throughout the entire time as I waited for their results was that I would not give up trying (Simmons & Moskins, 1998). I contacted Dr. Orloff about the status of his program. He informed me that the program and production were progressing very well, but he was still several weeks from having the video completed. Dr. Orloff, at my request, was kind enough to send me a few posters and two DVDs that he had previously produced about cancer. Both videos were short in length, but they were quality productions, thought provoking, and very informative. In the midst of viewing an excellent sample of what my cancer radiation treatment video might resemble, I finally received a response from the CCRRC Review Board from Thomas Jefferson University Hospital.

Review Results

After obtaining the results of the hospital's review, I immediately began to think about the numerous highs and lows that I had experienced throughout my career in any and every leadership position that I had ever held. I particularly remembered the high

point of being commissioned as a lieutenant and leader of Marines, only to be assigned to a platoon of Marines who had a history of poor performance and horrible fitness evaluations. That was definitely a low point in my young military career. Then there was the high point of landing a great opportunity with a Fortune 500 company, Johnson & Johnson, as a production supervisor. This high was immediately followed by a low of being assigned to a department that under-produced and had a very strong union presence. This project proved to be no different because of the many highs and lows that most individuals experience during their association with organizations (Deal & Peterson, 1999). Two items clearly resonated with me as I read the results from Jefferson's CCRRC Review Board. First, Jefferson definitely had a distinct culture and distinct procedures of how their business would be conducted (Deal & Kennedy, 1982). Second, this project required major revisions, but, more importantly, I needed to have the mental toughness and steadfast, focused leadership to complete this endeavor (Simmons & Moskins, 1998). The feedback I received from the hospital on my protocol caused me to question the very feasibility of the study. I received written feedback from the committee that basically indicated that many areas needed to be changed in my protocol from the pre-testing, the survey, some confidentiality issues, and other problems. The Jefferson review board found a number of items that needed to be addressed. The review outlined a number of concerns that had to be corrected prior to my gaining approval to move forward with the research. The review board found only two major problems with the protocol.

First, Jefferson cited flaws with the study design of my project, specifically as it addressed the interviewing and observation procedures. The committee reviewing my

protocol also found that the document was difficult to follow. My projected sample size of 50 cancer patients, according to the review report, was not large enough to represent the population of cancer radiation patients at Jefferson Hospital. The study design, in their collective opinion, could not accurately measure how improvements could be implemented based on my perception of the patients' knowledge. There were not enough details, in their opinion, for the SPSS statistical package to accurately analyze the statistical data that I collected. My study design made no mention of a multi-institutional plan that was mandatory for non-employees of Thomas Jefferson University Hospital. As a prerequisite for becoming involved in a study at Jefferson, I had to apply for volunteer status. When someone outside the hospital became involved inside Jefferson Hospital, the person was required to be formally inducted as a member of the staff as a volunteer and the person had to go through training, including all of the investigations and vetting that were made for any hospital employee. I needed, in essence, to become a new employee, and I had to be indoctrinated into their culture as I learned how to operate as a part of a new organization (Schein, 2004).

Regarding patient concerns, the committee was apprehensive about the comfort level of their patients, particularly sick patients who were undergoing scrutiny by an outsider (Bilodeau & Degner, 1996; Graydon et al., 1997; Harrison-Woermke & Graydon, 1993). The initial proposal was to show the video to the patients in the waiting area of the Bodine Center prior to or after their treatment. The proposal was that the video would run intermittently (looped) throughout the day on a television that I personally offered to buy and have installed in the waiting area. The committee also had concerns about methods to protect patient confidentiality since I had proposed that the

video would be viewed in the presence of other patients. Finally, the committee was concerned about the study's effect on the flow, or movement, of patients who were undergoing treatment. The members of the committee were concerned that the flow of patients would be changed or interrupted by my observations, interviews, and surveying of the patients. I felt that the committee basically told me to completely revise the protocol before resubmitting it for review.

I spoke with the one person in the hospital at the time who was pushing for this project to succeed, and that was Ms. Joy Soleiman. She candidly, but ever-so-politely, said that the protocol needed some work and that Dr. Myers, a hospital staff member and my assigned mentor which she had arranged for me, would help shepherd me through the process. I made an appointment to meet with my mentor. I interacted well with his secretary, and she quickly made an appointment for me to meet with him on February 16, 2009. In the interim, I sought the advice of my dissertation committee chairperson Dr. Walpole. I met with her to assess my disappointing review by Thomas Jefferson University Hospital. I wanted her opinion on whether this project could be revived, or if I should cut my losses and move on. After my conversation with her, Dr. Walpole told me that this was not a project that needed reviving or salvaging. She emphasized that Jefferson as a medical institution and Rowan as an educational institution have different assumptions about research. She stated that there were some things that needed to be revised, that the study was a worthwhile project, and that I should continue to work on it. And so I did.

On the afternoon of February 16, 2009, I met with Dr. Myers, my mentor assigned by Ms. Soleiman, from Thomas Jefferson University Hospital. After brief introductions

in the conference room of the building and some pleasantries, Dr. Myers gave me some background about himself. He had two doctorates in research design, and he was currently doing research on prostate cancer among African American men. After he filled me in on his background and explained the subject of his research, I felt blessed to have him as my mentor. The CCRRC review left me feeling numb. I was unsure of the message the governing body had sent me with the findings of the protocol I had submitted (Deal & Peterson, 1999). However, I felt that I had found in Dr. Myers, who was actually working in the field of cancer research, someone who definitely provided relevant expertise to the project. I immediately explained my project to him and attempted to outline for him what I intended to do. He was aware of the CCRRC review that I had received from the hospital. He looked over my draft, my protocols, my survey, and then he smiled broadly. After he finished telling me about himself and his background, I apologized for what I felt was wasting his time. I thought that he might have been stuck with me as a favor to Ms. Soleiman, but I was very, very grateful. In any case, after briefly speaking with him, it was immediately apparent that he would be an invaluable resource throughout this process.

After he reviewed my protocol, he commented that Joyce Soleiman might have served us better if she had delayed submitting the protocol until after we revised its weakest areas. Dr. Myers did not tear my project apart, instead he skillfully offered another model I could better utilize to capture the gained knowledge of radiation cancer patients after they had watched the video. He immediately went to the dry erase board in the conference room and designed a model to capture patients' beginning knowledge as they entered the waiting room prior to any treatment. After they received radiation

treatment and came back the following day (treatment was usually five days per week for several weeks), then they watched the video. I would later capture or assess what they had learned (end-knowledge) after they had watched the video. According to Dr. Myers, this was a simple method that I could use to assess what the patients had learned. He spoke about the knowledge scale and establishing a reliable scale as a means or an approach of collecting baseline information. Finally, we spoke briefly about the time needed for patients to watch the video and how often the video would run in the radiation treatment waiting area. Unfortunately, I was unable to give him any of that information since, as I told him, the video, and he knew this, had not been completed yet. I was really trying to speak intelligently about a video that had yet to be produced. It became immediately apparent during my meeting with Dr. Myers that I would quickly gain a clearer understanding of the hospital's organizational structure. In less than an hour, Dr. Myers had touched on the structural, human resource, and political frameworks of the hospital (Bolman & Deal, 2003).

For one of the few times in my life, I felt really totally inadequate while conversing with Dr. Myers. I felt completely out of my element in discussing research design, regardless of how simple he had made it seem. Moreover, Dr. Myers definitely said this project would have me distributing a survey to the patients, but not any time soon. I was under the distinct impression, having been schooled through Rowan, that this was a simple process. I thought the process would be that I designed a thorough survey, took it to Jefferson for immediate approval, installed the television, gave the cancer radiation patients a pre-test, and then gave them a post-test, and analyzed and wrote up my results. It did not work that way in a medical institution such as Jefferson (Deal &

Kennedy, 1982). I quickly realized that conducting research in a medical facility was a long, drawn out, arduous process that would be regulated, monitored, and verified. The reliability and validity of a research project must hold up to scrutiny throughout the medical community. After realizing that something as simple as a survey would not be allowed to be distributed for some time, it was becoming crystal clear that there were a whole host of hurdles that I would be required to navigate if I wanted this project to succeed. Several weeks after receiving the review results from Jefferson, I decided to proceed in a new direction with the project. After speaking with Dr. Myers and reviewing the model he suggested for use in the project, I immediately began to think about how to move the study forward. I realized that I needed to approach the project from a different angle.

My journal chronicled my thoughts as I seriously wondered, “Should I cut my losses and move on?” or scrap this project in its entirety and start completely anew on a different project. I was certain that during this part of the study that it was only my stubborn pride and sense of *esprit-de-corps* that kept me focused on completing this process (Simmons & Moskins, 1998). As I had never been one to surrender, I solicited the opinion of one of my instructors at Rowan University, devised a new leadership strategy, and moved forward (Heifetz, 1998; Simmons & Moskins, 1998). Although I entered in my journal, “I am crushed by the results from the CCRRC Review,” I quickly regrouped and began to implement a new plan of action as I revised my study (Heifetz, 1998).

Revising the Study

The direction I pursued to address the project dealt with the revision of the protocol to a standard that allowed the hospital enough latitude to accept my study. The process involved extensive planning with Dr. Myers, who was one of the chief researchers, grant writers, and professors at Thomas Jefferson University Hospital. From an organizational, political, structural, and human resource perspective, I could not have had a better representative of the institution with whom to work (Bolman & Deal, 2003). With Dr. Myers I tentatively outlined some of the steps required to complete the research project. I wanted and sought permission from Jefferson Hospital to just sit in as an observer in the radiation treatment waiting area of the hospital (Pope, 2005). I drafted a document to send to Dr. Myers, expressing my interest in only observing in the radiation therapy patients' waiting area at the Bodine Center.

However, prior to submitting this latest revision to my protocol, I presented it to Dr. Doolittle. As the instructor assigned as my Leadership Application Field Seminar during the spring 2009 semester, Dr. Doolittle's purpose was to provide support and guidance to each of her assigned students throughout the course semester. I asked her to review the comments and the recommendations made by the CCRRC board of Thomas Jefferson University. I suggested that she critique my document and edit it where she felt it needed revisions. She graciously helped me to design a new strategy dedicated to gaining tentative approval by the hospital. One of the premises of the new plan of action for the project was to specifically address the needs and preferences of the patients. I streamlined and condensed the 10-page protocol to a 2-page version of the initial protocol (Almquist & Bookbinder, 1990). The replacement protocol gave specific descriptions

rather than general and vague descriptions of my research study. Dr. Doolittle edited my protocol as she felt necessary and e-mailed it to me immediately. I took each of her suggestions and incorporated them into the document that I sent to Dr. Myers. Since I had revised the protocol, I resubmitted it to Dr. Myers who cautiously allowed me to move forward with the project.

He asked me to call his secretary the next day so we could chat. I called his secretary and scheduled a phone appointment. Motivated to discuss the project, I was ready to move forward again. I had a renewed sense of vigor that I would make this work. Unfortunately, on the day we were scheduled to discuss my latest plan of action for the project, Dr. Myers cancelled. We rescheduled our appointment for two days later. During our phone conversation, Dr. Myers gave me the name of the co-mentor for my project, Dr. Adam Dicker. I immediately set up an appointment to meet with Dr. Dicker, the interim director of the Radiation Oncology Department at the Bodine Center. I was very familiar with the Bodine Center since I had spent many hours sitting in that department's waiting area (the same area in which I wanted to conduct my research) with my wife who had received radiation treatments earlier during the year. Almost five years previously when she was diagnosed with non-Hodgkin's lymphoma, I was also with her as she was treated with radiation. Of course, I was very familiar with the area where Dr. Dicker worked. I was happy to receive his name and to be given an opportunity to meet with him to seek his approval for the project. Based on the recommendation of Dr. Myers, I had Dr. Adam Dicker, the interim director of the Radiation Oncology Department in the Bodine Cancer Treatment Center, as a co-mentor. I felt that Dr. Dicker would be one of the keys to the success of this project.

Dr. Dicker, as the head of the Radiation Oncology Department, was someone within this organization who had the power and authority to assist me with moving this project forward (Murphy & Drodge, 2004). I celebrated my good fortune and congratulated myself for my good luck. I had hopes that maybe, just maybe, the project was taking a positive turn, becoming concrete, or, at the very least, something was happening, and I could really start to move forward with the project. When I called Dr. Dicker the next day, he e-mailed me immediately since I had sent him the latest protocol. In my journal, I wrote, “Dr. Dicker said he loved the idea, and he is for it 100%.” He asked me to contact his administrative secretary to set up an appointment so that the three of us, Dr. Dicker, Dr. Myers, and I, could sit down and meet face-to-face. When we met, I was very impressed with Dr. Dicker. He was a no-nonsense person but with a great sense of humor. I realized immediately that both of these gentlemen were committed to helping me finish the project. I had exciting and helpful conversations with both of my mentors. Dr. Myers suggested that we rename the project. His suggestion was to title it so that anyone who heard it or read it had a complete understanding of the nature of the project by the title, thus my title became *Educating Newly Diagnosed Cancer Patients Who Are Undergoing Cancer Radiation Therapy*. Finally, my mentors suggested that I research additional tools in addition to the DVD to use in the event that Dr. Orloff was unable to produce the video in a timely manner. They felt that I needed the additional tools to undergird the hard work I had already put into this project. Thus, I immediately researched alternate media devices or alternate assessment tools that I would use in the event that Dr. Orloff was unable to complete the DVD/video in a timely manner.

Dr. Orloff Completes the Video

From November 11, 2008, until August 2009, I was in a never-ending series of project completion highs and lows with approvals, rejections, accomplishments, and setbacks. Every month when I called Dr. Orloff for a video completion update, he told me that they were ever-so-close to completing the project. Regardless of his optimism each and every month, the project was not completed until nearly 10 months after I had made my initial inquiry in early November, 2008. As a result of the delays I was constantly forced to adjust and readjust my time schedule (Heifetz, 1998). Curiously, each month I felt positive that Dr. Orloff would complete the video during that particular month. When I spoke with him, he always had good-natured remarks, he was positive, he was helpful, and he definitely had a giving attitude by allowing me to use his video upon its completion. My dilemma was twofold. I refused to waste the time and resources of anyone at Thomas Jefferson University Hospital. I definitely did not want to waste Dr. Myers's time. I knew that he was extremely busy as a professor at Thomas Jefferson University Hospital. I also did not want to waste Dr. Dicker's time, who was the interim director of the Radiation Oncology Department at the Bodine Center. I could not have imagined all of his responsibilities.

I had nothing to show for my efforts after months of research, but I continued to search for additional tools. I was no closer to being able to use the video in spite of my efforts. I could not continue to reference the very cornerstone of my project without some tangible evidence of the project. Rather than continue to meet with Dr. Dicker and Dr. Myers empty-handed, with very few of the additional media resources to show for my time and efforts, I suspended any data collection, questionnaires, surveys, and field

observations, along with a good portion of my hopes. Since I had no permission to work on these areas, I slowed to a halt until I could gather some positive news to share regarding the completion of the video. Consequently, in May through July of 2009, the extent of my communication with both of my mentors and with Ms. Joy Soleiman was limited to e-mails that provided them with updates on my monthly inquiries to Dr. Orloff regarding the production status of the video.

In early August 2009, I called Dr. Orloff and received assurance that the video would be completed within a week. As always, but with a slightly skeptical optimism, I wanted to believe Dr. Orloff. One week later I called to check on the status of the video, and to my amazement, Dr. Orloff informed me that it was 90 percent complete. He e-mailed me the link so that I could personally take a look at the video. To my astonishment and elation, after waiting for nearly a year, the video was worth waiting for. I again wrote in my journal, “Eureka!” I felt that I had finally found it. Having had the opportunity to view the video firsthand, I had a great sense of excitement that the opportunities to enhance patient education at Thomas Jefferson University Hospital were endless. The video was very brief. It required no more than 10 or 15 minutes to view in its entirety. The video consisted of five sections: introduction, radiation types, external radiations, internal radiations, and side effects. Additionally, the video had three sections labeled interviews, resources, and a transcript of the entire narrated video that was in PDF format.

I sent a copy of the link to Dr. Myers, Dr. Dicker, Dr. Gourley, and, of course, to my dissertation committee chair Dr. Walpole. I received responses, either verbally or in written form, from Dr. Myers, Dr. Gourley, and Dr. Walpole that the video was very well

produced. The only major point of concern was expressed by Dr. Myers when he commented that the video used an excessive amount of video time in explaining the many side effects of radiation therapy. Dr. Orloff was in the process of fine-tuning the video by putting the final touches on it at that time. He was gracious enough to send me a copy of the almost-finished video.

I thought that if I had not dedicated nearly two years of my life toward this project, obtained a complete understanding of my evolution and transformation toward servant leadership, developed a committed sense that this project would most definitely be beneficial to cancer patients who viewed the video, and received invaluable on-the-job training into the formal and informal organizational structure of a medical institution, it would have been easy for me to develop a defeatist attitude (Bolman & Deal, 2003; Spears, 2004). The possibility of success in assisting cancer patients who were receiving radiation treatment was very close. I was thankful that I did not give up on the project. I positively looked forward to helping cancer patients who were receiving radiation treatments to better understand those treatments.

Chapter 6

Cycle 2

Development, Implementation, and Analysis of a Survey Instrument

Prior to my development of a clinician provider questionnaire and a survey for cancer patients, Dr. Myers, my mentor from Thomas Jefferson University Hospital, suggested that I first needed to formulate a plan for the design and the development of the instruments. The reason for the planning and development of the clinician questionnaire was basically to have Jefferson hospital staff provide input into the design of the instrument. Their input, Dr. Myers suggested, added an element of validity and technical expertise to the project.

Outlining the Process

The main purpose of Cycle 2 was to outline the process of developing a pre-and post-intervention survey that I used to analyze patient knowledge about the radiation treatment process (Patten, 2001) prior to and after watching the DVD developed by Dr. Orloff.

Dr. Gregory Orloff from Emory University, in conjunction with the American Cancer Society, completed a 3-D educational video on cancer patient radiation treatment. The video was entitled “Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education.” The video was organized into five major sections: (1) an overall introduction to radiation, (2) the different types of radiation therapy, (3) external radiation, (4) internal radiation, and (5) the possible side effects of radiation. In designing the survey, I worked with clinicians from Thomas Jefferson University Hospital who

provided input on the sections and the elements within each of the five sections to be included in the patient surveys.

Action Plan

Step # 1 (October, 2009). My goal was to first select no more than 30 major educational elements from the video to include in the initial design of the patient pre and post survey, which I developed with input/feedback from Jefferson Hospital clinicians (Patten, 2001). Examples of these elements include: (1.) How important is it for cancer patients to understand that more than half the people diagnosed with cancer get some type of radiation therapy? (2.) How important is it for cancer patients to understand that radiation therapy is good at shrinking and destroying tumors without causing much damage to normal tissues?

From an educational vantage point, it was important that I incorporate input from hospital stakeholders into the design of the patient pre and post surveys. To obtain valid information for the patient surveys, I provided the hospital staff with an opportunity to view the video and a questionnaire to rank the educational elements from most important to least important (Patten, 2001).

Step # 2 (December 2009). I used input from Thomas Jefferson University Hospital researchers, specifically the eight clinicians who assisted me by viewing the video and completing the clinical questionnaires. Then I extracted, compiled, listed, and prioritized the educational elements from the video which the clinicians deemed to be the most important to use in the cancer patient surveys.

Outcome

Based on the clinicians' input and feedback, I ranked the information in major educational descending order from most important to least important (Patten, 2001). I then used the information I obtained to construct a patient pre-and post-educational radiation therapy survey instrument (an end-point knowledge assessment). After it was designed, I again asked the clinicians and Dr. Myers to review it and to approve it before I began its distribution to patients.

Reflection

First, to design a questionnaire of real substance was a difficult undertaking (Patten, 2001). Since I was keenly aware of the importance and significance of action research (Bogdan & Biklen, 2007), I worked to design a questionnaire of practical application for a group of experienced hospital clinicians.

Secondly, I felt limited by only a few telephone conversations with Dr. Myers on how he envisioned the development of the questionnaire. I realized that his time was valuable. I did not want, in any way, to interfere with his numerous additional duties at the hospital, as a faculty member, and his other teaching responsibilities, but, particularly at first, I felt that I needed a bit more input from the hospital.

As soon as I began the process, I started to conjure up some of the same feelings that I had when I presented my protocol to the CCRRC several months earlier. I felt that getting the questionnaire to the clinician's trial stage required my best efforts to smoothly gain acceptance for a suitable instrument from faculty members of Thomas Jefferson University Hospital who made their living by conducting and teaching research. Before I

began to work on the questionnaire, I directed my attention to planning the entire survey instrument process (Patten, 2001).

Developing an acceptable plan that Dr. Myers informally presented and discussed with some of the governing bodies within the hospital was very stressful. I gained solace in the thought that surely Dr. Myers would not allow me to submit documents to his colleagues that were not suitable. The title of the survey design and implementation process plan underwent several revisions until Dr. Myers and I settled on the title: “Plan for the Development of Survey Instruments to Be Administered in a Study Designed to Assess the Impact of an Educational Video on Knowledge about Radiation Therapy among Newly-Diagnosed Cancer Patients.” The plan for determining the items or educational facts included in the questionnaire was simple. Dr. Myers and I discussed capturing the educational facts from the video for use in creating a patient questionnaire.

All things considered, I felt very fortunate to have both Dr. Myers and Dr. Dicker working with me. Even with a less-than-stellar review of my initial protocol by the Thomas Jefferson University Hospital CCRRC Review Board several months earlier, Dr. Myers and Dr. Dicker had the power within the organization to allow me to move forward with the study (Bolman & Deal, 2003). Working with their guidance, supervision, and suggestions, I first distributed a questionnaire to the hospital staff about the video to gain their feedback. I used that feedback to design the cancer patient radiation pre and post surveys.

Heeding my mentors’ advice, I watched the video numerous times and dissected the video as I extracted important educational facts. My thoughts centered on obtaining a copy of the transcript of the video which allowed me to easily separate the video into the

various subject areas, which were the introduction, types of radiation, external radiation therapy, internal radiation therapy, and radiation side effects. Separating the sections of the video enabled me to more easily extract the major educational facts. After I obtained a copy of the video transcript, I systematically dissected each of the five sections. Dissecting the sections of the video allowed me to easily compartmentalize the numerous educational facts from the video.

My first attempt at constructing a clinician's provider questionnaire was not a great academic success. The initial draft of the questionnaire consisted of 28 educational facts. Each fact from the video had four Likert choices: very important, moderately important, somewhat important, or not important (Patten, 2001). The questionnaire also had some very brief instructions of how to rank the educational facts and how to complete the questionnaire. That was the extent of what I hoped to be the one-and-only version of the document. I submitted the questionnaire to Dr. Myers for his comments, and I quickly received his response. Dr. Myers noted that it was lacking in a number of areas, all of which needed to be corrected immediately. He kindly reminded me that the questionnaire was to be utilized by clinicians and that one of the purposes of the questionnaire was ultimately to become an instrument to assist in preparing patients to have an informed discussion with radiation oncology providers regarding their care. Secondly, the ranking system was unable to provide a clear-cut ranking of each of the educational facts in terms of overall importance using the Likert scale.

Moreover, even after spending nearly two years in a doctoral program and making strides in my scholarly writing, I did not feel that I was using the measurement instrument and evaluation phrases, jargon, and terminology that met Dr. Myers's standards (Patten,

2001). As a result, I revised, edited, and re-designed several provider questionnaires before I created a model that was acceptable to Dr. Myers. Truly, my initial questionnaire and the final approach product that Dr. Myers approved were very different.

The ultimate acceptable model or design had a number of elements that most of my previous designs were lacking. First, the title simply, but clearly, stated what the questionnaire was about: “Cancer Radiation Therapy Provider Questionnaire.” The approved design began with basic background information about me as the researcher, for example, that I was a doctoral student at Rowan University and the questionnaire was part of my dissertation study. Additionally, the introduction to the questionnaire clearly explained that the survey intended to ask the clinicians and participants for their reactions to a patient education video (Patten, 2001). It also clearly explained that the questions were extracted from the video and were summarized on the questionnaire according to the five sections within the video. The directions also succinctly outlined that I needed their opinions on the level of importance of each individual fact as a means of assisting and preparing cancer patients with their care. Finally, it outlined the steps for completing the survey and thanked the participants for helping with the project.

After numerous revisions and editing of items, in early November 2009, I finally completed a clinician provider survey that met with the approval of my mentor, Dr. Myers. Immediately, Dr. Myers e-mailed Dr. Dicker a copy of my finished questionnaire suggesting that I first have my committee review the document and then review the document with Dr. Dicker to plan the next steps. In Dr. Myers’s e-mail to Dr. Dicker, he included a brief note to give him a sense of my progress, explaining that the next step in this data collection process would be to meet with Dr. Dicker. Dr. Dicker

responded immediately and answered, “All sounds fine. My suggestion is that he first shadows us for a couple of days” (Bolman & Deal, 2003). I believed Dr. Dicker was suggesting that I familiarize myself with the up-to-date, day-to-day operations of the Bodine Center. Dr. Myers also suggested that Dr. Dicker provide me with an introduction to the clinicians who would complete the survey.

Shadowing and Introduction of the Hospital Clinicians

All signs pointed favorably toward forward movement and for finally gaining authorized access to the Bodine Center. I used a few days to prepare myself for the introduction to Dr. Dicker’s clinicians. I also prepared some items that I would need for a presentation (Pope, 2005). I did not want any of the physicians or clinicians who were taking the survey to be inconvenienced in any way. I understood from prior observations and from watching them during the last several years that they were extremely busy. With that in mind, I prepared materials that made accessing the video excessively easy. I had the technical advisor from my company, Encore Educational Institute, LLC, access Dr. Orloff’s website and download it with the radiation video and burn it onto eight DVDs/disks. From the DVDs, I had eight thumb drives made with a copy of the video on each of them. On each of the thumb drives and on the DVDs, I placed a word-for-word transcript of the entire educational video, as well as a complete copy of the clinicians’ provider questionnaire. My goal was to make the participant clinicians’ access to the video, the transcript, and the questionnaire as convenient for them as possible. Equipped with a brief outline of the information I would present to them when I met them, eight sets of DVDs, and eight thumb drives, I had a good sense of preparedness. On November 15, 2009, I contacted Dr. Dicker’s secretary as he had instructed me. I attempted to make

an appointment. She accepted my information and returned my call two days later. She said that Dr. Dicker was very interested in meeting with me, but he also wanted to schedule me at a convenient time that I could meet with him, his clinicians, and his head nurse who currently instructed the educational classes for radiation oncology patients. I spoke with Dr. Dicker's secretary again on Monday, November 30, 2009, for a time that was best for all of us to meet.

The conversation with Dr. Dicker's secretary was very brief. I did not get the sense, at the conclusion of our conversation, that I was getting any closer to actually gaining access to the doctors or to the head nurse as Dr. Dicker had suggested, not to mention shadowing (Bolman & Deal, 2003). I continued to wait for a call from Dr. Dicker's office, but it was a call that never came. One week became two, and two weeks became three. At the risk of becoming a nuisance, I decided to e-mail Dr. Dicker directly, along with my instructor and my committee chair, regarding my dilemma. Basically, I stated my situation to Dr. Dicker in my correspondence/e-mail at approximately 11:00 p.m. on December 8, 2009. I asked him to please forgive me for e-mailing him so late in the evening, but I was just trying to touch base with him to move the process along. I asked if he would be kind enough to offer suggestions. To my complete surprise, within minutes Dr. Dicker immediately e-mailed me and very pleasantly said that it was no bother and that if I contacted his head nurse, Susan Munro, the following day, she would be happy to set up a process to continue the process. I thanked him in a subsequent e-mail. The next morning I called Ms. Munro. She quickly set up an appointment for me to come in and meet with her on the morning of Tuesday, December 15, 2009. Ms. Susan Munro met me and politely greeted me in the lobby of the

Bodine Center. We then walked to the training room where I had met her five years earlier. At that time, I sat through one of her cancer radiation education classes as my wife was undergoing radiation therapy for Non-Hodgkin's Lymphoma. Five years later, Susan Munro was just as I remembered her, full of energy, extremely knowledgeable about the field of radiation/oncology, and now motivated to help me promote my vision (Kouzes & Posner, 1996).

Prior to handing her my questionnaire, thumb drives, and DVDs, I quelled my anxiety and took several minutes to introduce myself, discuss my connection with Jefferson as my wife was a cancer patient there on two separate occasions, and the purpose of my research project. After exchanging a few pleasantries and learning a bit more about Susan Munro and her role at Thomas Jefferson Hospital, we quickly got to the task at hand. I apologized wholeheartedly for possibly imposing on her valuable time. She was more than gracious and sincerely convinced me that she was genuinely interested in the project. After I used the time to explain the project to her in its entirety, she thought it was an excellent idea. As the educational teacher/lecturer for all of the newly diagnosed cancer patients undergoing radiation treatment, she thought this project would be a terrific resource for the patients.

After only watching the video for a few minutes, it was obvious by the expression on her face that she loved what she saw. Her first words were, "How can I get a copy of this video, and can I use it immediately?"

"Unfortunately," I told her, "this video is still the property of the American Cancer Society, and I only have permission to use it as part of this clinical trial."

She remarked at how interactive and well-made the video was (American Cancer Society, n.d.). This initial introduction to Ms. Susan Munro, the discussion regarding my project, and the overall meeting went better than I ever could have imagined. Ms. Munro could not have been more cooperative, and she volunteered to take my questionnaires, DVDs, and thumb drives to distribute to some of her radiation/oncology staff members.

As I developed the questionnaire with the assistance of Dr. Myers, he specifically had me note that a large sampling of questionnaires was not necessary for the clinicians. Dr. Myers suggested that surveying five or six members of the radiation/oncology staff would be more than sufficient. With those parameters for surveying the staff, I gave Susan Munro the clinician questionnaires and the additional materials. We briefly discussed how to complete them, and we concluded our meeting. I again reiterated that the members of the staff she randomly selected to participate in the study could view the clinicians' video on the DVD, they could use the thumb drive, or they could read the reprinted transcript of the video, all of which I provided ample samples of for the participants (Harrison-Woermke & Graydon, 1993).

We decided to meet again on the morning of January 11, 2010, so I could retrieve the completed documents. I eagerly returned on the morning of January 11. Susan Munro had eight completed clinicians' questionnaires for me. Each of the questionnaires also had a Rowan University consent form attached. The eight volunteer participants consisted of four registered nurses, one radiation therapist, two general nurse practitioners, and a medical student (all of whom worked in the radiation/oncology unit at the Bodine Center of Thomas Jefferson University Hospital). I thanked her graciously for her assistance. I told her that I would take the questionnaires and analyze them to get a sense of which

questions the participants in her unit thought were most important for cancer radiology patients (Patten, 2001). I told her that I would contact her as soon as possible with the results and that I would solicit her assistance for feedback or recommendations, which she might have for the next step in the process.

Results

Eight radiation oncology clinicians volunteered to participate in the completion of this questionnaire. Each participant read the transcript of the video or watched the DVD. Next, using the Likert scale, the participants chronologically ranked 26 questions in order of their importance for cancer radiation patients from five specific areas of radiation therapy (i.e., introduction to radiation therapy, types of radiation, external radiation, internal radiation, and radiation side effects). Based on the selection criteria, I chose the two or three questions from each area that the clinician participants felt were most important based on their observations of the video. To prevent the newly diagnosed cancer patients who elected to later participate in the study from becoming overwhelmed, I had them respond to no more than 10 yes or no, true or false, or not certain questions. The educational facts that the clinician participants felt were the most important follow.

Clinician Participants' Responses

I. An Introduction to Radiation Therapy. The most important education fact in this section of radiation therapy questions was the statement “Doctors use radiation therapy to treat cancer because it is good at shrinking and destroying tumors without causing much damage to normal tissues.” This statement was chosen as the number one most important statement by 62% of the 8 participants, or 5 clinicians. The second most important education fact in this section of radiation therapy questions was the statement

“Every day and everywhere we are surrounded by radiation.” This statement was chosen as the second most important statement by 25% of the 8 participants, or 2 clinicians. The third most important education fact in this section of radiation therapy questions was the statement “The high energy waves pass through the body to reach the cancer.” This statement was chosen as the third most important education fact by 37%, or 3 of the 8 clinicians who participated.

II. Types of Radiation. The most important education fact in this section of radiation therapy questions was the statement “The decision about which type of radiation to use is based on: the type of cancer, the location of the cancer, whether or not the cancer has spread, the current health of the patient, other treatments the patient is on or will be on.” Eighty-seven percent (87%) of the 8 participants, or 7 clinicians, chose this statement as the most important in this section. The second most important fact in this section of the radiation therapy questions was the statement “External radiation is when we use a very fancy x-ray machine and aim an x-ray into the body from away from the body.” Fifty percent (50%) of the 8 participants, or 4 clinicians, chose this statement as the second most important statement in this section.

III. External Radiation Therapy. The most important education fact in this section of radiation therapy questions was the statement “The machines focus the radiation and create a beam that can be aimed at the cancer.” Thirty-five percent (35%) of the 8 participants, or 3 clinicians, chose this statement as the most important in this section. The second most important education fact in this section of radiation therapy questions was the statement “External radiation therapy often requires a series of treatments.” Twenty-six percent (26%) of the 8 participants, or 2 clinicians, chose this

statement as the second most important in this section. The third most important education fact in this section of radiation therapy questions was the statement “The radiation coming from the machine cannot be seen or felt.” This statement was chosen as the third most important education fact in this section by 50%, or 4 of the 8 clinicians who participated.

IV. Internal Radiation Therapy. The most important education fact in this section of radiation therapy questions, as determined by the clinician participants, was the statement “Internal radiation therapy uses radiation that comes from tiny radioactive sources placed inside the body.” Sixty-two percent (62%) of the 8 participants, or 5 clinicians, chose this statement as the most important in this section.

V. Radiation Therapy Side Effects. The most important education fact in this section of radiation therapy questions was the statement “Other short term side effects that may occur, depending on area being treated, includes: diarrhea, hair loss (at treatment area), mouth dryness or mouth sores, nausea and vomiting, loss of sexual desire, erectile dysfunction (ED), swelling of areas being treated, bladder problems (such as bladder irritation that may cause a person to urinate frequently).” Sixty-two percent (62%) of the 8 participants, or 5 clinicians, chose this statement as the most important in this section. Based on the data and analysis of the educational fact responses compiled from the clinician’s participants, I constructed cancer patient radiation pre and post surveys.

I thought the surveys based on the clinicians’ responses that I designed and distributed to the radiation cancer patients were excellent data collection instruments. However, in retrospect, the initial surveys were not nearly as professional as the final

product, which I distributed to the patients nearly 18 months later. After critiquing my initial pre-and post-surveys, I clearly would have improved the final product with additional work (Patten, 2001). I found that the initial design of both surveys was far too simplistic and quite elementary for a major organization to distribute to its patients. My initial design lacked the expertise that an important instrument circulating throughout Thomas Jefferson Hospital, especially to cancer patients, should have had. Jefferson had a very high standard of how this project would be completed. After reviewing the surveys, I definitely understood that the instruments needed major revisions (Patten, 2001). At the time, without realizing that the surveys I had created needed some drastic editing and re-designing, I distributed and collected 30 pre-and post-surveys from the patients who appeared in the waiting area before their scheduled radiation treatments. I mistakenly thought that as the approved researcher, I had also met with the approval of the Jefferson administrative staff to distribute the surveys in the Bodine Center in late March and early April 2010.

Chapter 7

Cycle 3

Narrative Inquiry: Lessons Learned

One of the most important facets of this project, which I learned from the very beginning of my work at Thomas Jefferson University Hospital, was the crucial value of communicating early and often with the major stakeholders at the hospital. During one of the e-mail exchanges with Dr. Myers, in which I chronicled my progress with the surveys for the patients at the Bodine Cancer Center, he asked me if I had gone through the Jefferson Internal Review Board (IRB) process. It was a perplexing question for me because, until that moment (the middle of April 2010), I believed that the documentation that I had provided for each of the stakeholders at Jefferson Hospital satisfied all of their internal requirements. Unfortunately, I was unaware of a veritable plethora of additional IRB requirements. Dr. Myers asked that I temporarily suspend any and all survey activities until I could obtain Thomas Jefferson University Hospital's IRB approval. From the moment when I was asked to suspend all survey activity, I had the definite impression that getting the hospital's IRB approval was going to be a very difficult process (Bolman & Deal, 2003).

After surviving the shock of believing that I was very close to collecting all of the data that I needed to complete the analysis for the study and finding that I must suspend all activity concerning the data, I immediately began to rebalance to accommodate yet another change (Heifetz, 1998). In subsequent conversations with Dr. Myers, I learned that I must gain Jefferson committee approval. Without such approval, any and all results from the study would be considered unofficial or invalid. That would mean that I would

never be able to continue my worthwhile project at Thomas Jefferson University Hospital.

Even with 30 pre-surveys, 30 post-surveys, 30 signed informed consent forms, and 30 instruction sheets for patients completed, I was advised that none of the information collected could be used as the data source since it was completed before the Jefferson IRB approval was gained. This is a simplistic example of how difficult it was for outsiders to understand organizations. As a result of not being informed of the rules, but being allowed to proceed with the study, my progress in the study was sorely impeded (Bolman & Deal, 2003).

To move the process forward, I contacted Dr. Myers to gain a better understanding of the next step in obtaining IRB approval. He advised me to contact his research assistant, Ms. Martha Keintz. He assured me that, under her guidance, I would gain the necessary knowledge for approval. He reiterated that research was her forte, and she was the person who could shepherd me through the process of Jefferson's IRB approval.

Gaining IRB Approval at Thomas Jefferson University Hospital

At that point in the process, it was late April, 2010. Securing an initial meeting with Ms. Keintz proved to be most difficult. She and other members of Dr. Myers's staff were in the process of relocating their office spaces by physically moving into other work stations. After several days of attempting to reach Ms. Keintz, I finally talked with her on the telephone. The conversation with her was very informative. Subsequent correspondence with her by e-mail during the next several weeks clearly outlined the IRB approval process.

First and foremost in the approval process, and in addition to the steps I had already completed to satisfy Rowan University's IRB requirements, I had to learn and pass the requirements for certification from the Division of Human Subjects Protection (DHSP), Department of Health and Human Services' Training Program entitled "IRB Training for Human Subjects in Research." I studied from a training manual. I passed the certification examination, which tested knowledge of ethical principles and Federal Regulations protecting human subjects in research. I learned the difference between research and treatment, good clinical practice, non-compliance, Institutional Review Board structure and function, the informed consent document and consent process, a determination of risks vs. benefits, and the use of internal forms (Bolman & Deal, 2003).

A second requirement in the approval process was that I had to learn and pass the Protection of Human Research Subjects Training at Thomas Jefferson University Hospital. The HIPAA training provided an on-line review of the Manual, which contained the regulations embodied in the HIPAA Privacy Rule as it pertained to research involving human subjects. As of April 17, 2010, I was certified in both areas, IRB Training for Human Subjects in Research and Protection of Human Research Subjects for the next three years.

Ms. Keintz e-mailed me the next step in the process. The requirements for submission to gain IRB approval were: (1) an overview of the program, and (2) the completion of the new IRB checklist. In addition, a most important document was the accurate completion of the OHR-2 form, Thomas Jefferson University's Office of Human Research Summary of Human Subjects Research, as a complete and succinct protocol synopsis (Bolman & Deal, 2003).

As the initiator of the study, I was not an employee or formal researcher of Thomas Jefferson University Hospital; therefore, I would only be the co-investigator of the study. Dr. Ronald E. Myers was Professor and Director of the Division of Population Science at Thomas Jefferson University and also an Associate Director of the Population Science Department in the Department of Medical Oncology. Dr. Myers was the principal investigator of the study.

Because the teaching session at Jefferson University was over at the end of May, my obtaining IRB approval was delayed due to the time requirements and responsibilities required of Dr. Myers and Ms. Keintz. Changes and editorial comments for my presentation were necessarily delayed because of more pressing concerns of Thomas Jefferson University Hospital. Later, Ms. Keintz painstakingly supervised the Summary of Human Subjects Research form while guiding me through the completion of the document. Terms and practices, which were normally associated with educational leadership, such as action research and citations that identify and explain educational research, were not used in medical research with human subjects. A term such as “various levels of understanding” must be actually interpreted for the reviewing committee to easily determine the risks to participants.

Another area that caused consternation was determining the groups who would be eligible to become subjects in the study. Vulnerable populations were the undereducated, the medically illiterate, and those not capable of comprehending the content of the video. These subjects were to be given special considerations to protect their rights and welfare.

The discussions, editing, and e-mail messages necessary to complete the document, coupled with individual time schedules, vacations, and workloads, used most

of the month. I completed a working document and advanced to the next stage in the process. The next stage, Mrs. Keintz felt, was the editing of the pre/post surveys and the completion of the patient instructions.

When I first presented my pre/post surveys to Dr. Myers, he made several suggestions. I implemented those suggestions and used those surveys on a trial basis at the Bodine Cancer Center. The logistical process of distributing and collecting the pre- and post-surveys worked well, as did the patients' understanding and following of instructions (Patten, 2001).

However, with the guidance of Ms. Keintz on the pre/post surveys, I transformed a good document into an extraordinary document. The information that I believed gave clear instructions for the patients was dramatically enhanced when I incorporated Ms. Keintz's suggestions. Clearly, the attention to details and the specificity of the language requirements in the medical community added tremendously to the clarity of the surveys (Patten, 2001).

Informed Consent Document

For the trial surveys, I utilized a rather long and cumbersome written form for the Thomas Jefferson University Hospital Informed Consent Document. After some editing and very brief discussions with Ms. Keintz, I used a shorter Acknowledgement of Oral Consent Form for the patients.

The next step in the process was the development of descriptive information for the radiation therapy patients at Thomas Jefferson University Hospital's Bodine Cancer Center. The document was appropriately called "Cancer Radiation Therapy Patient Descriptive Information." It was a script that was presented to each potential radiation

therapy patient. In it, I introduced myself by name as the co-investigator of the study. I outlined the purpose of the study and briefly discussed the video. I outlined the patient's requirements if the person elected to participate in the study. Additionally, through the script, I informed the proposed participant that the survey information would be used to determine better ways that patients received information about their illness (Gibson, 1995). I informed them that the video would help patients to have informed discussions with the radiation therapy providers. Through this document, I also informed the proposed patient participant that the study and all information obtained from it were confidential and anonymous.

Protocol Information

Next, I reviewed the protocol. The protocol document basically outlined the scheduled approach for potential participants at Thomas Jefferson University Hospital. In essence, it was a sequence of events beginning with the time the patient participant at the Bodine Center met the co-investigator. The process required the steps to be listed and presented as a flowchart from the time the co-investigator began the recruitment of potential participants for the study. The sequence was as follows (See Figure 1):

1. Patients entered the Bodine Cancer Center for treatment.
2. The head nurse identified potential participants.
3. Potential participants were approached by an investigator to determine if they would be interested in participating in the study.
4. When a consenting participant was identified:
 - A. Participant was given descriptive information about the study.

- B. Participant was given the informed consent form and the investigator answered participant's questions.
- C. Participant was given the pre-survey, instructions, and gift card.
- D. Participant completed and returned the pre-survey in the waiting area.
- E. Participant received a copy of the DVD to view and to keep.
- F. At a future treatment, participant was identified and given the post-survey.
- G. Participant completed the post-survey.
- H. The investigator collected the post-survey.

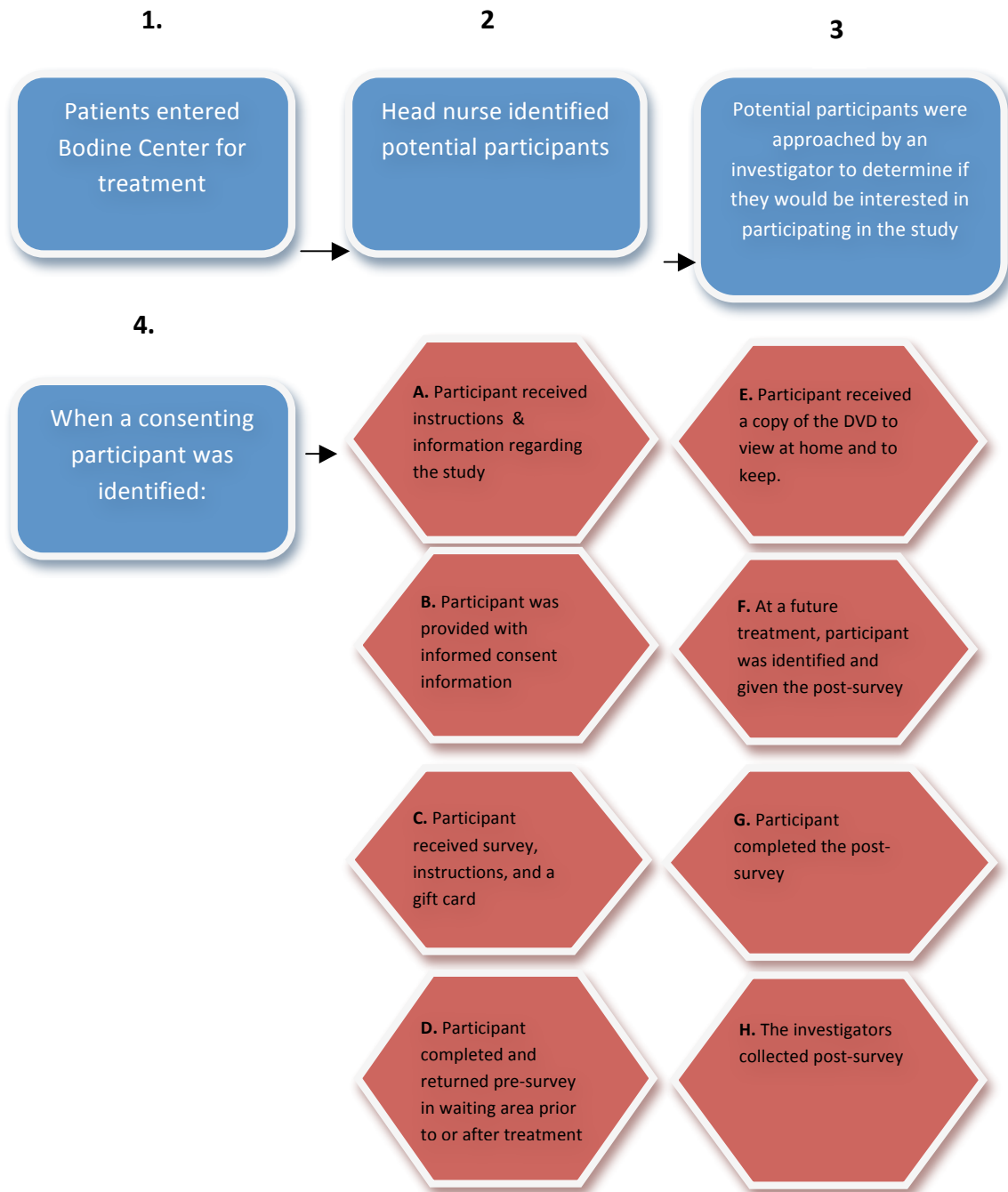


Figure 1. Study Visit Details Flow Chart: Scheduled Approach for Potential Participants

Disclosure Statement

I submitted a document in accordance with Thomas Jefferson University's Conflict of Interest Policy as an individual conducting research under the auspices of the University. I also declared that I, as co-investigator in the research, without a sponsor and without financial interests in the hospital, did not serve as a paid official for the hospital. I certified that I was without financial ties in any form to the hospital.

Study Proposal Transmitted and Approval Form

The final document that needed to be completed and submitted to the hospital by Dr. Myers, the principal investigator, was the Study Proposal Transmitted and Approval Form. The form declared that I, the co-investigator, subsidized the incentives to the participants in the study. The form included the proposed length of the project, the budget of the study, and the projected approved protocol by the Clinical Cancer Research Review Committee (CCRRC), and a copy of the approval letter.

Final Approval

As of November 2010, I was still awaiting IRB approval. As the required documentation attested, to gain approval by someone who was not part of the Thomas Jefferson University Hospital staff was very difficult. This process alone took almost six months for submission. I was most grateful, and I found solace in the fact that I was allowed to continue the study.

During the next several months, I was required to submit several additional documents that were necessary to obtain my study approval at Thomas Jefferson University Hospital. Then, nearly a full year later (February 14, 2011), I received "conditional" approval to complete the study, but only after I satisfied a few more IRB review inquiries:

1. The Thomas Jefferson University Hospital IRB committee had concerns about the format of the pre- and post-surveys.
2. They had questions about the accuracy of the data analysis.
3. They asked for the statistical methods used to test the results of increase in knowledge.
4. The committee wanted justification of the sample size.
5. They wanted to know more regarding the process for participant selection.

I felt fortunate that Dr. Myers, my mentor, and Mr. Wolf, who was recently assigned to work with me on this study, satisfied the committee's requirements with the additional information. I received full and final approval to continue with the study (see Appendix D).

Dr. Myers contacted Dr. Dicker at the Thomas Jefferson University Hospital Bodine Cancer Center to inform him that we had received official permission to resume the study. I immediately made an appointment to meet with Dr. Dicker's assistant, Dr. Showalter. I met with Dr. Showalter and supplied the necessary information regarding my action research project and its progress during the past two years. During our meeting, Dr. Showalter escorted me around the hospital and introduced and re-introduced me to members of his staff. Several days later he invited me to attend one of his staff meetings, at which time I formally introduced myself to his radiation oncology nursing staff. At the time I explained the reasons for my presence in the hospital and also how the pre/post survey distribution and collection process worked. I also thanked his staff for their patience and cooperation during the time of the study. The staff was very cooperative and seemed amenable to the entire idea of the study. I attributed their

acceptance to the fact that many of these same nurses were instrumental in the design and development of my clinical questionnaire a year ago. Many of them were familiar with the study and were vested and interested in the results.

Official Distribution: Patient Selection, Materials, and Methods

Between March 1 and April 9, 2011, with the assistance of Mrs. Sue Munro, head nurse in the Radiation Oncology Department of the Bodine Treatment Center, I recruited newly diagnosed cancer patients who were referred for radiation treatment at the center to participate in the study (Glesne, 2006). All diagnosed patients were eligible to participate in the study, regardless of their prognoses. Patients who initially agreed to participate in the study were given an explanation of the study and invited, even encouraged, to participate by Mrs. Munro. I received permission to conduct the study from Dr. Adam Dicker, Interim Director of the Oncology Department of the Bodine Cancer Treatment Center.

Official Survey Design

Prior to receiving radiation therapy, each newly diagnosed cancer patient participant was given a pre-survey to complete. The survey consisted of basic instructions for completion of the instrument, 10 true/false statements, several questions about marital status, racial background, levels of education, and medical history questions (Patten, 2001).

Immediately following the completion of the pre-survey, each patient received a copy of the DVD entitled *Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Treatment* for personal viewing. The patients were instructed to take the DVD home with them to view as often as they wanted (Carey et al., 2007). They were

advised that the DVD was theirs to keep. When they returned for radiation treatment, or at their next opportunity to do so, they were invited to complete the post-survey. The post-survey was usually completed from three-to-five days later. I provided the patients with note cards to record questions or comments for their oncologists that might occur to them as they watched the DVD about radiation treatments.

Sample Size

During a five-week period from March 1 to April 9, 2011, we approached 60 patients and received positive responses from 50 patient participants who agreed to be involved in the study, a response rate of 83% (Patten, 2001). My goal was to have no more participants than I could comfortably manage. After some discussion with my mentor Dr. Myers, we decided that 50-60 participants would be an adequate number of respondents for this pilot study (Patten, 2001). Since I was utilizing Jefferson University Hospital resources, I targeted my study to be completed within six weeks or less. Given extra time for future cancer treatment research, I would increase the number of participants to possibly 200 patients to get a greater representation and a larger sample of the radiation therapy population and to refine my methods and materials by identifying and removing any ambiguities in my survey questions (Patten, 2001).

Video Screening/Video Education

The DVD *Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education* was created and produced by Dr. Orloff from Emory University in conjunction with the American Cancer Society. The intent of the video was to improve patient education in the area of radiation therapy. The video clearly discussed a basic introduction to radiation therapy, types of radiation, external radiation therapy, internal

radiation therapy, and radiation therapy side effects. The premise behind the DVD was to provide visual cues and animation to supplement the information provided by the staff and printed information distributed throughout the hospital (Kinnane, Stuart, Thompson, Evans, & Schneider-Kolsky, 2008). The duration of the DVD was 11 minutes.

Several days after their initial radiation treatments, the patients were given the post-surveys and asked to complete them. Again, I had the assistance of Mrs. Munro. The primary difference between the pre- and post-surveys was the three DVD feedback questions and one open-ended question that offered the participants the opportunity to make suggestions that they felt would improve the education of cancer patients before they began radiation therapy (Holmes-Rovner, 2007).

Results: Surveys

Fifty cancer radiation patients agreed to participate, were recruited, and enrolled in the study. The largest group of participants enrolled in the study was married- 42% (See Table 1).

Table 1

Marital Status of Participants in Percentages

Marital Status	Percentage
Married	42.0
Living as married	10.0
Divorced	16.0
Separated	4.0
Widowed	8.0
Never married	20.0

Participants were asked about Hispanic ethnicity as a separate question, and 22% indicated that they were Hispanic. Sixty-two percent (62%) of the respondents were White; 36% of the respondents were Black, African American. No participants identified themselves as American Indian or Pacific Islander (See Table 2).

Table 2

Self-identified Ethnicity of Participants as Percentages

Spanish, Latino, or Hispanic Descent	Percentage
Yes	22.2
No	77.8
Racial or Ethnic Background	Percentage
White	61.9
Black, African American	35.7
Asian	2.4
American Indian or Alaskan Native	0
Native Hawaiian or other Pacific Islander	0
Other	0

A majority of the participants, 56%, had completed high school or less, as the highest level of education. Forty-three percent (43%) completed a non-college, business or trade school, received a 2-year Associate degree, or a college degree or above (See Table 3).

Table 3

Education Level of Participants in Percentages

Highest Level of Education	Percentage
Completed less than high school	22.9
Completed high school or equivalent degree	33.3
Completed non college/ business/trade/technical school	12.5
2-year Associate's degree	8.3
College degree and above	22.9

Participants were asked about their medical history related to their cancer diagnosis. Almost three quarters of the participants indicated it was their first diagnosis (See Table 4.)

Table 4

Medical History in Percentages

First Time Diagnosed With Cancer	Percentage
Yes	70.7
No, only skin cancer	4.9
No	24.4

The fifty participants enrolled in the study were required to respond to a pre-survey and a post-survey, each consisting of 10 questions, to which participants could respond true, false, or don't know. The survey questions used for the assessment were taken from the DVD they were asked to view entitled, *Cancer Treatment: Radiation Therapy and Interactive Approach to Cancer Treatment*. Table 5 provides the percentages of correct responses to each question.

Table 5

Participants' Correct Responses to Radiation Therapy Survey

Questions & Percentage of Correct Answer Choice	Pre-Survey Response	Post-Survey Response
A. Radiation Therapy		
1.A-1. Every day and everywhere we are surrounded by radiation.	59.2	98.0
2.A-2. Doctors use radiation therapy to treat cancer because it is good at shrinking and destroying tumors without causing much damage to normal tissues.	67.3	82.0
3.A-3. Low energy radiation waves pass through the body to reach the cancer.	22.4	44.9
B. Types of Radiation		
4. B-1. External radiation requires the use of a very fancy x-ray machine that spreads x-rays all over the body.	46.9	37.9
B-2. The decision about which type of radiation to use is based on all of the following:	80.0	92.0
<ul style="list-style-type: none"> ▪ Type of cancer ▪ Location of the cancer ▪ Whether or not the cancer has spread ▪ Current health of the patient ▪ Other treatments the patient is on or will be on 		
C. External Radiation Therapy		
C-1. The machines focus the radiation and create a beam that can be aimed at the cancer.	82.0	95.9
7.C-2. The radiation coming from the machine cannot be seen, but it can occasionally be felt.	34.0	42.9
8. C-3. External radiation therapy often requires only one long treatment.	52.1	58.0
D. Internal Radiation Therapy		
9. D-1. Internal radiation therapy uses radiation that comes from tiny radioactive sources placed outside the body.	24.0	22.0
E. Radiation Therapy Side Effects		
10. E-1. Long-term side effects that may occur, depending on the area being treated, include:	4.3	12.0
<ul style="list-style-type: none"> ▪ Diarrhea ▪ Hair loss (at treatment area) ▪ Mouth dryness or mouth sores ▪ Nausea and vomiting ▪ Loss of sexual drive ▪ Erectile dysfunctions (ED) ▪ Swelling of areas being treated ▪ Bladder problems (for example, bladder irritation that may cause a person to urinate frequently). 		

Although the majority of the survey questions were answered with true or false, a large percentage of the respondents answered “don’t know” or skipped a few of the questions entirely. The “don’t know” responses on both pre- and post-surveys are represented in Table 6.

Table 6

Comparison of Pre-Post Don't Know Responses in Percentages

Questions	Pre-Survey		Post Survey	
	N	%	N	%
1. Every day and everywhere we are surrounded by radiation.	13	26.5	1	2
2. Doctors use radiation therapy to treat cancer because it is good at shrinking and destroying tumors without causing much damage to normal tissues.	6	12.2	1	2
3. Low energy radiation waves pass through the body to reach the cancer.	17	34.7	3	6.1
4. External radiation requires the use of a very fancy x-ray machine that spreads x-rays all over the body.	17	34.7	3	6.3
5. The decision about which type of radiation to use is based on all of the following: <ul style="list-style-type: none"> ● Type of cancer ● Location of cancer ● Whether or not the cancer has spread ● Current health of the patient ● Other treatments the patient is on or will be on 	8	16.0	0	0
6. The machines focus the radiation and create a beam that can be aimed at the cancer.	6	12.0	1	2.0
7. The radiation coming from the machine cannot be seen, but it can occasionally be felt.	9	40.4	3	6.1
8. External radiation therapy often requires only one long treatment.	13	27.1	3	6.0
9. Internal radiation therapy uses radiation that comes from tiny radioactive sources placed outside the body.	20	40.0	3	6.0
10. Long term side effects that may occur, depending on the area being treated, include: <ul style="list-style-type: none"> ● Diarrhea ● Hair loss (at treatment area) ● Mouth dryness or mouth sores ● Nausea and vomiting ● Loss of sexual drive ● Erectile dysfunctions (ED) ● Swelling of areas being treated ● Bladder problems (for example, bladder irritation that may cause you to urinate frequently). 	11	23.4	0	0
Total Don't Know Responses	130	26.2	18	3.6

During the completion of the pre-surveys, more than 26% of the respondents answered “don’t know.” When the participants took the post survey, only 3.6% of the respondents answered “don’t know,” a substantial difference (See Table 6).

In 8 of the 10 questions, the percentage of correct answers increased from pre-survey to post-survey, yet on 5 of the post-survey questions, more respondents answered incorrectly than answered correctly. (See Table 7)

Table 7

Incorrect Responses on Selected Five (5) Pre-Post Survey Questions

Questions	Pre-Survey		Post Survey	
	N	%	N	%
3. Low energy radiation waves pass through the body to reach the cancer.	21	42.9	24	49.0
4. External radiation requires the use of a very fancy x-ray machine that spreads x-rays all over the body.	9	18.4	27	56.3
7. The radiation coming from the machine cannot be seen, but it can occasionally be felt.	12	25.5	25	51.0
9. Internal radiation therapy uses radiation that comes from tiny radioactive sources placed outside the body.	18	36.0	36	72.0
10. Long term side effects that may occur, depending on the area being treated, include: <ul style="list-style-type: none"> ●Diarrhea ●Hair loss (at treatment area) ●Mouth dryness or mouth sores ●Nausea and vomiting ●Loss of sexual drive ●Erectile dysfunctions (ED) ●Swelling of areas being treated ●Bladder problems (for example, bladder irritation that may cause a person to urinate frequently). 	34	72.3	44	88.0

When coding the responses, true was coded as 1, and false was coded as 2, and pre and post survey means for each question were calculated as presented in Table 8.

Thus, when comparing the means for a question answered correctly with True, the appropriate trend of the post-mean should be trending (lower) toward 1.00. Conversely, when comparing the means for a question answered correctly with False, the appropriate trend of the pre and post survey mean should be trending (higher) toward 2.00.

Table 8

Comparison of Pre-Mean and Post- Mean Responses

Number of Test Questions	Pre-Mean	Post Mean
1. (n=35)	1.00	1.17
2. (n=42)	1.19	1.24
3. (n=29)	1.34	1.45
4. (n=28)	1.71	1.46
5. (n=40)	1.02	1.10
6. (n=43)	1.06	1.02
7. (n=26)	1.58	1.35
8. (n=33)	1.70	1.61
9. (n=29)	1.38	1.24
10. (n=36)	1.06	1.08

When a t-test was performed of the individual pre-survey and the post-survey questions, using a t-test paired samples, only question number 1 was found to be statically significant at the 0.05 level ($p \leq .05$). The methodology of the t-test was chosen because it assesses whether the mean score on the pre-test significantly differed from the mean score on the post-test (Cronk, 2008).

(See Table 9)

Table 9

Paired Samples Test- Paired Differences 95% Confidence Interval of the Difference

		Lower	Upper	<i>t</i>	<i>df</i>	Sig. (2-tailed)
Pair 1	PrequesA1 – Post A1	.04007	.30278	2.652	34	.012*
Pair 2	PrequesA2 – Post A2	-.14647	.24171	.495	41	.623
Pair 3	PrequesA3 – Post A3	-.35952	.15262	-.828	28	.415
Pair 4	PrequesB1 – Post B1	-.02164	.52164	1.888	27	.070
Pair 5	PrequesB2 – Post B2	-.16031	.01031	-1.778	39	.083
Pair 6	PrequesC1 – Post C1	-.04735	.14038	1.000	42	.323
Pair 7	PrequesC2 – Post C2	-.05615	.51769	1.656	25	.110
Pair 8	PrequesC3 – Post C3	-.13271	.31453	.828	32	.414
Pair 9	PrequesD1 – Post D1	-.10529	.38116	1.162	28	.255
Pair 10	PrequesE1 – Post E1	-.15531	.09975	-.442	35	.66

* $p \leq .05$

Rating the Patients' Understanding/Knowledge of Radiation Treatment

One of the goals of my study was to determine whether patients could make sense of medical information presented to them in the diagnosis and treatment of cancer. When the patients were pre-surveyed, they were required to rate their knowledge/understanding

of radiation in several areas. Specifically, the patients were asked to indicate whether their understanding levels were low, average, or high. The data suggested that the patients overwhelmingly felt that they understood the process. The specific breakdown of the data on each of the above areas was as follows.

As presented in Table 10, on patient's knowledge of radiation procedures, 35% of the respondents indicated low levels of understanding. Thirty percent (30%) of the respondents reported average levels of understanding radiation procedures. Thirty-five percent (35%) responded that they had high levels of knowledge about radiation procedures (See Table 10).

Similarly, in the area of understanding the written information of radiation therapy, according to the data, 18% of the respondents reported having lower levels of understanding about written information. Thirty-six percent (36%) of the respondents reported average levels of understanding about the written information presented to them. Forty-five percent (45%) indicated that they had high levels of understanding about the written information they had received (See Table 10).

Finally, in the area of understanding the verbal information of radiation therapy, according to the data 13.6% indicated low levels of understanding about verbal information. Twenty-five percent (25%) reported average levels of understanding about the verbal information presented to them. Sixty-one point five percent (61.5%) indicated high levels of understanding of the verbal information they received (See Table 10).

Table 10

Patients' Pre-Survey Understanding/Knowledge of Radiation Treatment in Percentages

Patient Self-rated Understanding/Knowledge	Low	Average	High
Patient knowledge of radiation procedures	35	30	35
Patient understanding of written information of radiation therapy	18	36	45
Patient understanding of verbal information of radiation therapy	13.6	25	61.5

Additionally, on the pre-survey the patients rated the usefulness of several sources of information regarding their illness and its treatment. Healthcare professionals; booklets, pamphlets, and flyers; the education sessions and the internet were all rated as being useful or very useful in the patients' desires for additional information about their treatments (see Table 11).

Table 11

Frequency of Responses Regarding Sources of Information about Illness/Treatment

How participants gained information about illness/treatment	Not used	Not very useful	Useful	Very useful
Internet	11	5	16	7
Health care professionals	1	1	21	20
Magazines	26	6	4	0
Friends	9	6	22	1
Television	20	8	5	1
Radio	25	9	1	0
T.J Oncology Patient Education/Training Session	19	1	15	9
Booklets/pamphlets/flyers	14	2	21	4

Post-Survey DVD Feedback and Follow-up Questions

Patients were also asked about the video in follow-up questions on the post survey. Of the respondents, 75% indicated that the DVD provided information that was new to them. The patients overwhelmingly indicated, 90%, that the video provided information that was useful. After viewing the video, more than 60% of the patients had additional questions that they indicated they wished to ask their physicians about their radiation treatment (See Table 12). Moreover, 31.6% of the participants watched the

video more than one time, and 68% of the participants watched it once. Additionally, almost two-thirds, 64%, of the respondents had at least one friend or family member who also watched the video.

Table 12

Patient Post-Survey on Radiation Therapy (5) Follow-up Questions in Percentages

	Strongly Agree	Agree	Disagree	Strongly Disagree
F-1. The video Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education, provided information that was new to me.	20.0	56.0	16.0	8.0
F-2. The video provided information that was useful to me.	26.0	64.0	6.0	4.0
F-3. After watching the video, I have questions that I want to ask the physicians and nurses about my radiation treatment.	12.0	50.0	30.0	8.0

Finally, patients were asked on the post survey if they had any suggestions for improving the education of cancer patients. Only three patients responded to the question. Two indicated they did not have any suggestions, and one respondent wrote, “Great Job, Very informative.”

Analysis/Discussion: Research Questions

I suggested earlier in this study that I was convinced after discussions with friends and colleagues and after examining the literature on cancer patient education that an action research study at the Bodine Center would produce educational benefits for the patients. This study was designed to answer the two following research questions:

- 1) How did patients make sense of the medical information presented to them in the diagnosis and treatment of cancer?
- 2) How did the development of a cancer radiation educational videotape/DVD enhance the learning process for patients and increase their understanding of the effects and results of the radiation treatments?

By examining the study from an educational vantage point, the data suggested that more than half of the participants had completed high school or less as their highest level of education. I surmised that the large number of participants with lower levels of education affected the pre-to-post survey results. Ironically, even though 56%, the majority of the respondents, only completed high school or had less than a high school education, in 8 of 10 questions the percentage of correct answers increased from pre-survey to post-survey.

A majority of the positive overall increase in correct answers from the pre-survey to the post-survey could be directly attributed to the following: In the pre-survey a large number of respondents, 26%, answered with “don’t know.” Conversely, only a small number, 3.6%, responded with “don’t know” on the post-survey. This clearly suggested that the respondents answered with a sense of certainty on the post-survey. One hundred thirty (130) pre-survey “don’t know” answers decreased to 18 “don’t know” answers

after the patients viewed the video. I suggest that the DVD, as it was intended to do, provided needed information to a number of the respondents.

However, despite the increases in correct answers in 80% of the questions and the steep decline in “don’t know” answers in half of the questions, a majority of participants answered incorrectly on 4 of the questions (see Table 7). On a 5th question, a higher percentage answered incorrectly than correctly. Development of a cancer radiation educational videotape/DVD enhanced the learning process for patients and increased their understanding of the effects and results of the radiation treatments. The increased percentages of correct responses in 80% of questions and the decrease in respondents indicating they did not know the answer indicated the DVD did enhance the learning process and levels of understanding for participants, however there were additional educational needs that were not addressed.

The use of a paired samples t-test did not produce the results I had anticipated, only one question rendered a significant difference from pre to post survey. The positive trend in correct answers for 80% of the questions, however, spoke directly to the importance that patients placed on obtaining information about their cancer diagnosis and treatment plan (Brandt, 1991; Carlsson & Strang, 1996, 1998; Fallowfield, 1995).

A trend that deserved further examination was that on four of the post-test questions, a majority answered incorrectly, and the largest percentage answered incorrectly on a fifth question. This may be due to poorly worded or ambiguous questions (Patten, 2001), to patient’s ill health and inability to absorb information in a stressful situation (Wong, 1992), or to patients’ relatively modest levels of education. As found in

previous research, the reading levels may have been too high given the sample's education level (Wong, 1992).

Within my literature review I stated that part of my research focused on cancer patients' educational development, or, more specifically, on their need to better understand medical terminology relative to the particular care and treatment patients needed (Butow et al., 1998). Additionally, I suggested that patients needed concise and specific language so that their treatment decisions would be based on understanding and not on partial information picked up during the emotionally charged critical time of the cancer announcement (Chelf et al., 2002). Thus, one of the research questions this study was designed to answer was: How do patients make sense of the medical information presented to them in the diagnosis and treatment of cancer? The research in this study suggested that the vast majority of patients, 82%, responded they are able to decipher the written information, and 86% indicated they understood the verbal information that they were given. They also indicated that the medical professionals at the hospital; the booklets, pamphlets, and flyers provided; and the Thomas Jefferson Oncology Patient Education/Training were useful or very useful. Similarly, the data suggested that the patients believed they were also knowledgeable with 65% indicating an average or high level of understanding about the radiation process. Although other research suggested that patients were often confused and unclear about the medical information, the participants in this study overall responded that they understood and were knowledgeable (Butow et al., 1998).

This study produced a substantial increase from pre-to-post survey results in specific areas and significant increase on one question. Patients were asked to participate

in a study and demonstrate their knowledge about the treatment of their illness during a very traumatic period in their lives. Although the patients were allowed to view the DVD in the comfort of their homes as often as they felt they needed to, given these parameters and traumatic life-altering unfortunate circumstances, their post-survey increase in the percentage of correct answers in 80% of the questions was a tribute to the fortitude of these individuals, the Thomas Jefferson University Hospital radiation treatment program, and Dr. Greg Orloff and the quality of the video his staff produced.

However, within this study, there were a number of issues and areas that called for further analysis and discussion. Several results of the true/false questions brought to mind some interesting points, specifically as they related to the results of the post-survey (Patten, 2001).

Question #5 concerned “the basis for the decision about which type of radiation to use.” Most of the patients who participated in the post-survey showed a thorough understanding of why radiation was used. On the pre-survey, 80% of the patients correctly answered the question, and on the post-survey, 92% of the patients correctly answered it. The question #5 was very important as it established a basis or foundation for the overall decision about which type of radiation the medical professionals opted to use during patient treatment. On this question alone, there was a 12 percentage point increase from pre-survey to post-survey results (see Table 5).

Conversely, question #7 on the pre and post-survey dealt with “whether or not the patient can feel the radiation.” Twenty-eight patients or 57% of the patients answered the question incorrectly (see Tables 5 & 6). Three persons or 6% did not know and 25 persons or 51% answered true, which was incorrect. I surmised that the patients were

unable to separate the after-effects of radiation therapy (sometimes a burn) from the radiation (beam) itself (Chelf et al., 2002).

Question #10 on the pre and post-survey dealt with the difference in short-term and long-term side effects of radiation therapy (see Tables 5 & 6). Again, a large number of respondents, 44, representing 88%, were perhaps unable to distinguish between short-term and long-term side effects of radiation therapy and answered incorrectly (Chelf et al., 2002).

After reviewing and analyzing the results of both the pre-survey and the post-survey, I surmised that question #7 and question #10 may have been unclear, ambiguous, and/or misleading to the patients since a majority of the respondents failed to realize their correct meanings (Patten, 2001). These questions may also have posed a problem for the participants due to modest reading and education levels (Wong, 1992).

Examining Change

My change framework was crucial to the development, structure, implementation, and completion of all three of my cycles. Utilizing the Heifetz (1998) Seven-Step model afforded me the organization I needed to specifically explain the change process within these cycles.

Choosing the target, Step 1, was probably the only stage in the model that was relatively simple for me. I knew that I planned to seek participants in the Cancer Radiation Therapy Unit of the Bodine Cancer Center of Thomas Jefferson University Hospital. Some of the particulars, such as the sample size, the clinician questionnaire, the surveys, the time, and some of the rules and regulations were subject to change. The

target itself—the participation of cancer radiation therapy patients—was always the subject of my study.

Attempting to set goals, Step 2, was modified due to politics, regulations, time constraints, or resources, and made this process more challenging than I ever imagined (Heifetz, 1998). I felt fortunate, however, that I had Dr. Myers's and Dr. Dicker's support, as well as that of Mrs. Sue Munro, to assist me in setting the goals. All three were supporters of my project and helped in setting goals at different stages of the study. Without their input, awareness of internal organizational stumbling blocks, as well as the time and energy spent on the logistics of designing, distributing, collecting, and analyzing the data, the goal-setting stage of the process could have been an endless bureaucratic quagmire (Patten, 2001).

Heifetz (1998) suggests that the key to initiating action, Step 3, was a multi-person effort and needed multiple levels of expertise. I added to his definition by determining that it was even better if the multi-person effort was complemented by powerful, influential, and knowledgeable individuals from within the organization (Bolman & Deal, 2003). Thomas Jefferson University Hospital provided the kind of personal expertise that I needed to initiate and complete action on this project. Unlike many initiatives in which I had been involved throughout my career, both Dr. Myers and Dr. Dicker were involved in this study from the beginning. Both men were instrumental in what was once a stalled project in providing the permission, focus, and future for the project. These men provided the guidance to move this study forward. From the onset of the project, these gentlemen were not only helpful, but their ability, along with their combined efforts, made this project a success. During Cycle 3 of my dissertation and

using Step 3 of Heifetz's change cycle, initiating the action of change, actions that I initiated enabled me to make the necessary revisions and to adhere to hospital protocol and procedures. I often had to revise or alter many of my objectives, and I edited all of my documents, but I implemented most of the plans that I made during the goal-setting process of the study.

The turning point of Step 4, making connections (Heifetz, 1998), came when Dr. Dicker had me contact Mrs. Sue Munro, the head nurse in the Radiation Oncology Unit of Thomas Jefferson University Hospital. The connection that I made with her instantly gave this project the missing piece needed to move forward with the study. Normally and specifically during Step 4 in making connections, this change required a shift in the attitudes, values, and ways in which members of the organization conducted business. Making connections has led to the provision for changes in Jefferson Hospital's method of providing patient in-take information by handing out the DVD to their patients and by providing the patients with the web address to view the DVD to receive specific information about radiation therapy, a new way that they can conduct radiation therapy business. Fortunately, the recommended changes were almost instantaneous as soon as I led Mrs. Munro to understand the basis of my project. The total concept of the project became even more concrete and more easily grasped after Mrs. Munro viewed the video *Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education* developed by Dr. Orloff for The American Cancer Society at Emory University. Gaining access and making a connection with Mrs. Munro, Head Oncology Nurse in the Bodine Center, were two turning points of this study (Bolman & Deal, 2003).

The entire research process had been rebalanced to accommodate an inordinate number of changes, Step 5 (Heifetz, 1998) delays, IRB scrutiny, and new hospital procedures that were too numerous to accurately define. I initially believed that I would have access to the patients in the waiting area of the Bodine Cancer Treatment Center before, during, and after their viewing of the cancer radiation video. I determined, through conversations with Mrs. Munro, that a more private setting was needed by patients completing the paperwork and surveys because of confidentiality and anonymity concerns (Bolman & Deal, 2003). Accepting the suggestions from Mrs. Munro, I pursued her recommended course of action, which provided my desired outcomes, along with ensuring the confidentiality and anonymity concerns of the patients.

When I thought about consolidating the learning, Step 6, I considered whether my initial goals were achieved (Heifetz, 1998). I answered with a resounding, “Yes, they were achieved!” One of my goals was to determine if the cancer radiation patients were able to make sense of the information that was presented to them. Based on an analysis of the data, the overwhelming majority of the surveyed participants answered that they understood the information they were presented, either verbally or in written form. The participants had various educational backgrounds. Several were high school graduates or less, some had taken some college coursework, and several were college graduates. Step 7 of the Heifetz (1998) change cycle, planning for the next change effort, afforded me a distinct opportunity plan for the next change effort. I have already begun planning for the next change effort. Looping the video into the television already installed in the treatment waiting area and publishing a pamphlet with 10 quick facts about cancer radiation treatment are areas that I have examined as part of my planning for a future cycle.

Organizations as Cultures

I needed to understand how Thomas Jefferson University Hospital's organizational culture affected the change that my project made. To better comprehend the effect that Jefferson's culture, as a large successful urban medical institution, had on the study, I needed to examine the definition of culture as it pertained to organizations. Schein (2004) contended that culture was a deeper level of basic assumptions and beliefs that were shared by members of an organization. The assumptions and beliefs became so accepted, so automatic, and so ingrained in the organization's routine practices that they were automatically taught to its new members (Schein, 2004). As an outsider and a new member to Jefferson Hospital's culture, I was taught the "correct way" to perceive, think, and feel about problems, specifically relative to this study (Schein, 2004). Clearly, the function of Thomas Jefferson Hospital, in this instance, was to initiate new members and to have them become immersed into the culture of the institution. The initiation process included, but was not limited to, the process of gaining access to the institution, acquiring IRB review and approval, vetting of new members to include unaffiliated investigator agreements, disclosure statements, and a host of HIPPA testing and safety analysis indoctrinations. Since I was fortunate enough to survive that process, there was an added host of internal scrutiny and overall committee approval required, particularly for new members. With the multiple layers of political, structural, human resource, and symbolic frameworks, making any change, significant or not, was extremely difficult (Bolman & Deal, 2003). Gaining access to the organization was a most difficult process (Bogdan & Biklen, 2007). I gained access to the institution in a circuitous manner. I placed a telephone call to Jefferson's Human Resource department where I was fortunate enough

to have been given an appointment with a social worker. The social worker referred me to Mrs. Joy Soleiman, who was interested enough in my project to grant me a short session to explain the plan for the study. Persuading the appropriate members of the institution of the usefulness of the project was a massive, ongoing struggle. Finally, my ability to persuade the decision makers within the organization of the benefits of my study was the key to launching this project.

The psychology, attitudes, actions, and artifacts at Thomas Jefferson University Hospital were deeply embedded (Schein, 2004), making the change at this institution a slow, structured, heavily regulated process. Everything from the title of my study to the exact manner in which the study would be conducted was a source of approval/permission, review, communications, and negotiation. The organization had a profound effect on each and every aspect of my study from the inception of the idea, to the completion and collection of the surveys, to the follow-up and constant updating of Jefferson's administrators on my progress. Even with the organizational cultural challenges, from the development of the clinical questionnaire and the pre-and post-survey responses, to the responses of the DVD feedback questions, implementing this change through my study seemed to have a positive effect on the respondents' knowledge and understanding of radiation therapy. Even though only one question proved to have a significant increase in correct responses from pre-to post-surveys, there was an overall increase in the percentage of correct answers on 80% of the questions from pre-to post-survey. The patients overwhelmingly agreed that the DVD was useful and one third of the participants viewed the video multiple times.

The organizational culture at Thomas Jefferson University Hospital definitely had an effect on the change that I proposed for the hospital. The culture directly affected the change in the two specific areas of space and time (Schein, 2004). Of these two areas the greater effect was on time as it related to me as the researcher and Thomas Jefferson University Hospital as the large organizational culture. Schein referred to incorrect assumptions made regarding time. I misjudged the time required to process change in this large cultural organization, and I had to become immersed in the way things worked at the hospital (Schein, 2004). In my initial meeting with Dr. Myers, I suggested that I would be able to draft, design, and distribute a survey to the cancer patients in less than a month's time. Dr. Myers' timeframe, based on the organizational culture at the hospital, suggested that this process would take several months before any such survey instrument would be ready to distribute to the patients. These two drastically different assumptions of timeframes exemplified why it was essential that I used Heifetz's (1998) seven-step change model to guide my study through the organizational culture at Thomas Jefferson University Hospital. First, with such a large disparity in the timeframe for the study between my idea and the idea of the hospital administrator, it was incumbent upon me to begin resetting the change goals. Next, due to the organizational culture at the hospital as it referred to time, it was important that I rebalance to accommodate the necessary timeframe changes. Finally, again because of the large disparity in time, it was incumbent upon me to initiate the change of action to continuously reinforce the importance of change during the extended periods of relative inactivity.

The second greatest effect the organizational culture had on the change project specifically dealt with the space I initially envisioned for the setting of the study (Schein,

2004). I planned that my change project would take place in the waiting room of Jefferson's Bodine Cancer Center. This proved to be another incorrect assumption on my part. Ultimately, the space that I utilized for my change project was on multiple levels of the hospital. Once again, I used a number of Heifetz's (1998) seven steps to accommodate the change in space for my project.

The changes had an effect on the culture of the participants who were involved in the study as well as on the anticipated use of the DVD in the future. With the acceptance of one or more of my suggestions, I contended that sustainable change would be attainable. The administration at Jefferson suggested that the DVD be adopted as part of the normal intake process for all newly diagnosed cancer radiation therapy treatments. A prototype of a pamphlet outlining the 10 important questions about cancer radiation (the same questions which I utilized on my surveys) would be developed and implemented and then placed in the waiting areas throughout the Bodine Radiation Center. Finally, the original idea that I had when I conceived of this study initially was that the television in the radiation therapy waiting area would be configured to loop the 11-minute cancer radiation DVD entitled *Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education* intermittently throughout the day. These suggestions were based on the promising results of my study.

Another goal of my study was to determine how the development of a cancer radiation educational videotape/DVD enhanced the learning process for patients and increased their understanding of the effects and results of the radiation treatment. One of the true/false questions had a statistically significant outcome. Additionally, 8 of 10 questions exhibited an increase from pre-to-post survey score. Additionally, the patients

overwhelmingly felt the DVD was beneficial, and a majority of the patients opted to view the DVD on more than one occasion. These results provided credibility and certainty that the cancer radiation educational videotape/DVD increased and enhanced the learning process for those patients.

The next step for me was very clear. Having had a number of relatives and friends who were patients in the Bodine Center, I decided to follow-up on a regular basis to determine if the change I began was continued. As a researcher in the change process for Thomas Jefferson University Hospital, I had a desire to become part of the process to follow-up and to assist in maintaining the highest level of education for cancer patients. To sustain the change, I volunteered my services at Jefferson Hospital to work with patients as a consultant or in any way I could be useful (Fullan, 2007). I proposed to help write grant proposals for funding and to train patients in their understanding of the video. Ultimately, as a servant-leader of this project, my goal was to continue to serve in any capacity in which I was needed.

Overall Perspective on Change and Organization Culture

I am elated with the manner in which I was able to conduct this study. However, there are several lessons I learned about leading the change process and about how an institution's culture can affect change. Not unlike my days in the military, I learned that it was essential that I had a well-scripted and well thought-out plan of engagement (Simmons & Moskin, 1998). Trying to get a major organization interested in a study without evidence of a thorough plan of attack is futile. At the time I presented my study to Jefferson, I thought my plan was solid. I was wrong. A plan which was acceptable in the educational community did not quite meet the organizational or cultural (Bolman &

Deal, 2003) requirements and standards needed for a medical regulatory agency such as Thomas Jefferson University Hospital.

I learned that in trying to infiltrate and launch a project in a major institution such as Jefferson, it was imperative that I gain a firm understanding of the change process. In this case I chose the Heifetz (1998) Seven-Step Change Cycle. Jefferson had a number of different time, space, and human relationship restrictions that affected the study. By utilizing Heifetz's (1998) concepts I was afforded the flexibility and structure to implement a series of alternate strategies, which I needed to continue and to complete my study. Finally, I learned that my charge as the leader of this study was to overcome, or to adapt to, the organization's cultural arena (Schein, 2004) as I continued making progress toward accomplishing my vision.

The completion of this project had literally taken almost two years to come to full fruition. In hindsight, waiting for a video to be completed that had not even been started was shortsighted of me. Accepting a promise of the video's eventual completion and the use of this unseen medium as the cornerstone of my study was not something that I would ever have contemplated, until I actually did it, especially for an organization with the size, scope, and regulatory oversight of Thomas Jefferson University Hospital. Trying to sell any major organization on a vision without tangible evidence was naive on my part (Bolman & Deal, 2003).

The cooperation that was afforded me by everyone at Jefferson Hospital with whom I interfaced was always professional, caring, and open. They accepted me not only as a person; they accepted my vision with just a skeletal foundation. I thought back to Joyce Soleiman, one of the first administrators with whom I spoke. Mrs. Soleiman was

excited about my project without any evidence that I could complete the study. She introduced me to Dr. Myers and secured his assistance as my mentor. Dr. Myers introduced me to Dr. Dicker, who became another mentor to me. Dr. Dicker introduced me to Mrs. Munro. And so the list continued.

Recommendations

Based on the information gleaned from the post-survey analysis, I propose several recommendations for the continuance of change. At a minimum, at least two important education facts would be reinforced and reviewed with the cancer radiation patients by the oncologists at Thomas Jefferson University Hospital:

- a. Radiation from the machine cannot be seen nor felt. I emphasized this since it was one of the concepts that few of the patients seemed to understand.
- b. The difference between long-term side effects and short-term side effects of radiation treatments should be discussed at length between the medical professionals and the patients. I emphasized this since it was one of the concepts that few of the patients seemed to understand.
- c. A simple, easy-to-read pamphlet that included most of the radiation treatment facts would summarize cancer radiation treatments. The pamphlet would be included or inserted into the patient's initial admittance package. It would also be placed in the radiation treatment waiting area to reinforce patients' understanding of the radiation treatment process.
- d. When I began this project, Dr. Orloff, in conjunction with the American Cancer Society, had not yet given permission for the video to be disseminated for public use. Now, almost a year later, the video is available to everyone by

accessing his website at

http://www.cancerquest.org/demo/ACS/RT/RadiationTherapy_V2.swf

However, I recommend that a copy of the DVD be presented to patients during the radiation therapy intake process.

Based on the availability of the video, I have the following suggestions:

1. All cancer radiation patients would have access to, and/or be made aware of, this website as a part of their patient radiation/oncology intake package/process.
2. The video would be placed in the waiting area of the oncology radiation department waiting area. My original suggestion, when I began this study, was to have a flat screen television installed in the waiting area with the video running or looped intermittently throughout the day. Since the study began, a flat screen television set was installed in the waiting area of the radiation/oncology department. It would be a fairly simple process to have the video downloaded for patient viewing from that flat screen television set.
3. A policy would be adopted that the video feed would be an ongoing and permanent part of the Thomas Jefferson University Hospital radiation/oncology weekly classes for newly diagnosed cancer patients.

Many of these suggestions have already been discussed with hospital staff and administrators. I have agreed to assist Jefferson by helping to shepherd them through the process.

Chapter 8

Leadership

Introduction

Theorists and authors I have read and studied frequently referred to the importance of having a vision and using the vision to lead (Kouzes & Posner, 1996). From the inception of this project to its completion, I have envisioned the wealth of benefits it could provide for a great many people, not only at Thomas Jefferson University Hospital, but throughout the medical community. However, completing the project has been an ultimate labor of love, persistence, stubbornness, and, of course, leadership. As part of my dissertation, I kept a journal throughout, and have analyzed those data. I also wanted to interview Dr. Myers and Dr. Dicker, but they were unavailable. In this chapter, I present my leadership in the study supported by journal data, analyze the change I was able to make, examine the organizational culture, and close with a final reflection. I have two research questions that I answer in this chapter. They are:

- 1) How has my leadership shaped this research project?
- 2) To what extent did I utilize servant and transformational leadership during this study to improve patients' education?

Leadership Revisited

In an earlier chapter, I cited a definition from Howard Gardner (1984). Gardner writes, "...leadership is the process or example by which an individual (or leadership team) induces a group to pursue objectives held and shared by the leader and his or her followers" who will carry out the necessary work to obtain the objectives (p. 17).

In Chapter 2 of this dissertation, I outlined my leadership platform and I examined several of my approaches to leadership, including both transformational and transactional styles of leadership. Previously, as a leader I gravitated toward one of these two leadership styles (Burns, 2003). Since I had experienced a modicum of success using these two leadership styles in the past, I assumed incorrectly that I would be able to once again utilize either a transformational or transactional style of leadership or a combination of the two for the completion of this cancer research study. However, nothing in my previous experiences—not the military, not the business sector, and not the educational setting—had adequately prepared me for what I faced as I tried to implement a change project at Thomas Jefferson University Hospital.

I started the project because I felt deeply that it could serve a number of people who could use some additional and much needed information about their illness and treatment, and that this information could lead to more informed discussions with their physicians. My vision, therefore, was simply to educate patients about their radiation treatment for cancer.

Therefore, my thoughts gravitated toward the type of leadership I would utilize or exhibit to have my vision become a reality. In my journal I wrote, “As a former Marine, manufacturing supervisor, and principal, I know how to get the job done.” I had no idea when I began this study of the changes, directives, regulations, mentoring, and networking that would be necessary to complete the project. Just gaining access to Thomas Jefferson University Hospital so I could showcase my project and gain acceptance of the study from the hospital staff was a 12-month emotional rollercoaster of setbacks and advancements.

Prior to beginning the process at Thomas Jefferson University Hospital, I was secure in my leadership skills. As a former principal I used both transactional and transformational leadership styles depending upon the situation (Bass, 1990; Murphy & Drodge, 2004). I was a successful and confident leader in the educational, business, and military arenas. I expected to use transactional and transformational leadership, and I did, to some extent. I readily used transactional leadership in one context, when I used gift cards to motivate participants.

Transactional Leadership

In an earlier chapter on my leadership platform, I wrote that a transactional leader strives to develop a relationship of exchange with subordinates and co-workers in which the subordinates receive some reward in return for compliance with the leader's expectations (Doherty & Danylchuk, 1996). The subordinates receive rewards relative to the low-order needs of the subordinates, sometimes as little as recognition for their accomplishments. In return, the subordinates comply with the expectations of the leader. I resorted to transactional leadership (Friedman, 2004), specifically incentives, briefly, as a means to quickly obtain the subjects' active participation. Most of the completed surveys were returned in a timeframe that allowed me to comfortably complete the study within the parameters as planned. I wrote in my journal, "I need motivated participants. Twenty-five bucks for a 10-minute survey will work." Immediately, I presented all of the patients who agreed to participate in the study a 25 dollar gift card to instantly develop a relationship of exchange and reward that I cited as a primary reason for an 83% participation rate among all of the participants who were asked to enroll in the study. I congratulated myself in my journal, "I knew the incentives of 25 dollar gift cards would

entice the patients to participate in my study.” Although I extolled the importance of both transformational (Murphy & Drodge, 2004) and primarily servant leadership (Greenleaf, 1991) throughout this study, I believe this project would have been delayed indefinitely without transactional leadership. I patted myself on the back in my journal when I wrote, “That was brilliant. I wish everything would work that well.”

Transformational Leadership

As I discussed earlier in my leadership platform, my leadership development was enhanced through the use of various transformational approaches as a means to complete this project. The experts in this field suggest that transformational theory can best be described using four basic leadership components: (a) Intellectual stimulation, (b) Individualized consideration, (c) Inspirational motivation, and (d) Charisma along with communication as an essential component to the completion of the vision of the leader (Doherty & Danylchuk, 1996). Doherty and Danylchuk posit that intellectual stimulation is best defined by the leader’s ability to motivate followers to be more curious and creative in thinking and problem solving. Motivating and stimulating the hospital staff and administrators at Jefferson to take an interest in my study was probably one of the greatest challenges I overcame throughout the study. Through continual self promotion of the study and numerous meetings and presentations, I was able to successfully get them not only interested in the study, but to become supportive, curious, and open to the idea of educating newly diagnosed patients differently. I wrote in my journal, “Ok, the staff loves the concept and are very receptive to the idea of using a DVD to inform the patients.”

Individualized consideration, a second tenet of transformational leadership, suggests that the leader provide support, encouragement, or somehow recognize the individual on a personal level (Murphy & Drodge, 2004). The basic foundation on which this study was conceived rested on the premise that I would provide a medium that would enhance, support, and give encouragement to newly diagnosed patients sorely in need of encouragement. I noted in my journal, “I am ecstatic about the number of patients this DVD will help.” I contend, based on years of personal medical issues, that a better understanding of my illnesses not only provided support, but refuted many of my personal assumptions. I also believe that a better understanding of cancer patient’s illnesses will give these individuals the encouragement one often needs to deal with a catastrophic illness such as cancer. I suggested earlier in this paper that my goal was to relate to these patients on a personal level. By providing them with information without excessive jargon, in the comfort of their homes, I provided additional supportive, educational information that increased their ability to make sense of their illness.

Inspirational motivation, the third component of transformational leadership, discusses the emotional ties one has to an organization (Doherty & Danylchuk, 1996). Since my wife was actually a patient at this hospital and one of the fundamental reasons for my initiating this project at Jefferson, inspirational motivation was not an issue. I was emotionally tied to this organization from the very beginning, and the staff and administrators were keenly aware of my emotional attachment. I wrote in my journal, “I can’t believe how many people remember me from my trips to the hospital with her.” When hospital staffers alluded to my dogged persistence, I could only turn to my emotional attachment to the study.

The final component of transformational leadership is idealized influence (charisma), an approach I relied on heavily as a young officer to elicit a desired response or behavior. It was not by sheer accident that thousands of men followed Hannibal, Patton, and McArthur. In addition to being brilliant tacticians, these individuals were able to lead using the transformational leadership characteristics of idealized influence. Trust, conviction, commitment, and ethics are a few of idealized influential elements of transformational leadership (Webb, 2007). Jefferson Hospital has an excellent reputation in the Philadelphia and tri-state area. It was important for me to maintain a sense of trust, commitment, ethics, and conviction during this entire process. Although on a number of occasions I could have easily lost my temper, I consistently opted to keep my focus and professionalism. I once wrote, “I must remain calm, even though I am really, really upset.” My ultimate goal was to complete this project despite adversity and any perceived loss of trust, commitment, dedication, or purpose on the part of the hospital staff, which could have been very costly in terms of the completed project.

Leadership Discovered: Servant Leadership

As I began to develop my vision of ultimately enhancing the patients’ understanding of radiation therapy, I started to gravitate toward a servant leadership style. I wrote in my journal, “Did my use of servant leadership evolve out of desperation, organizational survival, or necessity?” I needed to better understand my use of servant leadership. Using Greenleaf’s (1991) suggestion that one is a servant first, I knew that I wanted to serve patients by providing the means for their increased education about radiation treatment. With that decision, I was ready to lead by assuring that the patients’ needs were met within the study and that they would be wiser through the process and

more able to discuss their treatment with healthcare workers. I answered the question in my journal when I wrote, “I created this project to help cancer patients increase their understanding about radiation treatment so that they could discuss their illness and treatment with their doctors, nurses, and other healthcare workers. Serving patients is a necessity!”

After reading Greenleaf (1991), I was struck by his writing and how well it applied to the purpose of my study. From the onset of the study, I had a vision of how I could improve the lives of these patients through their understanding of the radiation process. In using servant leadership to complete my vision, the data suggested that the patients we served did indeed grow in terms of their knowledge and understanding. My servant leadership style of a strong commitment to the growth of understanding in the patients, along with my sense of stewardship, coupled with my ability to communicate my vision, were a few reasons why members of the hospital staff often commented about how worthwhile this project was and the benefits that would be derived by the patients from a study of this nature. After an early morning meeting with the nurses, I wrote their comments in my journal. “Several nurses told me this morning that this is a really good, interesting, and worthwhile study. Their words were inspirational to me. I needed their support to continue my work. More than one nurse told me that this will really help the patients.”

Greenleaf (1991) also contends that those being served become healthier, wiser, freer, and more autonomous. In my journal, I wrote, “As an advocate for the patients, I utilized my servant leadership by enhancing the patients’ understanding of their illness.” The data suggested that with increased percentages of correct responses in 80% of the

questions and with the decrease in respondents' indications they did not know the answer, they have become educationally healthier and intellectually wiser, which may create a sense of freedom through the power of knowledge and their greater understanding about radiation treatment.

Finally, Greenleaf (1991) suggests that the least privileged of a group or society will benefit from the servant leader's work or, at least, not be further deprived because of it. One of the overarching premises of the study was founded on the theory that all participants in the study could benefit. Patients undergoing radiation treatment for cancer were definitely a vulnerable population and benefitted from the study. Based on the data from both surveys and the DVD feedback questions, I stated in my journal, "All participants derived benefit from the study."

Assessment of My Servant-Leadership Characteristics

To better assess my transition to servant-leadership, I reviewed several of Greenleaf's (1995) 10 characteristics of servant leadership. The first, which is listening, according to Autry (2001) refers to the commitment the servant-leader has to listen to others. At Thomas Jefferson University Hospital the one essential characteristic that the newly initiated member must have is the inherent ability to listen. I noted in my journal, "I have definitely learned from the Jefferson Hospital administrators, particularly my mentors, by listening." As a new member I was literally told how business is conducted at the facility and how the study would be conducted. For me to serve, listening was the most important element as I was the person who was trying to better understand servant leadership. I noted in my journal, "It is important for me to listen because all of the information I am hearing is absolutely foreign to me." I wrote in my journal, "How am I

ever going to understand all of this medical jargon?” If I wanted to be successful, it was imperative that I understand this new environment and that understanding would begin with my ability to listen effectively. After one of my earlier meetings, I wrote in my journal, “I must remind myself constantly to listen carefully. Listening is the key to completing this process.”

Empathy, or the ability for the servant-leader to understand and empathize with others, was another important element in servant leadership (Greenleaf, 1991). I was able to empathize more than some people at the cancer radiation treatment center. I wrote in my journal, “I have experienced the radiation treatment procedures on two separate occasions with my wife. I empathize with anyone who must undergo radiation treatments.” Undertaking the study project was conceived partly because of the empathy I felt for her as well as the empathy I felt for the hundreds of other people with whom I came in direct contact during a two-year period. In my journal I often referred to feelings of suffering that the cancer patients had to endure. I wrote, “I pray that this project works because it would truly help a lot of people.” I felt that through this project I could ease some of the suffering of these patients by providing them with the knowledge and tools that would allow them to make better decisions regarding their illness and treatment.

Awareness, as defined by Greenleaf (1995), is that of self-awareness developed in self-reflection. I began to realize not only the completion of my vision but the development of my own self-awareness through this project. I began to see my servant leadership qualities emerge to the forefront of my mind and ultimately to develop through my actions. I suggested in my journal, “I really do have servant leadership skills. I am truly working for the benefit of cancer radiation patients.” Greenleaf suggests that the

servant leader will view most situations from a more integrated and holistic vision. I began to view the organizational structure of the hospital as it related to routines, rituals, and procedures as a comprehensive unit. In my journal I noted, “Jefferson Hospital is a wonderful place to work. Every employee that I contact seems happy to assist. They are genuinely interested in helping the patients.” Finally, in a regulated environment such as that at Jefferson, I wrote, “I have to have a keen sense of general awareness since the hospital’s unwritten code of ethics seems to be about deeds not dialogue.” After one of my visits to the hospital, I wrote in my journal,

Everyone is concerned about how the patients are progressing and if the patients are getting healthier. I am very aware that the hospital staff is there to move the patients from a state of illness to one of better health.

The power of persuasion, another servant leadership characteristic that I found I possessed, was inherently necessary to the overall success of the project. Greenleaf (1995) suggests that the servant-leader seeks to convince others, rather than coerce compliance. Although I had no powers of coercion at Jefferson Hospital, I did not feel that coercion would help me to gain access nor would it help to educate cancer patients. I did quickly surmise that I could influence (convince) the decision makers by highlighting the benefits of conducting a study of this importance in their facility. I noted in my journal, “I have to find someone at Jefferson who will listen to my ideas. I can convince whoever will listen that my ideas are sound, and my project will help Jefferson’s patients.” My ultimate vision and passion for serving the cancer patients at Thomas Jefferson University Hospital would be realized through my servant leadership. I was happy to write in my journal, “I knew my project would benefit cancer patients. I just needed to continue to work for its completion.”

Conceptualizing is the ability of the servant leader to dream great dreams

(Greenleaf, 1991). I chronicled in my journal,

With the help of Dr. Myers and Dr. Dicker in directing me toward the completion of the many necessary steps in reaching for my dream within Jefferson Hospital, along with many of the Jefferson radiation treatment staff members, I was able to turn this vision I had for several years into a reality.

This project was my great dream. I had the ability to see the whole in the perspective of history—past and future as Frick and Spears (1996) suggested. I stated in my journal, “Until now, there was not a suitable DVD for cancer radiation patients. Dr. Orloff’s DVD will help many patients now and in the future.” My leadership allowed me to state and to adjust goals, to evaluate, to analyze, and to foresee contingencies a long way ahead. I stated in my journal, “Even with the many changes I have made in my project, I will be able to complete it soon.” Conceptualizing, though, was possibly one of the most difficult elements for me. I was able to easily dream the big dreams. My journal states, “I know I can help patients who are undergoing radiation treatments to more fully understand the process with the DVD.” The difficult part of conceptualizing in my leadership capacity at Jefferson was the large number of changes, the restating of goals, the re-evaluating, and the multiple new contingencies that had to be provided for even after being given specific and definite assurances that the final product was ready for approval and movement to the next step in the process. My journal is a testament to the changes and my frustrations at the slow pace of moving the project forward. “Today, Dr. Myers suggested that I change my approach to patient surveys.” At another time, I stated, “Dr. Dicker wants me to shadow the people in his department, but I am unable to get a confirmation from his office.” Often in this study I referred to the Heifetz (1998) change model to guide my servant leadership and to ultimately complete my vision

(Heifetz, 1998). This model also afforded me the structure to help me to better understand some of the assumptions that I had regarding the organizational culture of the hospital (Schein, 2004). I wrote in my journal, “All of these changes remind me of the words of Thomas Paine when he stated, ‘These are the times that try men’s souls.’ ” I continued to write, “How am I going to understand the rules if they keep changing them?”

Servant leaders have a commitment to the growth of people. In this study, the patients’ knowledge grew, consistent with servant leadership (DePree, 1989). I forged the study on the premise that by enrolling in my study, at some point in the process or on some level, the individual would grow (Greenleaf, 1991). The data suggest that the majority of the respondents did experience growth. I told my journal, “I knew patients would understand cancer radiation treatment better after watching the DVD, just as I understood my eye operation better after watching a DVD.”

Finally, healing, stewardship, foresight, and building community are the final tenets of servant leadership (Greenleaf, 1991). Helping to heal others is why I began this journey. Allowing patients to better understand their illness and help to assist their recovery through enhanced educational awareness should help their healing process. Stewardship, or holding something in trust for the greater good of society (Greenleaf, 1991), is part of the reason Jefferson allowed me to lead this project in their institution. Cancer research is based on helping to find a cure for the greater good of society. The educational opportunity I presented them is just a fraction of the overall societal scheme of improving the health of their patients through service. Using foresight (Greenleaf, 1991) as a servant leader, I better understand the lessons learned from this study as well

as the implications this study can have on the patients who use this educational tool. More importantly, the commitment to growth (Greenleaf, 1991) that I think any patient will have who views the DVD will substantially improve his/her understanding of the radiation treatment process.

Leadership Discovered: Political Leadership

Throughout parts of this dissertation I referred to my need to use my political leadership or my political leadership skills to overcome in most cases some glaring obstacles that could affect this study. I will give greater clarity to political leadership. First, I present a definition of the term political leadership. Bolman and Deal (2003) offer an interesting question, “Is political leadership an advocate or a hustler?” It is an interesting question that I will answer in the following pages.

Bolman and Deal (2003) suggest that political leaders usually subscribe to a set of structured rules and have some basic inherent skills that aid them in their quest to achieve their desired goals. First, political leaders clarify what they want and access what they can get. In other words, Bolman and Deal suggest that political leaders are realists and they ardently avoid letting what they want interfere with what may actually be possible. Similarly, as I began to launch this study at Thomas Jefferson University Hospital, I clearly understood what I wanted. Although the possibilities for improving the educational process for cancer patients at Thomas Jefferson University Hospital were endless with our current social media and technological advances, I knew that I wanted to utilize a DVD as a means to achieve my goal.

Secondly, Bolman and Deal (2003) suggest that political leaders access the distribution of power and interest. This accessing of the distribution of power suggests

that one accesses the political terrain as well as taking inventory of the key players by asking, “Can those key players provide the support that I need?” As chronicled in this chapter, I did in fact survey the political terrain and was able to identify four important and vital key players at Thomas Jefferson University Hospital. Those key players were Ms. Soleiman, Dr. Myers, and Dr. Dicker, as well as Mrs. Sue Munro. As the director of the Bodine Cancer Center and a long time tenured faculty member and department chairperson, a high ranking administrative official, and the head oncology nurse, these were powerful people whose support I needed. These individuals made battles winnable, (Bolman & Deal, 2003). I wrote in my journal, “Myers, Soleiman, Munro, and Dicker have been a godsend, all too often they have made problems disappear.”

Third, Bolman and Deal (2003) suggest that political leaders build linkages to key stakeholders by building relationships and networks. One of the lessons that I learned early in this study was the importance of personal contact, honest and frank face-to-face conversations, as well as frequent follow-up phone calls, emails, and unscheduled visits to the hospital. I wrote in my journal kiddingly, “I am glad I have an unlimited calling plan; otherwise, my phone bill would be outrageous.” Without a doubt my relationship with these powerful individuals has easily helped me to eliminate a lot of stumbling blocks.

Finally, Bolman and Deal (2003) suggest that political leaders persuade first, negotiate second, and coerce only if necessary. Prior to my introduction to Thomas Jefferson University Hospital administrators, as a leader I rarely had to persuade or negotiate as a means of achieving my goals. However, true to form as Bolman and Deal suggest, I needed persuasion to get this project off the ground. In doing so I had to not

only persuade, but convince the stakeholders that this would be an excellent opportunity for the cancer patients at Thomas Jefferson University Hospital. I understood that my influence and success would begin with me making the stakeholders understand that I knew and understood their concerns and interests and that I knew what was important to them (Bolman & Deal, 2003). I wrote in my journal upon reflection of a few conversations with Thomas Jefferson staff members, “Did I do a good job of persuading them that this project has merit?”

Bolman and Deal (2003) pose an interesting question. Is the political leader an advocate or a hustler? Based strictly on my experience at Thomas Jefferson University Hospital surely I was an advocate for cancer patients at the hospital. My purpose, ethics, commitment, and service to this project would suggest a high level of advocacy for this project. However, just being an advocate for this study was not enough. In order to complete this project, I contend that a political leader must have a sense of a common street hustler somewhere embedded in his repertoire of persuasion to include a silver tongue and iron will (Bolman & Deal, 2003). This is also consistent with my servant and transformational leadership skills of commitment, individualized consideration, inspirational motivation, and charisma.

Leadership Synthesized

Successfully completing this study was a complex melding of transactional, transformational, servant, and political leadership approaches that I utilized to effectively lead this project. To better understand the importance of each of these leadership approaches I think that it is important that I briefly discuss them. At the onset of this study, I was not quite sure to what extent I would utilize transactional leadership, but

because time constraints were important and I needed patients that would be motivated about filling out two surveys as well as viewing the video in their homes, I could not think of anything better than to offer the patients a reward (Friedman, 2004). I did not, however, expect to receive an 83% participation rate as a return on my investment in these participants. I wrote in my journal, “I feel blessed that I have the funds to offer to these patients.” I am convinced after listening to some of the studies that took place at Thomas Jefferson Hospital with the length of time that these studies took and the relatively small participation rate, that offering an incentive, a transactional reward, was the key.

My use of transformational leadership (Doherty & Danylchuk, 1996) is dated back a number of years from my time as a principal in an urban school district as well as my time spent in the military leading marines. I used all of the tenets of transformational leadership during the course of this project, that is, intellectual stimulation, individualized consideration, inspirational motivation, charisma, and communication to successfully complete this project. Whether I was trying to stimulate the hospital staff, providing support for my project, strengthening my conviction, commitment, and trust, or strengthening my ties to the organization, all of these components of transformational leadership were vital to my success.

As an outsider at Thomas Jefferson University Hospital I did begin to gravitate toward a servant leadership style (Greenleaf, 1991). I was short on understanding the organizational culture, technical, and medical expertise, as well as the normal day-to-day operations of the hospital. So I quickly did more listening, attempted to gain greater awareness, use more of my persuasive ability, as well as enhancing my commitment to

enabling the growth of these cancer patients through my study. However, as I chronicled throughout this chapter, servant leadership was fairly new to my leadership repertoire. Yet, even though servant leadership may have been a dominant leadership approach, the others I have discussed so far were no less important to the completion of this study.

Using my political leadership style (Bolman & Deal, 2003) was paramount to promoting the importance and need for this project. From the outset I was clear and realistic as to what I wanted to do at Thomas Jefferson University Hospital. From the first day that I entered the hospital I immediately began to access the power brokers in the organization and how I could get them on my team. Without them, winning any battles would be difficult. Once I secured these stakeholders, I immediately began to build the necessary relationships and networks. Finally, political leadership, I learned, was an ongoing cycle of persuasion, convincing, and negotiation.

At the beginning of this study I was focused on one of my research questions which states, to what extent do I use servant (Greenleaf, 1991) and transformational leadership (Doherty & Danylchuk, 1996) during this study to improve patient education? However, in retrospect, it is clear that although servant leadership was a dominant approach throughout this study, followed closely by transformational leadership, each of the leadership approaches were significant to the overall success of ensuring the enhanced educational process for patients newly diagnosed with cancer. Without transactional leadership (Friedman, 2004) I am convinced the study would have been delayed significantly and my participation rate would have been significantly lower. Without transformational leadership (Doherty & Danylchuk, 1996), listening, awareness, empathy, healing and the other tenets of this leadership style, would have hampered the

success of this project. Servant leadership truly added another leadership tool for me to utilize not only with the stakeholders at Thomas Jefferson Hospital but in my everyday life. It was important for me to understand that through servant leadership, and not my normal pedestal to the medal leadership approach, I was able to still successfully lead. Finally, the last leadership approach I utilized was political leadership (Bolman & Deal, 2003). It, too, was a vital component to the success of this project. Each of these leadership approaches is complex, but skillfully woven and blended together created a leadership masterpiece for success at Thomas Jefferson University Hospital.

Heifetz (Leading Change)

The plan of action, beginning with the initiation of the project through the implementation phase of the project, had rules, regulations, and protocols that are detailed in the earlier chapters. I used each step of Heifetz's Seven-Step Change process from step one through step seven repeatedly (Heifetz, 1998). The change strategy gave me the kind of structure that I needed to organize, reorganize, and often completely change facets of my research study as required by the hospital administration personnel. I wrote in my journal,

If I am going to be successful and convince the people here at Jefferson of how valuable this project is, I need to follow a change process that gives me structure and a process that I am familiar with if I expect them to take me seriously.

Planning the change is the initial step in the Heifetz (1998) model since it is imperative to understand why the change is necessary and why the change is important.

Before I met anyone in charge at the hospital, I wrote in my journal,

I know from personal experience with my wife that Jefferson Hospital could use assistance in providing cancer radiation patients with education about the radiation process. As educators, she and I did not fully understand the information

we were given before and during her radiation treatments on two separate occasions.

Understanding the importance of the change and why the change is needed was the primary foundation and focus as I literally planned and presented my project to anyone in Thomas Jefferson Hospital administration who would give me more than a minute of his or her time. After my first meeting with an administrator, I left the hospital and wrote in my journal, “I can’t believe that they are finally giving me the signal to go ahead. They will listen to my ideas.” Surprisingly, the administrators were quickly able to share my vision of the future based on my ability to articulate my vision and the benefits I indicated could be derived from the study (Heifetz, 1998). I wrote in my journal, “Ms. Soleiman liked my ideas enough to suggest the kind of information I needed to provide the reviewers, and she has named a mentor for me to be able to meet the hospital’s rules and regulations.”

Step two of the Heifetz (1998) model, the setting of change goals, was more difficult than I had anticipated. My vision for the design, planning, and implementation was vastly different from that which would be required by the hospital. Although I did not detect any discernable internal hospital resistance to my project, I struggled with administrative and organizational obstacles. For example, understanding hospital protocol, learning the hospital’s chain of command, and getting a better feel for the organizational culture of the hospital were all hurdles that impeded the change process and kept it from moving forward (Heifetz, 1998; Schein, 2004). After many encounters at the hospital, I finally wrote in my journal, “The playing field at this hospital is huge. Will I ever learn the players, and will I ever learn to play the game using their rules?”

Initiating the action of the change, step three of Heifetz's (1998) seven steps, was crucial. At every meeting, e-mail, phone call, and informal conversation, in all contact venues, I used intellectual stimulation (Greenleaf, 1991) constantly to reinforce the importance of the change. I wrote myself notes in my journal:

Tell them about your student status and your dissertation study. Tell them about your research. Tell them about the DVD on the eye surgery and how it helped to understand that process. Tell them about the lack of understanding when your wife underwent radiation treatments on two separate occasions.

I used my servant and political leadership (Bolman & Deal, 2003; Greenleaf, 1991) ability to convince the hospital administrators at every available opportunity of how my project could better serve cancer patients undergoing radiation therapy treatment.

If it were not for my ability to master step four, making connections, I doubt very seriously if I could have completed the project. Through the initial presentation I was able to communicate my vision (Kouzes & Posner, 1996) for the study to Ms. Soleiman, as one of the top administrators at the hospital, she was impressed with my ability to lead the project. She then convinced Dr. Myers, a long-time tenured faculty member and department leader, and Dr. Dicker, the interim director of the Bodine Cancer Center, to become my mentors for guiding the project through the hospital's rules and regulations. These powerful people were my connections and conduits to reinforcing the importance of change as a process and not simply as an event (Heifetz, 1998). I wrote in my journal, "This is a pure stroke of luck that I am able to connect with these powerful people." In addition to securing connections with Dr. Myers and Dr. Dicker, through my political leadership and ties to these two powerful men I was able to forge and establish important relationships with Ms. Sue Monro, the head nurse of the oncology unit, and with Mr. Wolf, Dr. Myers's new assistant. Bolman and Deal (2003) discuss the importance of

forming coalitions inside the political arenas of organizations. I even wrote in my journal, “Sue Monro reminds me of myself as a Marine lieutenant. Her ability, her drive, and her emphasis on completing this project are amazingly familiar.” I used my servant leadership (Greenleaf, 1991) to persuade the administration at Jefferson to invest in this project. Without successfully making the connection with these powerful political allies who shepherded me through the Jefferson experience, this study would not have been possible. Using the servant leadership characteristics of foresight, a greater awareness of the organization’s culture (Schein, 2004), and persuasion, along with the connections I was fortunate to establish, enabled me to work through many of the obstacles that became a normal part of the process (Greenleaf 1995). I wrote in my journal, “Having friends on the inside makes life a lot easier.”

I have chronicled throughout this dissertation that in step five, the importance of being able to make adjustments, Heifetz (1998) suggests that I had to be able to rebalance to accommodate the change. As a leader from the inception of this project, whether it was suggested that I adjust my vision, make changes to my surveys and questionnaires, rework my timetables, or familiarize myself with hospital procedures, making the necessary accommodations for change was an extremely urgent and critical facet of this study. The greatest challenge to my leadership flexibility during this step was trying not to get frustrated by the multitude of changes and trying not to become cynical or disenchanted with the numerous adjustments that were always necessary. I wrote in my journal, “Michael, you must keep your emotions in check regardless of how many changes they make. I must remember that I am a guest in their house.”

Through it all, the one constant for me in Heifetz's (1998) change process was step six, consolidating the learning. Consolidating the learning was a significant step throughout the entire research project and throughout each cycle of the process. This step allowed me to accurately plan, act, observe, and reflect on each of my many courses of action as the leader of the project. I found this particular step to be the most instrumental and the most important in my leadership growth. Even though I always coordinated my plan of action with the powers-that-be at the hospital, when the plan was sorted through the various levels of hospital administration, my original design rarely remained the same. I confided in my journal, "Where is that one administrator in the hospital that has the final determination?" At the core of my consolidation of learning, I was taking feedback and adjusting and readjusting to the suggestions of the organization while still managing to keep my vision of educating cancer patients fundamentally intact. As a servant leader I advocated for my vision (Greenleaf, 1991) but sometimes settled for a different process for reaching it than that which I had conceptualized. In my journal I sarcastically wrote, "I want birds of paradise, but in order to get this project completed, I will settle for daylilies." I maintained the basic foundation and core of the study, which was to present radiation cancer patients with a process to enhance their information about the illness and its treatment.

Finally, moving to the next change cycle involved my leadership ability to ensure that the change is sustainable (Heifetz, 1998). I had written in my journal, "Dr. Orloff has given me permission to use the DVD in my study." Later I noted, "Sue Munro asked if she could use the DVD in her training sessions. I had to tell her that unfortunately I had permission to use it only in my study." Emory University is now making the DVD

available to everyone at Thomas Jefferson University Hospital and the Bodine Cancer Treatment Center through the website (American Cancer Society, n.d.). I believe that the change will become imbedded as an intake ritual for newly diagnosed cancer patients. I wrote in my journal,

I could not allow the DVD to be used for the initial intake for newly diagnosed cancer patients as I carried out my study since I only had permission to use the DVD in the study. Now that the DVD is available through its website, I believe that it will be a valuable tool for educating new patients through the intake process.

Moreover, I plan to continue my leadership by involving myself in future negotiations with Thomas Jefferson University Hospital to loop the DVD with the television that is already mounted in the Bodine waiting area. I added a note in my journal, “As an approved volunteer at Jefferson, I will continue to negotiate with the hospital to loop the DVD with the television set which has been installed in the waiting area of the radiation treatment center.” As a leader, the planning for the next phase of the change is a relatively easy operation to complete to ensure that all radiation patients have daily access to the video. My vision and my leadership will have come together completely.

Organizational Culture

I learned a great deal during the research project. The important lessons were about my ability to adjust and to change my leadership perspectives to match those that work best for the organization while still accomplishing my goals (Heifetz, 1998). Additionally, from this process I gained a better overall and more well-rounded perspective for what is required to work with large organizations. I wrote in my journal, “I am really learning about servant leadership. I now know I can change leadership

approaches and still lead effectively.” Through this study I now understand the ties that link leadership, the culture of organizations, and the change process. For me, the servant leadership approaches of persuasion, commitment, and awareness (Greenleaf, 1991) were tied to some of the cultural organizational tenets like time and space (Schein, 2004). The process of change (Heifetz, 1998) was directly connected to how well I led the study and how well I was able to understand and navigate the cultural organizational climate at Jefferson Hospital. Each facet of this process was needed for me to complete my vision of better educating cancer patients.

Leadership, ironically, has taken on a whole new meaning for me. In the past I have characterized and associated leadership with my ability to maintain nearly 100 percent of the control as illustrated best when I was a Marine Corps officer and even when I was a school principal (Tannenbaum & Schmidt, 1973). However, now having extensively experienced the use of a different form of leadership, servant leadership (Greenleaf, 1991), and the utilization of a vastly different method of operation through this research study, my entire view on leadership has taken a dramatic shift. I wrote in my journal, “Now that I am adding servant leadership to my repertoire, it reminds me of a teacher learning a new teaching strategy.” From firsthand experience as a complete outsider attempting to facilitate change in an organizational culture that is highly regulated, often I was virtually powerless to make decisions without the aid of a hospital administrator to correctly apply the organization’s regulations (Schein, 2004). This situation forced me to lead the project from a very different vantage point. I led using more of a servant and participatory style of leadership, and I was able to successfully complete the project (Greenleaf, 1991).

Outside the Organizational Loop

It is clear that when a person from the outside who is lacking the knowledge of, expertise in, and, above all, membership in the organization, is seeking access to make a change in any kind of regulatory agency, almost insurmountable obstacles will appear (Bolman & Deal, 2003). After meeting with Ms. Soleiman, I had naively written in my journal, “I do not see any obstacles to my study. Ms. Soleiman asked for written information. This will be easy.” The obstacles, which one might consider to be resistance, were not from any one individual or even from one group of individuals. They were more the required procedures and process that come as part of the organizational culture (Schein, 2004) of many large organizations. Clearly, Thomas Jefferson University Hospital has a blueprint and protocol for its process of doing business. If I expected to survive, implement, and successfully carry out the project, it was imperative that I become not only aware of the structural framework of the hospital organization, but I, the leader, must be able to use political leadership for the success of the end product using my political leadership skills (Bolman & Deal, 2003). I wrote in my journal, “Ok, I can do this! Political leadership for me has always been a piece of cake, and Jefferson is no different.”

With a great number of the procedures and regulations which are deeply imbedded in the organization, some of the greatest skills I was able to refine in the area of leadership were my political skills (Bolman & Deal, 2003) of patience and persistence, along with the development and frequent use of awareness, foresight, and listening, which are all important servant leadership traits (Greenleaf, 1991). My journal notes, “I listen to learn from Dr. Myers, my mentor. He is a medical researcher at Jefferson.” As

the leader of the proposed project, I searched for almost six months for a medium suitable for my project that would visually display radiation therapy education. When I initially met Dr. Orloff from Emory University through his website, he was in the planning and very early developmental stages of creating a radiation video. The persistence and patience necessary to continue to research and to follow-up with Dr. Orloff (during a six-month period) were indeed great accomplishments for me personally and as the leader of the project. I wrote in my journal, "I am here for the long haul, and I don't care how long it takes. I am not going away."

From the initial planning stages of the hospital study, I had to exhibit an unwavering sense of servant leadership and vision (Kouzes & Posner, 1996). Kouzes and Posner suggest the vision of a leader should contain a number of distinctive attributes. These theorists suggest vision is about possibilities or one's desires for the future. It is steeped in thinking or rationale that opens up the leader to considering an infinite number of possibilities. I, the leader, certainly had the vision about the possibilities for cancer radiation patients. My journal has my ideas, "I will find a medium that is suitable for educating cancer radiation patients about their illness and about its treatment. If there is a DVD on eye surgery, there must be one for radiation treatment of cancer."

My vision for this study through the use of my servant leadership characteristics of awareness, listening, persuasion, foresight, stewardship, and a commitment to the growth of people (Greenleaf, 1991) was to examine the various levels of understanding that patients had about cancer when they had been diagnosed with the illness and to improve their understanding of the radiation treatment process through the presentation of an educational video (Wong, 1992). I wrote in my journal, "I know in my gut that if

the patients could only see the video, they would have a better understanding of their treatment. That is all I want.”

Since patients often remained confused and thereby missed vital information, regardless of how many explanations or how much information they had been given to explain cancer and the options they had for treatment (Eiser et al., 2005; Kodish et al., 2004), my vision was to improve their educational awareness. Additionally, my vision (Kouzes & Posner, 1996) was to lead this study as a servant leader (Greenleaf, 1991) and advocate toward the goal of satisfying the need for cancer patients to understand the radiation treatment process and the terms and jargon used by the medical community. I wrote in my journal, “If my wife and I had trouble understanding the medical terms concerning the radiation treatments, I know other patients will struggle to understand, as well.”

Along with a growing familiarity with the elements necessary to succeed at Thomas Jefferson University Hospital, I discovered very early that video-based education was important and that it would truly benefit and serve a great number of people (Kinnane et al., 2008). As a servant leader it was my personal commitment and vision in the final product that kept me focused and committed (Kouzes & Posner, 1996; Greenleaf, 1991). To realize the desired vision and ultimate goal of an enhanced educational experience for the patients at Jefferson Hospital, I communicated with the administrative staff on a regular basis. I wrote in my journal, “Touching base with the nurses and staff is becoming easier. They actually know who I am now.” Throughout this study I needed communication, a transformational leadership characteristic, to bring this educational change to fruition (Deluga, 1990). I communicated with the administrative

staff at Jefferson as a means not only to lead this project but to also to keep abreast of the status of the change process. It was my premise that I could enhance the procedure of providing cancer radiation information to patients of Thomas Jefferson University Hospital. Through a technological presentation specifically on radiation therapy, my vision was to relate to these patients on a personal level. By providing easily understood information without excessive amounts of technical and confusing jargon, this study provided the patients with additional educational information to enhance their abilities to make sense of the radiation process. I noted in my journal, “Dr. Orloff and I made excellent partners. He supplied the means for educating the patients, and I, eventually, supplied the cancer radiation patients at Jefferson Hospital who determined that the DVD had valuable information in an understandable format.”

Because setbacks are an inherent part of any change project, Kouzes and Posner (1996) suggest that leaders must have future orientation or the ability to look forward and have a long-term vision or direction. My vision of leadership had to encompass both serving and leading (Trompenaars & Voerman, 2009). Whether I was listening more intently or being more persuasive and convincing in my interactions with the hospital staff, which are servant leadership approaches (Greenleaf, 1991), or whether I was being more inspirational, charismatic, or providing intellectual stimulation, all transformational leadership approaches (Doherty & Danylchuk, 1996), I did whichever was needed to lead and move this project forward. I wrote in my journal, “Just like the Marines, everything I have been taught was about, leadership. But at Jefferson sometimes I needed to lead, sometimes I needed to follow, and sometimes it was best that I just get out of the way.”

A key cultural component, at least initially, was attempting to better understand the organizational landscape that permeated both Emory University in Atlanta, Georgia, and Thomas Jefferson University Hospital in Philadelphia, Pennsylvania. Bolman and Deal (2003) suggest that organizations are coalitions of diverse individuals and interest groups. The coalitions within organizations were never more evident than at Emory University and Thomas Jefferson University Hospital. As I examined Dr. Orloff's organization from an outsider's viewpoint looking into its facilities, he and his staff were completely cooperative, collaborative, and transparent with me from the moment I first contacted him. Gaining access to any of his materials was as easy as asking for them. I wrote in my journal, "Gaining access to Emory University and Jefferson University Hospital are as different as day and night." Dr. Orloff also was more than amenable in sharing his time, his resources, and his expertise. Although I understand that Emory University has diverse cancer related interests, Dr. Orloff's staff, along with his co-workers and staff at the American Cancer Society, demonstrated a similar passion for sharing, collaborating, and offering assistance.

Organizational Procedures, Rules, Protocol, and Paperwork

My servant leadership, political leadership, transformational leadership, (Bass, 1990; Greenleaf, 1991) and learning to work through the structural framework of the hospital were required to gain access to Thomas Jefferson University Hospital's organization to complete the study (Bogdan & Biklen, 2007). Completing the 16-page Human Study Application, a hospital requirement, was a tremendously laborious task, but I was able to complete it through the political coalition with Dr. Myers's research assistant, Mrs. Martha Keintz. I wrote in my journal, "I should have realized the

importance of documentation in a hospital. But, this seems like an endless paper trail.” In addition, through her advice Mrs. Keintz helped to develop an acceptable Descriptive Information Document to present to each patient. Developing a suitable Study Visit Detailed Flow Chart, along with designing and implementing an approved schedule for potential participants, was another Jefferson organization necessity, which I, as the project leader, was able to provide. However, one of the greatest challenges I faced was the successful format, development, and implementation of a Pre-and Post-Survey to include demographics, medical history, and feedback questions that the Jefferson IRB committee would deem suitable to distribute to 50 cancer patients who were undergoing radiation therapy. I wrote in my journal, “Will I ever get this survey right?” The entire process was a project unlike anything which I had encountered in my entire life. I successfully navigated through these areas as a servant leader working within an unfamiliar organization to complete every aspect of the project (Bolman & Deal, 2003). Obviously, procedures, rules, protocol, and paperwork are a part of large organizations. The procedural and structural framework (Bolman & Deal, 2003) of Jefferson Hospital was confusing and frustrating. But my charge as the servant leader of this project was to continue to focus on my vision, understand the facts, and rely on logic rather than on personal emotion (Greenleaf, 1991).

To name all of the positives I have gained from working with the staff of Thomas Jefferson University Hospital would be most difficult, but they have definitely enhanced my intellectual abilities, my resourcefulness, and my leadership. From an intellectual standpoint, researching this topic was an extremely uplifting enterprise. As an outsider with no medical expertise except for being a patient, the resourcefulness and innovations

I needed and used as a leader to satisfy hospital rules and regulations surprised even me. I wrote in my journal, “There are a lot of multi-talented people in this hospital.” Finally, vacillating among transformational, servant, and, occasionally, transactional leadership as the situations dictated was exhausting, but exhilarating (Bass, 1990; Greenleaf, 1991). Both mentors helped me to understand the organizational structure that exists at Jefferson. Bolman and Deal (2003) suggest that organizations have several inherent needs. After nearly two years of studying and working with the staff of Jefferson University Hospital, as an outsider I still always felt valued. Regardless of the many obstacles and dead-ends I encountered, someone was readily available to offer an encouraging word. The words that resonated throughout the study were, “The project will provide an excellent service to the patients at Jefferson University Hospital.” This project helped to clarify many of the characteristics of the servant leadership I exhibited. First, to complete a project as an outsider in a large organization like Jefferson, I acquired a sense of heightened awareness of the organization, a tenet of servant leadership (Greenleaf, 1991). Often I was required to persuade or convince members of the administration of the benefits of the study, another servant leadership tenet. I wrote in a journal entry, “If I plan this study properly, the patients at Jefferson will receive an excellent service.” I also notated, “If I implement the study properly, the patients will become much more knowledgeable about their radiation treatment process.” Ultimately, from an overall servant leadership perspective, the patients grew educationally more healthy and intellectually wiser (Greenleaf, 1991). My journal noted, “The results of my study show that the cancer radiation patients at Jefferson Hospital who watched the DVD and

answered the pre-and post-surveys grew educationally. I expect many more patients to access the DVD in the future.”

Leveling the Organizational Playing Field through Leadership

As I chronicled earlier in my dissertation, my political leadership led to the gaining of approval for my questionnaire, the first hurdle in my quest to gather the necessary data for the project (Bolman & Deal, 2003). My will to achieve my vision, my endurance to work for the success of the project, and my leadership helped to complete the actual patient survey. I wrote in my journal, “I can’t understand how something so simple could take nearly a year to complete.” By designing, developing, and distributing the Patient Survey instrument, complete with demographic information and open-ended questions, I proved to myself that my leadership could overcome one of my greatest challenges. I noted in my journal, “Finally, with prompting and approval of my mentors, I made it.” I settled on a suitable Likert scale after consultation with my political allies. I formed suitable questions for the survey, and I formed the correct format for presenting the questions through a coalition with the clinicians (Patten, 2001). In my journal, I wondered, “Why do I have to prepare an additional survey?” After the submission of the clinicians’ questionnaires, I wrote, “That was a really good idea. This narrows my Patient Survey to a workable level.” As obstacles arose, I was able to summon various levels of my emotional attachment to the project, rely on the trust in me that the Jefferson staff had, use my political leadership skills, and describe a sense of purpose and commitment to achieve the desired outcome of completing my vision using various transformational and servant leadership approaches (Doherty & Danylchuk, 1996; Murphy & Drodge, 2004).

Discussion: Research Questions

I suggested earlier in this study that through my leadership I would provide the patients at Jefferson Hospital with enhanced educational benefits in the area of radiation therapy. This study was designed to answer the following two leadership research questions:

- 1) How has my leadership shaped this research project?
- 2) To what extent did I utilize servant and transformational leadership during this study to improve patients' education?

I contend without my leadership this study would not have been completed. Although the project was well received at Jefferson, it was by no means the kind of study that would prompt anyone at the hospital to impose deadlines and or inquire about completion dates. Without my leadership this project would have very easily ended right where it began, as a draft of something potentially good for the newly diagnosed cancer patients at Jefferson. When action was to be initiated (Heifetz, 1998) on the progress or status of this study, it was initiated by me. This project moved forward specifically as a direct result of my insistence and leadership. My leadership shaped the completion of this research project.

However, during this study, I noticed an interesting dichotomy in the later stages of the project. My leadership was shaping the course of events in the study. Instead of seeking a minimum of editing and revising of materials, I was actually leading the project by presenting my ideas for submission to Jefferson Hospital administrators for their approval. I wrote in my journal, "Finally after a year, I am getting the hang of this project." After interacting with administrators and working in this highly-regulated and

structured environment for nearly 18 months, I became familiar with the culture and understood the requirements for administrative approval at Jefferson Hospital (Bolman & Deal, 2003). I wrote in my journal, “I am actually having fun at Jefferson. I have a chance to lead very important people in recognizing how important my study can be for cancer radiation patients at Jefferson.” The recommendations and suggestions from Jefferson administrators were fewer and farther between as the project progressed. Through my familiarity with the organization and excellent on-going communications with the Jefferson staff at all of the internal administrative structural levels, I have effectively led this project. I bragged in my journal, “I have learned much, and I have also taught knowledgeable hospital administrators something that they apparently were unaware of.” Challenging the former process of how patients were informed of radiation treatments for cancer, and now winning the hard fought battles at Jefferson to present the information in a new way has helped my leadership shape this project, and I defined my legacy at the hospital as a leader who has purpose, an emotional attachment to the patients, and one who will not retreat but is committed to seeing my vision through to completion (Kouzes & Posner, 1996). Additionally, my vision, patience, persistence, and political skills all shaped the project. As the leader and co-investigator of this project utilizing transformational and servant leadership, it was of paramount importance that the staff at the hospital realize that under no conditions or circumstances would I abandon my vision merely because the project often ran into organizational barriers (Webb, 2007). After a meeting with the nursing staff, I wrote in my journal, “I believe they are pleasantly surprised that I am seeing this project through to the very end.”

My leadership shaped this project in other aspects during the course of conducting the study. My ability to adhere to rules, regulations, and restrictions imposed by others increased in innumerable ways. Prior to my involvement in the study, I was always the leader responsible for dictating the status quo or the way things were to be done (Murphy & Drodge, 2004). I was the regulatory agency. I usually had the autonomy to conduct business as I saw fit. Rarely was I the person required to take stringent, structured directions (with the exception of my training and responsibilities in the Marines three decades ago). It was extremely difficult, initially, at Jefferson to take directions instead of giving directions. Following instead of leading is not a position I have ever relished. I wrote in my journal, "Following can often be just as stressful as leading." However, my vision (Trompenaars & Voerman, 2009) was to improve the patients' understanding of the radiation therapy process. At points in this process, I had to follow in order to learn the structural organization of Jefferson Hospital, and by learning I made my vision a reality. Reshaping not only my leadership style, but suppressing my normal learned, if not inbred, tendency to take control immediately, became a complete reversal of my leadership experiences and truly enhanced my growth as a leader. These changes demonstrate how I also was changing and learning through this project. A transformational leader now promulgating servant leadership tenets where I could best serve the needs of the cancer radiation patients gives testimony to how I was affected by the changes I was attempting to bring to cancer patients through education (Burns, 2003; Greenleaf, 1991). I wrote in my journal, "I have to change from a transformational leader to a servant leader if I ever want to complete this project. I have to change my approach."

Earlier in this chapter I discussed how using a transformational approach aided me in the completion of this study. Whether I utilized intellectual stimulation, individualized consideration, inspirational motivation, or idealized influence as one of my transformational approaches, each of these characteristics was important to the success of this project (Doherty & Danylchuk, 1996). However, one of the driving characteristics was the inspirational motivation and emotional attachment that kept me focused on completing this study (Doherty & Danylchuk, 1996). Like servant leadership, I did use transformational leadership to a great extent to improve patient education.

Initially, I thought that my use of a servant leadership style would play a limited role in the study (Trompenaars & Voerman, 2009). With limited expertise and as a new member to the Jefferson organization, I had to utilize a servant style of leadership to complete the study and to serve the patients by increasing their knowledge of the cancer radiation process at Thomas Jefferson University Hospital (Greenleaf, 1991). Utilizing persuasion, empathy, healing, conceptualization, listening, and awareness—all servant leadership approaches—I led the powers-that-be at the hospital into a successful way of providing their patients with enhanced education in the area of radiation therapy.

Conclusions

I learned that in leading sustainable change, specifically in an institution in which I am not a member but an outsider, implementing change is a long, arduous, regimented, and precise process (Schein, 2004). Moreover, my previously most used leadership styles—autocratic, dictatorial, and transactional—all played a limited or even non-existent role in this process (Doherty & Danylchuk, 1996; Holmes, 1993; Simmons & Moskin, 1998). I learned that if I were not completely open to suggestions from the organization,

flexible enough to rebalance to accommodate change, and heavily servant in my leadership style, the change process in this institution for this project would not have succeeded (Greenleaf, 1991).

I have meticulously implemented Heifetz's (1998) Seven-Step Change Cycle throughout this study. As a result of the steps – planning the change, setting and resetting goals, initiating the action of the change, making connections, rebalancing to accommodate the change, consolidating lessons learned, and moving to the next change cycle (Heifetz, 1998) – I am confident this change is sustainable. I wrote in my journal, “Change, sustainable or not, is an exhausting process in a large organization like Jefferson.” As a leader, I learned that Jefferson Hospital, even with stringent rules, regulations, and procedures, is not a closed-door organization. I found that after I satisfied their requirements, there were numerous individuals and groups within the hospital who were willing to accommodate me as the leader and support the project of making it possible for cancer radiation patients to become more aware of the radiation process and their choices for treatment. In my journal, I griped, “If I had only done more research on the organization, I feel that my study would have progressed much more quickly.” Jefferson Hospital has a very specific manner in which it operates, and I learned as a leader to adhere to their stipulations (Bolman & Deal, 2003). Because of my ability to utilize the Heifetz (1998) Seven-Step Change model, I enabled patients to become better educated at Thomas Jefferson Hospital and prompted the hospital to want to incorporate this project as part of their daily intake and patient educational operations. I suggested their interest early in my journal when I wrote, “Ms. Soleiman wanted to include the DVD in the daily intake packages even before it was completed. Mrs. Munro

asked to include the DVD in her patient training classes before it was released in the website.”

The possibilities for Thomas Jefferson University Hospital to take advantage of what was gleaned from cancer radiation patients’ learning opportunities are endless. Mrs. Susan Munro, head nurse of radiation/oncology at Thomas Jefferson Hospital, requested to use the videotape/DVD with her patients. She will certainly be able to do so now that Dr. Orloff has released it in the website. Mrs. Joyce Soleiman, the Clinical Administrator for Thomas Jefferson University Hospital, wanted to use my ideas for her intake packages (Carey et al., 2007). The intake packages are rituals and routines that are well ingrained in hospital policy and daily activities. Making the DVD a part of the existing intake package will solidify it as a sustainable change in the way Thomas Jefferson University handles new patients.

Given the results of the data, specifically the information gleaned from the DVD feedback questions, Thomas Jefferson University Bodine Cancer Treatment Center will examine the use of the videotape/DVD, the world wide web (www), podcasting, Skyping, and other technological possibilities brought to focus through my research study. As a servant leader, I believe that the hospital will include the utilization of a very simple pamphlet entitled “For Your Information, Quick Facts Reference Guide” which summarizes educational facts that I took from Dr. Orloff’s videotape (Chelf et al., 2001). In my journal, I wrote, “I will design a pamphlet entitled ‘For Your Information, Quick Facts Reference Guide’ which the hospital can make available to patients in the Bodine Center waiting area.”

Finally, the entire process of creating a means through the use of a DVD for educating cancer radiation patients is actually coming to an end. More importantly, I better understand through journaling how my utilization of servant leadership has dominated my study. I wrote, “Reflecting toward many years ago on my leadership growth and development, although submerged under various ego-driven, autocratic, and transformational leadership characteristics, my core may have been ultimately servant.” I cited many years of community involvement, fraternal service to our youth organizations, serving my country through military induction, and, of course, one of the basic premises of this study, service to others. Earlier in this chapter I discussed the 10 characteristics that Greenleaf (1995) cites as traits of servant leadership. The documented similarities in my leadership style with those Greenleaf suggests for servant leaders are clearly evident throughout my study.

Upon further reflection had I been aware of the rigors of Jefferson’s administrative structure and logistical enormity of this type of study in an organization such as Jefferson Hospital, I might have opted to examine other research projects. As this project was coming to an end, I wrote in my journal, “I am excited to have worked with Jefferson, but I am equally glad that the process has finally ended.” However, having completed the process and having enabled patients to become better educated by this process, having grown intellectually and in my leadership, I am thankful to have had the opportunity to partner with Jefferson to complete my vision of educating cancer radiation patients.

Unique Contribution to Broaden Educational Leadership

From the survey data and the DVD feedback responses from the patients, this study has provided a unique contribution that has broadened the field of educational leadership. Since this process has come to an end, I have had an opportunity to examine this study from both a medical and an educational vantage point in an effort to assess any unique contribution this study has made to broaden the field of educational leadership. Many of my colleagues have conducted studies that have directly correlated to the field of educational leadership, either from a higher education, secondary, or primary educational context. As a result of the context, their projects overwhelmingly took place in an educational institution. When I was first questioned concerning how I thought this study contributed to broaden educational leadership, I really did not understand what, if any, ramifications or impact my study may have made. Several days later after having ample time to really reflect on this theme, I have several thoughts about how this study did broaden the contribution to educational leadership.

This study successfully made the transition from its original design and inception in an educational institution to its development and implementation in a medical institution as the setting for conducting the study. Breaking from the traditional setting of most educational leadership projects, this study was not relegated to the normal public school, private school, or higher education institution setting. Instead this educational leadership study was entirely conducted in a medical facility. I used education as the foundation for this project as well as chronicled leadership strategies throughout this study to introduce/infuse a new educational process into a medical facility, Thomas Jefferson University Hospital. That alone, I would suggest, has broadened the educational

leadership field; however, I have several additional areas where contributions to our field have been made.

Breast cancer campaigns have permeated every aspect of our daily lives through an enhanced awareness of the illness. This educational leadership study lends itself to promoting a greater awareness about radiation therapy through the medical community. It will definitely create a greater understanding about radiation treatment, which will, in turn, create a broadening effect to our field of educational leadership. I feel a sense of personal contribution through the design, development, and implementation of the clinician questionnaire and the pre/post surveys as evaluation instruments. It is important to remember that these documents were forged on an educational leadership platform. They were presented to the medical community for their approval and, hopefully, will be used for cancer radiation patients and additional research everywhere. This contribution from the educational leadership community to the medical community is somewhat unique from my perspective.

The greatest educational leadership contribution I could have provided for the radiation patients is found in the information that can now be easily obtained through the in-take process for newly diagnosed cancer patients who are undergoing radiation treatments, through easy-to-understand pamphlets in the waiting areas of radiation treatment facilities, and through the use of a readily accessible and informative video in a format that offers patient-friendly information to those in need of radiation treatment information.

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Appendix A

Cancer Radiation Therapy Provider Questionnaire

December 15, 2009

Dear Radiation Therapy Provider,

My name is Michael Mimms. I am a doctoral student at Rowan University in Glassboro, New Jersey. As part of my dissertation in the Educational Leadership Doctoral Program at Rowan University, I am conducting a survey of radiation oncology providers. The survey is intended to ask for reactions to a patient education 3-D animated video (or the printed transcript), developed by Emory University and commissioned by the American Cancer Society. I would like to ask you to participate in this survey.

Specifically, I would like to ask that you review the information abstracted from the video and summarized on the survey according to the sections of the video. In each section, please indicate, in your opinion, the level of importance of each one relative to preparing patients to have an informed discussion with radiation oncology providers about their care. The sections of the video are as follows:

- I. An introduction to radiation therapy
- II. Types of radiation
- III. External radiation therapy
- IV. Internal radiation therapy
- V. Radiation therapy side effects

Steps for completing and returning the survey:

1. Please rank/order the educational facts from each section. Write "1" next to the most important information, "2" next to the next most important, and so on.
2. Place the completed survey in the folder marked "Surveys" at the Radiation Oncology patient sign-in desk.

Thank you for participating in my project.

Sincerely,

Michael Mimms

Cancer Radiation Therapy Provider Questionnaire

Instructions

I. Introduction to Radiation Therapy

Please rank/order 10 educational facts from this section.

Write "1" next to the most important information element, "2" next to the next most important, and so on.

_____ Every day and everywhere we are surrounded by radiation.

_____ The light we use to see, heat, radio waves, and the microwaves we use to cook are all forms of radiation.

_____ The sun, TV remote controls, and even some minerals are all sources of radiation. Radiation is also a common cancer treatment.

_____ In fact, more than half the people diagnosed with cancer get some type of radiation therapy.

_____ These treatments all have one thing in common: they all use high energy waves to kill cancer cells.

_____ Doctors use radiation therapy to treat cancer because it is good at shrinking and destroying tumors without causing much damage to normal tissues.

_____ The high energy waves pass through the body to reach the cancer.

_____ Cancer cells divide faster than normal cells and don't obey the rules of the body.

_____ When the cancer cells are hit with high energy radiation, they are damaged. If they don't die right away, they die the next time they try to divide. As the cancer cells continue to die, the tumor shrinks.

_____ Most normal cells don't die with radiation therapy because they are not dividing, and they are better able to repair themselves.

II. Types of Radiation

Please rank/order 4 educational facts from this section.

Write "1" next to the most important information element, "2" next to the next most important, and so on.

_____ Basically it comes down to external radiation or internal radiation.

_____ External radiation is when we use a very fancy x-ray machine and aim an x-ray into the body from away from the body.

_____ Internal radiation is when we use radioactivity and place it near to or into a tumor within the body.

_____ The decision about which type of radiation to use is based on:

the type of cancer

the location of the cancer

whether or not the cancer has spread

the current health of the patient

other treatments the patient is on or will be on

III. External Radiation Therapy

Please rank/order 8 educational facts from this section.

Write "1" next to the most important information element, "2" next to the next most important, and so on.

_____ Radiation for medical use is usually produced by sources inside of machines.

_____ The machines focus the radiation and create a beam that can be aimed at the cancer.

_____ The radiation coming from the machine cannot be seen or felt.

_____ In most cases external radiation is a local treatment; it is aimed at a specific part of the body.

_____ Your skin may be marked with a special ink that will remain during treatment. The marks allow technicians to position you the same way each time, and make sure that the radiation is always hitting the right spot.

_____ External radiation therapy often requires a series of treatments.

_____ It is usually given 5 days a week, Monday through Friday, for 2 to 10 weeks depending on the type of cancer and its location.

_____ Sometimes treatments might be given twice a day. The treatment usually takes less than an hour, and you do not need to stay in the hospital.

IV. Internal Radiation Therapy

Please rank/order 3 educational facts from this section.

Write "1" next to the most important information element, "2" next to the next most important, and so on.

_____ Internal radiation therapy uses radiation that comes from tiny radioactive sources placed inside the body.

_____ The radiation source can look like a small seed, pill, or wire. The implants are placed in or around the cancer by a doctor.

_____ Internal radiation therapy is used for cancers of the head, neck, breast, uterus, cervix, prostate, gall bladder, esophagus, eye, lung and some others.

V. Radiation Therapy Side Effects

Please rank/order 3 educational facts from this section.

Write "1" next to the most important information element, "2" next to the next most important, and so on.

_____ In most types of radiation therapy, the area exposed to radiation is limited. The possible side effects depend on the area being treated.

_____ Other short term side effects that may occur, depending on the area being treated, include:

diarrhea

hair loss (at treatment area)

mouth dryness or mouth sores

nausea and vomiting

loss of sexual desire

erectile dysfunction (ED)

swelling of areas being treated

bladder problems (such as bladder irritation that may cause you to urinate frequently)

_____Some possible long-term side effects, again depending on the area being treated, might be:

infertility

lymphedema or swelling of an arm or leg (usually when combined with surgery)

mouth problems

second cancers

joint problems including pain and damage

Return the completed survey to the folder marked "Surveys" at the Radiation Oncology patient sign-in desk.

Appendix B

Pre-Survey on Radiation Therapy

Name _____

Study ID no. _____

Pre-Survey on Radiation Therapy

Instructions

- Today**
 - Please complete this survey. It probably will take about 10 minutes to finish.
 - Turn in the survey to Ms. Sue Monroe, Head Oncology Nurse, Bodine Center.
 - Receive a DVD call *Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education*.

- At home**
 - Please view the DVD before returning for your next appointment at the Bodine Center. Keep the DVD for your personal use.
 - You can also view the same video by accessing it online at:
http://www.cancerquest.org/ACS/RT/RadiationTherapy_V2.swf

- When you return for your next appointment**
 - Receive the second (post) survey from Ms. Sue Munro, Head Oncology Nurse when you arrive at your next appointment at the Bodine Center.
 - Complete the second survey. Place it in the envelope provided and seal it. Return it directly to any of the nurses in the radiation oncology department.

Background

This study is being conducted by Michael Mimms, a doctoral student at Rowan University in Glassboro, New Jersey. He is working in collaboration with the Departments of Radiation Oncology and Medical Oncology. As part of his dissertation for the Educational Leadership Program, he is looking at knowledge about radiation therapy among newly-diagnosed cancer patients.

The information you give us on the survey will be used to find better ways to provide cancer patients with information about radiation therapy. The information you provide for this survey will remain anonymous and confidential. Your name and identifying information will not be used in any reports, articles, or presentations.

Thank you for participating.

Patient Pre-Survey on Radiation Therapy

Directions: For each statement, circle your answer. If you are not sure whether the statement is true or false, circle "Don't know."

A. Radiation Therapy

- | | | | | |
|------|--|------|-------|------------|
| A-1. | Every day and everywhere we are surrounded by radiation | True | False | Don't know |
| A-2. | Doctors use radiation therapy to treat cancer because it is good at shrinking and destroying tumors without causing much damage to normal tissues. | True | False | Don't know |
| A-3. | Low energy radiation waves pass through the body to reach the cancer | True | False | Don't know |

B. Types of Radiation

- | | | | | |
|------|--|------|-------|------------|
| B-1. | External radiation requires the use of a very fancy x-ray machine that spreads x-rays all over the body. | True | False | Don't know |
| B-2. | The decision about which type of radiation to use is based on | True | False | Don't know |
| | ... Type of cancer | | | |
| | ... Location of the cancer | | | |
| | ... Whether or not the cancer has spread | | | |
| | ... Current health of the patient | | | |
| | ... Other treatments the patient is on or will be on | | | |

C. External Radiation Therapy

- | | | | | |
|------|---|------|-------|------------|
| C-1. | The machines focus the radiation and create a beam that can be aimed at the cancer | True | False | Don't know |
| C-2. | The radiation coming from the machine cannot be seen but it can occasionally be felt. | True | False | Don't know |
| C-3. | External radiation therapy often requires only one long treatment. | True | False | Don't know |

D. Internal Radiation Therapy

- | | | | | |
|------|---|------|-------|------------|
| D-1. | Internal radiation therapy uses radiation that comes from tiny radioactive sources placed outside the body. | True | False | Don't know |
|------|---|------|-------|------------|

E. Radiation Therapy Side Effects

- E-1. Long term side effects from radiation therapy may occur, depending on the area being treated, include: True False Don't know
- ...Diarrhea
 - ...Hair loss (at treatment area)
 - ...Mouth dryness or mouth sores
 - ...Nausea and vomiting
 - ...Loss of sexual desire
 - ...Erectile dysfunction (ED)
 - ...Swelling of areas being treated
 - ...Bladder problems (for example, bladder irritation that may cause you to urinate frequently)

F. Demographics

- F-1. What is your current marital status?
- Married
 - Living as married
 - Divorced
 - Separated
 - Widowed
 - Never married
- F-2. Are you of Spanish, Latino, or Hispanic descent?
- Yes No
- F-3. Which of the following categories best describes your racial background? Are you . . .
- White
 - Black, African American
 - Asian
 - American Indian or Alaskan Native
 - Native Hawaiian or other Pacific Islander
 - Some other? [SPECIFY] _____
- F-4. What is the highest level of education you have completed?
- Completed less than high school
 - Completed high school or equivalent degree (GED)
 - Completed non college/ business/trade/technical school
 - 2-year associate's degree
 - College degree and above

G. Medical History

- G-1. Is this the first time you were diagnosed with cancer? Yes No, only skin cancer No
- G-2. **When you came to your appointment today, how would you rate your knowledge about radiation therapy?**
On a scale of 1 to 10
- | | | | | | | | | | | |
|--|---|-------------|---|---|---|---|---|---|------------------|----|
| | | | | | | | | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| | | Poor | | | | | | | Excellent | |
- G-3. How would you rate your understanding of the written information you have received about radiation therapy?
On a scale of 1 to 10
- | | | | | | | | | | | |
|--|------------------|-------------|---|---|---|---|---|---|------------------|----|
| | | | | | | | | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| | Not rec'd | Poor | | | | | | | Excellent | |
- G-4. How would you rate your understanding of what you have been told orally about radiation therapy?
On a scale of 1 to 10
- | | | | | | | | | | | |
|--|-----------------|-------------|---|---|---|---|---|---|------------------|----|
| | | | | | | | | | | |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| | Not told | Poor | | | | | | | Excellent | |
- G-5. Listed below are ways you might have gotten **useful information about your illness** (cancer) and how it is treated. Rate each based on your experience.
- | | |
|---|---|
| | Rate each based on your experience. |
| a. Internet | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |
| b. Health care professionals (physicians, nurses, etc.) | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |
| c. Magazines | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |
| d. Friends | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |
| e. Television | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |
| f. Radio | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |
| g. Thomas Jefferson Oncology Patient Education Training session | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |
| h. Booklets / pamphlets/ flyers | <input type="checkbox"/> Not used <input type="checkbox"/> Not very useful <input type="checkbox"/> Useful <input type="checkbox"/> Very useful |

Appendix C

Post-Survey on Radiation Therapy

Name _____

Study ID no. _____

Post-Survey on Radiation Therapy

Instructions for Patient

- Complete post-survey.
- Place it in the envelope provided. Seal the envelope and hand directly to any of the nurses in the radiation oncology department.
- Keep the DVD for your personal use or to share with others.

Background

This study is being conducted by Michael Mimms, a doctoral student at Rowan University in Glassboro, New Jersey. He is working in collaboration with the Departments of Radiation Oncology and Medical Oncology. As part of his dissertation for the Educational Leadership Program, he is looking at knowledge about radiation therapy among newly-diagnosed cancer patients.

The information you give us on the survey will be used to find better ways to provide cancer patients with information about radiation therapy. The information you provide on this survey will remain anonymous and confidential. Your name and identifying information will not be used in any report or presentation.

Thank you for participating.

Patient Post-Survey on Radiation Therapy

Directions: For each statement, please your answer. If you are not sure whether the statement is true or false, circle "Don't know."

A. Radiation Therapy

- | | | | | |
|------|--|------|-------|------------|
| A-1. | Every day and everywhere we are surrounded by radiation | True | False | Don't know |
| A-2. | Doctors use radiation therapy to treat cancer because it is good at shrinking and destroying tumors without causing much damage to normal tissues. | True | False | Don't know |
| A-3. | Low energy radiation waves pass through the body to reach the cancer | True | False | Don't know |

B. Types of Radiation

- | | | | | |
|------|--|------|-------|------------|
| B-1. | External radiation requires the use of a very fancy x-ray machine that spreads x-rays all over the body. | True | False | Don't know |
| B-2. | The decision about which type of radiation to use is based on | True | False | Don't know |
| | . . Type of cancer | | | |
| | . . Location of the cancer | | | |
| | . . Whether or not the cancer has spread | | | |
| | . . Current health of the patient | | | |
| | . . Other treatments the patient is on or will be on | | | |

C. External Radiation Therapy

- | | | | | |
|------|---|------|-------|------------|
| C-1. | The machines focus the radiation and create a beam that can be aimed at the cancer | True | False | Don't know |
| C-2. | The radiation coming from the machine cannot be seen but it can occasionally be felt. | True | False | Don't know |
| C-3. | External radiation therapy often requires only one long treatment. | True | False | Don't know |

D. Internal Radiation Therapy

- | | | | | |
|------|---|------|-------|------------|
| D-1. | Internal radiation therapy uses radiation that comes from tiny radioactive sources placed outside the body. | True | False | Don't know |
|------|---|------|-------|------------|

E. Radiation Therapy Side Effects

- E-1. Long term side effects from radiation therapy may occur, depending on the area being treated, include: True False Don't know
- ...Diarrhea
 - ...Hair loss (at treatment area)
 - ...Mouth dryness or mouth sores
 - ...Nausea and vomiting
 - ...Loss of sexual desire
 - ...Erectile dysfunction (ED)
 - ...Swelling of areas being treated
 - ...Bladder problems (for example, bladder irritation that may cause you to urinate frequently)

F. DVD feedback

- | | | | | | |
|------|--|---|-----------------------------------|--------------------------------------|--|
| F-1. | The video, <i>Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education</i> , provided information that was new to me. | Strongly
Agree
<input type="checkbox"/> | Agree
<input type="checkbox"/> | Disagree
<input type="checkbox"/> | Strongly
Disagree
<input type="checkbox"/> |
| F-2. | The video provided information that was useful to me. | Strongly
Agree
<input type="checkbox"/> | Agree
<input type="checkbox"/> | Disagree
<input type="checkbox"/> | Strongly
Disagree
<input type="checkbox"/> |
| F-3. | After watching the video, I have questions that I want to ask the physicians and nurses about my radiation treatment. | Strongly
Agree
<input type="checkbox"/> | Agree
<input type="checkbox"/> | Disagree
<input type="checkbox"/> | Strongly
Disagree
<input type="checkbox"/> |
| F-4. | How many times did you watch the video? | _____ | | | |
| F-5. | How many other family and friends watched the video? | _____ | | | |

Comments [optional]

Do you have any suggestions about what the Thomas Jefferson University Hospital and the Bodine Cancer Radiation Center might do to improve the education of cancer patients **before** they begin radiation therapy?

Appendix D

Complete Internal Review Board Application



Department of Medical Oncology
Division of Population Science

T 215.503.7801 F 215.503.9506

Mr. Michael Mimms
71 Orlando Drive
Sicklerville, NJ 08081

January 3, 2011

Dear Mr. Mimms,

Enclosed please find a copy of the package submitted to the Thomas Jefferson University Institutional Review Board for your project, "Educating Diagnosed Cancer Patients Who Are Undergoing Radiation Therapy" under Dr. Ronald E. Myers.

These materials were received and stamped by the TJU IRB on 12/30/2010. Usual processing time is between 4-6 weeks. I will keep you posted regarding correspondence we receive from the IRB concerning your project.

Tom Wolf

A handwritten signature in black ink that reads "Tom Wolf".

December 22, 2010

Bruce Smith, MD, CIP
Research Associate Vice President
Office of Human Research
Thomas Jefferson University
1015 Chestnut Street Suite 1100

Dear Dr. Smith:

I am submitting for review by the IRB a study entitled ***Educating Diagnosed Cancer Patients Who Are Undergoing Radiation Therapy***. I am working Michael Mimms, a doctoral student at Rowan University. We have met with Adam P. Dicker, MD, PhD, Chair, Department of Radiation Oncology who also supports this study.

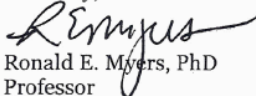
Enclosed are the following documents:

- OHR-1 proposal transmittal
- OHR-2 Summary of Human Subjects Research
- OHR-3 Request for Waiver of Authorization to Collect Protected Health Information
- CCRRC materials

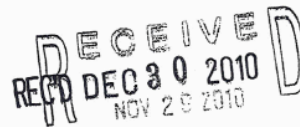
- OHR-8H Acknowledgement of oral consent and consent script
- Data collection instrument Pre survey on Radiation Therapy
- Data collection instrument Post survey on Radiation Therapy
- Description of study for potential participants (one page)
- Disclosure Statement for non-TJU/non TJUH employees conducting research
- Unaffiliated Investigator Agreement for Thomas Jefferson University

Please contact me at 215-503-9506 if there are any questions about this study.

Sincerely,


Ronald E. Myers, PhD
Professor

copy: Kyle Conner, MA, CIP
Associate Director
Division of Human Subjects Protection
Office of Human Research



BY:.....

Thomas Jefferson University
Division of Human Subjects Protection/IRB

PROPOSAL TRANSMITTAL AND APPROVAL FORM

SECTION 1

PRINCIPAL INVESTIGATOR: Ronald E. Myers, PhD **Dept/Div:** Dept of Med Onc/ Div of Population Science
Tel 215-503-4085 **Fax:** 215-503-9506 **Email:** ronald.myers@jefferson.edu

CO-INVESTIGATOR(S): Michael Mimms

STUDY TITLE: *Educating Diagnosed Cancer Patients Who Are Undergoing Radiation Therapy*

IF RESUBMISSION, WHAT WAS ORIGINAL IRB CONTROL NUMBER? Not applicable

If part of Program Project, include full project title and name of PI: Not applicable

WHO IS PAYING FOR THE STUDY? Unfunded

ORA ACCOUNT NUMBER: Not applicable

GRANTEE (If subcontract to TJU): Not applicable

SPONSOR CONTACT PERSON (For-Profit): Not applicable **Tel:** **Fax:**

TJU CONTACT Ronald E. Myers, PhD [see contact information above]

PROJECT PERIOD: 1-Dec 2010 to 30-Nov-2011 **INITIAL BUDGET PERIOD:** Not applicable. Unfunded

SECTION 2

TYPE OF PROPOSAL/PURPOSE:	DOES THIS PROJECT INVOLVE:
New <input checked="" type="checkbox"/>	1. Human subjects? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
Basic Research <input type="checkbox"/>	Data review? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
Clinical Trial <input type="checkbox"/>	Human specimens? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
Program Project <input type="checkbox"/>	2. If applicable, will federal application be submitted with IRB review pending? Not applicable <input type="checkbox"/> Yes <input type="checkbox"/> No
Resubmission <input type="checkbox"/>	
Recombinant DNA Technology <input type="checkbox"/>	3. Have all key personnel completed the mandated training programs? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
Investigator-initiated? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	4. If commercially sponsored, has ORA approved contract? Not applicable <input type="checkbox"/> Yes <input type="checkbox"/> No
Multi-center clinical trial? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No	5. Inpatient treatment with investigational drug or device? Not applicable <input type="checkbox"/> Yes <input type="checkbox"/> No

Please be reminded that a sponsored study may not begin until the sponsored agreement is fully executed by the sponsor and Thomas Jefferson University. Contact the Office of Research Administration for more information.

HOW TO SUBMIT: For full IRB review, submit 35 stapled, collated packets of the OHR-1, OHR-2, OHR-8 (consent form) and all supplemental materials (e.g., advertising, recruitment letters, questionnaires, etc.). For expedited review or exemption request, submit 4 packets. Provide 4 copies of the sponsor protocol if commercially sponsored, 4 copies of the grant if federally funded, or 4 copies of the investigator-written protocol if unfunded. For a study involving investigational drug(s)/device(s), include 4 copies of the investigational drug/device brochure(s). If the study involves a drug(s)/device(s) that is not investigational, include 4 copies of the package insert(s).

SECTION 3

EMERGENCY DEPARTMENT APPROVAL

[] If your study involves human subjects from the Emergency Department (ED), please certify that the ED has been notified, and attach a copy of the ED letter of acknowledgement. **YOU MAY NOT SUBMIT TO THE IRB UNTIL YOU HAVE THIS LETTER.** Contact the ED at 955-1993 for more information.

CCRRC APPROVAL

—1 Does the scope of your research involve cancer (patients, tissue, data, blood charts, etc.)? [X] Yes [] No

2. IF YES, certify that the KCC Protocol Coversheet has been completed and submitted to the CCRRC (clinical Cancer Research Review Committee). Include a copy in the IRB submission. [] Yes [] No **Not applicable**

3. Confirm that your trial has been approved by the CCRRC or has been given a waiver from CCRRC review. Include a copy of the CCRRC approval or waiver email in the IRB submission. [X] Yes [] No

YOU MAY NOT SUBMIT TO THE IRB UNTIL YOU HAVE CCRRC APPROVAL or WAIVER. Contact the CRMO at 955-9244 for more information.

SECTION 4

CERTIFICATION OF CONFLICTS OF INTEREST

This certification must be completed and all the required signatures must be obtained before this protocol/research project may be administratively processed.

Refer to the following definitions for answering the questions 1 and 2 below.

“Immediate Family” means spouse, dependent children, and all other persons living in the same household, and any associated entity.

“Associated Entity” means any trust, organization or enterprise other than the University over which the covered individual, alone or together with his / her immediate family, exercises a controlling interest.

“Financial Interest Related to the Research” means financial interest in the sponsor, product or service being tested, or competitor of the sponsor or product or service being tested.

For Question 1 below, do you or your immediate family have any of the following?

- Ownership interest, stock options, or other financial interest related to the research unless it meets four tests:
 - Less than \$10,000 when aggregated for the immediate family.
 - Publicly traded on a stock exchange.
 - Value will not be affected by the outcome of the research.
 - Less than 5% interest in any one single entity when aggregated for the immediate family.
- Compensation related to the research unless it meets two tests:
 - Less than \$10,000 in the past year when aggregated for the immediate family.
 - Amount will not be affected by the outcome of the research.
- Proprietary interest related to the research including, but not limited to, a patent, trademark, copyright or licensing agreement.
- Board or executive relationship related to the research, regardless of compensation.
- Consulting fees; honoraria; gifts or other financial compensation; or "in kind" compensation from a financially interested company for any purpose not directly related to the reasonable cost of conducting the research (as specified in the research agreement) or engaging in the activity; that when aggregated for the covered individual

and his/her immediate family in the prior calendar year exceeded, or in the next calendar year are expected to exceed, \$10,000.00.

- Royalties, or inventor's share of royalty income pursuant to the University's Patent Policy, or the right to receive future royalties or such inventor's share under a patent license or copyright agreement or any other type of agreement, where the research or activity is directly related to the licensed technology or work.
- Any non-royalty payments (or entitlements to payments) in connection with the research or activity that are not directly related to the reasonable costs of the research (as specified in the research agreement between the sponsor or company providing research funding and the University) or activity. This includes any bonus or milestone payments to investigators in excess of reasonable costs incurred, whether such payments are received from a financially interested company or from the University.

Each Investigator and all Key Personnel must answer the following questions in relation to this proposal. The TJU ID# requested can be found in the box on the left side of your pay stub. For non-Jefferson employees, this section should be left blank.

Principal and Co-Investigators & Key Personnel:

Copy this section as necessary to accommodate all personnel on study.

Name: Ronald E. Myers, PhD

TJU ID #

1. Do you or an immediate family member have any of the above financial interests? Yes ___ No
2. Do you or an immediate family member have a significant financial interest that may pose a conflict of interest as defined in the TJU Conflicts of Interest Policy 107.03? Yes ___ No

If you checked "yes" to either question above, describe the financial interest below and any steps planned to prevent the financial interest from interfering with the design, conduct, or reporting of the research, including interfering with the protection of participants. Attach separate sheet if needed.

Name: Michael Mimms

TJU ID # Not applicable

1. Do you or an immediate family member have any of the above financial interests? Yes ___ No
2. Do you or an immediate family member have a significant financial interest that may pose a conflict of interest as defined in the TJU Conflicts of Interest Policy 107.03? Yes ___ No

If you checked "yes" to either question above, describe the financial interest below and any steps planned to prevent the financial interest from interfering with the design, conduct, or reporting of the research, including interfering with the protection of participants. Attach separate sheet if needed.

If you are a TJU employee or faculty member, or a TJUH employee you must have submitted an up-to-date Disclosure of Conflicts of Interest to University Counsel. If you have not, please complete an on-line Disclosure that can be accessed via the Pulse homepage or a hard copy that may be obtained on the Office of University Counsel website. If you are not a TJU employee, TJUH employee, nor a TJU faculty member, you must file a Disclosure Statement for Non TJU/TJUH Employees Conducting Research indicating either the nature of the conflict of interest, if any, or certifying that you do not have a conflict of interest in a financially interested company with regard to this proposal.

RELATIONSHIP(S) WITH OTHER ENTITIES

The Principal Investigator must complete the following:

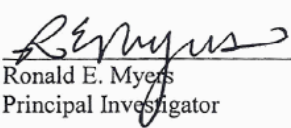
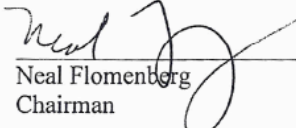
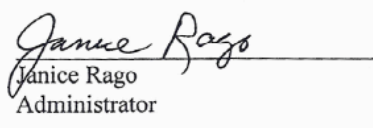
Other than the entity paying for the study or as disclosed in the protocol, will any OTHER ENTITY(S):

- 1. Require and/or receive reports or other information regarding this study? Yes No
If yes, list entity (s) Rowan University
- 2. Be identified in any reports submitted to the FDA or other regulatory agencies? Yes No
If yes, list entity(s) _____
- 3. Be given access to study data? Yes No
If yes, list entity(s) _____
- 4. Be given attribution in any publication or presentation regarding this study? Yes No
If yes, list entity(s) Rowan University

The IRB must be notified in writing by the PI should any of the answers to the above change.

The OHR-1 must be signed by ALL KEY PERSONNEL participating in the project and their DEPARTMENT CHAIRPERSON and ADMINISTRATOR. The Principal Investigator agrees to accept responsibility for the conduct of the project according to the tenets of Good Clinical Practice (DHSP Policy GA 124. "Good Clinical Practice for Investigators") and to provide the required progress reports if a grant/contract results from application/proposal. Department Chairs certify that the project meets Departmental standards with respect to scientific validity and that the project is consistent with Departmental goals. Administrators certify that the project meet applicable federal fiduciary requirements. All Key Personnel certify that, to the best of their knowledge, all information provided for Committee reviews is correct and in compliance with University policies

Please print all names below signature lines.

 _____ Ronald E. Myers Principal Investigator	 _____ Neal Flomenberg Chairman	 _____ Janice Rago Administrator
---	---	--



Thomas Jefferson University—Office of Human Research
Division of Human Subjects Protection
SUMMARY OF HUMAN SUBJECTS RESEARCH

Please address all applicable points to create a complete and succinct synopsis of the protocol. If a point does not apply to your study, please state "NA." Use language, insofar as is possible, that can be understood by a layperson, and provide meanings for all acronyms used. Please maintain all questions in the body of the text. Form, must be typewritten.

PART A. SUMMARY OF STUDY

1. Provide a brief (2-3 sentences) lay language synopsis of the study. Include an explanatory sentence about the study article (e.g., product X is a compound that increases excretion of salt and therefore may be of use in the treatment of high blood pressure).

Study Title: *Educating Diagnosed Cancer Patients Who Are Undergoing Radiation Therapy*

The purpose of this study is to measure the knowledge that diagnosed patients have about cancer radiation treatment. The research goal is to improve patients' knowledge of cancer radiation treatment. The study intervention is a 3-D animated educational video, "Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education," developed by Emory University and commissioned by the American Cancer Society. The study intervention is a showing of a video with no additional discussion or written material. The study assessment is a pre and post survey that includes 10 knowledge items.

NOTE: If this submission is for an extension study of an IRB approved protocol, please provide a copy of the most recent IRB approved OHR-9 form in addition to a short (one paragraph) lay-language synopsis of the original study plan.

2. **Objectives and Significance**
 - a. State the primary objective(s) of the study.
Improve cancer patients' knowledge of cancer radiation treatment.
 - b. State the secondary objectives(s) of the study.
Find better ways cancer patients can get information about the treatment of their illness.
 - c. What benefit or knowledge will be gained?
Investigators will learn about the impact of the intervention on the knowledge of patients.
 - d. State hypothesis you are testing.
Patients will increase the number of correct responses from the pre-test to the post-test after viewing the intervention video.
3. Briefly describe the background and rationale for the research in lay language. Please limit response to one paragraph. State the perceived problem and why it is being investigated. (*Do not include references and please do not cut and paste grant application or review article. "See investigator brochure" is not an acceptable response.*)

According to the National Cancer Institute, about half of all cancer patients receive some type of cancer radiation therapy sometime during the course of their treatment. Radiation Therapy can be given for several reasons, including (1) Curative intent (that is, with the hope that the treatment will cure a cancer, either by eliminating a tumor, preventing cancer recurrence, or (2) Palliative intent, (that is, not to cure but to relieve symptoms and reduce the suffering caused by cancer). The purpose this study originates in the need for all patients receiving radiation therapy to understand essential information about the process and what they are likely to experience. This information needs to be presented in a way patients can understand and retain. This study will focus on cancer radiation information among diagnosed cancer patients before their first radiation treatment and assess if the study intervention (educational DVD) improves the knowledge of cancer patients about of the cancer radiation treatment process.

4. Briefly describe the research design. (Use charts and flow diagrams if applicable. "*See investigator brochure*" is not an acceptable response.)

a. Subjects: State inclusion and exclusion criteria.

Study participants will include diagnosed cancer patients who are undergoing initial radiation treatment at Thomas Jefferson University Hospital Bodine Center for Radiation Therapy. A convenience sample of 50 patients will include men and women as well as patients from all racial/ethnic groups who receive treatment at Bodine. The demographic characteristics of the potential participants will be collected when the participants complete the pre-survey.

- b. Procedures:** Provide study visit details. (Study team standard operating procedures should not be addressed here. Use diagrams or flow charts when appropriate. For an investigator initiated study, this form should NOT substitute for a separately drafted protocol which should be included in the IRB packet as a separate document)

Potential participants will be identified as follows:

- Patients will enter the Bodine Center for Radiation Therapy to begin treatment for a specified number of radiation treatments.
- The head nurse of the Radiation Oncology Department will identify potential participants from the patients who are scheduled for long-term radiation treatments and/or patients who attend the weekly radiation oncology education classes.

Interested potential participants will be recruited as follows:

- Potential participants designated by the head nurse will be approached by the co-investigator to determine if they would be interested in participating in the study. All potential participants will be notated by the co-investigator as interested, not approached, and refused/not interested. These notations are to prevent co-investigator's repeated approaches to uninterested patients.
- Participant is provided with a one-page description of the study.
- Participant is given an opportunity to ask questions of the co-investigator about the study

Data collection (assessment)

- Participant will complete the pre-survey and give to the co-investigator in waiting area.
 - If participants are unable to complete the pre-survey prior to their scheduled appointment, co-investigator will hold survey so that the participant can complete it afterwards.
 - NOTE: After pre survey, participant is given a copy of the DVD entitled, "*Cancer Treatment: Radiation Therapy, an Interactive Approach to Cancer Education.*"
- Participants are given the post survey when they return to the Bodine Center to begin treatment schedule. The head nurse will collect the completed post-surveys to give to the co-investigator.
- c. Data analysis: (*Provide statistical design for primary endpoint only. Please indicate how the study is powered and what statistical tool(s) will be applied. Please do not cut and paste entire statistical section from the sponsor protocol. Pilot studies do not require a statistical plan.*)

The research study will test whether the intervention increases the knowledge of patients about radiation treatment. Through a pre/post survey design, the investigators will assess the changes in knowledge of the participants. Both the pre/post surveys will consist of 10 (True, False, Don't know) statements based on educational facts taken from the DVD, "*Cancer Treatment: Radiation Therapy, An Interactive Approach to Cancer Education.*" The pre/post survey knowledge items will be scored and the number of correct answers will be tallied. The study investigators will analyze the pre/post survey data to determine the impact of a video presentation on cancer patients' knowledge by using the Statistical Package for the Social Sciences (SPSS). The investigators will analyze the pre/post survey scores and their association with demographics characteristics as age, gender, marital status, and years of education.

5. Delineate procedures that are standard of care from those that are being performed specifically for the research.

N/A. This is an educational research study not a therapeutic study. Participants can receive whatever educational materials or programs currently offered to all patients at Bodine Center for Radiation Therapy.

6. Describe the Data and Safety Monitoring Plan (DSMP) for this protocol. See DHSP Policy G 607 for guidance. (*For minimal risk studies, indicate only how accuracy of data will be assessed.*)

Principal Investigator will review pre/post survey responses to ensure data completeness and quality.

- a). For externally funded clinical trials: N/A Is there a DSMP? If yes, please describe:
- b). For Investigator Initiated Trials:
 - i. Is there a Study Monitor or a Data Safety Monitoring Committee (DSMC)? No
 - ii. If yes, please describe mechanism for insuring accurate data and subject safety.
 - iii. What are the stopping rules for the study? N/A

7. Identify the sources of research material obtained from individually identifiable living human subjects in the form of specimens, records, or data.

The only sources of research materials will be data recorded by the participants on hard copy questionnaires. No specimens will be collected. No medical records will be accessed.

8. Indicate how and where data on identifiable subjects will be stored and secured to protect data integrity and confidentiality.

To maintain confidentiality all participants will be assigned a unique study identification number for all participants. All electronic files will be stored on the computers of the principal and co-investigator. Following the completion of the research and at the end of the study, all hard copies of research materials will be shredded. Only principal and co-investigators will have access or authorization to research materials and data. To maintain confidentiality all participants will be assigned a unique study identification number for all participants.

9. Will the subjects bear any costs that are not part of routine clinical care?
 Yes No

a) If yes, please list the relevant tests, procedures, hospitalizations, etc., for which they would be liable. N/A

b) Are there means of subsidizing these extra costs for subjects who cannot afford them? If yes, please explain. N/A

PART B. SUBJECTS AND FACILITIES

1. What is the expected number of subjects to be enrolled?

No. subjects per year at TJU	Total No. subjects at TJU	No. Subjects Nationally or Internationally (if applicable)	No. subjects at collaborating Institutions (if applicable)
50	50	N/A	N/A

2. Are sufficient numbers of potential subjects available in the PI's practice (or group practice) to meet recruitment goals for this study? X YES ___ NO

The number of participants needed to complete the study is 50. Approximately 25-40 patients are treated daily at the Bodine Center for Radiation Therapy. About 50% of the patients treated daily are undergoing their initial treatment. Patients receiving radiation therapy come in for treatment during a number of consecutive days. The convenience sample of at least 50 patients is achievable during a four-week accrual period. The co-investigator will keep an accurate tally of the number of possible participants during the recruiting process

- a. If no, identify other sources of potential subjects. N/A

3. Identify where the research will be conducted and describe the adequacy of facilities.

~~Participants will be recruited by the co-investigator at the patient intake area of the Thomas Jefferson University Hospital Bodine Center for Radiation Therapy or the radiation oncology education classroom.~~

4. Please identify any facilities to be used for research other than those assigned to Department or division. N/A

5. Describe provisions to protect the privacy of participants during the course of the study. (Privacy can be defined as the participant's desire to control the ways in which s/he is approached and/or the ways in which his/her private information is shared with others.)

The head nurse of the Radiation Oncology Department will identify potential participants from the patients at intake who are scheduled for multiple radiation treatments and/or patients who attend the radiation oncology education classes. The head nurse will ask potential participants if they would be interested in learning about a brief educational research study. The nurse will indicate the voluntary nature of learning about and/or participating in the research study. If indicated by the head nurse, potential participants will be approached by the co-investigator to who describes the study and obtain consent. All potential participants indicated by the head nurse will be notated as approached/not approached and interested/ not interested. These notations are to prevent any repeated approach to refused/ not interested patients. The study intervention (watching an educational video) takes place at the participant's homes. Participants are free to discuss or watch the video with family and/or friends.

6. How has the research staff been trained regarding study protocol and their duties related to the protocol (in-service, investigator meeting, etc.)?

17-Dec-2010

The research staff consists of the principal investigator, the co-investigator, and the head nurse. The protocol has been developed by the principal investigator, an experienced behavioral researcher at Thomas Jefferson University, and the co-investigator who has been oriented to conducting research at a health care facility and who has taken all required human subjects training. The head nurse is accustomed to working with radiation oncology patients, identifying patients who might be eligible for a research study, and asking if they would be interested in learning more about a study.

7. Which of the following groups are eligible to be subjects?

a.	Cognitively- or decisionally-impaired persons Cognitively- or decisionally-impaired individuals should only be included only if the study targets conditions specific to this population or if there is potential benefit	Yes	X	No
b.	Women of reproductive potential	X	Yes	No
c.	Pregnant Women	X	Yes	No
d.	Men of reproductive potential	X	Yes	No
e.	Minorities	X	Yes	No
f.	Prisoners: If it is expected that prisoners will be enrolled into the study, the PI must notify the IRB in advance of the meeting so that specific issues may be addressed.		X	No
g.	Other vulnerable populations: (students, aged and infirm, substance abusers, fetuses, under-educated, terminally ill, very sick, etc.)		X	No

8. What additional protective mechanisms are in place to protect the rights and welfare of these vulnerable populations? N/A

9. Explanation of Exclusion

NIH policy requires that minorities and women be adequately represented as research subjects. If this is an NIH-funded study and you checked "no" to either of these categories, you must provide a scientific reason for such exclusion.

Based on the demographic characteristics of patients treated at the Bodine Center, both minorities and women will be represented adequately in the pool of potential participants. Based on the characteristics of the pool of potentially eligible patients, about 75% will be female and 25% will be male. In addition, about 25% of the females will be minorities and about 50% of the males will be minorities.

PART C DRUGS AND DEVICES

I. General Information

1. Identify all investigational drugs and/or devices to be used in this study and provide related information: N/A

Drug or Device	IND#/IDE#	Organization/Person Holding IND/IDE
N/A	N/A	N/A

If research involves an investigational drug or device the Principal Investigator (PI) will confirm that the IND or IDE numbers are valid by providing the IRB with one of the following:

- The sponsor protocol imprinted with the IND or IDE number
 - A written communication from the sponsor documenting the IND or IDE number
 - A written communication from the FDA documenting the IND or IDE number (required if an investigator listed on the protocol holds the IND or IDE)
2. When the investigator or TJU holds the IND/IDE, the investigator/TJU becomes the “sponsor” of the research and assumes responsibility to ensure that all FDA regulatory criteria for sponsors are met. Please provide your plan for meeting FDA regulatory criteria for sponsors. N/A

For example:

- Investigator who holds an IND or IDE will assign some or all responsibilities to meet FDA sponsor requirements to a contract research organization (CRO).
- Investigator will undergo an audit by a CRO to ensure that procedures are in place so that all FDA regulatory requirements of sponsors will be met.
- Investigator will assign responsibility of compliance with some FDA regulatory requirements to a CRO and investigator will obtain an audit from a CRO to ensure that procedures are in place so that all other FDA regulatory requirements of sponsors will be met.

NOTE: If you intend to use someone who is in-house and who has expertise on sponsor requirements, please justify that that person has equivalent expertise to a CRO.

3. Identify all non-investigational medications and/or devices specified in the protocol that the subject will receive while on this study. *This refers to drugs or devices that are: 1) FDA approved; 2) not under investigation in this study; 3) an integral part of the protocol (for example, the standard of care drug(s) that the subject will be receiving in addition to the experimental article).* N/A

II. Drugs

1. Provide the following information for investigational drug(s): N/A
 - a. Class of drug (i.e., anti-hypertensive, anti-emetic, etc.)
 - b. Mechanism of action (i.e., beta-adrenergic receptor blocker, anti cytokine, monoclonal antibody, etc.).

2. Will the study drug(s) be dispensed by the Investigational Drug Service (IDS)? Yes No
N/A
NOTE: The IDS must receive, track, and dispense drugs for all in-patient clinical trials. If this is an out-patient study and the IDS is not dispensing the study drug, please provide answers to each of the following questions and include a copy of the form you will use for documenting investigational drug receipt, storage and dispensing.
- Where will drug be stored? N/A
 - Who will have access to drug? N/A
 - Who will maintain drug accountability logs, and dispense drug? N/A
 - What measures to maintain security of drug storage and access are in place? N/A
3. Is the sponsor providing the test article free of charge? If not, who will cover costs of the drug and its administration, if applicable? N/A
4. If sponsor is not supplying test article, is it listed in the TJUH formulary? If not, where will it be obtained and who will pay for it? N/A
5. Please briefly summarize relevant human clinical data for the study drug. Standard of care drugs should be addressed only if they are part of randomized design in this study (i.e., they are part of the research). N/A
6. Please list the known side effects for each study drug. N/A
7. Does this study include an off-label use of an FDA-approved drug? If yes, please explain. N/A

NOTE: All 6 items below must be checked in order for the IRB to determine if your research is exempt from the IND requirement. If all of the criteria do not apply in your study, you must apply to the FDA for an IND# and provide the IRB with the FDA letter indicating the IND# or a copy of an exemption letter from the FDA. The FDA reviews applications and makes a decision (exempt or requires an IND) within 30 days of receipt of the application. You may submit your proposal to the FDA and to the IRB for review simultaneously, but you may not initiate any research procedure(s) prior to meeting the IND requirements and obtaining IRB approval.

8. If the investigational drug does not have an IND#, please certify that its intended use meets all of the following FDA criteria for waiver of this requirement for the off-label use in question: N/A
- It is not intended to be reported to FDA in support of a new indication for use or to support any other significant change in the labeling for the drug;
- It is not intended to support a significant change in the advertising for the product;
- It does not involve a route of administration or dosage level, use in a subject population, or other factor that significantly increases the risks (or decreases the acceptability of the risks) associated with the use of the drug product;
- It is conducted in compliance with the requirements for IRB review and informed consent [21 CFR parts 56 and 50, respectively];
- It is conducted in compliance with the requirements concerning the promotion and sale of drugs [21 CFR 312.7]; and
- It does not intend to invoke an exception from informed consent requirements for emergency research [21 CFR 50.24].

The sponsor must obtain an IND# from the FDA unless all of the above criteria are met.

III. Devices

1. Will the investigational device be purchased via Supply Chain Management? ___ Yes ___ No
N/A
2. If no, please address the following: N/A
 - a. Where will the device be stored? N/A
 - b. What security measures are in place to prevent the device from being used in a patient who is not enrolled in the research study or by a physician not involved in the study? N/A
 - c. Provide details as to how device will be tracked (logged in, stored, assigned to subject, implanted, etc.)
3. Who will teach investigators how to use the device and who will determine competence? N/A
4. Federal Regulations at 21 CFR 812 describe two types of investigational devices: Significant Risk (SR) and Non-Significant Risk (NSR). With respect to this study, the device meets criteria for: N/A
 - ___ a significant risk device
 - ___ a non-significant risk device
 - ___ an abbreviated IDE or IDE exemption
5. ~~IDE Exemptions. For a proposed NSR device, provide the investigator/sponsor rationale for the designation and any relevant correspondence from the sponsor and FDA, as well as approvals and risk assessments by other reviewing IRBs, if applicable. If the TJU IRB disagrees with the NSR designation, the investigator/sponsor must submit an IDE application to FDA. FDA will either issue an IDE# or concur that the device is NSR. N/A~~
6. For Device Studies, certify below that you will meet the responsibility requirements for investigators found at 21 CFR 812 subpart E: N/A
 - Study will be performed according to the signed agreement with the sponsor.
 - Study will not be initiated until FDA and IRB approval is obtained.
 - Informed consent will be obtained from all subjects after FDA and IRB approval is obtained.
 - Any financial conflicts of interest will be disclosed prior to starting the study and updated as appropriate during the conduct of the study.
 - Device will be disposed of as per sponsor directions and any remaining unused devices will be returned to the sponsor.
7. Is the sponsor providing the device free of charge? If not, who will pay for it? N/A
8. Please briefly summarize relevant human clinical data for the study device. N/A
9. Please list the known or potential side effects for the device. N/A

PART D RISKS, BENEFITS, AND ALTERNATIVES

1. What are the risks of the research? (Please note: this is not the same as the description of the known side effects of the test article(s))

This is an educational intervention. The risk to participants is very low (minimal). It is possible but unlikely some participants could become disturbed by the factual content about radiation therapy in the video (intervention).

2. Discuss measures taken to minimize risks and maximize benefits associated with this study. (Consider number of subjects required to answer the research question, frequency of tests for adverse events, specific exclusion criteria, etc.) N/A

3. What are the potential benefits of participation?

The participants, diagnosed cancer patients, are given an opportunity to increase their knowledge about the radiation treatment process and the terms and jargon used by the medical care providers.

4. Explain how the risks of the research are justified by potential benefit to the subject or society.

There are virtually no risks to this research, which is an educational intervention. The participants might benefit individually. The study might support more orientation and education for radiation oncology patients in the future.

5. How would you treat this patient in a non-investigational setting?

Please describe the treatment that is considered standard of care, as well as any alternative procedures or drugs or other courses of therapy that might be used, if such alternatives exist (include palliative care). N/A

6. How do the risks and side effects of the standard therapies compare to those associated with the study therapy? N/A This is an educational intervention not a therapeutic study.

7. If this is a placebo controlled trial, please provide rationale for use of placebo. N/A

8. If subjects will not receive standard of care, provide rationale for this and address risks of not receiving standard of care. N/A

9. Please address any risks associated with a "washout" period if applicable. N/A

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PART E CHILDREN

1. Will this study involve children (age 17 or under)? Yes ___ No X
(If no, address question # 11 below and then go to Section F).
2. Discuss your plan for recruitment of children. N/A
3. Describe standard of care related to this research for children (if relevant, i.e., what is the standard treatment of the condition being investigated in the age group to be studied) N/A
4. Justify the age range of children to be enrolled. N/A
5. Choose the applicable child risk category and answer related questions: N/A

 Minimal Risk - Risks are not greater than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations

Describe why this study should be considered minimal risk. N/A
Please describe any potential benefits that justify anticipated risks.

 Greater than Minimal Risk

Does the study present the prospect of direct benefit to individual subjects either by the procedure or by the type of monitoring the subject will receive? Yes ___ No ___
Assess the risks/benefits of the research as opposed to available alternative treatments/approaches.

 The research poses a Minor Increase Over Minimal Risk and offers no prospect of direct benefit to subjects.
 - a. Describe what generalizeable knowledge may be gained about the subject's condition and how this will be applied with respect to the understanding or amelioration of the subjects' disorder or condition. N/A
 - b. Describe the risks inherent in the actual or expected medical, dental, psychological, social or educational situations, and justify the minor increase in risk with respect to the proposed treatment/intervention. N/A
6. Indicate the expertise of the research team with regard to children. N/A
7. Describe the facilities to be used for children in this study. N/A
8. Indicate the number of children required to give sufficient power for meaningful analysis. N/A
9. Describe how the parental permission and child assent process (for 7 to 17 year olds) will be carried out. N/A

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10. Will competent minors be asked to read and sign a consent form as opposed to signing the assent form? N/A
11. If this proposal is a Type 1 NIH application/proposal, you must include children, defined as individuals under the age of 21, as subjects unless there are scientific or ethical reasons for excluding them. If excluding children, please justify your exclusion by choosing one or more of the following exclusionary circumstances, as per NIH policy:
- Not a Type 1 NIH study
 - The research topic is irrelevant for children
 - Children are barred by law from participation because of the risk
 - Study is redundant; knowledge is being obtained in another study or is already available
 - Separate age-specific children study is preferable
 - Rarity of disorder makes inclusion of children extremely difficult
 - The limited number of available children are already enrolled in a nation-wide pediatric disease network
 - Study design precludes direct applicability to children
 - Insufficient adult data to judge potential risk for children
 - Study design is a follow-up of an adult study

The educational intervention being tested (that is, the video) is intended for adults.

PART F RECRUITMENT, EQUITABLE SELECTION, AND CONSENT PROCESS

1. Discuss the recruitment plan and describe recruitment methods and materials (e.g., physician referral, newspaper ad, radio, TV spot, e-mail, etc.). Please attach all relevant materials for IRB review and approval. See Attached Cancer Radiation Therapy Patient Descriptive Information

Participants will be recruited by co-investigator at the in-take area and radiation oncology education classes conducted at the Thomas Jefferson University Hospital by the Bodine Center for Radiation Therapy.

Advertising and recruitment materials using the TJU or TJUH logo must be submitted to the Trademark Committee for approval. Call the Office of University Counsel at 955-8585 for information. N/A

2. Will all qualified subject populations have adequate access to recruitment materials? Please explain.

N/A There are no recruitment materials

3. Is the location and cultural setting of the research equally accessible to all qualified subject populations? **Yes** If not, what can be done to make the location and setting more accessible?
4. If you are requesting a waiver of written consent, describe the information that will be provided to participants.

The oral consent protocol to be followed was previously approved by the TJU IRB. The consenting participant will sign an acknowledgement of oral consent and be given a copy.

5. Who will conduct the consent interview?

The co-investigator who will identify himself as a doctoral student from Rowan University.

6. Who will provide consent or permission (e.g., subject, legally authorized representative, parent, caregiver, etc.)? Subject

7. Where will the consent interview take place?

In the waiting room of the Bodine Center or in the radiation oncology education classroom.

8. Provide a step-by-step description of the consent process.

Each patient approached by the co-investigator will be given a one-page description of the research study. After answering the potential participant's questions and ascertaining interest in participation, the co-investigator will follow an oral consent protocol previously approved by the TJU IRB and adapted to this research study.

- Confirm that the potential participant has had an opportunity to read a one-page study description and has had their questions answered.

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- Review with potential participant all the points of the oral consent protocol.
 - Ask potential participant to read and sign the Acknowledgement of Oral Informed Consent
 - Give participant a \$25.00 gift card redeemable at Wal-Mart or Sam's Club.
9. Describe your plan to assess a person's capacity to consent. N/A
10. Will you seek assent from decisionally-impaired individuals? If so, describe your plan for obtaining assent. No
11. Will the potential subject be informed of the research or be provided a copy of the consent to review prior to the actual time of consent? If so, how much time in advance? How much time will be available for the consent process? No
12. What provisions will be made if the potential subject does not wish to proceed with the consent interview at the first encounter? That individual will not be asked again to participate in the study.
13. If the potential subject does not understand spoken English, will an interpreter be present?
YES ___ NO X
14. Is surrogate consent involved? YES ___ NO X
- ~~15. Will subjects be paid or receive any other inducements for participating? If yes, please explain. Please note that payment of subjects must be on a pro-rated basis unless there are compelling reasons not to prorate. There cannot be a requirement to finish all visits in order for subjects to be paid, as this is considered coercive.~~
- Each participant will be given a \$25.00 gift card for participating in the study. Participants will receive the gift card regardless of completion status of the pre/post surveys.
16. Describe any steps taken to minimize the possibility of coercion or undue influence.
- All oral communication will make clear the voluntary nature of the research study and that participants can watch the video (educational intervention) at home alone or with others and once or multiple times.

PART G STANDARD / EXPERIMENTAL RADIATION USE

1. Does this study involve the use of radioactive material or radiation source?
 Yes No (If no, skip to section H)
2. a) Will the subject receive radiation greater than normally received in the course of standard therapy? Yes No N/A
b) If yes, indicate what type of radiation the patient will be receiving: N/A
 Diagnostic Therapeutic Both. Please explain.
3. Is any radiation modality experimental? Yes No. If yes N/A
a) What are the risks associated with the experimental modality? N/A
b) Please append a copy of the approval letter from the Radiation Safety Committee. N/A

PART H - LOCATION/COLLABORATION

1. This study involves research to be performed at/in/with (check appropriate entries):
 - TJU only
 - TJU and JCN Network sites
 - TJU and Methodist
 - Methodist only
 - TJU and Other Institution(s) Please name institutions only for investigator-initiated and federally funded studies where data will be shared between institutions. Please provide copy of collaborating institution IRB approval letter if applicable. The DHSP will affect IRB Authorization Agreements with collaborating institutions as required.
 - Collaboration with City Services (City of Philadelphia IRB must approve study. For more information, go to [http://www.phila.gov/health/irb/.](http://www.phila.gov/health/irb/)) Please list collaborating city services.
 - Unaffiliated investigators. Please specify by name and role in study.
Michael Mimms – co-investigator
2. If the investigator is the lead investigator or TJU is the lead site in a multi-site study, please address the following: N/A
 - a. Where is the repository for adverse events and unanticipated problems and how will information be disseminated to other sites? N/A
 - b. Who will tabulate and disseminate interim results?
 - c. Who will provide information to other sites concerning protocol modifications? N/A
 - d. Describe how information that is relevant to participant safety will be managed (i.e., notifying site investigators of SAEs and Unanticipated Problems Involving Risks to Subjects or Others, communicating DSMB or Interim Reports, etc.) N/A

Collaborative Studies: For investigator-initiated studies that are collaborative or multi-center, or for federally funded studies where TJU is the lead site, please provide IRB approvals for each collaborating institution. If the institution does not have its own IRB, then the institution must first obtain a Federal-Wide Assurance (FWA) from the Office of Human Research Protection (OHRP). This registers the institution with the federal government for conducting human subjects research. The institution should then fill out an IRB Authorization Agreement (IAA) that ties the institution to the TJU IRB for this study. For more information, go to <http://www.jefferson.edu/osa/irb/forms/>. Unaffiliated investigators involved with this study should fill out an Unaffiliated Investigator Agreement, also available at the above Website address.

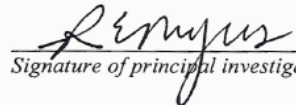
PART I - CERTIFICATION

Federal Regulations require the following responsibilities of the Principal Investigator. Please check those items to which you have conformed, and sign.

As Principal Investigator, I certify that: (check appropriate boxes)

- X I have read the IRB Policy and Procedures Manual.
- X I understand the federally-mandated responsibilities of a research investigator in conducting a clinical protocol.
- X I will conduct this clinical protocol in accordance with these responsibilities.
- X I will consent all subjects with an IRB-approved consent form, if applicable to the project, and store the consent forms in a safe repository.

- X I will provide all subjects with a copy of their signed and dated consent form.
- X All personnel have been appropriately trained for their assigned roles in this research.
- X If this study utilizes an investigational agent(s), the dose(s) of the agent(s) cited in the IRB, internal forms and the consent form agrees with the dose(s) cited in the protocol.



Signature of principal investigator



Date