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DETERMINANTS OF PATIENT BEHAVIOR IN CHRONIC ILLNESS: EXAMINING EDUCATIONAL INTERVENTIONS FOR GLAUCOMA PATIENTS.

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Arts in Educational Psychology

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ABSTRACT

Providing chronically ill patients with informational support is crucial for successful disease management. The effectiveness of educational interventions was examined utilizing three questionnaires which assessed glaucoma patients' health beliefs, disease knowledge and medication compliance. 60 chronic open-angle glaucoma patients either: watched a glaucoma film, read glaucoma information pamphlets, received instruction verbally from their ophthalmologist or proceeded with their regular check-up. Measures were taken pre-intervention, then 2 and 30 days later. A 3 x 4 mixed ANOVA found a significant interaction between time and intervention in the film group. The relationship between the degree of patient's visual field loss and measures on compliance, health beliefs, and knowledge was also assessed. The positive correlations indicate that patients with modest visual field losses are also those with the highest scores on the three dependent measures. Patients, who have less visual field loss, may possess the behavioral, affective and cognitive components required to successfully manage their illness regimens.

RESUME

Pour permettre aux malades chroniques de gérer efficacement leur maladie, il est crucial de les soutenir en leur fournissant de l'information. L'efficacité des interventions éducatives a été examinée par le biais de trois questionnaires évaluant, chez des patients atteints de glaucome, leurs croyances par rapport à leur santé, leur connaissance de la maladie et leur adhésion au traitement médicamenteux. Soixante patients souffrant de glaucome à angle ouvert chronique ont soit regardé un film sur le glaucome, soit lu des dépliants traitant du glaucome, soit reçu des renseignements communiqués verbalement par leur ophtalmologiste, soit poursuivi leurs visites périodiques chez le médecin. Des mesures ont été prises avant l'intervention, 2 jours après, puis 30 jours après. Chez le groupe ayant regardé le film, les analyses de variance 3 X 4 ont indiqué une interaction importante entre le moment de l'intervention et l'intervention même. L'étude a également établi le rapport entre d'une part la gravité de la perte de champ visuel et d'autre part le degré d'adhésion au traitement, les croyances sur la santé et l'étendue des connaissances. Les coorélations indiquent que ce sont les patients dont la perte de champ visuel est légère qui ont obtenu les résultats les plus élevés aux trois tests de mesure dépendante. Il se pourrait que les patients dont la perte de champ visuel est la plus faible possèdent les outils affectifs, cognitifs et comportementaux nécessaires à une gestion réussie de leur maladie.

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Tristan, I thank you for being patient with me; your stressed out mama is now ready to play.

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CHAPTER 1

Introduction

At the beginning of the 20th century, infectious disease was the greatest detriment to human health. Illnesses such as tuberculosis, pneumonia, and influenza were the leading causes of death and resulted in high rates of infant mortality and shortened life expectancy (Petrie & Moss-Morris, 1997). However, changes in living conditions, the development of antibiotics, and advances in medical research have turned many previously deadly infectious diseases into treatable conditions. As the rate of infectious disease has declined and life expectancy has increased, there has been a corresponding rise in the number of people suffering a chronic illness at some point in their lives. Now, as we head into the 21st century, illnesses such as heart disease, arthritis, diabetes, hypertension, and cancer are part of the daily lives of a relatively large segment of the population (Petrie & Moss-Morris, 1997). These illnesses bring with them considerable difficulties in terms of adjustment, management, and coping. The biomedical model had enabled researchers to make impressive advances in conquering infectious diseases through the development of vaccines and treatments (Sarafino, 1998). Recently, however, more researchers have come to recognize that the individual aspects of patients, such history, personality, social relationships and lifestyle, mental and biological processes, must all be included in a complete conceptualization of both illness and health in modern chronic maladies.

This thesis explores the above factors in relation to glaucoma patients, and to their medical regimens. Study one was designed to identify effective clinical interventions that would educate and ameliorate medication compliance in glaucoma patients. A second goal was to assess the efficacy of specific educational interventions, which varied in terms of presentation style. The third goal was to contribute to the theoretical understanding of health behaviors in relation to the patients' personal beliefs and perceptions about glaucoma. Study two builds on the first study by investigating the relationship between the glaucoma patient's visual field loss (impairment) and measures of health beliefs, compliance and disease knowledge.

The following review of the literature addresses the current state of affairs regarding chronic illness with respect to compliance, as well as the cognitive and affective components required for behavior change. Internal and external sources of support for the ill are reviewed along with patient education programs and various interventions.

Chronic Illness: The Current State of Affairs

In our rapidly changing health care environment, where the onus of health and recovery is shifting from the professional to the novice, patients and their families will be carrying out tasks that were previously performed by nurses and other health care professionals. The average hospital length of stay is much shorter now than it had been in the past, and thus, patients leave the hospital earlier in their period of recovery. When discharged, they tend to be sicker and require more support in the home environment. It is essential for both patients and caregivers to have adequate knowledge of the illness, to recognize signs and symptoms of the disease, to be able to administer proper care, and to understand how to prevent complications. They also need to be aware of the resources that are available to assist them in meeting those needs. Therefore, health professionals need to employ effective strategies to educate individuals to cope with chronic illness, to become better informed, and to be more effective consumers of medical services (Meyers, 1997). The major objective of health instruction is to make all patients as knowledgeable, functional, and independent as possible.

Problems with Chronic Illness and Long Term Behavior Change

The main health problems, and causes of death, in the United States today are chronic diseases. These are degenerative illnesses that develop and persist over long periods of time (Tapp & Warner, 1985). Approximately two thirds of all deaths in the United states are caused by three chronic illnesses: heart disease, cancer, and stroke (USBC, 1995). Chronic illnesses also introduce psychosocial challenges and adaptive demands. These include physical and cognitive disabilities, diagnostic uncertainties, a dependency on professional expertise and biomedical technology, and lifestyle disruptions (Devins & Binik, 1996). Chronic illness is often characterized by uncertainties that elicit substantial anxiety and emotional distress. Unfortunately, many conditions, including glaucoma, remain difficult to diagnose until well after the onset of physical symptoms (Devins & Binik, 1996). Pain is common in chronic illness (Devins & Binik, 1996) and can limit the ability to maintain involvement in valued activities and interests, thereby compromising the quality of life (Devins, 1994).

The initial psychological adjustment following a diagnosis of a chronic illness is usually related to a loss of function (Petrie & Moss-Morris, 1997). Individuals at this stage of diagnosis confront the reality that their state of health has inexorably changed and that the integrity and functioning of their body has been limited in some way. Managing the on-going demands of a chronic illness often requires learning new skills and adjusting to a new daily lifestyle. Illness related tasks that face the individual include: adjusting to symptoms and incapacities brought on by the illness, dealing with and learning any special treatment required, and maintaining adequate relationships with health-care providers (Moos & Schaefer, 1984). For instance, insulin-dependent diabetes and end-stage renal disease require patients to learn specific techniques for controlling symptoms (for example dialysis). Additionally, an active awareness and monitoring of bodily function may be required in disease like diabetes, in order to avoid medical crises (Moos & Schaefer, 1984).

Although all health care consumers can be considered dependent on service providers, the ongoing nature of chronic illness amplifies this dependency on professional expertise and biomedical technology. For example, in kidney disease, health-care providers monitor interdialytic weight gains, which is an index of compliance to the relatively strict fluid intake restrictions that accompany treatment. They also routinely monitor blood pressure and serum electrolytes to evaluate the patient's adherence to dietary limitations and the complex medication regimen (Devins & Binik, 1996). Due to the stringent restrictions and the complex regimen associated with treatment, noncompliance is widespread and considered a serious violation of the dialysis patient's role and responsibilities (Kirchenbaum, 1991). Not surprisingly adherence to therapeutic regimens often serves as the battleground on which a variety of struggles are played out between dialysis patients and their health care providers, resulting in significant interpersonal strain and stress related adjustment problems for both parties (Devins & Binik, 1996). Individuals with chronic illness are often the objects of negative biases and stigma. Health care providers, who frequently interact with the chronically ill, often maintain negative stereotypes that portray affected individuals as helpless and depressed (Devins & Binik, 1996). Social stereotypes and stigma may compromise the patient's feelings of independence autonomy, and self-esteem.

Coping with chronic illness has become an important area for research and intervention in health psychology because of the large numbers of individuals suffering from such diseases. Petrie and Moss-Morris (1997) believe that the patient's own understanding of the illness and the perception of the level of social support are key factors in promoting successful long-term coping. Interventions that educate, and develop coping strategies, and improve the match between the use of problem-focused or emotion-focused strategies with the characteristics of the situation, appear to provide a promising venue to improve the quality of life for patients living with chronic illness. The following section addresses glaucoma, a chronic illness that has specific management requirements. Patients diagnosed with chronic open-angle glaucoma, must typically take medication, in the form of eye drops for the rest of their lives.

Glaucoma

Glaucoma is the leading cause of irreversible blindness throughout the world (Shields, 1992). In the United States alone, glaucoma is the leading cause of preventable blindness; more than two million people have glaucoma and 80,000 Americans are legally blind as a result of the disease (Vaughan & Riordan-Eva, 1992). Glaucoma affects one in every one hundred Canadians over the age of forty (C.N.I.B., 1989). Glaucoma is commonly referred to as the 'sneak thief of vision' because extensive, irreversible damage to the optic nerve can occur before the individual notices any symptoms. Primary open-angle glaucoma is the most common form, affecting about .4% to .7% of persons over the age of forty and 2% to 3% over the age of seventy (Vaughan & Riordan-Eva, 1992).

Glaucoma is preventable and responds well to treatment, provided it is diagnosed in time. Treatment usually consists of eye drop medication, taken one or more times a day, which reduces intraocular pressure by either ameliorating fluid drainage or by decreasing its production (Shields, 1992). Eye drops are not without adverse side effects however; these include burning, stinging, reduced vision and more potentially serious reactions such as depression, asthma and congestive heart failure (Ellis, 1992). The side effects of medications combined with an asymptomatic, chronic disease, provide fertile ground for noncompliance with medication regimens. Despite the serious consequences, such as going blind, noncompliance is still a common phenomenon in the treatment of glaucoma. The next section reviews this problem with illustrations from the vast research on compliance.

Compliance

Patient noncompliance is a substantial obstacle to the achievement of therapeutic goals; some authorities consider it to be among the most serious problems facing medical practice (Becker & Maiman, 1980). Even for those diseases for which effective medication is readily available, there is no way to ensure that patients will follow the physician's directions for using the prescribed medication (Lasagna & Hutt, 1991). Depending on the characteristics of the condition, the treatment, the patient and the setting, estimates of noncompliance rates typically range from 30% to 60%, with the situation worsening where patients are symptom free. Noncompliance is more common with preventative treatment than with treatment for acute symptomatic illness.

Rankin and Stalling (1996), reviewed the patient education literature, and identified several variables that influence an individual's decision to disregard the recommendations of health professionals. They found that lack of cooperation is common among patients of all economic and educational backgrounds, and that rationalization and denial are recurrent problems encountered in patient education and are often seen in the management of chronic illness. Indeed, the nature of chronic illness, with its remissions and exacerbations, heavily influence patients' attitudes toward compliance. Higher rates of noncompliance are seen with prescribed drug regimens; up to 50% of all patients fail to achieve full compliance, and as many as a third never take their prescribed medications at all (Rankin & Stalling, 1996).

Both participants (the health care provider and patient) in the medical encounter play an active role in compliance with medical regimens. Patients interpret, evaluate, and accept or reject physicians' recommendations based on their own personal experience of symptoms in the context of their lives (Dye & DiMatteo, 1995). Though patients rarely volunteer their own ideas, research has demonstrated that they have specific requests and expectations in mind when they visit their health care provider (Lazare, Eisenthal, & Wasserman, 1975; Dye & DiMatteo, 1995). Patients typically adhere to recommendations that coincide with their own ideas (Tuckett, Boulton, Olson & Williams, 1985). Patients theorize about the cause and likely course of their illnesses as well as appropriate diagnostic procedures and treatment (Dye & DiMatteo, 1995). These ideas influence patients' experiences of and expectations about their illness. Therefore, if a physician approaches the problem from his or her purely medical perspective, there is a risk that consensus will not be reached. When the health care provider fails to solicit the patients perspective, Dye and DiMatteo (1995) point out that the physician may prescribe for an illness that the patient does not believe they have, while failing, in the patients view, to treat the "real" problem.

Noncompliance and Glaucoma

Noncompliance with ocular therapy is a major problem in the prevention of blindness from glaucoma (Kass et al., 1984; Shields, 1992; Vaughan & Riordan-Eva, 1992). Although compliance rates vary from study to study, the literature reveals noncompliance with ocular therapy to be between 25% and 50%, as seen in outpatients on chronic treatment (Kass et al., 1984). Unfortunately, there is often little immediate reinforcement for the patient to continue treatment (Kass et al., 1984) with an asymptomatic illness such as glaucoma, which produces no pain or immediate disability. An extensive review of the compliance literature by Kass et al. (1984) found that none of the usual demographic variables, such as education and socioeconomic status, correlate consistently with compliance. Compliers and non-compliers have been compared on personality characteristics, demographic variables such as education and income, and variables such as ethnicity, all to no avail (Leventhal, Zimmerman & Gutmann, 1984). However, there are several variables which do correlate with noncompliance: (a) unfavorable attitudes towards physicians, (b) dissatisfaction with the prescribed treatment, (c) poor understanding of the disease and its treatment, and (d) adverse health beliefs (Kass et al., 1984).

Noncompliance typically takes four forms: (a) the failure to take medication is the most common form, including missed doses and premature discontinuation of therapy, (b) excessive use of medication, seen in some patients who hope to gain additional benefit from added doses, (c) taking the medicine at different times or intervals than directed, or (d) administration of a treatment not prescribed by the physician; this occurs when patients use drugs remaining from previous prescriptions or have access to drugs prescribed for other individuals (Kass et al., 1984). The reasons for noncompliance are numerous, including forgetfulness, confusion, adverse reactions, apprehension about drug-related hazards, misunderstanding instructions, poor practitioner-patient relationship, and the belief that medication has failed or is no longer needed (Davidson & Akinbehin, 1980).

Severity of Symptoms and the Relationship to Patient Health Behavior

There is a paucity of information in the current literature on the association between severity of illness symptoms and measures of health behaviors. Different illnesses generate different symptoms. and patients may have different expectations about the ways in which treatment should affect these symptoms. For instance, does the disappearance of symptoms imply that the treatment is working and, therefore, should it be continued or stopped (Leventhal et al., 1984)?

Are patients who have potentially disabling health problems more likely to comply with their treatment regimens than are individuals with less serious illnesses? The literature suggests that it depends on whose perspective of illness severity is considered, that of the patient, or of the healthcare providers (Sarafino, 1998). When physicians judge the severity of illness, patients with serious illnesses are no more likely to comply than those with less severe health problems (Becker & Rosenstock, 1984; Haynes, Taylor & Sackett, 1979). One explanation for these finding is that many very serious health problems, such as hypertension and atherosclerosis, have no symptoms that cause individuals to be concerned or that interfere with their normal functioning (Sarafino, 1998). Alternatively, many less serious illnesses do have troublesome symptoms. When patients themselves judge illness severity, compliance increases with severity (Sarafino, 1998). Those patients who perceive their illness as relatively serious typically show better compliance to their treatment than do those who perceive their illness to be less severe (Becker & Rosenstock, 1984).

In the older literature, Haynes et al., (1979) wrote that features of the disease were unimportant with respect to compliance, since less than half of the studies at that time reported any significant correlation between the two. Five of eight studies reporting a link between diagnosis and compliance examine psychiatric patients. In 1979, Haynes et al. concluded that not a single study had found that increasing severity of symptoms encouraged compliance. Four studies showed reduced compliance with more severe symptoms, and these were balanced by three studies that showed a positive relationship between degree of disability and compliance (Haynes et al., 1979). Finally, clinical improvement also appeared unrelated to compliance in a systematic manner; it was followed by reduced compliance in some instances, and bore no relationship to compliance in others, and patients reported improvement as a reason for stopping medication in 13 studies according to Haynes et al. (1979). The impact of treatment duration and regimen complexity on compliance is strong. For instance, 12 studies showed higher levels of compliance for short-term than for long-term treatment regimens, and another 13 found higher levels of adherence to less complex than to more complex treatment regimens (Haynes et al., 1979).

Thus, it seems that compliant behavior in the realm of chronic disease management stems from multidimensional sources as varied as attitudinal, experiential, and perceptual. Clearly, further efforts will be necessary to enumerate and chronicle the effects that these constitutional and environmental factors have on compliance.

Illness and the Patient: Appraisals of Threat

Illness is not simply disordered pathophysiology since it involves more than just a physical state. Illness happens to an individual and involves changes in the person's feelings and abilities. Moreover, becoming ill, seeking care, getting well, and staying well all have social determinates. Patient-hood is a psychosocial role, not a biological state, and knowledge of the patient as a person is essential to the biopsychosocial approach to the patient (Coulehan & Block, 1997). For the patient, a health problem or illness carries a different significance than it does for the physician; the patient may view the illness as a barrier to leading a 'normal life'. The experience of illness and its psychosocial impact are profoundly shaped by culturally based practices, attitudes and beliefs. Devins and Binik (1996) feel that research to date has ignored these important issues when designing interventions to facilitate coping with chronic illness. Research in medical anthropology has identified explanatory models (Klienman, 1980) and conceptual frameworks within which the experience of illness is perceived and defined, as powerful influences than can dramatically shape appraisals of the illness experience. Cross-cultural differences in explanatory models can lead to different interpretations of objectively similar constellations of signs and symptoms, illustrating significant discrepancies in perceived causes of illness, patterns of distress, anticipated course of illness, and help-seeking behavior (Weiss, 1988). Given the multicultural make-up of our country, these important issues must be considered in each and every medical encounter.

According to self-regulation theory (Leventhal et al., 1984) individuals construct a cognitive representation of salient health threats and engage in efforts to manage their emotional reactions and confront the danger. The roles of specific cognitions and emotions that become activated during the processing of health-related information require attention. For example, when faced with the diagnosis of breast cancer in the family, a woman may experience strong emotions about her vulnerability and may overreact to dangers. This in turn, can trigger intense anxiety, intrusive ideation, and avoidance of threat-related experiences, such as undergoing mammograms (Lerman et al., 1996). This model can be generalized to patients with glaucoma since there is also a hereditary component in this disease A glaucoma patient whose parent has lost his/her vision to glaucoma, may avoid threat-related experiences such as having ones eyes examined, or having ocular pressures checked.

Like scientists, lay people seek meaningful causal connections among the myriad of correlation events that they encounter, often looking particularity hard for causal explanations for unusual events (Halpern, 1998). Naive and flawed reasoning practices, such as illusory correlations (believing that variables are connected when they are not), are very resistant to change because they make sense to the individual, and the individual believes that they work (Halpern, 1998). Cognitive behavioral interventions are predicated on the hypothesis that it is the individual's interpretation of events, and not the events themselves, which determine the subjective experience and behavioral response to the event (Morley, 1997). Explicitly assessing patients' health cognitions is important because their perceptions of the health problem may be composed of their anticipation or experienced symptoms, and, of information from family members, friends, and the media as well as from health care providers. Patients integrate information from all these sources in responding to a current illness episode or a future illness threat (Dye & DiMatteo, 1995).

Petrie and Moss-Morris (1997) explain that individuals with chronic illnesses seem to organize their representations of illnesses around five major cognitive components: (a) identity, which is composed of the label and symptoms of the disease, (b) cause - personal ideas about etiology, (c) time-line - how long they believe the illness will last (d) consequences - expected effects and outcomes of illness and (e) cure/control - how one recovers from or controls the illness. Cognitive illness representations which direct coping strategies and emotional responses to an illness, do so in a parallel process that feeds back again to influence the patient's own illness model. Petrie and Moss-Morris (1997) illustrate this with an example of a patient who attributes her hypertension to stress caused by work and who subsequently leaves her job only to discover that this has made no difference to her blood pressure levels. This patient is likely to revise her view of the cause of her hypertension. Particular illness models may be associated with more functional coping strategies (Moss-Morris, Petrie & Weinman, 1996) and illness representations may play a critical role in influencing adjustment to a range of common chronic illnesses such as heart disease, cancer, glaucoma and diabetes.

Lazarus & Folkman's (1984) transactional model has had the largest impact on the current conceptualization of coping with chronic illness, according to Petrie and Moss-Morris (1997). This model views the patient's coping response as being determined by both the appraisal of the degree of threat posed by an illness, and the resources seen as being available to assist them in coping in the situation. Coping responses in this model are divided into emotion-focused (affective) and problem-focused (cognitive) strategies. The function of problem-focused coping is to actively alter the stressful situation in some way, while emotion focused-coping is directed at regulating the patient's emotional response to the stressor. Each response can be adaptive or maladaptive depending on the situation. Reframing the illness in a positive light, acceptance of the disease, and utilizing social support appear to be adaptive coping strategies across many chronic illnesses (Petrie & Moss-Morris, 1997). Petrie and Moss-Morris (1997) remark that problem-focused strategies, which, in theory, should have a greater adaptive control, have frequently failed to show a strong relationship to outcomes in chronic illness.

Research has shown that compliance is affected by internal factors such as patients' beliefs about health and illness, attitudes, and values; as well as by external factors, such as cues to action, cultural norms, social support and barriers. Both cognitive and behavioral variables are modifiable by the purposeful exploration and exchange of information between healthcare providers and patients (Dye & DiMatteo, 1995). Achieving patient cooperation is an implied goal of every medical interview in which a treatment regimen or life-style modification is prescribed. Because of the crucial influence of compliance on the efficacy of medical treatment, clinicians and social sciences have invested substantial effort in compliance research. Research in health behavior and of the dynamics of the doctor/patient communication have provided a broader understanding of what actually occurs in the medical encounter (Dye &

DiMatteo, 1995). The following section explores both affective and cognitive issues in relation to support for the ill.

Support for the Ill

Chronic disease has become the dominant form of illness and the major cause of disability (Bandura, 1997). Seeking information about the illness and planning are two strategies that have the most consistent relationship with positive outcomes. Furthermore, these strategies seem to have the greatest effect when the stressor is appraised by the patient as controllable (Petrie & Moss-Morris, 1997). Ideally, interventions should be developed for patients with chronic illness to more accurately match the coping strategy to the characteristics of the situation.

When teaching patients, many healthcare providers concentrate more on information concerning the illness rather than on the handling of treatment (Jacquemet, Lacroix, Perrolini, Golay, Assal, 1998). Enhancing self-efficacy through education may be critical to learning and performing certain healthcare routines. The treatment of chronic illness should focus on the self-management of physical conditions over time, (rather than on cure). This requires, among other things, pain relief, enhancement and maintenance of functioning with growing disability, and development of self-regulatory compensory skills. According to Bandura (1997) the more the self-management program enhances the patient's sense of efficacy to exercise control over health functioning, the greater the health benefits achieved.

In the follow-up of patients with chronic diseases, the healthcare provider assumes multiple roles; care provider for the illness itself, and educator to the patients and their families. They are thus implicated in interpersonal relationships, where the emotions and experiences of the patients must be considered and respected. After frequent visits for medical services, experience with treatment sessions, and self-examination, chronic patients progressively accumulate empirical knowledge; they acquire medical expertise, which the care provider should not ignore. The patient's expertise must be taken into account in any therapeutic relationship or pedagogy of interaction, and incorporated into all education programs for patients. The clinical process should be seen as a partnership, a collaboration between two individuals who have differing expertise but who enjoy mutual respect, share a desire for consensus, and seek a common goal of health improvement (Billings & Stoeckle, 1999).

Affective: Social and Emotional Support

Social and partner support plays an important role in adjusting to chronic illness (Petrie & Moss-Morris, 1997). A number of studies have shown social support to be related to improved disease outcomes and psychological adjustment in a variety of illnesses. Each chronic illness is comprised of a large number of stressors, and patients may apply different coping responses to each of these illness-related problems.

A large follow-up study of chronically ill patients found that social support was beneficial for health over time and that this effect was strongest in older patients (Sherbourne, Meredith, Rogers & Ware, 1992). Social support has been associated with ameliorated metabolic control in diabetes patients (Marteau, Bloch & Baum, 1987) as well as improved outcomes in breast cancer, (Waxler-Morrison, Hislop, Mears & Can, 1991) kidney failure (Dimond, 1979), and heart disease (Wiklund et al., 1988). Sometimes, however, support can be too intrusive and individuals may feel deluged with help or conflicting advice, which may actually result in negative outcomes. Helgeson and

Cohen, (1996) report that patients found emotional support to be the most helpful kind of support, regardless of which network member is involved, and informational support as helpful from healthcare professionals but unhelpful from family and friends. Factors related to the disease itself in terms of its stage and progression, physical characteristics, and symptomology are important to patients, both emotionally. and functionally. The next section reviews the importance of such information for successful illness management.

Cognitive: Informational Support

Informational support involves the provision of information used to guide or advise. A diagnosis of serious illness challenges the basic assumptions about the self and the world, and successful adjustment involves restorations of these assumptions (Taylor, 1983). Such a diagnosis may lead to a sense of personal inadequacy, diminished feelings of personal control, increased feelings of vulnerability, and a sense of confusion.

Supplying information can lead to perceptions of control by providing patients with ways of managing their illness and coping with symptoms. Learning how to effectively manage the illness may also enhance patients' optimism about the future and thus reduce feelings of future vulnerability. Informational support can also help to reduce the sense of confusion that arises from being diagnosed with serious illness by helping the patient understand the cause, course, and treatment of the illness (Helgeson & Cohen, 1996).

Helgeson and Cohen, (1996) reviewed the literature on the associations of emotional, informational and instrumental social support to psychological adjustment to cancer. They found that educational groups aimed at providing informational support appear to be as effective as, if not more effective, than peer discussions. The provision of information is a relatively simple task for trained healthcare professionals, yet it is a crucial ingredient for successful patient outcomes. Peck and Bowland (1977) illustrate just how valuable information can be; out of 50 patients undergoing radiation therapy, the majority of patients felt that their physicians had not prepared them for the treatment. In these studies, the lack of information was directly associated with unnecessary and irrational fears (Helgeson & Cohen, 1996).

Billings and Stoeckle (1999) highlight the sensitivities that physicians must consider when informing the patient. They recommend that physicians must be mindful and respectful of the potentially enormous discrepancy of medical knowledge between the health care provider and even the most intelligent, well-informed patient. The explanations that the physician delivers in a few minutes involve concepts the physician has learned over long periods of intensive study. To help their patients learn essential information, physicians must set aside enough time and try to keep the message simple. Unfortunately, physicians' explanations are frequently overloaded with elaborate discussions of pathophysiology, differential diagnosis and alternative approaches to illness management. These 'mini-lectures' reflect major preoccupations for some doctors, but may have little interest or use for most patients (Billings & Stoeckle, 1999). Physicians should use lay terminology, and focus on key points. They should keep in mind the patients ability to understand which may depend on their intellectual background, the complexity of the material, the limited time frame and the problem of learning new material in the potentially anxiety-ridden setting of the physician's office. When presenting large amounts of information Billings and Stoeckle (1999) suggest that healthcare providers lead off with key points, since the initial message is often the best retained. One should commence with a summary of the conclusions, putting forth the main message in a clear, brief, well-organized fashion. When communicating a complex message, the physician must assist the patient in organizing new knowledge and remembering it by explaining what kind of information they will be providing. A good explanation of patient's diagnosis, treatment and prognosis should refer to what the patient already thinks is wrong. The practitioner should acknowledge concordance as well as differences between the patient's attributions and the clinician's diagnosis (Billings & Stoeckle, 1999).

Medical settings, particularly physicians' offices, can and should be a major source of information for illness management and preventative behavior. There are advantages and disadvantages in using medical settings as sources of information; the advantages are that many people visit their physician at least once a year and respect healthcare providers as experts. The disadvantages are that these efforts take up precious time in an already busy practice and that some medical personnel may not know how to help individuals overcome the challenges they experience when following recommendations. One possible solution to this problem is to teach patients how to employ self-management techniques.

Self-Management

In medicine, the therapeutic education of patients requires that the patient be taught to manage his/her own treatment. Self-management refers to the behaviors that patients and their family members perform to lessen the impact of a chronic illness. It is not equivalent to compliance, but is composed of complex cognitive-behavioral skills including self-monitoring, decision-making, and communication about symptoms and treatment regimens (Redman, 1998).

Self-regulatory, self-control, or self-management capabilities represent a distinct human attribute. Not only do we react to external events, but we are also self-reactors with the capacity for self-evaluation and self-directed action. Self-regulatory capabilities allow us to exercise some control over our motivation and actions. The salient processes in the self-management of health problems according to Creer and Holroyd (1997) include: (a) goal selection, (b) information collection, (c) information processing and evaluation, (d) decision making, (e) action, and (f) self-reaction. Goal selection occurs only subsequent to systematic preparation; individuals must acquire sufficient knowledge of the illness or condition that is to be prevented or managed. Patient education provides the basis for self-management actions to be later performed by those patients. Once provided with relevant health information including the skills they need learn to manage their disease, specific individual goals must be identified that, if achieved, are likely to enhance the health and well being of the individual. Usually these goals are established collaboratively through consultation with healthcare professionals (Creer & Holroyd, 1997). Positive outcomes of goal selection include: establishing preferences about what is a desirable outcome; enhancing the commitment of individuals to perform goal-relevant self-management skills; establishing expectancies on the part of the patient that trigger effort and performance. Ideally, posit Creer and Holroyd (1997) individuals start to believe that in performing certain self-management activities, they can become partners with their physicians in managing their care, rather than remaining passive recipients of health care interventions. Goal selection however, is the only activity where there is true collaboration between patients and their physicians, concludes Creer and Holroyd (1977). Once goals are established, it typically becomes the responsibility of individual patients to perform whatever self-management skills are necessary to attain those goals. Physicians and other healthcare providers then typically limit themselves to tracking the individual's behavior.

Self-management approaches have adapted cognitive-behavioral and behavior modification techniques to the situation of chronic illness, and have borrowed heavily from other disciplines such as physio- and occupational therapy and nursing. Much of this work is grounded in Bandura's (1986) social cognitive theory. The underlying premise is that individuals affected by chronic illness can be enlisted to collaborate actively with healthcare workers in minimizing, if not outright controlling, disabling systems and treatment side-effects through the mindful use of cognitive and behavioral self-management skills (Devins & Binik, 1996). Unfortunately, one-trial interventions are rarely sufficient for long-term behavior change. The Stanford Arthritis Self-Management Program (ASMP) is a structured group program that exemplifies the self-management approach and is designed for long-term maintenance. The program consists of six weekly 2-hour group sessions, led by a lay leader (who has experienced the disease). Program components include information sharing (education), including features of the disease, prognosis and treatment, myth dispelling, orientation to self-management philosophy, exercise training, pain management, problem solving, joint protection, energy conservation, sleep hygiene, mood management, diet and nutrition, medications, and communicating and collaborating with physicians and other health professionals (Lorig & Fries, 1986). Contingency contracting and social support components are also utilized to enhance compliance and to provide encouragement in continuing to follow the program. Experimental results are impressive. Participants experience substantial improvement in a variety of clinical outcomes, including self-efficacy and psychosocial well being, and these persist for as long as 4 years following completion of the program. Fortunately, it is not necessary to master the entire set of self-management skills in the ASMP. Lorig and Fries (1986) assert that patient's enhanced confidence in their ability to perform self-management behavior skillfully (self-efficacy) is the single most important factor responsible for improvement (Devins & Binik, 1996).

The Doctor-Patient Relationship

The consultation between the patient and doctor lies at the heart of all medical practice (Weinman, 1997). The information transmitted during the consultation is very often critical in the formulation of diagnoses and in the organization of treatment. Thus, states Weinman (1997) effective communication is necessary to ensure that not only the patient's problems and concerns are understood by the physician, but also that relevant information, advice and treatment is received and acted upon by the patient.

Although most healthcare providers agree that relating information to patients is important, they grossly underestimate how much information they actually provide (Putnam & Lipkin, 1995). In one general practice study, (Waitzkin, 1984) physicians spent less than one minute in a twenty minute interview giving any medical information at all; yet they reported that they spent nine times this amount. The positive relationship between patient satisfaction and the perceived amount of information received by the patient is one of the most consistent findings in the literature (Stiles, Putman, Wolf & James, 1979; Putman & Lipkin, 1995). For instance, in a meta-analysis of all studies published through 1985, the mean correlation between satisfaction and information received by the patient was r = .33 (Hall, Roter & Katz, 1988). Medical information was also correlated with compliance (r= .16) and recall of medical regimens (r = .40). Putman and Lipkin, (1995) propose that in physicians haste to cure all their patients' ailments, they often forget that often all patients expect or desire is merely information.

Patients are unique learners; their ability to comprehend health instruction is often impeded by factors such as physical discomfort, anxiety and unfamiliarity with the hospital or clinic environment (Estey, Musseau & Keehn, 1994). Adding to this problematic situation is the fact that the healthcare provider must facilitate a technically competent interview with patients who may be in pain, frail, hard of hearing, visually impaired, or suffering from memory loss (Coulehan & Block, 1997). Furthermore, it is not unreasonable to assume that many patients find their level of arousal to be high during encounters with their physicians. Unfortunately, significant increases in arousal may decrease a patient's number of available cognitive resources, further impairing their attention and memory.

Many difficulties in medical care are neither technical, nor are they questions of competence, but are ones of communication. According to Hall, Irish, Roter, Ehrlich and Miller (1994) in the past decade we have gone beyond the perfection of technical standards to the ability of the health care provider to gather and give information using interpersonal skills. The capacity to show empathy, to counsel when needed, to ask questions about psychosocial functioning and to encourage and assist patients to participate in the clinical interview and subsequent decisions requires communication skills. Coulehan and Block (1997) emphasize that medical interviewing is a basic skill, which can be taught and learned. It is not a matter of common sense, nor does it come, necessarily, with experience.

The importance of the medical interview cannot be overestimated (Billings & Stoeckle, 1999) considering that approximately seventy percent of diagnoses are made on the basis of patient interviews. Primary physicians spend the largest part of their clinical time talking with patients; they generate most of their diagnostic hypotheses on the basis of the patient's history, and the most significant pieces of information arise from this dialogue (Coulehan, Block & Davis, 1997). Even in high-technology settings, such as university training programs, residents generally regard the medical history as having greater diagnostic value than either the physical examination or laboratory and radiographic tests (Coulehan & Block, 1997). The well-conducted patient interview will yield a large and valuable database on which to design an efficient diagnostic plan.

Effective patient education should be duly recognized as an integral building block in the entire health delivery process, of equal importance to clinical and technological advancements in the field (Cole, 1996). Recognizing the importance of patient education is the first step. The second step is learning techniques involved in the communication-interview process, which will enable the effective education, and motivation of patients, encouraging them to be active participants in their own health care.

For the chronically ill, relationships with healthcare providers can be a major source of difficulty in the management of their illness. The issue of patient autonomy versus independence from healthcare professionals is often an ongoing problem in long-term treatment programs (Petrie & Moss-Morris, 1997). Increasing patient participation in the management of chronic illness by promoting greater involvement in the medical interview has been shown to result in improved healthcare outcomes and quality of life. Petrie and Moss-Morris (1997) propose that further work is required in this complex domain to determine exactly which behaviors in medical encounters are critical in fostering participation.

An illustration of a situation in which effective communication is particularly valuable is prior to stressful medical procedures or investigations. There is now considerable evidence that the provision of clear sensory and procedural information about an impending procedure can be extremely beneficial (Weinman, 1997) in helping patients cope with the procedure as well as promoting better recovery.

Recent social and economic trends have brought about dramatic changes in the doctor/patient relationship. Many of today's patients are more informed and consumer-oriented than ever. Dye and DiMatteo (1995) conclude that although some health care providers may still believe otherwise, few patients expect or want to occupy the traditionally passive role. Patients are more satisfied with care and more successful in following the treatment when they feel that they have been actively involved in its design. Ideally, active patient involvement in the medical encounter occurs when consensus is achieved concerning the nature of the problem; specific roles in its treatment are delineated for both physician and the patient; realistic health goals are mutually defined; and methods of achieving these goals are agreed upon by both parties (Dye & DiMatteo, 1995). Encouraging patients to express their beliefs about the problem, and to share in responsibility for its treatment fosters an optimal outcome.

The most effective medical interview is one in which the health care provider directs their behavior toward eliciting and enhancing active patient participation in determining the diagnosis and implementing treatment. These behaviors enhance patients' satisfaction with the therapeutic relationship, increase the probability of a constructive rather than destructive exercise of control, and facilitate patients' assumption of responsibility for their health. Dye and DiMatteo (1995) stress that only by incorporating the patients perspective is optimally effective care accomplished. Given the tremendous importance of the physician's role in communication and patient education, one of the intervention groups in the present study was designed to have the ophthalmologist deliver information (via script) verbally to the patient.

Models of Health Behaviors

The Health Belief Model (HBM)

During the past two decades, considerable attention has been given to viewing patient noncompliance as a problem in health-related decision making, where the individual is guided by attitudes and beliefs that may operate independently of levels of information and objective features of the condition and the regimen (Cummings, Becker, & Maiman, 1980). Beliefs that have been found most consistently to produce significant relationships with compliance to health and medical care recommendations have been the components of the Health Belief Model (HBM) (Janz & Becker, 1984). The HBM assumes that a person's behavior is determined more by perceived reality than by the objective environment (Aiken, West, Woodward, & Reno, 1994). The model emphasizes four conditions that are hypothesized to precede an individual's decision to undertake a health action: (a) they must perceive themselves to be susceptible to the disease, (b) they must perceive the consequences of the disease to be severe, (c) they must believe that the health action to be taken will reduce or eliminate the threat of the disease, (e) they must perceive that impediments to taking the health action can be overcome.

The HBM was perhaps the first behaviorally oriented conceptual system in health education (Elder et al., 1994). The HBM posits that health behavior is a function of both knowledge and motivation. It emphasizes the role of perception of vulnerability to an illness and the potential effectiveness of treatment in decisions whether to seek medical attention.

Of all the existing models of health-related behaviors, the HBM has received the most extensive research attention, and has been applied to widely diverse populations, health conditions (acute and chronic), and recommended behaviors. A large body of evidence has accumulated in support of the HBM's ability to account for the undertaking of preventative health actions, seeking diagnosis, and following prescribed medical advice (e.g. compliance to regimens). Though the HBM specifies relevant attitude and belief dimensions, it does not dictate any particular intervention strategy for altering these beliefs (Janz & Becker, 1984).

Elder, Gellar, Hovell and Mayer (1994), who reviewed numerous HBM studies, were surprised by the lack of research examining the HBM as a complete model. Unfortunately, the vast majority of HBM-related research analyze the models constructs separately (Stretcher & Rosenstock, 1997). Stretcher and Rosenstock (two of the authors of the HBM) recommend that one test the HBM as a model, or, at minimum, as a combination of constructs, not as a collection of equally weighted variables operating simultaneously. They propose that it makes little sense to throw the HBM variables into a multivariate analysis, that is to select the "strongest swimmers" and to claim that these are the factors on which to intervene. The present study adheres to Stretcher & Rosenstock's (1997) recommendations and employs the HBM as a complete model, in its totality.

Self-efficacy

People have always striven to exercise control over events that affect their lives and well being (Bandura, 1997); by exerting influence in areas over which they command some control, they are better able to realize desired futures, and forestall undesired ones. According to Bandura (1997) people's level of motivation, affective states and behavior are based more on what they believe than what is objectively the case. Social cognitive theory is a useful framework for examining the determinants of behavior since it is based on reciprocal and dynamic relationships between environmental factors, personal factors (cognitive, affective and biological), and behavior (Allison, Dwyer, & Makin, 1999). Self-efficacy deals with cognitions of confidence, competence, and capability on the basis of past experience and other sources of information. It refers to an individual's belief in his or her capacity to execute behaviors necessary for specific performance attainments (Bandura, 1997). These self-evaluations influence the goals for which people strive, the amount of energy expended toward goal achievement, and behavioral performance (Forsyth & Carey, 1998).

Self-efficacy beliefs are hypothesized to vary depending on the domain of functioning and circumstances surrounding the occurrence of behavior. Measures that are consistent with self-efficacy theory (SET) should share three features: beliefs, behaviors and circumstances.

Stretcher and Rosenstock (1997) recently added the concept of self-efficacy (or efficacy expectation) to the HBM, in order to increase its explanatory power and enable it to become a useful tool for the practitioner. It should be a particularly good predictor of behaviors that require significant skills to perform. Outcome expectation, defined as a person's estimate that a given behavior will lead to certain outcomes, is quite similar conclude the authors, to the *perceived threat* and *perceived benefits* of the HBM (Self-efficacy is defined as the conviction that one can successfully execute the behavior to produce the outcome).

This construct is not without some methodological challenges. For example, self-efficacy and health risk-reduction associations may be influenced by ceiling effects, response bias, and measurement error, which are associated with self-report measures of risk behavior (Weinhardt, Forsyth, Carey, Jaworski & Durant, 1998). Measurement error remains a considerable challenge to the reliable and valid assessment of self-efficacy. Efficacy scores may be influenced by the tendency to respond in socially desirable ways. In health risk behavior research, just as certain potentially dangerous behaviors may be underreported, beliefs such as self-efficacy for risk reducing behaviors may be over reported. The assessment of response bias, specific to this domain, warrants increased attention according to Forsyth and Carey (1998). Since self-reported compliance measures are known to be subject to ceiling and floor effects, this model is unsuitable for the present study. The HBM was considered a more appropriate construct.

Theory of Reasoned Action

Reasoned action, according to Fishbein and Ajzen (1975) emphasizes the role of personal volition in determining whether a behavior will occur. In turn, this behavioral intention can best be predicted by expectations regarding the outcome of a behavior, other attitudes toward the behavior, and 'normative' beliefs with respect to what 'influentials' (i.e., peers) would do in this situation (Elder et al., 1994). It specifies the causal relationships between beliefs, attitudes, intentions and behavior. Sutton (1997) points out that the model assumes that most behaviors of social relevance (which includes most health-related behaviors) are under volitional control, and that the intention to perform a behavior is both the immediate and the single best predictor of that behavior. Intention is held to be a function of two basic determinants, one personal, and one reflecting social influence. The personal factor (attitude) is the individual's positive or negative evaluation of performing the behavior. The second determinant represents the perceived expectations of important others with regard to the behavior in question, (referred to as the subjective norm). As a rule, people will have strong intentions to perform a given action if they evaluate it positively, and if they believe that important others think they should perform it (Sutton, 1997). In short, behavioral intentions and, hence behavior depend ultimately on beliefs concerning (a) the possible consequences of performing the behavior and (b) the expectations of important others. It follows that, in order to change behavior, it is necessary to change these underlying beliefs. Unfortunately, many health behaviors cannot simply be performed at will; they require skills, opportunities, resources, or cooperation for their successful execution.

Sutton (1997) concludes that the theories of Reasoned Action and Planned Behavior appear to be best suited for studying one time or occasional behaviors (e.g. inoculation) rather than frequently repeated behaviors, like those required to follow medical regimens. Hence these theories were not deemed suitable for the present study which examines long, rather than short, term behaviors.

The conceptual framework underlying each of these three theories has been shown to be quite similar. The decision to adopt a new behavior is based on an analysis of the relative costs and benefits associated with various courses of action. The main difference between these theories is captured in the particular set of beliefs that is predicted to be most closely associated with a decision to take action (Rothman, 2000). Researchers have used these theoretical models to explain why individuals adopt healthy or unhealthy behavioral practices, and they have relied on the specifications of these models to design health behavior interventions (Rothman, 2000).

Behaviorist/Behavior Modification

Elder, et al. (1994) state that proper health behavior may be absent for one of three reasons: (a) lack of adequate knowledge, (b) lack of adequate motivation, and/or (c) lack of adequate skills to perform the required behavior. The field of behavior modification is aimed at the latter two categories, motivation and skills. The behavioral model, however, is not without its limitations in that behavior refers primarily to the observable performance of an individual that can be objectively defined (Elder et al., 1994) and remedied based on various contingencies of reinforcement. For long-term chronic illness, especially asymptomatic illnesses such as glaucoma and heart disease, the motivation may have been present at the onset of the illness, but has waned over time.

This is particularly important in these types of illness since, as we have seen earlier, what little reinforcement exists, is primarily negative due to the side effects of medication.

Unlike models of health behavior such as the HBM, social learning theory and other theoretical approaches, behaviorism de-emphasizes unobservable processes such as emotions, attitudes and knowledge. These variables are thought to be very subjective and, therefore, difficult to measure scientifically. Instead, behaviorists focus on specific behaviors or their products, which can be objectively observed, or measured. (It is much easier to measure attendance at a health clinic than attitudes about the clinic.) Unfortunately, behavioral based interventions often fail; perhaps the problem lies beyond the reach of observable behavior. If the patient knows how to manage the illness, and has the required skills to do so, and still fails to undertake the desired behaviors, further explanation is required.

Theory driven health education programs and interventions require an understanding of the components of health behavior theory, as well as the operational, or practical, forms of the theory. Health behavior change programs include, but go beyond, more traditional health educational approaches to changing knowledge and attitudes. Educational objectives help to establish the cognitive, affective, and psychomotor endpoints we hope to reach with health promotion interventions, and thus, guide the development of our intervention strategies. Fundamental to all intervention approaches is the need to establish specific goals and objectives, which allow us to know not only where we are headed, but also when we get there.

Patient Education Across Illnesses

Patient education efforts have traditionally focused almost exclusively on providing information about (a) the causes, course and progression of a condition, (b) nutrition, medication, and treatments, including an outline of intended treatment and common side-effects and (c) the treatment setting, health care providers, financial issues and the available social services (Devins & Binik, 1996). Educational media can take many forms such as short courses, lectures, discussion groups, films, video or audio tapes, written materials such as booklets, or pamphlets, and more recently, computer software, and the internet. A growing body of evidence supports the value of patient education to facilitate adaptation to, and management of, chronic illness. Although Binik, et al. (1993) propose that the majority of studies have failed to evaluate the effectiveness of educational interventions directly; several studies have demonstrated that such efforts are capable of ameliorating illness-related knowledge. Research has begun to test the assertion that the provision of illness and coping related information can result in improved psychosocial outcomes (Devins & Binik, 1996). Devins and Binik's literature review concludes that even simple, minimal contact interventions such as an introductory letter to new clinic attendees has been shown to enhance patients' appraisals of their potential to influence the recovery process (Johnston, Gilbert, Partridge & Collins, 1992), a required ingredient for successful outcomes.

Patient education involves a process of training that must, like all treatment procedures, be shown to be efficient. There is no simple blueprint that educators may utilize to achieve this efficiency. At one end of the spectrum, teaching dispensed is based on informative tendency; transmission of knowledge, medical information on the disease, and monologue. This unidirectional flow of information is not uncommon when healthcare providers transmit medical information to patients. The patient is expected to be the passive recipient of information, whereas the physician is the active dispenser of information. Alternatively, at the other end of the spectrum, teaching is oriented towards encouraging training and learning processes; problem solving, exchange of knowledge and experience, and debate (Jacquement et al., 1998). Therapeutic education looks at both the achievements and difficulties encountered by patients in the management of their treatment. The interactive sharing of implicit theories and experiences corresponds well to the structure of the adult learning process, as opposed to the notion of transmitting knowledge from expert to neophyte (Jacquement et al., 1998).

Learning theory (Bouton, 2000) and preliminary evidence from health behavior research suggest that long term maintenance of behavior change may be facilitated by a number of factors including: (a) situating the learning in the most relevant contexts, (b) providing retrieval cues after new learning is complete, and (c) varying the context in which the new learning takes place. Real life thinking is done in context, and a good learning environment provides a believable context for learning. Modern educational theory stemming from research in the cognitive sciences indicates that knowledge gained through activity that is motivating and authentic is learned more deeply and is more useable than knowledge gained through memorization, prescriptive activities, or word problems (Kolodner, 1997) An important prerequisite to deep and effective learning this research tells us, is knowing why one needs to learn something.

Glaucoma Education

Glaucoma patients should be made aware of their disease and its potentially serious consequences without creating undue apprehension and fear (Shields, 1992). The information provided must be clear enough for them to understand. It should include an explanation of what glaucoma is, that they do, indeed, have glaucoma, that glaucoma can lead to total, irreversible blindness, but that blindness can be prevented with proper treatment (Shields, 1992). Surprisingly, it is not unusual for patients who have been taking anti-glaucoma medication for years to still to be unaware that they have glaucoma (Shields, 1992). Some patients fail to relate their disease to blindness, while others may live in daily fear that they will inevitably go blind (Shields, 1992). In a study of glaucoma patients by Vincent, patients were informed that, if they did not take their eye drops as instructed they would go blind. The results were unsettling; 58% of patients still did not adhere to their treatment regimen. Even when these patients had started to experience significant visual loss in one eye, compliance improved only by an additional 16% (Weinman, 1997).

Information cannot change behavior unless it is received and understood, retained and believed, and then acted upon. One problem that is frequently overlooked is that the complexity of educational materials used in many medical settings far exceeds the powers of comprehension of the intended audience (Carr, 1990). Davidson and Akingbehin (1980) argue that explanatory pamphlets that are written by clinicians are too difficult to understand for most patients, who have no elementary technical or medical knowledge. To ensure adequate comprehension, educational material should be designed at a level suitable for the comprehension skills of the average seventh grade student (Estey, Musseau, & Keehn, 1994).

Even if we could ensure that patients adequately comprehend materials, Sumartojo's (1993) research in compliance concludes that education alone is not a highly successful intervention. A major difficulty here is that evaluations normally examine education in combination with other interventions so that the independent effect of education cannot be measured. Sumartojo (1993) feels that the best educational interventions instruct patients in ways of changing their behavior rather than simply providing information about their disease. A theoretical model of behavior change predicts that educational interventions will be effective only when patients are convinced that they need to alter their behavior and are open to new information on what is required of them (Sumartojo, 1993).

Kass et al., (1984) propose the following strategies to increase compliance: (a) increase patients' knowledge of the disease and its treatment by discussions, written material and audiovisual presentations, (b) reduce patient error by providing clear verbal and written instructions, (c) tailor the regimen to the patient by reducing its complexity, selecting medications with the fewest side-effects, reducing barriers to follow-up and integrating the treatment into the patients' daily routine, (d) use behavioral approaches such as external cues, positive or negative rewards, and, (e) encourage greater participation of the patient in decisions concerning the treatment. Unfortunately, simple interventions rarely produce long-term changes in patient behavior. A combination of strategies repeated at specific intervals throughout treatment seems to offer the best chance of reducing noncompliance (Ashburn, Goldberg & Kass, 1980; Kass et al., 1984).

Becker and Maiman (1980) emphasize that health related behaviors are multicausal and that education strategies should attempt to influence at least three classes of determinants, that is, motivational, enabling and reinforcing factors. The video intervention employed in the present study was designed to influence each of these three determinants.

When learners actively construct meaningful mental representations from presented information, this is known as constructivist learning. Within the context of our video learning environment, active construction processes include selecting relevant phrases and image sequences concerning glaucoma and its treatment, organizing them into coherent causal chains of the steps required to mange glaucoma (internal connections) and integrating them with one another and with relevant prior knowledge (external, or referential connections) (Mayer, Moreno, Boire & Vagge, 1999). Learning outcomes were evaluated by various measures including the understanding of glaucoma, its causes, treatment and management.

Interestingly, some of the ophthalmology literature suggests that compliance with ocular therapy depends, to some degree, on the ability to instill eye drops (Kass, 1994). In a study of 100 glaucoma patients, Apt, Henrick and Silverman (1979) found that 63 of the 100 patients did not shake their bottles of medication as required, despite being asked to read the label on which was typed, in red letters, “Shake Well”. Of the 37 patients who did shake the bottle, 18 (48.6%) did so fewer than ten times. Hence, they received less than half of the maximum concentration of the four drugs used in the study (Apt et al., 1979). Considering these findings, it seems reasonable to assume that videotapes, which visually instruct the viewer on how to properly instill eye drops, will prove to be an instructive educational intervention.

The Role of Memory in Illness Management

The most common complaint patients make about their medical care in both the United States and Britain is that they are not well enough informed by their physicians (Stewart, 1995). Even when doctors do provide information, there is a resulting dichotomy. The information related is neither remembered nor understood by approximately half the patients (Ley, 1983; Stewart, 1995). In a synopsis of three separate investigations, the percentage of general practice patients who did not understand what they were told about their diagnosis varied between 7% and 47% (Ong, DeHaes, Hoos, & Lammes, 1995). Between 13% and 53% of these patients did not comprehend what they had been told about the prognosis of their disease.

In any medical setting, some patients will not understand what is expected of them, and these patients naturally have much higher rates of nonadherence than do others. Poor recall is part of the problem (Esposito, 1995). Studies have shown that after five minutes patients forget about half of the doctor's instructions and remember best the material in the first one-third of the presentation (Becker, 1990; Davidson & Akingbehin, 1980). Further, they recall the diagnosis better than the prescribed therapy. These findings suggest that the physician should speak briefly and selectively, emphasizing the information necessary for compliance clearly and early in the interview, then repeat that information, both verbally and through written instructions to which the patient may later refer. A combination of oral and written instructions results in the highest level of patients' information retention (Becker, 1990).

Numerous studies confirm that patients remember only 29% to 72% of what doctors tell them and, the more information presented, the lower the recall rate according to Houts et al. (1998). In Hughe's (1993) study of cancer patients, subjects were only able to recall a relatively low percentage of previously conveyed information. 48% of subjects who selected lumpectomy could recall only 1 of 13 possible information items presented during the clinic visit. The recall ability of the mastectomy group was similarly poor, with 66% unable to recall a single item, despite the fact that most subjects were presented with 10 information items pertaining to the mastectomy option. Both groups were unable to reiterate the risks associated with either treatment choice: 50% of the lumpectomy group and 66% of the mastectomy group could not properly identify a previously enumerated risk. Patients' recall of information around the time of diagnosis is exceedingly poor. Their ability to restate key aspects of various treatment alternatives was minimal, and identification of treatment risks was virtually nonexistent, despite the fact that such information had been conveyed (Hughes, 1993). The fact that this well-educated group of patients displayed such poor recall was of concern to Hughes (1993).

Houts et al. (1998) hypothesized that when information about managing cancer symptoms at home is presented orally accompanied by pictographs, and the same pictographs are presented during recall, memory will be greater than when the same information is presented without pictographs. Pictographs add a visual dimension to learning; a page of pictographs with written instructions on the refrigerator door may attract more interest and attention than a page of writing alone, thereby facilitating frequent reviews of instructions and increasing the likelihood they are carried out as directed. All of Houts et al.'s (1998) subjects had higher recall with pictographs than without, and the lowest recall score with pictographs (55%) was higher than the highest recall score without pictographs (32%).

These results illustrate how pictographs can improve short-term memory of medical instructions; for many subjects, the recall rates were close to perfect with their usage. In Houts et al. (1998) study, learners had to remember between 38 & 50 pieces of information per symptom. In reality, people with serious illness frequently have multiple symptoms. For pictographs to be clinically helpful, numerous pieces of information may have to be recalled with a high degree of accuracy (Houts et al., 1998). This study tested only short-term memory; in clinical situations, family caregivers and patients must remember instructions for periods from days to years. Research has shown that 'retrieval cues', such as pictures, enhance long term memory, but the degree to which pictographs enhance long-term memory of medical instructions has yet to be determined (Houts et al., 1998). Given the success of pictographs, one of our intervention groups employed two pamphlets containing textual instruction combined with multiple pictographs.

In terms of memory enhancement, simply allotting more time spent processing information is not the solution. As long as information (Wolfe & Schirm, 1992) is processed at the shallow, non-semantic level it is unlikely to produce a more durable memory than a short time processing at a semantic level (Best, 1991). Our memories are not controlled by our intentions but rather by the mode of processing. The schema, which is basically an organized cluster of generic knowledge, is retrieved initially and is used to guide the collection of additional, specific facts. Ald & Hasher (Best, 1991) propose that the final result of the encoding process is an event they call 'integration' in which a holistic, unified, mental representation is created, incorporating aspects of the stimulus, its context and previous knowledge.

The representation of information in memory is a difficult and abstract concept, because of the way it is stored and the manner in which it is used for a particular purpose. Cognitive psychologists think of meaning as the way a concept is embedded in a web of related concepts. A concept has a deep or rich meaning when it has many connections to other concepts (Halpern, 1998). When activated or brought to consciousness, a concept may act as a recall cue for the related concepts to which they are connected. One way to promote effective organization is through the use of elaboration, which develops interconnected knowledge structures. Halpern (1998) posits that the greater the number of connections to information stored in memory, the greater the likelihood that it will be recalled. When an individual elaborates a concept many meaningful connections are formed. That is, the concept becomes related to other relevant concepts. An effective technique for elaboration, according to Halpern, (1998) is the use of thoughtful questions that require the learner to create the necessary connections. This is a good technique because recalling a fact or a concept is not equivalent to learning it. The best way to ensure recall is via meaningful practice with feedback. The questions used to develop connected knowledge structures need to be drawn from the real-world contexts that are frequently encountered in everyday life. This requirement ensures face validity and will be consistent with the principals of situated cognition (Halpern, 1998).

Reflection is needed to promote analysis and the encoding of experiences in ways that will make them useful and accessible in the future at opportune times. Although it is impossible to encode experiences in ways that will guarantee they will be retrieved at the appropriate right time, research on memory retrieval from both artificial intelligence (Kolodner, 1983; Shank, 1982), and psychology literature suggests that one can enhance the ability to recall by anticipating the situations in which a lesson learned might be usefully applied. Kolodner (1998) sites Ross (1986,1989) who showed that when people learn a new skill they often refer back to previous problems in order to refresh their memories.

Aging and Memory

It is projected that by the year 2000, 35 million Americans will be over the age of 65; by the year 2030 this number will increase to 64 million (Esposito, 1995). About one third of the 1.5 billion prescriptions written annually are for people older than 65 (Wolfe & Schirm, 1992). As the age distribution of the population shifts upward, the health care and medical concerns of the elderly assume greater importance. Of particular interest to researchers and healthcare providers is the use of medication by the elderly, who show a disproportionate pattern of drug use relative to the general population (Isaac & Tamblyn, 1993). Recent studies have tried to link cognitive status in elderly patients with abilities that are believed to be necessary to accurately administer medication. Accurate recall of instructions printed on the pill bottle label has been the main focus of both observational and intervention studies. The results show better recall of medication instructions among subjects with higher scores on tests of general literacy and those subjects provided with prompts, reminders, and mnemonic strategies for remembering highly organized prescription information.

When examining the various issues in compliance and cognitive functioning, Isaac and Tamblyn (1993) found support for the theory that not all dimensions of memory change equally. There is some disagreement in the literature about whether verbal or visual memory skills are more vulnerable to age related decline. The literature proposes that older patients are at a disadvantage in terms of drug compliance because prescription information is typically delivered verbally (spoken or written) and the elderly are most susceptible to impairment in visual abilities; however, Isaac and Tamblyn (1993) disagreed. They concluded that the ability to understand, recall, and plan medication consumption may not be mediated simply by verbal skills. Visual perception and visual memory may be important components of medication management in elderly patients as well. Some patients appear to recognize and recall their medication primarily by shape and color rather than by name and dose. Their findings suggest that attention/ concentration; visual and verbal memories are all related components in accurately following medication regimens and instructions.

Any discussion of the myriad components of memory must also, however, take into account the curious phenomenon of forgetting.

Forgetting

Failure to recall events and instructions in the healthcare domain is not an unusual occurrence and may carry grave consequences for the patient. The most common explanations for forgetting are (a) failure to encode, (b) failure to retrieve, and (c) interference (Driscoll, 1994). Failure to encode infers that the information sought during retrieval was never learned in the first place. Failure to retrieve information that has been encoded in memory refers to the inability to access previously learned information. (Dual code theory would propose that the more often encoding cues are generated in both the verbal and imaginal systems, the more likely retrieval will be facilitated.) Interference means that other events or information get in the way of effective retrieval. An example of retroactive interference is that when one reads this chapter and the next, one may have difficulty recalling information from the former. Later learning interferes with the recall of earlier learned material, especially as practice on the later material increases (Driscoll, 1994) Information learned later is more recent, and is likely to yield stronger memory traces than information learned earlier.

Proactive interference occurs when previous learning interferes with later learning. The degree of interference is related to the amount of practice on the original task. Proactive interference has been demonstrated in the learning and memory of verbal materials with aging adults (Driscoll, 1994). Rice and Mayer (1985) looked at "memory deficits" among older adults. They investigated the premise that older adults remember less from prose passages than do younger adults. They concluded that older adults, because they had so much more experience and prior knowledge, tended to get caught up in the details of the passage and lose sight of the main ideas they were to recall. When main ideas were signaled, however, the effects of the interference were averted, with older adults remembering as much as younger readers. Fry (1992) suggested that visual displays of how the subject matter is structured and how concepts are related provides useful encoding and retrieval cues for older adults. Because problems in learning and memory in adults seems to be a function of declining speed rather than declining mental powers, allowing adults to work at their own pace is a helpful instructional strategy (Driscoll, 1994). Thus, sending patients home with educational material, such as pamphlets and videos, provides these individuals with the opportunity to repeatedly review the materials at their convenience.

Interventions

Cognitive/Behavioral/Educational

A number of successful intervention strategies have recently been developed for patients suffering from chronic illness. These programs vary in their focus from being strictly information based to teaching specific skills that help address problems faced by the patient (Petrie & Moss-Morris, 1997). Treatment programs also differ in terms of the degree to which they have been theoretically derived from the coping/educating literature.

To facilitate coping with chronic illness, cognitive-behavior therapy proposes that it is the *interpretation* of illness-imposed stressors and constraints that produce psychosocial threats and adaptive demands. It is also the individual's response to this appraisal that determines whether the psychosocial consequences of coping effort will be positive or negative (Devins & Binik, 1996). Cognitive-behavioral therapy focuses on problematic appraisals, such as irrational beliefs, cognitive errors, and coping skill deficits that are believed to account for difficulties in adapting to life with a chronic illness (Devins & Binik, 1996). Cognitive reframing involves restructuring a potentially threatening situation into a challenge, so that it creates opportunities and motivates patients to respond adaptively.

Successfully managing chronic illness requires more than the initiation of behavioral changes; it requires the maintenance of these modifications. There is considerable evidence that behavioral initiation is positively related to the individual's beliefs about both the likelihood and the value of future outcomes (Bandura, 1997). Furthermore, interventions that emphasize the desirable consequences afforded by a new pattern of behavior have had considerable success generating changes in behavior (Rothman, 2000). Given the role that expectations play in the process of behavior initiation, individuals are likely to hold clear expectations about what a new pattern of behavior will provide. To the extent that people's experiences meet or exceed their expectations, they will be satisfied with the behavior and be motivated to maintain it. However, when individuals' experiences fail to meet their expectations, they will be dissatisfied with the change in behavior and less motivated to sustain it. An important implication of this framework is that interventions that heighten expectations about a new pattern of behavior may encourage the initiation of change. However, over time they may lead people to be less satisfied with the outcomes they actually attain, thus undermining health behavior maintenance (Rothman, 2000).

Behavior change, posit Grueninger, Duffy and Goldstein (1995), typically occurs in the following five domains: (a) cognitive, (b) attitudinal, (c) instrumental, (d) planning and coping, (e) and social support. Interventions targeted at these five domains have assisted patients in moving forward through the cycle of learning and change. In the cognitive domain, the explanations of healthcare providers, directed reading, audio and videotapes, and lectures can foster patients' awareness and comprehension of problems (Grueninger et al., 1995). In the attitudinal domain, the healthcare provider can clarify patients' beliefs, worries, and personal motivations; assess patients' readiness to change; and build patients' commitment to change via discussion, feedback and negotiation. In the instrumental domain, the healthcare provider can build patient's skills in respect to optimizing and managing health. Successful coping with forthcoming difficulties involve the observation of demonstrations by the physician, and/or the performance of required behaviors and skills through trials and role-playing. The clinician can reinforce the skills required by having patients perform them repeatedly, and through providing immediate feedback (Russell, 1986). In the planning and coping domain, patients prepare to adopt and maintain new behaviors in their daily lives via planning reminders, incentives, rewards, self-monitoring procedures, and the anticipation and solution of problems. The healthcare provider can support the patient's efforts through specific counseling techniques such as improved self-efficacy, assertiveness training, and behavior modification (Russell, 1986). In the social support domain, patients need to identify and mobilize support in their environment in order to maintain new behaviors and to prevent relapse. It has been well established that environmental support and resistance are strong determinants of successful behavior change (Grueninger, et al., 1995). Patients can find this support, (or resistance) from the healthcare provider, a partner or family member, support and self-help groups.

Educational interventions can help to restore the patient's loss of control by providing information about the cause, course, and treatment of the illness and by teaching ways to manage the illness and its side effects. Because of their expertise, healthcare professionals, not peers, are the most effective and accurate sources of information about the disease, its course, treatment, and side effects. Educational interventions have the potential to provide meaning for the experience, restore self-esteem, and instill optimism about the future (Helgeson & Cohen, 1996). The education component of treatment is an integral part of contemporary psychological management and serves to engage the patient as an active collaborator in the process of disease treatment (Morley, 1997).

Description of Study One

Many healthcare providers acknowledge that health education is a process necessarily linked to health behavior, but most still do not give priority to health education. Interventions must be preceded by behavioral and educational diagnoses, since most health problems elicit some behavioral response on the part of the person experiencing them. The present study proposed that more attention should be devoted to both monitoring and motivating the patient along the HBM dimensions. The degree to which a provider can modify health beliefs is more difficult to assess than the extent to which more (and better) information can be transmitted or characteristics of the regimen changed. Nevertheless, research has demonstrated that these attitudes and perceptions can be altered (Becker & Maiman, 1980; Stretcher, McEvoy-DeVillis, Becker & Rosenstock, 1986).

This project investigated whether educational interventions correlated with improved medication compliance. Specifically, the study addressed the issue of which mode of instruction, videotape, pamphlets, or verbal instruction is associated with ameliorated compliance. Is a clearer picture painted when viewing a videotape depicting a glaucoma 'patient' tackling difficulties common to all glaucoma patients? Is information presented in this format more salient, easy to identify with and process? Or do patients learn more by reading concise information about glaucoma, as presented in pamphlets? Since it is known from the literature that the patient-provider relationship is a major factor in noncompliance, perhaps information delivered by the physician himself would have the strongest impact. We know that learning tasks, like real-world tasks, should be rich in information. However, some of the information available may not be relevant, and part of the learning exercise involves deciding which information is essential. The learner's use of information is a critical issue in both teaching and learning. Learning exercises should focus on the critical aspects of problems and their potential solutions. This requires thoughtful analysis, synthesis, and is facilitated through the repeated use of authentic materials, or materials that are similar to real-world situations (Halpern, 1998).

Research Questions: Study One

The utility of the HBM to compliance behavior was assessed due to the recognition that increased knowledge does not necessarily equate to an increase in compliance, and that, when it does, the effects may be transient. Since glaucoma patients must take long-term medication, it was expected that a shift in health beliefs would be required for an enduring change. It was hypothesized that compliance would improve in the long-term only if a significant change in health beliefs also occurred. Knowledge scores were expected to increase in the short-term but reduce over time to a midpoint between pre- and post-test levels.

The present study was undertaken to explore the relationship among medication compliance, knowledge, and health beliefs. These three variables, as measured by scores on questionnaires, were assessed before and after glaucoma educational interventions. Three interventions were designed to provide information to the subjects (a) verbally by the ophthalmologist, (b) via videotape, or (c) in pamphlets. It was hypothesized that these interventions would result in an improvement in scores from pretest to posttest compared with the control group, who proceeded with their regular check-up without further intervention. It was also expected that scores on each variable, compliance, health beliefs and knowledge, would change over time, with an improvement at day 2, and a decline towards baseline by day 30. Finally, it was hypothesized that there would be an interaction between the mode of intervention (video, pamphlet, verbal) and dependent measures (compliance, health beliefs, and knowledge), over time (pretest, posttest day 2, posttest day 30).

Description of Study Two

This second study builds upon study one and investigates the relationship between visual field loss and medication compliance, health beliefs, and knowledge. Specifically, do levels of visual functioning/impairment correlate with measures of health beliefs, compliance and knowledge prior to interventions? Do levels of visual functioning correlate with improved measures following one particular mode of intervention as opposed to the alternatives? Do patients with poorer vision respond better to information concerning their illness; are they more eager to learn, as a result of deteriorating eyesight? Perhaps patients with minimal visual impairment have not yet lost their motivation to comply. This scenario could be seen in two ways: if the visual loss is minimal, patients may not feel threatened and, hence, would be less willing to take preventative action by strictly following their regimens. Conversely, the fact that they have minimal visual field loss may provide reinforcement in terms of self-efficacy rendering them more receptive to interventions that provide illness related information. In other words, does more severe visual impairment relate to enhanced or diminished measures of health beliefs, compliance and knowledge?

Greater visual loss may infer less positive reinforcement. It also results in more time for medication side effects to take hold, and lessens the sense of control or self-efficacy. Un fortunately, despite following their regimens, some patients will continue to lose vision. Are these patients less or more likely to be amenable to educational interventions? The HBM proposes that patients' own perceptions of susceptibility, severity, benefits and barriers will determine the level of preventative action and adherence to medication regimens. Will we find that patients' who had higher scores on the HBM questionnaire, are also the ones who have experienced more visual loss?

Self-efficacy theory would suggest that patients who have fairly good vision are likely to feel more confident, competent and in control of their illness and its regimen. The patient's success at managing their treatment serves as a form of self-reinforcement.

The Theory of Reasoned Action states that people are more inclined to perform a given action if they evaluate it positively and if they believe that important others think they should perform it. Levels of visual functioning may effect these subjective evaluations. For example, perhaps the less vision lost, the more positive the evaluation, or conversely, the greater the visual loss, the less positive the evaluation. In respect to the second component in Reasoned Action regarding the opinion of important others, it seems reasonable to assume that as the patients vision deteriorates, both family members and physicians will increasingly value the importance of management behavior.

Will patients who had higher scores on each of the three dependent measures, health beliefs, compliance and knowledge, also be the ones who experienced greater visual loss, or vice versa?

Research Questions: Study Two

Three research hypotheses are examined in study two. First, measures of visual functioning are expected to correlate with measure of patients' health beliefs, medication compliance and glaucoma knowledge. Secondly, measures of visual functioning should be correlated with changes in scores over time, from pre to post tests. Finally the patients' level of visual functioning is expected to correlate with an improvement or a decline in scores in one particular intervention group over another.

CHAPTER 2

Methodology: Study One

Subjects

Participants were 36 male and 24 female patients diagnosed with chronic open angle glaucoma. Subjects ranged in age from 31 years to 79 years with an average age of 55. Criteria for inclusion was fluency in English or French and visual acuity better than legal blindness (> 20/200 or 6/60). These subjects were patients of a glaucoma specialist at the Sir Mortimer B. Davis Jewish General Hospital. A total of sixty patients were randomly assigned to each of the four conditions (film, pamphlet, verbal, control) resulting in 15 patients per group.

Materials

In the film intervention group, the materials used consisted of a videotape cassette titled " Sight Unseen: Blindness and You, A Patient Education Video on Glaucoma" (Motolko, 1996). In the pamphlet group, two published glaucoma information pamphlets entitled 'Understanding and Treating Glaucoma' (Peters, 1996), and 'Glaucoma, It can take your sight away' (Canadian Ophthalmological Society, 1989) were utilized. In the doctor group, the ophthalmologist followed a script designed to duplicate the main points covered in the video and in the pamphlets (see Appendix A).

A review of the literature did not reveal a questionnaire that specifically measured health beliefs, levels of knowledge or compliance with glaucoma regimens. Nor were there any validated general questionnaires, which could be used across different diagnostic categories. Therefore, three questionnaires were developed from a review of the literature on glaucoma and other similar chronic, asymptomatic diseases such as diabetes, and hypertension.

In addition to the interventions, three questionnaires were administered to test beliefs about health, general knowledge of glaucoma, and medication compliance. These three questionnaires were created for the purpose of this research. No existing tests for this field existed thus based on an extensive literature review and examination of tests in other chronic disease categories.

Knowledge Questionnaire (see Appendix B).

This scale was compiled to duplicate the major points covered in the glaucoma video. The questionnaire and the videotape were circulated to glaucoma specialists at three different hospitals for their comments and recommendations. The amended questionnaire contained 23 true/false items. Following item reliability analyses, 7 items were dropped from the questionnaire due to the questions having little variance and low correlations in contributing to the questionnaire as a whole. The final scale yielded a Cronbach's alpha coefficient of reliability of .73. Responses were scored as correct (2 points) incorrect (1 point) yielding a total ranging from 16 to 32, with higher scores signifying better knowledge.

Compliance Questionnaire (see Appendix C).

This questionnaire was modeled after the medication questionnaire validated by Marquis, Ware and Relles (1979), in their report to the U.S. Department of Health and Welfare on measures of diabetic patient knowledge, attitudes, and behavior regarding self-care. A glaucoma specialist reviewed the questionnaire and provided recommendations. The amended scale contained 14 multiple choice questions. Following item reliability analyses, 4 items were dropped from the questionnaire due to no variance or low correlations. The final scale yielded a Cronbach's alpha coefficient of reliability of .78. Possible total scores ranged from 14 to 27, with higher scores signifying higher compliance.

Health Belief Model Questionnaire (see Appendix D).

This questionnaire was a modification of Bradley's (1994) Health Belief Model Scales. Bradley developed the scale using health beliefs about diabetes. Only minor modifications to the wording of Bradley's validated scale were made, such as the substitution of the word 'diabetes' for the word 'glaucoma'. The scale contains 32 questions on a five point Likert scale with endpoints of 'strongly agree' and 'strongly disagree'. Following item reliability analyses, the questionnaire yielded a Cronbach's alpha coefficient of reliability of .82; thus, no items were dropped. Possible total scores ranged from 0 to 128, with higher scores indicating higher perceived susceptibility, lower perceived barriers, higher perceived benefits and higher perceived severity.

Procedure

The study was approved by the ethics committee at the Sir Mortimer B. Davis Jewish General Hospital (see Appendix E). Glaucoma patients were approached while waiting at the hospital for an appointment with the ophthalmologist, were informed of the purpose of the study and asked for their voluntary participation. Individuals who agreed to participate were assured of confidentiality, and their written informed consent was obtained (see Appendix F). The subjects were then escorted to another room where they were instructed to answer every question on each of the three questionnaires. The sixty participants, through random assignment, entered one of the three intervention groups or the control group, resulting in fifteen patients per group. Following the pretest, the research assistant verified that all questions had been answered, and then directed the subjects to one of the three interventions. One group watched an 18-minute glaucoma video; a second group read two glaucoma information pamphlets; and subjects in either the doctor or control groups were returned to the waiting area outside the ophthalmologist's examining room. For the 'doctor intervention', a script to be followed by the ophthalmologist was inserted into the patient's file. The control group proceeded as usual with their appointments. The experimenter was blind to the patients' group assignment and, apart from the script intervention, the ophthalmologist was not aware of the treatment condition for any given patient. In fact, he did not know which of his other patients were, or were not, involved in the study and proceeded with his workday as usual.

Before leaving the hospital, subjects were given an envelope containing the first set of post-test questionnaires. They were requested to open the envelope and complete the questionnaires in two days, when they would be called and asked to read their responses over the telephone.

Approximately three weeks later, all participants were sent a letter thanking them for their participation and containing the final set of questionnaires for completion. The final post-test data were collected 30 days following the hospital appointment. This was done over the telephone in the same manner as the two-day post-test.

The questions in each of the questionnaires were presented in different orders upon each administration. This was an additional measure to ensure that the patients had actually read and responded to each question on each questionnaire at each posttest condition and had not simply read off the same responses from the previous questionnaires.

Methodology: Study Two

Subjects

Participants and parameters were identical to those in study one.

Materials

Glaucoma and the Humphrey Visual Field Analyzer

The purpose of visual field testing is to provide information critical to diagnosing and monitoring the progress of ocular diseases, especially glaucoma. Visual field testing can lead to early detection and treatment of the disease. In the case of glaucoma, this testing plays a major role in identifying visual field defects and in evaluating the effectiveness of therapies used to control the disease process.

When evaluating visual performance, clinicians are primarily interested in two retinal functions: resolution and contrast sensitivity. Resolution is the ability to identify discrete forms (letters, numbers, symbols) and is commonly measured with the visual acuity test. Resolution rapidly diminishes with increased distance from the fovea and is, therefore, a poor indicator of overall visual performance. Contrast sensitivity testing is a better means of evaluating visual functioning, especially concerning those areas less sensitive than the fovea. Contrast sensitivity is the ability to detect a stimulus (spot of light or other target) against a darker or brighter background. Standard Humphrey perimetry (visual field testing) may be thought of as contrast sensitivity testing applied throughout the peripheral visual field.

In perimetry, the term *threshold* is used to describe a very specific level of stimulus detection. The threshold represents the point at which a stimulus is seen 50% of the time and missed 50% of the time. The assumption is that all stimuli brighter than the threshold value will be seen and all stimuli dimmer will be missed. Reviewing the threshold value at each point tested in the visual field is an important part of the diagnostic process.

The visual field normally extends more than 90 degrees temporally and 60 degrees nasally and superiorly, and about 70 degrees inferiorly. That means that stimuli can potentially be perceived within this range while a fixed point is stared at. A more comprehensive understanding of the normal visual field takes into account the fact that visual sensitivity is not constant (or equal) throughout the range. Vision is most acute around the fovea and decreases toward the periphery of the retina. Several factors affect the normal hill of vision causing variations in its overall height and shape. Among them are a patient's age, ambient light, stimulus size, and stimulus duration. In general, deviations from the normal hill are viewed as visual defects and are presumed to be caused by some pathological change.

The patient's date of birth must be entered prior to beginning the test since a hill of vision is assigned to the patient based on their age. The expected threshold at the hills' peak, the fovea, is called the central reference level. This central decibel value is indicated on the test screen and is reported on the printout. (The patient's refractive error is corrected by trial lens.)

Unfortunately, numerous factors affecting reliability, improper or erratic fixation, false positive/negative errors can make test results meaningless.

The STATPAC analysis provided by the Humphrey provides a variety of output measures. This study assessed mean deviation (M.D.) scores, which are the average elevation or depression of the patient's overall visual field compared to the normal reference field. If the deviation is significantly outside the population norms, a p value is given. For example, if $p < 2\%$ this means that fewer than 2% of the normal population shows an MD larger than that found in this test. A significant MD may indicate that the patient has an overall depression, or that there is significant loss in one part of the field and not in others. Table 7 contains the means and standard errors for all Humphrey visual field scores.

Procedure

The clinical files of the sixty patients that participated in study one were obtained from the Sir Mortimer B. Jewish General Hospital. Patients with chronic open-angle glaucoma typically have multiple visual field tests over time, in order to monitor the progression of the disease. The visual field tests conducted closest to the date of the interventions in study one were collected from the patients' files. Because Humphrey visual field data report separate measures of both the patients eyes, scores for the best functioning eye were selected.

Table 7

Means and Standard Errors* for all Humphrey Visual Field deviation scores

Humphrey Visual Field

Control	Pamphlet	Doctor	Film
-3.20 (1.26)	-3.80 (1.46)	-.82 (.78)	-1.83 (.71)

*Standard error of the mean enclosed in brackets

CHAPTER 3

Results

This section reports results obtained from both studies. In study one, data includes a between-group analysis of variance on the effects of three educational interventions as contrasted with a control group. A within-groups analysis of variance assessed the effects of these interventions over time, that is, a short-term effect two days following intervention and longer-term effects 30 days subsequent to intervention.

In study two, a more physiological, as opposed to psychological, measure was assessed. Humphrey visual field data was obtained from the hospital files of the patients who participated in study one. The best-eye visual field scores were correlated with the dependent measures in study one to assess the relationship between visual field loss and measures of health beliefs, compliance, and knowledge.

Study One

It was hypothesized that the interventions would result in an improvement on compliance, knowledge, health beliefs scores from pretest to post-test over the control group. It was also expected that scores would change over time, with an improvement at day 2, then a decline toward baseline by day 30.

On each of the three dependent measures, compliance, knowledge and health beliefs, raw data reflected the total score for each of the three questionnaires. In each case, a higher score signified the optimal response. The scores for two of the three dependent measures, knowledge and health beliefs, were calculated for the pretest, post-test day 2 and post-test day 30. The compliance measure was calculated only for pretest and post-test day 30, since day 2 would not have been a useful measure because compliance cannot reasonably be measured in a 48 hour period. Appendix G contains the means and standard errors for all dependent variables as a function of intervention group and time.

A 2 (time) x 4 (intervention) mixed ANOVA tested for main effects and interaction for compliance. As shown in Table 1, there was no significant main effects for time or intervention, nor was there a significant interaction. These results are illustrated in Figure 1.

A 3 (time) x 4 (intervention) mixed analysis of variance (ANOVA) tested for main effects and interaction for knowledge and health beliefs. For knowledge, as shown in table 2, the ANOVA revealed a significant interaction between time and intervention, $\underline{F}\ (6,112) = 4.22$, $\underline{p} < .01$. Though not statistically significant, each of the four groups' knowledge scores increased, particularly in the short term; from pre to post test day 2. It is further clear from Figure 2 that the interaction was mainly due to the film group.

As shown in Table 3, there was no significant main effect of time, or intervention, for health beliefs. Nor was there a significant interaction. These results are illustrated in Figure 3.

For the knowledge variable, the film group had pretest scores, which were noticeably lower than the other groups. In order to ensure that there was no statistically significant difference between the film and the control group at pretest, a Student's $\underline{t}$ test was calculated and failed to show any significant difference.

As expected, the three dependent measures correlated positively with one another on pretest (see Table 4). Table 5 contains the means and standard errors for all measured variables in Study One.

Table 1

Analysis of Variance for Compliance

Source	SS	df	MS	F
A (time)	1.41	1	1.41	1.62
AB (interaction)	1.63	3	.54	0.62
AS:B (error for A+AB)	48.46	56	.87	
B (intervention)	.43	3	.14	0.02
S:B (error for B)	394.07	56	7.36	

*$p < .05$ ***$p < .001$

n=60

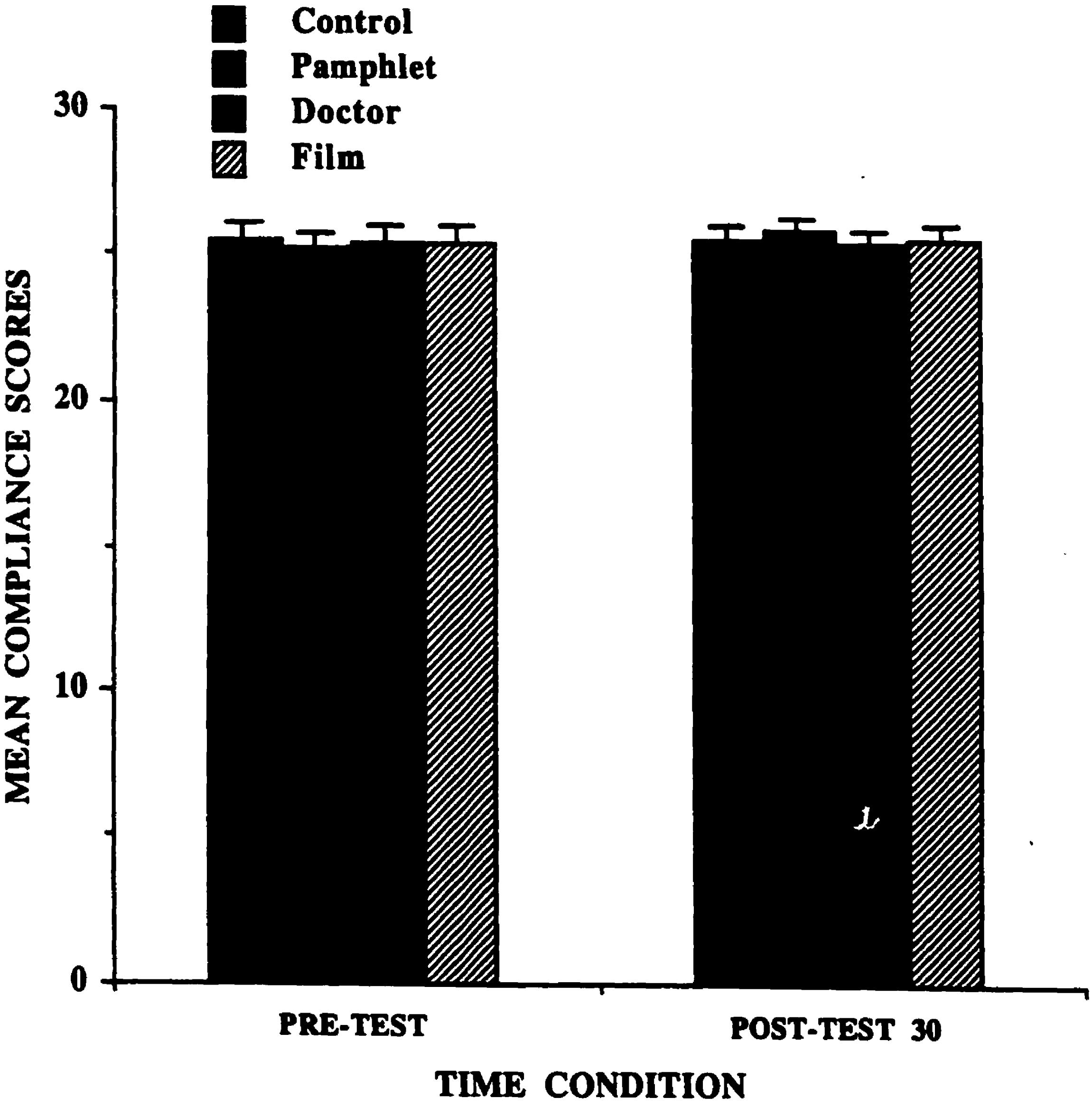

Figure 1. Mean compliance scores for control, pamphlet, doctor and film groups in pretest and posttest day 30 conditions.

Table 2

Analysis of Variance for Knowledge

Source	SS	df	MS	F
A (time)	67.30	2	33.65	35.42***
AB (interaction)	24.03	6	4.01	4.22*
AS:B (error for A+AB)	106.67	112	.95	
B (intervention)	20.15	3	6.72	0.76
S:B (error for B)	496.40	56	8.86	

*p < .05 ***p < .001

n=60

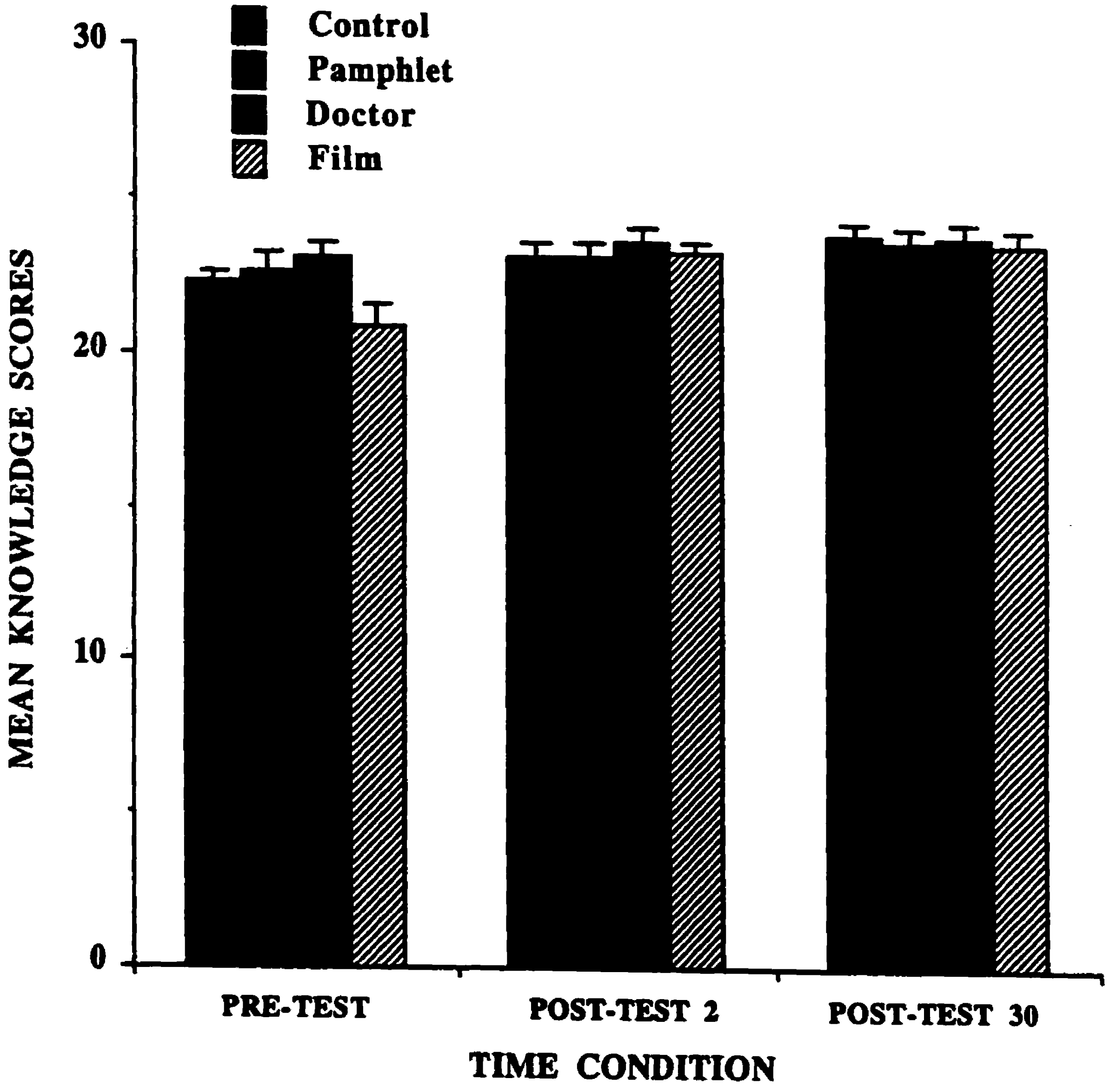

Figure 2. Mean knowledge scores for control, pamphlet, doctor and film groups in pretest, posttest day 2 and posttest day 30 conditions.

Table 3

Analysis of Variance for Health Beliefs

Source	SS	df	MS	F
A (time)	134.58	2	67.29	1.24
AB (interaction)	255.50	6	42.58	0.78
AS:B (error for A+AB)	6,083.96	112	54.32	
B (intervention)	1,665.74	3	555.25	2.30
S:B (error for B)	13,511.25	56	241.27	

$*p < .05$ $***p < .001$

n=60

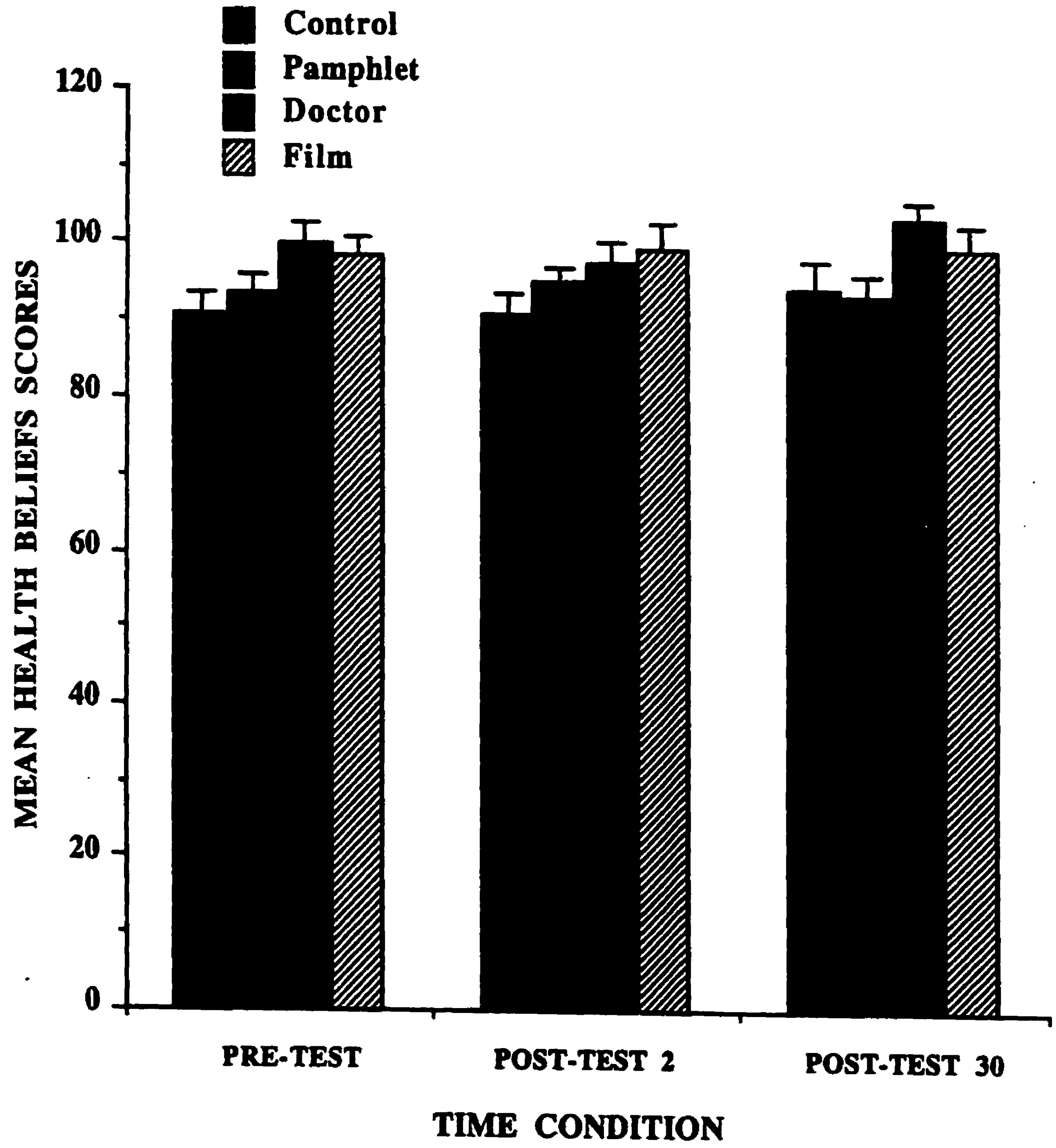

Figure 3. Mean health beliefs scores for control, pamphlet, doctor and film groups in pretest, posttest day 2 and postest day 30 conditions.

Table 4

Correlations between dependent measures on pretest*

Measures	Compliance	Knowledge	Health Beliefs
Compliance	1.000	.934	.887
Knowledge	--	1.000	.867
Health Beliefs	--	--	1.000

*n=60

Table 5
Means and Standard Errors* for all measured Variables

Health Beliefs	Control	Pamphlet	Doctor	Film
Pretest	90.46	93.47	99.73	98.07
	(3.16)	(2.62)	(2.74)	(2.83)
Posttest day 2	90.53	94.73	97.53	99.20
	(2.84)	(2.27)	(2.94)	(3.41)
Post-test day 30	94.06	92.80	103.07	99.53
	(3.54)	(2.97)	(2.41)	(2.80)

Compliance	Control	Pamphlet	Doctor	Film
Pretest	25.50	25.30	25.40	25.40
	(.61)	(.45)	(.59)	(.60)
Post-test day 30	25.50	25.90	25.40	25.60
	(.51)	(.51)	(.49)	(.48)

Knowledge	Control	Pamphlet	Doctor	Film
Pretest	22.30	22.67	23.07	20.87
	(.40)	(.58)	(.50)	(.62)
Posttest day 2	23.13	23.13	23.60	23.20
	(.50)	(.51)	(.55)	(.43)
Post-test day 30	23.80	23.60	23.73	23.55
	(.39)	(.50)	(.50)	(.52)

*Standard error of the mean enclosed in brackets

Study Two

A Pearson product-moment correlation was employed to assess the relationship between a patient's Humphrey visual field measure and each of the three dependent measures (a) compliance, (b) health beliefs, (c) knowledge. All tests were analyzed for significance at $p < .05$ unless otherwise noted. Bivariate correlations between Humphrey visual field scores and health beliefs, compliance and knowledge variables are illustrated in Table 6. Correlations were also assessed to examine changes over time, from pre to post test. In all cases the correlations were positive. The better the vision, that is, the less visual field loss, the better were the scores on each of the dependent measures.

As the Humphrey visual field deviation scores reduce, indicating better visual functioning in terms of detection thresholds, measures of health beliefs increase ($r = .412$; $p < 0.01$), at pretest. The correlation between visual field measures and the health belief scores at the post-test day 2 measure were also significant, ($r = .413$; $p < 0.01$) and followed the same pattern as seen in the pretest results. The post-test measures for health beliefs at day 30 were significantly correlated with the visual field scores ($r = .305$; $p < 0.05$).

The magnitude of the correlations between visual field scores and compliance measures were statistically significant only at pretest ($r = .388$; $p < 0.01$).

The knowledge variable scores were significantly related to visual field measures only subsequent to intervention, at day 2 ($r = 3.19$; $p < 0.05$).

Table 6 contains the means and standard errors for the Humphrey visual field measures as related to intervention group.

Table 6

Correlations between Humphrey scores and dependent measures on **pretest**

Variables	Humphrey	Compliance	Knowledge	Health Beliefs
Humphrey	1.00	**.388****	.090	**.412****
Compliance	**.388****	1.00	-.055	.184
Knowledge	.090	-.055	1.00	-.130
Health Beliefs	**.412****	.184	-.130	1.00

Correlations between Humphrey scores and dependent measures on **Post-Test day 2**

Variables	Humphrey	Compliance	Knowledge	Health Beliefs
Humphrey	1.00	N/A	**.319***	**.413****
Compliance	N/A	N/A	N/A	N/A
Knowledge	**.319***	N/A	1.00	.033
Health Beliefs	**.413****	N/A	.033	1.00

Correlations between Humphrey scores and dependent measures on **Post-Test day 30**

Variables	Humphrey	Compliance	Knowledge	Health Beliefs
Humphrey	1.00	.273	.141	**.305***
Compliance	.273	1.00	-.132	.047
Knowledge	.141	-.132	1.00	.110
Health Beliefs	**.305***	.047	-.110	1.00

** Correlation is significant at the 0.01 level (2-tailed)
* Correlation is significant at the 0.05 level (2-tailed)

CHAPTER 4

Discussion

Study One

The central issue addressed by this study was the efficacy of educational interventions in ameliorating medication compliance. Although compliance rates failed to increase significantly, there was a significant improvement in knowledge. This seems to correspond to the literature suggesting that knowledge is necessary, but not sufficient, for improved compliance (Morris and Halpern, 1979). Previous research has found interesting relationships between subjects' knowledge of illness, and compliance. For example, in a major literature review by Carr (1990), it was found that, in more than 90% of studies, providing information led to an increase in the patients' knowledge about their illness; in 60% of the studies, it led to improved compliance and in 57% it led to substantial improvement in overall outcome. Morris and Halpern (1979) studied 230 hypertension patients who received an intensive health education intervention including brochures, slide-tape presentations and pill-taking reminders. A reverse trend was found; the education program was highly effective in teaching subjects about the management of their disease, but it did not lead to improved compliance. Providing information to individuals who are motivated to comply, but ignorant of the correct procedures, should be beneficial (Becker & Maiman, 1980). Perhaps this was the case with the subjects in the film intervention group who started off with lower scores, but rose above the others following intervention.

The fact that knowledge increased over time in all groups in the present study is not surprising. This makes sense intuitively; when subjects are presented with a questionnaire assessing knowledge of their disease, it seems reasonable to assume that they would seek out the responses to questions they could not answer. The impressive finding is that, given this expectation, the film group did so much better than the other groups. The representation of imagery has been explained in two ways; a unitary view of visual and verbal encoding postulates that information about pictures is represented in the same way as verbal information (Driscoll, 1994). The dual-code or dual systems approach (Pavio, 1971; Mayer, 1989) proposes that there are two systems of memory representation, one for verbal information, and another for non-verbal information. The meaning of words can be represented by the verbal system, and the images of the words can be represented by the imaginal system. Learners, with two memories available at recall, should have a superior memory than those with only one available (Driscoll, 1994). This dual code position posits that the memory system will function better when both verbal and analogue systems are brought to bear on a specific memory. Therefore, pictures should be remembered better than words since the former can be presented both visually and verbally (Best 1991).

If there is indeed a strong connection between verbal and imaginal systems, then the instructions to form images, and the use of visual aids for instruction, are both likely to enhance learning of some verbal material. Driscoll refers to Kossly (1980) who proposes that images are important to the process of learning by enabling learners to represent what is not depicted in the instruction. These representations are then transformed to facilitate comprehension and problem solving. Booklets and pamphlets about glaucoma are important, useful, and easily accessible materials facilitating successful patient education. Videotapes have also been shown to be an effective method of educating glaucoma patients (Shields, 1992).

Semantic networking theory (Johassen, Reeves, Hong, Harvey & Peters, 1997) proposes that our memories are organized semantically according to meaningful relationships between ideas, or schemas, in memory. The attachment of meaning to information anchors and embeds it within the learner's cognitive repertoire. Meaning is also facilitated or impeded by the information load of the message. This information load is the product of the number of chunks of information and the saliency, or previous experience, with the information (Richey, 1986). If the message is well designed, then the material should carry the appropriate information load to the receiver. Judging from the statistical results and informal post study comments from patients, the video was well designed, carried the appropriate information load and, thereby, benefited from a dual encoding of cognition and memory. The video integrated principals of situated learning and live modeling of required techniques.

Communication norms (and research in psychology and cognitive science) suggest that the order of presentation is important when giving instruction. This primacy effect refers to material that was presented first; the memory of this information is, therefore, the oldest. Information presented first should be recalled more easily than information appearing later. Recency, on the other hand, refers to the greater likelihood of memory retrieval when the serial position of material is at the end (Ebbinghaus, 1964). In the healthcare domain, the delivery of important information early in the interview, and its repetition towards the end, utilizes primacy and recency effects to improve recall. It accomplishes this by reducing retroactive and proactive inhibition of storage in memory (Kendrick, 1997). The patient's attention is raised to receive information by emphasizing the importance of what is about to be expressed. Thus, the presentation of important issues, such as the disclosure of bad news, should be presented first in order to improve patient recall of verbally presented information. The video intervention facilitated the transmission of these communication norms in ways that the pamphlets and verbal instructions could not.

Compliance

Several findings in the present study deserve elaboration. The high compliance scores on pretest were unexpected, and a review of the literature revealed that previous research had been inconsistent and arbitrary in terms of defining compliance. The literature reveals that noncompliance is relative; that is, each researcher sets his/her own criterion level. The substantial rates of noncompliance reported in previous studies may have been a result of stringent operational definitions. For instance, in Vincent's (1972) study of glaucoma patients, compliers were defined as those who admitted to missing their drops not more often than once a month. This was a very rigid criterion and, not surprisingly, out of the 62 respondents, only 26 were classified as compliers; the remaining 58% did not follow their doctors' prescriptions and were deemed noncompliant (Vincent, 1972). Kass et al. (1984) acknowledged that the enormous variation in the compliance figures reported in the literature, which ranged from 4% to 82%, could be explained by differences in the definitions of compliance. Patient's self-reports correlate reasonably well with other methods of assessment, with the average correlation being approximately r = 0.47 (Ley, 1997). The weakest method seems to be the clinician's estimate with an average correlation of approximately r = 0.21 with other methods. Conversely, patient satisfaction with the consultation is consistently associated with compliance, as confirmed by Ley (1997).

Several factors may have influenced the overall results obtained in this study. The cause of noncompliance can frequently be traced to the failure of communication between the physician and patient (Morris & Halpern, 1979). This suggests that an essential ingredient in compliance is the doctor-patient relationship (Agras, 1989; Davidson & Akinbehin, 1980). Many studies report positive correlations between patient satisfaction and compliance (Becker & Maiman, 1980). Furthermore, dissatisfaction with the relationship is known to be associated with the failure of patients to follow the advice and the treatment proposed (Rutter, Quine, & Chesham, 1993). In the present study, when asked to rate the statement "I can't really talk to my doctor", more than 80% of the 60 patients strongly disagreed. None of the subjects in the present study were newly diagnosed, nor were they new patients to the ophthalmologist. These factors, combined with the positive response to the above statement, make it reasonable to assume that the patients were mostly satisfied with the patient-provider relationship. This may also help to explain the high baseline compliance rates.

Demographic variables are often included in studies of compliance, but are inconsistent and unreliable predictors of compliant behavior. (Davidson & Akingbehin, 1980; Matthews & Hingson, 1977; Sumartojo, 1993). For this reason, typical demographic variables such as race, income and education were not taken into account in the present study. One might speculate that compliance is too general a human behavior to be easily categorized according to demographic factors.

In summary, several conclusions about measuring compliance can be drawn. Certainly the best approach is the use of multiple measures, including some combination of medication monitors, physiological testing, and patient self-reports. It is known that a strong indicator of patient compliance is the quality of the patient-provider communication and relationship. The results of this study appear to support Sumartojo's (1993) observations that some physicians have patients who consistently complete treatment and preventative therapy. The ophthalmologist who participated in this study appeared to be among these successful physicians. Finally, although patient education should be an integral component of any compliance intervention, it must be recognized that increasing patients' knowledge about their illness does not necessarily translate into increased compliance.

The HBM is a model that incorporates expectancy values of perceived barriers, benefits, seriousness and susceptibility (Kiley, Lam, & Pollak, 1993). Contrary to expectations, health belief concepts measured in Study One did not change across time in any of the intervention groups. This may be due to the well accepted notion that beliefs are relatively stable and may require repeated interventions and a longer period of follow up for any change to be noticed. However, since the HBM and compliance scores correlated highly at pretest ($r = .887$) it may be assumed that, in prospective studies, the HBM would contribute significantly to the understanding of compliance in glaucoma patients given that it specifies several psychological dimensions that contribute to understanding health behavior (Stein, Fox, Murata, & Morisky, 1992).

Despite the success that the HBM has had, it is not without its shortcomings. For example, it does not account for health related behaviors that people perform habitually, that is, behaviors that probably originated and have continued without the individual's consideration of health threats, benefits, and costs. A further limitation is that there is no standard way to measure the HBM's components, such as perceived susceptibility to, and severity of, illness. Different studies have used different questions to measure the same factors, thereby making it difficult to compare the results across studies (Sarafino, 1998).

The replacement of beliefs that have been constructed over many years, and the habits of mind that have developed along with them, will require multiple learning experiences, distributed over time and settings. In order to change a mental model of how the world works, instructors need to comprehend the mental models that exist prior to instruction. They must design learning activities that expose the errors in these naive models to make the benefits of the new model obvious (Halpern, 1998). It should be noted that the patients in the present study were not necessarily representative of the broader population of patients with chronic open angle glaucoma. The patients who participated in this study were recruited from outside the waiting area of their ophthalmologist's office. Given the ceiling effect on the compliance measures, it seems reasonable to assume that these patients were probably more complaint than those patients who do not show up for their check-ups. The less compliant know that their pressure will be verified; thus, there is little point in attending check ups.

In a randomized controlled trial, Fawzy et al. (1990) combined components of patient education, problem solving training, relaxation-based stress management, and social support from treatment personnel to develop a brief program of group therapy for cancer patients with melanoma. The results showed that therapy participants experienced substantially more vigor at the end of the 6-week program. Follow up data collected 6 months later showed that the benefits produced by the experimental intervention had intensified so that therapy participants were found to be significantly less depressed, fatigued, or confused than their control group counterparts. Recognizing the importance of measuring coping behavior directly, the researchers also assessed behavioral and cognitive responses utilized in coping with illness. At the end of therapy, participants used active-behavioral coping methods far more frequently than did the control group (Devins & Binik, 1996). Moreover, the intervention group continued to use significantly more active-behavioral coping techniques than did the control group when they were assessed at the six-month follow-up. These are very encouraging findings, considering that many interventions result in an improvement in the short term, but fall back to baseline in the long term.

The dominant theoretical approaches to the study of health behaviors reviewed in chapter one offer little guidance as to how the processes that govern the initiation and the maintenance of those behaviors might differ. Because health maintenance has been traditionally operationalized as actions sustained over time, it is predicted to rely on the same set of behavioral skills and motivational concerns that facilitate the initial change in behavior (Rothman, 2000). Unfortunately, this perspective is at odds with the repeated finding that those who successfully initiate a change in their behavioral practices often fail to maintain that pattern of behavior over time. Repeated application of intervention strategies that facilitate short-term success does little to improve rates of long-term success. Thus, the premise that there are important differences in the psychological processes that govern behavioral initiation and maintenance appears worthy of consideration (Rothman, 2000).

Study Two

The central questions addressed in part two of this study were: (a) Do patients who have substantial visual field loss comply more (or less) with their medication regimens than those patients with less visual field loss? (b) Are patients with relatively good vision more likely to take an interest in, and process, glaucoma information more effectively than those whose vision is worse? (c) Are the health beliefs significantly different in patients with minor, versus substantial, visual field loss?

For patients with long-term chronic illness, especially those of an asymptomatic nature such as glaucoma, heart disease, and diabetes, the motivation to adapt may have been present at the onset of the illness, but has waned over time. The significant positive correlations between Humphrey visual field measures and patients' scores on the HBM appear to support this theory. Patients who have lost the least vision (presumably those more newly diagnosed) have the highest HBM scores, have higher compliance score on pretest, and show significant improvement following intervention in the knowledge variable in the short term, at posttest day 2.

In study two, visual field loss was significantly correlated with measures on the health belief model both pre and post intervention. The HBM suggests that patients whose perceptions correspond with its four dimensions will be more likely to follow regimens recommended to them than will patients not holding these beliefs (Matthews & Hingson, 1977). It appears that patients with less visual field loss are more likely to (a) feel susceptible to problems or complications because of their illness, (b) believe that their illness could pose serious consequences for their health or daily functioning, (c) feel that the proposed treatment regimen will be highly effective in treating their illness, and, (d) do not foresee major obstacles to compliance, such as adverse drug effects, cost of regimen, or perceived lack of medication safety. To maximize the utility of this, or any other model of health behavior, future research needs to extend the focus beyond the relationship between the beliefs patients report immediately following treatment interventions, and their actual behavior maintenance practices.

Limitations

A potential methodological limitation of the present study was dependence on self-reports of medication compliance. The results revealed no improvement in compliance and this appears to have occurred due to a ceiling effect on the pretest questionnaire. Twenty-one of the 60 subjects reported perfect compliance on pretest, hence, there was little or no room left for improvement on posttest. There were a number of possible reasons for this high rate of compliance.

Identifying effective means of enhancing compliance requires accurate methods for its measurement, and a fault proof method has not been discovered to date. All of the most commonly used methods for assessing compliance have both strengths and weaknesses that must be considered in their implementation. The self-report method, as used in this study, is influenced by both patient and provider characteristics (Rand, 1990). Elderly patients with memory impairment, who often are taking multiple medications, may not be capable of accurately describing their pattern of usage of any one drug (Rand, 1990). Patients on long-term medication (as required with glaucoma) may be able to accurately report their recent usage patterns, but may be unable to report their usage patterns for the weeks prior to their physician visits. Because there is no evidence to suggest that compliant patients will misrepresent themselves as noncompliant, self-reports allow the simple identification of many candid noncompliers (Gordis, 1976). Sumartojo (1993) reiterated that patient self-report may not seem to be a reliable measure of compliance due to problems such as forgetfulness, unwillingness to admit to not taking medication, or fear of the medical provider. However, there is evidence that patients with a variety of medical conditions who have had experience with a regimen can predict their own level of adherence, and careful questioning by physicians and other healthcare providers can yield correct information about compliance (Sumartojo, 1993).

The main alternatives to self-reports are physician estimates, biochemical analysis, and medication monitors. Physician estimates are poor predictors of compliance (Kass, 1990; Keller & Carroll, 1994; Rand, 1990). Kass et al. (1990) found that there was a low correlation ($r = .12$) between physicians' estimate of the number of doses of eye drop medication administered in a month, and the number of doses as recorded by a medication monitor.

Studies with medication monitors (Elixhauser, Eisen, Romies & Homan, 1990) have found that increased compliance may have been due to a short-lived impact of the presence of the monitors, thus suggesting a novelty effect. When using these monitors, Elixhauser et al. (1990) concluded that it is important to collect data for an extended period of time to assess whether behavioral changes are sustained after interventions. When monitored, there is a strong possibility that patients' compliance behavior will be altered to meet the demand characteristics of the monitoring situation (Rand, 1990). The only method of compliance measurement that confirms that the patient has actually taken the medication is biochemical analysis. While it permits a very direct assessment of medication use, it can provide a measure of compliance only for a single test, and it is costly and invasive. The main disadvantage is that it cannot realistically be used to measure day-to-day compliance with long-term medication. Also, as in the case of glaucoma, patients are aware that their intraoccular pressure will be measured during their appointment; they will thus take their drops before the appointment. This results in various problems, one of which is that the ophthalmologist may be misled by the normal tension in the eye (which has developed damage to the optic nerve with visual field loss) and may, consequently, label the condition as 'low tension' glaucoma (Davidson & Akingbehin, 1980).

The inclusion of one or more objective measures when assessing compliance would confirm patients' self reports, but Rand (1990) cautions that their potential reactive affect should be weighed. The present study could have benefited from a secondary measure to help substantiate the self-reported high levels of compliance. However, this was impossible given the limitations of this study.

Advances in information and communication technologies provide new vehicles for targeting and individualizing health behavior change and maintenance interventions. In the past twenty years, progress has been made in helping individuals change behavior in the short term. It is now time to direct attention to the important, and more difficult, issue of maintenance behavior change.

Future Directions

A generation ago, the field of health education drew a distinction between knowledge change and behavior change, placing increasingly greater emphasis on the latter (Elder et al., 1994). In his groundbreaking work, Bloom (1956) described a taxonomy of educational objectives which included three major categories, namely "cognitive", "affective" and "psychomotor". This taxonomy operationalized the knowledge-behavior distinction. The cognitive domain emphasizes specific intellectual processes and tasks, typically referred to as "knowledge", "understanding", and "memorization", etc. The affective domain includes the feelings and attitudes people experience with respect to certain information, health topics, other people, etc. The psychomotor domain consists of specific behavioral skills, whether they are related to athletic performance, technical ability, or ease and efficiency with which one performs a particular task (Elder et al., 1994). Although it fails to give sufficient credence to motivational aspects of human behavior, this taxonomy of educational objectives lends itself to specific operationalization of goals and objectives from a wide variety of areas. According to Elder et al., (1994) Bloom's taxonomy is especially useful in fields such as health promotion, where standardization is needed to coordinate and integrate the efforts of individuals from various disciplines.

A relatively new intervention referred to as the Coping Effectiveness Training Program (Chesney & Folkman, 1994) focuses both on the way patients appraise the stressors associated with their illness, and with the strategies used to deal with it. Petrie and Moss-Morris (1997) stressed that the important emphasis in this program is on the promotion of matching illness appraisals and coping strategies. For example, when situations are appraised as uncontrollable, emotion-focused strategies are encouraged. Conversely, problem-focused strategies are advocated for the controllable aspects of the illness. Interventions may also benefit from the recognition of the distinction between individual coping styles (Lazarus & Folkman, 1984). Interventions that focus mostly on improving problem-focused coping would include patient education and behavioral self-management, which requires the acquisition, and manipulation, of illness related information.

Most of the models and theories driving current research derive from cognitive behavioral models of behavior maintenance processes that were developed over a decade ago and that have not been significantly revised or expanded since. One strategy for expanding the current theoretical base is to integrate models from other relevant fields. These include motivational interviewing goal setting, extrinsic-intrinsic motivation, risk perception, and the study of self-concept and self-schema in health behavior change and maintenance. Another strategy is to use a more inter-disciplinary approach, linking biomedical and behavioral ideas to gain a deeper understanding of maintenance as a dynamic process. This process involves the interaction of multiple individual influences such as those considered to be biological, behavioral, cognitive and motivational.

Research on health behavior change and maintenance requires greater attention. In contrast to interventions that produce short-term behavior change, maintenance interventions have not improved much over the last 20 years. To move the field forward we need comprehensive, social-ecological models of population based health behavior change and maintenance, that is, a broader view of maintenance as a dynamic process rather than as a static state.

Computer technology has the potential to provide detailed and personalized instruction, contingent upon the particular knowledge, strengths, and weaknesses of individual learners. Devins and Binik's (1996) wrote that Wetsone et al. have developed extensive computer assisted lessons for two common disabling illnesses, systematic lupus and rheumatoid arthritis. A variety of central topics were presented together with detailed multiple-choice questions designed to assess specific gaps in knowledge and individual learning requirements; these directed the user to those topics in need of increased coverage. Results in both illnesses groups indicated that health care consumers are willing, ready and able to engage in computer-assisted patient education and that substantial improvements in illness-related knowledge follow exposure to such programs (Devins & Binik, 1996). Expectations for a good prognosis and optimism about the potential for a good life, despite chronic, at times disabling, illness also improved substantially.

During the last decade patient education has developed from a general, often hospital-based approach, to a specific and more patient-centered activity. With this change in paradigm, the patient is increasingly being seen as responsible for his/her own recovery and as someone who makes independent choices in this respect. Patients must base important decisions on the information available to them. The ability to decide which sources of information are more credible is a higher order cognitive skill. It is a judgment task in which the variables that affect credibility are multidimensional and change with context. In real life, critical-thinking skills are required whenever people grapple with complex issues and messy, ill-defined problems (Halpern, 1998).

The information explosion is yet another reason why specific instruction in thinking skills need to be provided. People now have an unprecedented wealth of information available at their fingertips, via the Internet and other remote services. The problem has become knowing what to do with this deluge of data. The information has to be selected, interpreted, digested, evaluated, learned, and applied says Halpern (1998); it is of no more use on a computer screen than it is on a library shelf. If individuals cannot think intelligently about the myriad issues that confront them, they are in danger of having all the answers, but not knowing what the answers actually mean. The dual capabilities of knowing how to learn and knowing how to think clearly about rapidly proliferating information will provide the best education for citizens of the 21st century (Halpern, 1998).

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Appendices

Appendix A

Script for Doctor

- Glaucoma is serious, and if left untreated can result in blindness. Remember, glaucoma has no noticeable warning symptoms until it is too late, once vision has been lost it can not be restored
- Changes over time must be monitored by ophthalmologist. If glaucoma is left untreated you will first loose peripheral (side) vision then eventually, all vision (blind).
- To control glaucoma must take drops exactly as prescribed, every day preferably at the same time for life, even if you have no symptoms or feel fine.
- There is no cure for glaucoma, but eye medication therapy can control and halt the disease. Remember, glaucoma will progress if you stop taking your medication.
- Compliance. Everyone misses a drop or two now and then, but continual nonadherence is risky.
- Develop regimen to suit your lifestyle. Use reminders that you associate with daily rituals such as shaving or brushing your teeth. Set an alarm on a wristwatch. Leave medication in full view, in places that you are likely to be in at medication times.
- Medication: Get drops into the eye properly. Not too much or too little. Make a pocket in the eye lid, look up and squeeze drop into lower lid. Release lid and close the eye. Apply slight pressure on inside corner of the eye to help get all the medication in the eye. Can also purchase an eye drop aid from the pharmacy. Properly space the dosage and the order of the medication.
- Keep your appointments with your ophthalmologist EVEN IF YOU FEEL FINE. Let your doctor know if you have any problems with your medication such as side effects.

Appendix B

Study number______

Glaucoma Questionnaire

1. Glaucoma is a disease in which the eye pressure is too high for the optic (eye) nerve to function normally. True False

2. Glaucoma may be treated with eye drops, pills, laser or surgery. True False

3. Glaucoma is contagious. True False

4. If a patient is on more than one eye medication, it's likely that the medications need to be taken in a specific order. True False

5. If a person has glaucoma, but no symptoms, no treatment is needed. True False

6. As people get older, they are at an increased risk of developing glaucoma. True False

7. You are at a greater risk for developing glaucoma if someone else in your family has glaucoma. True False

8. Glaucoma can be treated but not cured. True False

9. Glaucoma can be caused by poor diet or stress. True False

10. You should not bother your doctor about any side effects or problems with taking your medication(s); there is nothing they can do about it. True False

11. If you feel fine on the day of your doctor's appointment it is all right to cancel. True False

12. People with glaucoma will all go blind with, or without, treatment. True False

13. Eye drops work to reducing the pressure in the eye by, either by allowing more fluid to escape, or by reducing the amount of fluid produced. True False

14. Eye drops should be taken at the about same time everyday. True False

15. Glaucoma has no warning symptoms until it is too late. True False

16. If you miss a dose of your medication, you should double up. True False

17. The purpose of treating glaucoma is to slow down or stop the loss of vision. True False

18. An acceptable schedule for eye drops prescribed two times a day could be: 7:00 am and 10:00 am. True False

19. Diabetics are at an increased risk for developing glaucoma. True False

20. Applying pressure to the corner of the eye with your index finger is a good idea to avoid loss of drops through the tear ducts. True False

21. Medications used for glaucoma do not have side effects. True False

22. Vision lost to glaucoma can be restored. True False

23. A person with glaucoma will first start to lose their peripheral (side) vision. True False

Appendix C

Medication Questionnaire

1) Some people are not able to take their eye drops all of the time because the time or the place may be inconvenient. Can you give me an idea about how many times in the past month you were not able to take your drops?

a) Over ten times
b) Ten times
c) Five Times
d) Once

2) At any time in the last 30 days, did you ever take fewer drops than you were told to because your glaucoma was not bothering you?

a) Yes
b) No

3) Many people who take glaucoma drops find they don't take them all the time. Would you say that you have taken your drops:

a) 25% of the time
b) 50% of the time
c) 75% of the time
d) 100% of the time

4) When I don't take my eye drops it is usually because:

a) I forget to take them
b) I run out of my drops
c) I forget to have my prescription filled

5) How many times in the last 30 days, did you ever take fewer drops than you were told to because your vision wasn't bothering you?

a) Less than five times
b) Five to ten times
c) Ten to twenty times
d) More than twenty times

6) Many people find their eye drops may cause a burning sensation. Should this happen to you; does it ever prevent you from taking your drops?

a) Yes
b) No
c) Sometimes

7) Some people forget to bring their eye drops with them when they leave home. Do you find that this is a problem for you?

a) Yes
b) No

8) The last time that you ran out of your eye drop medication, did you contact your doctor for a renewal:

a) The same day
b) Within a few days
c) A week or more later

9) Within the last week, on how many days did you take fewer eye-drops than you were supposed to?

a) Every day
b) Most days
c) Some days
d) Never

10) How many times in the last 30 days, did you forget to take your eye drops?

a) Less than five times
b) Five to ten times
c) Ten to twenty times
d) More than twenty times

11) When did you get your prescription for your eye-drops refilled the last time?

a) Before I ran out
b) Within a day or two after I ran out
c) A week or more after I ran out

12) Think about taking your eye-drops during the last 30 days. Have you done what your doctor's office or clinic told you to do?

a) Yes, exactly
b) Yes, most of the time
c) Yes, some of the time
d) Yes, a little of the time
e) No, not at all

13) How many times in the last year did you ever miss taking any eye-drops because you didn't get your prescription filled?

a) Less than five times
b) Five to ten times
c) Ten to twenty times
d) More than twenty times

Appendix D

Study number____

Health Belief Model Questionnaire

In this section would you please circle one of the numbers on each of the scales to indicate how strongly you agree or disagree with each of the following statements.

On these scales
0 = would indicate that you strongly agree
1 = agree
2 = neither agree nor disagree
3 = disagree
4 = strongly disagree

	Strongly Agree				**Strongly Disagree**
1. If I take my eye-drops regularly I can avoid serious loss of vision	0	1	2	3	4
2. If I don't take my eye-drops as instructed, my glaucoma/vision won't get worse.	0	1	2	3	4
3. Should my vision deteriorate, my family life would suffer. 0	1	2	3	4	
4. When eye pressure readings are high, eye-drop medications can reduce the pressure.	0	1	2	3	4
5. Having my eyes tested could reveal glaucoma/high-pressures even if I feel no symptoms.	0	1	2	3	4
6. It can be uncomfortable to insert my eye-drops	0	1	2	3	4
7. It takes a lot of effort to remember everyday just how many drops are needed and when.	0	1	2	3	4
8. If I take my medication long enough, once my eye pressure is controlled, I can then stop taking it.	0	1	2	3	4
9. Blindness can be prevented if glaucoma is detected and treated early.	0	1	2	3	4
10. I feel assured when my ophthalmologist regularly checks my eye pressures.	0	1	2	3	4
11. I can't really talk to my doctor.	0	1	2	3	4
12. I find that taking care of my glaucoma is time consuming.	0	1	2	3	4
13. It is difficult to get the right amount of medication/liquid in my eye.	0	1	2	3	4

14. If the pressure in my eye/s is above normal, I probably need to be treated for glaucoma.	0	1	2	3	4
15. If I don't follow my doctors instructions, I may end up experiencing pain in my eye/s.	0	1	2	3	4
16. The side effects of some eye-drops are annoying	0	1	2	3	4
17. By taking my eye-drops as prescribed I am reducing the chances of needing eye surgery.	0	1	2	3	4
18. I can't feel any pain in my eyes so I can not really have a problem with my eyes.	0	1	2	3	4
19. I am not the type of person to get serious health problems, and that includes glaucoma.	0	1	2	3	4
20. I don't seem to see as well as I used to.	0	1	2	3	4
21. If I do not take my eye-drop medication I may go blind.	0	1	2	3	4
22. If some vision is lost due to untreated glaucoma it can be restored.	0	1	2	3	4
23. Finding the time to see my ophthalmologist is a problem.	0	1	2	3	4
24. Glaucoma eye-drops are getting to be expensive.	0	1	2	3	4
25. Even though I have no symptoms, glaucoma can destroy my vision.	0	1	2	3	4
26. I could lose my job if my eye sight is not maintained at a reasonable level.	0	1	2	3	4
27. My eye-drop medication controls my glaucoma so I don't have to worry about serious loss of vision.	0	1	2	3	4
28. Eyesight can be saved with early treatment of glaucoma.	0	1	2	3	4
29. I am not sure if I *really* have glaucoma.	0	1	2	3	4
30. Should my glaucoma become worse, I may not be able to drive.	0	1	2	3	4
31. My life would be very difficult without good vision .	0	1	2	3	4
32. If one of my parents had glaucoma, this increases my chances of having glaucoma.	0	1	2	3	4

Appendix F

Sir Mortimer B. Davis Jewish General Hospital Study number___
Department of Ophthalmology

Title: Investigating the Relationship Between Medication Compliance, Health Belief Measures, and Glaucoma Knowledge in Chronic Glaucoma Patients.

Consent Form

This study is a student project conducted in the Department of Ophthalmology at the Sir Mortimer B. Davis Jewish General Hospital. It is designed to investigate the effect of providing information to glaucoma patients about their eye disorder and its treatment. This could provide important information about methods of educating glaucoma patients on issues concerning their eye problem.

If you participate in this study, while waiting to see your ophthalmologist, you will be asked to complete some questionnaires regarding your health in general, glaucoma specifically, and the problems associated with glaucoma. These questions are not routinely asked of glaucoma patients but are related to this particular study. You will be assigned by chance (like a flip of a coin) to one of the following situations: (1) you will be shown a short glaucoma-related video; (2) you will be asked to read some glaucoma-related pamphlets; (3) you will receive glaucoma information verbally from your ophthalmologist or (4) you will simply proceed with your appointment as usual. You have a one-in-four-chance of being in one of these groups. The total time required for these tasks is about 15 to 30 minutes. Two days and again 30 days later you will be asked to respond to the same questions initially asked on the questionnaires. This will be done over the telephone at a time that is convenient for you.

It is understood that the information you provide will be kept in strict confidence. Your responses to the questionnaires will not be given to your ophthalmologist. He will receive only a summary of all the information collected in the study. Following the completion of the study, upon request, you will be informed of the findings. Should the results of this study be published, neither your name nor any other information that would allow identification of you, will be used.

Your participation is completely voluntary and you remain free not to participate or to withdraw from the study at any time. This will not affect the care you receive from your ophthalmologist.

Your signature below indicates that you have read this consent form and that you agree to participate in the study. A copy of this consent form will be given to the participant.

_______________________ _______________________
Participant's name Participant's signature(and telephone)

____
Date

Supervised by : Dr. O. Overbury, Associate Professor, Ophthalmology 340-8284
Dr. O. Kasner, Glaucoma Specialist, Ophthalmology 340-8284