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IMPROVING COMPLIANCE LISTENING TO THE PATIENT'S PERSPECTIVE

Faith Coleman Becker

A thesis submitted to the Department of Nursing in partial fulfillment of the requirements for the degree of

Master of Science in Nursing

UNIVERSITY OF NORTH FLORIDA

COLLEGE OF HEALTH

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Abstract

A large number of patients do not follow medical advice for reasons generally unclear to the health care provider. Significant morbidity and mortality can be outcomes of noncompliance. The purpose of this naturalistic inquiry was to study and clarify from the patient's perspective, issues identified as influencing the ability to comply with provider recommendations. Data collection and analysis occurred simultaneously as a fluid process of organizing and synthesizing qualitative material into categories or themes that emerged to illuminate a phenomenon. Seventy-six percent of participants described themselves as 100% compliant though they did not take medications as prescribed or failed to follow through with other recommendations, such as lifestyle changes. Participants listed positive perceptions when the provider: related to them, listened, addressed concerns, and included them in the plan of care. The provider behavior of listening was important to patients but was not the only aspect identified with a potential influence on compliance levels. Unexpected study findings included connections between symptomatology and medications, control issues between patient and provider, and the patient's perceptions of office personnel attitudes.

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CHAPTER 1

The fact that patients do not take medications as prescribed has troubled health care providers for decades. After more than 40 years of research on patient noncompliance, with over 4000 papers written on the subject in the last 10 years alone (Playle & Keeley, 1998), the problem remains unsolved. Researchers have examined patient characteristics such as age, sex, race, marital status, support systems, economics, and education without arriving at successful, widely applicable interventions (Blackwell, 1981; McDonald, 1988). Studies classifying disease states, types and dosing of medication, along with concomitant levels of health, also noted only weak associations between intervention and outcome (Haynes, 1979; Cameron & Gregor, 1987; Roberson, 1992). Cameron and Gregor (1987) observed that when health care providers disregarded patient opinions about illness and treatment, noncompliance resulted. Twenty-seven years ago Stimson (1974) proposed that an alternative approach be used to impact patient noncompliance. He suggested a focus on the social aspects of patients in which illness is experienced and treatments used. Could it be that solutions for noncompliance rest with health care providers rather than with patients?

Problem Statement

The majority of patients do not follow medical advice for reasons generally unclear to the health care provider. The numbers of patients who are "mis-taking" medications has been estimated at a relatively low level of 20% to an astounding 94% (McCord, 1986; Trick, 1993; Lerner, Gulick, & Dubler, 1998). The disparity between percentages was related to the type of treatment in question. Studies that sought to identify and quantify patient characteristics, a particular illness, or a certain prescribed treatment as reasons for noncompliance supplied only indeterminate results (Stimson, 1974; Kruse, 1992).

One limitation of research is the inadequacy of measurement tools for assessing compliance. Kruse (1992) noted that a lack of appropriate methods has "hampered major progress in compliance research, with regard to both descriptive and explanatory sides of the problem" (p. 163). Another problem with applied methods is that the techniques designed are often unrelated to the patient's reasons for noncompliance (Heszen-Klemens, 1987).

Significant morbidity and mortality can be outcomes of noncompliance. Strand (1994) observed that noncompliance commonly results in "suboptimal clinical outcomes" (p. 48) and also reported that 125,000 deaths each year are attributable to noncompliance. Recent struggles to develop new specific and broad-spectrum antibiotics were preceded by years of inappropriate prescribing and the patient's inability to follow the therapeutic regimen (Trick, 1993).

Noncompliance often results in increased health care costs to the consumer in out-of-pocket costs, lost work income, and higher insurance premiums. Sterler (1996) estimated the annual cost of morbidity and mortality in the United States for 1995 at \$76.6 billion, excluding expenses related to lost work productivity. Work days lost totaled \$1.5 billion in a 1992 report (Epill, 1999).

Noncompliance has been used to define patient behaviors when the prescribed plan of care is not followed. Stanitis & Ryan (1982) postulated that the negativity associated with the term could result in health care providers avoiding noncompliers thereby delivering inadequate care. Ross (1991) proposed that providers view compliant patients as "good" and noncompliers as "bad." The connotations confer unspoken assumptions and perhaps outright dislike of patients when they are labeled as (a) disobedient (related to not following doctors' orders), (b) uncooperative (undermining their own good), and (c) guilty (patient is to blame for the illness or worsening condition). Moore (1995) noted that when the cause for noncompliance is focused solely on the patient, health care providers sidestep important issues that may have led to noncompliance, such as inadequate patient education, discounted patient and family concerns, or a lack of long-term goals.

Researchers observed the influence of making value judements and labeling patients. Trostle (1988) recognized that providers are prone to make value judgments about noncompliant patients--separating themselves from the

relationship rather than attempting to understand patients' actions. When interactions between patient and provider were analyzed researchers recommended that changes in the relationship such as communication styles, attitudes, beliefs, and the patient's level of participation could contribute to improved compliance (Yoos, 1981; Delbanco, 1992; Deber, 1994). While these studies have shown promise, providers may be reluctant to attempt these types of interpersonal improvements due to time constraints experienced in their practices (Quill, 1983; Lowes, 1998; Gottlieb, 2000). In other studies, however, there was no relationship between the length of clinic visit and negative perceptions of the patient-provider relationship (Yoos, 1981; McCord, 1986; Anderson & Zimmerman, 1993).

Purpose of the Study

The purpose of this naturalistic inquiry was to study and clarify from the patient's perspective, issues identified as influencing the patient's ability to comply with provider recommendations. Analysis of patient interviews uncovered patient-derived meanings for noncompliant behavior. Once these meanings are defined, interventions for daily practice can be designed and tested. Such interventions would address the psychosocial, economic, and physical factors that influence patients.

Significance for Nursing

The unconditional accepting of patients where they are at the moment, providing support, comfort and encouragement are concepts deeply entrenched

in nursing. Nursing as a helping profession has long been concerned with the relationships developed during the care of patients. Yoos (1981) emphasized the importance of employing nursing's tradition of therapeutic interaction with patients. This naturalistic research, proposed an understanding of the patient's view as an opportunity to study aspects of noncompliance. The study provided explanations for behavior, and supported the application of nursing-oriented interventions for future practice.

Working within the framework of an adaptation model (University of North Florida, 2000) nurses should act as facilitators and advocates in a joint experience with the patient, employing empathy and understanding, while promoting independence. Shared responsibility for health promotion in a mutual patient-provider relationship fosters an environment for growth, learning, and self-care.

Advanced practice nurses are in a unique position to affect compliance by continuing the holistic patient approach while providing care. The nurse practitioner can address patient concerns and anticipate solutions to potential compliance problems by (a) listening to patients, (b) accepting the patient's

personal choices, (c) providing education about health and illness, and (d) ensuring continuity of care and treatment with regular follow-up.

Research Questions

The research questions for this study were: (a) What are patients' perceptions of illness and treatment in their daily lives? (b) What constraints do patients encounter which prevent effective management of illness? (c) What aspects of the patient-provider relationship impact compliance?

Definition of Terms

Noncompliance: Nurses are in a unique position to affect compliance through their interpersonal caring and knowing of patients.

Carpenito's (1997) definition of noncompliance was used in this study: "the state in which an individual or group desires to comply but is prevented from doing so by factors that deter adherence to health-related advice given by health professionals" (p.498).

Examples of medication noncompliance included (a) failing to have prescriptions filled, (b) not taking medication as prescribed, (c) taking medication prescribed for someone else, (d) misusing over-the-counter medications, and (e) using illegal drugs or alcohol while taking prescription medications (Fogarty, 1997; London, 1998; Powerpak, 1999). Treatment of noncompliance might also include making dietary changes and avoiding

substances known to be harmful, such as alcohol, tobacco, and illegal drugs (Wissen, Litchfield, & Maling, 1998).

<u>Patient-provider relationship</u>: A negotiated, mutual association in which both parties participate equally and are responsible for the risks, benefits, and outcomes (Yoos, 1981).

<u>Paternalism</u>: The practice of interacting with people in a parental manner without regard for their inherent rights, preferences, or responsibilities (Costello, 1997).

<u>Maternalism</u>: Rather than overtly acting for the patient, maternalism supplies stated consequences, often undesirable, as a means to coerce patient decisions (Taylor, Pickens, & Geden, 1989).

<u>Compliance</u>: The study definition used was "patients doing what the health professionals want them to do" (Fletcher, 1987, p. 453).

Overview of the Study

Past research has failed to identify a composite description of the noncompliant patient based on general characteristics. Noncompliance is not an all-or-none phenomenon because patients may be compliant with one or several aspects of a prescribed treatment while totally noncompliant in other aspects. Interventions designed thus far have not proved to be widely applicable in patient populations. Delving into patients' personal meanings may give insight

to the problem. Patients construct personal definitions of compliance. Roberson (1992) suggested that patients who self-tailor their medical recommendations according to lifestyle, preferences, and economics would otherwise be considered noncompliant by health care providers. These patients, however, tend to think they are doing a "pretty good job" (Roberson, 1992, p. 8).

This purpose of this naturalistic inquiry was to study and clarify from the patient's perspective, issues identified as influencing the patient's ability to comply with provider recommendations. A demographic survey was completed by each participant. Interviews were conducted to assess participant's personal experiences. Thematic analysis was applied in order to group the data into a meaningful set of causes for noncompliant behavior. Using this method uncovered meaningful interventions for improving health through compliance.

CHAPTER 2

Review of Literature

Early research on noncompliance, based on the medical model of paternalism, viewed patient-provider interaction as one in which the father-provider bestowed prescriptions for health and illness upon the child-patient (Szasz & Hollender, 1955). Lerner's (1997) literature review demonstrated prejudice evidenced against those patients who would not acquiesce to medical pronouncements...the poor, immigrants, transients, and alcoholics, many of whom were infected with tuberculosis. Terms such as "incorrigible, irresponsible, and vicious" (Lerner, 1997, p. 1424) were applied to patients labeled as health hazards. Thus began a long cycle of patient-blaming, fault-finding, and downright loathing of those who do not follow medical advice.

Prior to the 1960s there was limited research on patient compliance though Trostle (1988) reported that this deficit did not necessarily mean that patients were any more compliant then or that providers were not concerned about the probability of noncompliance. A more likely scenario, according to Trostle, is that after 1960 the availability of prescription drugs increased resulting in growing numbers of drug companies encouraging compliance through their media advertisements. At that time the terms "compliance and its opposite,

noncompliance" (Lerner, 1997 p. 1426) began to appear in research. This finding prompted health educators, recruited by biomedical researchers, to design interventions to assure compliance. The result was a prolific body of literature on the subject of patient noncompliance.

Cameron (1996) noted that over 200 characteristics of compliance were researched with conflicting results. The relationship between noncompliance and a number of variables has been studied: patient demographics, support systems, illness, treatments, patient education, patient satisfaction, and patient-provider relationships. (Blackwell, 1981; Hughes, 1991; Fosu, 1995; Fogarty, 1997; Mansoor, 1998; Mgebroff, 1998). Patient education and chronic illness interventions were the only two facets shown to positively affect compliance (Cameron, 1996; Roter, Hall, Merisca, Nordstrom, Cretin & Svarstad, 1998; Colorado Health Net, 1999). Clarence (1992) stated that providing patient education pertaining to medications (generic or brand name; method of action and side effects, when to take and whether with or without food) is key to increasing compliance.

Barriers to improved compliance levels were thought to include the number of medications taken daily, dosing schedules, side effects of medications, lifestyle changes, knowledge deficits, and type of chronic illness (Kunze, 1982; Thorne, 1990; Ward, 1997; Lerner et al., 1998; Lowes, 1998; Roter et al., 1998;). In one study (PowerPak, 1999), twice-daily dosing was recommended owing to the

fact that noncompliance in daily dosing could result in possibly greater than a 24 hours lapse in medication. However, even once-a-day dosing failed to guarantee 100% compliance (Sbarbaro, 1985; Kruse, 1992).

Prevention of disease with long-term therapy exhibited dismal compliance rates according to the American College of Preventive Medicine's report in October of 1999. Hormone replacement therapy (HRT) in postmenopausal women has been shown to reduce incidence of heart disease and osteoporosis yet only 18 to 20% of the eligible candidates use HRT, and of this number less than 30% comply (Clinical Briefs, 2000). Patients with peptic ulcer disease, in one study, showed improvement in treatment outcomes as their involvement increased (Greenfield, Kaplan, & Ware, 1985). Eight of 14 studies which examined compliance and treatment knowledge found no correlation (Yoos, 1981).

Fosu (1995) attempted to develop profiles of noncompliant elderly patients with hypertension in an effort to intervene before decline in health status or hospitalization ensued. Her study examined the importance of social support provided to these elderly patients by their female caregivers. Increased social support was expected to positively influence compliance levels. No significant difference was associated with race, gender, or education, though participants older than 85 and younger than 65 years of age were less compliant. Married participants were noted to be more compliant than their single,

divorced, or widowed counterparts. Participants who lived alone and in rural areas were found to exhibit higher compliance levels. No explanations were given by the researcher for this apparent contradition. Brearley (1990) found that while support systems are important to the patient and can improve compliance, caregivers who reported increased levels of personal stress often perceived their own health as being worse than that of the patient. Suboptimal patient compliance may result when caregivers unintentionally impose personal feelings while interacting with the care recipient.

Assuming patients are noncompliant by willful choice discounted that patients, especially the elderly, encounter problems such as (a) an inability to read or understand label instructions, (b) poor vision, (c) childproof lids that cannot be opened, (d) a lack of knowledge about the action and side effect of a medication; or (e) forgetfulness (Young, 1986; Merkatz & Couig, 1992; Curtin, 1995; Spaeth, 1995). Cost of medications is a factor in many cases of noncompliance; especially medications for hypertension (Oparil & Calhoun, 1998). These authors suggested that health care providers actively search out reasons for patient noncompliance, provide appropriate education about the treatment, and select the most effective, convenient, and affordable medication.

Measurement Issues

Along with efforts to define characteristics of noncompliant patients, tools for assessing compliance have been designed and applied. Pill counts, urine and

blood assays, electronic medication records, patient record reviews, and patient interviews have been tried, though as Kruse (1992) noted, there is no gold standard compliance measurement tool for qualitative or quantitative research.

A potential problem with ethics can also manifest itself when measuring compliance. Patients have been reported to change noncompliant behavior when they are aware of monitoring (Trick, 1993). In an effort to maintain validity, reported Haynes, et al. (1981), some compliance research involved patient deception related to assessment methods.

The expense involved in laboratory testing and the high cost of electronic equipment prohibit research at many levels. Correlating physiologic medication response and compliance has proved futile related to the variance between individual metabolic and excretory rates and the potential for laboratory error (Kruse, 1992; Playle & Keeley, 1998). Also, as Marland (1998) noted, measurements taken immediately after the medication has been taken could be erroneous. Kyngas and Lahdenpera (1999) evaluated hypertensive patients for a correlation between blood pressure control and compliance. They found none. The rates of compliance did not correlate with the high blood pressure readings. Proposed explanations were (a) refractory hypertension, (b) secondary sources of hypertension, and (c) inappropriate medication. Kruse (1992) further added that "evaluation of the relationship between compliance and dose response is impossible" (p. 164).

Several studies compared patient interview with other methods for assessing compliance (Haynes, et al., 1981; Craig, 1985). Patient interview was not only effective in many cases, it was also less expensive in terms of personnel and equipment, as well as often more accurate.

Consequences of Noncompliance

Providers are often misled in thinking their patients are compliant when in actuality they are not. Potential consequences of noncompliance also include extended recovery time in acute illnesses, rapid disease progression in chronic illnesses, and the likelihood of needing more intensive and invasive treatments. In a 1997 report, hospital admissions, nursing home admissions, and office visits related to noncompliance with medication for hypertension, cost approximately 15 billion dollars (Medical Tribune, 1997). Wasted health care resources and frustrated healthcare providers are additional abysmal side effects of noncompliance. Noncompliance is fated to remain an enormous problem for all involved: The receivers, the providers, and the financers (Madsen, 1992).

Cameron (1996) and Marland (1998) observed that some studies anticipated a degree of noncompliance. The question of how much noncompliance is permitted before the patient is deemed noncompliant was left unanswered. Fogarty (1997) quantified compliance into total, partial, consistent partial compliance, and outright noncompliance. Hill & Berk (1995) noted that there are "no standardized criteria defining acceptable compliance levels" across

many settings (p. 37). This lack of consistency has created problems with measuring noncompliance in both qualitative and quantitative research.

Could there be extinuating circumstances in which a diagnosis of noncompliance would be inappropriate? Holm (1993) noted that providers often prescribe a standard treatment for a certain condition without taking into consideration the patient's circumstances, wishes, or needs. Likewise, Carpenito (1998) proposed that when providers hastily toss a preprinted diet or other set of instructions to a patient, they are sending the message that "all clients are the same and that he or she will not be treated as an individual" (p. 3). Carpenito further explained that such cookie-cutter medicine ignores the patient's desires and assumes cooperation.

Ross (1991) outlined a definition of compliance judgment. Compliant patients were viewed as good and noncompliers were deemed bad. Recent authors have recognized that the term noncompliant may be less than politically correct and some have attempted to substitute more neutral language. Ward-Collins (1998, p. 27) conceded, "To influence a patient's behavior, we sometimes have to start by changing our terminology." Holm (1993) made a convincing case for deleting the term compliance when he wrote:

As we move away from the paternalistic conception of the doctor-patient relationship, to a form of relationship where the patient's autonomy and fundamental right to self-determination is [sic] acknowledged, we should

also abandon the present conception of compliance. If it is ultimately the patient who has to decide, after being duly informed and advised, then he cannot be noncompliant. He may be obstructive, foolish, or stupid if he blatantly disregards the decisions to which he is a party, but since they are his decisions and not the doctor's orders, this does not imply noncompliance. (p. 108)

Maternalistic approaches are more likely to be used by female healthcare providers (Taylor, Pickens, & Geden, 1989). The term is closely related to paternalism though with a twist. Paternalism involves authoritative decision-making for someone else while maternalism subtly coerces patient decisions that are aligned with those of the provider. As Taylor (1985, p. 12) elaborated, "If the practitioner is skilled at describing consequences, the patient can easily be led into an appropriate decision."

The problem of noncompliance appears to be multi-faceted and widespread among all ages, genders, and races. A report from Epill (1999) noted that one-third of patients take some of their medications, one-third take all of them, and one-third take none. Researchers seemed to abandon searching for the perfect specimen of noncompliance after countless studies could not identify specific traits or make accurate predictions about the patient population in general. Young (1986, p. 31) surmised that for every trait of noncompliant behavior

identified in research, "another study contradicts it." No patient profile or single, one-size-fits-all remedy for noncompliance exists at this time.

Strategies for Enhancing Compliance

The historic approach of patient blaming (Stimson, 1974) continued to decline as researchers delved into interpersonal aspects of the patient-provider relationship. Seley (1993, p. 391) noted, "paternalistic medicine has taught us that telling someone what to do is not enough." By the 1980s, researchers such as Brody (1980), Yoos (1981), and Roberts and Krouse (1990), began to dissect the patient-provider relationship into its qualitative aspects of respect, autonomy, communication and negotiation. They recognized that the behaviors and attitudes of each party were an integral part of communication and affected outcomes of patient compliance, satisfaction, and improved health status. Coy's (1989) research proposed that interactions between the parties may be enhanced if providers cease making the following assumptions about noncompliant behavior "(a) all cases of noncompliance are problems in need of a solution, (b) the solution to noncompliance is compliance, (c) all instances of noncompliance are problematical, and (d) the locus of the problem of noncompliance is the patient" (p. 827).

Patients create their own attitudes and beliefs about medicines and do not

"take them in a thoughtless vacuum," reported Stimson (1973, p. 101). Their reality is derived from past experiences in both personal and social contexts.

Many people in a patient's environment may be consulted about physical ailments and supposed treatments long before the first office visit with a health care provider. Patients' decisions regarding therapy often depend on personal experiences such as "economics, family, culture, and values" (Wuest, 1993, p. 220). Prescriptions for acute or chronic illnesses are more likely to be taken when the rationale fits the patient's beliefs and expectations about the disease and treatment. According to Porter (1994) the days when patients passively took their medicines without hesitation are gone. Employing active communication and ongoing negotiation with patients concerning treatments are steps toward compliance improvement because these actions acknowledge patient attitudes, beliefs, and preferences. Stewart (1984) also noted a positive effect on compliance when patient input was encouraged.

Providers often have no idea of patients' reasons for noncompliance (Nymberg & Selby, 2000). These researchers proposed that providers actively seek defining factors for noncompliance and work toward negotiation with the patient to develop a mutually agreed upon treatment plan. Included with their recommendation was a plan for formulating a differential diagnosis solely for the particular instance of noncompliance. Efforts at defining the patient-provider relationship brought about an abundance of studies aimed at correcting

problems between the two parties (Forman, 1993; Deber, 1994; Porter, 1994).

Strand (1994, p. 163) stated that the relationship between the provider and patient is based on the "least scientific but perhaps the most important aspect of compliance."

The building of a therapeutic relationship with patients is thought to be time-consuming and therefore unlikely in today's busy medical practices. McCord (1986) found that the amount of time spent with patients was not linked to compliance or increased patient satisfaction, but rather demonstrated that actual communication patterns and interaction quality were more essential components. Matthews, Suchman, and Branch (1993) also disagreed with supposed time contraints and stated, "eliciting the patient's full spectrum of concerns and allowing her to tell her story without unnecessary interruptions conveys the interviewer's interest without adding to the length of the visit" (p. 974). They further offered that nonverbal communication such as eye contact and nodding builds rapport. Gottlieb (2000) observed that high volume practices often do not allocate adequate time for discussing compliance issues. He proposed that addressing these concerns early could save time in the long run by decreasing the potential for extra testing or changes in medications precipitated by noncompliance. Follow-up with educational materials such as brochures, appointment reminders, and pill calendars could be delegated to office

personnel. Many video teaching tools are available which could be used as a way to provide needed patient education and save time (Oparil & Calhoun, 1998).

A large amount of noncompliance research has been conducted using quantitative rather than qualitative methods. Quantitative research designs for the study of compliance demonstrate most efficiently that noncompliance exists. Pill counts, urine and blood tests to detect medication levels, or measurements of blood pressure and blood glucose all serve to establish noncompliance. Even though problems have been reported with this type of testing such as allowances for distribution and elimination of drugs according to gender, body chemistry, and body composition, and the lack of standardized laboratory procedures, most scholars accept the numerically driven results. Qualitative research is designed to study the "why" of noncompliant behaviors by eliciting personal insights from participants.

The past four decades of noncompliance research queried thousands of patients and health care providers on various aspects thought related to the phenomenon. Some of these issues are patient satisfaction, type and scheduling of medications, chronic disease management, patient characteristics, and organization of care. Although there have been many qualitative studies published, most have not emphasized taking the patient's perspective when designing interventions for noncompliance (Blackwell, 1981; Kasch & Knutson, 1985; Roberson, 1992; Hill & Berk, 1995). The noncompliant patient cannot be

identified solely by demographics, disease, or treatment. No single, effective, universal "fix" for noncompliance has been found because it does not exist in this form. Patients are individuals before they are patients. People create their personal reality by defining and redefining their immediate world, to give form and meaning to each encounter. Personal interpretations of illness and treatment have been firmly entrenched in their lives long before coming into contact with the medical profession. Britten (1994) noted that prescriptive care should follow the patient's concepts of illness and treatment. When health care providers fail to accommodate patients' perceptions of the impact of illness and treatment within their world, patients are likely to become noncompliance statistics. This research proposed to study and clarify from the patient's perspective, issues identified as influencing the patient's ability to comply with provider recommendations.

CHAPTER 3

Methodology

Research Design

The research was a descriptive qualitative study that used the natural inquiry approach as described by Streubert and Carpenter (1995):

Natural inquiry is a research methodology wherein the researcher implements beliefs of the naturalistic domain. Two tenets describe the naturalistic domain: investigating phenomena as they occur naturally and deriving research outcomes inductively. Researchers investigate a phenomenon as it occurs naturally by observing it in its natural setting or by listening to individuals describe their experience of the phenomenon as it occurs for them. (p. 248)

This methodology is useful to nurses because it presents a view of the patient within the patient's own context: personal reality, meanings, and goals. As questions about noncompliance are answered from the patient's belief system, our understanding of the patient's context of health and illness will increase. This increased knowledge about the causes of noncompliance will enable health care providers to focus on interventions that the patient identifies as being relevant.

A demographic survey (Appendix A) was completed by each participant and analyzed for similarities and differences within this population. Participant interviews were conducted using the guidelines in Appendix B. Data analysis was completed using Boyatzis' (1998) approach to thematic analysis.

Conceptual Framework

Qualitative research allows individual perceptions to be explored from an emic approach defined as, "understanding life from the perspective of the participants in the setting under study and everyday life is examined in an uncontrolled, naturalistic setting" (Morse & Field, 1995, p. 21). An inductive design was best suited for the purposes of this study because it is concerned with the lived experience of the participants who provide personal interpretations of illness and treatment. During the analytic process the organization and interpretation of subjective information provided a holistic view of the participant's experiences and related how these factors played a role in whether or not the participant accepted or rejected treatment.

Within the framework of symbolic interactionism and the application of inductive research, patient perspectives about illness and treatment were revealed. Delbanco (1992) encouraged patient and provider to remain open to the preferences and values of each other, fostering an opportunity for mutual decision-making as well as problem-solving.

The nature and design of this research necessitated the use of constructs describing human action as an outcome of human interaction. The premises of symbolic interactionism were found to aptly illustrate that patient's perceptions could affect compliance. Blumer (1969) proposed that human interaction:

Consists of the fitting to each other of the lines of action of the participants. Such aligning of actions takes place predominantly by the participants, indicating to one another what to do and in turn interpreting such indications made by the others. Out of such interaction people form the objects that constitute their worlds; people are prepared to act toward their objects on the basis of the meaning these objects have for them . . . Human action is constructed by the actor on the basis of what he notes, interprets, and assesses. (p. 49)

Symbolic interactionism is "the philosophy of science on which qualitative research is based" (Wilson & Hutchinson, 1996, p. 138). Morse and Field (1995) described symbolic interactionism as "behavior that is developed through interaction with others, through continuous processes of negotiation and renegotiation" (p. 26). People define and react to their world through symbols, each of which has different meanings in different settings, and at different times. Symbols represent words, acts, and social objects, and are used for "representation and communication" (Charon, 1979, p. 40). Symbols, both

internal and external processes of the individual, include perspectives that are situational and constantly changing. Charon further explained that perspectives are not a passive learning process but evolve during social interactions and are changed, discarded, or redefined as they are shared with other individuals. Internal symbols might contain personality traits such as memory, emotions, and personal preferences while external symbols might describe living with others, societal functioning, and perceptions of others' intents. This framework was used to show that reactions evidenced by people are not static but change as personal environments change, creating a new reality for that particular instance.

Voluntary participants included a purposive sample of 12 English-speaking males and females (older than 18 years of age) from an internal medicine practice in St. Augustine, Florida, and five participants from a retail store in Palm Coast, Florida. Inclusion criteria were met when each participant had at least one chronic condition that involved the use of at least one daily medication or treatment. Patients currently under treatment for an acute or self-limited condition (with or without medications) were excluded from participation in the study. Patients with acute illness were excluded due to a relatively short duration of medical treatment. The first site was chosen because the researcher had good rapport with both staff and patients, was comfortable with the office set-up, and was afforded flexible hours for scheduling interviews.

The patient population also offered a variety of medical diagnoses and treatments that enhanced the diversity of the sample.

The second site was chosen due to its convenient location and the large number of shoppers observed by the researcher. The patient-counseling area adjacent to the store's pharmacy was used for conducting participant interviews. Instruments

A demographic survey completed by each participant was used to describe sample characteristics (Appendix A). A guide for the interviewing process was used (Appendix B) as a basis for starting the conversation with the participant. Questions were not asked in the order written, rather, they were interjected during conversation that was driven by participant response.

Procedure

Twelve participants were interviewed individually in a private office within the internal medicine practice in St. Augustine, Florida. The interviews were conducted by the researcher and audiotape recorded. Each interview lasted approximately 30-45 minutes. Field notes made during the interviews were analyzed for complementary information. Tape recordings were researcher transcribed as soon as practical after each session. Only the researcher and the members of her thesis committee had access to tape recordings, field notes, and transcriptions. Participant confidentiality was protected and responses were not shared with any physician or staff member in the practice setting.

Five participants volunteered to participate in the study from a retail store location in Palm Coast, Florida. Interviews were conducted in the patient counseling area of the pharmacy. Other aspects of the research (demographic survey, field notes, transcriptions) were identical to the first site.

Ethical Considerations

Prior to beginning research, University of North Florida Institutional Review Board (IRB) approval was obtained. Informed consent (Appendix C) was obtained from each participant prior to interview along with completion of the demographic survey. The demographic data were kept under lock and key and destroyed after the data were analyzed. The primary investigator transcribed the audiotaped interviews and destroyed the tapes when data analysis was complete.

Privacy of the participants was assured at both study sites. The researcher alone conducted the audiotaped interview and answered questions or defined terms as appropriate.

Confidentiality of participants was maintained. No identifying names, numbers, or codes were used on the demographic survey, during the interview, or on any field notes. Only the researcher and members of this thesis committee were allowed access to completed surveys, interview tapes, transcriptions of tapes, and field notes. Transcription and destruction of tapes were the

responsibility of the researcher. No patient-identifying information was included in the transcription. Physicians and other staff within the medical practice were not given any information regarding the identity or responses of participants in order to protect confidentiality.

Recruitment of Participants

Recruitment was conducted by placing notices about the proposed study in the waiting areas and by direct inquiry from the practice's patient database. Recruitment at the retail store site was accomplished by asking people if they wanted to answer some questions related to how medications are taken and the effects treatment entails. Participation was voluntary. The purpose of the study was explained in detail and questions answered by the researcher. An informed consent form was provided and clarifications given as necessary. After informed consent was obtained an audiotaped interview was conducted or an appointment made to conduct the interview at another time.

Data Collection

The setting for this study was a private room in an internal medicine practice in St. Augustine, Florida and a retail store in a shopping center in Palm Coast, Florida. Data were collected from December 2000 through March 2001. Twelve participants from the practice's patient database and five volunteers from the retail store were interviewed face-to-face. The interview was designed to elicit information about the participants' perspectives of illness and management

within their daily lives. During the interview process the guidelines (Appendix B) were altered as conversation led. Interviews lasted from 30 to 45 minutes each.

Demographic surveys were completed on paper by the participants and collected from them by the researcher. Participant interviews were conducted by the researcher and audiotaped. Transcription of the audiotaped interviews as well as any field notes were carried out by the researcher as soon as possible after each interview.

Coding of Data

The researcher, under the supervision of members of the thesis committee, categorized the information contained in the demographic surveys and transcriptions of audiotaped interviews. Transcripts were coded based on key word(s) identification and grouped into appropriate exclusive categories. No identifying information was used in order to protect the privacy of the participant.

Data Analysis

The informed consent, demographic survey, audiotapes, and any field notes made by the researcher were numbered and placed into an envelope for each participant. Transcriptions of the audiotapes were placed in each participant's envelope. The numbering system did not identify participants except in a file accessible only to the researcher.

Data collection and analysis occurred simultaneously as a fluid process of organizing and synthesizing qualitative material into categories or themes which emerged to illuminate a phenomenon. Verbal data and behavioral observations were organized into themes and patterns in an effort to reveal causes for patient noncompliance from the patient's perspective. The processes of "comprehending, synthesizing, theorizing, and recontextualizing" (Estabrooks, Field & Morse, 1994, p. 505) were used in the analysis of interview content to identify themes and patterns related to noncompliant beliefs and behaviors.

Boyatzis (1998) outlined theme and code development in the following steps: "(a) reducing the raw information, (b) identifying themes within subsamples, (c) comparing themes across subsamples, (d) creating a code, and (e) determining the reliability of the code" (p. 45). The application of systematic data review served to familiarize the researcher with the material gathered from transcripted interviews and field notes, allowing for pattern recognition as themes emerged. Boyatzis (1998) recommended comparing preliminary themes or patterns for similarity and continuance throughout item analysis in order to "determine the presence or absence of each of the themes" (p. 48). Interrater reliability and consistency between reviewers were assessed by visual comparisons of collected data as a final analysis for the validity of content.

Methodological notes made by the researcher during the course of patient interviews were included to maintain a check on personal thoughts, feelings, and

attitudes. These notes, according to Wilson & Hutchinson (1996), "promote research reflexivity and minimize interviewer or observer bias" (p. 110). Memoing, proposed Hutchinson (1993), includes such methodological notes and is useful as data collection strategies are refined and clarified. Hutchinson stated, "in order to capture the initially elusive and shifting connection between the data," memoing is a record of the researcher's thinking process that will become invaluable as concepts and themes emerge (p. 201). During the research process, inductive and deductive reasoning were used to assess content of memos written during interviews. Recurring themes were inductively identified from the initial data-coding and memoing. Data analysis enabled conclusions to be drawn based on the coded data. Transcribed interviews were coded to isolate key words which were grouped into categories as repeating themes emerged.

Maintaining Rigor

In qualitative research, the researcher seeks to understand the influence of personal and professional experiences on data collection. During the course of interviewing participants, this researcher used field notes and memoing to record nonverbal events related to the participants, and to note any personal thoughts or feelings in an effort to avoid bias by manipulating data content.

Credibility, applicability, and confirmability are components of scientific rigor that must be addressed in qualitative research (Guba & Lincoln, 1981; Sandelowski, 1986; Guba, 1989). A credible qualitative study is one that is

believable and makes sense to the reader. Confirmability is demonstrated when members (participants) or colleagues (peers) agree with the analysis. Both credibility and confirmability can be checked by providing a participant with an analysis of an interview and asking if the analysis agrees with the participant's intentions. The researcher used comments analyzed from earlier participant interviews to confirm themes identified in later interviews.

Sandelowski (1986) likened applicability in qualitative research to external validity in quantitative research when deciding whether or not the data obtained are representative of the participants studied. Peer checking for applicability was accomplished, as the interview transcriptions were read and coded for analysis by two members of the thesis committee.

CHAPTER 4

Results

The main objective of this qualitative research was to study and clarify from the patient's perspective, issues identified as influencing the patient's ability to comply with provider recommendations. No quantitative tools for assessing compliance were used in the study. The demographic survey completed did not ask study volunteers if they were or were not compliant with medications or treatments. Participants were simply asked how they managed taking medications in their daily routine. Follow-up questions led to discussion about the extent of compliance exhibited along with factors that precluded compliance including the patient-provider relationship, social and family dynamics, financial considerations, and participants' perceptions of disease and therapy.

Description of participants

After 12 interviews were conducted the researcher noticed a lack of ethnic diversity among participants. Though other races (Blacks, Hispanics, and Asian Americans) were asked to participate in the study none volunteered. A request was made to the Institutional Review Board (IRB) for an additional study site in order to increase the diversity of the study population and reduce a potential

bias in data collection. The original study site was a medical office and it could be argued that participants were already at least somewhat compliant to the extent that they were recruited from a medical setting in which they had an appointment.

After obtaining IRB approval five additional interviews were obtained from volunteers at a shopping center in Palm Coast, Florida. Procedures for participant recruitment, demographic survey completion, and informed consent were identical to those followed in the first site. Privacy was ensured by conducting the interviews in the patient counseling area adjacent to the pharmacy located in the department store.

A total of 17 interviews and demographic surveys were obtained, transcribed and coded for content. Interviews lasted from 30 to 45 minutes. Pertinent field notes (2,553 words) made by the researcher were also used to provide complementary information in order to recreate the general tone of the interview and the general thoughts and feelings of the researcher. A total of 99 type-written pages with three-inch left margins were analyzed and thematically coded for content.

Ethnic groups represented in the study population were 12 Whites, four Blacks and one Hispanic with an age range of 31 to 74 years (mean age 61). Participants were either married or widowed, and all had at least one child. Only one participant did not have a high school diploma. High school graduates

numbered six with 10 participants having completed from one to four years of college. Yoos (1981), McDonald (1988), Madsen (1992), Anderson and Zimmerman (1993), and Trick (1993) found no significant trends relating compliance to financial status. Therefore no data on socioeconomic status were solicited.

All participants were insured either through Medicare, Medicare with a supplement, health maintenance organization, point of service, or group insurance. Fosu (1995) found that patients insured through Medicare coverage were more likely to be compliant with hypertensive medications. In this research it was noted that the three Medicare-only insured participants diagnosed with hypertension stated 100% compliance with medications, while the majority of hypertensives covered by Medicare plus a supplemental insurance were less than 100% compliant. This finding is interesting in that Medicare-only coverage currently does not pay for medications while Medicare plus the supplemental insurance often covers prescriptions.

Participants' medical conditions included: Hypertension, coronary artery disease, non-insulin dependent diabetes mellitus, depression, asthma, arthritis, gastroesophageal reflux disease, hypercholesterolemia, chronic renal failiure, congestive heart failure, chronic back pain, obesity, allergic rhinitis, fibromyalgia, anxiety, small cell lung cancer, hypothyroidism, peripheral vascular disease, sexual dysfunction, irritable bowel syndrome, anemia, and polyneuropathy.

Medications prescribed for participants ranged from one to 14 medications daily. Four participants took five separate daily medications, two listed six daily prescriptions, two had nine daily prescriptions, and the remaining nine individuals took one, three, four, seven, eight, 11, 12 and 14 daily medications. Instructions to alter lifestyle by diet, exercise, or smoking cessation had been prescribed for 15 participants.

Patients' Perceptions of Illness and Treatment

Patients' perceptions of illness and treatment in their daily lives ranged from minor inconvenience to major aggravation. Of all participants, six who listed more serious diagnoses (congestive heart failure, coronary artery disease, small cell lung cancer, hypertension, and chronic renal failure) and who averaged seven daily medications, reported less than 100% compliance. Most of the participants expressed a belief in medication efficacy, improvement of health status with prescribed medications, and a positive relationship with the health care provider. When asked about taking medications, one participant stated, "I have to take them [medicines] or else I'm really going to be screwed up." This same person also felt that his health was "pretty good," and regarding his health care provider stated, "He listens to me."

Patients' Interpretations of Compliance

Patients create their own meanings of compliance. Seventy-six percent of participants described themselves as 100% compliant though they did not take

Compliance

medications as prescribed or failed to follow through with other provider recommendations. Nearly one-third of this group considered themselves compliant with medications but not with lifestyle changes. Participants felt that they were compliant if they took medications as ordered regardless of whether or not they made lifestyle changes such as diet, exercise, or smoking cessation. Only four participants stated 100% compliance with both medications and lifestyle changes.

Patients do not necessarily accept or understand that diet, exercise, and smoking cessation constitute a prescription. One of the most difficult lifestyle changes to make is smoking cessation. Three participants admitted that they still smoked cigarettes even though they had been advised by physicians to quit. One man noted:

Of course they all want us to stop smoking but I don't think it's going to happen in my lifetime, even though we try to slow down, but it's just, you know, one of the bad things. We know it's bad and the doctor knows it's bad, but it keeps me going.

Patients encounter various constraints which prevent effective management of illness and hinder health promotion. Some of these problems may be related to work and school schedules, social activities, personal preferences, and forgetfulness. On the whole, participants reported that they tied their daily medications with meal or bedtime schedules.

Participant's perceptions of therapy inferred a connection between symptomatology relief and medication. A conversation with one participant about the celecoxib she takes for her arthritis elicited this statement: "I usually take it mid-evening and I remember because I hurt if I don't." Another, when asked why she continued to take her medications replied, "Probably because I know it works--like if I miss a day I can tell." A statement about allergy medication prompted this comment, "If I feel that my allergies are out of whack then I'll take the Claritin...it really works." An overweight participant noted the improvements she enjoyed once she was on a diet medication, "I was feeling very sluggish. . . always tired, sleeping. Not now. I feel good." One participant related that she took her medications faithfully, stating, "Well, the two that I take, the hormones and the lipitor, is the blood work. The cholesterol was through the roof and I had to have blood testing." This same participant also reported that she continues to have regular laboratory tests related to the atorvastatin because, "I'm afraid of it going to my liver, so I go every three months."

Seven participants related that beliefs in medication efficacy prompted them to take medications regularly. One reported, "I figured it [medication] was good for my health." Another recalled a time when she decided to discontinue a medication , "With the Prozac I thought, I don't need this . . . and I found out that I did." One of the participants who listed serious diagnoses and who takes

12 daily medications explained his beliefs in medication this way, "If I don't take them--I die."

Reports from other participants indicated that side effects or lack of efficacy of medications resulted in self-altering of treatment plans. One participant explained that her antianginal medication had been switched from a twice daily dose to once daily. She commented, "I was not getting the correct medication. I started having angina within four days." One gentleman had noted that his tongue was turning brown and complained, ". . . something's in my medications . . . it's screwing up my tongue."

Another participant experienced problems with an antidepressant that was prescribed for him to take three times daily. He stated:

I am taking one a day. I reduced that primarily because it was causing my heart rate to go very low, which the doctors told me would cause that particularly in older people. And so, they prescribed several other alternatives, but I could not take any of them. They all put me to sleep.

Whether or not these participants considered themselves compliant, 71% felt that prescribed treatments improved their health status. Interestingly, the five participants who listed the most chronic and potentially disabling diagnoses responded "pretty good" when asked about their current level of health. One patient, who reported 100% compliance and was on seven daily medications,

stated that she was "unhappy and felt bad," noting that physicians had failed to "listen" or had discounted her concerns.

Forgetfulness was reported by several participants. Explaining why he sometimes forgets to take his heart medications, one participant stated "I don't have a lot of problems with it [heart] now . . . the back medication, if you forget to take it, it reminds you."

Self-tailoring of prescribed therapies was mentioned by 76% of participants. One man decided not to take a prescribed oral medication for Type 2 Diabetes Mellitus, using diet and exercise instead to control his blood sugar. When his sugars were indeed controlled in this way, his noncompliant behavior became self-treatment that worked. "I just felt I was OK with dieting and exercising and that's the way it turned out. My sugars verified that I was OK."

Two other participants, who listed serious health care problems and who were not compliant, seemed angry and disgusted when describing interactions with providers. The tone of these two interviews evidenced the impact of a negative relationship on both perceived health status and patient empowerment, findings substantited by Wissen, Litchfield, and Maling (1998). Both participants stated problems with untoward medication side effects, lack of concern and follow-up from providers, dissatisfaction with office staff, and the arbitrary changing of medications by the insurance company. When asked what prompted visits to the doctor, one woman stated, "Asthma. I usually end up in the

emergency room. Sometimes twice in the same day." During the interview it was discovered that there have been major miscommunications between her insurance company and her health care provider, resulting in the patient's feeling that she "may never get medications straightened out." She explained, "They have changed quite a few . . . it's not just the generic for that medication, it is another medication." The woman admitted that she had not made any recent attempts to rectify problems in obtaining medications stating, "It's hopeless, really. You can't win. The insurance companies give you what they want to."

When asked specifically about current level of health, two participants simply listed diagnoses. A possible explanation could be that these individuals identify themselves by diagnoses and don't desire a participatory, active role in treatment. Waterworth and Luker (1990) noted that some patients don't want to be consulted about their plan of care. While this may be true, a lack of participation does not necessarily mean tacit agreement and compliance.

An important aspect of these two interviews is that both participants admitted to modifying medication dosing (gabapentin, triazolopyridine, calcium channel and beta blockers) without informing their health care provider. Reasons for not discussing this issue with the provider were not expressed or implied by the participants. Both participants did indicate a need for teaching regarding medication action, side effects, and dosing.

Lack of patient education related to medications or other treatments was felt to be a problem by 29% of the participants. "There are some [doctors] that have lots of patience with you and explain stuff to you; and then there are others that you go in and diagnose your own problem and they give you some medicine for it. I 've had some like that." One participant stated that getting detailed information from her doctor was difficult. "It is my body and I want to know everything that he knows about. You know, I don't like surprises."

Another woman stopped taking simvastatin for her high cholesterol due to having some hair loss. She had not been told that this could happen and stated that she "would never take another kind of those drugs."

Failure to determine the feasibility of incorporating lifestyle changes may contribute to a patient's noncompliance. One participant found it difficult to follow her low-fat diet because she lived with someone who was not on dietary restrictions. "Well, when you are cooking for someone else, it is hard. You know, when they are eating something different than what you are supposed to have. It makes it a little bit difficult." She had never been referred to a dietician in the community and acknowledged that doing so "probably" would have made a difference in her compliance with dietary recommendations.

Patient-Provider Relationship

Thematic analysis illuminated several important perceptions of participants associated with the patient-provider relationship. Negative

attributes of patient-provider interactions were identified as discounting patient concerns, being dissatisfied with office personnel, lacking patient education about medications, and being rushed through an office visit. Participants listed positive perceptions when the provider related to them, listened, addressed concerns, and included them in the plan of care. An accommodating office staff who exhibited behaviors expressing warmth, friendliness, and efficiency was also reported appreciatively by participants.

Unexpectedly, during several interviews the issue of control regarding health care decisions was highlighted. One participant stated that she takes methotrexate for her rheumatoid arthritis but wanted to wean herself from it. She believed that her provider, "Gives me an option. I don't try to run my care but he is informed of my wishes." She acknowledged that her doctor, "Always listens. He listens to what I ask him for and if he thinks it's appropriate he'll tell me and if not he'll tell me that too." Another participant, while describing lack of control with one provider, noted this reaction to being prescribed eight daily medications, "I felt depressed by it, because I'm not a person who likes to take a lot of medications." When asked about his level of input into the treatment plan, one man stated, "I don't actually feel that I had input but because I'm not skilled at this...the doctors... they're trained." Another reported that if she decided to alter a medication schedule she first informed the health care provider,

explaining, "Because I'm not that stupid. I want them to know what I'm taking because then I give him that kind of control."

The provider attribute most often mentioned by participants was listening (64.7%). During interview sessions 59% of the participants used the verb "listens" to describe a positive aspect of the relationship with their health care provider and 64.7% referred to the act of listening in the interviews. One participant was asked if she felt that her provider listens. She stated, "Oh yes. He pulls up the stool and sits here before he ever puts the stethoscope on you. Whatever you have to say . . . he's right here with you." This same woman also stated that the relationship with her provider directly influenced her compliance with treatment.

McCord's (1986) research confirmed findings in this study of the positive influence on compliance when the patient judged the health care provider as caring, interested and concerned about all aspects of the patient's life. One participant expressed her patient-provider relationship in this way:

Oh, I love Dr. D. Because he takes time to talk to you about whatever the situation is. Like I can come in to him and say such and such is the case . . . and you know, he listens. And then, he speaks on the subject."

She went on to explain that she reserves final approval on treatments: "If he gives me medications that he feels is proper then I'm going to take it. And if I feel anything different then I would tell him."

Still another participant admitted that consistent advice from his provider made a positive impact on his smoking habit. He stated:

They told me if I keep smoking—it's the heart. I was smoking two packs a day. I quit altogether and then, you know, things started bothering me so I smoke a little bit once in a while. Otherwise I don't bother with it like I used to.

One man stated that his provider, "Made you feel at home . . . at ease. And as far as I'm concerned the way he talks to you . . . very friendly." He insisted that the relationship with the provider did not have any bearing on his compliance but added, "Course, it hasn't aggravated the situation, and I might change my mind but so far . . . no problems."

Three others perceived a negative trait of "doesn't listen" or "doesn't address my concerns" related to their health care providers. This was clearly a problem with one participant who expressed, "A lot of times, you know, we see doctors and they will just give you a few pills and send you home, not knowing, you know, they don't explain a lot of things to you."

Discounting patient concerns is also a source of angst for many patients noted Thorne (1990). She found that pre-judging patient conditions is often construed as cookie cutter, one-size-fits-all medicine that only serves to frustrate and anger patients. Participants in this study mentioned some of these issues.

One woman who was interviewed complained to her doctor that her neck was

hurting only to have him ask "Well what do you expect for a woman your age?" The patient stated that she was 50 years old at the time and did not feel that she was particularly "old" and so replied, "I should feel a hell of a lot better than I feel." Another participant stated that she has had high cholesterol levels for four years which has yet to be addressed by her physician. Her aggravation was evidenced by her statements "I don't feel like he listens to me well enough to understand me and give me input as to what I can do to help."

As participants related experiences of feeling rushed through a doctor's appointment, their comments reflected disappointment with the interaction. A woman described her relationship with a previous provider, "I've had another doctor . . . you were in and out before you knew it . . . he handed you your prescription . . . like it was all right whether it was all right or not." Another participant stated that she felt doctors often narrowly focus on the presenting complaint, and "they get complacent unless you look really sick or act really sick." Yet another participant lamented:

You know, I don't think he ever put the stethoscope to my chest and listened to my lungs or any of those things. He just talked to me for a few minutes and then gave me a prescription for medicine and sent me on my way and that was it.

Patient Perspectives on Office Staff

A separate aspect of compliance mentioned by four participants related to the staff in physicans' offices. One man called to make an appointment with his family doctor for an acute problem and was sent instead by the office staff to a specialist. He stated, "They just take it on themselves a lot of times to do something that they don't tell you about." Three participants mentioned "lost charts" or the inability of office staff to retrieve pertinent information when requested. Follow-up with patient concerns such as lab results often plays a significant role in fostering a good relationship with health care providers. One participant noted that she missed the "follow through" enjoyed with a previous physician's office:

Whenever he did lab work, within three or four days, we would get not only a copy of the lab work, but typed in on the bottom was his interpretation of the lab work and what we needed to do, and how we needed to follow-up because of that lab work.

Five patients volunteered that part of the overall satisfaction with their health care provider related to the office staff. One patient explained the relationship with her provider, "I think it's a good one and his wife is right out there in the reception. She is very nice. I feel like they know me. They understand." When one participant was asked about specific provider attributes that contribute to a good relationship, she responded, "I feel good when the

nurse or the receptionist . . . when I call they recognize your voice on the phone if I think that I need to see the doctor . . . they'll try to accommodate you." Another participant was asked to describe the relationship with her provider. She replied, "With Dr. C. and his nurse and staff . . . they feel like family . . . very personal."

One participant strongly linked satisfaction with provider, staff, and compliance in this way, "That has a great bearing on whether or not if I'm happy or if I'll follow through . . . with what I think of the doctor and the doctor's staff." Summary

Listening was identified as an important provider behavior though it was not the single, most significant finding. Health care providers have an obligation to explore patients' reasons for noncompliance, and listening is one way to determine what factors prevent patient compliance.

Another significant finding was that patients who are not 100% compliant with medications or other parts of the treatment plan did not percieve themselves as so. Including the patient in the plan of care is one way the provider can ask the patient for his perceptions of compliance, explore potential obstacles, and work toward building a positive relationship--another result noted in this research.

Providers have a responsibility to ensure that appropriate patient education includes medication efficacy and possible side effects. It is also

incumbent on providers to consider the following factors: the patient's current perceptions of illness and treatment; any environmental factors that may affect compliance such as finances, work or school schedules; and those obligations patients must meet as members of a family group.

Several factors identified with treatment compliance could be equated to concepts of symbolic interactionism. The internal aspects of compliance could be considered as the personal preferences of patients, symptomatology, forgetfulness, and depression. External aspects could be derived from social interactions such as patient education, office staff behaviors, work and school schedules, and whether or not the provider listens and relates to the patient. Though these relationships are complex and varied, the potential exists for interventions to be developed to improve compliance. Examples of interventions might include relating symptomatology to the particular drug prescribed, screening for depression, considering the patient's personal preferences, following-up to ensure continuity of care, being realistic with dietary and exercise recommendations, using calendars and pagers to decrease forgetfulness, using patient feedback to demonstrate the importance of office staff behaviors, and listening to the patient.

Medicine in the 21st century offers almost miraculous, life-saving, though often expensive technology and is still trailing by decades in improving patient compliance with treatments. Wasson & Jette (1993) surmised that modern health

care interactions focus on high-cost technology; ignoring that old-fashioned continunity of care and open communication have been shown to optimize patient outcomes. Participants in this study verified the importance of providers' making an attempt to understand what disease and treatment mean to them based on personal beliefs, lifestyle, and wishes. Symbolic interactionism offers a vehicle for such an approach. It forces reflection on the non-static, potentially alterable state of beliefs and perceptions. Applying this theory to patient compliance fosters inclusion of the patient's perspective, promotes a negotiable balance between what the patient wants and the current standard of care, and supports acculturation of social contexts into optimizing patient outcomes.

CHAPTER FIVE

Past research of noncompliance focused on several different perspectives, such as the types of diagnoses and varities of medications ordered, patient-provider relationships, and patient satisfaction. Twenty-seven years ago Stimson (1974) encouraged researchers to delve into the problem of noncompliance from the patient's point of view. The theory of symbolic interactionism provides an avenue for understanding patient noncompliance by using the patient's perspective to define the phenomena, thereby illuminating beliefs, including misconceptions, in order to develop treatment plans from the patient's frame of reference. Taking the patient's perspective starts with listening to the patient's story. During this narrative the health care provider listens for the patient's meaning and the significance placed on health and illness based on life experiences. As values are identified and misconceptions noted, the provider is able to visualize the internal patient and can then address misconceptions, using the patient's stated values and definitions to jointly develop a plan of care.

Discussion

This study proposed to study and clarify from the patient's perspective, issues identified as influencing the patient's ability to comply with provider recommendations. Analysis of interviews showed that the provider's ability to

listen was interpreted by many patients as a positive attribute. The majority of the participants also percieved that their health care provider understood them, included their input into the plan of care, and was concerned about them. The data did not concretely link these perceptions to improved compliance though 71% of these patients felt they were compliant. Findings of Hill and Berk (1995) support that patients' perceptions of the benefits and complications of treatment influence decisions to adhere to recommended treatment and engage in recouperative behaviors.

The connection discovered between symptomatology and medications indicated that the responsibility of a health care provider is not over once the prescription is handed to the patient. Conscientious education about medications should be provided to all patients. Understanding patients' perceptions fosters a relationship in which patients feel free to contact the provider should they desire a change in a medication or schedule of dosing.

Providers adopt a narrow, one-sided view of patient noncompliance when looking at the phenomenon of noncompliance only from the perspective of health care professionals. This attitude prevents acknowledging patients' perspectives which are divergently influenced by culture, socialization, education, and experience. Social and cultural awareness may offer providers the opportunity to enhance patients' beliefs while altering misconceptions.

Recognizing and incorporating patients' perceptions of the psychological and logistical barriers to compliance are imperative for improving patient outcomes.

Limitations

The majority (88%) of these 17 participants expressed positive feelings about many aspects of the relationship with their health care provider and the treatment plan. Compliance was reported by 71% of this population. A larger patient population may yield percentages sufficient to determine if negative feelings or experiences affect compliance levels.

Questions developed as guidelines were written to elicit information from participants that would lead to other discussions during the course of the interview. For example, the question 'What do you expect from your health care provider' could possibly have been more fruitful had it incorporated a more detailed aspect of the patient's view of the interaction. However, the data provided preliminary support for using symbolic interactionism as a basis for improving patient compliance.

Past research has indicated that social support affects compliance. Fosu (1995) noted that married persons are more likely to be compliant with treatment related to an aspect of perceived spousal support. This fact may be an inherent bias considering that no single participants volunteered for this study.

The researcher anticipated a lack of minority volunteers related to problems they may have experienced when seeking health care due to lack of financial resources. This position is supported by Skosey's (1998) findings that minorities' lack of access to primary care as well as lack of knowledge about research hampers recruitment. Durso (1997) reasoned that the infamous Tuskegee Syphilis Study from the 1960s has contributed to minority suspicion about participating in research. Another problem identified is that minorities frequently are underinsured and have difficulty accessing and negotiating the health care system. As a result, many minority ethnic groups are largely mistrustful of the medical community. A larger population increases the likelihood of obtaining a wider ethnic diversity than was noted in this study.

After conducting the initial interviews of 12 Whites, the appropriateness of the site came into question. Looking critically at the study at this time, the researcher questioned whether these 12 participants leaned toward compliance to the extent that they were recruited from a medical setting. Seeking to increase the diversity of the population as well as remove the potential bias for the medical setting, IRB approval was obtained to add a more neutral site. The remaining five interviews were then conducted in the pharmacy's patient counseling area within a large retail store.

Persons asked to volunteer for the study included Blacks, Hispanics, Whites, and Asian Americans. In the final analysis, there were 12 Whites, four

Blacks, and one Hispanic who volunteered and were interviewed for this research. Gender representations included seven male and 10 female participants. By including the additional site, the study population distribution met United States census figures for Flagler County for the year 2000 (U.S. Census Bureau, 2000).

Participants were not directly asked whether they were or were not compliant. Definitions of compliance outlined in chapter one did not include an all or none phenomenon. Cameron (1996) recognized that many different definitions of compliance have been generated, but none addressed an acceptable amount of noncompliance before labeling the patient as such. Could a participant comply with taking medications but not with other aspects of the care plan and still be considered compliant? Could the participant be successful with diet and smoking cessation though noncompliant with exercise and still be considered compliant? The indicators of compliance often are not equal thus quantifying the level of compliance became a dilemma for the researcher.

Implications for Future Research

Interpretations of noncompliance, anecdotal reports, and research papers numbering in the thousands have been based largely on the notion that noncompliance is an irrational patient behavior. Total compliance is expected by the medical community though this quantification neglects patients' definitions and reasons for their actions. It could be argued that patients' reasons for

noncompliance may be justifiable. The assumed superiority of providers bestowing treatment ignores patient perceptions. Future research should focus on aspects of chronic disease management, taking into consideration patients' perceptions of disease, treatment, and identification of factors responsible for compliance. Symbolic interactionism offers a contemporary model of patient care in which patient and provider share mutual respect of values, acknowledge meanings, and open communication to set the stage for working toward realistic and relevant goals.

All participants in this study were insured either through Medicare with or without supplementals or private or group insurance. No participant was uninsured or insured through Medicaid. Future studies with those who are under-insured or have no health care insurance should be conducted to analyze the experiences of patients as they traverse the medical system.

Participants expressed a strong connection between taking medications and symptom relief. Future research should attempt to link these two interpersonal aspects to compliance levels.

The issue of control in the patient-provider relationship has been noted in past research, often associated with providers' paternalistic attitudes. Results of this study indicated that some patients overtly give control to their providers and some retain control. More study in this area may reveal connections between control and compliance.

This study unexpectedly discovered the role office personnel behaviors play on the subsequent compliance or noncompliance of patients. Office staff are often the patient's first impression of the provider. This ongoing contact with staff seems to permeate the patient-provider relationship and deserves closer inspection in future studies.

Implications for Practice

Patients are the experts of their own social context. Clark (1996) proposed that a more "humane way of practicing medicine would be to give conscious recognition to the patient's context of his problems, and to be more responsive to the patient's experience and feelings" (p. 752). The health care provider can then complete the record using the patient's interpretations in a restatement of the perceived problem in medical terminology.

When diagnosed with a chronic illness, some patients may rise to the challenge while others are defeated at the outset. This study agreed with authors such as Siegel (2000), noting that patients with identical diagnoses and treatments often experience markedly different reactions. The strong link noted between medication and symptomatology necessitates that providers educate patients about medications prescribed. For example, patients may not complete a 10-day course of antibiotic therapy because they feel better after four or five days. Teaching should be tailored to the medication's efficacy, response expected, and possible side effects.

Only by asking patients about subjective experiences and encouraging open communication can health care providers explore the unique needs of patients. Engaging in mutual decision-making, providing appropriate education, and conveying positive feedback are ways to discourage patient self-tailoring of medications. Determine how much control, if any, patients want in medical treatment plans. Ask patients what they want, what their concerns are, and then listen.

Active listening provides a strategy for discovering insights and underlying concerns that may not be succintly stated. Stone, Bronkesh, Gerbar, and Wood (1998) acknowledged that patients are usually the most reliable source of information about their lifestyles and perceptions of medical care and treatment. This research encourages improving patient compliance through: (a) accepting patients' beliefs about therapy while correcting misconceptions through patient-teaching; (b) building therapeutic patient-provider relationships; and (c) recognizing and promoting the importance of caring behaviors in office staff.

The patient-provider relationship offers an opportunity for sharing information. Included on the periphery of this relationship are the ancillary office staff who should create an atmosphere in which the patient feels recognized and appreciated. This type of individualized approach involves the patients in their care by employing active listening while addressing patient concerns. These

actions promote compliance. As providers use open communication strategies, patients are able to sense genuine concern, build rapport, and actively negotiate treatment. Using Dorsky & Dorsky's (1999) blueprint for interaction the provider consciously (a) engages the patient, (b) shows empathy, (c) educates the patient about health, illness, and treatment, and (d) enlists the patient 's perceptions into a jointly formuated plan of care.

Prescriptive therapy should include patient education concerning the medication method of action, side effects, and duration of treatment. Participants in this study often reported positive links between symptomatology and medication. Exploration of a patient's belief in the efficacy of medications could potentially enhance compliance.

Many physican providers acknowledge limited skills to provide patient teaching in areas such as smoking cessation and dietary regimens. Attempts to break away from a medical model of providing care resulted in the social, familial, spiritual, and financial aspects of the patient being incorporated into the arena of nursing. These facets of care helped to create the uniqueness of nurses' interactions with patients. Conclusions of Jacobs (1980) and Kasch and Knutson (1985) corroborate the use of nurse pratitioners as an added focus to primary care because of their adeptness in health counseling, interpersonal relationships, family dynamics, and psychosocial perspectives of patients. Nurses have been trained to consider the subjective response of the patient to health and illness and

the plan of care is constructed within the patient's perspective. In this way, it can be argued that nurse practitioners have the potential to positively affect compliance and improve outcomes through their specialized patient interactions.

Conclusion

Thousands of studies during the past 40 years failed to paint a portrait of the noncompliant patient . . . or the compliant one. There were too many confounding factors. These patients could not be identified by gender, age, race, religion, marital status, economics, number of diagnoses, or medications used. Testing for drug levels in blood and urine are not optimal methods due to both the physiologic differences in individial metabolic rates and the expense of laboratory testing. The whys of noncompliance have been and will probably always be elusive.

When a simple cause for noncompliance could not be identified, health care providers blamed the patient for noncompliance and its dismal companion, poor patient outcomes. Researchers such as Forman (1993), encouraged unlabeling the patient as the guilty party, noting that responsibility for compliance rests with both patient and provider. It is time providers ask themselves: Are we using active listening with our patients? Do we know anything about our patient's homelife, family and employment? Does the patient have adquate resources for medication expenses after meeting the obligations for food, shelter, and clothing? Do we consider whether or not the patient wants to

take a particular medication or make life style changes? Is it feasible for the patient's routine? Do we give patients with chronic conditions any credit for successfully managing illness the 99% of the time that they are not in our offices?

The health care provider is the one common thread among all patients, compliant and noncompliant. No other single factor with the power to affect compliance is more common among patients. This research has shown that patients (a) desire that the provider listen and relate to them; (b) place great importance on caring behaviors of office staff; (c) self-tailor medications to fit lifestyle and preference; (d) make direct correlations between medications and sense of symptom relief; and (e) retain or give control of their health care to the provider. Patients want health care providers to have an idea of what health, illness, and treatment mean to them personally. Improved health outcomes are not likely to result in a system that precludes compliance by generalizing the patients as well as the medications.

Appendices

Demographic Survey

Consent Form

Interview Guides

IRB Approval

Appendix A

Demographic Survey

Interview # Date Time Location
Age Gender Race
Education Level
Marital Status
of Children
Household Members
Occupation
Hobbies/Activities
Medical Insurance(Yes)(No)
If (Yes) Type: HMO PPO Medicaid Medicare Other (Circle One)
Current Medical Problems
How many medications (including vitamins/herbals) do you take each day?
What are they?
Are there other things prescribed for you that are NOT medications? For
example, increasing exercise or diet change.

Appendix B

Interview Guide

Tell me about your current level of health. How do you decide to consult the doctor?

What do you expect from your office visit (s)? What do you think will happenwhat do you think the outcome will be?

What kind of medication (or treatment) was prescribed for this?

What is the difference in what your doctor has prescribed and what you are currently doing related to medication (treatment)?

What has influenced you most to continue (or discontinue) medication (treatment)?

How much input do you feel you had in to your treatment plan? Would you have liked more?

How would more involvement been helpful to you?

How do you feel about the relationship you have with your healthcare provider?

Appendix C

Informed Consent for Clinical Interview

I. PURPOSE

Some patients have difficulty taking medications, having medical tests done, and don't understand exactly how these treatments will improve their health. My interest is in finding out how patients follow their doctor's instructions and incorporate the treatment into their everyday lives. This study does not involve the use of medications. You do not need to change or discontinue any of your current medications when you participate in this study.

II. EXPLANATION OF STUDY

To participate in this study, I will interview you and ask questions relating to how illness and its treatment fit into your lifestyle. You are free to answer questions, give opinions, ask for further explanations, have words defined, or make comments during the interview. The interview will be conducted as if you were having a conversation with another person and will last approximately 30 - 45 minutes.

A tape recorder will record the interview so that it may be typewritten and reviewed for similarity of content at a later time. The actual recording will not be available to any one other than myself. Interview content will be analyzed by myself and my faculty advisor(s) in the Department of

Nursing at the University of North Florida. The information will be used as part of my master's degree thesis. You will be asked to complete a survey about your age, race, work status, etc. prior to the interview. This information will be used to assess how the participants are alike and different.

III. RISKS AND DISCOMFORTS

There are no risks and/or discomforts directly associated with participation in this research study. You will not receive any mediation and you will not be asked to stop taking or change your other medications. Your involvement will only consist of the interview and completing a questionnaire regarding your age, gender, race, work status, etc.

IV. BENEFITS

Although you may not benefit directly from participating in this research study, the knowledge gained from your participation may help in the development of new methods to better assist patients when they are adapting to lifestyle changes resulting from illness.

V. VOLUNTARY PARTICIPATION

Your participation in this study is voluntary. You may refuse to participate. This decision will not affect your medical care in any way.

VI. PAYMENT FOR PARTICIPATION

There is no monetary reward for participation in this study. It is hoped that your satisfaction in having a potential impact on medical care will be sufficient.

VII. CONFIDENTIALITY

Your identity will remain confidential. Your name will not appear in any publications or reports produced from this research study. Your answers, comments, or any other information obtained during the interview will not be shared with your physician.

Tapes and any typed data will be kept under lock and key. Tapes will be available only to myself and destroyed after transcription. Only my thesis committee and I will look at the data. Transcribed data will be destroyed after one year.

VIII. RIGHT TO ASK QUESTIONS

If you have questions about your participation in this study at any time, you can contact Faith Coleman Becker, RN BSN at 904-586-5724 or Katherine M. Robinson, PhD RN at 904-620-2684.

I have read and I understand the procedures described above. I agree to		
	participate in the study and I have received a copy of this consent form.	
	Signature	Date
	Faith Coleman Becker	Date
	Principal Investigator	

A COPY OF THIS CONSENT FORM WILL BE GIVEN TO YOU

Compliance

*7*5

Appendix D

IRB Approval

ACADEMIC AFFAIRS 4567 St. Johns Bluff Road, South Jacksonville, Florida 32224-2665 (904) 620-2455 FAX (904) 620-2457

Division of Sponsored Research and Training

MEMORANDUM

TO:

Faith Coleman Becker

Nursing Department

VIA:

Dr. Katherine M. Robinson

Nursing Department

FROM:

James L. Collom, Institutional Review Board

DATE:

February 20, 2001

RE:

Review by Institutional Review Board

"Improving Patient Compliance: Practicing Within the Patient's

Perspective"

This is to advise you that the changes to your project "Improving Patient Compliance: Practicing Within the Patient's Perspective" has been reviewed on behalf of the IRB and has been approved as described in your memo of February 9. This approval applies to your project with the same survey instrument and informed consent document previously approved.

If you have any questions or problems regarding your project or any other IRB issues, please contact this office at 620-2455.

dch

c: Dr. Lucy B. Trice

ACADEMIC AFFAIRS 4567 St. Johns Bluff Road, South Jacksonville, Florida 32224-2665 (904) 620-2455 FAX (904) 620-2457

Division of Sponsored Research and Training

MEMORANDUM

TO:

Faith Coleman Becker

Nursing Department

VIA:

Dr. Katherine M. Robinson

Nursing Department

FROM:

James L. Collom, Institutional Review Board

DATE:

November 29, 2000

RE:

Review by Institutional Review Board

"Improving Patient Compliance: Practicing Within the Patient's

Perspective"

This is to advise you that your project "Improving Patient Compliance: Practicing Within the Patient's Perspective" has been reviewed on behalf of the IRB and has been approved as submitted. This approval applies to your project in the form and content as submitted to the IRB for review. Any variations or modifications to the approved protocol and/or informed consent forms must be cleared with the IRB prior to implementing such changes.

If your project extends beyond 12 months in length, you must provide an annual status report to the IRB. The above annotated approval date establishes the baseline date for this required annual status report.

If you have any questions or problems regarding your project or any other IRB issues, please contact this office at 620-2455.

dch

Attachments

c: Dr. Lucy B. Trice

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Author Note

Faith Coleman Becker graduated from the University of North Florida in 1995 with a baccalaureate degree in nursing. She was accepted into the first primary care nurse practitioner program at UNF in 1998 with expected date of graduation as May 4, 2001. Mrs. Becker's nursing career has included long-term care facilities, intensive care units, as well as gastroenterology and family practice clinics. She plans to work as a primary care nurse practitioner in the Palm Coast area.

Mrs. Becker also wrote an article accepted for publication in Clinical Excellence for Nurse Practitioners. She has been a spokesperson for the American Heart Association and has active memberships in Sigma Theta Tau International (Lambda Rho Chapter), the American Nurses' Association, Florida Nurses' Association, the Northeast Council of Advanced Registered Nurse Practitioners, and the American College of Nurse Practitioners. Mrs. Becker is also a wife, mother of six, and grandmother of one.