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Patient Education and Involvement in Care

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PATIENT EDUCATION AND INVOLVEMENT IN CARE

By
Linda Reynolds Andiric

A dissertation submitted to the Doctoral Program Faculty
in Educational Leadership
in partial fulfillment of the requirements for the degree of
Doctor of Education

UNIVERSITY OF NORTH FLORIDA
COLLEGE OF EDUCATION AND HUMAN SERVICES

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Appreciation is also extended to my UNF dissertation committee who provided invaluable guidance, critique and encouragement.

Dedications

I dedicate this dissertation, first of all, to my brother Bill Reynolds who before he left us much too young, encouraged me in everything I attempted throughout my life.

Secondly, I dedicate this work to my children: Timur Reynolds Andiric and Calee Reynolds Lugo to whom I have repeatedly stated that learning is a life-long pleasure.

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ABSTRACT

A study conducted on patients who underwent total knee arthroplasty indicated that participants who were offered preadmission education for their procedure had statistically better outcomes than patients who had not attended an educational class. The study further focused on patients' confidence in their ability to take control of their health situations as well as the effect of encouragement and motivation to provide active involvement. Two surveys, the Krantz Health Opinion Survey and the Multi Dimensional Health Locus of Control, were used to assess patients' innate desires to be involved in their care and if they felt they could render any control themselves on their health.

The study showed a statistically significant better outcome when patients received education prior to their procedure. When patients were encouraged and motivated to participate and take control of their rehabilitation after knee surgery, the outcomes were better than with education alone. It is a worthy endeavor therefore for education to be provided before total knee arthroplasty and to identify those patients who need additional encouragement to gain confidence in their abilities in order to positively affect their outcomes. Providing healthcare professionals information about patients' innate traits regarding their desire or self-confidence to engage in their care could also be useful to allow caretakers to work with patients in the most advantageous manner to achieve better outcomes.

CHAPTER 1

Introduction

Patients with chronic health conditions, in order to manage their disease, must monitor their symptoms and understand the right time and the appropriate manner in which to perform preventative measures that will prohibit the development of a medical crisis. Monitoring symptoms or adjusting the medication regimen often accomplishes averting a crisis. In light of the increasing age of our population, it has been estimated that the necessity for patients to monitor their health and perform self-therapy will increase remarkably in the next decade. The challenges in the accomplishment of disease management must therefore be shared with a patient who is motivated and trained to do so and has proven reliable and able to accept this responsibility (Fitzmaurice et al., 2005). In a British review of 12 discrete studies that looked at patient and public involvement in self-medical management, a major conclusion as interpreted by Cayton (2004) was

Patient involvement increases patient satisfaction. Benefits also include greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust, better relationships with professionals and positive health effects.

(p. 193)

Patients' acceptance of this responsibility, once they understand the importance to their well-being, is necessary if optimal outcomes are to be achieved. Although many

patients do engage in their care and health maintenance, many others seem unwilling or unable to do so. The medical environment in which they have had no previous experience is often overwhelming or they have anxiety about the medical problems they face. Some lack the ability to communicate with their health providers, and some are fearful and sense the unfamiliarity of the highly technical environment that they experience (Ferguson et al., 1998; Jackson, 1992; Sullivan, White, Young, Scott, & Mulgrew, 2008). Even though these reasons are recognized and acknowledged by healthcare providers, efforts to overcome them amount mainly to providing patients with written materials and specific education about the patients' particular conditions (Jacobson et al., 1999; Perneger et al., 2002; Schaffer & Tian, 2004).

Little attention is paid, however, within most community-based practices, to patients' ability to comprehend the materials or to understand the subsequent medical instructions they are given. There is a lack of commitment to recognize and overcome the barriers that hinder patients' effective involvement in their care. Time constraints of medical practices and facilities, especially during hospitalizations, have relegated patient education to the one-sided provision of educational materials presented with rapid-fire medical explanations often in technical jargon (Jackson, 1992; Kaplan, Greenfield, Gandek, Rogers, & Ware, 1996; Marvel, Epstein, Flowers, & Beckman, 1999; Schillinger et al., 2003; Street, 1992; Sullivan et al., 2008). Providers rarely consider comprehension on the part of the patient or whether or not patients are in a suitable physical or mental state to grasp the content of the educational offering. Immediately before and after a medical procedure are probably the two worst times to provide important information; yet these are the opportunities selected to do just that, times of anxiety and compromised

concentration. From many patients' perspectives, medical care belongs exclusively with medical providers who know best. Patients trust that their caretakers have their best interest at heart and defer all decisions passively to them (Beisecker & Beisecker, 1993; Elder et al., 2007; Flynn & Smith, 2007).

The Need for Medical Education for Patients

Given the exponentially increasing number of persons who have or will have chronic medical conditions that require life-long surveillance and attention, it is critically important for patients to engage and become active in their health care. Patient education is an essential component to this end. The provision of information, knowledge, self-care skills, and self-efficacy encouragement, in order to produce active participation, results in safer improved care and control of the illness including a better prognosis and outcome. The development of education to enable healthcare providers and caretakers to deliver appropriate medical information to patients and to recognize the most effective ways to deliver it to different patient types requires not only medical understanding but also educational leadership in the methods and types of information to be offered.

The literature has repeatedly shown that the best health care results are those based on collaboration between the healthcare provider and the patient (Ballard-Reisch, 1990; Brashers, Haas, & Neidig, 1999; Woolf et al., 2005). It follows that patients who are knowledgeable and possess accurate and complete information about their health and medical condition are better able to understand and follow their physicians' instructions (Curtin, Bultman Sitter, Schatell, & Chewning, 2004; DeWalt, Boone, & Pignone, 2007; Gold & McClung, 2006; Heisler, Cole, Weir, Kerr, & Hayward, 2007; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). When patients acquire information and education, they

are able to discuss, question, and collaborate with their doctors in the decisions required for their care to obtain the best and most successful health outcomes (Kaplan et al., 1996; Levey, 1988; Quill & Brody, 1996). They are informed of possible side effects from medications as well as the importance of maintaining and following the treatment regimens and protocols as given by their healthcare providers (Gold & McClung, 2006). Furthermore, they are much less anxious about their health and are overall more satisfied with the health system. In chronic conditions such as diabetes, hypertension, and congestive heart failure (CHF), patient involvement is essential for optimal well-being and disease control (Curtin et al., 2004; Drose, 2008; Gold & McClung, 2006). In life threatening situations such as cancer or with end of life decisions, choices that are congruent with the patient's ultimate desires should be the priority (Heady, 2007; Hofmann et al., 1997).

The Need for Self-advocacy Also Important

Patients with the ability to self-advocate, who are active and engaged, and who are in control of their health care present the desired situation. All persons, however, do not possess the essential traits to accomplish this goal. Bandura (1994) indicated that self-efficacy and confidence in one's abilities to handle complex and unfamiliar situations are often lacking. Additionally, according to Krantz, Baum, and Wideman (1980), there is a natural predisposition for some individuals to participate in their care and become involved rather than to remain passive and dependent upon others. Rotter (1982) suggested that some persons believe that many situations are beyond their ability to render any control over at all and that their health situation is therefore one they must accept as their "destiny." Patients who have the belief that their destiny is dependent on

external forces are said to have an external locus of control. On the other hand, patients who have the belief they can control the things that happen to them have an internal locus of control.

Overcoming the barriers that prohibit patients from active engagement in their medical care is essential, and healthcare providers must recognize the necessity to eliminate them. Addressing barriers and the development of patients' abilities and self-efficacy is necessary if progress in self-care and self-management is desired. Doctors' awareness of the cues of patients who desire involvement is also important so that they may react to each patient in a flexible and respectful manner according to each individual's needs. Both doctor and patient must strive to communicate in such a way as not only to understand one another's advice or wishes, but in a manner that is not defensive or aggressive on either part. Dialog is informational and accommodating. The practice of these characteristics will lead to a collaboration of care and to patients who fully understand and follow their care plan. Self-care instructions and overall improved patient behavior will result.

Purpose of Study

The purpose of this study was to understand if the information and education provided to patients prior to their procedure resulted in better outcomes than for patients who chose not to attend education classes. Additionally, a portion of the class participants in a later phase of the study received additional motivation to be active in their care with the purpose to encourage more passive patients to become engaged in their care and once again achieve a better rehabilitation after a period of 2 months.

Also of interest was to understand if caretakers and healthcare providers were able to recognize patients' beliefs in their ability to affect their own outcomes and if they had a propensity to engage in their own care with self-confidence. If patients do not have the ability to be active and involved in their care, it must be encouraged. To be able to detect these naturally active or passive traits in patients by caretakers and providers is valuable so that appropriate measures might be taken to encourage their participation

Conceptual Framework

Patient activism and therefore self-advocacy seems best viewed on a continuum with passive behavior at one extreme and active involved behavior at the opposite end. The challenge is to provide passive patients effective and sufficient skills to enable them to participate appropriately in their own health care and decisions. Clearly, to motivate this type of behavior requires a different approach for a more passive patient than for the patient who is naturally predisposed to have a more active assertive manner.

The promotion and teaching for self-efficacy so that patients can more positively affect their health outcome is of particular importance in assisting passive patients to gain control and to achieve involvement in their health or medical care (Bartholomew, Parcel, Swank & Czyzewski, 1993; Harvey et al., 2008; Lorig et al., 2001). The establishment of some degree of self-confidence to seek and understand medical information or to form a collaborative, decision-sharing relationship with caretaker(s) is equally important. The promotion of self confidence in passive patients is necessary before (or concurrently with) training and educating for self-management skills such as self-medication, self-monitoring, or most importantly, autonomous self adjustment of regimens and routines (Luszczynska, Tryburcy, & Schwarzer, 2007; Test, Fowler, Brewer, & Wood, 2005).

Education for this population of patients requires coaching, confidence building, and continued effort (Bartholomew et al.,1993; Saarmann, Daugherty, & Reigal, 2000). Educator expertise is likewise important in order to provide the necessary information and education for the specific and appropriate needs of various patient types.

In Figure 1, it is shown that patients with activist traits can more than likely progress immediately to self-advocacy and therefore receive education for self-care, self-management, and even collaborative decision sharing. For passive persons who lack the belief in control over their health, education must focus initially on supporting a belief of internal control over their outcomes as well as the simultaneous promotion of self-efficacy building and empowerment. The establishment of self-confidence before

Passive Active

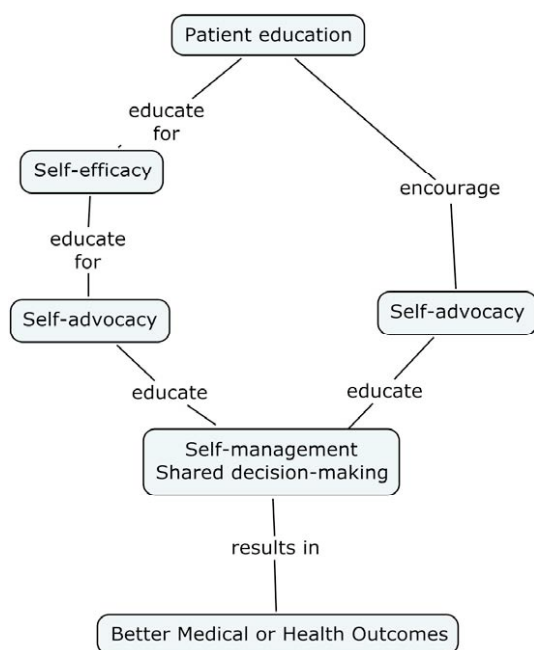


Figure 1. The provision of appropriate education in accordance with the patients' active or passive demeanor is able to produce better outcomes than patients who receive no education or incomplete education.

patients are ready for the challenge to manage their health care and to act as a self-advocate is a requirement. Soliciting patients' needs for information and for their care plans is worthy of consideration. Sullivan et al. (2008) found that focus groups were able to generate input on the kinds of information that patients want and the ways they prefer to receive it with regard to (in this particular case) a stroke prevention program. Patient input provided useful information around which to design a stroke prevention program. In general, a lack of understanding of the causes of stroke and the risk factors was seen as critically important. Information provided directly from the professional healthcare community was seen as very important, but it was also necessary that instruction be presented in non-medical terms. Participants were willing to attend the class if their doctor suggested it to them; that is, the offering needed only the physician's endorsement in order for the patient to attend. It was essential that the content be useful, relevant, and specific to the patient's medical situation.

The encouragement of patients' self-efficacy and active involvement in their healthcare is an important goal for better health outcomes. The recognition and monitoring of symptoms in order to react appropriately along with the maintenance of medication regimens, including pain control, and possibly medication dosage adjustment, are examples of patient involvement. To reach this goal, step-wise development of patients' medical knowledge of their condition and then the self confidence to utilize this knowledge in order to become active participants in their care is the conceptual framework that guided this research. Active participation can become and is often self-perpetuating for a patient as greater involvement can result in more knowledge, more

confidence, and therefore more self-efficacy to take control, to self-advocate, and to manage one's illness for the best possible outcome.

This current study assessed the nature and ability of patients with a specific medical condition to be active participants in their medical care and to utilize the information provided them during the preadmission education that was offered. The study examined the difference in outcomes after 2 months between patients who were active participants in their medical care and those who were passive participants. Both patient groups were offered similar information, instruction, and care plans. In a later phase of the study, in addition to the routine medical education, benefits of active participation, and the promotion of self-efficacy for successful involvement were added to the educational materials. Patients were supported to be active in their health care with the use of simple follow-up interventions of encouragement and self-efficacy before, during, and after their hospitalization. Outcomes at 2 months were analyzed for differences.

Research Questions

Individual traits of patients and their ability to accommodate and respond optimally to the challenges of their healthcare are factors that affect the level of success in disease management. Patients who seek information and knowledge are better informed about their diagnosis, are more successful in the management of their illnesses, and are better able to communicate effectively with their healthcare providers. Information, knowledge, and communication skills enable them ultimately to achieve collaborative participation in medical decisions that affect their lives, their health, and satisfaction with their care. Patients' beliefs that they can effectively exert control over

their lives and health is of primary importance to this end (Rotter, 1982). Of equal importance is a patient's self-efficacy to utilize the acquired knowledge and skills in order to carry out self-management of care. This achievement of self-management as well as collaborative decision-making is built step by step, with the recognition that it begins with patients' realization of the benefits of active involvement, followed by the desire to be engaged in their care. As these initial steps are accomplished and the patient's confidence and self-efficacy are developed and improved, collaborative participation becomes possible (Ballard-Reisch, 1990; Chiou & Wan, 2007; Coffman, 2008; Schlichting et al., 2007). For the present study, a patient group of participants with the same medical condition was followed with the purpose to understand if they could be assessed successfully in regard to their active or passive behaviors in medical issues and whether or not the provision of education and motivation, when appropriate, affected their medical outcomes.

The current study addressed the following research questions:

1. What is the difference in patients' rehabilitative outcomes between those who are assessed by caretakers to be actively engaged in their healthcare processes and those patients who are assessed by caretakers to be passive recipients of care?
2. What is the difference in outcomes when patients choose to attend a pre-admission education offering for their condition?
3. Can patients be effectively assessed by healthcare providers or caretakers in order to understand those patients' propensity for active involvement?
4. In a subsequent phase of this current study (Phase II), can the use of additional interventions, such as more educational evidence and motivational reminders for the

purpose of improving patients' belief in their personal control and self-efficacy, promote even more involvement in health care and therefore produce improved outcomes?

Design of the Study

At the community level, patients face issues concerning their healthcare such as the management of medical conditions that occur periodically, for example viral and bacterial infections or those relating to chronic diseases such as diabetes, CHF, and hypertension, or acute situations such as malignancies or surgical interventions to correct or improve lost functional abilities. In all these medical circumstances, it is thought that active involvement and participation of the patient is an important contributing factor for the achievement of a better outcome.

In the environment of a community hospital, which lent itself well to the investigation of active or passive patient participation, a subpopulation of patients, defined by a particular diagnosis, was studied. Although the diagnosis for all patients in the study was the same, the demographics of the patients had the potential to differ. The study participants were divided into two groups according to the choice of whether or not to attend a pre-admission education offering on their medical procedure. The education session entailed expectations before, during, and after surgery as well as during the post hospitalization rehabilitation process. Patients who attended this education session were group one. The second group, who chose not to attend the pre-admission education, was given the standard in-hospital education normally given patients for this procedure by all the participating care disciplines. The second group lacked only the pre-admission preparatory education. The two groups were defined as: group one, members of which by choice actively and preemptively selected to become involved in their medical

experience by attending a 1-hour educational offering on their procedure before hospital admission; and group two, members who selected not to attend the pre-admission educational session. Two surveys used for both groups (either at the pre-admission education activity or upon hospital admission) determined both participants' innate desire to be involved in their medical care and their beliefs regarding their ability to alter and to have an effect on their own outcomes.

Later in the second part of the study (Phase II), patients who attended class also received additional interventions to support their ability to take control of their health situation. It was thought that for patients who were specifically identified by the survey instruments or caretaker assessments to lack the impetus to engage in their health experience, simple interventions could provide an emphasis on their ability to affect their own outcome. The importance of active engagement in care and the bolstering of patients' self-efficacy was the intent of the interventions.

Encouragement occurred before, during, and after the procedure, during hospitalization, and periodically throughout the recovery by email or post card. The pre-admission education also included additional self-efficacy messages for patients in Phase II of the study who chose to attend class. All patients in the study, regardless of whether or not they attended preadmission education and regardless of their active or passive group designation by the two surveys, had equal contact with healthcare provider(s) with the opportunity to communicate, to ask questions, and to voice their concerns. Daily, multidisciplinary caretakers assessed the patients' participatory behavior according to prescribed criteria for active or passive participation. Two months after discharge, a

telephone survey assessed functional ability, the continued use of pain medication, and overall patient satisfaction with their experience.

The Significance of this Research

For conditions that require medical care and attention, the knowledge of expectations with focused engagement on the part of patients regarding their care, achieved by active participation (as opposed to merely receiving care), seems to result in quicker, more satisfactory, and complete recovery. The significance of the ability to discern patients who are passive and require extra encouragement and motivation is a valuable tool, particularly in this participant group that had almost exclusively passive medical behavior as was determined by the surveys. With the identification of patients with passive traits for whatever reason, including the lack of self-efficacy, appropriate education and/or interventions for motivation might be used to bring about a better outcome.

This proved to be true for this present study and for this particular medical condition, and it may be also applicable to other conditions or illnesses. Patients who better understood their medical instructions became more actively involved, followed better their regimens, and acquired better functionality more quickly. This model of care has the potential to result in overall fewer follow-up visits to a doctor as well as fewer complications. Medical problems that might have occurred during the course of rehabilitation, through improved patient understanding about ways to cope, may have resulted in better control of symptoms.

The Need and Use for Educational Leadership.

The provision of education prior to a medical procedure or for the purpose of informing patients on ways best to care for themselves when they have chronic healthcare issues requires an understanding of patient needs and ways best to provide for these needs. Information must be jargon-free and presented in a manner that is not misunderstood by those whose knowledge of healthcare is minimal. A focus on careful and attentive curriculum planning for patient education that portrays expectations from both the perspectives of the healthcare recipient and the healthcare provider is essential. Motivation and encouragement, as shown in this study, should be incorporated into the curriculum in order to serve those who need it. Only with attention to these necessary but specific components, which have been by design included within the curriculum, can optimal outcomes occur.

Similarly, there is a need to educate caretakers as either a part of their healthcare training or as continuing education on how to recognize patients that need extra motivation and encouragement in order to engage in their care. The role of healthcare education has then several aspects or foci – that of the provision of needed patient information and that for caretakers who require the ability to discern their patients' needs.

Summary

Everyone at some point in life will face the need for medical care. Studies have shown that many persons are able to take the necessary steps to accomplish their health care goals, while others appear less able to do so and are at the mercy of the healthcare system. Some patients are able to assert themselves not only to follow the direction of their healthcare provider but also to go beyond routine recommendations and to educate

themselves preemptively about their conditions. They are able to personalize their lifestyle with health improvement measures and proactively face medical treatment if necessary. Others, however, appear to lack the will or confidence to do so and may be non-compliant with basic self-management directives.

Optimal health care outcomes occur at times when patients are knowledgeable and confident in expressing their choices and managing their self-care requirements. It follows also that people are most satisfied with their care when they are included in health decisions that are in keeping with their values and desires. Engagement by patients in their own health care seems to promote both collaboration with their healthcare team and better results and is therefore an important goal.

In this current study, the effect of education before a surgical procedure was assessed in order to understand if outcomes are improved when education precedes a medical procedure. Additionally patient active or passive receptivity to education is considered with the use of two surveys that determine a patient's desire to be involved in their medical care and whether or not they believe in their own ability to take control of their care successfully to allow for a better outcome. Finally of interest is the ability of caretakers to assess active and passive patient traits so that providing the appropriate approach to education for either type patients can be utilized.

The study focused on the promotion of the best health care that patients were able to achieve by the encouragement and provision of opportunities for their personalized involvement in their care and therefore their optimal outcomes and good health. As this study is further defined and results are analyzed throughout the succeeding chapters, it will be shown that when caretakers have the ability to discern a patient's active or passive

traits in regard to health care participation, and when education and/or motivational techniques are utilized to assist to bring about a better outcomes, a more satisfied health care consumer also results.

CHAPTER 2

Literature Review

Approximately 50 years ago, patients were generally under the care of only one very familiar family doctor who was perhaps their life-long medical caretaker from birth to death. Patients were, for the most part, fairly uninvolved in their medical care and completely dependent on their physician (Nettles, 2005). Because of the exponential expansion of medical knowledge in the recent decades and the increased utilization of diagnostic and treatment protocols for standards-based care, the family doctor was no longer able solely to manage all the patient's needs – particularly for serious or chronic conditions and illnesses. It became necessary, for optimal care, to refer patients to specialists for diagnostic procedures and/or treatments. This process quickly became the norm for all healthcare. For the patient, this change meant contact with many healthcare providers, most of whom had little knowledge of the patient as an individual other than basic demographic information and a suspected or perhaps confirmed diagnosis. Patients were scheduled in rapid succession and many times, after only a single visit, were never seen again. The health system that evolved was that of a patient who became less well known as an individual and often recognizable merely as “a case” or number.

Particularly vulnerable were the elderly who came from an era when the doctor was not only authoritarian but was also paternalistic and hopefully beneficent (Beisecker & Beisecker, 1993; Elder et al., 2007; Nettles, 2005). Minorities and the less educated, who

were perplexed by the technical circumstances in which they found themselves, were especially less able to cope with the new problems of a depersonalized medical system. This system, despite its sophisticated knowledge and its state-of-the-art treatment protocols, has not only failed to achieve acceptable patient outcomes and satisfaction, but it has resulted in 100,000 lives lost annually from medical errors due to negligence (Kohn, Corrigan, & Donaldson, 2000). It is, therefore, vitally important for the welfare of all to focus on ways that patients might take responsibility for the management of their own healthcare. It is, in fact, a matter of life and death to provide information, knowledge, and skills so that individual engagement in one's health becomes the norm in America.

In recent years, as a result of both safety concerns and public dissatisfaction regarding not only access to care but also the quality of medical care, the rights of patients have been addressed with the proposal and adoption of a Patients' Bill of Rights (McLellan, 2001) that not only attempted to protect patients from shoddy care and the lack of diligence, but focused on the right of patients to obtain information regarding their medical condition in order to take part in the medical decisions that affect their lives. It attempted also to encourage the provision of appropriate cautionary information so that patients could be vigilant in order to detect and prevent potential errors if they had the occasion to be shuttled through the vast medical system of tests and treatments. Information in regard to recourse if patients were victims of carelessness or misadventure was also included as part of these rights (McLellan, 2001). With these adjustments and considerations, it was hoped that healthcare and medical outcomes might be improved.

With this quite abbreviated glimpse of the evolution of healthcare in the past 50 years to the present day, the intent of this review shall be to examine those practices that are successful in producing optimal patient health outcomes given the many different locations and healthcare providers to whom patients may be sent for diagnosis and/or treatment. Specifically, what are the means and processes that have been found to produce the best results for patients to maintain good health, which is particularly important for those who have chronic on-going conditions? Of equal importance, what are the means and methods that patients use and the traits patients possess in order to remain involved in their care and health management? Considered also are patient traits that hinder the success of care, such as passive, non-assertive behavior, or a lack of self-efficacy and/or the inability to advocate for themselves.

This literature review will initially look at the benefits of health knowledge through purposeful education either provided to the patient by healthcare providers or sought by the patient him or herself via public media. Next, the review will focus on the effects of patients' beliefs in their ability to control their own health and the confidence in their capability to manage and take charge of their own care. This part of the review will include literature addressing ways for patients to advocate for themselves and the benefit of doing so. It will also touch on healthcare provider and patient communication and the role of communication in fostering a participatory relationship leading to collaborative decision-making.

This literature review began with a search in current medical practice journals for the utilization and practical techniques of patient education. Additionally, academic research on the effects of communication in healthcare and social cognitive theories as

applied to patient behavior were also reviewed. Search engines used for this literature review included MedLine and ProQuest. Keywords such as *patient education*, *patient locus of control*, *patient self-efficacy*, *patient self-advocacy*, *doctor/patient communication*, and *collaborative doctor/patient decision-making* were used to search the literature.

Although there were literature reviews related to educational material and its usage, there were no reviews that looked at the other keywords included in this current search in conjunction with education. Topics such as patient locus of control and self-efficacy have been heavily studied and recognized to be a factor in patient health outcomes; however, there were no reviews found that looked at the ways these factors taken together related to better patient health outcomes.

Current Knowledge on the Production of Better Health Outcomes

Several decades ago, a different perspective on health called salutogenesis was introduced. Salutogenesis advocated engagement in practices, behaviors, and lifestyles that promoted good health with the result of an immense decrease in human suffering as well as a major positive economic impact. Not only could healthcare costs be directly lessened, but also there could be less nonproductive time in the workplace. Salutogenesis (the origins of health), as suggested by its founder, Antonovsky (1987), promotes and prevents, as well as cures and rehabilitates. Holistically, it seeks to provide the best health possible by a focus on the avoidance of risk factors rather than a focus on disease and pathogens. Salutogenesis encourages the active promotion and practice of lifestyle behaviors that produce and maintain health. A continuum model (Antonovsky, 1996), with individuals at some point between health and disease, advocates moving a person

toward better health and includes all aspects of a person not merely that of alleviating current symptoms. The maintenance of health or movement toward health is thought to be a function of a person's generalized coping ability, referred to as a sense of coherence (SOC), with life stressors that are potential compromisers to health. Stressors are risk factors of health, balance, and homeostasis and include germs, viruses, trauma, environmental factors, emotions, and even personality type. Salutogenesis also entails one's ability to cope with, manage, and rehabilitate from stressors in order to achieve wellness. The whole human rather than the "sick part" is emphasized, and emotional, psychological, and sociological factors in addition to biological factors are considered. This viewpoint recognizes that antibiotics and medication are only part of the cure. The focus is on things that cause wellness rather than the things that cause disease, for example, the traits that an individual possesses and uses in order to cope with the stressors in life. Antonovsky's (1987) theory for the basis of salutogenic orientation, instead of studying Type A individuals with coronary disease, looks at Type A individuals who do not have coronary disease and attempts to discover the things that protect them. The interest is the nature of their "coping" resource and the ways that this resource can be replicated or adapted for others so that they can also cope successfully.

One's SOC is thought to be varied in strength and is developed and shaped by life experiences, social structure, and culture. In salutogenesis, one's SOC is the basis of health promotion and often requires strengthening so that people can move toward health on the continuum. Willful action on the part of the patient is essential in the achievement of the goal of health. Eriksson and Lindstrom (2008) recommended the promotion of salutogenesis in all public health policies as well as a learning process in school curricula

for developing health practices, which will then last throughout life. Although with its holistic approach salutogenesis has acquired an active following, it has not yet caused a general shift in the focus of medical research (i.e., to study ways and factors that enable healthy people to maintain their health so that this information can be used, adapted, and applied to others in distress).

Once patients become ill and are diagnosed, particularly with chronic life-altering conditions, they are traditionally thrust into a situation in which much of their daily care, by necessity, becomes the responsibility of the patient or the patient's family. Many studies have verified that outcomes for health problems, particularly for chronic health conditions and illnesses, are better and more successful if patients are informed and educated in regard to the symptoms, the course of their condition, and ways to cope and care for themselves successfully in order to live as normally and fully as possible (Curtin et al., 2004; DeWalt et al., 2007; Drosey, 2008; Gold & McClung, 2006; Heisler et al., 2007; Lorig et al., 2001).

Patient education

One of the most important factors to insure the best outcome of medical care is the acquisition of knowledge and understanding by patients or their families about their particular condition(s) and a comprehension of the importance of following the care instructions they have been given (Curtin et al., 2008; Drosey, 2008; Gold & McClung, 2006; Heisler et al., 2007). Knowles, Holton, and Swanson (2005) in their studies of adult learning theory confirmed that adults are quite successful and internally motivated to learn at times they have a need to do so, at times that learning is experiential, and at times learning is meaningful in their lives. On the occasion of illness, particularly chronic

illness, patients have a vested interest in the most successful outcomes they are able to achieve. The provision of healthcare education by healthcare providers and medical facilities provides the most reliable and accurate of all sources of information.

Education from healthcare providers.

Education from providers of care is often based and focused on specific medical needs to ensure there is compliance with treatment regimens. Drosey (2008) described a hospital-based program in which the hospital's emergency room physicians referred diabetic patients for education on better ways to manage their condition. Training was provided in nutrition, self-monitoring of blood sugars, and then appropriate self-medication as a result of self-monitoring. After only four classes during a year, the referred patients had overall lower blood glycohemoglobin averages than in their prior histories. They also had no additional hospitalizations or emergency room visits. Gold and McClung (2006) found that patient education that emphasized, in particular, compliance to treatment and medication regimens resulted in better management for all chronic diseases. If patients were informed of the possible negative outcome of non-compliance to their regimens, they were more apt to continue their medication in order to avoid the negative outcomes. Likewise, if patients were told of possible side effects of medication and were given information regarding possible drug reactions, they were more apt to report problems and work through them with the help of their healthcare provider. Patients who understood that there were often side effects to drugs tolerated the treatment better and adhered better to their regimens.

The assessment by healthcare providers of the level of patient's knowledge regarding a care plan was also important in order to ensure that there was sufficient

understanding in order to adhere to a treatment plan. Often, patients reported that their lack of compliance was related to the feeling that there was no real benefit from the treatment and that it was not really necessary (Arnstein, 2004; Gold & McClung, 2006; Heisler et al., 2007; Schaffer & Tian, 2004). For patients with congestive heart failure, Hanyu et al. (1999) found that if patients understood and followed simple guidelines such as fluid control, proper nutrition, and appropriate medication, with the addition of basic education regarding the successful management of their condition, hospitalization and rehospitalization were prevented or significantly reduced. This information, given to the patient and understood, was an important strategy in the management of congestive heart failure (CHF) even though periodic repetition of the information and its presentation in many different modalities were also important and necessary. Mazor et al. (2007) estimated that 93% of patients on anticoagulant therapy had adverse preventable errors from inadequate understanding and knowledge about managing and monitoring their medication.

According to Schillinger et al. (2003), after a medical encounter less than 50% of the information given to a patient is recalled by the patient. It is therefore important to repeat the information and ask patients to restate instructions to ensure that they understand and retain them. Louis-Simonet et al. (2004) found that, particularly in cases involving medications, if a patient was given an individualized treatment card in a standardized format which reinforced their discharge medication instructions (the medication's name, dose and frequency, purpose, precautions to observe, and possible side effects) and if this information was reviewed with the patient before hospital discharge, adherence to treatment instructions improved. One week after discharge, a

telephone survey verified the information and provided additional knowledge if needed. Greater knowledge, particularly regarding potential side effects, reduced the number of patients who discontinued their medications.

For patients with literacy issues, very simple flyers with basic information that also contained the suggestion for patients to “ask your doctor” resulted in a five-fold increase in these patients receiving a preventive treatment (Jacobson et al., 1999). In a study in the Netherlands, Kocken, Joosten-van Zwaneberg, and de Hoop (2008) focused on female migrant patients who presented with lasting stress-related psychosomatic complaints. If the women were educated with coping strategies and with the understanding of ways they could restore balance in their lives, their situations improved significantly. The women with the intervention not only had improvement in coping with their pain, but they also had a general improvement in health, both physiological and psychological. Likewise, in a randomized trial, Perniger et al. (2002) found that minimally educated adults with asthma who received education as hospital inpatients and then had active follow-up with additional education as outpatients to prevent acute incidents of asthma, accomplished marked improvement in the control of their disease. They also had a greater knowledge of the prevention of behaviors leading to asthma incidents. Similarly, Schaffer and Tian (2004), in a study originally designed to compare the effects of a printed booklet on asthma control with the effects of the use of an audiotape (or both the modalities together), found that the modality was not of significant importance. If they were utilized, both promoted and resulted in better adherence to medication schedules.

In a very detailed and extensive study by Curtin et al. (2004) on the self-management ability of kidney dialysis patients, who required everyday management for successful functioning and well being and whose successful management in turn predicted both morbidity and mortality, the researchers found that self-management education programs produced a positive impact in medication use, communication with doctors, and other health status variables. This study assessed not only the nature of the self-management skills that patients learned and used, but also the patients' general knowledge about kidney disease and their understanding of the relationship between good self-management and knowledge to good physical and mental functioning.

Despite recognition of the value and need for patients to have information and knowledge in order successfully to care for themselves, Woolf et al. (2005) estimated that 33% of patients leave their doctors' visits without having their questions answered or gaining sufficient information to manage their own care. Marvel et al. (1999), found that despite the recognition by physicians that patients need information, the time actually spent with a patient was quite short and hurried. The average time available for patients to express their concerns was found to be 23.1 seconds.

Recognition that better outcomes require resources to provide education for the self-management of care leads to the recognition that better outcomes also require greater involvement by the patient in decision-making regarding their care and treatment choices. Decision-making requires yet another level of knowledge, namely information on available choices and ways best to make satisfactory choices based on patients' personal situations and their individual needs and values. This additional level might be manifested by consumer behavior and a level of involvement that seeks accurate and

reliable information on all alternative choices that are worthy of consideration. Again, several decades before this time, the trusted family doctor was the only resource consulted and the prescribing of medication was left to the sole discretion of that doctor (Beisecker & Beisecker, 1993). Today, however, pharmaceutical companies market to both the doctor and the patient; and, although the FDA reviews all medications, not all medications fit every patient or every situation. This manner of the dissemination of information is passive for the patient in that it requires only turning on the TV or looking at a magazine. The costs of advertising, however, are embedded in the marketed product and clearly not inexpensive. It is, therefore, important for the patient and the doctor to choose wisely and to understand the medication's effect and its potential for success in their situation (Robinson et al., 2004).

Internet and public information.

Many of today's patients have little loyalty to any one entity for their care or medical knowledge. They often take action and search for medical information using their own devices. Hesse et al. (2005) suggested that currently more patients than ever look online for information before talking to their doctor(s). According to Hesse (2005), data collected by a telephone survey from a Health Information National Trends Survey (HINTS), solicited every two years by the National Cancer Institute for the purpose of monitoring the availability of information, revealed about 66% of people surveyed looked for health information online. The dominant demographics of those who sought such information were young, female, and white with higher education and income. Even though most respondents (62%) still trusted their physician overall, their second resource for information was the Internet. Furthermore, 9% purchased medication and vitamins

through the Internet, 7% communicated with their doctors by email, and 4% participated in support groups online. Murray et al. (2003) surveyed a very large group of patients ($N=3,209$) and found that respondents who sought and found information on the Internet often requested their doctor's opinion rather than overtly requesting a specific Internet-recommended intervention.

A literature review conducted by Fagerlin et al. (2004) on education materials for prostate cancer examined publicly available educational material (Internet, print, multimedia sources) for patient use in making informed decisions. The researchers examined 546 items of patient education material and found that 504 of the total did not describe all the possible available standard treatments. The 42 remaining items did not have all choices compared in any one single summary, and the role of watchful waiting was not mentioned at all. Furthermore, all were lacking the provision of decision aids that highlighted tradeoffs for different treatments. Many also left out important information regarding side effects of treatments, and most materials were written above a ninth grade reading level. Much of the information avoided the discussion of negative outcomes or discomfort, and none mentioned possible death. In another review of the literature, Finney Rutten, Arora, Bakos, Aziz, and Rowland (2005) looked at both the resources and the needs of cancer patients from five information sources: health care professionals, printed material and media, interpersonal, organizational, and scientific. From the 112 articles summarized (from 1980-2003), patients' needs and desires were mainly focused on information for diagnosis and treatment in order to make good decisions. Also important were resources explaining treatment choices, coping skills, anxiety and mood changes, post treatment information, and family communication.

Information on treatment side effects was also deemed essential. The majority of the 112 articles were written after 2000, an indication that there has been a recent growth in the availability of information. Although healthcare providers were considered very important in providing information, Internet health sources were also influential with patients who chose to do Internet research. Patients were in need of all topics on the cancer care continuum – including recovery, survivorship, and the end-of-life experience in planning for their care. Even though public information resources are needed and are of great value, the use of them by all patients is not assured. Many patients seem to lack the will to take an active part to even acquire knowledge or familiarity with their condition.

Patient Psychological Factors for Participation

The propensity for patients to participate in any manner in their medical care seems to be a trait that is possessed within a person's psyche. It exhibits itself on a continuum ranging from that of a passive recipient of care to that of being involved in every facet of their care.

Locus of control.

Medical outcome evidence has led to the conclusion that, in addition to the acquisition of information and knowledge, better outcomes require patients to be active participants in their care, acquire good self-management skills, and develop the ability to advocate for themselves (Brashers et al., 1999; Woolf et al., 2005). These characteristics in turn are dependent on the patients' belief that their efforts and actions can have a real and positive effect on their own individual situations. Psychologist Julian Rotter (1982) carried out extensive studies and concluded in 1966 that individuals differed in their

belief that rewards or reactions were controlled by an individual's own actions as opposed to external causes. He stated that if a reaction or reinforcement was perceived by a person to be that of the individual's own action or behavior, then there was a belief in one's own internal control of the action (internal locus of control). On the other hand, if individuals believe that their destiny was a result of luck, chance, fate, or under the powerful control of another, their belief is in external control (external locus of control). Rotter's social learning theory stated that reinforcement (a positive reaction to one's behavior or action) strengthened the expectancy of an individual that future behaviors and actions could also be likewise positively reinforced. This expectancy of one's action or behavior which is causal to the reward or reinforcement can also be applied to self healthcare: that is, it is in one's control to bring about behaviors and actions that have positive and real effects upon one's own health. However, if a reinforcement fails, expectancy may thereafter be decreased and even extinguished. Such is the case at times when a disease process progresses rapidly despite sustained patient effort as, for example, in failed organ transplants. Patients may then reappraise their disease process as a result or reflection of external factors that are beyond their control. At times patients perceive that they have achieved disappointing results and a loss in control, a shift in their focus to problem-solving and self-care that is again achievable and within their control is recommended (Quinan, 2007).

Rotter (1982) found that individuals who had external control beliefs were generally passive and often had feelings of powerlessness, which they attributed to luck or fate. This rationalization was seen as a possible means for individuals to preserve their self-esteem in the face of failure. Ferguson et al. (1998) in numerous studies with

African American patients identified faith in God to control one's destiny as a recurring theme in this population, which, among other findings, was an important factor in their decision-making. Krause (2007) stated that an individual's belief in internal control can often decline with age and suggested it is, in fact, nonlinear. That is, as people age their feelings of control decrease at an accelerating rate, especially if there is a concurrent decline in functional ability, living arrangements (ability to live independently), and financial independence. Subjective life expectancy (the number of years an individual expects to live) is also a factor in the shift of perceived control from internal to external. Sparks, Zehr, and Painter (2004), who studied predictors of life satisfaction in the elderly, concluded that, in addition to health, social position, social interaction, self-esteem, and mobility, perceived personal control was a factor of some significance in life satisfaction.

Generally, people have a need for achievement; and, if they have a belief in their own ability to determine their outcomes by their own efforts, then they will exhibit more active behaviors to accomplish a successful outcome (Rotter, 1982). In the medical context, if individuals see their wellness or healing is outside their control and not contingent upon anything they might do, they are less likely to adopt behaviors and actions that might improve their circumstances. They will interpret the course of illness as dependent on fate, chance, others, or as unpredictable. An individual's own behaviors or actions are therefore of lesser importance, and they are not likely to be pursued and strengthened. Assessing this personality variable can, therefore, be very important for understanding whether or not patients become fully engaged and involved in their own healthcare, and it should be considered when patients demonstrate passive or detached

behavior. If one does not have the inclination that the control of healthcare is internal, the expectation for patients to self-advocate is not realistic.

Self-advocacy.

Self-advocacy suggests self-determination. It includes a person's knowledge, skills, and beliefs that enable him or her to be goal-directed and to pursue self-regulated and autonomous behavior (Test et al., 2005). It leads to empowerment as well as to the active acquisition of information (Brashers, Rintamaki, Hsieh, & Peterson, 2006).

Brashers, Haas, Neidig and Rintamaki (2002), who worked with HIV positive patients, stated that in a comparison of activists and non-activists there were predisposed factors for activist group membership, which enabled more problem-solving coping and less use of emotional coping. Activists had a greater social network for support and they acquired specific and more extensive knowledge. Brashers, Haas, and Neidig (2002) found that for patients to exercise self-advocacy, they required adherence to standards of ideal discussion in order for the conversations to be useful and bring about positive results. For patients to present their ideas and desires in a manner that fostered collaboration, it was necessary not to engage in communication with their physician that was argumentative and demanding. The asymmetrical power of doctor and patient relationships required knowledge and education for both on strategies for assertive communication skills, which allowed patients to enter into constructive discussions regarding decisions about their healthcare (Brashers et al., 2006).

Merely having membership in support groups seemed to have a positive overall effect for patients. Anglin (1997) reported an ethnographic study on the implications of breast cancer activism and found that activist women with breast cancer sought and

achieved information on alternative treatments for themselves and others in their support group. In addition, they were able by their persistence to gain the right for women to make their own choices regarding treatment and surgical procedures. Anglin further noted that NORCAL (North California), a California activist group, was responsible for making breast cancer a national priority. The group also addressed issues of class and poverty and pressured government and pharmaceutical companies to make new treatments and drugs available sooner, including “compassionate” release of experimental drugs.

In behavior that demonstrates self-advocacy, Test et al. (2005) asserts there is a belief by the person in personal capabilities along with an underlying understanding and confidence in personal strengths (and limitations) so that the individual can exert greater control over his or her life. In medical situations, this means people will take greater control of their medical decisions and care. Embedded in this concept of self-advocacy are four components: (a) self-knowledge; (b) knowledge of a person’s rights; (c) the ability to communicate; and (d) some degree of leadership (Test et al., 2005). To advocate for one’s self, then, requires knowledge of one’s situation and the environment in which one finds oneself. Specific skills such as assertiveness and the development of appropriate communication are necessary for patients who may often lack these particular traits. In studies of individuals with varying disabilities, interventional communication education achieved a positive impact on the person’s ability to self-advocate. Interventions such as role-playing, prompting, video examples, one-on-one instruction, and group activities improved both communication skills and the ability of the

participants to interject their opinions and concerns appropriately and effectively (Test et al., 2005).

Self-efficacy – self-management.

Closely associated with assertiveness and an important part of self-advocacy is the belief in one's capabilities to produce some level of performance that will bring about a desired outcome. Bandura (1994) in his landmark studies was the first to state in his social cognitive theory (SCT) that confidence and assurance in one's own ability or one's self-efficacy to influence events that affect one's life is then of paramount importance in actually being able to take control (internal locus of control; Rotter, 1982) and to advocate for oneself. Perceived self-efficacy is essential and is a necessary precursor of self-advocacy. Bandura further stated, "A strong sense of efficacy enhances human accomplishment and personal well-being in many ways. People with high assurance in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided" (p. 71).

To develop self-efficacy, the provision of successful experiences is perhaps the most effective way to accomplish and master feelings of confidence. Failures undermine self-efficacy; so care should be taken, when working to improve a person's feelings of confidence, to provide at least some success. It is worth noting, however, that if people only experience easy and quick successes, they will become easily discouraged and overwhelmed with any degree of failure. Resilience in efficacy is therefore important and requires experiences that allow persons being trained to persevere in overcoming the obstacles they may encounter. Setbacks and difficulties can serve as useful and purposeful experiences to teach and to provide the lesson that successes usually require

effort and diligence. After people realize they can succeed if they persevere and face adversity, they not only rebound in future setbacks but they emerge stronger and each time gain more confidence (Bandura, 1994).

Another successful method for creating efficacy is to expose the individual in a group setting with others who are in similar situations – but who have succeeded. This process is a social model methodology in which seeing others similar to one's self succeed, strengthens the observers' belief that they too can succeed and that they have the capabilities to master comparable activities. Such social models transmit knowledge and teach vicariously effective strategies and skills in the management of the requested task (Bandura, 1994).

In medical settings, Bartholomew et al. (1993) saw that with low levels of self-efficacy (particularly if accompanied by high levels of outcome expectation) there was a lower level of interest by the patient. To reduce the stresses involved in achieving a desired behavior, coaching was used and mentoring was helpful for patients who lacked self-efficacy, as it seemed to increase people's belief in their ability to achieve a desired outcome (Luszczynska et al., 2007). Since people naturally avoid situations and activities they believe are beyond their capabilities, such persons should be challenged appropriately with situations they will judge themselves capable of handling, even if it must be done in small steps or levels of difficulty (Bandura, 1994).

Recognizing already activist patients and educating them is somewhat more straightforward than promoting confidence in more passive (pacifist) persons who lack self-confidence in their capabilities. Some minimum level of confidence and self-efficacy is required before health or medical education can begin and before patients can

be expected to advocate for themselves. This difference in patients (who might be considered to have activist or pacifist predispositions) indicates the need for a very different approach for each of these patient groups, and the identification of such individuals early in their medical experience is useful for the provision of a more meaningful medical educational experience. The HIV Patient Self-advocacy Scale (PSAS) Brashers et al. (1999), which measures patients' involvement in health care decision-making interactions, and the Krantz Health Opinion Survey (HOS; Krantz et al., 1980), which assesses patients' behavior in seeking information and their desire for involvement in their care, are both excellent choices for preliminarily categorizing patients into activist or pacifist categories.

It follows, then, as with patients who acquire more knowledge and information, that patients with higher levels of self-advocacy and self-efficacy are better able to manage their self-care and ultimately achieve better outcomes. A reasonable expectation in the preparation of patients both to become involved in their health and medical care and eventually to self-manage is the assurance of some degree of self-efficacy. This prerequisite is important before assuming that a patient is capable of handling medical self-management skills and self-care. Self-management refers to patients' ability to monitor their disease condition (including their prescribed medications) and to recognize symptoms requiring action either by notifying the healthcare provider or by making appropriate adjustments as previously instructed by the healthcare provider. Australian patients ($N=175$) in an 18-month longitudinal study by Harvey et al. (2008) showed statistically significant improvement in self-management knowledge and skills as measured by several assessment surveys. A key health indicator in this study found to

have significant improvement was the reduction of health service utilization (fewer visits to doctors, specialists, or hospitalizations). Other health indicators such as general health and well being, pain levels, level of frustration with illness, anxiety, and worry about the future and illness were also significantly improved. It appeared advantageous to mentor some patients and coach them in the development of self-efficacy and self-advocacy abilities before endeavoring to teach them independent skills or medical self-care tasks. Lorig et al. (2001) described a program implemented to instill self-efficacy along with the mastery of skills for self-care and concluded that success in both was achievable. In this study, a long-term program was established which consisted of seven meetings of 2.5 hours each in which the information provided ranged from basic medical care skills to exercise regimens, communication, and patient action plans. Improvement in outcomes was measured in such things as overall health status, health behaviors, perceived self-efficacy, and additional health service utilization. The results of the program, one year after completion, showed improvements in 7-9 health status indicators.

Fraser and Polito (2007) found that self-management skills and self-efficacy were dependent on one another. Bartholomew et al. (1993) found that self-management education alone did not produce better self-management until an effort to promote self-efficacy and confidence was added to bring about a change in behavior. Jackson, Tucker, and Herman (2007) suggested that as value was attached to good health along with personal beliefs such as a person's self-efficacy, the perception of the value of good health had an important influence on health behavior change. The perception of the value of good health and one's ability to achieve it with the use of self-management strategies have, then, a promise of illness prevention and can foster health behaviors that decrease

the future likelihood of cancer, diabetes, hypertension, obesity, arthritis, and substance abuse. In other studies conducted to understand patients' ability to function with their individual diseases, self-efficacy strategies as interventions were valuable in the enhancement of self-management skills and, in fact, were found to be mediators (responsible) for health behavior change (Coffman, 2008; Fraser & Polito, 2007; Luszczynska et al., 2007; Zinken, Cradock, & Skinner, 2008).

Saarman et al. (2000) added that learning to change behavior entailed learning in stages and that the mere distribution of educational information was insufficient for improvement in outcome. It was imperative to work stepwise and develop self-efficacy as part of the education process for those patients who needed it. Patients should not be pushed, confronted, nor treated with paternalistic attitudes, but coached and encouraged to achieve progress at a comfortable rate. Some degree of personalization (perhaps by categorization of activists and pacifist characteristics) was recommended with behavioral change strategies such as structured and sequential stages of change, motivational interviewing, or cognitive-behavioral consulting with the focus on moving the patient to only the next stage in a series of progressive steps. At times that issues of literacy and understanding were a concern, repetition of the instructions, probing, and prompting patients to ensure that they understood proved useful (Schlichting et al., 2007).

Chiou and Wan (2007) found in medical circumstances that positive task experiences enhanced self-efficacy in persons with lower levels of confidence in such matters. Coffman (2008) likewise found that additional support with specialized education to achieve diabetes self-care efficacy in low or primary education level patients (in this case a Hispanic population) was successful. At times that supportive resources

specific for disease management were provided, which included healthier lifestyle choices, healthier behaviors were produced and adhered to, including the selection of better food choices, the maintenance of exercise plans, and utilization of improved cooking options. Additionally, it was particularly important for individuals to have not only the ability and the self-efficacy to self-manage, but also to have faith that the processes they were asked to adopt were worthy. Surprisingly, in contrast, DeWalt et al. (2007) found that low literacy was not particularly associated with self-efficacy but that low literacy patients overall had a lesser desire for participation in their care and health decisions. To assist in the involvement of such patients, boosting the patients' feelings of trust that their care plan would improve their situation was as important as coaching confidence and self-efficacy. The patients' trust in their health plan along with encouragement, in turn, yielded better outcomes. Wangberg (2008) found for Type 2 diabetes specifically, interventions that utilized an Internet-based diabetes self-care plan with strategies that targeted the improvement of self-efficacy resulted in the immediate decrease in blood Hgb A1c (hemoglobin A1c) levels; however, this effect waned over time.

Van der Bijl, Poelgeest-Eeltink, and Shortridge-Baggett (1999) similarly found self-efficacy important to achieve desired self-care behavior in their study of diabetic patients. Providing education alone was not sufficient to achieve complex self-care activities such as (a) the performance of activities essential for treatment, i.e., medication, maintaining diet, exercise; (b) self-observation and monitoring glucose in urine, body weight, and skin conditions; and (c) self-regulating activities (i.e., correcting hypo and hyperglycemia, adjusting diet to different needs, self regulation in the case of extra

weight). Self-efficacy and its relation to self-esteem, self-confidence, and locus of control were situational to the task at hand but were important for optimal outcomes. Self-efficacy was found to influence patients' choices and aspirations including the amount of effort they were willing to expend in achieving their goals. The greater the self-efficacy, the better the outcomes, as posited by Bandura (1994). By directed interventions, self-efficacy can be influenced, and, in turn, this increased self-efficacy positively influenced behaviors relating to diabetic self-care activities.

In the case of HIV patients, life adjustments for personal growth, goals, positive refocusing, replanning, and life reappraisal were found to be more easily accomplished in those individuals with higher levels of cognitive coping and self-efficacy (Kraaij et al., 2008). Johnson et al. (2007), who worked with HIV patients in treatment that involved anti-retroviral therapy (ART), found that self-efficacy support was very important and that the development of interventions to reduce non-adherence in taking ART medications was critical because discontinuation or skipping doses compromises the treatment's effect. Integration of the medication regimen into one's lifestyle and perseverance were necessary for success in order to cope with their disease despite the other challenges of HIV.

Finally, Luszczynska (2008) found that an individual's perception of his capability to exercise control and overcome challenges could be enhanced by verbal persuasion. Self-efficacy was found to be the largest determiner of behavior change in this regard and was accomplished in concert with action-priming and social-cognitive interventions (such as education). Luszczynska used such an intervention via the Internet to affect self-efficacy beliefs. Furthermore, the question was posed as to whether or not the effect of

self-efficacy was moderated (influenced) if the patient had a diagnosis of diabetes or CVD. The results of the study confirmed Bandura's SCT, i.e., self-efficacy was enhanced by verbal persuasion and produced also an emotion that was positive about changing behavior (the frequency of physical exercise in this case). The self-efficacy intervention in the study affected both behavior and beliefs and was particularly influential as a moderator of behavior with those patients with diabetes or CVD. Self-efficacy was established as a mediator (responsible agent) for change by Burke, Beilin, Cutt, Mansour, and Mori (2008) in a multi-variable study of behavior change in a lifestyle program for patients with hypertension. The study included dietary and physical activity behavioral changes.

The development of self-efficacy as a result of the influence of a medical condition or from verbal persuasion appears to be an important factor for change in the aspect of active engaged behavior. It also follows that engaged behavior on the part of the patient is an essential precursor for the development of health provider and patient collaboration.

Doctor/Patient Relationships - Communication, and Collaboration

Although most patients feel they have the right to challenge their physician on health or medical issues, very few do so (Beisecker, 1990). Additionally, some patients have a desire for participation in decision-making, while others do not. The inclination for participatory decision-making depends on the degree of expressed doctor/patient power and has three influencers: (a) sociodemographic, which is the effect of income, education, cultural background, and gender; (b) individual characteristics of both parties (doctor and patient), which include the attitudes of each and the patient's propensity to be

a consumer of medical care or rather to view the doctor/patient relationship as paternalistic; and (c) situational factors such as the type of illness, the presence of a companion, and the length and time for interaction. Epstein (2006), a physician himself who experienced serious illness, suggested that patients' desire for involvement was dependent upon the severity and debilitating nature of the illness and the degree of pain they experienced at the time that decision-making was required. Although participation in decision-making varied from person to person, it was to some extent dependent upon how sick the patient was. Deber, Kraetschmer, and Irvine (1996) suggested this was true as well.

When patients desired information, however, the physician did not always recognize this desire. Women and more educated patients generally ask more questions during their visits; lower socioeconomic class patients ask fewer (Beisecker, 1990; Fox & Chesla, 2008). In contrast, Bell, Kravitz, Thom, Krupat, and Azari (2001) in their studies found women and minorities less active. Fox and Chesla (2008) found that women who had chronic illnesses perceived their health to be significantly affected by their relationship with the health care provider. They experienced a greater sense of well-being and security, including feelings of greater self-efficacy and motivation to manage their illness, if they had a good doctor/patient relationship. Cooper-Patrick et al. (1999) found that African American patients had less participatory visits with their doctors than white patients. This situation was also confirmed by Bell et al. (2001) for other minorities. This trend was, however, not true for all minorities in the Cooper-Patrick et al. study. Ferguson et al. (1998) reported that African American patients often felt overwhelmed by doctors who used technical language rather than clear concise recommendations and

explanations. They felt generally talked about, rather than talked to. Interestingly, and described in the same study, female doctors conducted more participatory visits than male physicians, and patients with race concordant relationships rated their visits as more participatory. Gender concordance of doctor and patient was not significant in this respect.

Street (1991) found the degree to which physicians attempted to engage patients in partnership building was related to verbal responsiveness on the part of the patient. Encouragement of patients by their doctors to take active rolls, to ask questions, to give opinions, and to communicate concerns was strongly related to the degree to which patients expressed their opinions, feelings, and concerns. It was also dependent on the way that the interactants, especially the physician, adapted their style of communication with the person to whom they were communicating. In another study, Street (1992) found that physicians spent a large proportion of their time providing information and issuing directives to their patients, but little time offering socio-emotional remarks or otherwise engaging their patients in the development of partnership-building.

In situations during which patients (or parents of children who were patients) asked fewer questions or offered fewer opinions and did not express concerns or relay their thoughts or suggestions, team building was minimal. On the other hand, more educated patients who asked more questions and particularly parents who expressed greater concerns elicited more communication from their physicians. Even though it was realized that active doctor and patient interaction resulted in overall better patient outcomes as well as greater patient satisfaction, partnership-building utterances from physicians to their patients were infrequent during consultation. This pattern occurred

even if patients demonstrated the desire for more active participation. Beisecker (1990) noted that, at the times doctors seemed to solicit questions, they often ignored or gave ambiguous answers in response to a patient's inquiry even though they recognized that the information patients requested or provided could lead to a better understanding of patients' problems. Furthermore, participatory patients demonstrated more hopeful outlooks and had less anxiety and fear. It was noted as well that although doctors generally hesitated with the explanation of their uncertainties, patients preferred discussions on uncertainties and the fact that they failed to ask did not preclude the expectation. Evidence confirmed also that patients wanted this information but were often hesitant to ask. They might be, however, successfully coached to ask questions and to be more active. In one particular study (as reported by Beisecker, 1990) if patients were prompted (by the study organizers) to be active, some doctors reacted with anxiety and anger to this unexpectedly active role of questioning despite the fact they had previously agreed that active and effective information-seeking behavior had a positive effect on medical outcomes. In some cases, doctors interpreted the patient's questioning as a power struggle between doctor and patient.

Medical outcome was found to be positively affected by doctor-patient rapport. This rapport was manifested by asking questions from both parties, information volunteered by patients, the expression of patients' opinions, and the clarification of medical instructions in order better to understand the treatment regimen (Ballard-Reisch, 1990; Beisecker, 1990; Guadagnoli & Ward, 1998). If the prescribed treatment had side effects or disrupted normal activities, patients who demonstrated good rapport were even more willing to question. Guadagnoli and Ward, in a review of research in favor of and

against patient participation in medical care, found most patients wanted to participate in therapeutic decisions even though they preferred the doctor to do the actual problem solving. Any engagement in behavior, in fact, resulted in a better outcome. For example, preoperative education and pain control information alone eased the surgery experience for the patient, and at times a patient assertively took the initiative to question and express concerns the physician was, for the most part, more apt to engage in partnership-building communication (Street, 1992).

The consensus among health professionals, as well as the general public, according to Beisecker (1990) was (a) it is important to establish an agreed-upon authority relationship; (b) communication with one's doctor should be in a collegial manner with active and assertive discussions; (c) there should be active participation in decisions regarding treatment plans; and (d) patients should always be given broad-based information about treatment options. These things, however, were rarely found or practiced by either the doctor or the patient, which indicates that there is a particular need for physician training in this regard. Even though doctors felt that patients should be assertive, doctors' curtailing behavior inhibited patients' assertiveness. In a later study by Beisecker and Beisecker (1993), in which patient/doctor relationships were reviewed in light of two metaphors (paternalistic and that of consumerism), these two styles generated different attitudes, behavior, and expectations by both doctor and patient. If the attitude and expectation did not agree, conflict between the doctor and the patient most likely occurred.

Flynn and Smith (2007) posited that there were three models of decision-making: (a) paternalistic: the doctor makes all decisions; (b) informed: the doctor provides

relevant information for the patient to make the decision; (c) shared: doctor and patient participate equally. Flynn and Smith suggested, in addition, it was important to respect patients' preferences even though it has been suggested that patients' personality traits affect the doctor/patient relationship, which then also has an effect on decision-making style. Several factors of personality were associated with a lesser desire to be active in taking part in medical choices. Agreeableness characterized by cooperativeness implied less confrontational behavior on the part of patients and, therefore, doctors who were traditional in making all or most medical decisions did not bother them. Similarly, patients with neuroticism, who were more anxious and self-conscious, found that discussions and choices relating to health decisions distressing and anxiety-provoking. On the other hand, patients who were conscientious, which was associated with self-discipline and openness to experience, had a preference for medical decision-making. They preferred an active role in the avoidance of detrimental behaviors and the adoption of beneficial practices. According to Flynn and Smith patients with a rural origin, it seemed, preferred a more traditional doctor/patient relationship than women, who, for the most part, preferred a more active role in decision-making. Higher education and higher cognitive ability were postulated to result in the patients feeling more at ease and having greater confidence in their ability to engage in discussion and to make decisions. Surprisingly, there was a negative association of patients with fewer medications and their desire to be involved, and the length of the doctor-patient relationship was not found to be associated with decision-making desire on the part of the patient.

Both Flynn and Smith (2007) and Beisecker and Beisecker (1993) stated that it was important to know appropriate times to encourage participation and the times to

respect a patient's wish not to participate. Geist and Hardesty (1990) concluded that patients' cues often influenced doctor behavior and the ways they responded to and treated patients. Patient cues were delineated as social, physical, emotional, attitudinal, and personality from which the physician might categorize patients as a "good" or "problem." The cues given by patients affected physicians' attempts to communicate with them and subsequent attempts to engage in collaborative decision-making about treatment. This information suggested that it was important to teach patients who desired involvement in their own care to give the correct cues to their doctors. If a physician perceived the patient as passive, this was interpreted by the doctor as a patient who did not seek information. Because communication is two-way, physicians must receive the right cues and then respond accordingly in order to have effective communication.

Expectations, both by doctor and by patient, therefore, must match for optimal care. The paternalistic style encompasses complete trust in the doctor's decisions, which results in the obligation to the patient's health as a beneficent caretaker requiring only the patient's cooperation. The doctor is viewed as the expert and the dominant decision-maker, and the patient leaves all decision-making to the doctor. Consumerism, however, emphasizes patient input, patient rights, equal power, and shared decision-making (Beisecker & Beisecker 1993). Brashers, Haas, Klinge, and Neidig (2000), in their work with HIV positive patients, found clear indication from patients themselves that the establishment of empowered dialogue with their doctor enabled them to choose their treatments and therefore make desirable decisions affecting their futures. These relationships sometimes develop over time as patients learn tempered assertiveness particularly when authoritative traditional physician communication was encountered.

One such patient explained:

I've gone to several [physicians] over the years; some have been rather arrogant and argumentative. But, in general, over the years as I have educated myself, I've noticed that they have seemed to be more cooperative and seem to treat me with more respect. They listen to what I have to say, and honor my point of view.

(Brashers et al., 2000, p. 389)

Quill and Brody (1996) advocated that physicians move away from an assumed paternalistic approach to that of patients' choice. They should actively promote doctor/patient collaboration so that patients are able to make informed choices. Patients require expert advice and recommendations to become good decision-makers. To accomplish this, counsel and advice should be provided with respect and with adequate time taken to consider individual nuances. To enhance patient autonomy in decision-making, physicians should share their medical expertise with slow, clear transmission of facts in easily understandable language. They should listen to the patient's perspective and values. Doctors should also take into consideration both the clinical facts and their own previous personal experience in similar cases they have treated, as they give advice to patients. Quill and Brody (1996) also advocated that doctors should acknowledge their own personal biases, because these biases may be integral and affect the discussion and ultimately the decision-making. Health goals should be the focus rather than detailed specialized technical information or options, and advance directives or patients' desires on end-of-life issues should be clarified. Misunderstanding regarding advance directives can be avoided with discussion on any disagreements. These considerations, if addressed, assist in the achievement of the goal, which may be a final choice by a fully

informed patient who has a common understanding with his doctor for the course of action desired. This requires that physicians learn to express their personal values and opinions in an open modulated manner. They should be direct and honest with their patients and with their opinions and biases, but they should try not to over or under influence. Jackson (1992) and Sullivan et al. (2008) also found patient comprehension to be very important and that incomplete comprehension and inability to recall instructions compromised successful outcomes. Furthermore, the use of technical and complex language significantly hindered a patient's ability to comply. The lack of complete understanding on the part of the patient had an important impact on an individual's ability to comply as directed, including the positive or negative perception of their overall care.

Patients should always be given the opportunity to participate even though it must also be realized that some patients might not wish to do so. Guadagnoli and Ward (1998) identified three categories of patients in a breast cancer study: (a) delayers who were undecided; (b) deferrers, who accepted their doctor's decision; and, (c) deliberators, who weighed the pros and cons until they arrived at a satisfactory decision. There were similarly four types of patient responses: (a) "You decide"; (b) "I demand you do X"; (c) "I cannot decide"; and (d) "Give me the options and recommendations." In regard to doctor and patient negotiation of these issues, Ballard-Reisch (1990) described (a) patient autonomy; (b) patient abdication; (c) collaboration of doctor and patient; and (d) relationship termination as possibilities. It was seen as the doctor's responsibility to modify and adapt to each patient's level of response. Physicians should endeavor to engage patients but also should consider the patient's expressed desire and readiness.

Patient trust.

Piette, Heisler, Krein, and Kerr (2005) found that trust in one's doctor was also an important factor in a patient's ability to engage in decision-making. Lack of trust was a strong determinant for discontinuing medications particularly at times the cost of medications was a problem. Greater trust seemed to foster better communication and understanding and resulted in greater patient treatment, decision-making, and subsequent compliance to prescribed regimens. In the Ferguson et al. (1998) study on participatory decision-making, African Americans expressed a lack of trust and a feeling of discrimination in both the health care system overall (often contributed to by the lack of insurance or other financial issues) and in physicians, who were perceived by African Americans to be prejudiced and even dishonest. Keating, Gandhi, Orav, Bates, and Ayanian (2004) looked at the issue of trust with specialty physicians with whom patients might only have one visit. Most patients in this study (79%) reported confidence and trust; again, however, African American patients were less trusting than white. Torke, Corbie-Smith, and Branch (2004) found that African American patients, as a group, regarded the recommendations of their physician as one of the most important factors of their care regardless of the fact that African Americans had less trust overall in the medical system. They, like all patients, desired information whether or not they took an active role in the decision-making.

In Keating et al.'s study (2004), patients were more trusting at times they felt listened to, received as much information as they asked for, were advised about the possible continuance of symptoms or problems, were involved in decisions if they desired to be, and allotted as much time as they wanted for their doctor visit. Deber et al.

(1996) concluded that in a trusting doctor/patient relationship, if provided with emotional support, the choice of alternatives for treatment, and assistance with difficult choices, the patient was more inclined to leave solutions and problem-solving to the physician.

Patient requests.

Kravitz (2001) looked at the type of requests patients made of their doctors and established a Taxonomy of Requests by Patients or TORP, which included questions for information regarding symptoms, treatment, and requests for tests, procedures, or prescriptions. Because patients' requests were complex and often "veiled" (Kravitz et al., 2003), an exchange and negotiation between the doctor and patient was necessary in order to give attention to patient needs. TORP was useful in that it provided a link between patients' unarticulated desires and their expectations. Kravitz (2001) found that it was also important for doctors to explore their patients' constructs of their particular situations. In order for negotiated decision-making to occur, the doctor must understand the patients' expectations, concerns, and beliefs regarding their illnesses. Communication should consist of direct opening questions and vigorous exploration of the patients' complaint as expressed from the patients' perspective including their history and their perception of previous experiences and encounters with other health care providers (Kravitz et al., 1996)

Marvel et al. (1999) found that during the agenda setting of a medical visit with a patient, the physician often interrupted (preferred term "redirected the conversation") and focused on the initial problem expressed by the patient before the patient had communicated all concerns. If given the opportunity to verbalize them, an average of three concerns per patient was typical. Physicians frequently redirected patients' initial

statement after only 23.1 seconds on average. In one particular study, 76% of redirections occurred after the first concern patients expressed. Once a discussion was focused on a particular concern, there was only 8% likelihood to return to complete the agenda. Solicitation of all concerns of patients early in their visits resulted in more effective interviews in that all concerns were usually related thus allowing physicians to prioritize better their actions. In 24.6% of all visits, there was failure to solicit patients' entire agenda. Among physicians observed, 28.4% used closed questioning (questions answered by yes or no). It was noted that physicians who had trained as fellows (more specialized training) often allowed patients to finish their concerns. An effective doctor communication skill was the use of open questioning directly asking the reasons patients were there and the nature of their specific concerns. (Kravitz, 2001; Marvel et al., 1999)

Internet and e-mail effect on doctor/patient relationships.

Murray et al. (2003) looked at Internet health information vis-à-vis its potential to change doctor/patient relationships. Patients who researched health information on the Internet were overwhelmingly positive with their resulting information. In summary, 97% believed that health information obtained from the Internet promoted more confidence in discussing their concerns with their doctor; 96% thought that it helped them improve their understanding of their conditions; 85% felt that it helped them understand and follow their doctor's advice; and 93% felt that if patients had access to information, it challenged doctors to be more up-to-date with the latest treatments. Some adverse effects suggested were possible unnecessary visits to the doctor (39%) and utilization of more of the doctor's time during a visit (37%). Another 22% considered that this information might interfere with the patient/doctor relationship. Less than 1%

thought the information was harmful. About 50% took the information to their physician but hadn't scheduled the visit based on the found information. Seventy-one percent wanted their doctors' opinions on the information and felt in better control with greater confidence during the consultation as a result of the information. Patients felt that doctors reacted positively 67% of time; 15% said that doctors acted "challenged" and that some doctors appeared to have a lack of necessary communication skills either to discuss the information or to interpret it. Some doctors responded as if their professional authority had been challenged. According to Murray et al., doctors who felt challenged were associated with a lesser quality of care. These studies however remain unpublished. Medical Internet information allowed a more proactive approach to healthcare for some patients who, in turn, utilized this resource and then rated their physician lower than other patients who hadn't used the resource. Seeking Internet health information was strongly associated with the younger, wealthier, and a better-educated patient. African Americans were less likely to use this resource to look for information. Access to Internet information for disadvantaged patient groups is in need of improvement as is public education to improve information searches and appraisal skills (tutorials provided by the government, for example). Murray et al. also advocated the need for physicians to develop communication skills that facilitate discussions with patients about the Internet information they have brought to a visit.

Mandl, Kohnae, and Brandt (1998) found that email between providers and patients significantly improved access to healthcare and the involvement of patients by the enhancement of contact ability between the doctor and patient. Patients with e-mail access to their doctors felt less isolation and a more personal availability of their

provider. The optimal role of e-mail must be determined, however, so that priority messages (those needing emergency or rapid responses) are received in a timely manner and so that physicians or members of their staff are not overwhelmed by lengthy and frequent e-mail messages. Emergency messages should not be channeled by email even though there is the beneficial property for all e-mail communication in that it can be linked with the medical record and therefore provide easy documentation. E-mail inherently provides superior documentation over telephone consultations. Additionally, if patients requested medical information from their doctors, email facilitated both the request and the doctors' response as the medical literature was both reviewed and approved by the physician.

Prior to the universal routine doctor/patient use of email, it is important to (a) define the appropriate use for email for the various modes of patient/doctor communication; (b) address the security and confidentiality of messages; (c) create links with the use of technology that "guide" patients to effective and appropriate sources; (d) define the medicolegal liability inherent with this use of technology; and (e) ensure its availability to multicultural and multilingual populations as well as to those with varying degrees of literacy (Mandl et al.,1998).

As previously noted, patients' desire to communicate and make decisions was dependent on the acuity of illness of the patients or the degree of pain they were experiencing (Epstein, 2006). Hofmann et al. (1997) noted that seriously ill hospitalized patients rarely communicated their desires regarding resuscitation or ventilation or any end of life preferences even though many patients were interested in doing so. Patients with poor quality of life were similarly interested in such discussion. On the other hand,

those with excellent prognoses and good quality of life rarely wanted this sort of discussion. More effective communication was necessary as well with patients with limited English proficiency particularly for discussions about the risks of procedures and when informed consent was needed (Heady, 2007). When such discussions did not occur because of the lack of effective communication, the result was unwanted interventions for some and/or the possibility of misunderstanding the patient's desires.

Shared decision-making

Levey (1988) stated that the shared decision-making model (SDM) was no longer only visionary but for everyone, including the underprivileged and mental health patients. Makoul and Clayman (2006) stated that 31 separate concepts of SDM were found and that only 2 of the 31 concepts were present in 50% or more of the models. In a study with two separate groups of concepts (essential and ideal), essential elements must be present for a fully integrated model of SDM. These elements were (a) define/explain the problem; (b) present the options; (c) discuss the pros/cons (benefits/risks and costs); (d) consider the patient's values and preferences; (e) discuss the patient's self-efficacy and ability; (f) consider the doctor's knowledge and recommendations; (g) check and clarify any misunderstandings; (h) make or explicitly defer decisions (patient); and (i) arrange mutual follow-up. In addition, SDM has been rooted in the transactional model of communication as messages are affected by interaction and bilateral simultaneous influence of doctor and patient. Kaplan et al. (1996) recognized that participatory style was an indicator of quality interpersonal care and, therefore, patient satisfaction, and that abbreviated and rushed doctor visits with less time per patient inhibited this desired outcome. Despite the concern with cost, more time used for quality interactions and

better developed interviewing skills allowed doctors to elicit better information from their patients. One study associated doctors who were less conversationally controlling with patients (i.e., asked fewer closed-ended questions, gave fewer directions, and interrupted less) with more involved patients. This ability had an important positive effect on patient loyalty and satisfaction and subsequently patients' outcomes. Robinson and Heritage (2006) found also that patients' satisfaction with their physician was highly associated with a doctor's use of open-ended questions, particularly at the beginning of a medical interaction. This initial feeling of openness resulted in even more patient satisfaction than the total time spent or the feeling of completion in relating their problem. Doctors with personal autonomy in their professional situations were overall more participatory than those dissatisfied with the control of their group practice situation. In this particular study, it was found that non-white doctors were somewhat less participatory than white.

Torke et al. (2004) advocated fully informing patients regardless of their desire to share in decision-making. Doctors were urged to provide guidance concerning their patients' condition so that patients could become involved if they chose to do so. Once again, Flynn and Smith (2007) suggested there were three situations for patient decision-making (similar to patient active involvement characteristics). These situations were (a) the provider makes the decision; (b) there is joint decision-making by both patient and doctor; and (c) the decision is entirely that of the patient. Torke et al. (2004) emphasized the importance of patients' trust in such situations and urged that physicians' demeanors remain patient and kind. Physicians should not withhold information or appear rushed or hurried as, for the most part, patients want control of their own body and life. Patients require information and knowledge about their tests and procedures if they desire an

active role in decision-making. Physicians should accommodate patients' decisions with their own recommendations, yet allow patients to be in control of their own life and body as they desire. A physician's approach must be flexible and respond to the patient's individual preferences.

As a solution and a response to patients' desire to have and exercise control over their health and their lives, patient-centered care (PCC) has resulted, which considers, above all, the patients' choice, their culture, and their desire for dignity. It individualizes the care they receive and the medical choices they make. The provision of factual information that enables a patient to make informed choices is critically important if the patient is to be considered foremost, and it is essential for the satisfaction of both the patient and the patient's family (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). Sidani (2008) summarized PCC as consisting of two components: (a) patient participation, whereby the patient is involved in self-care and decision-making and performs activities related to the management of the specific condition; and (b) individualized care, which is personalized according to the patient's needs and preferences. It is holistic in that it also considers in addition to physical needs, the psychosocial and spiritual needs of the patient as well. Outcomes for this approach have yielded better patient functional status by informing patients of all available treatments and involving them in the selection of an option appropriate for them. This process simultaneously increases patients' self-care knowledge, their sense of control, their active engagement, their satisfaction with care, and an improvement in overall well-being. It empowers the individual and promotes a feeling not only of being cared for, but, of being valued as well.

Limitations of this Literature Review

Despite the obvious benefits found in wellness research for the elimination of disease and the pre-emptive maintenance of health, the efforts of this literature review are aimed at patients who experience illness and who need information and knowledge that can affect the course of their treatment and ultimately provide for them better health outcomes. Although most medical research is focused on particular disease processes with the intent to provide health care management for patients with chronic conditions, there are a number of long-term studies that focus on lifestyle changes such as nutrition and exercise that positively affect patient outcomes and ultimately their overall health. The consideration of salutogenesis served to emphasize the importance of this very important avenue for research and progress. Likewise, with the completion of gene mapping as a result of the human genome project, studies to manage patients with genetic predisposition to certain diseases have also commenced. This literature review has not included these aspects of health prevention and maintenance. Rather, the intent has been to focus on the problems, needs, and desires of patients who suffer from serious or chronic medical conditions as they attempt to manage their conditions to maintain the intent of control of their own health and healthcare.

Generalizations from the literature

Based on past research, a consistent causal relationship appeared to be demonstrated in which any degree of active purposeful involvement or participation on the part of an individual achieved a better medical outcome than the outcomes for patients who were passive or mere recipients of medical care. Fundamental information regarding the achievement of good health or the care and maintenance of one's self as

medical conditions arise was critical. Knowledge and skills were requirements in order for patients to function as well as they could in any circumstance, health maintenance, coping with an acute illness, or living with a chronic medical condition. The literature has shown that on occasions patients were provided information and education regarding their conditions, and if they had some degree of understanding, the acquired information and their understanding of it enabled them to communicate better with their health care providers and to recognize the importance of following all medical instructions. This process also fostered adherence to medication regimens and the where-with-all to monitor and to report unexpected medical and physical occurrences that were questionable. Educating patients regarding specific conditions and ways optimally to adapt to them for a better life was thus a primary step in the facilitation of their involvement and participation. When patients were actively involved in their care, their participation led to better communication with their health care providers and ultimately to a relationship with their providers that promoted collaborative decision-making and improved patient self-advocacy. Coincidentally, their participation also resulted in greater satisfaction with their care.

Achieving patient involvement in healthcare is a critical factor in the accomplishment of the goal of better health outcomes. Two factors that play primary roles in the facilitation of this goal are the physician's ability to draw out a patient's participation and the patient's desire to be part of the decision-making in medical care. Doctors, as part of their medical education, need specific training in ways to interview patients, not only to understand fully their complaints and medical problems but also to understand patients' ability and desire to be involved. When the physician or healthcare

provider understands patients' abilities, not only can they be better honored, but also care plans can be fashioned in accordance with these abilities rather than under the assumption that all patients are alike. Involvement can further be encouraged by working with patients to develop their confidence to participate at the highest possible level. This process can occur stepwise with the provision of information and education leading perhaps to full collaboration and decision-sharing.

Successful health management by the patient is a subject of study not only in the field of pure medical research but also by psychologists, sociologists, and communication experts. Educational leaders also have a role to design training for health care workers' awareness and the discernment of patients' active or passive traits. As traits are revealed, the development of education that suits patient type can also be developed and used. Educational leadership is an important component for this health management plan in that medical information should be presented to active and passive patients in a manner appropriate for their dispositions. Recognition of patient types by their caretakers followed by health or medical information provided to patients accordingly can serve better to engage patients in their care as well as improve their medical outcomes.

It seems universally agreed that persons actively engaged and involved in their care have better prognoses and subsequent outcomes. Currently the question has arisen that despite the success of patient involvement and the recognition that some patients, with certain personality traits, assertively acquire the information and knowledge they need, why aren't all patients inclined to engage actively in their care? Concepts such as self-efficacy and an individual's perceived internal locus of control have been recognized and acknowledged as important considerations, yet these concepts are missing in health

care practice for individuals who lack these traits. Addressing these issues with such patients before they are expected to take part in the self-management of health care is important. Is an individual's perceived locus of control related to his or her demonstrated self-efficacy? Can these deficiencies, if present, be successfully altered for patients to become more actively engaged? Absent in the literature are studies that indicate the need to assess all patients and provide for those who need greater self-confidence to participate successfully in their care.

The Joint Commission on the Accreditation of Health Care Organizations (JCAHO; 2008) has recognized the importance that education plays in successful patient management of health and has made it a requirement in the hospitalization experience for inpatients. The inpatient setting may not, however, provide the optimal time and place to teach patients complex and technical concepts and practices. Furthermore, how can education best be provided for those who are not hospitalized? If a stepwise, individualized outpatient approach is more successful, is it plausible? Are there easy interventions that can be used to assist toward this end? These questions are not directly addressed in the current literature. From patients' perspectives, what barriers do they face if they are given a diagnosis that is life-threatening or life-altering? What are their feelings and how do they begin to navigate with any degree of active involvement through the unfamiliar healthcare system? Personal perspectives on this issue are virtually unreported in current medical research. If the patients' perspectives are not well understood, how then can the barriers be resolved?

A model set forth by Ballard-Reish (1990) is useful for patients and providers who want to consider the patients' choice in regard to their desired degree of involvement

in their treatment and care. The model is presented in three phases (a) diagnosis; (b) exploration of alternatives; and (c) decision, implementation, and evaluation. Although the diagnostic phase is primarily the responsibility of the physician in that information (for example, history or test results) must be gathered and interpreted, patients must also participate with the provision of their health information in a forthright manner as well as cooperate fully with diagnostic testing and its related requirements. Ballard-Reish states that as the physician relates the diagnosis and its ramifications, both the patient and doctor must decide on their future relationship. The choices include (a) patient autonomy or patients who decide entirely on their own; (b) patient abdication or patients who defer entirely to the physician's decisions; (c) doctor/patient collaboration with care and treatment negotiated between them; and (d) relationship termination if neither the doctor nor the patient can find common ground for agreement in treatment and care.

If the doctor and patient (and/or the patient's family) become collaborative partners in the health venture, the resulting interaction progresses to the second and third phases. In the second phase, treatment alternatives are negotiated with consideration of costs, benefits and risks, the culture and values of the patient, and the physician's experience and expertise. In the third phase, the alternative is mutually agreed upon, implemented, and then continually reassessed and perhaps even renegotiated. Consideration for this type of doctor/patient model provides opportunities for involvement of patients with all levels of healthcare sophistication and ability. Patients can gradually move on to greater and greater participation in their care until true and complete collaborative decision-making is reached.

Conceptual Framework Derived from Literature Review

The medical model for the twenty first century with its specialization and the resulting lack of familiarity with individual patients by healthcare providers has resulted in the need for safe and effective care that includes the ability of patients partially to share responsibility in the management of their own medical conditions. The importance for patients to become actively engaged in their own care is therefore critical, as is the patients' belief that they can successfully affect their own outcomes. These are worthwhile characteristics to encourage, develop, and support. For some patients, involvement in their own care by seeking information and receiving education so that they can carry out self-management tasks and advocate for themselves is innate (Krantz, et al., 1980). They do not require motivation or justification to do so. They choose to have control in the things that happen to them, and they believe their control is important for a successful outcome. These patients have an internal locus of control. They are also receptive and expectant of medical direction and they perceive themselves capable (self-efficacious) in their abilities to carry out their care instructions. In contrast, others are overwhelmed by the situation in which they find themselves and may lack confidence that they have the ability to affect their health outcomes. They may hold the belief that their health is a factor completely outside of their control. These patients have an external locus of control (Rotter, 1982). For this latter group of patients, the expectation that they can become part of their own healthcare solution is questionable until they recognize and adopt the belief that they can have an effect on their situation as well as gain the confidence needed to do so. Providing and fostering support and encouragement to build patients' self-efficacy and to change their beliefs concerning the importance of personal

control in their health outcomes is a worthy endeavor for the overall goal of better medical outcomes. The focus on education within health care is essential for the achievement of this end. Educational leaders in healthcare will not only recognize the differences in patients but will facilitate and enable the training of health care providers and caretakers also to discern patient traits. Leaders in healthcare education can then not only provide and present medical information appropriately to all patients according to their abilities to respond, but, in addition, develop and implement justification for patient involvement so as to instill the belief of self-efficacy in patients in order to be successful in the participation and/or management of their medical situations. Clearly, changing the thought patterns of passivity may not only take time for some, but will require a different approach to achieve involvement and engagement in their care. It is therefore important that the active or passive traits of patients must be reliably assessed before an appropriate approach to education can be individualized and used. Even the achievement of small steps in engagement and involvement will most likely produce improved outcomes.

Figure 2 illustrates schematically the education process for these two groups of patients. Type 1 patients have an internal locus of control as described by Rotter (1982). They demonstrate assertiveness in seeking education and information regarding their illnesses and typically do so because they believe that their participation is important for a good outcome. They believe that by engaging in their care, they maintain control, which in turn leads to better results. They willingly accept their responsibilities (given the proper guidance) because they realize their best welfare is at stake. They actively engage in learning ways best to manage their illnesses and frequently form relationships with caretakers that enable them to collaborate and share in all decisions involving their

care. They are vocal, forthright, and diplomatic in the communication concerning their care, which ultimately leads to better medical outcomes and also to greater satisfaction

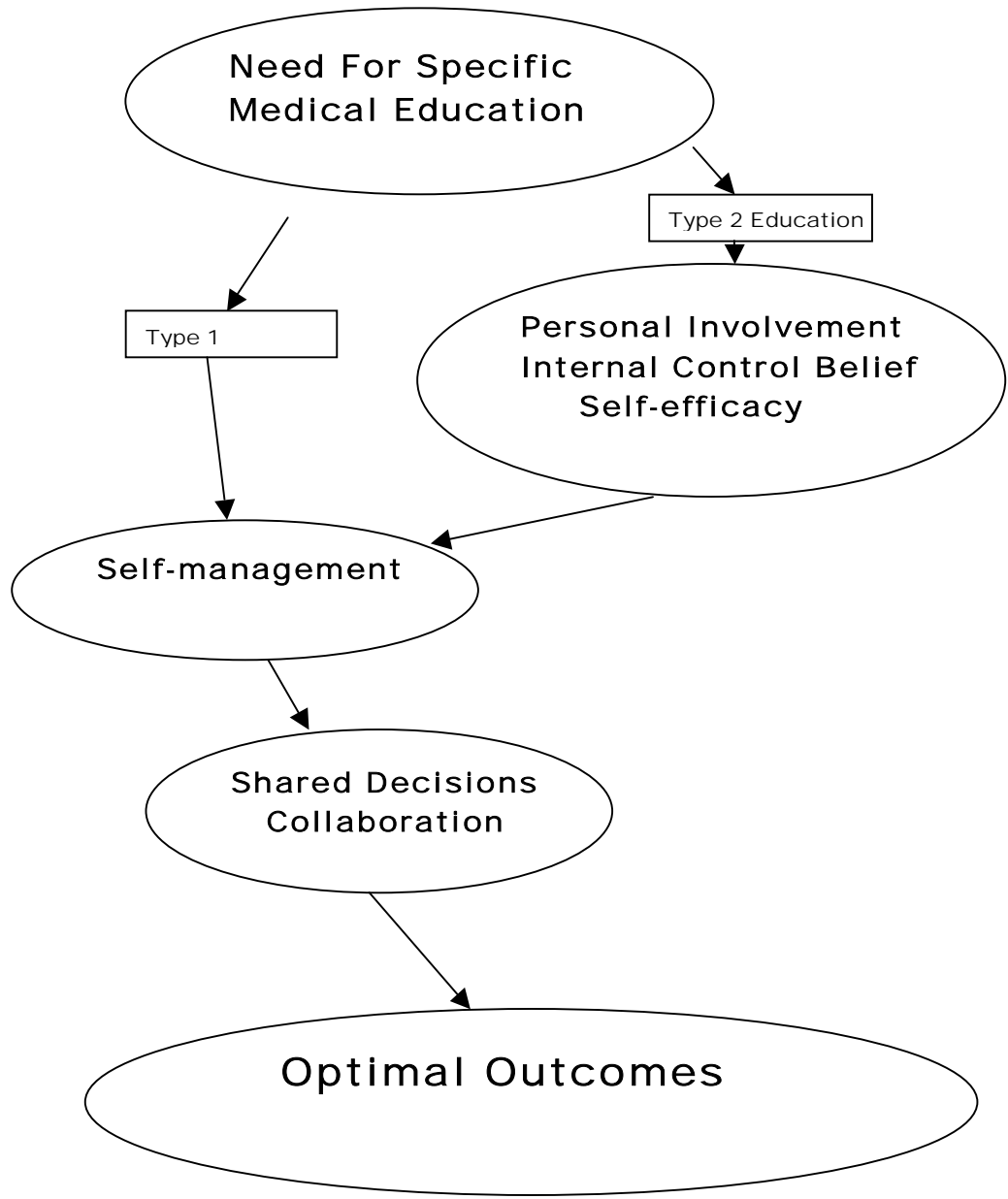


Figure 2. Pathways for optimal medical/health outcomes for two patient types.

with their care plans. Because they share in the planning, they understand the reasons that specific care tasks are important. Type 1 patients do not require motivation to become active, nor do they need to change their orientation regarding their capability to carry out the tasks that will be asked of them during their procedures, protocols, and treatments. They are ready at the onset to learn the things that are required to manage successfully and cooperatively to manage their care.

Type 2 patients, on the other hand, have an external locus of control (Rotter, 1982) and cannot advance to a level of self-management until they accept and are supported in the belief that their health is affected by their own good or bad behaviors and that they are in control of those behaviors. They often need assistance to realize that it is their responsibility to engage in their own care to produce positive changes rather than passively leave their health and care to others who are less concerned with their welfare than they are. Patients must be convinced that their involvement and participation in their care and, therefore, the control of their own destinies is beneficial. This process may, however, prove to be complicated. Patients may feel that they are incapable of accepting responsibility to carry out medical instruction and self care tasks. It is necessary, therefore, to boost their self-confidence and self-efficacy, as described by Bandura (1994), so that they can actively engage in their care and therefore affect their outcomes as optimally as possible. Finally, after these preliminary skills are present and the patients believe in the importance of them as well as in their own ability to use them, this patient type is then better able to carry out the expectations of self-management and perhaps even share in decisions in care planning. Clearly, even if Type 2 patients do not progress to the point of sharing in care decisions, their ability to follow instructions

confidently and successfully to manage their care as directed will create a much better outcome than that of passive recipients of care who have little understanding and therefore little knowledge of the actions they need to take or the reasons they need to take them.

The following chapters describe an investigation of this concept with a study of patients who underwent an inpatient surgical procedure. An assessment of patient type (active or passive, including a lack of self-efficacy) and a choice to attend formal, structured education was provided participants in an experimental group. The difference in outcomes was compared with those not receiving education who acted as control participants in the study.

CHAPTER 3

Methodology

This quasi-experimental study followed a sequential monomethod multistrand design designated as QUAN → QUAN with two strands of research design that occurred in a sequential order. The second phase of study was developed on the basis of the outcomes and inferences gleaned from the findings of the first phase (Teddlie & Tashakkori, 2006). The study, as Creswell (2005) described, consisted of the collection of data that measured distinct individual attributes (by surveys and assessments) and subsequently compared these attribute factors of individuals (or groups of individuals) with the outcomes of interest, i.e., health outcomes in this study. In addition, with the comparison of the difference in each group's mean, the use of experiments (interventions) provided understanding if the interventions (pertinent education or motivation) had effects on outcomes.

Research Questions

The questions answered in this study were the following:

1. What is the difference in patients' rehabilitative outcomes between those who were assessed by caretakers to be actively engaged in their health care processes and those patients who were assessed by caretakers to be passive recipients of care?
2. What is the difference in outcomes when patients chose to attend a pre-admission education offering for their condition?

3. Can patients be effectively assessed by healthcare providers or caretakers in order to understand those patients' propensity for active involvement?
- 4: In a subsequent phase of this current study (Phase II), can the use of additional interventions, such as more educational evidence and motivational reminders for the purpose of improving patients' belief in their personal control and self-efficacy, promote even more involvement in health care and therefore produce improved outcomes?

Methodological Design

This research project had two phases and is summarized as follows. Patients who are engaged in their medical care have better and more satisfying outcomes than those who passively receive care and expend minimal effort. It was further hypothesized that these two groups of patients have different personal traits that affect their will and self-perceived ability to become actively involved in their own care.

For purposes of this study, two survey instruments that were originally designed by researchers in clinical psychology were used to discern patients who needed encouragement and support to become engaged in their care. The recognition of the very close association between internal or external locus of control and the propensity for individuals with such traits to involve or not involve themselves in situations (in this case their health condition) is essential so that these beliefs can be altered, if necessary. Those who seemed to have an external locus of control were given evidence of the positive influence and efficacy that patient participation and involvement have on medical outcomes. The accomplishment of this change in outlook is necessary before these individuals can be expected to engage and to become part of the solution to their health problems. The Multidimensional Health Locus of Control (MHLC; Wallston, Wallston,

& DeVellis, 1978), an adaptation of Rotter's original Locus of Control Survey, was used to assess the degree to which patients believe they can render any effect upon their health or disease process. Second, a survey developed and validated by Krantz et al. (1980), the Krantz Health Opinion Survey (HOS) was used to assess preferences for information and involvement in health care. It was hoped the results of these two surveys would serve to categorize individuals as to their personal traits, desires, and propensities to engage in their health care programs. The survey responses were to give indications and demonstrate which patients needed support in the development of self-efficacy so that effective engagement in their care could be encouraged, supported, and hopefully achieved.

In order to compensate for a lack of will and the perception of incapability, simple interventions were provided for patients who lacked self-efficacy in their abilities. Patients were given evidence that emphasized the value gained by active involvement in their care and also an intervention that provided encouragement and support for the development of self-efficacy and the patients' ability to succeed as they became involved.

Phase I of the study consisted of the provision of a formalized preadmission opportunity for education (and therefore engagement) for all patients who had a specific diagnosis and who were to undergo a specific medical procedure. A less formal "routine" provision of the same educational material was given during hospitalization to those who, for reasons including the lack of will, were unable to attend the pre-admission educational offering. Both groups of patients (therefore all patients) were given surveys to assess their individual personality locus of control orientation in health issues and their propensity for healthcare involvement. Both groups of patients were followed for 2

months. The difference in the functional ability of both groups of patients was compared for those who attended class and were thought to have personal traits to engage in care and those without those personal traits who did not engage and did not attend a class.

In Phase II, patients were given an educational intervention supporting self-efficacy and their capability to improve and succeed in their outcome. The intervention additionally emphasized that there are better outcomes in patients who engage in their care with the belief that this would help their outcomes. The intervention was to be given to all patients regardless of their survey-assessed propensity for involvement, their perceived self-efficacy, or their attendance to the preadmission education. However by this time in the study (Phase II), the majority of TKA patients attended a class and it became doubtful that a sufficient number of non-attendees would be available to have any statistically significant findings. The control group therefore remained the non-class participants for the entire study (Phase I and Phase II) who received no intervention beyond the usual in-hospital education normally given.

As mentioned, during the Phase II formal education class, some time was dedicated to augmenting self-efficacy as well as the benefits of engagement in one's own health care. Contact after hospitalization also supported and encouraged self-efficacy. The resulting difference in the improvement in outcome functionality was again measured and compared to the outcome functionality of patients without efficacy intervention in Phase I. The improvement in functionality in the patients who perceived themselves incapable of affecting their success was of special interest.

Phase I: Detail of design.

As part of a larger study at an acute care hospital to assess the effects of pain management in patients with orthopedic knee replacement surgery also called TKA (Total Knee Arthroplasty), preadmission education was offered to this group of patients with the hope that their understanding of the procedure would prepare them not only for the things to expect during and after the surgery, but also for ways effectively to manage their rehabilitation and their pain. This study took place in 2009 over a 6-month time period, which included the time from the pre-admission education to the 2-month follow up after the surgical procedure. It was hoped that the choice of whether or not to attend this educational offering would coincidentally indicate patients' willingness to engage in their care, although one might argue that patients might attend only because their health care provider instructed them to do so.

In that same light, attendance to such an event does not guarantee maximum outcome improvement if participation by the patient still remains passive. It was also realized that some persons by means of ability, mobility, or a conflict with the time of the offering were not willing or able to attend this preadmission event. In this study, all patients who underwent TKA were given educational material. The difference was that one group (the preadmission education group) had a specifically designed information booklet and a formal focused presentation by a registered, certified orthopedic nurse who was also part of the patient's care team during their hospitalization. All patients, including the patients who elected not to take the pre-admission education offering, received the typical in-patient education given during hospitalization for the TKA

procedure. This consisted of commercially purchased information on TKA and the opportunity to ask questions of their caregivers.

All patients who attended the pre-admission session were given Wallston's MHLC Survey (Wallston, 2007) and the Krantz HOS (Krantz et al., 1980) prior to the session in order to understand their locus of health control and their desires and beliefs regarding involvement in their medical care. The orthopedic-certified RN educators taught the classes for this procedure with an emphasis on the offerings to prepare patients for surgery prior to hospital admission including what to expect during and after the procedure. The presentation included the importance of immediate controlled use of the affected limb by following caretaker's direction and management of the resulting pain associated with this type of surgery. The rehabilitative process with physical therapy information was also reviewed, and the rehabilitative process including the necessary exercises that would speed the patient's recovery process after surgery was covered. Social service information emphasized the need to plan for assistance after discharge. The information in the preadmission education event was, for the most part, also given to patients unable to attend the preadmission offering; however, it was, by necessity, given in a more piecemeal hospital-formatted manner. The intent of the educational material was to be helpful for the surgical experience if the patient actively used it before, during, and after the procedure.

During the hospitalization after the TKA surgery, all patients were treated in the same manner with the exception that patients who did not attend the pre-admission education event were surveyed as in-patients with the same instruments (Wallston's MHLC survey and the Krantz HOS) in order to discern personality traits that indicate the

patients' locus of health control and desire for involvement in their care. An assessment of all patients for functional ability at admission by nursing personnel using the PLOF (Prior Level of Function) indicator was also done. The PLOF assessment was done for the purpose to exclude those patients who were judged to be unable to achieve normal function after the procedure. Physical therapists daily used the FIM (Functional Independence Measure) scale to grade the patient's ability for independent movement which determined if the patient could be discharged directly home if they desired or to a rehabilitation facility. The majority of patients were discharged to a rehab facility. During the course of each patient's hospital stay, a brief daily multidisciplinary (RN and PT) assessment of the patient's active engagement in his or her care as well as their perceived willingness for involvement in care was done. (See Appendix A for questions and measurement criteria.)

After hospital discharge at 48-96 hours (depending upon the weekday the patient was discharged), a telephone follow-up was to be conducted to inquire if (a) the patient understood post discharge care instructions; (b) the frequency and type of pain medication used; (c) the patient's functional ability on a 0-5 scale; and (d) the patient's overall satisfaction with his care while hospitalized. This initial follow-up proved to be impossible to conduct because, as was previously stated, the patients were, for the most part, discharged from the hospital to a rehabilitation facility for up to 3 weeks and were not able to be reached.

The 2 months telephone follow-up was conducted, however, and patients were asked if they continued routinely to use pain medications or analgesics. The medication that the patient still used was thought perhaps to be an important indicator of recovery

progress. That is, analgesics in place of a stronger narcotic might indicate a more rapid recovery. This information was not useful in this regard as the choice of analgesic or narcotic was based on what the patient could tolerate rather than what they actually preferred and/or needed. The patient's functional ability was assessed on a scale from 1 to 5 at this time and became the primary indicator of the success of their outcome.

Phase II: Detail of design

The second part of the study was carried out in a manner very similar to that of Phase I with the educational intervention given to patients in this phase at the preadmission education event. The content of this intervention added information about patient behavior that could result in successful outcomes. The information included persuasive encouragement that reinforced the patients' ability to succeed. These behavior change techniques were agreed upon by a consensus of expert psychologists on behavior change theory and were linked to the improvement of capabilities (Mitchie, Johnson, Francis, Hardeman, & Eccles, 2008). Evidence-based examples of successful outcomes at times when patients actively participated in the prescribed processes of care emphasized the importance of active committed participation by patients in their care plan and ways that this affected outcome in a positive way. The evidence stated that active participation in carrying out the prescribed tasks, regardless of the difficulty and/or the degree of discomfort, would result in a quicker and better final outcome. At 1 month after hospital discharge, an email or post card intervention was sent with a message of persuasive encouragement to continue exercising. Another similar message sent 2 weeks later (at 6 weeks after discharge) encouraged and expressed belief in the patient's ability to successfully do the exercises. (See Appendix B for message content.)

Sampling, Consent, and Confidentiality

Participants for this study were selected by convenience sampling in that the study was limited to a specific group of patients who had a specific diagnosis and underwent a specific procedure during an established period of time (6 months). Patients were invited to be part of the study if they were 50 years of age or older. Decreased mental capability, limiting co-morbidities, and non-English speaking patients were not candidates for participation. Patients assessed to be unable to achieve normal functionality were also not accepted as participants. The research was quasi-experimental (Creswell, 2005) with the patient study groups defined by class attendance (thought to be more active involvement) or non-attendance (thought to be more passive in their care). Despite the group (active or passive involvement) with which a patient was associated, every patient was offered the same choices, similar educational materials, and identical treatments. The primary difference was the selection and utilization of the pre-admission education and the response to that information as demonstrated by the active involvement and engagement in care. The patients who did not attend a class as part of Phase II did not receive emails or post cards of encouragement after discharge.

Limiting factors other than a patient's self-efficacy and personality traits can also affect outcomes. The patient's general health and possible co-morbidities, for example, might complicate and confound the patient's rehabilitation. The nursing admission assessment PLOF (Prior Level of Function) was used to exclude patients from the study who were assessed to be unable ever to achieve independent living. Limitations of the study that were not controlled for were the surgeon's technique, the patients' educational

level, gender, marital status or family support system, socioeconomic status, pain threshold, and cultural/personal beliefs regarding the use of pain medications.

Patient confidentiality during the study was assured and addressed in the following manner. Although during the educational offering, hospitalization, and follow-up, it was necessary to associate patients' names with their care and treatment, at the time the participants initially granted permission to become part of the study with a signed informed consent, they were guaranteed confidentiality at the conclusion of the outcome reporting. Beginning with the survey process, patient identification was obscured for data collection by assigning each participant a unique identifier that consisted of the patient's surgery date (mm/dd/yy) plus two alpha characters corresponding to their first and last name. Provision had been made so that if two patients had the same alpha characters on any given date, separation of the two patients would be accomplished by the addition of a number corresponding to their surgery sequence on that particular day. Accurate and traceable identification was necessary because of the need to contact patients for follow-up activities and post surgery data collection. Since no duplication occurred with patients having the same initials, no additional number assignment was required. The identification of each patient became irrelevant after the data were collected and was, at data analysis, eliminated entirely. The plan and format for this study underwent review and were approved by both the hospital Institutional Review Board and the UNF Institutional Review Board. (See Appendix C for documents of approval from both sites.)

Variables and Data Collection

Data collected for both Phases I and II of this study are listed below and occurred sequentially:

1. Survey administration
 - a. Wallston's Multidimensional Health Locus of Control (MHLC)
 - b. Krantz Health Opinion Survey (HOS)
2. Daily in-hospital assessment by multidisciplinary caretakers as to patients' active engagement in their recovery procedures. Daily FIM scale scores were also available but had no relevance for the 2-month outcomes.
3. Two-month follow-up indicated the frequency and type of analgesics or other pain medication and the 2-month functional ability assessment. Type of medication, analgesic or narcotic, as an indicator of recovery progress had no meaning for this study as patients' seemingly random intolerance for either drug type eliminated any pattern or usage.

Data were identifiable by the assigned unique identification number and recorded and collated using this unique number in a master ledger. The recorded data consisted of survey scores, daily participation assessments by caretakers, and the follow-up outcome reports at 2 months.

Surveys

The Multidimensional Health Locus of Control (MHLC; Appendix D) is an adaptation for health issues (Wallston et al., 1978) of Rotter's (1966) psychological concept that an individual's locus of control is an important aspect of one's personality and an indication of the manner with which one reacts to events in life. If individuals

have an internal locus of control, in general they see themselves as having personal control over their life, including responsibility for the things that happen to them as well as self-determination in the choices they make in response to situations that occur. Behavior is guided, therefore, by personal decisions and actions (Neill, 2006). An individual with an external locus of control, on the other hand, considers events in life outside personal control (external) a factor of fate, luck, God's will, destiny, or another's influence rather than anything an individual might or might not do. Although locus of control is best conceptualized on a continuum ranging from those with external locus of control beliefs to those who believe they are entirely self-agents of their own destiny (internal locus of control belief), in reality few people are at either extreme but most exhibit, at one time or another, personality traits ascribed to both internal or external beliefs (Rotter, 1982). These beliefs have special meaning for patients who develop medical situations and the manner in which they react to them, i.e., with passive acceptance as a situation of fate or by exerting their own control in order to overcome them. Wallston et al. (1978) developed the Multidimensional Health Locus of Control (MHLC) in three formats denoted as A, B, and C in order that one of the formats might fit any medical situation.

For this project, format C was chosen because its reference point is a medical condition (knee replacement surgery) rather than a disease state or more chronic illness. The instrument provided statements that determined the patients' locus of control. The available answers were selected by choosing a number (1-6) that indicated the patients' agreement with the statement. The response 6 indicated total agreement and the response 1 indicated the weakest agreement. The survey discerned the two overall categories of

internal or external locus of control. External locus of control was further sub-categorized to chance, doctor, and others. The breakdown of possible points for each category was as follows: Internal 6 – 36 and three external subcategories, Chance 6 – 36; Doctor 3 – 18; Others 3 – 18. Doctor and others are often combined to suggest “Powerful Others” with the total possible score ranging from 6 – 36.

Analysis of responses for this current study looked primarily at the strength of the patients’ internal locus of control in relationship to that of powerful others, which was a combination of doctor and others (this might be the doctor and other health care workers or possibly the patient’s family). The analysis also considered whether or not the score for each patient was above or below the midpoint of possible scores for each subcategory. As an example, for the subcategory “Doctor” that had a total possible score of 18, although a score greater than 9 indicated the doctor was influential, as the score approached and became closer to 18, the belief in the doctor’s influence was interpreted as very important.

Validity and Reliability of Surveys

Wallston et al. (1978) assessed the reliability and validity of the data for this instrument and reported a reliability range of .67 – .77 (Cronbach’s alpha) and a test-retest stability coefficient ranging from .60 - .70. These findings were verified by an independent group of researchers in Japan (Kuwahara et al., 2004) who also reported sufficient reliability and validity in their Japanese population. Validation and normalization of scores on the MHLC survey was accomplished with the use of analysis of variance on mean differences for Internals vs. Externals (Locus of Control) participants in several studies by Wallston, Wallston, Kaplan, and Maides (1976).

Wallston (2007) reported that positive correlation data between the MHLC scales and health-related behavior are evident in hundreds of studies as reported in the literature. Validity, however, cannot be generalized without knowing for what specific purpose the survey will be used because the range of human conditions and patients' response to them are endless. The MHLC has been placed by Wallston (2007) into "public domain" since 1993 and may be used freely for public research if acknowledged appropriately. Because this survey has been used extensively and previous applications had demonstrated acceptable reliability and validity, it did not undergo pilot testing for the present study.

Krantz et al. (1980) originally developed the Krantz Health Opinion Survey HOS with the recognition that individuals have differing receptiveness to information as well as for involvement in their health care and treatment. The ability to measure, in some manner, a patient's preference for involvement was thought to relate directly to treatment outcomes. The results of such an instrument then guided healthcare providers to encourage active involvement and self-care for patients who desired to be involved and likewise to provide an understanding of patients who did not want active involvement. The survey might also provide clues for caregivers of a patient's self-efficacy and allow for coaching or staged instruction for situations in which the patient with lesser self-efficacy is required to take some responsibility for compliance in daily regimens.

The Krantz HOS was designed to determine the domain of preferences for an active and informed clientele or a somewhat inactive but trusting one. The survey contained the questions which remained after a factor analysis was done on the original 40 statements, which were submitted for the purpose of encompassing the full domain of preferences from active and informed to relatively inactive and trusting. The resulting

17-item survey (after factor analysis) consisted of two subscales: (a) assessment of information desire and (b) behavioral involvement tendency (Krantz et al., 1980).

Predictive, construct, and discriminant validity of the data were established with three different populations of students. The studies were triangulated to confirm validity in the situations studied; however, all behaviors were related to routine medical care and predicted behaviors related to short-term or minor illness. This current study focused on a short-term condition. For situations of chronic or serious illness, it was suggested that further validation studies might be warranted (Krantz et al., 1980).

Internal consistency reliability of the data was analyzed using a Kuder-Richardson 20 analysis with the total Krantz HOS scale's reliability of .77 and subscale reliabilities of .74 for Behavioral Involvement and .76 for Information Desire (Krantz et al., 1980). Additionally the two subscales of the HOS correlated only slightly with one another and shared less than 9% of the variance. There was little correlation (.31) with other known established surveys that were meant to measure an individual's expectancies about the control of his health including Wallston's initial Health Locus of Control HLC (Krantz et al., 1980).

The Krantz HOS appears to be a usable instrument in predicting behaviors among persons who have characteristics of desiring knowledge and information regarding their health conditions and who most likely will take responsibility in their self care and management and exhibit active behavior.

Prior to using the Krantz HOS in this current study, two questions of interest were added and the wording of the survey was slightly altered to modernize the verbiage in that the original Krantz HOS was developed in 1980. Questions 18 (I prefer to be

involved in my own healthcare because sometimes healthcare providers make mistakes and I feel safer when I am involved.) and Question 19 (Managing some of my own health care needs after instruction will result in better and more stable health for me.) were added to provide a sense of rationale for a patient to choose to be more or less active. A pilot study to assess content validity was done by a panel of experts within the medical profession, and reliability was rechecked by giving the questionnaire to hospital employees, 45% of whom were healthcare practitioners and 55% of whom were clerical or non-licensed staff members.

Of the 47 distributed surveys, 35 were returned (74% return rate), and their responses were input into the data file for Version 15 of SPSS statistical software in order to reconfirm internal consistency reliability. Prior to running a Cronbach's alpha for reliability, it was necessary to reverse score questions 1, 3, 5, 6, 9, 10, 11, 12, 13, and 15 so that agreement with these questions indicated the desire for information and involvement by the respondents regarding their healthcare as did questions 2, 4, 7, 8, 14, 16, 17, 18, 19. The Cronbach's alpha for scores on the total survey was .76. The original study's survey score reliability was .77 (Krantz et al., 1980). The second internal consistency estimate of reliability was accomplished by a split-half coefficient expressed as a Spearman-Bowman corrected correlation. The scale was split into two halves designed to maintain the two halves as equivalent as possible. Alternate questions were selected for each of the two halves (one half: 1, 3, 5, 7, 9, 11, 13, 15, 17, 19; the second half: 2, 4, 6, 8, 10, 12, 14, 16, 18). The split half coefficient was .73.

Of note is the fact that there was zero variance in any of the 35 respondents to Question 19. This question was therefore removed from the scale for the calculation of

the Cronbach's alpha and the Spearman-Bowman split-half coefficient. (See Appendix E for the final version of the Krantz Health Opinion Survey.)

The survey was scored to indicate a patients' total desire for involvement in their care, which had a maximum of 18 points. This was the combined desire for information and the desire for active behavior or involvement in their care. The survey consisted of statements with which the patient agreed or disagreed. Nine statements probed a desire for information, and nine statements determined a desire for involved behavior in their health care. For each patient who participated in the survey, there was a total score (maximum 18 points) and two subcategories of desire for information (maximum 9 points) and desire for active behavior (maximum of 9 points).

Interpretation of the scores of the Krantz HOS followed closely the original scheme of Krantz et al. (1980) who denoted low and high scores with a narrow range of intermediate scores (a range of 2 points). For this current study, the midpoint of each total score was used (i.e., intermediate scores were not recognized) to determine a patient's propensity toward active or passive desire. Therefore, a total score greater than 9 was interpreted as active, while a score less than 9 indicated a more passive total score. A score of 9 (similar to intermediate) was considered equivalent. For the subcategories of the instrument, desire for information and desire for behavior, both of which had a total possible score of 9, scores greater than 4.5 were interpreted as more active and scores less than 4.5 were considered passive. If the score was exactly 4.5, it was interpreted as equivalent.

Consideration was given to the fact that the scores on the Krantz HOS produced variable results that could have more definitively positioned patients on the continuum

from passive to active in their desires for involvement in care. With the truncation of the numerical value of the Krantz HOS scores into two categories, i.e., active or passive, variances in the desires for involvement (either for information or behavior) of patients cannot be precisely discerned. The categorization of patients into an active or passive grouping might therefore oversimplify their desires and ability for involvement. Krantz et al. (1980) interpreted scores of the original survey in a similar manner, that is, a high or low score dichotomy. A high score indicated a desire for information or for behavior that was active and participatory, and a low score indicated little interest in information or active behavior. Mid-scores were in a very narrow range and were considered ambivalent. Although this may oversimplify the traits of patients and their desire for involvement, the practicality in a medical situation for an easy categorization of patients as having either active or passive traits was considered important.

Correlation of the Krantz HOS with the Wallston MHLC scale showed only a moderate correlation, indicating that the scales measure different individual processes of patient behavior (Krantz et al., 1980).

Nurses' and physical therapists' assessments.

Daily, the patients' nurse and the physical therapist who assisted them in their rehabilitation were asked to assess each patient's participation and involvement in their care by selecting a response to two questions.

1. Does the patient demonstrate engaged effort in recuperative protocols?
 - a. Puts forth the maximum effort to follow instructions.
 - b. Listens and actively tries to accomplish the assigned task
 - c. Follows instructions but "gives up" quickly.

- d. Reluctantly puts forth any effort at all and requires much encouragement.
 - e. Is quite passive in all respects.
2. Does the patient have questions and is he/she actively interactive during treatment?
- a. Interacts with zeal.
 - b. Interacts with willingness
 - c. Interacts somewhat
 - d. Must be prodded to interact.
 - e. Is essentially passive with little or no interaction.

Scoring was as follows:

“a” answer received 5.0 points

“b” answer received 4.0 points

“c” received 3.0 points

“d” received 2.0 points

“e” received 1.0 point

The scores for each (nurse and physical therapist) were averaged together for the patient's entire hospital stay to obtain an average score from the nursing perspective and an average score from physical therapy's perspective regarding the patient's involvement in care. An average score for each allowed leeway for the day immediately following the surgical procedure when patients might have felt groggy and out of sorts. Physical therapists also saw patients twice a day and had 2 scores each day whereas nurses only recorded one score daily. Averaging the scores helped to equilibrate the assessments. The ratings of nurses and physical therapists were interpreted to be active involvement in

care at 4.0 or greater (for the average score) and passive for a score less than 4.0. The decision on the way to score and interpret active or passive involvement in care was a multidisciplinary decision by nurses and physical therapists and was based on their understanding of the questions they used for patient observations during their interactions.

Two-month follow up assessment.

At 2 months after the surgical procedure, the patient was contacted by telephone for the purpose of assessment of the progress they had made since their discharge from the hospital. (See Appendix F for the complete list of questions asked.) The question of primary interest was the patient's functional ability at 2 months. The scores ranged from 1 to 5 with 1 the lowest achievement in functional ability and 5 essentially a return to normal functioning. This score was used to denote patient outcome for this current study.

Data Analysis

Question 1: What is the difference in patients' rehabilitative outcomes between those who were assessed by caretakers to be actively engaged in their healthcare processes and those patients who were assessed by caretakers to be passive recipients of care?

The hypothesis was that there is a difference between functionality 2 months after TKA surgery for patients who were actively involved in their care and patients who were passive. The difference in functionality between active and passive patients (active or passive as assessed daily by multidisciplinary caretakers) was determined by an independent-sample t-test analysis (with a significance of $p < .05$). The difference, if

any, in patient functionality at 2 months indicates the different outcomes of active and passive patients.

Question 2: What is the difference in outcomes when patients choose to attend a pre-admission education offering for their condition?

The hypothesis for this question was that patients who attended pre-admission education for knee replacement surgery had better outcomes (functionality) than those who had routine in-patient education. This question was answered by comparing the differences in functionality (after 2 months) for each group of patients – those who attended pre-admission education and those who received only routine education during their hospitalization. This process was again accomplished by an independent-samples t-test ($p < .05$). The difference indicates the effect pre-admission education had on patient outcome.

Question 3: Can patients be effectively assessed by healthcare providers or caretakers in order to understand those patients' propensity for active involvement?

Survey results from the Wallston MHLC and the Krantz HOS were used to determine whether patients were active or passive in health care situations. A statistically significant Pearson's correlation of survey results for the Wallston MHLC and the Krantz HOS with nurse and physical therapist assessment would indicate an acceptable method for determining patient active or passive participation in health care without the use of a formal survey such as the Wallston MHLC and/or the Krantz HOS.

Question 4: In a subsequent phase of this current study (Phase II), can the use of additional interventions, such as more educational evidence and motivational reminders for the purpose of improving a patients' belief in their personal control and self-efficacy,

promote even more involvement in health care and therefore produce improved outcomes?

An intervention focused on the importance of an internal locus of control and on self-efficacy might improve TKA surgery outcome (functionality). The difference in functional outcome was compared in patients with and without the additional intervention. This difference was assessed by an independent-sample t-test with a significance of $p < .05$.

Limitations

In addition to the previously mentioned lack of physical ability of some patients to achieve full independent recovery after knee replacement surgery (a low PLOF assessment), it was recognized that there were other limitations to this study. Mentioned earlier, but worthy of repetition, was the assumption that patients' decisions not to attend the pre-admission education might not indicate a lack of will for involvement or the desire for information about their procedure, but rather non-attendance might be attributed to an inconvenient date and time or a physical inability to attend. Similarly, class attendance may be the results of the patient's health care provider's recommendation and have little to do with the patient's desire to attend. For these possibilities, the daily caretaker assessment was the important indicator to measure patient attitude for active engagement in care.

This study was limited to a relatively short-term medical condition (TKA surgery) and, therefore, the outcomes cannot be assumed to apply to more long-term chronic illnesses such as diabetes, asthma, or other situations in which life-long active patient self-management is required. The question of life-long lifestyle changes for healthy

living, such as diet and exercise, cannot be assumed to continue after education is provided and patient self-efficacy is initially addressed. Prolonged encouragement and support may be necessary to ensure their continuation.

Summary

The research study with the questions posed in the above-described methodology was conducted in an acute care hospital with the cooperation and assistance of both the nursing and physical therapy departments over a 6-month time period. It includes approximately 100 patients who underwent the TKA surgical procedure. The majority of patients attended pre-admission education, however, those who did not attend, for whatever reason, and agreed to participate as controls, were valued. The data collected were analyzed and are described in Chapter 4: Data Analysis.

CHAPTER 4

Data Analysis

A study of the effects of pre-surgical education for Total Knee Arthroplasty (TKA) patients took place in a 364-bed acute care hospital in northeast Florida. The study consisted of two phases. In the first phase, patients scheduled to undergo Total Knee Arthroplasty (TKA) were invited to attend a pre-surgery, pre-hospitalization education class designed to inform and to educate them on ways to prepare for their eminent surgery and for the post-surgical rehabilitation that would follow. The offering for the class also included an invitation for a “coach” to accompany the patient and to assist during the hospital stay, recovery, and rehabilitation. Those patients who chose not to attend the class or could not attend because of a time conflict became part of the control group if they agreed and signed the informed consent to participate in the study.

The second phase of the study proceeded in a similar manner as the first with the exception that Phase II classes emphasized more strongly that successful and rapid recovery to normal activity depended upon patients’ active participation in their care and specifically their effort in doing the assigned exercises for the affected knee. The necessity of diligent attention to the exercise program was emphasized due to the importance of this regimen for the highest level of success. This effort was presented as “their responsibility.”

Additionally, after discharge, Phase II participants received two messages by email or by post card that encouraged them to continue their exercise program. These short messages reminded patients that the continuation of their daily exercises was an important factor in the obtainment of a successful outcome. One of the emails or post card messages arrived 1 month after the surgical procedure and the second at 6 weeks post surgery.

Educational Materials

Prior to beginning the study project, a spiral-bound booklet on orthopedic Total Knee Arthroplasty (TKA) prepared collaboratively by the hospital's physical therapy department, occupational therapy department, social services, and orthopedic surgeons was revised and reprinted. The design for the content of the instructional booklet followed a model from the Cleveland Clinic with the purpose to inform patients about ways to prepare themselves for their procedure beginning with the things they should do 2 to 4 weeks before they arrived at the hospital. It included consideration for the requirement of a general medical clearance, the importance of not smoking to insure better clearance of anesthesia, and ways to prepare their homes for after discharge from the hospital or a rehabilitation facility. Most patients were discharged to a rehabilitation facility for transitional care after their 4-day hospital stay.

The educational presentation covered the events to occur when they arrived as out patients at the surgery department for their knee arthroplasty, and it included the procedures and care given when they first arrived on the orthopedic floor after surgery until they were discharged 4 days later. The patients also received information on ways to recognize complications and emergency situations, if they occurred. The class consisted

of a Power Point presentation and followed closely the information contained in the booklet they were given. An orthopedic-certified nurse taught the material and answered patients' questions in a classroom on the orthopedic unit. The class took place at 10 a.m. every Monday. A project coordinator on the eighth floor, with the use of a surgery schedule, contacted patients about the class and invited the patient and his/her coach to attend. This contact generally occurred any time from 3 to 4 weeks prior to surgery to, on occasion, the day before the class in the same week as their surgery.

At the beginning of each class, the research project was explained and class attendees were invited to participate. If they were willing, the participants completed the consent form and the two surveys, the Krantz Health Opinion Survey and the MHLC (Multidimensional Health Locus of Control). The control group for the study consisted of those who did not attend the class but were willing to participate in the research. For the control group patients, the eighth floor project coordinator provided the consent form and surveys on the first day after surgery.

Prior to the start of this project, each orthopedic surgeon received a visit to explain the study and to ask for their encouragement for their patients' participation in the project. One surgeon, who did the majority of the total knee arthroplasties, expressed such enthusiasm that he requested the booklets be given to him so that he might distribute them to all his TKA patients at his office whether or not they attended the class. This surgeon also co-authored a portion of the manuscript and was permitted to distribute the booklets to his patients. The receipt of the books by patients did not guarantee that they read or used the books, and it was also not the intent of the study to withhold information from patients.

Final Participants for Data Analysis

This research study was open to patients who were age 50 years of age or older. Non-English-speaking patients, patients who were judged mentally incapable of participation, and those assessed at admission to be unable to achieve normal functionality were ineligible to participate. Total participants in the study were $N = 108$ with $n = 33$ in Phase I and $n = 34$ in Phase II. Control group patients who did not attend a class but took part in the surveys and as participants for the study were $n = 41$. Nine patients were eliminated from the study as it progressed. Four patients from the control group (those who didn't attend class) were removed; three of these control participants were unable to be contacted at 2 months after surgery and the fourth had severe and prolonged complications that resulted in admission to the surgical intensive care unit for several weeks following the surgery. Two participants from Phase I (class only) were removed, including one who at 47 years old was too young as defined by the study criteria that stated only patients 50 years of age or older were eligible. The other participant was a mentally challenged patient who became easily stressed. Three patients were also eliminated from Phase II (class plus interventions) for the reasons that one participant had both knees done at the same time, one patient had a concurrent difficulty from a pre-existing condition (multiple sclerosis) and had to be sent to a nursing home for several weeks, and the third participant in the Phase II group also had a compromised mental state in addition to hearing impairment. Both eighth floor nurses and physical therapists observed daily class participants for Phase I and II as well as the control group participants (a multi-disciplinary assessment) during the hospitalization in an attempt to assess their degree of active involvement in their care.

Study Findings: Descriptive Analysis

Version 17.0 SPSS was used for statistical data analysis for this study. The outcome measurement for participants was their degree of functionality or activity (from 1.0 in a skilled nursing facility or house bound to 5.0 normal activity). Descriptive analysis on participant demographics or prior knee surgery was also done and is shown in Table 1. The analyses indicate that among these participants, there were little observed differences in the mean outcomes for gender, age, or whether the patient underwent surgery for the first total knee arthroplasty or whether it was the second such procedure. Outcome appeared to be slightly better for the 50-year old participants however this might be because of better general physical condition for this younger group.

Table 1

Mean Activity Outcomes for Participants

Gender	Female	SD	Male	SD				
	3.975	.854	3.851	.865				
Age groups	50-59	SD	60-69	SD	70-79	SD	>80	SD
	4.105	.679	3.865	.969	3.900	.707	3.912	1.004
Surgeries	First knee	SD	Second knee	SD				
	3.947	.816	4.000	.787				

Note: Response categories ranged from 1.00 (housebound or SNF) to 5.00 (completely normal) at 2 months after surgical procedure

Findings for the Krantz Health Opinion Survey and the MLHC also showed some differences for age and gender. Some age groups showed slight differences in their desire for involvement in their care or their ability to affect their own outcomes. Particularly in the 50-year old category, there was a slightly greater indication (mean) in the desire for involvement in their care (total Krantz HOS) than for the other age groups.

Overall, participants in this study, as shown by the means for gender, most age groups, and whether or not they chose to attend a class, indicated that these participants, in regard to the Krantz Health Opinion Survey Total Score, had at most only a slight desire (between 9 and 10 out of a possible score of 18) to have active involvement in their care. (See Table 2.) The age group greater than 80 showed a passive total score of less than 8.

Table 2

Krantz HOS Mean Scores

Gender	Female	SD	Male	SD
Krantz total	9.52	3.29	9.34	2.64
Krantz info	6.57	1.97	6.32	1.71
Krantz behav	2.95	1.93	3.05	1.85

Age	50-59	SD	60-69	SD	70-79	SD	>80	SD
Krantz total	10.58	2.80	9.65	3.25	9.25	2.69	7.94	2.89
Krantz info	7.26	1.85	6.73	1.82	6.38	1.74	5.06	1.48
Krantz behav	3.32	1.97	2.92	1.91	2.88	1.96	2.94	1.77

Attendance	No class	SD	Class I	SD	Class II	SD
Krantz total	9.54	3.18	9.42	2.86	9.37	3.14
Krantz info	6.69	1.89	6.32	1.78	6.37	1.96
Krantz behav	2.36	1.91	3.10	1.89	3.03	1.92

Krantz total maximum score = 18 Class I - education only
Krantz information maximum score = 9 Class II – education and intervention
Krantz behavior maximum score = 9

As previously described in Chapter 3, interpretation of the scores of the Krantz HOS followed closely Krantz et al. (1980) who denoted low and high scores with a narrow range of intermediate scores (a range of 2 points). For this current study, the midpoint of each total score was used (i.e., intermediate scores were not recognized) to determine a patient's propensity toward active or passive desire. Therefore, a total score greater than 9 was interpreted as active, while a score less than 9 indicated a more passive

total score. A score of 9 (similar to intermediate) was considered equivalent. For the subcategories of the instrument, desire for information and desire for behavior, both of which had a total possible score of 9, scores greater than 4.5 were interpreted as more active and scores less than 4.5 were considered passive. If the score was exactly 4.5, it was interpreted as equivalent.

When the sub-components of the total Krantz HOS were examined, the Krantz info survey questions that indicate an active desire to obtain information and the Krantz behavior survey questions that determine a desire for more active behavior, the scores showed that participants in this study were more active in their desire for information but rather passive in their desire for more active behavior. This disparity may be a trait of participants 50 years of age or older.

Likewise, the MLHC survey designed to indicate a person's internal locus of control as the strongest influencer in the maintenance of health (as opposed to either chance or powerful others in their lives, including their doctor), indicated strongly that these participants believed that their doctor, in particular, had the most important influence on their health maintenance. It can be seen in Table 3 that, out of a total score of 18, this particular group of participants scored greater than 15 for all age groups, either gender, and whether or not they attended a class. All patients showed an apparent greater influence on their health from powerful others, especially their doctor, than their own internal control of their health. For this study, the average score for doctor's influence on healthcare was between 15 and 16 (out of a total possible score of 18). Only 25% of patients had scores less than 15. Whether or not this is true of other age groups (ages less than 50 years) is of interest for a future study.

Table 3

MHLC Mean Scores

Gender	Female	SD	Male	SD
Internal	22.42	7.16	23.11	5.49
Chance	12.12	5.78	13.79	7.05
Doctor	15.80	2.84	15.32	3.28
Others	10.05	3.91	10.66	3.27
Powerful others	26.05	5.18	25.97	5.28

Age	50-59	SD	60-69	SD	70-74	SD	>80	SD
Internal	22.84	5.95	22.26	6.36	24.04	6.42	21.50	7.93
Chance	12.11	4.77	12.61	5.68	14.63	9.01	11.19	3.97
Doctor	15.32	3.15	15.32	2.28	16.17	3.25	15.81	4.04
Others	10.37	2.79	9.79	3.96	10.88	4.03	10.50	3.43
Powerful others	25.68	4.22	25.37	4.81	27.13	5.64	26.31	6.48

Attendance	No class	SD	Class I	SD	Class II	SD
Internal	22.91	7.04	22.00	5.91	23.13	6.70
Chance	13.51	7.41	11.77	6.08	12.94	5.20
Doctor	16.17	2.32	16.17	3.43	15.23	3.25
Others	10.80	3.72	9.71	3.43	10.29	3.85
Powerful others	26.97	4.38	25.32	5.13	25.65	6.03

Internal score range = 6-36

Powerful others = Doctor + Others

Chance score range = 6-36

Doctor score range = 3-18

Class I education only

Others score range = 3-18

Class II education and intervention

Powerful others score range = 6-36

The descriptive analysis above was very valuable to consider possible explanations as this research project progressed in a sometimes unexpected manner. The research questions specifically posed for the project were the following:

Question 1

What is the difference in patients' rehabilitative outcomes between those who were assessed by caretakers to be actively engaged in their healthcare processes and those patients who were assessed by caretakers to be passive recipients of care?

Both eighth floor unit nurses and physical therapists assessed patients daily and independently, using the same two questions of observation for each patient. The independent scores of nurses and physical therapists were then averaged for the entire hospital stay to give one assessment score for nurses and one assessment score for physical therapists. Active involvement was defined as 4.0 or greater and passive behavior was less than 4.0.

The variable for outcome was the functionality/activity level of the patient 2 months after the surgical procedure. Score options were identified as follows: 1.0 –Skilled nursing facility or homebound with needed daily assistance; 2.0 – very limited indoor activity only; 3.0 can go out but must remain close to home; 4.0 - fairly normal with some limitations and 5.0 – able to do anything.

Pertinent findings: Question 1.

For the hypothesis that active patient behavior as assessed by caretakers (nurses and physical therapists) has better outcomes, an independent-sample *t*-test was conducted with patient activity/outcome as the test variable and nurse and physical therapist assessment as the grouping variable (Group 1 = greater than 4.0 and Group 2 = less than 4.0). The test results were statistically significant for nurses' assessment of active patients $t(96) = 2.24, p = .03$ with active-assessed patients' outcome ($M = 3.98, SD = 0.81$) indicating better functional activity than passive-assessed patients outcome ($M = 3.33, SD = 1.09$). Physical therapists' assessment of patients was also statistically significant, $t(95) = 3.60, p = .001$, with active-assessed patients' outcome ($M = 4.02, SD = 1.08$) and passive-assessed patients' outcome ($M = 3.05, SD = 1.34$) The effect sizes were calculated manually for each group according to this formula: the difference in the

means ($M_1 - M_2$ for assessed active and passive patients) divided by the standard deviation for passive activity. An effect size greater than 0.50 is large. There was a large effect size for nurses of 0.60 and also for physical therapist of 0.70. The two patient groups were somewhat disparate in number with $n=89$ assessed as active and $n=9$ assessed as passive by nurses and $n=87$ for active assessment and $n=10$ for passive assessment by physical therapists.

Even though the daily interactions with the participants were quite different for nurses than the interactions of physical therapists (nurses assisted patients' in pain management whereas physical therapists exercised patients, which was often the source of pain), the ability to assess active or passive traits appears to be a useable possibility. Exercising is in itself a more active behavior while accepting care, including pain medication, is, by nature, more passive. Noteworthy is the fact that the active assessment by nurses and physical therapists in this particular study contrasted somewhat with the scores of the Krantz Health Opinion Survey that indicated that this group of participants had quite passive scores for engagement behavior. Rapport with the patient might have been instrumental in the encouragement of patients' to participate in their care. This is especially valuable for tasks that might cause discomfort (such as exercise) and are typically avoided by patients. This apparent patient rapport along with the provision of education and information is all that may be necessary for optimal outcomes for many patients in some circumstances.

Question 2

What is the difference in outcomes when patients choose to attend a pre-admission education offering for their condition?

This question's intent was to understand whether or not attendance at an hour-long, pre-operative orthopedic surgery class with the purpose to inform patients on ways to prepare themselves and their homes for their eminent Total Knee Arthroplasty (TKA) procedure made a difference in their outcomes at 2 months. Goals for the class were to educate patients in the prevention of emergency situations such as blood clots or pneumonia complications and additionally to allow patients to acquire knowledge on what to expect before, during, and after their procedure so that anxiety of the unknown was minimized. The class emphasized patient responsibility with regard to pain management and the rehabilitative exercise program that was deemed necessary for a successful outcome. The measurement for this hypothesis was the activity level at 2 months after the surgical procedure.

Pertinent findings: Question 2.

An independent samples *t*-test was conducted to evaluate the effect of class attendance on outcome using outcome activity as the test variable and class attendance ($n = 62$) or non-attendance ($n = 37$) as the grouping variables. The results of the *t*-test were statistically significant $t(96) = 5.796, p = <.001$ for class attendance ($M = 4.18, SD = 0.65$) as compared to no class attendance ($M = 3.50, SD = 1.00$). The effect size was calculated according to this formula: the difference in the means $M_1 - M_2$ of the two groups (class attendees and non class attendees) divided by the SD for class attendance. The effect size of 1.046 indicated a very strong effect (greater than 0.50 is a large effect) from participation in the pre-surgery class. For this analysis both Phase I attendees (class only) and Phase II attendees (participants who had the class plus interventions) were included. Noteworthy is the fact that patients who attended the class may have done so

for reasons other than their own predisposition for active behavior as was originally expected. Although the patients in this particular study showed a desire for information on the Krantz sub survey for information, as already noted, they also demonstrated by their MHLC survey scores that they were highly influenced in their healthcare decisions by the powerful others in their lives with a particularly strong influence from their doctor. This influence, that is, the advocating and promotion of the class by their physicians, perhaps became the most important indicator for attendance to an educational offering.

Patients who attended the pre-surgical class in order to be informed about the upcoming procedure, hospital experience, and the necessity to continue exercise after hospital discharge, resulted, despite the fact that these participants did not demonstrate a propensity for active behavior, in statistically significant better outcomes. The demonstration of some degree of active behavior by patients was perhaps a result of both class content and physician encouragement.

Question 3

Can patients be effectively assessed by healthcare providers or caretakers in order to understand those patients' propensity for active involvement?

The surveys given to both class attendees and to those who did not attend a class ($N = 108$) were selected to attempt to understand if patients had a propensity and desire for active involvement in their care (the Krantz Health Opinion Survey) or a more passive attitude toward involvement. The MHLC survey sought to understand if participants saw themselves as the most important influence of their health (internal locus of control) or if others held more powerful influence in their care or even if participants believed their health status was left to chance (external locus of control). With both surveys (Krantz

HOS for assessment of active involvement and MHLC for determination of internal locus of control concerning health), it was hoped that patients' propensity to engage actively could be determined and understood. If an association was found between survey findings and caretaker assessments, then the use of surveys would not be necessary to assess patient traits; rather, after some training, caretakers alone would be able to make the assessments.

To understand if an association existed between the Krantz Health Opinion Survey/MHLC survey scores and the nurse and/or physical therapist assessment of the patient's active behavior, a Pearson correlation coefficient was computed. The correlation used the total Krantz Health Opinion Survey scores and the scores for internal locus of control on the MLHC Survey with the nurses' and physical therapists' assessments of participants' active behaviors.

Pertinent findings: Question 3.

The results of this analysis are shown in Table 4, and indicate a statistically significant association between physical therapists' assessments and the Total Krantz Health Opinion Survey. Although statistically significant, the effect was weak, and therefore the association may be of little use in practice. The correlation showed no association for nurses' assessment of patient's active role and the Total Krantz Health Opinion Survey.

Because of the number of nurses and physical therapists involved in the daily assessments and the inability to ensure they all clearly understood the purpose for the assessments, it is possible that the failure to find a stronger correlation (or any correlation for nurses) of active behavior with validated surveys was a factor of assessors'

commitment and understanding of purpose. Although instruction and explanation sessions were held for nurses and physical therapists, nurses in particular were often absent for these information sessions and were therefore informed second-hand.

The data from the Krantz HOS survey were analyzed for internal consistency reliability for this study's participants and were found to be of lesser internal consistency than the previous pilot study conducted within the medical community. The pilot study data yielded a Cronbach's alpha of .756; the data from the survey in the present study had a Cronbach's alpha of .633. A split-half coefficient expressed by a Spearman-Brown coefficient was .525. Of note, patients were given the surveys either as an in-patient (for control patients) or before the class began (for patients given the class intervention). Overall, by many patients' comments, they did not seem to like or understand the purpose of the survey.

Table 4

Correlations of Average Nurse and Physical Therapist Patient Assessment (with Questions) with Krantz Health Opinion Survey and MHLC Survey

Subscale	1	2	3	4
1. Nurse Assessment	-	.360	-.024	.097
2. PT Assessment		-	-.286 *	.078
3. T Krantz HOS			-	-.140
4. Internal MLHC				

Note: Nurse and PT scores were an average of the two questions (average score for nurse and for PT); Krantz HOS total score was used; internal LOC score was used for MHLC

* Denotes statistically significant result at $p \leq .05$.

The MHLC had no statistically significant association with either nurses' or physical therapists' assessment. This was not surprising because locus of control beliefs are more psychologically innate and therefore less easy to assess.

Question 4

In a subsequent phase of this current study (Phase II), can the use of an additional interventions, such as more educational evidence and motivational reminders for the purpose of improving a patients' belief in their personal control and self-efficacy, promote even more involvement in healthcare and therefore produce improved outcomes?

For the purpose of encouraging self-efficacy in patients who might otherwise not be actively involved in their care, additional interventions were added to the class to emphasize the need for consistent exercise to enable and ensure success. An additional four Power Point slides added to the class presentation focused on evidence-based data that showed that doing the exercises, and doing them regardless of discomfort, was essential for a successful outcome. Two handouts were prepared and given each class attendee, one a hard copy of the Power Point presentation for after-class reference and the other a print out of several paragraphs that encouraged the continuation of exercise after hospital discharge. (See Appendix G.) The message embedded in this additional material emphasized patient responsibility to do the exercises and encouraged the patients' ability to take an active approach in their rehabilitation.

One month after the surgery, an email or post card (if the email address was not available) was sent with a short text of encouragement for the participant diligently to continue with the exercises. At 6 weeks, the patient received a second similar message of encouragement that once again reminded him/her to continue active exercise. The second message included a statement that assured the patient that this effort was beneficial for recovery.

Pertinent findings: Question 4.

An independent sample *t*-test was conducted to assess the hypothesis that, even though a better outcome was achieved for patients attending a pre-surgical class than for those patients who did not attend a class for their procedure (Phase I of the study), a simple, easy follow-up intervention in addition to a class with more evidence of the effect of involvement resulted in further improvement. This was especially true for those patients needing a boost in self-efficacy. The test variable, the patient's level of functionality/activity at 2 months and the grouping variables of class only (Group 1, $n = 31$) and class with interventions (Group 2, $n = 31$) were used for the analysis. A statistically significant result ($t(60) = 2.143, p = .05$) was obtained indicating that class with intervention attendees ($M = 4.339, SD = .651$) had better outcomes than the class-only participants ($M = 4.016, SD = .612$).

The effect size was calculated according to this formula: the difference in the means $M_1 - M_2$ of the two groups (class attendees and class attendees plus additional interventions) divided by the SD for the class with intervention. The effect size of 0.50 was large as a result of the additional interventions in the pre-surgery class and the motivational follow-ups. If the class with additional interventions had been composed of only patients who were passive in their involvement and lacking in self-efficacy, an even larger effect might have occurred.

Qualitative Aspect During Follow up Patient Contact

Patients' feelings and their reactions to the class or the class plus the interventions (as in Phase II of the study) were not a pre-defined part of this research. However, during follow-up telephone conversations to assess the participants' level of activity at two

months, patients freely offered their feelings when asked if the class had been helpful to them. Virtually 100% expressed the belief that the class had been useful, had answered their questions, and had most importantly lessened their anxiety about hospitalization and the TKA procedure. Knowing what to expect before, during, and after the procedure and ways to manage their pain were two important factors that participants noted had allowed them to focus better on their rehabilitation regimens. Satisfaction with the class and with their hospital experience became a frequently expressed comment.

New orthopedic patients who needed TKA surgery began to inquire about the class, and a larger classroom had to be obtained to accommodate more attendees. Recently, hip arthroplasty classes have also been added to the orthopedic curriculum, and a newly created hospital orthopedic education coordinator has been hired so that further expansion of classes for shoulder and spine surgeries can occur. Orthopedic classes outside of the immediate geographic locale have also entered the planning stages in order to market the hospital's orthopedic program. Classes for other medical conditions have also been contemplated.

Many participants unexpectedly responded to the emails of encouragement that were part of the Phase II intervention. Even though both email and post card messages were very short –just two sentences (see Appendix B) - the perception of the recipients was that they were receiving the messages because the hospital and the orthopedic department cared for them as individuals. Many answered their motivational emails with statements that described the exercises they were doing and the progress they had accomplished. The responses indicated pride in their rehabilitation efforts with their progress, which according to their doctor, was quicker than anticipated. They were, in

essence, ahead of the expected recovery schedule; and their satisfaction was evidenced by their praise not only for their surgeon, but also for the hospital, the eighth floor nursing unit, the social workers, and the physical therapy department.

Summary of Statistical Findings

In this study, the demographic factors of age and gender had no outcome differences for the participants as a whole with the exception of the 50-59 year-old patients who had a slightly better outcome than the older age categories. The experience of having undergone a previous surgical procedure for TKA also did not result in outcome differences.

As a group, the decade of over 50-year-old patients to 59 years of age, showed slightly more inclination for an active total desire for engagement in their medical care, which when broken down into sub components, showed a fairly active desire for medical information, but like the other age categories, a quite passive desire for behavioral engagement. Similarly, the MHLC indicated the largest influence on medical issues was by powerful others and in particular their doctors than by their own internal locus of control. This might suggest lesser confidence in their own abilities to render any influence over their own medical outcomes.

The most noteworthy statistically significant finding was the difference in outcomes (achieved level of normal functional activity at 2 months post procedure) for those patients who attended a pre-hospitalization class verses those patients who did not attend a class. An even better outcome was achieved when (in Phase II of the study) patients were given evidenced-based motivations and encouraging messages to assist with what they needed to do to ensure a successful rehabilitation. The messages were

given only twice after hospitalization and before follow up at 2 months. This improvement occurred despite this study groups' overall lesser desire for active participation. Motivation and encouragement for the purpose of improved self-efficacy is felt to be especially important for patients with less confidence in their own ability to influence their outcomes. Furthermore, if caretakers had the ability to assess this trait in patients, steps could be taken immediately to address the self-doubt of patients and encourage more active behavior on their part.

In this study, nurses and physical therapists were somewhat able to assess active or passive traits in the patients with whom they interacted by considering the behavior of patients with the use of two questions. It was hoped that with the use of the two questions, an easy method for categorizing active or passive patients would result. The results of nurses' and physical therapists' assessments were somewhat disparate, however, in that only 9 patients ($n=89$) were assessed as passive by nurses and only 10 patients ($n=87$) were assessed as passive by physical therapists.

To understand if nurses' or physical therapists' ability to assess patients' active or passive desires for involvement in their care had an association with the Krantz HOS, which was designed to indicate a patient's desire for information or involvement in their care, an association of the caretakers' assessments and the Krantz HOS indicators was analyzed. The association was weak for physical therapists and showed no significant finding for nurses. There was also no association of these assessed traits with the patients' locus of control as defined by the MHLC survey for either nurses or physical therapists. For this study group, internal locus of control (for medical situations) was not as influential as was powerful others, i.e., their doctor and possibly also other healthcare

workers (an external locus of control). It was shown however that there was quite a significant verification that educational offerings prior to hospitalization affected the outcomes of those patients who chose to attend. It will be seen subsequently what these findings might mean for health care outcomes overall.

Chapter 5

Drawing Conclusions

The findings of this research project have verified the model described earlier, which asserted that the provision of information and education is an important factor for the achievement of successful and optimal health outcomes. This was previously reported in the literature; however, in this current study, the provision of education prior to hospitalization was also shown for some situations to be an effective way to provide patients the information they need in order for it to be the most beneficial. Also seen in the study, as described in previous chapters, the majority of patients (approximately 75%) were very passive in their desire for involvement in their care, as revealed by their scores on the Krantz HOS subscale for behavioral traits. With additional motivation and self-efficacy development, however, they succeeded, to some degree, when encouraged and informed of the reasons to be participants in their health care (Phase II of the study).

For those patients who lacked self-efficacy to be assertive participants, the additional contact interventions used to motivate and encourage the necessary active behavior (exercise in this case) were shown to assist in the achievement of the desired outcome. Provision of the additional encouragement interventions administered to all patients, in fact, seemed to serve all patients well. For those who needed a motivational boost in confidence, the interventions in Phase II of the study were shown to be successful in the achievement of a better outcome. In addition, at the 2-month follow up,

virtually all patients mentioned their appreciation for the motivational messages with the result of increased patient satisfaction with their medical experience for those individuals. These findings, if applicable to other situations and medical conditions, provide promise that patients can be motivated to achieve better outcomes when encouraged and coached appropriately; and providing motivation for all patients is also a beneficial practice.

Throughout this concluding chapter, evidence will be reviewed regarding the importance of health and medical education for patients who are attempting to manage their own health conditions. This discussion will include the best times to provide education and the challenges associated with providing it. Secondly, the need for health care workers and particularly physicians to understand better the active or passive medical/health traits of their patients will be emphasized so that treatment and self-care can be facilitated with appropriate teaching methods. When these traits are understood for each patient, a more individualized education approach can be fostered and implemented. The importance of leadership for medical education will also be acknowledged for its role in the establishment of education programs both for patients and for the training of health care workers in the importance as well as the methodology for discerning patient types. The goal of effective and beneficial education for all patients will then be possible. With the achievement of better patient education, improved health management and patients who share in the responsibility for their health will most likely evolve. Lastly, recommendations on ways to apply the lessons of this research will be touched upon as well as the limitations of the findings of this one study. The needs for future research will be mentioned for the purpose to instigate better

understanding of the education that all patients, regardless of their diagnoses or conditions, need for the most optimum outcomes.

Effective Patient Education Now Mandated

The JCAHO (Joint Commission for Accreditation of Healthcare Organizations) has recognized the value of patient education and has mandated education for hospitalized patients. Prior to this requirement, only marginal efforts by hospitals and providers were made to ensure that patient education was available. The acquisition of information was largely left to the patient, and any distribution of general medical information by the patient's doctor was in the format of simply written booklets on certain procedures or conditions. Several reasons for the absence of attention to education include the lack of dedicated time to accomplish it during office visits and the additional cost for personnel to provide it in a professional, organized, and structured manner. The typical method to provide education today, with the requirement by the JCAHO for hospitalized patients, consists almost exclusively of printed material from a computer-referenced medical resource often written in language and style difficult to understand for lay persons unfamiliar with medical terminology. On many occasions, the information is bundled with hospital discharge papers and sent home with the patient with little explanation even though it has been documented in the patient's medical record that pertinent education has been carried out..

Structured Classroom Education Important for Best Outcomes

An important inquiry in this research project was whether a difference in participants' outcomes occurred for patients who attended an educational offering before their procedure as compared to the outcomes of those who did not attend a class but

received the normal in-hospital education. The outcome indicator was the patients' activity level at 2 months after a total knee arthroplasty surgery. As shown in a previous chapter, patients who attended the class included those patients whose survey scores revealed both active and passive characteristics. The reason for class attendance was, for many, their doctor's recommendation rather than their desire to be involved in their care. Despite the reason for attendance, the participants who attended the class showed statistically significant improvement in outcome at 2 months as compared to those who did not attend.

This finding aligned with previous findings reported in the literature that indicated information and education improved outcomes. Roumie et al. (2006) found that patients assigned to patient education groups for hypertension had better blood pressure control after specific education about their condition. Mazor et al. (2007) and Fitzmaurice, Murray et al. (2005) saw the same success after education programs for anticoagulation therapy. Berger and Muhlhauser (1999) likewise saw improvement in diabetic patients' laboratory data as a result of education on strategies for changes in diet and lifestyle. Hanyu et al. (1999) found similar better outcomes in treatment for congestive heart failure when patients understood the guidelines for their own self-management. Perniger et al. (2002) and Schaffer and Tian (2004) arrived at a similar conclusion for asthma patients who received education as outpatients, and Curtin et al. (2004) saw the same improvements for kidney dialysis patients who demonstrated more successful management of their condition when they had access to education programs. For these studies reported in the literature, the reasons for which patients sought information or attended educational offerings were unknown. The literature revealed only that most

patient outcomes were more successful when they received and acquired knowledge and information.

Education with self-efficacy yields even better outcomes.

Even if patients attended a class because of their doctor's recommendation, as in this study, it was not certain that all patients would engage actively in their care. They might only passively listen with little effect on their behavior. Some patients might require additional effort to become actively involved and engaged in their care. For example, they might require more interventions than the provision of information or self-management skills. This group of patients might require encouragement and the development of confidence in their ability to help themselves achieve the best outcome they were able to obtain. Bandura (1997) stated that individuals' confidence and the assurance of their own ability and their self-efficacy to influence events in their own lives are important factors for persons actually to take control for their life and health. Patients must perceive that they are capable of influencing their own situation. This is also a necessary precursor for self-advocacy. Because the majority of patients in this study were shown by the Krantz HOS subscale to be behaviorally passive, all patients who attended a class in Phase II of this study received several interventions to encourage more active engagement in their care. Beside the additional class material with an emphasis on active participation and its benefits, personalized messages were also provided with the purpose to improve patients' self-efficacy and to promote more active behavior in their health care. It was hoped the achievement of better outcomes would also be a result.

Luszczynska's (2008) studies found that verbal persuasion could enhance a person's perception of ability and capability to overcome challenges in order to make

positive changes. Self-efficacy was also found to be the largest determiner of enduring behavioral change. For this research study, the provision of only two short messages of persuasive encouragement with an expression of faith in the patient's ability to carry out the behaviors necessary for improvement in his or her condition resulted in a significant increment of improvement in the achieved activity at 2 months. This increment of improvement was in addition to benefits gained by patients only attending an educational class prior to their surgery. In the Phase II classes, the additional interventions emphasized evidence of the benefits of active involvement. This additional educational material, along with the post hospitalization messages for self-efficacy, was given to all patients regardless of their self-motivation to engage. Had the class been composed of only participants who needed a boost in self-efficacy, it is possible that the improvement effect size might then have been larger. A future study using this concept would be useful to verify this speculation.

Understanding Patient Active or Passive Health Care Traits

In the investigation of Question 1 of this research, it was hoped that nurses and physical therapists, with the use of two specific questions, would be able to assess patients' propensity to engage actively in their care. If nurses and physical therapists were successful in their assessments, this process would provide a means to understand better their patients' active or passive traits. The ability to characterize patients' active or passive traits using a simple, straight-forward assessment tool by daily caretakers would enable patients to receive information, education, and instruction in a manner that was best suited for them. If the caretaker assessment indicated the need for a greater degree of coaching and confidence building in order for the patient to engage, then the caretaker

could immediately adapt enhanced methods of instruction. The inquiry suggested in the first question of the research project asked if there was a difference in patients' outcomes between those assessed by caretakers to be more actively engaged in health care processes and those who were assessed as more passive recipients of care. No direction was given to nurses and physical therapists to adapt to patients who manifested different traits.

Healthcare workers demonstrated some ability to assess patients' active or passive traits despite the little instruction or training that was provided for them in this study. A disparity was evident, however, as a greater number of patients were categorized as active by the nurse/physical therapist assessors than the Krantz HOS subscale for behavioral activism or patient outcomes indicated (if indeed a better outcome indicated active engagement). Only a few patients ($n=9$) were actually assessed by caretakers as passive. The results of assessments, in this particular study, indicated that the observations by healthcare workers for engagement behavior of patients was not specific or precise and had a great deal of overlap – especially among patients who appeared to caretakers to be more actively involved than they actually might have been. The assessments in this particular study were most likely affected by daily social discourse in the case of nurses, whose daily tasks involved more mundane passive care that required a lesser need for a patient to engage in care. It would therefore be advantageous to develop this assessment skill in order to be able to approach such patients in a manner to encourage their self-efficacy. Education of caretakers in ways to accomplish an effective assessment would be a valuable tool so that patients with passive traits can be interacted with accordingly to achieve the best results. Of note also in this study was that many

health care assessors used the assessment questions without first-hand guidance as to the intentions of the patient observations. First-hand instruction for ways to assess patients was fraught with difficulties, particularly in the case of nurses, and the assessments were most likely not carried out as designed for this study. The fact that only a few patients were actually assessed as passive by nurses (in spite of the fact that the Krantz subscale indicated a majority of patients in this study had passive traits) indicated there were likely more subjective and judgmental assessments made that were based on conversational interchange rather than assessments on patients' actual engagement activity with their healthcare.

In contrast with this method for assessment of a patient's ability to engage in care by nurses and physical therapists, two well-established surveys were also given all participants to understand their active and passive traits according to these resources. The Krantz Health Opinion Survey (HOS; Krantz et al., 1980) assessed participants in accordance with their desire to obtain information as well as their desire to become involved in active health care behavior. The MHLC survey (Wallstrom, 2007), on the other hand, looked at the participants' locus of control in a medical situation. The MHLC survey, an adaptation for medical use of Rotter's (1982) locus of control survey, indicates whether a person has an internal locus of control and feels in control of personal health, or whether the person has an external locus of control and believes chance or others are more important determinants of health. Locus of control research by Rotter (1982) looked at individuals' beliefs that their efforts and actions could have positive effects on their own situations, or, contrary to this, individuals who lacked internal motivation and believed that external factors have greater influence in their lives. The hope in this

research was that with the use of the two surveys, a better understanding of patients' propensity to be involved in their care might be realized. The internal consistency reliability for the participants in this study was not as strong as that reported in the literature or in the pilot study previously reported. Patients frequently commented that overall they did not like taking the surveys. The surveys were also either given prior to the class or during their hospital stay (for control participants), and patients may have felt rushed or unfocused on the task.

The third research question considered whether effective assessment of active or passive patient traits by nurses, physical therapists, or other caretakers could be useful as an indication of which patients might naturally engage in care and which might need coaching or extra motivation in order to engage. If an association was shown between the Krantz or MHLC survey results with the assessment from the questions used by nurses and physical therapists, the caretakers' assessments alone might then be useful to indicate the need to coach certain patients. Coaching and encouragement for self-efficacy could then be immediately individualized for each patient accordingly. In this study, no association was found for either nurses' or physical therapists' assessments with the MHLC. A significant association, however, did occur for the physical therapist's assessment and the Krantz HOS total score. The effect, although somewhat weak in this particular study, warrants further investigation, as exercises during physical therapy require patients' active participation to achieve optimal outcomes particularly for orthopedic procedures. The effectiveness and success of the exercises are very dependent upon patients' engagement and their diligence to accomplish daily the exercise regimen, particularly after hospital discharge. Because this study group did not express an internal

locus of control in the MHLC survey as their strongest influence, this might account for the lack of association of active behavior in physical therapy and the physical therapists' not-so-strong ability to discern active behavior.

Recommendations for Practice Based on Study Findings

Understanding the effect and influence of patients' doctors, as revealed in this study by the MHLC survey, might have great value in relation to health care behavior for this group of greater than 50 years of age participants. Physicians' awareness of their powerful influence with certain patients might lead them to consider more effective ways to use this influence for their patients' benefit. That is, physicians might be persuaded to exert their influence to improve the process of medical education among their patients. Specific recommendations by doctors for patients to engage in more active behavior with physical therapy exercises might also be an effective influence leading to better outcomes. Currently patients are "sent" for physical therapy with many times little emphasis on its critical importance for recovery.

For all patients to take the two surveys that were used in this particular study is probably not practical even though both are available for public use. The usefulness of understanding patients' position on the continuum from active to passive behavior, or their desire for information, or the person they see as the most powerful influence on their health care is, however, immensely valuable to discern and understand which patients should receive extra coaching and encouragement in order to engage in their care.

Questions adapted from the Krantz HOS and the MHLC surveys might be considered for new patient orientation at times when patients are accepted into a doctor's practice. It is realized that discernment of a patient's type and therefore identification of

which patients need additional effort and encouragement to engage in their own care is not easy. Physician office visits are tightly scheduled, and patients during hospitalization endure continual interruptions for diagnostic tests, treatments, procedures, visits by practitioners, visits by family, meals, and hygiene tasks. Social interaction skills that are used during daily discourse may likewise mask an understanding of a patient's propensity for engagement. A possible solution is to understand patient traits when they first present as new patients with their physician. Questions or surveys such as those used in the current research are public domain, and abbreviated formats that assess patients' desire for information, active behavior, or whether or not they have an internal locus of control could provide a means to understand these characteristics and patient types. For patients who have contact with caretakers for the first time, or for a short time such as in a hospital setting, specific questions that reveal a patient's traits might also be developed, as was attempted in this study. The results of these assessments should then be entered into a patient profile. Even though the questions used in this project were not as successful in patient assessment as hoped, the lack of their effectiveness could stem from the assessors not understanding the intent of the questions because of the minimal training given them for this project.

An important requirement for this type of patient assessment is for physicians and other caretakers to understand the importance of patients' active or passive traits and the ways to detect these traits in order appropriately to assist and react to patients. The need to inspire and encourage patients, as applicable, is very important in order to boost patients' ability to be active and to engage in their care. Education and focused attention on the development of these abilities for providers and caretakers during medical training

is then important for all those who must discern patient traits for the purpose of fostering patients' involvement in their health. The need for this type of patient information to encourage active engagement in health processes crosscuts all specialties from pediatrics to geriatrics and from the management of wellbeing to that of managing critical illnesses. It includes general health, health maintenance, chronic and acute illness care, and end-of-life planning.

Not only active patients attend class.

The doctors' influence was also an important factor in this study in regard to class attendance. A beginning hypothesis for this research project was that patients with a propensity and desire to engage and participate in their health care would choose to attend an educational offering that informed them about the procedure they were about to undergo. This meant that participants who scored as active on the Krantz HOS and/or those who showed a strong internal locus of control on the MHLC would be the patients most likely to attend the class. This proved not to be the case in this current study, however, as the scores from both the Krantz HOS subscale for active behavior and the MHLC score for internal locus of control indicated more passive behavior and an external locus of control for health issues. The Krantz HOS subscale for information did, however, indicate an active desire for information. The mean scores for both surveys (including the two subscales for the Krantz HOS) were essentially the same for both groups of patients whether or not they chose to attend the class. For many in this group of participants, it appeared that the main determinant for class attendance and the full benefit of medical education was not a factor of the patient's particular behavioral trait but rather the influence of the doctor and the doctors' recommendation to attend class.

The doctor, regardless of the patients' Krantz HOS score that indicated their desire for information and/or involvement, was the stronger influence for many patients in the decision to attend the class. The strong MHLC scores for powerful others and particularly for doctors to be the most influential accounted for the deference to the doctor's recommendation for most participants. The fact that not all patients attended a class in this study was most likely a conflict with the date or time of the class offering rather than a disregard for their doctor's recommendation. Additional research to confirm the reasons why patients choose to attend a class would be useful knowledge.

Education Before or After Hospitalization

Even though the JCAHO has mandated education for all hospital inpatients according to their diagnosis, the provision of this education has, for the most part, proven to be ineffective, cursory, and fragmented. Documentation of the provision of inpatient education is a required entry into the patient's medical record during hospitalization and is monitored during JCAHO onsite accreditation surveys. Success of in-hospital education, in terms of better outcomes or reduction of recidivism, however, is questionable and for the most part seems unrealized.

As shown in the research of this TKA education project, a better requirement might be education given before the event, which was quite effective in the provision of information on what to expect before, during, and after the surgery in this particular study and for this medical situation. Such timing of education informs the way that patients prepare themselves and their homes for the procedure and its aftermath and delineates the tasks for which patients themselves are expected to be responsible. The information included not only the activities that patients were not able to do immediately following

their procedure but, also, it laid out for them the activities they could and were expected to do – their responsibilities. In the case of TKA, the information was focused to assist with pain management and especially to carry out the prescribed regimen of exercises that was critical for the rehabilitation, despite the discomfort they were certain to encounter.

An important finding in this study, based on the patients' comments during contact at 2 months after surgery, was the fact that the anxiety and anticipation before and during the hospital stay were substantially lessened by the education session. In this TKA circumstance, patients were then better able to focus on "their responsibilities." In contrast, when the provision of information and the clarification of patients' expectations took place during hospitalization, as with the control participants in the current study, the patient were often at this time groggy from anesthesia, under the influence of pain medication, or in the midst of uncomfortable physical therapy. Information provided in this context was less effective. With the addition of simple motivational interventions to encourage patients' ability to do the exercises (in this TKA case) after the procedure including after hospital discharge, a statistically significant better outcome than with the provision of information alone was achieved. TKA represents a rather temporary condition for the most part, one in which a situation can deteriorate and if the deterioration cannot be arrested or the condition improved, the knee joint is replaced; the limb is rehabilitated with a new appliance, and optimally the situation is resolved. In situations such as TKA or other self-limiting conditions, simple interventions most likely would suffice.

The Use of Doctors' Influence

When patients engage actively in their care in order to take charge of their health, they are, in many instances, manifesting some degree of internal locus of control in that they, at least temporarily, see themselves, to some extent, as able to influence their health destiny. Persuasion, especially at a time of potential relapse, encourages and reinforces the development of an internal locus of control.

The participants in the TKA research project (patients 50 years of age and older) presented a situation, as was revealed by the MHLC survey, that suggested most patients saw their doctor as the most important influence in regard to their health. They engaged in more active behavior in attending a class because of their doctor's recommendation to do so. Merely attending the class, however, did not ensure that all patients engaged actively in their care. The possibility to have only passively listened with little effect on behavior should also be considered. For many in this group of older patients, it appeared that additional effort to promote active involvement and engagement in their care yielded a better outcome. More intervention than the provision of information or self-management skills seemed to be necessary. This group of patients may require encouragement and the development of self-confidence in their ability to help themselves achieve the best outcomes they were able to obtain.

Bandura (1997) stated that individuals' confidence and assurance in their own ability or their self-efficacy to influence events in their own life is an important factor actually to take control of their life and health. Patients must perceive that they are capable of influencing their own circumstance, as this is a necessary precursor for self-advocacy. For patients with less confident characteristics and who coincidentally see their

doctors as a powerful influence for their health, doctors should consider using this influence not only to provide information, but to delegate to patients their expected responsibilities. Doctors might vary and adjust their direction and instruction to match their patients' beliefs about the factors that influence their health. In doing so, they would provide for patients opportunities to achieve successful experiences in health care management that could also build self-confidence. Patients are then taught by successful experiences to help themselves - including the shifting of responsibility for their health to themselves. The patient might then shift, from the physician as the primary influencer, to a greater internal locus of control with the physician in consult.

The Big Picture

Patients who have an understanding of their illnesses and are educated with the tools and knowledge to manage their own health care are typically more satisfied with their care and do better in their ability to maintain positive progress and stability in their lives as a result of their involvement. Persons who are able successfully to manage their health are also hospitalized on fewer occasions, rarely visit emergency rooms, and overall require less medical attention and fewer treatments (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Curtin et al., 2004; Drosey, 2008; Gold & McClung, 2006; Hanyu et al., 1999; Perniger et al., 2002). These reductions translate into savings of time for the health care provider, for the patient, and for the entire health care system as it also saves costly resources and expensive treatments. Citizens of the United States spent \$2.5 trillion in 2009 on health care, or \$8,160 per U.S. resident. This expenditure represents 17.6% of the GDP compared to 10-12% of GDP in other developed European nations or 8.1% in Japan and 8.4% in the U.K. Health care spending, since 1970, has increased

about 2.4% faster than the GDP (National Center for Health Statistics, 2007). From these data, it is clear that health care costs are increasing rapidly, especially when compared to health care in other developed countries.

Preventative education is an avenue for healthcare cost control and savings for all citizenry whether or not individuals require medical care at any given moment. Emphasizing healthy lifestyles and living, including the abatement of smoking and alcohol consumption, is a worthy beginning in this effort. Education for a healthy America and the acceptance by citizens of their responsibility to take charge of their day-to-day health in terms of better nutrition and exercise habits will most assuredly lessen future serious health problems and crises that arise from obesity, for example, and its associated co-morbidities. These focused initiatives could save millions of dollars in health care costs but require patient responsibility for prevention, the acknowledgement of its worth, and subsequent buy-in.

Patient Education Is Achievable

For patients who have short-term medical conditions such as TKA surgery as in this study, this research has shown that rehabilitation is improved when the patient is informed, engaged, and knowledgeable of the expected responsibilities. If the outcome for this study is applicable to other medical situations or disease states and patients experience fewer crises and better control as a result of education and responsibility involvement, once again health care costs in time, money, and effort could decline significantly.

Knowles et al. (2005) stated in regard to learning that adults are able to learn successfully when the subject matter is beneficial to them and is applicable to their lives.

This learning was demonstrated in the participants in this study who attended class or had a class plus interventions for self-efficacy and who, despite more passive behavioral traits, had successful and more rapid rehabilitation. Patients suffering from lifelong chronic diseases such as diabetes, asthma, heart disease, arthritis, and metabolic syndrome also have a responsibility to engage and self-manage their conditions effectively for the reason that 24-hour care is not likely, practical, or possible, but, also because their overall health will be in greater control. It is prudent, therefore, to teach people ways to help themselves, and it is essential that people gain confidence in their ability for self-care. The middle of a medical crisis is the worst time to begin to acquire a general medical acumen. Instead, familiarity and comfort with medical issues should be acquired and practiced throughout life.

Self-efficacy Can Evolve into Self-advocacy

For many people today, as was considered in the present research study, knowledge and information must be accompanied with self-efficacy. Without self-efficacy and self-confidence, people cannot be expected to advocate for themselves (Bandura, 1994). Walsh-Burke and Marcusen (1999) declared that for cancer survivors, self-advocacy is an essential skill. Respondents to a survivor survey of highly educated patients between the ages of 31 and 60 years reported that when they first received a diagnosis of cancer they were unable effectively to communicate their needs and lacked the skills necessary to make decisions or to negotiate with healthcare providers, insurers, or their employers. Oncology professionals, including nurses and social workers, agreed that in this group of patients particularly, education and the development of confidence and self-advocacy were very important. Patients need education and knowledge of the

actions necessary for the best management of their serious situations. Additionally, motivational coaching that is easy and simple, as in the TKA study, that gave patients the confidence to do the exercises, could have a similar effect for patients dealing with life-threatening conditions such as cancer.

In educating patients about ways to help themselves, knowledge is first and foremost an essential element; however, the use of that knowledge and the insight that results from it are also important. Knowledgeable patients can assist in their care and not only advocate for their own needs, but they can also expedite diagnosis and treatment progress when they give their caretakers critical information that allows the provider or caretaker to assess accurately and expeditiously the patient's response to a treatment or procedure. Collaborative interchange between patient and physician or caretaker is helpful to understand if the patient is progressing in the right manner and should continue with the current treatment or if another plan should be considered. Collaboration many times includes learning techniques for self-management, which are applicable to medication management, diet, and lifestyle changes as well as daily management of chronic conditions.

Technological developments using electronic patient support so that communication with one's health care provider is facilitated and allows patients to participate in self-management guides, has shown great promise (Osterber & Blaschke, 2005). Haskell et al. (1994) in a four-year study of diet management reported up to 47% less artery plaque buildup was found with the use of a self-management computerized program guide compared to the usual medical care which showed 0% decrease in plaque buildup. Self-help programs can be designed to allow patients to set goals, provide self-

motivating incentives, and self monitor their compliance. Patients are able to achieve success in their health with such self-help activities when their healthcare provider or their healthcare facility guides them. They are not only more satisfied, but they take pride in their achievement (Bandura, 1997). This was seen when many TKA patients in Phase II expressed pride in their self-directed exercise accomplishments after hospitalization, that put them ahead of the usual recovery schedule of similar patients who had the same procedure.

Participation in collaboration or in taking charge of one's health management requires not only the know-how but also the motivation and confidence in one's ability to do so. Appropriate and effective education provided with every medical experience and procedure is a solution that has the potential to achieve this goal and simultaneously result in a more satisfied patient as well as tremendous savings in health care. Rates of hospital admission recidivism and medical crisis requiring emergency care can be greatly reduced. Education can also prevent conditions from developing, as healthier lifestyles are promoted and practiced. The provision of medical and health education with self-efficacy development, if needed, is an important way to curb the usage of the health care system and allows patients to be knowledgeable, responsible, and competent users of health and medical resources and to adopt the life style changes that are necessary for healthier living.

Study Limitations Lead to the Need for Further Research.

This current study was carried out for one medical condition whose participants were within a particular age group of the general population. The results, therefore, may not be the same for other age groups, including their scores on the Krantz HOS indicating

their feelings concerning involvement in their care by both the desire for information and the passive desire (in this case) for involvement in health behaviors. Likewise, deference to the doctor as the most powerful influence on individual health might be a trait of this age group only and not seen in other age groups of patients. It would be beneficial to understand if other age categories showed similar survey scores or if, in fact, age categories within the population demonstrated unique findings and traits that would indicate perhaps a different handling of each type of patient in any given health care circumstance.

In like manner, the TKA procedure is a very limited condition with an outcome not necessarily reproducible in a more chronic, long-term disease or condition. Success with patient education and the building and sustaining of self-efficacy in long-term situations may require more and different effort in order to succeed to the optimal level. The simple interventions in this study may be insufficient for more complicated or for long-term conditions. This would be useful and necessary information for the design and implementation of specific patient education programs.

More practical assessment capabilities of patient type (active or passive traits) are also useful tools to study, develop, and test. In order to match the educational needs of individual patients whose active or passive health behavioral traits exist on a continuum, a method to understand the place patients are on the continuum would be useful so that individual learning needs might be met. Further study for the development of caretakers' assessment abilities with simple categorizing questions would be very useful. Care should be taken to have those assessing patients in this manner understand the reasons that they are being asked to assess them (the purpose) as well as the methods

of assessment and which patient behaviors to assess. This was a weakness in the TKA study described.

Lastly, it would be very useful to research the basis of salutogenesis mentioned in the literature review with a particular focus on what active, engaged patients actually do and ways they think differently as compared with passive patients. Insight might be gained to improve ways to engage patients who are less motivated or less willing to engage in their care. This would be particularly relevant in the development of formal curricula for school students as well as for patient self-efficacy efforts

The Role for Educational Leadership

Educational leaders in place within the health care system at the time of this research are rare unless they are associated with curricula for the education and training of health care personnel for specific disciplines. There has been no reported role for specifically designated educational leaders for patient education. This task is, for the most part, assigned to nurse educators who may or may not have the ability to establish a teaching plan for a particular disease or condition for which they have acquired experience or specialty training. Understanding the variances in their target recipients of the education is mostly lacking with little differentiation of patients' individual needs. Patients are viewed as persons needing medical information either for their treatment regimens or as recipients of education to fulfill the requirement for accreditation. Educational leaders can be extensively involved in the development of curricula, especially when it is individualized for patients with special educational needs.

Ways to assess patients' needs by health caretakers and ways to engage patients by both caretakers and providers might also be best addressed by educational leaders.

The development of effective programs for patient education, as was implied by this study, suggests that active engagement in care is more successful when it meets the needs of patients' individualized traits. Additionally, special training for caretakers and providers on the importance of meeting passive as well as active patients' needs is necessary to ensure that all patients are able to be participants in their own health management and control.

Educational leaders are also needed in policy development for school curricula from elementary school through high school. Advanced curricula should also be considered for undergraduate college education in order to foster the encouragement of individuals' responsibility for their health care. With exposures to these types of curricula throughout a students' school life, citizens will naturally be informed to be more active and to engage in their health for better outcomes for lesser costs, with fewer health crises, and with better self-management when faced with health issues as adults.

Appendix A**Daily Assessment: Name** _____ **Date** _____

Multidisciplinary caretakers will do a daily in-hospital assessment of a patient's involvement/engagement in his/her care. The patient's nurse and physical therapist will discuss the patient's effort and each will complete the daily assessment form.

1. Patient demonstrates engaged effort in recuperative protocols?
 - a. Patient puts forth maximum effort to follow instructions of caretaker
 - b. Patient listens and actively tries to accomplish the assigned task
 - c. Patient follows instruction but "gives up" quickly
 - d. Patient reluctantly puts forth any effort at all and requires much encouragement.
 - e. Patient is quite passive in all respects.

2. Patient has questions and is actively interactive during care?
 - a. Patient interacts with zeal
 - b. Patient interacts with willingness.
 - c. Patient interacts somewhat.
 - d. Patient must be prodded to interact
 - e. Patient is essentially passive with little or no interaction

RN: _____**PT/Rehab:** _____

Appendix B E-Mail or Post Care Messages

It is very important now that you are home from the hospital that you continue your daily exercise routine for your knee. Doing this as you were taught during your hospital stay will improve your recovery and you will be able to resume your normal activities sooner. Keep up the good work you will be rewarded!



We hope you are still doing the exercises you were given in the hospital and by now you are witnessing some of the benefits of doing them. It is likely you are still experiencing discomfort, but soon it will be much better. Keep doing your exercises, they are working for your benefit!

Appendix C: UNF and Flagler Hospital IRB



Office of Research and Sponsored Programs
 1 UNF Drive
 Jacksonville, FL 32224-2665
 904-620-2455 FAX 904-620-2457
 Equal Opportunity/Equal Access/Affirmative Action Institution

MEMORANDUM

DATE: July 30, 2009

TO: Ms. Linda Andiric

VIA: Dr. Marcia Lamkin
 Educational Leadership

FROM: Dr. Christopher Leone, Interim Chair,
 UNF Institutional Review Board

RE: Review by the UNF Institutional Review Board IRB#09-065:
 "Patient education and involvement in care: Outcomes for total knee
 arthroplasty"

This is to advise you that your project, "Patient education and involvement in care: Outcomes for total knee arthroplasty" has undergone "expedited, category 7" review on behalf of the UNF Institutional Review Board and approved. A stamped and dated copy of your protocol and approval letter will be electronically forwarded in the near future.

As you may know, your **CITI Course Completion Report** is valid for 3 years. Your completion report is valid through 03/30/2012.

Your study has been approved for a period of **12 months**. If your project continues for more than one year, you are required to provide a Continuing Status Report to the UNF IRB prior to 06/29/2011. *We suggest you submit your status report 11 months from the date of your approval date as noted above to allow time for review and processing.*

This approval applies to your project in the form and content as submitted to the IRB for review. Any variations or modifications to the approved protocol and/or informed consent forms as they relate to dealing with human subjects must be cleared with the IRB prior to implementing such

changes. Any unanticipated problems involving risk and any occurrence of serious harm to subjects and others shall be reported promptly to the IRB.

Should you have questions regarding your project or any other IRB issues, please contact the Office of Research and Sponsored Programs at 904.620.2455.

Thank you,

Research Integrity Staff

Protection of Human Subjects
Assurance Identification/IRB Certification/Declaration of Exemption
(Common Rule)

Policy: Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (56FR28003, June 18, 1991) unless the activities are exempt from or approved in accordance with the Common Rule. See section 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the Common Rule.

Institutions must have an assurance of compliance that applies to the research to be conducted and should submit certification of IRB review and approval with each application or proposal unless otherwise advised by the Department or Agency.

1. Request Type <input checked="" type="checkbox"/> ORIGINAL <input type="checkbox"/> CONTINUATION <input type="checkbox"/> EXEMPTION	2. Type of Mechanism <input type="checkbox"/> GRANT <input type="checkbox"/> CONTRACT <input type="checkbox"/> FELLOWSHIP <input checked="" type="checkbox"/> COOPERATIVE AGREEMENT with UNF <input type="checkbox"/> OTHER: <u>Education Leadership</u>	3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No.
4. Title of Application or Activity <u>Total Knee Arthroplasty Patients Outcomes: Effects of Education and Active Involvement</u>		5. Name of Principal Investigator, Program Director, Fellow, or Other <u>Linda Reynolds Andiric, BS, BA, M.Ed.</u>

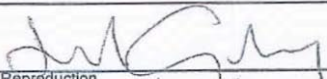
6. Assurance Status of this Project (Respond to one of the following)

- This Assurance, on file with Department of Health and Human Services, covers this activity. Assurance Identification No. _____, the expiration date _____ IRB Registration No. _____
- This Assurance, on file with (agency/dept) Flagler Hospital, covers this activity. Assurance No. FWA00003766, the expiration date _____ IRB Registration/Identification No. IRB00006886 (if applicable)
- No assurance has been filed for this institution. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.
- Exemption Status: Human subjects are involved, but this activity qualifies for exemption under Section 101(b), paragraph _____.

7. Certification of IRB Review (Respond to one of the following IF you have an Assurance on file)

- This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations. by: Full IRB Review on (date of IRB meeting) _____ or Expedited Review on (date) _____
 If less than one year approval, provide expiration date _____
- This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments Study is non-invasive to patients. Provision of educational materials as interventions, questions for patients and observation of outcome progress

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed until study closure and certification will be provided.	10. Name and Address of Institution	
11. Phone No. (with area code)		
12. Fax No. (with area code)		
13. Email:		
14. Name of Official <u>Joseph Gordy</u>	15. Title <u>Chairman, Flagler Hospital IRB</u>	
16. Signature 	17. Date <u>4/18/09</u>	

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Public reporting burden for this collection of information is estimated to average less than an hour per response. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: OS Reports Clearance Officer, Room 503 200 Independence Avenue, SW., Washington, DC 20201. Do not return the completed form to this address.

Appendix D

Name _____

Multidimensional Health Locus of Control Questionnaire (MHLC)

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item please circle the number that represents the extent to which you agree or disagree with the statement. The more you agree with the statements, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make certain that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs and there are no right or wrong answers.

		SD	MD	D	A	MA	SA
1=STRONGLY DISAGREE (SD)		4=SLIGHTLY AGREE (A)					
2=MODERATELY DISAGREE (MD)		5=MODERATELY AGREE (MA)					
3=SLIGHTLY DISAGREE (D)		6=STRONGLY AGREE (SA)					
1	If my condition worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my condition, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5	Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6
10	In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
15	If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my condition will get better.	1	2	3	4	5	6
17	If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6

Multidimensional Health Locus of Control Scales (MHLC) adapted from Julian Rotter's Locus of Control studies for medical use by Kenneth A. Wallstron, PhD. Vanderbilt University School of Nursing, Nashville, TN.

Appendix E

Krantz Health Opinion Survey

The following questions ask for your opinion about different kinds of health care. For each statement below, decide whether you agree or disagree and circle the answer, which best fits your opinion. Each person is different, so there are no “right” or “wrong” answers. Even if you find you don’t completely agree or disagree with a statement, choose the one answer that comes closest to what you believe. Please try to circle an answer for each question.

- | | | |
|---|-------|----------|
| 1. I usually don’t ask my healthcare providers many questions about what they are doing during a medical exam | AGREE | DISAGREE |
| 2. Except for serious illness, it’s generally better to take care of your own health than to seek professional help. | AGREE | DISAGREE |
| 3. I’d rather have a healthcare provider make the decisions about what’s best than for them to give me a lot of choices. | AGREE | DISAGREE |
| 4. Instead of waiting for them to tell me, I usually ask the doctor, nurse, or other healthcare professional about my health immediately after an exam. | AGREE | DISAGREE |
| 5. It is better to rely on the judgments of doctors (who are experts) than to rely on “common sense” in taking care of my own body. | AGREE | DISAGREE |
| 6. Clinics and hospitals are good places to go for help since it’s best for medical experts to take responsibility for health-care. | AGREE | DISAGREE |
| 7. Learning how to care for some of my health needs without always contacting a physician is a good idea. | AGREE | DISAGREE |
| 8. I usually ask the healthcare provider lots of questions about the procedures during a medical exam. | AGREE | DISAGREE |
| 9. It’s almost always better to seek professional help than to try to treat yourself. | AGREE | DISAGREE |
| 10. It is better to trust the doctor, nurse or other healthcare provider in charge of a medical procedure than to question what they are doing. | AGREE | DISAGREE |
| 11. Learning how to cure some of my illnesses without contacting a physician may create more harm than good. | AGREE | DISAGREE |

12. Recovery is usually quicker under the care of a healthcare provider than when patients take care of themselves.	AGREE	DISAGREE
13. If it costs the same, I'd rather have a healthcare provider give me treatments than to do the same treatment myself.	AGREE	DISAGREE
14. It is better to rely less on physicians and more on your own common sense and knowledge when it comes to caring for your body.	AGREE	DISAGREE
15. I usually wait for the doctor or other healthcare provider to tell me about the results of a medical exam rather than asking them immediately.	AGREE	DISAGREE
16. I'd rather be given many choices about what's best for my health than to have the doctor make the decisions for me.	AGREE	DISAGREE
17. Programs to teach people to treat themselves will probably result in better health for the people involved.	AGREE	DISAGREE
18. Managing some of my own healthcare needs after instruction will result in better and more stable health for me.	AGREE	DISAGREE

Scale:

Information subscale – 1,3,4,8,10,15,16,17, (18)

Behavioral Involvement – 2,5,6,7,9,11,12,13,14,

Appendix F

Two-Month Follow-up Knee Surgery Patients

Name _____ Date _____

First TKA _____ Second TKA _____

1. Do you still take pain medication or an analgesic regularly for knee discomfort?

Regularly (daily) ___ As Needed ___ Occasionally ___

Please list pain medications: _____

2. Please describe your ability to move about at this time.

1. I am in a SNF or homebound with daily assistance required
2. I am able to do very limited indoor activity only
3. I can go outside but must remain very close
4. I can get about fairly normally with some limitations
5. I can do anything I want to

3. Have you continued the exercise program you were given while in the hospital? _____

4. Is your ability to move about without pain better than before your surgery?

_____yes _____no

5. Do you use a walker, cane or other walking aid regularly _____ occasionally _____
never _____?

6. Satisfaction with Flagler Hospital and your care there?

1. Excellent
2. Very Good
3. OK
4. Needs Improvement
5. Did not have a good experience

Appendix G Class Handout

ORTHOPEDIC SURGERY: AFTER THE HOSPITAL

During the recovery from your orthopedic surgery, it is important to realize that your active participation in the recovery process is a key factor in how quickly you will be able to return to your normal activities. After you leave surgery, the doctor has done his part and now it is time for you to do your part. Mostly this consists of doing the daily exercises you learned while you were hospitalized.

At first this will be uncomfortable, but it is very important that you keep trying in order to speed your recovery. No one else can do this for you and following the instructions given to you in the hospital by your therapist will gradually and daily improve your ability to move about. The exercises, when done correctly, are structured for patients who have had your type of surgery. They will not hurt you but on the contrary, will help you progress even when the exercises are not easy to do. Please keep trying to do

them exactly as you learned in the hospital. You CAN succeed in this!

A helpful tip may be to take whatever pain medication your doctor has prescribed for you approximately 30 minutes before you do the daily exercises so that you will do them properly and the discomfort will be lessened. This way you will gain the most benefit from your sessions and lessen the discomfort associated with the movements.

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Professional Career:

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Bispebjerg Hospital, Copenhagen, Denmark – Laboratory hematologist

Max Planck Institute, Munich, Germany – Biochemistry research assistant

University of Florida, Gainesville, Florida – Research assistant, Pharmacology

University of Florida, Gainesville, Florida – Clinical laboratory supervisor

Alachua General Hospital, Gainesville, Florida – Assistant Chief Technologist
Educational Coordinator

North Florida Regional Medical Center, Gainesville, Florida – Chief Technologist
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LabCare & Associates, Sole Proprietor founded 1982 – Consultant Laboratory Management

Flagler Hospital, Inc., St. Augustine, Florida – Administrative and Technical Director, Laboratory Services

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