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A constructive view of the non-compliant patient: Understanding barriers to compliance and proposed solutions

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A CONSTRUCTIVE VIEW OF THE NON-COMPLIANT PATIENT:

UNDERSTANDING BARRIERS TO COMPLIANCE

AND PROPOSED SOLUTIONS

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A Project

Presented to the

Faculty of

California State University,

San Bernardino

_____

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

Barbara Smith

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ABSTRACT

Patient non-compliance is a complex, multifaceted phenomenon. Using a constructivist paradigm, this study examined the diverse perspectives of hospital employees on non-compliance, the barriers to compliance and possible solutions. Information gleened from this study supported the literature in that education, culture, language barriers, apathy among patients and staff, patient support systems, financial and resource issues, and limitations of staff impact a patients ability to comply with a regimen and must be taken into consideration when attempts are made to improve compliance rates. Understanding reasons for non-compliance is critical to arriving at a solution(s) due to the changing nature of the health care system. Early intervention by the hospital social worker will continue to increase in order to assess doctor/patient communication, family perception of the patient's disease, the patient's understanding, and ability to follow the post-hospital regimen. The "constant comparative method" proposed by Lincoln & Guba, (1985), was used for data analysis.

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Focus of Inquiry

The health care industry is currently experiencing

many changes. Managed care is altering the way health care

is delivered through advances in technology and new

approaches in financing (Berkman, 1996). As a part of this

transition, importance will be placed on patients becoming

better consumers and "participants in determining their

health care service needs." The focus of this study is on

the non-compliant patient and the many factors that revolve

around this topic. This issue was explored within the

boundaries of a hospital setting in the State of California.

Although patient non-compliance could be taken as an

issue within the domains of direct practice, community

interventions or administration and policy, this research

proposal focused on the arena of direct practice issues,

directed towards the patient/health care provider

relationship and the effects of that relationship on

compliance and non-compliance with follow-up regimens.

This included, but was not limited to, follow-up

appointments following a hospital discharge or a doctor

visit, filling a presciption and taking the medications as

prescribed, or adhering to a diet and exercise plan

according to health needs.

Statement of Purpose

Patient non-compliance has been identified as a major

public health problem (Donovan, 1995). According to

DiMatteo (1995), two factors influence compliance: 1.

Patient's beliefs in the value of the regimen, and 2.

Patient's ability to overcome practical barriers to

adherence. Coons et al. (1994), show that "higher

socioeconomic status, a greater number of prescribed

medications, and higher psychological distress scores" are

significantly related to non-compliance. Age does not seem

to be a factor in compliance rates, but aging can create

additional barriers. Compliance rates can range anywhere

from 10% to 94% (Simons, 1992) which can have severe impact

on increased medical costs, affecting society as a whole.

In addition, patients may suffer "complications of the

disease process, exacerbations and prolongations of

illness." Non-compliance may also cause a health care

professional to "misdiagnose an illness or inappropriately

alter the treatment" (DiMatteo, 1995). With the advent of managed care and the push to control costs by improving efficiency(Sharp, 1995), and an emphasis increasingly towards the outpatient setting (Kiefe, 1993), it is up to all health care providers to understand and work as a team with their patients to "understand each others goals' and preferences" to enhance compliance and avoid costly rehospitalizations.

Literature Review

The term non-compliance carries negative connotations for most, but if we review the definitions of "compliance" we also see the negative presumption this word can denote. Paine, (1996), in her paper on "Non-Compliance as a Patient Right" discusses the concept of compliance as: A. Black's Law Dictionary: "Submission; obedience; conformance." B. Dorland's Medical Dictionary: "a quality of yielding to pressure or force without disruption." C. Stedman's Medical Dictionary: "The consistency and accuracy with which a patient follows the regimen prescribed by a physician or other health professional." D. Ballentine's Law Dictionary: "Comply" - "To perfect or carry into

effect; to complete; to perform or execute in accord with a previous contract or arrangement." Scofield (1995), defines non-compliance as "the failure of the patient to cooperate in carrying out that portion of the treatment plan that is under his or her control."

These definitions can carry with them "an underlying authoritarian, dictatorial tone on the part of health care givers and a yielding, acquiescent image of clients" (Simons, 1992). The above definitions illustrate the need to understand the physician / patient relationship from both perspectives to hopefully enhance the effectiveness and delivery of health care. Non-compliance is a "complex, subtle, and multifaceted phenomenon" that is poorly understood (Scofield, 1995). Because of this lack of understanding, resolutions are proposed that are groundless and do not help to resolve the issue. Non-compliance can be viewed as patient autonomy to self-neglect and finally to self-destructive tendencies. The paradox here is that autonomy is associated with the "principle of self-determination" which is something society places value on. So, in order to be compliant, does the individual abandon

his or her values and power of choice? These are terms that society has created which can sensitize us to the real issues of non-compliance. When an individual chooses a certain life style, the medical community places (subjective) judgment on them whether they deserve to be treated or not. This is another way of possibly denouncing the patient's values. Also, in order for patients to comply, they must first believe in the "medical model of illness and disability" (Scofield, 1995). There are also individual and cultural differences that can cloud one's perception of the benefits of modern medicine. In addition, how do we rate the patient who is partially compliant? This is the patient who may completely comply one day and not the next, or comply within some gray area between compliance and non-compliance. DiMatteo (1995), discusses the fact that some patients "honestly forget" to take their medications, and the more dosages they are required to take daily, the greater chance they are to forget. There does not seem to be any objective way to really measure compliance.

Judgment over a patients compliance should first take

into account the many factors that may affect an

individual's ability to comply. Such variables as "age,

sex, sexual orientation, socio-economic status, education,

occupation, ethnicity, religion, race, lifestyle, and the

nature of their illness or disability" should be accounted

for before a judgment is made (Scofield, 1995). Also,

obstacles account for many patients failure to comply. For

instance, we must take a step back and decide what is a

reasonable regimen to follow, taking into account that the

patient is capable of following a regimen. How much control

do they have to follow through with the doctor's

expectations for them? Physical, visual, and hearing

impairments may hinder their ability to comply. In

addition, these impairments may increase over time, making a

once compliant patient, non-compliant. Also, the mental

ability of the patient must be accounted for. Scofield

(1995), describes an individual as needing the ability to

"pay attention, learn, remember, organize, initiate, execute

and integrate a therapeutic regimen into his or her life."

Alzheimer's disease, or a traumatic brain injury may "impair

their cognitive functioning." Even emotional disorders must

be taken into consideration which can be long standing or be

triggered by an illness. These emotional disturbances can

be on a continuum and may also impede the attention normally

given to one's physical care. Also, one often over looked

aspect is the fact that many individuals are not able to

read or write. Illiteracy may affect the individuals

ability to comply, being too proud to disclose this

information.

Many patients may wish to comply, but illness and

disability (that can potentially last 20 to 50 years plus)

can make adhering to a medical regimen burdensome. Scofield

(1995) discusses how patients are sent home and expected to

manage "catheters, bowel and bladder programs, injections,

dialysis, complex medication arrangements, ventilators, and

stomas of many sorts" in addition to managing life-long

medication schedules. "The longer lasting and more

extensive the medical intervention, the greater the chances

of non-compliance" (Frank,1992). "The emotional reaction of

the chronically ill patient to his condition may represent

the most significant obstacle to his treatment"(Meisekothen,

1993). Although estimates vary, approximately "one half of

patients with chronic diseases do not comply with their program of medical therapy"(Orenticher, 1991). Similarly, an article in Modern Healthcare (Scott,1996), discussed the fact that one half of patients do not take their medicines correctly and approximately 17% of patients leaving their doctors offices decide at that time "they're not going to take their medications". This may result when patients do not feel comfortable discussing issues with their doctor and decide privately that they are not going to comply, which gives them a sense of control over the situation (DiMatteo, 1995). For some elderly patients, their inability to open some medication bottles, specifically the "push and turn" kind result in their not taking the drug (Nikolaus et al, 1996). When presciptions are frequently changed, especially during a hospital stay and after discharge, the more drugs that are prescribed will increase non-compliance rates. In addition, "drugs and dosages differ from those prescribed", sometimes because the presciption was illegible. This results in an estimated $76 billion worth of direct medical costs each year. "Between 3% to 5% of hospital admissions stem from patients' failure to comply with drug orders"

(DiMatteo, 1995; Coons, 1994). From these rates, 90% of
this non-compliance is due to under-compliance; patients
taking less medication than prescribed (Leirer et al. 1991).
Also, the more complex the schedule, the more increase in
non-compliance. In addition, many times patients stop
taking their medicines after a few days because they feel
better and are ignorant of the consequences which can be
detrimental with chronic diseases like hypertension and can
also lead to a premature death. Also, combining certain
drugs can increase or decrease their effects.

From the physician's perspective, pressure is likely to
increase to resolve the issues of the non-compliant patient.
Because the "health care system" is entering into the
"managed care system", outcomes and the efficient and
effective use of resources are becoming ever more important
(Scofield, 1995). Out patient services will continue to
increase, making compliance ever more important "in the
delivery of cost-effective health care"(Ibach 1995). Being
responsible for ones own lifestyle and use of health care
resources wisely is becoming an expectation by the medical
community and society that will only continue to increase.

It is frustrating and costly for physicians to prescribe a treatment regimen only to see it undermined by non-compliance. "It over utilizes the time, medication, equipment and space, money, and personnel devoted to providing health care"(Scofield, 1995). A patients refusal to comply can also effect their relationship with friends, family members, their physician, and can cost them "time, money and energy".

Hippocrates discussed with physicians that "patients often fail to take their medicines aprescribed"(Orentilcher, 1991). These relationships were paternalistic, where the physician gave the orders and it was assumed that the patient would comply (Brock, 1990) Patients must share the responsibility to comply with their treatment, but how do physicians handle the patient who is truly responsible for their non-compliance? Currently, there are no hard and fast rules over whether a physician can deny treatment to a patient for non-compliance. Documentation and legal interventions are sometime needed to resolve this issue.

From the patient's perspective, the variables involved are numerous. First, Scofield (1995) uses the term

"intelligent non-compliance", based on the fact that

patients may deliberately modify, reduce, or stop the

regimen all together because of disagreeable side-affects

from drugs, their lifestyle or schedules. These patients

are compliant in "spirit" unless this proves to be harmful

to their overall health and well being. Non-compliance may

be the result of the "patient's family, living and

employment situation or the patient's financial and

insurance circumstances". Ibach, (1995), also points to

"communication problems, absence of a sense of urgency for

keeping an appointment, lack of a personal physician, and

ignorance of one's medical condition". Some families are

not supportive of the patient's medical needs and regimen

(Orentlicher,1991).

In other cases, patients choose to decline treatment

which is the only control they are able to exert in their

lives. As a result of this independent stance, "patients

are willing to trade length of life for quality of life."

Some patients suffer from depression or are suicidal and

therefore act out in ways that are self destructive. They

may become hostile or refuse to take medications, they may

miss follow-up doctor appointments or avoid "stress

provoking activities"(Meisekothen, 1993). When health care

providers are not cognizant of this, it becomes very easy to

"label" them non-compliant. Patients view many physicians

as paternalistic and are reluctant to share their feelings

and concerns with them. They feel that the physician

becomes offended when questioned over treatment issues and

the patient does not want to get on their bad side (Cole,

1992). Bayley (1996), discusses in her paper "Tough

Choices" that "84 year old Arne" is a challenge to a case

management department because he frequents their hospital ER

which is a result of Arne taking his medicine every other

day, instead of daily as prescribed. Arne then discusses

quality of life issues and that on a fixed income he cannot

afford to buy all of his medicine and play Bingo too.

Losing his wife years ago, bingo is the only social activity

he has to look forward to even if it means that his health

will suffer. Patients must feel that they have a life

outside of the sick role and this is their way of balancing

their priorities (Cole, 1992).

Difficulties also arise over responsibilities for

family members which may make it nearly impossible to leave

the house to fill prescriptions, or to comply with out

patient office visits. Even the most "well intentioned"

(and normally compliant) individuals may fall short of their

own expectations while confined to the boundaries of home

and family responsibilities. Transportation problems are

another issue that will prohibit an individual from

complying, if they are unable to drive themselves or do not

have family or friends to help them, (eg. picking up

prescriptions from the pharmacy, or following up with a

doctor's appointment etc),(Orentlicher,1991).

Likewise, just as illiteracy was discussed above as an

obstacle to compliance, so is knowing too much. When there

is too much information to attend to, patients may have

trouble believing one source over another. Journals, books,

newspapers, radio and television and support groups may all

be sources of information which may confuse and over-ride

the ability for an individual to comply. Non-compliance may

be the result of denial by the patient due to psychological

stresses of their disease. It is cited that as many as 11%

of deaths in hemodialysis patients result from the patient

stopping treatment (Brock, 1990). Another study by

Meisekothen, (1980), found that 61% of hemodialysis patients

expired as a result of failing to comply with treatment

regimens.

Lastly, some patients are willing to take a gamble and

think they can "beat the odds." They either accept their

medical problem or view it differently from the doctor, or

may have had such a bad experience in the past with a

certain treatment that they become almost "paralyzed with

fear" thinking about it. Finally, sometimes patients do

not understand the rational for making small gains in their

health. This happens when the physicians are concerned with

the overall health benefits of their community or country;

eg. a national campaign to lower serum cholesterol. For

example, the physician makes a request of the patient to cut

down on red meat consumption from four times a week to

three. This may prove to be beneficial to the overall

population, if all individuals complied with this request,

but may not seem important to one individual.

Non-compliance is a "multidimensional" problem (Leirer,

et al, 1991). Proposed solutions may rest on physicians or

other health care providers to take the time to establish

"what information the patient is capable of understanding,

and to consider whether extraneous sources of information

are interfering with the patient's desire to carry out the

treatment plan"(Scofield, 1995). Having a deeper

understanding of their patient's lives outside of treatment

would help to define what treatments are reasonable and the

patient is able to follow through with (Frank, 1992). This

would help to reduce non-compliance overall. Many patients

seek medical attention for "sympathy, reassurance, and

validation(Redeimeier et al, 1993). Communication and

education is also of utmost importance (Scofield, 1995).

Many patients do not clearly understand what is expected of

them. A physician's subjective view that instructions and

explanations were adequate can surely be debated by many

patients. Treatment goals must be "collaboratively" reached

between physician and patient. This creates an investment

by the patient to adhere to the regimen. Also, the way in

which the physician "frames" the intervention will depend on

how the patient interprets the information and whether or

not he or she will accept it (Redeimeier, 1993). Without

exploiting the physician's perspective, information can be

presented in a non-threatening manner when attempting to

persuade a patient to comply. A physician should also take

the time to understand what is influencing the patient's

behavior to prompt their non-compliance. In addition to

patients forming perceptions about their own medical needs,

they also form perceptions about their doctors in regard to

their "knowledge, beliefs, and attitudes" (Ibach,1995).

Health care providers must also have an awareness of

patients that are passive and do not question the regimen,

these patients are more likely to be non-compliant than

those who "question recommendations, offer ideas and

opinions, and even attempt to negotiate more acceptable

regimens" (DiMatteo, 1995). Non verbal communication is

just as important; "body language, eye contact, warmth, and

empathy proclaim respect by the doctor. Respect is earned

by developing a "rapport" with the patient which allows for

trust to evolve. Patients will believe their physicians

when there is trust between them. Physicians also need to

take more responsibility when the desired outcomes are not

achieved and not automatically blame or label their patients

non-compliant. "How much these 'lay' persons retain the ability to direct their own lives during treatment is a constant sore point with professionals, who then diagnose their own soreness as patients' 'non-compliance'"(Frank, 1992). It is a conflict over control; over empowerment and disempowerment. Self evaluation by a physician would be justified in order to balance the blame and attempt to rectify the situation.

Suggestions to increase patient compliance with medication usage have included, giving patients "week-long color coded pill trays, or daily tear-off calendars"(Leirer, et al, 1991). Engaging the patient in discussion about the need to comply with the doctor's orders before discharge from the hospital can increase compliance. In their study, Leirer, et al, found that using a voice mail system, called "TeleMinder", whereby computer softwear was programmed to dial a patient's home phone and relay a recorded message to remind them to take their medication. "The sender can increase the sophistication of the voice mail by asking the receiver to press buttons on the telephone keypad to: answer senders' questions, confirm the reception of the message,

request additional information, or branch to additional parts of the message". In this particular study, non-compliance was nearly eliminated. It has also been suggested that pharmacists counsel patients on proper drug use and provide educational pamphlets, in addition to new "disease management programs" which try to avoid serious set backs with patients and their chronic conditions (Scott, 1996). Another pharmacy selectively despatches "electronic pill vials" and absorbs the $180 cost. In an Iowa study, pharmacy computers are checking new prescriptions against a "central Medicaid databank of patients' medication profiles".

Managed care and its focus on efficiency and cost containment, may prove a detriment to the doctor/patient relationship. The focal point of managed care is to limit the utilization of unnecessary health services by "altering treatment processes in various ways"(Berkman, 1996). The autonomy between doctor and patient will decrease as the "institutions" of managed care make more and more of the choices and arrangements once held exclusive within the doctor/patient relationship. Capitation under managed care

provides incentives and rewards to those providers who keep

patients healthy and out of the hospital. Increased patient

loads will not permit physicians to spend the needed time

with their patients to adequately educate them on the

rational for adhering to a regimen, and many are not

organized to deal with the "long term as well as the acute

care needs of persons with a chronic illness or disability".

As Scofield, (1995) states: "the non-compliant patient is

likely to be the creation of the health care system itself."

Because the promotion of health and disease prevention

is becoming more important, and hospitals who come under

capitation will be financially rewarded for keeping patients

out of the hospital, identification of the non-compliant

patient will be essential for health care organizations to

remain viable (Berkman, 1996). Collaboration among all

health care providers is necessary in order to come to some

agreement over the causes and possible solutions with the

non-compliant patient. "The framework for practice in

health care must include an understanding of the interaction

among psychological, social, cognitive, and biological

factors" of the patient. It will be paramount for health

care providers to screen patients that may be "at risk for physical, social, or psychological regression" in order to provide intervention in a timely manner to enhance compliance and deter hospitalization.

From the perspective of this social worker, experience shows that working in a hospital setting and working with "non-compliant" patients, provides many challenges for the doctor and all disciplines involved. Multiple readmissions require time, energy and resources. Resistance by patients to "comply" with doctor/staff recommendations and orders, in time, may begin to change the perception of the patient by staff. These perceptions can guide doctor/staff behavior, where investment in the patient's health and outcome may lessen. Emotions, such as frustration, disengagement, and the involvement of additional staff, most likely a social worker (in the hopes that someone can convince this patient to comply), ensue.

A constructivist study, engaging hospital health care providers, that will take a comprehensive view of the "non-compliant" patient, and what that means to staff, may help to educate and provide a base level of understanding of them

(the non-compliant patient) and the circumstances or
barriers that prevent compliance. "It is estimated that by
the year 2000, 90 percent of all medical benefits
administration will be handled by managed care
organizations" (Berkman, 1996). Because the structure of
health care will continue to change and evolve, it is
essential for all health care providers to advance their
understanding of the human component and what it means to be
a "patient", and determine how best to meet the needs within
the doctor/patient relationship.

Figure 1 - Working Hypothesis:

1. Emphasis on education on the patient's disease
process may help to increase patient compliance.

2. Shared decision making between health care worker
and patient may help to increase compliance.

3. With increased understanding, it is hoped that
hospital staff will take a more empathetic stance with non-
compliant patients.

4. Looking at the patient from a holistic point of

view and understanding possible barriers to compliance may help to adjust treatment regimens in order to increase patient compliance.

5. Intense follow up by health care professionals may help to increase compliance.

Determining the Fit of the Paradigm to the Focus

Review of the literature on non-compliance highlights the variable accounts of this phenomenon. There is certainly no quick fix to the problem. Of course, to some, there is no problem and this varies by degree or can be viewed on a continuum. Every article addresses another aspect of why individuals are non-compliant. Patients are involved with an array of professionals during and after a course of illness, from hospital staff (which are many), to pharmacists, to follow-up appointments with their physician, to specialists, to counselors, to the social security office, to social workers, to clergy, to many other community agencies. The list could go on and on as every person has their own unique needs. Resolution to such a complex issue is nearly impossible if we continue to look at it as a "problem" of sorts. There are many views on what

non-compliance is depending on whose perspective your looking at. Because society takes on a certain structure, accomplishments are based on the individuals within that society, falling into line, with what has been considered normal by the consensus. Since there is a polarization of views between compliant and non-compliant, how does society come to terms with all the sub-definitions in between? How do we encourage our professionals, when dealing with patients, to take that one step further into their lives to develop a holistic understanding of their perspectives on life, their fears about their illness, treatment issues and what is reasonable to expect from them, obstacles to follow-up treatments and many other issues. Patients also must be encouraged to ask questions when they do not understand what is being asked of them. It has been said in the past that patients usually retain about 20% of what is told to them. So to remedy this, many agencies give patients handouts to read. How many of those handouts do they ever really read? Answers do not come quietly.

Increasing Communication Using a Constructivist Approach

Because of the diversity of this issue, and the
relative nature of the term,constructivism seemed to be the
appropriate paradigm that was equipped to address the many
dimensions that non-compliance brings forth within this
hospital setting. There are no policy and procedure manuals
within the hospital under study, to follow, in dealing with
non-compliant patients. There is professional communication
between departments as patients undergo different procedures
during their hospitalization but there is no uniformity
among staff when a non-compliant patient is identified and
in how they are dealt with. Because non-compliance, as a
term, is so subjective, constructivism supports the view
that nothing is objective, that concepts change over time.
There are only working hypothesis that change and evolve as
concepts change. It is the subjective views of reality by
key stakeholders within the hospital that have any relevance
to the situation. By using a "hermeneutic" dialectic
process, these key stakeholders came together to ask "how"
interventions may play a role to reduce the problem of
patient non-compliance. Reality is a shared construction

which can change as new information is brought to light.

Because constructivism relies on the subjective accounts of stakeholders, the researcher relied on their accounts to be accurate and truthful. The researcher may never be completely aware of when a participant is giving inaccurate or skewed data, or what the reasons are for doing so. But because of the open process that was used to gather and refine data, no one piece of information was able to destroy the end result. Each piece of information was weighed and challenged by all other stakeholders in the circle.

Constructivism can be argued to be the more appropriate paradigm for this study, as it allowed for an emergence of ideas to develop and converge from those professionals that invest the most time and energy with the patient. Through critical analysis of shared ideas by each stakeholder, the term non-compliance was continually reshaped within the hermeneutic circle. Each idea hopefully inspired the thoughts of the next stakeholder to formulate new ideas based on the previous stakeholders ideas. Because no two people, or their experiences, are the same, dealing with the

non-compliant patient took on separate meanings for all. But like a puzzle, the final picture emerged as a complete construction of what non-compliance is and means. Pieces were continually added until there was a general consensus to what the problem is and how it can be approached. Through "expansion research" (Erlandson,1993), studies may be conducted in different settings to "examine the credibility or transferability of the constructed realities found in one setting in a different setting."

Comparing Constructivism to other Research Paradigms

It should be discussed that because constructivism is an alternative paradigm, it was possible this hospital may not have been as receptive as they would be to traditional research. If resistance had been encountered to this new approach, an explanation of the process and advantages of constructivism would have been given focusing on the non-compliant patient. Acknowledgment would have been given to the merits of positivism, post positivism, and critical theory, each in their own rights. Each of these aims to predict and control through the process of being objective and value free. Although post positivism combines

qualitative research with quantative research, the resulting

quantative data is used to convey the truth of the

phenomenon. Each paradigm is guided by its own rules for

inquiry and each must specify its own design and

instrumentation before the research begins. Because non-

compliance entails so many variables, constructivism would

be argued as the more appropriate paradigm because of the

nature of the inquiry. The aim is not to measure one piece

of data against another, but to create an understanding of

what non-compliance is, with all its variables, and how it

can be approached, by one human to another, to hopefully

attempt to resolve or at least lessen the problem. Results

can then be broken down into separate units and traditional

research can be carried out at that time, eg. measuring

medication compliance or physician follow-up appointments.

Data Collection

Data was collected within a hermeneutic dialectic

circle. This means that the researcher sought to interpret

and organize information, or constructions, obtained from

the participants, through patterns or themes. Constructions

are "compared and constrasted" (Erlandson et al. 1993), in

an attempt to integrate information. The researcher

attempted to understand the phenomenon from the participants

view and "special meanings"(Rubin & Babbie, 1997), they

attach to it.

Participants were chosen from key departments within

the hospital. Before key stakeholders were interviewed, the

confidentiality and anonymity of all participants was

protected. This was accomplished by verbal explanation, and

a consent form that was reviewed and signed by each key

stakeholder in addition to hospital administration as

appropriate.

Figure 2 - Initial Hermeneutic Dialectic Circle

                        Doctor
        Administrator   Pharmacist
        Clergy   Social Worker
    Nurse/Case Manager   Medical Eligibility
        Financial Counselor   Patient
                    Researcher

All of the above staff members were chosen as they

represent many of the key departments in the hospital and

each member could potentially have contact with the same

patient or their contacts are many to allow them contact
with similar types of patients inside the hospital setting .
It was understood that these staff members might not
complete the research project and others might be added. In
addition, sub-circles of any of the above staff members
might form.   Rubbin & Babbie also discusss the "snowball
sample" that could be incorporated as appropriate. The
hermenectic circle could expand from referrals from current
participants to others that could contribute relevant
information.

Using a contructivist paradigm allows for modification
of the proposed hermenuetic dialectic circle. As
interviews preceded, other participants were added to the
circle either out of the staff members eagerness to
participate in the study, referrals from existing
participants, or the researchers observation that other
departmental staff could contribute valuable information to
the study.

Figure 3 - Modified Hermenectic Circle

```
                   2 Case Managers
           Dietician          Infection Control
        Health Educator          Financial Counselor
       Chaplain                          Social Worker
  Floor Nurse                                 Cardiopulmonary
      Home Health Nurse                   Administrator
         Patient Relations        Clinical Psychologist
            Physical Therapist  Pharmacist
                     Doctor     X Ray
                        Researcher
```

To allow for an orderly emergence of new members to the hermenectic circle, one of the above staff members was chosen and interviewed for their input and perspectives on the issue of the non-compliant patient. According to Erlandson et al.(1993, pg 91 & 124), after this interview was completed, another staff member was chosen or agreed upon. Before interviewing the second staff member, notes from the first interview were "analyzed" by the researcher and the first interviewee to check for accuracy. The second staff member then had an opportunity to voice their opinions fully. When there were no other perspectives to contribute, the opinions from the first staff member were shared and

the second staff member then had a chance to respond to these opinions. The pattern continued until all staff members chosen, or those who were available, were interviewed.

Further discussion points to the fact that what the researcher was focusing on were staff members that could contribute "divergent constructions" (Erlandson et al., 1993). He goes on to state that information may ultimately become "redundant" or the constructions will form "two or more categories that remain at odds with each other". Second interviews may be held given the availability of staff and time permitting but only one interview was conducted due to time constraints of staff and of this researcher. It should be noted that sometimes the members of the circle will change for various reasons. In this case, accommodations were made for two participants that had to drop out of the study. Although they left for other employment opportunities, they permitted this researcher to use their information for this study. The process continued as constructions were shared from the previous staff members

with the next member until some sort of consensus was

achieved.

Successive Phases of the Inquiry

Phase 1 "Orientation and Overview"

After discussions with the hospitals administration,

and managers of the departments of the key stakeholders, and

with their permission, the researcher informed the

participants of the research topic of non-compliance and

requested their opinions and thoughts on the issue. All

participants were advised that any information they gave

would be shared with all other participants in the study.

They were advised of the process involved in a naturalistic

study, time commitments, and possible outcomes that will

result. The researcher obtained a signed, informed consent

to protect all involved. A review of the literature on the

non-compliant patient was done to aid in the understanding

of the topic, the important issues and variables involved.

This allowed this researcher to develop the most appropriate

questions in an effort to elicit the richest answers.

This researcher took a holistic stance while conducting

the interviews, taking the participants whole context into

account; office environment, dress of participant, formality observed, tone of voice etc. This was to help understand the participants value system, past and present views of the non-compliant patient and their prediction of the future for resolution if possible. The conversation flowed in an open-ended manner and the researcher remained flexible as the participant took the lead. Opinions and facts were gathered within this dialogue. If terms or expressions were not understood, the researcher clarified with the participant the true meaning the participant wished to convey. The researcher was also obliged to not interfere by interjecting his/her opinions into the conversation.

Phase 2 "Focused Exploration"

This phase occurred after all key stakeholders had contributed their opinions one by one, with each stakeholder hearing all of the contributions from the previous stakeholders. This researcher then focused on the themes that had emerged. A shared meaning around the issues began to develop. The researcher looked for redundancy in their ideas which completed the interview process. When the information gathered showed a discrepancy between the

literature and the participants perspective, it prompted

this researcher to ask "why" and look into this discrepancy

further (Strauss & Corbin,1990).

Phase 3 "Member Check"

This was a very important part of the process of

assuring that accurate information was documented from the

participants perspective and not the researchers. Member

checking is a way for the researcher to validate his/her

documentation by allowing the participants to review the

material recorded to check for accuracy. It was done

throughout the study and was done "formally and informally".

The researcher may conduct member checking at any time

during or after the interviews. Earlandson et al. (1993),

discusses (pg. 142) the various ways member checking is

executed. This researcher was also cognizant of the fact

that there may be strong reactions to the information and

without support from all that are involved, member checking

may become the responsibility of a handful of individuals.

Inaccurate information also may emerge if none of the

participants wish to be critical in their review, but this

remains covert knowledge. This researcher was sensitive to

unspoken "beneath the surface" agendas.

Determining Instrumentation

The researcher is the primary "instrument" in a
constructivist study. Interviews were also used by this
researcher as a method of instrumentation. In addition,
observations by the researcher were documented. Choosing
key stakeholders within this researcher's area of interest
provided many points of view, adding to the richness of the
data. It was imperative that each participant be treated
with respect and their thoughts with privacy. Questions
asked by this researcher were important in determining what
direction the interviews took and how the study developed
(Strauss & Corbin, 1990). Participants were asked seven
questions. Conversations started out in a broad manner and
became more focused as participants shared their
constructions.

Figure 4 - List of Questions

1.   What is your definition of a non-compliant patient?

2.   Why do you think patients are non-compliant?

3. What are the barriers they face?

4. How does staff relate to a non-compliant patient?

5. What are the consequences of non-compliance?

6. What are the benefits of non-compliance?

7. What are some proposed solutions to non-compliance?

The experienced researcher has had the opportunity to develop proficiency in the field by "comparing and evaluating alternative research designs, data collection techniques, and analysis strategies"(Erlandson et al, 1993). This allows the researcher to develop a "sensitivity to social issues". For the less experienced researcher, being constantly aware of the emotions being felt as issues are discussed and debated and perhaps waiting for a short time before recording the information may help the researcher to be more accurate in his/her narrations. Also, before approaching the key stakeholders, this researcher took into account any personal or professional experiences they have had with the topic, and remained cognizant that experiences vary from one person to another (Strauss & Corbin, 1990). As the perception of an experience may be different from one person to the next, information gleaned may also be "context

specific." In addition, the knowledge gleaned from a

literature review gave familiarity with the "phenomenon".

This added to the researchers "theoretical sensitivity."

Strauss & Corbin see this as an "attribute of having

insight, the ability to give meaning to data, the capacity

to understand, and capability to separate the pertinent from

that which isn't." This researcher was aware that internal

feelings may affect the ability to collect and analyze data

accurately. Documenting daily thoughts and feelings allowed

this researcher to reflect on the feelings experienced,

allowing for internal growth and expansion.

Planning and Data Collection and Recording Modes

To collect information accurately, the researcher must

look to gather information from many sources. A method

called "triangulation" was used whereby the researcher

gathered information through multiple sources of "data,

methods, investigators or theory" discussed by Erlandson et

al. (1993). Being observant to the participants

surroundings helped to paint a picture of the individual and

their values. Using the researchers "five senses" allowed

for an abundant amount of knowledge to be absorbed. Using

"thick description" in narration helped others visualize

what the researcher experienced. Using "purposive sampling"

helped to identify "who and what to study" after the

researcher has identified the issue of interest. This is

also discussed as a "process of elimination" of what not to

investigate. Data collection stems from the dialog between

the researcher and the participant in addition to the above

discussion of the participants environment. Information was

documented using pen and paper, and because key stakeholders

were agreeable, tape recorders were used, which also ensured

accuracy. This also assisted the researcher in looking back

on interviewing skills and the ability to refine them as

needed.

Recording data using "critical incidents" assisted the

researcher in capturing the main functions of the key

stakeholders. Critical incident referring to a "significant

feature of the social context" (normal or abnormal). This

was done after the researcher had time to familiarize

herself to the surroundings of the hospital to make sure it

was significant to the hospital and just not this

researcher. Rubin & Babbie (1997), point out that the

researcher runs the danger of observing only those things

that support the researchers "theoretical conclusions."

Constant self-reflection is required by the researcher to

accurately reflect documentation. Earlandson defines this

as "thinking and feeling."

Files were created with separate categories relevant to

the topic of non-compliance to be used as a starting point

for filing information (Rubin & Babbie,1997). Categories

were added and revised as appropriate.

Planning Data Analyses

Using the "Constant Comparative Method" (Lincoln &

Guba, 1985; Rubin & Babbie,1997), the information gathered

in interviews and observations was categorized depending

on its "theoretical properties."   The processing of data

began with the first interview. The categorization of

"incidents" or "units" of data was classified under initial

headings which was revised as themes became clearer. The

researcher's task was to develop the initial headings and

incorporate those that emerged from the data. Descriptive

and explanatory categories emerged from the themes that the

researcher developed and those that emerged from the

participants. Later on, as more information was gathered,

the researcher began to analyze data by themes.

Categorizing data and analyses was simultaneous. The

researcher engaged participants and other "teammates" in

constant clarification of the data collected to ensure

accuracy.

All information collected from one interview was

analyzed for accuracy and categorized before moving on to

the next interview. The gathering of information from

observations was compared to previous information. The

categories were refined as new information was introduced.

Information called "units of data" should have two

characteristics; 1. Data must be aimed at "some

understanding or some action that the inquire needs to have

or to take", and 2. "It must be the smallest piece of

information about something that can stand by itself."

This is information that needs no other information to be

understood. Information was then coded on index cards. The

source of the information was noted on the back of the cards

by either numbers linking them to a list of participants or

in other ways that would represent the source, as

confidentiality must always be maintained. Although at
first many index cards emerged, less arose as the study
becomes more focused. The process began by reading card
after card whereby different piles emerged depending on the
contents of the information. Each pile represented a
different category. For those cards that did not fit the
established categories, a miscellaneous pile was made that
was assessed for later relevance. Working hypotheses and
concepts continued to develop throughout the information
gathering process. Thoughts were expanded by writing them
out and sharing them with peers for clarification.
Properties of the categories were explored and listed to
help define them. Questions arose as gaps in information
became obvious which helped to guide forth coming
interviews. As the process continued, more categories
developed to the point where new information fit into
existing categories. Categories became "saturated" or "well
defined" and eventually led to "closure" of the study.

Prior Logistical Considerations.

Consideration was made whether one or more hospitals should have been involved in the study. But there was such a rich mix of professionals within the boundaries of one hospital that ample information was available for this study. Reviewing literature on non-compliance was key before attempting any involvement with hospital staff (Rubin & Babbie, 1997). As discussed in question #4, hospital administration was involved to gain access to the hospital. Discussion of the length of the study was negotiated according to time constraints of the researcher and the participants, given school time frames and work schedules. Also, a study on non-compliance would allow for "expansion" research to be carried out later on, in the same or different hospital, to compare and strengthen findings.

Choosing a hospital setting allowed the researcher to capture the views of the primary professionals in the field that deal with the same issues, in the same environment. Non-compliance is an issue each professional has encountered at some level and has discussed with some degree of interest

either to share feelings on the subject or in an attempt to resolve individual patient issues. Non-compliance posed as an interesting subject as there are no simple solutions. Using a "working hypothesis", and focused questions as an approach to open up discussions, allowed for participants to air their feelings and thoughts. It also gave "meaning and direction" to the research. There was an understanding that the hypothesis may change as the process of interviews and information began to emerge. The researcher's goal was to define the meaning of non-compliance among the key people in the hospital that the patient will most likely encounter. Using a "purposive sample selection", an array of key stakeholders was identified, as it was expected that some may not wish to participate and others may drop out during the study. <u>The researcher must always remain flexible and open to new and changing ideas.</u> A comprehensive knowledge of non-compliance by all those concerned helped those professionals to better understand the many variables involved and therefore enable them to deal with patients on a different level. In an effort to reduce non-compliance, healthcare professionals need to act in a more

preceptor/educator role vs. just treating the physical part

of the patient.

Ethical issues were explored to safeguard all

participants. As Erlandson et al. (1993), states "subjects

must be protected against physical or psychological harm,

including loss of dignity, loss of autonomy, and loss of

self-esteem. In addition, protection of privacy and

confidentiality is mandated, although it was communicated to

the participants that contact may be required at unscheduled

times to clarify information or change meeting times etc.

The subject was also protected against unjustifiable

deception and informed consent was needed to participate".

The researchers aim was to "empower and educate" the

participants. The researcher took the stance of "observer-

as-participant" (Rubin & Babbie, (1997), which would have

the researcher "interact with the participants in the social

process but make no pretense of actually being a

participant".

After completion of the study, the goal was to

communicate the findings to hospital administration, and all

departments involved in the study. Also, a summarized

document of the findings was distributed throughout the hospital as requested.

Logistics in the Field

Erlandson et al. (1993), talks about using your "five senses" plus intuition while conducting research. Using self awareness to attend to the many details that was experienced aided in developing a holistic picture of the hospital environment. Interviews with the various disciplines within their departments and watching them interact with their coworkers, within and outside their department, gave a sense of their daily routines and the problems they encounter. This researcher was always observant to the surroundings while doing interviews which helped to explain the participants realities. Showing interest in the participant and using listening skills enhanced the conversation and information gathered (Rubin & Babbie, 1997). In addition, Oakley (1990), suggested "a balance must be struck between the warmth required to generate 'rapport' and the detachment necessary to see the interviewee as an object under surveillance". Rubin & Babbie (1997), also discussed remaining objective. This

researcher attempted to avoid answering questions posed by the participant although in some cases it was unavoidable.

Participants may also have other meanings attached to the information they are giving and the researcher will not be able to reconstruct, accurately, their "reality" without making sure they clarify terms that are unclear. In other cases, the participant may not be able to accurately describe his/her reality to the researcher but the goal was to clear up any misunderstandings by the "member checking process". Also, building a level of trust by "prolonged engagement" with the participants allowed the researcher to engage in more comfortable conversations and therefore be more apt to ask for clarifications. It also allowed the researcher to follow up with the participants when further contact was needed. Arrangements were also made whereby the participants were able to get in touch with the researcher if any questions or concerns arose. This issue was also discussed in part A, whereby participants agreed before the interview process began that unscheduled contact may be required. Consideration was taken into account as to work schedules and when the appropriate time would be to

make contact.

Logistics of Activities Following Field Excursions

The researchers observations were noted during or soon
after the interview to capture the full meaning (Rubin &
Babbie, 1997). As discussed in question #4, after an
interview, "member checking" was accomplished by
transcribing the interview, delivering the participant a
copy and requesting feedback and clarification. "Peer
debriefing" used on occasion, to gain valuable feedback in
an objective manner on the study by someone known and
trusted by the researcher. This was a "peer" of the
researcher not connected with the study. An "audit trail"
was used as a way to add "dependability and confirmability"
to the study by keeping records of all documents to support
and authenticate the data.

Logistics of Closure and Termination

Bringing closure to an interview consisted of reviewing
and clarifying the information that was documented with the
participant. Each participant was thanked at the end of the
interview for their time, energy and honesty. After all
interviews were completed, the participants were asked to

attend a meeting, held in the hospital, where a number of

key stakeholders came together to discuss the researcher's

findings. The findings were presented to each stakeholder,

in outline form, one week before the scheduled meeting. All

participants were asked to review the outline and present

their feedback (criticisms, additions, deletions etc.) in

the meeting. During the meeting, valuable information was

shared and all feedback was taken into consideration when

writing up the final draft. Corrections were made as

appropriate. It was important though to not bring closure

to the relationship as additional information may have been

needed or the participant may have had additional

information to add.

Terminating the study came when the researcher felt

competent that adequate information had been gathered and

participants were in agreement on the findings. Attentive

review of all documents was imperative. After an external

audit was performed and the trustworthiness of the study was

agreed upon, a final bound report was submitted to all key

stakeholders and hospital administration for their review as

requested.

Quality Control

To make this a good constructivist study, the researcher kept in mind, (from an ontological stand point), that reality is a perception of the beholder and that individuals perceive their reality within the "context of a mental framework" (Guba, 1990). Interpretation was therefore dependent on a "window of theory". The methodology of constructivism was discussed in question #4, but to briefly review this approach, the researcher compares and contrasts each participant's constructions to eventually come to a level of consensus. The researcher must take a subjective stance as the constructions of those interviewed, develops. This epistemological notion sees the results of the study, a "creation of the process of interaction" between the researcher and the participant. As identified in question #3, a hermeneutic dialectic circle, which consisted of eighteen hospital employees, were interviewed from key departments. Participants were added to the circle as more information was needed, interest in the study was voiced, and others were identified as able to contribute relevant information. As a result, the researcher obtained

considerable amounts of information which made it imperative

to continually analyze and organize data throughout the

study.

Erlandson (1993), uses the term "gestalt" to define the

process of data collection from beginning to end. In the

beginning, a considerable amount of data was collected. The

continued analysis and categorizing of this information

brought the researcher to a point where interviews no longer

yielded new information. This signaled the researcher to

look for gaps in the information that had already been

gathered which helped to narrow the focus of the research.

The researcher continued to refine the categories and their

properties.

An "audit trail" evolved as the researcher organized

the documentation collected which allowed for verification

of information at any point and time, during or after the

study. The researcher was always willing and open to throw

out or change the ideas discussed. Protecting the identity

of the participants was also important as to avoid any

repercussions within the hospital and later on. Establishing

trustworthiness was key and as Erlandson et al. (1993),

points out "the probability that the findings and
interpretations of a naturalistic study will be found to be
credible depends on the inquires demonstration of a
prolonged period of engagement, providing evidence of
persistent observation, triangulating sources and methods,
conducting extensive member checks, and guarding against
both going native and premature closing".

RESULTS

Introduction

The purpose of this study was to capture one hospitals'
perception of non-compliant patients. Through
constructivist research, eighteen hospital staff members,
from various departments, were interviewed with the intent
to examine and understand their definition of non-
compliance, the barriers and possible solutions to non-
compliance. A single round of interviews was conducted in
addition to a round table meeting to discuss the results.
The researcher made every effort to include males and
females and various races. Caucasian, African American,
Hispanic, and Filipino were represented. As noted in " Data
Collection ", all participants were chosen either because
they worked in a specific department, became aware of the
study and wanted to participate, the researcher received a
referral from a participant that addressed another staff
persons expertise, or the researcher acknowledged others
during the interview process that were thought to be
valuable contributors. All interviews were held in the
hospital and at the participants convenience. Each

participant was asked the seven questions and given as much time as needed to answer the questions. Clarifications were made by the researcher, as appropriate, to fully understand the participant's constructions. After the participant answered the seven questions, the researcher read back to them the constructions from the previous participants. If this brought new information to light, the participant was given the opportunity to add to his/her constructions.

The topic of non-compliance brought forth a pattern of many similar responses from all participants interviewed. What was interesting was that although there was much agreement in all areas, each participant was able to add a piece of new information to the subject that no other participant voiced. Although there was consistency among staff as to problems created by non-compliance, the researcher noted that participants were able to acknowledge that they were responsible for shouldering some of the responsibility for this occurrence, either by their attitudes toward the patient or because of a lack of time.

Interviews were then transcribed, and given back to the participant for review. The researcher encouraged all

participants for their feedback, either in writing or verbally. Interviews continued until the information became redundant. The information was then broken down onto 3 x 5 cards. Using the "constant comparative" method, the unitized data was then sorted into categories according to ideas. After enough cards were assembled, each category was labeled depending on the main idea of the data. All cards were coded to protect the identities of the participants, for easy referencing and accessibility, and to create an "audit trail." The narrative was developed by organizing the categories from thickest to thinnest pile of cards (the researcher assumed that the thicker the pile the more agreement there was on that particular theme and thus, more important. Many themes became a focus of attention by the participants as reflected by the patterns that evolved in all seven questions. The following analyses is presented which represents the constructions that were established after exploring the various opinions of hospital staff, regarding the issue of non-compliant patient's.

1. What is your definition of a non-compliant patient?

The majority of participants stated their definition of

a non-compliant patient was when there is a resistance by

the patient to follow a prescribed treatment. This

researcher found that cooperation on the part of the patient

was an underlying theme regarding their resistance to follow

a regimen. Many terms were used to describe the subjective

nature of non-compliance such as "lacking adherence", "an

act of will or choice", "does not cooperate", "refuses",

"not willing or does not obey", or "not consistent". Even

anger on the part of the patient was seen to be reflection

of non-compliance. Responses indicated that patients

deliberately did not follow the recommendations of their

health care provider or appeared receptive to the education

offered by staff and then chose not to comply. Patient's

were also seen to sabotage the plan by not doing it right.

Degrees or the depth of non-compliance were evident as

participants gauged their answers according to the range and

complexity of patients they have cared for. It was evident

that non-compliance is seen on a continuum as patient's were

observed to "not follow any instructions or only some of the

instructions" given to them. Many times answers were

reflective of the specific departments of which the staff

member worked and thus the type and intensity of the

relationship between the staff member and the patient.

Examples of this would be "an individual who does not

consistently follow a prescribed medical or nutritional

therapy regimen" or "a person that does not obey what is

written or given to them in instructions for insurance

purposes." Therefore, many answers reflected a particular

component to the overall issue of non-compliance.

A majority of responses though were more generic in

nature and echoed the stance of health care provider versus

patient. One participant voiced that a non-compliant

patient was someone "who by their actions or non-actions

does not benefit from the treatment that has been planned

for them." Another respondent stated that a non-compliant

patient was a patient who "refuses a treatment or a

procedure that is supposed to be done or ordered for them,

refuses medications, or refuses to do what the doctors or

nurses think would be a good thing for the patient to

recover." Family members who are caregivers of patient's

were also seen as being responsible for a patient's

compliance as when they do not completely take care of

necessary therapies for the patient which included

medications, appointments and doctor's visits.

Some patient's were seen to possess a lack of

understanding of what the main goals were for their

treatment. Many of these goals were goals that patient's

have participated in making. Respondents state that the

patient has then flatly refused to follow through for

reasons unknown to staff. One participant responded by

saying,

"A non-compliant patient is someone who has given

instructions or education as to what steps they need to take

and they do not proceed to do that. It could be either

conscious or unconscious. I don't think that they are

necessarily aware that they are rebelling against being

compliant. Sometimes that non-compliance needs to be

confronted. They need to understand that they are being non-

compliant."

Lastly, it was relayed that there are those patients that

are unable to comply, not by choice but by circumstances,

where due to expense and monetary resources, the patient is

not able to follow instructions. The participant did not

consider this to be a form of non-compliance. They felt that would be the responsibility of the health care professionals to intervene and provide the means by which they would be able to follow instructions.

2. Why do you think patient's are non-compliant?

A lack of education or understanding was sited as a reason that patient's were non-compliant. Health care professionals are attempting to bring forth an alteration that is going to affect the patient's life and some just don't understand why they have to make these changes. Patient's may not know how their non-compliance will affect them in the future. Patient's are not convinced that the outcome is worth the effort and the ramifications of their non-compliance are not obvious to them. Goals may have been set by the patient and staff but the patient may misunderstand the process of what the goals originally were or what the plan of treatment was or they have perceived that they cannot follow through with the regimen. The information has not been integrated into their thinking and feeling which creates non-compliance.

The way in which health care professionals are

addressing issues with patients may have an effect on their

level of understanding. "Depending on how you instruct

someone or give directions, the patient may have a different

type of learning style." Patients may not have regimens

explained to them properly or the information was not

processed correctly. There is also the issue of

communication barriers and how the patient is filtering the

information presented to them. It was stated that doctors,

nurses, all of us tend to assume that patients understand

why they have to make changes, but this is not always the

case.

"I think we have to be careful to determine what

standard of compliance is for certain people. When you have

a patient that is low functioning, that may be depressed,

that may have psychotic features, so their life is difficult

anyway, their rate or type of compliance is different and we

need to be careful of what we expect of them and make

requests for compliance realistic."

A patient's culture may also dictate whether they will

integrate a regimen into their lifestyle. Staff may ask a

patient to comply with a procedure or life change and it is

against their religion or ethnic background. In turn, their cultural background may dictate that they do certain things that staff do not want them to do or may think those things are wrong. For example, "in Thailand they do something called coining. It leaves marks and bruises on their body and we may think it is child abuse of some type." Another participant stated that a patient's culture and religious beliefs are not explored properly by health care professionals. There might be something in the history that is not included and it might be something very simple, it might be a basic belief that if explored, might result in a higher degree of compliance.

Patient apathy was viewed as a component of non-compliance. Some patients have adopted a lifestyle or a habit that they have become comfortable with and they do not see it as a detriment to their health. These patient's are advised to change these habits and they do not understand the consequences or they do not care about the consequences, "I'm going to continue to smoke and I don't care, it gives me pleasure. I can't stop, I'm going to do this no matter what it costs, as far as my health and all is concerned."

Looking at smokers for example, and the lung disease

resulting from smoking, the attitude is "the damage is done

and why change? I've been doing it for 20, 30, 40 years now

and what difference is it going to make?" It was voiced

that those kind of individuals are very hard to change.

For those patient's who attempt to make a change for the

better, they may try at first but without understanding the

outcome or the benefits, making the sacrifice to change

becomes too much of an effort and they lapse back into

familiar habits.

Other patients may be angry about what's going on and

they think they can avoid the problem by avoiding the

treatment. Some patients give up, they get disappointed and

have no more hope that they will feel better. One

participant stated, "I once had a patient and I said, 'why

aren't you following what the doctor tells you?' He said,

'what's the sense of doing it, I will die anyway.'" In

addition, one participant added that some patients are

depressed and have a hard time doing much of anything,

especially anything out of the ordinary. They may be able

to get up eventually and get dressed and do what is in their

normal routine but making any changes in their own behavior,

accepting any interventions is very difficult.

Patient non-compliance may also be attributed to the

way in which staff comes across to a patient. If a health

care professional comes across in a dominant, controlling

manner, the patient who feels provoked by that type kind of

attitude might develop non-compliance because of this. A

participant added that, "our society is not good at stepping

out of their comfort zone to make things a little different,

to make the effort to do them."

Patients may have support systems that may not be conducive

to assisting patients to comply. Some patients do not have

the proper support systems to help them make changes or

their support system, supports them not to change. Others

that do not have a good support system may not feel

accountable to anyone for failing to follow a regimen.

"Because they are not accountable, they are more prone to

stop following a prescribed regimen." Lastly, cultural

expectations may not support some of the things health care

professionals attempt to educate patient's on.

Financial issues and resources in general can impede a

patient from complying. Some patients are not able to

comply with a regimen due to the cost of their diet or the

cost of the medicine they have been prescribed.

"I think resources can have an effect on compliance and

non-compliance.

There is consequential non-compliance where the person

is just a victim of their circumstances and really does not

have the resources and may want to do what they know they

are supposed to do and just absolutely can't for on reason

or another."

Taking the time to see patients for who they are was a

major theme. It is suggested that staff do not want to take

the time to sit down with patients to discuss issues. Some

patients are fearful of the system and distrustful of it.

Spending time with patients to make them comfortable would

add to their internalization of information. Viewing this as

a "multidisplinary problem", health care providers are not

addressing the full picture of the patient. It was

suggested that staff needs to examine the patient's whole

make up before so they will know what will be the trials

and tribulations with the patient or the family. "We need

to examine what makes them tick, what makes them do what they do, their style." Therefore, taking time to get to know the patient versus the health care professional coming in with their own agenda may be helpful.

Staff may come in and due to time constraints, and feel that they must educate the patient in a certain amount of time. The patient may be set up to fail if staff is not aware of all of the dynamics. A patient may be someone who has always been successful and in control and all of a sudden they are sick and feel out of control and this is very difficult to handle. This individual is sick and helpless and they have to depend on somebody else which can be very frustrating. It was stated that frustration may cause a patient to take their anger out on the people who are taking care of them. "Sometimes you assume but do not really understand. If you understand the need and can relate to the patient on that level, the patients might be more compliant".

An interesting comment was made relating to the easy access patients have to the hospital. "They can go in and out of the hospital, sign out against medical advise (AMA)

and get readmitted within 1 hour by calling 911, and come into the hospital by ambulance rather than by their own private car or by bus."

Lastly, one participant asserted that what is non-compliance to a health care professional, may not be non-compliance to a patient. For example, "if a doctor or healthcare professional tells me to do something and I chose not to do it, I don't know, if in my perception, that would be non-compliance. It's non-compliance to the person giving the information - the health care provider is recommending something and the person doesn't follow it, so they are considered non-compliant."

3. What barriers do they face?

Many patients are resistant to make changes in their lives. People become set in their ways and change poses a threat to the normalcy of their routines. These alterations can be very scary, even if it will increase an individual's health status. "People get accustomed to what's normal for them", and may not be willing to take the extra time and energy it would take to comply with a regimen.

Barriers that inhibit a patient to comply may be

internal ones. Sometimes education is well received by the patient but other times they have just made the decision that they will not comply and become their own barrier. In addition, decreased will power, and commitment in addition to low self esteem are all factors that play a role in non-compliance.

Many times patients have good intentions when they receive information, but then 2-3 weeks go by and without any external reinforcement, these patients do not stay on track and they slip back to their normal habits. "There is not enough follow-up designed in our educational programs to allow them to be accountable over a 2-3 month period of time to make a change happen." One participant agreed that there is a lack of reinforcement accorded the patient but feel that it is still the patient's responsibility to follow through, but acknowledged that some patients are able to do this better than others. Patients must be true to themselves and feel the effort is worth it. The question is, how do you reinforce individuals that they are doing a good job?

Support systems may be severely lacking in the

patient's life. The patient may be on their own and there

is no one to take care of them or check in with them. A

solid support system can provide a patient the drive and

motivation to follow through. In some cases though, the

support systems that would normally be available to the

patient may have "embittered" feelings towards the

individual. "The driving feeling is that they did this to

themselves and now they can live with it." Others may have

negative support systems which reinforce the patient's

negative habits. Another interesting comment made by one

participant was that "many times if you are seen as non-

compliant, people will brush you off. You have already been

"x'ed" out so we won't worry about them. So people have

these vibes, an attitude against you. You think, 'ok, I

won't go back.' So many times it is the way, we as

providers, have our notions, or our biases. We may not even

realize it." In addition, if the health care professional

is the only support system the patient knows, "be it from

ethnic, social or gender limitations, then when we are taken

out of the picture, the patient's drive or ability to comply

is greatly compromised."

A lack of education or knowledge creates barriers to compliance. This can be the responsibility of either staff or the patient. Health care providers may attempt to educate the patient but many times they do not have the time to spend with patients to ensure they have a full understanding of the material. The patient may go home with one understanding that does not align with the original information given which can contribute to non-compliance. If a patient is illiterate and not able to read or understand what staff are relaying, they may become confused or forget and won't go along with the regimen because it is of no use to them and most are too embarrassed to let you know their deficits. Some patients have learning barriers, cognitive deficits that limit their ability to process, understand and retain information. Other patients have a fear of authority figures and institutions. This type of patient is not willing to listen even if they are able to understand the information. Lastly, some patients may experience a health crisis but when it is over they feel everything is going to be fine and they can resume their normal lifestyle. The patient feels they no longer have to

take their medicine or alter their habits. "They don't

recognize what caused the problem in the first place."

Cultural barriers may serve to limit compliance.

Cultural beliefs can dictate how patient's function within

their family unit. It may create a "codependency" type of

situation where other cultures may promote more

independence. There are differences within cultures in "how

they care for the sick, how they care for the disabled and

what expectations they place on the sick or disabled

individual in the family."

One participant stated that in some cultures the

females take care of everything and so the males do not

follow through. Problems have also arisen when an

examination is scheduled for a woman but because of her

cultural belief, she is not supposed to expose herself. In

one situation, the husband would not leave the room for fear

she would be exposed or something would happen to her.

Other cultures have "native or faith healers." The

individual is permitted to see a medical doctor only is

cases of severe distress. The doctor gives the patient

certain instructions for aftercare and it may not fit in

with the patient's way of looking at their illness. This

creates a conflict when the patient's culture dictates a

contrary regimen.

We are a multicultural society, therefore language

barriers exist. Although the hospital has an list of staff

interpreters within the hospital, and use of a phone system

that has interpreters available, problems may arise if for

some reason there is not an interpreter available or known

for that language. Sometimes an interpreter with limited

language skills may not be able to adequately relay

information due to the inability to define particular

meanings in that language or due to a different dialect.

One staff member stated that sometimes meanings can be

completely reversed when trying to interpret information.

Also, because information is given mostly in English, health

care professionals use medical terminology and "just a level

of language that a lot of patients are not familiar with.

They are not familiar with the words, the syntax, or the way

that you say things so they don't understand."

The ability to comply also depends on the patient's

financial resources. Limitations on financial resources can

create an enormous burden in regards to following a regimen. This relates to those patients who also have no insurance benefits or insurance that only covers a portion of what is required. Special diets and treatments, lack of transportation to appointments and monthly medication bills can limit a patient's ability to comply when financial resources are in short supply and when they do not know who to call for help.

Follow up care by health care organizations is also monetarily driven. When the patient transitions from in-patient hospitalization to home, the ability to provide adequate home health and out-patient care can be restricted when organizations must operate within the scope of reimbursement limitations. Sometimes the patient is discharged from service, "basically to fend for themselves" when their insurance benefits are exhausted.

Many of the patients in the hospital are elderly, thus, age and physical limitations become a factor in compliance. These two variables can decrease a patient's ability to understand instructions. In addition, their vision may be reduced, or their hearing impaired. Other patients are

either wheelchair or bed bound. One patient relayed to a

participant, "I'm too old, that's fine for a young person to

exercise but I'm old and it's not going to do me much

benefit." One of the greatest issues facing elderly

patients is the reality that because of their age, they will

never be restored to the functional level they once knew

which can lower their motivation.

Feeling entitled to health care was also a barrier

noted by one participant. They addressed this fact by

saying, "there is another element to non-compliance, the

overriding feeling, even in managed care, that health care

is a right and that we are entitled to it and it should be

provided for us. There is a lack of personal accountability

and responsibility for ensuring that you're getting the

things that you need. So, there may be some resource driven

reasons but I still see under the advent of managed care a

lack of personal accountability; my health is my

responsibility, I need to pick up the phone and find out

where the resources are that I need and how I can tap into

them, instead of waiting for someone to recognize that I

don't have the resources and find them for me. There needs

to be more pro-activity on the patient's part too, to take that responsibility for what they know is in their best interest."

Question 4. How does staff relate to a non-compliant patient?

The attitude of the health care professional toward the patient may help to ingrain or promote a level of non-compliance. Many staff members responded negatively toward patients they considered non-compliant. Patients were profiled, labeled, ignored, given up on by staff, given a bad reputation due to repeated hospitalizations, seen as unmotivated, written off or "disposed of". It was stated that some staff just don't care. A few staff have become frustrated, irritated or angry and at times have become confrontational with patients, instead of trying to find out what the problems are. Others become disgusted and don't want to deal with the patient. They felt it was the patient's responsibility to comply, that it was their life. One participant stated that some non-compliant patients can be manipulative, so they may be giving you lip service by listening and saying they want to get help but do not have

any intentions of following through. This attitude gets carried over to other staff and therefore they may not do a full assessment of the patient or develop a predisposed idea of a patient who is non-compliant. One participant stated that when this picture is painted in your mind, your doing an dis-service to the patient because that patient has already been labeled.

When a patient is encountered, at least initially, the staff person may have trouble separating themselves from a non-compliant patient's responses and they may get angry or frustrated. This type of attitude creates a barrier between the patient and the health care provider. It was suggested that health care professionals do a self evaluation where the situation can be looked upon objectively and where the staff person can realize they need not take it personally. In doing so, they may be able to look at the patient and evaluate why they are non-compliant.

"When you have a consistently non-compliant patient and you're spending your time and energy trying to help that person and you're not getting any cooperation, it's hard for staff to deep on trying. All in all, what generally happens

with a non-compliant patient, is the health care system, either individual pieces of it, or the whole system in general, just gives up on them and they get moved from place to place and everybody looses. At some point they are going to get lost in the system."

There does not seem to be enough investment toward understanding the non-compliant patient. Non-compliance is very individualized but when a patient has repeated hospitalizations, a reciprocal reaction can occur between the patient and health care professional. A level of non-compliance can develop among the staff person whereby they do not try as hard to create changes in the patient. "Staff are just trying to do their job and the patient won't let them. Very seldom will a staff person step in and go the extra mile to help motivate the individual to go on." For example, "a patient come in and they are not supposed to smoke and they have been in 6 or 7 times during the year. There isn't even a question that they are allowed to go anywhere they want; no one even discusses it anymore."

One participant stated that some non-compliant patients may be angry and it may take awhile to get past what they

are angry about to make any difference in their ability to comply and the staff does not have to time or the patience to wait.

"People, unfortunately, are here for 8 hours, 'just let me do my job and go home'. Then the non-compliant patient falls through the cracks because of the lack of drive on the staff's behalf to motivate the patient to identify the causes or reasons for non-compliance and attempt to resolve it."

In addition, exploring the rational for non-compliance may uncover facts such as when a patient has been hospitalized 4 or 5 times, and you perceive this patient to be non-compliant, then you discover that they can't pay for their medications. The issue of non-compliance could have been reduced or resolved had someone taken the time to look into the patient's situation on the first visit.

Even though some staff are biased toward non-compliant patients, they attempt to communicate with them the best they can. Staff document their interventions, such as the patient's response to the intervention, the encouragement given to the patient and family involvement, etc. One

participant added that occasionally interventions are documented in such a way as to make their paperwork look good when in reality staff did not do anything for the patient. But even with the best intentions, interventions can be hampered depending how aggressive the doctor is in implementing what is being recommended. If the doctor is aggressive in his treatment approach, there seems to be a more team approach in the among the staff. "But if the doctor is passive, 'well, Mr. Smith is kinda like that', then Mr. Smith tends to be treated a little less assertively than somebody the doctor is a little more focused on." In other words, staff become '"lax" in their attitude toward the patient.

Other participants felt that staff relates well to non-compliant patients. "They relate better to a non-compliant patient than a compliant one in meeting their demands, but it is the attitude of those patients who are non-compliant." They stay non-compliant in spite of all the repeated instructions and repeated hospitalizations, nothing changes. Some patients are then asked to discuss the issues with their doctor if the patient and health care professional

cannot reach an agreement.

Empathy among staff was also voiced. Patients must be seen as people first. "Whether they comply or not, we are professionals and we have to help them." This may require staff to be more inventive in their approach with the patient to work through certain issues. "If the patient is never able to go to their doctor appointments, and we find out it is because of transportation, then we will try to arrange transportation." Staff must reflect on the reasons they think the patient is non-compliant and then discuss this with the patient. This entails the health care professional "to take matters objectively and try to maintain a calm but firm attitude." Showing a calm and confident attitude makes the patient more comfortable which may reduce non-compliance.

"The idea should be to challenge non-compliant patients to understand them better and when you can understand why they are non-compliant, try to work within their limitations and be more accepting and lower the standard of how they can comply."

Education and communication skills were seen as way

towards reducing the occurrence of non-compliance. This was accomplished in different ways. Staff have been seen to work one on one with patients, giving patients advice, sympathizing with patients, and referring patients to resources within the hospital.

One participant stated that sometimes it takes a number of times and a number of different people and a number of different approaches to get the one staff person that finally clicks with that patient, that makes them realize that it's OK to make a change or that it's time for them to make that change. Giving up on them may be that time when that patient is really ready to make that change.

Length of stay also was seen to have an impact on the health care professionals ability to educate the patient. Limited stays in the hospital reduce the amount of time staff have to educate patients. Staff attempt to provide patients with as much information and education so they will follow through.

Patients may be working against limitations that staff are not aware of. Working with patients to find out if they had received appropriate information and how they were

informed during their last hospitalization helps staff to relate to a patient on their level. Patients are given a lot of critical information that they are expected to retain when they are discharged from the hospital. "How can you retain something in your long term memory that has only been explained to you in 5 minutes?" It was suggested that staff need to break down information into a simpler form, according to the patient's level of understanding. "Maybe what we are trying to teach is too complex." Staff need to examine why the patient was non-compliant during the admission process to get a better picture of where the patient comes from, their personal issues and home life. "We don't have any idea what life is like on the other side for them." Staff, as a team, need to be able to ask themselves "why" when they encounter a non-compliant patient.

Staff also use networking with other staff or the patient's family or caretaker as a way to effectively deal with patient issues. Working with the family or caretaker helps the staff to better understand what the patient likes or dislikes. They can get a better picture of what works at

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home or what has worked in the past for this patient. This "historical perspective" allows staff to look for other ways to communicate or help that patient work through some of the issues. Goals can be set when there is cooperation between the patient, health care professional and family member or caretaker.

Staff can accommodate patient treatment goals when they work together effectively. One participant stated that there have been a few times when a nurse has said to her, "what did you say to her because there is a big change here." This individual staff member had a lot more time to spend with the patient to be able to get past what all the barriers were that were causing the non-compliant behavior. Another participant stated that some patients are prejudiced and do not trust certain races. This participant was able to ask someone of the patient's own race help and the patient did not have any complaints and complied with the procedure.

Question 5 What are the consequences of non-compliance?

Non-compliance may create complications for the patient, especially in the long run versus the short term.

Medical problems can increase that require readmissions to the hospital, more testing and surgeries. Delays in the healing process may occur which coincide with malnutrition, increased morbidity and mortality, and depression. Diabetic patients are also at special risk. One participant stated diabetics have frequent admissions and when they do not control their disease by medication they can suffer complications of hyperglycemia, which entails worsening vision or blindness, diabetic retinopathy, kidney failure requiring dialysis, amputation of limbs, decreased energy level depression and death. "It's a spiral going down hill."

Sometimes a patient's behavior is a part of their overall makeup and non-compliance is a choice that they are making. But when patients do not make the effort to make changes in their life, there is an overflow effect into their personal life. Emotional problems arise, family life and their job may be affected. "It's a "multi-disciplinary" issue in that health care professionals need to continually educate patients so they do not continually end up back in the doctors office or the hospital.

Another consequence of non-compliance is the way in which staff relates to the patient. Staff develop an "attitude" towards these patients and they do not get the care that they need. If patients do not cooperate, "staff does not have all day to play around" with the individual. These patients are encouraged to discuss these issues with their doctor. With regards to the elderly, they face increasing dependence on the health care system, family members or other people. Staff may be seen as not complying with the needs of this population.

"Our focus is very seldom with regards to promoting that independent lifestyle that the elderly really need. This aspect of their care is frequently ignored. Our education is focused on how they need to do everything as opposed to how they need to remain independent."

There will be conflicts between patients and their families. Patients are continually being told something they do not want to hear and do not want to do. This can produce conflict within the family. Family members or caregivers may become "irritated and discouraged" in dealing with the non-compliant patient. This can create alienation

between the patient and family. Conflicts also arise

between staff members as far as how the treatment plan is

carried out. Staff members have different approaches in

relating to patients whereby the patient may react

differently to certain staff members, complying to one

request and not to another. Staff may also question their

own integrity and become frustrated when they attempt to

educate patient's but they keep coming back to the hospital

for the same problems. "It's like you're teaching them

something but you think you are not doing the right thing

because they are not following through. The staff may think

there is something they are not doing and that is why the

patient is not getting better." This can create a sense of

failure within the staff person.

A lack of support from the medical community, the

physicians, and hospital staff was also seen as a

consequence of non-compliance. "Why should I care about

this person that doesn't care enough about themselves to do

anything about it and so they get abandoned, to one degree

or another. Maybe not flat out abandoned but they don't try

as hard for this person that doesn't do anything for

themselves." Lastly, one participant stated that non-compliance causes an erosion in the health care system; it's basic mission, objectives and goals.

Financial consequences are a major issue. Taxpayers must assume the great financial cost when patients do not follow their regimen. Non-compliant patients become a burden on the system when they are readmitted to the hospital or are continually seen by their doctor for the same problem. Hospitals may be penalized if patients are admitted to a non-authorized hospital. They may suffer a reduction in payments or the patient may have to pay a higher co-pay or deducible. Out patient services have had to work with insurance companies to extend their coverage when non-compliance is an issue. When patients are non-compliant and are no longer eligible for services, it becomes abandonment if the patient is still greatly in need of service.

Financial restrictions also become an issue when the patient does not change their lifestyle in order to improve their health. "All of a sudden now you can't do what you used to do. You might not be able to provide for yourself

or your family, so it would really have a financial impact in several different areas."

One participant felt that non-compliant patients get excellent care. They come in "totally sick" and they go through the Intensive Care Unit and the next thing they do is continue with their non-compliant habits "like smoking while they are getting breathing treatments and eating candy while they are getting their insulin injections. The social worker talks to them to try and help them with their problems, the dietician goes and talks to them about their problems, and if the patient has pulmonary problems, cardio pulmonary talks to them. But they are still non-compliant and are not going to change."

Question 6 What are the benefits of non-compliance?

This was a particularly interesting question as participants at first appeared puzzled. But then many were able to focus on the times they have been non-compliant and relate these benefits to the patients they serve.

A minority of participants felt that non-compliance was not worthy of any benefits unless, in the end, it was able to turn the patient around for the better. One participant

stated that non-compliance may push the patient to the worse

they can get which will finally wake them up and create

motivation to change. Another participant stated that

individuals should care, and if these individuals were

caring people they would know they were non-compliant and be

aware of what should have been done on their part.

Patients should be educated on their options for

treatment and only when they opt to decline all options

presented, and continue the road they are on, should they be

considered non-compliant. One participant stated if

patients are presented with only one option, and told "this

is what you have to do" and they decline, this should not be

termed non-compliance. Also, some health care professionals

have not taken the time to listen to the patient when they

decline a treatment, medication etc., and because of this

are quickly labeled non-compliant as opposed to an

individual who knows and understands what is best for them.

"That patient, in refusing to follow doctor's orders or

treatments is basically looking out for the well being of

themselves."

A majority of participants felt that non-compliance was

a way that patients were able to take control over their
illness, "to doctor themselves" versus giving up control to
someone else. It was a decision based on a control or
power issue or in some situations, to try other treatment
alternatives.   The domain of alternative medicine was
discussed as an area wide open for the non-compliant
patient. "There are alternatives available now, whether
their efficacy and effectiveness are proven or not proven
because the motivations behind non-compliance is one of
authority and control issues. So the fact that they make
the choice for any avenue for assistance is a positive one."
One participant felt that patient's should always have a
choice accepting a treatment option, but then have to be
okay with their choice and the consequences it may bring for
themselves and whom ever else this choice may effect. Along
the same lines, it was voiced that patients who desire
alternative treatments should always discuss this with a
health care professional first to make sure that it is a
viable option.

    Non-compliance was also a way to manipulate an
individuals family or environment through their illness. "If

you don't have that illness anymore you might not have a tool to do the manipulation you want to do. Somebody that has trouble breathing and everybody panics when they can't breath, if they give up smoking and get healthy, they no longer have control over others around them where everyone had to rush in and fix it." In essence, the patient can continue their "habits, vices, and inappropriate lifestyle choices."

Cultural beliefs may dictate the way in which patients comply with regimens. Participants felt that patients should voice cultural concerns they have with staff to test the validity of their beliefs. For example, one participant shared that there was a child who was diabetic and their parents wanted to have this child drink carrot juice which they believed would control their child's blood sugar and make the diabetes go away. This was not a viable option and staff were able to educated the parents on appropriate options. This is also a way to challenge staff and study more of what they are dealing with. It gives them more experience to deal with a diverse population and personalities. "We cannot always have patients that agree

to everything."

Another participant stated that not all recommendations
are good, so non-compliance may be a good thing, at least
temporarily if it allows the patient to make their own
decision by asking more questions and then in the long run
be more compliant. Or the patient may find out that they
were given the wrong information or new information about a
certain treatment was discovered that was actually
detrimental to a person's health. For example, one
participant discussed the information that came out about
Phen/Phen. Non-compliance would have been a benefit for a
person who declined to take this drug. Non-compliance may
also benefit those patients who are very well read and very
understanding of their disease process. They have a well
founded understanding of what "medications, treatment
modalities or protocols are most effective." "Doctors and
nurses are not 'God', they don't always have the right
information." In addition, occasionally health care
professionals will see an acceleration in the healing
process because restrictions have been too stringent.

"I think it takes a very sophisticated, educated

person, very knowledgeable and in tune with themselves, a different kind of personality to have beneficial kind of non-compliance. There may be those people that can recognize when something that has been told to them is not right. However, in the case of physicians who are the most knowledgeable in our healthcare system, they are the worst patients in the world."

One participant stated they were more of a negotiator than a non-compliant person. This person disagrees with the health care professional on the front end and together they come to a conclusion as to what might be best for their health and what will fit with their lifestyle. Therefore, the doctor has their agreement that they will follow through with a regimen. They have been proactive with their health care.

Patients may benefit from being non-compliant whereby they receive more attention from health care professionals, but it was noted to be negative attention. With this in mind though, staff may be reinforcing that behavior.

On the other hand, staff may ignore patient's complaints which can lead to major complications. One

participant stated that non-compliant patients were an

irritation to the medical staff. "In a hospital

environment, you get rid of the patient who is a pain and a

hindrance and everyone feels relieved when they leave."

Teaching approaches by staff are challenged by non-

compliant patients. This type of patient gives staff an

opportunity to get in there and get to know the patient and

work through the issues and try to work as a team to meet

the needs and be better in the future in handling issues

that come up because they have had to work through

situations.

"When we take time to listen we can frequently address

the issues that are there and identify the resources,

support groups, and other elements that would be key in the

patient's success."

One participant stated when they work with patients

with regards to oxygen treatments, the focus is on the fact

that the patient wants to be independent, they want to do

the things that they used to do. "So this oxygen treatment,

this cannula around your head or your face is not to tie you

to home but rather to get them out of the house so they can

go out to dinner with their husband, wife, family, or children, or fly across the country and do more than they have done in the past due to their disease process."

Organizations may benefit from non-compliant patients on the "front end" in regards to capitation. Non-compliance may help to keep the patient's care profitable because non-compliant patients do not make appointments, do not fill presciptions etc., therefore that is not money coming out of the system. But what happens is that this patient ends up hospitalized and costs much more on the "back end".

7. What are some proposed solutions to non-compliance?

A major theme that was discussed was that health care professionals need to have a better understanding of what the patient's life has been like. Taking the time to sit down with the patient and do an intensive assessment may uncover background information that is better uncovered in the beginning of their hospitalization, rather than shortly before their discharge and finding out they cannot or will not comply with the regimen. Lack of transportation, no phone or just wanting the opportunity to care for their own needs may be obstacles professionals face. Financial issues

may also play a role in non-compliance. If staff expects a diabetic patient to adhere to a 1200 calorie diet, then it is imperative to know that the patient can only afford "beans, lard and flour tortillas". If staff are able to discover what the issues are, what the patient's home life is like and what is preventing the patient to comply with a regimen, it might be possible to look at alternative options that would work better with their life style and increase their ability to comply. "This is what we want to offer you and this is what would be best for you, but how is this going to work for you?"

"I think it's scary for staff to change the way we approach patients because due to time constraints and patient load, we develop a method that is efficient for us and to have to change that method, stop and redo something- to take time to figure out what's going on with the patient takes more time and energy and creative thought on our part."

Listening to the patient is key to understanding what the issues are to non-compliance. Just doing 10 minutes of basic care on a patient and asking simple questions like

"what works for you in this setting?" can yield information
that their doctor was not aware of in years of caring for
this patient. When the patient can verbalize what the
issues are in their life, what they understand of their
illness, and what has been discussed with them as a plan of
treatment, staff have a greater chance of understanding
where the patient stands. Once you have gained the trust
and respect of the patient, there is a possibility of coming
up with a new term instead of non-compliance and see it as
the patient's choice even if we do not agree.

Taking a more "passive or subordinate" stance may help
to bridge obstacles regarding issues of independence.
Establishing a "rapport", while remaining objective,
especially with elderly patients may allow staff to work
closer to them and preventing them to otherwise "tune out"
what was being said. One participant felt that some elderly
have the mindset of, "I'm not going to let that young kid
tell me what to do." They went on to say that if we
approach them with respect and understanding, listening to
their concerns, frequently the issue of non-compliance can
be side-stepped.

"Staff needs to work with the patient on what the possible things they can do to help themselves. We need to work with the patient's limitations - that maybe they can be compliant with 5 things but not with 10 things. Staff need to be more intuned with what the patient is capable of doing to comply. I think the professional needs to be less narcissistic about what they think is best for the patient and sit with them and get participation in what is realistic for that patient and see if they can get their attention and their needs met in a more positive way."

Using a team approach, with a variety of professionals to discuss the patient's issues is well worth the effort to provide the patient with the care they need and also prevent them from abusing the system. Providing ongoing monitoring and communication to the patient to answer questions and intervene when cultural or language issues arise may help to reduce non-compliance. Multidisplinary rounds are key to identifying and dealing with non-compliance issues. "Generally, in a group of 4 to 5 team members, there is always one individual who has found the key to the problems which are relating to the elements of non-compliance. So if

one person has identified the way into the patient's heart

or understanding and sharing that with the rest of the team,

this facilitates everyone's ability to work with the patient

and deter or turn around the elements of non-compliance."

Having patient care conferences that allow staff to

discuss issues, specifically when they are not making "head

way" with a patient, may help staff to figure out new

approaches. Creating a "forum" among peers and problem

solving together helps to generate new ideas. If needed,

other health care professionals can be utilized that have

expertise in certain areas, depending on the issues

involved.

Patients may take an independent stance in their life,

an attempt to be autonomous and assert their rights. They

may voice their "needs and wants" and this may perceived as

non-compliance. The patient may not want to comply, feeling

they will lose their individuality, or leverage with their

environment. Mental illness or their emotional makeup may

be a factor in their definance. One health care

professional stated there is an increase in patient's

signing out against medical advise (AMA) on the 1st and 15th

of the month because their social security checks have been

mailed out. They need to pay their bills, so in this case,

if they are physically able, patients should be granted a

pass so they can go home for a couple of hours, take care of

their business and then return to the hospital. This would

also be appropriate if there were an emergency. "Since the

law does not allow them to go out on a pass, they sign out

AMA and become non-compliant in spite of their desire to

comply." Health care professionals cannot limit care or

write these individuals off because staff perceives them to

be non-compliant. "We must give these individuals

permission to be that way even if the health care

professionals do not totally accept it."

The need to improve communication due to cultural

factors may play a role in non-compliance. Asking a patient

to make a change in their life that is against their

culturally beliefs may prevent the patient from complying.

It may be the patient's self interpretation of what they

should comply with, a misunderstanding because of their

culture.

"If a culture says that fat people are desirable and

the fatter you are the more prosperous you are, more

prestige you have in your culture and your doctor comes in

and says you have to lose weight because it is putting

stress on your heart, it is not going to make any sense to

them, so you have to get around that cultural difference by

educating them on the reasons why this is so important while

recognizing that this cultural issue is important."

Health care professionals must be able to use problem

solving skills in order to help patients realize the

benefits of following a regimen. It is necessary to find

out what their life style is like and "individualize the

benefits for them." Using creativity, explore why they're

having a difficult time and help them overcome those

problems on an individual basis. This may save time in the

long run. One staff member suggested that instructions need

to be communicated by using pictures, if necessary, which

may help those who cannot read or have a language barrier.

One participant stated that another key issue is to

acknowledge the non-compliance with the patient. Let them

know that you know they are being non-compliant and what

your seeing as the non-compliance issues and whether they

are aware of it. If a patient is not willing to comply with

one regimen, they may be willing to verbalize what they are

willing to comply with.

Non-compliance may also be addressed by education.

First, staff must be educated and aware of the differences

among individuals. Health care professionals then need to

help the patient to understand the reasons behind what is

being recommended which may take a long time. Very few

individuals will take the time needed to explain the

treatment plan. The doctor comes in and says "this is what

you need and this is why you need it" and leaves. The nurse

may explain it a little more but maybe not adequately for

the patient to understand. One participant added that

looking at the "staff matrix" on the floor, there is not a

lot of time to get out there and educate patients as much as

it is needed. There are many constraints staff are up

against which makes it so important to be creative in their

approach.

"I would think the main factors would be trying to

educate in terms that the patient can understand. The

appropriate language, words in that language, and what the

patient's priorities are - what outcomes to they see - and how to blend their recommended treatment into those priorities." Therefore, the ability to identify non-compliance, how to ask questions, create and introduce solutions and spending more time with the patient may help in the education process. This includes the patient's doctor who must speak with the patient so they can anticipate what the treatment process will be. "If you don't know what's going on and someone walks in and starts doing things without you knowing, you will be kind of afraid, but if the doctor explains what will happen before doing a procedure, the patient will buy into the program more."   Another participant added:

"Have the patient verbalize and list the effects of non-compliance. Maybe that would make it real for them. Let's say you have a neighbor that has this situation. What do you think the effects will be, what is real to them as far as the effects. Take it away from them and have them objectify it a little bit more and then turn it around and say 'do you realize that this situation applies to you?' Is it important to you?"

Many participants felt that taking a proactive stance

in order to prevent non-compliance is needed. This would be

accomplished through community programs that address health

issues. Visiting school sites and focusing on the need to

take responsibility for ones' own health needs, and seeing

this as a process throughout the life span, thus avoiding

major problems in the future is needed. Senior centers and

health clinics are also a target for involvement. There is

a need to address issues such as drug education, lifestyle

changes and the like. In addition, self esteem issues are

an important topic. Focusing on specific issues in people's

lives, how they can make their own choices, and what type of

choices they should make is needed. In addition, there

would be more time to discuss these topics in these settings

"versus 10 minutes in the doctors office where the patient

is given a presciption and out the door they go." Once they

are in the hospital it is very difficult to make major

changes unless there is someone that is caring and wants to

sit down and listen to the patient.

"I think as health care providers, we need to get out

there in the community and encourage community educational

programs. I think that by the time patients hit the door, they are on their way out the door and so therefore we don't have the time to educate our patients in regards to their compliancy. I think the key would be to get out there in the community, doctors offices, schools etc. and be a little more proactive in regards to education."

Lastly, follow-up care was seen as a deterrent to non-compliance. Addressing a patient's accountability by making verbal or written agreements and encouraging them to adhere to a certain regimen may increase compliance. Using home health or social workers to contact patients at home by phone or in person to make sure the patient understands the instructions correctly is important. One participant stated that they had made a home visit and a patient was not taking their medicine because he was told he could not smoke and he was going to smoke so this was something the nurse and patient had to work out together. If the home health nurse had not gone out, the patient would not have taken his medicine, his ulcer would have gotten worse and eventually he would have been readmitted to the hospital.

One last comment was voiced:

"Some type of mechanism is needed to monitor

improvement in non-compliant patients. Maybe someone has

been non-compliant 100% of the time and now they are non-

compliant 70% of the time.

Well, that is an improvement that you can build on.

You can definitely build on someone that is trying to change

their behavior instead of someone who is totally determined

to not change."

ROUND TABLE SUMMARY

Overview

Upon completion of the draft, this researcher sought to "test the credibility of the inquiry" (Erlandson et al., 1993). To do this, an outline was developed that attempted to highlight the main constructions established by the participants. The outline was given to the sixteen remaining participants for their review and a round table meeting was scheduled for one week later to discuss the results. Participants were encouraged to be prepared to offer their feedback, suggestions, or revisions as they felt appropriate, in writing and verbally.

The meeting was held in a conference room in the hospital. Four out of the sixteen participants attended. The completed draft was also available for review if there were any concerns or questions about the information in the outline. The meeting lasted approximately 45 minutes and all four participants, in addition to this researcher, participated in the discussion. The outline was discussed, question by question. Recommendations were sought as to the validity of the themes.

DISCUSSION OF RESULTS

Overall, the feedback was positive as participants

relayed the information was appropriate, accurate and

confirmed many of the issues that staff were already aware

of. Participants agreed on the definition of non-compliant

patient's and the many components of this phenomenon.

Discussions focused around the issues of staff and patient

responsibility, caregiver burnout, education on prevention

and self esteem issues and lastly, the complexity of this

phenomenon.

Participants also felt that many of the patient's

needs were not being addressed in the decision making

process. This also included cultural and language barriers.

Expectations were placed upon patients without looking at

everything that may be impacting their lives. Neglecting to

observe the pressures patients may be facing could very well

indicate that patients are seeing staff as judgmental or not

caring about them, only the regimen they are being asked to

follow. It was agreed that some staff become "disengaged"

toward non-compliant patients and a lack of time adds to

their anger or frustration which may enhance a patient's

non-compliant behavior. It was brought to light that there was not a general consensus throughout the hospital, that some staff become angry or frustrated when a patient is non-compliant. Many staff voiced that they were "shocked" that some staff would behave in this manner. Staff are seen to be working against limitations and constraints, at times, that inhibit their ability to completely attend to the patient's totality of needs.

One participant reiterated that there is a perception of "entitlement" to health care. For example, if a patient has diabetes and decides he/she does not want to follow their diet, they can eat what ever they want, have their blood sugar soar out of control, and come back to the hospital and they will "fix it for me." Patients must take responsibility in their own health care needs, but the question was how this would be successfully accomplished. Problem solving is a key issue that takes time by staff and the ability to gain the trust of the patient so they feel comfortable to express their concerns. It is very important to negotiate short term and long term goals with the patient in an attempt to educate them on their health care needs and

that wellness is a process that assumes responsibility on the part of the patient and health care professional alike.

It was expressed that the scope of this issue extends beyond the patient, in that breaking the cycle of non-compliance is difficult and for those caregivers of non-compliant patients. Hospitalization or other out of home placement, for health related needs, provides a needed break from the patient. Caregivers become isolated and drained of energy in their attempts to provide for the patient's constant needs or efforts to get the patient to comply to their regimen. The patient is "well taken care in the hospital, gets three meals a day and is medically stabilized." Occasionally, for the caregiver who has dealt with the patient for a long time, hospitalization becomes a final shift of responsibility where the caregiver chooses to sever their caregiving obligations and the healthcare professional is given the challenge to secure out of home placement for this patient.

Participants felt that follow-up services and education focused on prevention and self esteem issues are extremely important in order for patients to comply with

medical regimens that they may have to follow for the rest of their lives. One participant runs a support group and felt that compliance is directly related to the way patients feel about themselves and this can vary week to week, month to month. Participants were able to relate to this intimately as stories were shared about personal experiences and how their moods directly effect their willingness to comply with even voluntary matters, such as a diet or an exercise routine. Having the extra support, post hospitalization, when the patient can be in a vunerable state and can decide to either follow through or not is when follow-up services could benefit the patient the most.

All participants agreed that non-compliance is a complex issue that will not be remedied over night but health care professionals must take the first step to assess the patient using a "systems" perspective to accurately address the many barriers patients face and through trust, confrontation, education, negotiation, support and accountability, patients may acquire the internal and external support they need in order to perceive compliance as a necessary component to a healthy future.

Review of the above results confirms the researchers initial working hypotheses, as listed in Figure 1 page 11, that education, shared decision making, increased understanding by staff, viewing the patient in a holistic manner and follow-up services are all measures that can open communication between patient and healthcare professionals and thus increase compliance.

Discussion

Fit of Constructivism to This Inquiry

The main goal of this study was to "demonstrate that stakeholders have been empowered, educated, and connected with the constructions of other stakeholders in the social context to promote a richer level of understanding and insight for all participants" (Erlandson et al., 1993). The advantage of using constructivist research is the ability to develop a "theoretical understanding" (Rubin & Babbie, 1996) of your observations in order to formulate a conceptual framework in which to understand the phenomenon under study. Constructivism seemed well suited to explore the issues of non-compliance within a hospital setting and demonstrated at the conclusion of the study that indeed participants showed

a commitment to share their thoughts, concerns, and ideas with the researcher and each other. The hope is that new perspectives on non-compliance will be facilitated through this process that will in turn improve the interactions between healthcare professionals and patient's with the goal of reducing the occurrence of non-compliance.

Emergent Themes

Many themes emerged that focused on the need for increased education for patients and staff, cultural and language issues, apathy among patients and staff, issues related to support systems, financial and resource issues, and lastly, staff limitations and constraints. These themes surfaced in all seven questions. In addressing the problems of non-compliance, it became clear that approaching a solution(s) is a complex, multifaceted issue that must take many variables into account. Although this study is focused on the micro-level, attempting to address these issues only on a mirco-level would do an injustice given the severity and scope of the problem. Indeed, macro-level issues emerge based on the impact that non-compliance has on families, institutions, financial implications and the health and

welfare of the patient. Just as policies guide a society's thoughts and feelings on a particular issue, so does our definition of non-compliance. We define the term non-compliance within a certain framework which guides our perceptions and actions. We may short change ourselves in the long run by taking a stubborn or apathetic stance to non-compliance if we take a "we" versus "them" attitude. Our thoughts and feelings will be focused on a straight and narrow path rather than relating these non-compliance issues to our own lives. Every participant admitted to being non-compliant, to some degree, at one time or another, in their life. Attempting to negatively judge anothers' situation only serves to shorten our attention and tolerance towards either redefining what non-compliance means or looking at the many issues that can create non-compliance.

Many factors help to shape and sway an individual's opinion. One person's opinion is a part of a much larger puzzle that includes our past and present experiences, how the people we associate with think, how our community approaches the subject and how newspapers and the media project opinions. Just as constructivist research seeks to

reduce all data to the smallest "unit" of information that will stand alone, this researcher believes that non-compliance should be accorded the same scrutiny so patterns can emerge and be treated individually, on their own merit. This may assist healthcare professionals to focus their recommendations and/or solutions to non-compliance to the appropriate and specific areas versus profiling each non-compliant patient as the same.

Comparison of Findings and Literature Review

The research results showed considerable consistency comparing it to the literature review. Although the literature review described issues in greater detail, participants expressed many of the same concerns from the perspective of their interactions with patients at the hospital. As cited earlier in the review, a patient's beliefs in the value of the regimen and their ability to overcome practical barriers to adherence seem to be a starting point that only touches the surface of this phenomenon. The issues discussed in the literature review extend beyond the hospital setting and into the community where much of non-compliant behavior takes place.

Healthcare professionals must deal with the consequences when the patient is hospitalized and this pattern of behavior has a major impact in many areas discussed in eariler sections.

Participants were cognizant of the many variables that either lead to or reinforce non-compliant behavior but only briefly mentioned how managed care plays into this issue. This researcher believes that managed care will continue to play a greater role in how healthcare professionals deal with non-compliant patients and how they may be compelled to look for creative, "cutting edge" measures to engage individuals at a younger age to develop a passion for a healthy lifestyle, just as any other institution in our society sets out with an advertising campaign in an attempt to engage its target population with its product.

Limitations of the Study

Constructivism is an alternative paradigm which seeks to understand a phenomenon, not to measure it. It may show patterns and relationships but not cause and effect. The tools to measure the phenomenon are developed by the researcher, which may include observations and open ended

questions, whereas the more traditional paradigms base their results on rigorous sampling and standardized measurements. Because of the subjective nature of the inquiry, information gained is less generalizable to other similar sites of inquiry. Specific issues may be common characteristics to one institution but cannot in anyway infer the same characteristics exist in another similar institution. Erlandson (1993), states that "no true generalization is really possible; all observations are defined by the specific contexts in which they occur." Because of this, the constructions that emerged may have relevance in another hospital due to shared characteristics, but in no way are these results equivalent to other institutions. Differences can be significant when variables such as the location and demographics of the community, patient population mix and staff characteristics are considered. Conducting a similar study, called "expansion research", may help to strengthen the generalizability of the results but cannot be deemed as "replication" as in traditional research.

Suggestions For Further Research

Using a constructivist paradigm opens the doors for

further research in other acute care hospitals in the

attempt to form a level of consensus regarding non-compliant

patients and how healthcare professionals define the various

aspects of this phenomenon. Because the literature review

was, for the most part, based on quantitive studies, it

would be interesting to continue this qualitative endeavor

in other areas of the community, comparing constructions, in

an effort to rule out specific concerns that are distinct to

one area. Considering the fact that non-compliance is a

symptom of issues beyond the scope of this paper, this type

of research could continue in many other healthcare

settings. Also, this research only addressed a select

number of key questions. Questions are the instrument to

exploring other areas of concern which will open the door

and lead to a greater understanding of non-compliant

behavior. I hope that as managed care extends greater

responsibility on the patients they serve that a shift in

perception and definition of non-compliance can take place.

Creative ways to support patients need to be developed that

will afford the patient autonomy without sacrificing their

health while still perserving the dwindling healthcare

dollar.

Implications For Social Work Practice

The constructions expressed by the participants addressed a range of opinions and concerns and confirm this researcher's construction that non-compliance is a phenomenon that must be viewed on a continuum and from how we perceive and define non-compliance. With the economic pressures of managed care patient compliance is becoming an increasingly important factor in the delivery of cost-effective health care. Mechanisms for examining the causes in order to reduce non-compliance are key. Because the root of non-compliant behavior is different for each individual, identifying the relationships between the patient's lifestyle and factors that may trigger non-compliance must be acknowledged so healthcare professionals understand why patients are making these choices. There needs to be a shift in emphasis and focus toward how health professionals can learn to contribute effectively to patient decision making, for example, by tailoring their advice so that it fits into patients' existing beliefs and expectations and takes into account the constraints imposed by individuals'

everyday lives. Effective strategies will require

healthcare professionals to work as a team, in the true

sense of the word, so each staff member is able to best

utilize his/her skills in order to properly diagnoses the

reasons for the patient's non-compliance.   Healthcare

professionals can encourage, preach, even argue their

position, but in the end, it is the patient, in his/her own

environment, who will decide what direction to take.

Addressing the needs of a non-compliant patient can be

taxing when healthcare professionals already express a lack

of time to spend with patients. Using a systems

perspective, hospital social workers are in a prime position

and well equipped to effectively approach this issue. They

have the skills to provide education, counseling, and

communicate to patients with a multitude of problems.

Social workers can act as mediators between the patient and

staff and search out interventions that will impact and

enhance patients' ability to adhere to their prescribed

regimens.   Assessing the patient within their environment

can lead to better communication and coordinated efforts in

an effort to provide comprehensive services, with the end

goal of increased compliance.

APPENDIX A - INFORMED CONSENT

Dear participant,

You have been asked to participate in a study on non-compliant patients. The purpose of this study is to understand the various perspectives on non-compliant patients by hospital staff, in key departments, within the hospital setting. At the end of the study, it is hoped that a common understanding can be reached, and solutions proposed, to reduce the occurrence of non-compliance.

This study has been approved by the Cal State San Bernardino Institutional Review Board. This study will be conducted by an interview process by one graduate student interviewer, Barbara Smith. You will not be asked to fill out any questionnaires or surveys. Tape recorders may be used, unless you oppose. Your honesty in answering questions is of utmost importance. It is also an important aim to keep an open mind about how your perceptions may change during this study. After your information is analyzed, you will be asked to review it for accuracy. Initial interviews will take approximately one to two hours at the most. If time permits, one additional interview may

be held.

There will be approximately five to ten other participants in this study. These participants will consist of one (maybe two) people from key departments within the hospital. Although your name will be kept confidential, the information you share, will then be shared among all other participants. Each participant will have the chance to share their perspective on the non-compliant patient, whereby each successive participant will review the previous participants' perspectives. At the end of the study, all participants will be asked to attend a roundtable meeting to hopefully come to some common understanding of what non-compliance means and what steps can be taken to reduce non-compliance, as noted above. A final draft of the study would then be provided for your review. Total participation time will be approximately five hours.

I understand that your time is valuable so all interviews will be held at your convenience. You also may withdraw from the study at any time, even after interviews have been completed. You would have the option of withdrawing the information you shared also, or allow this

information to be used with complete confidentiality. If at any time you have questions or concerns, you may contact my advisior Dr. McCaslin, at (909)880-5507, or myself, at 880-5501. If you are agreeable to participate in this study, under the above conditions, please sign below. I appreciate your time and information.

Sincerely,

Barbara Smith

Name_____Date_____

APPENDIX B - DEBRIEFING STATEMENT

Thank you for taking part in this study and contributing your views on non-compliant patients. All information that you have shared and any observations I may have made will be documented to the best of my ability and resubmitted to you for your clarification. Any information that you disagree with or change your mind about will be deleted. The goal of this study is to share perceptions on patient non-compliance between yourself and other hospital employee's. It is hoped that by reaching a consensus that patient non-compliance can be reduced.

I will be contacting you in the near future to review the information from our interview. If you have any questions or concerns about this study before this time you may contact myself or my adviser, Dr. McCaslin.

Barbara Smith

Dr. Rosemary Mc Caslin

Thank you again for your participation in this study.

APPENDIX C - INTERVIEW QUETIONS

1. What is your definition of a non-compliant patient?

2. Why do you think patient's are non-compliant?

3. What barriers do they face?

4. How does staff relate to a non-compliant patient?

5. What are the consequences of non-compliance?

6. What are the benefits of non-compliance?

7. What are some proposed solutions to non-compliance?

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