2002

What influences patients to change?: a qualitative exploration of health decision-making factors among diabetes patients

William Ralph Garris Jr.

Iowa State University

Follow this and additional works at: https://lib.dr.iastate.edu/rtd

Part of the Family, Life Course, and Society Commons, Psychology Commons, and the Public Health Commons

Recommended Citation

Garris, William Ralph Jr., "What influences patients to change?: a qualitative exploration of health decision-making factors among diabetes patients" (2002). Retrospective Theses and Dissertations. 373.

https://lib.dr.iastate.edu/rtd/373

This Dissertation is brought to you for free and open access by the Iowa State University Capstones, Theses and Dissertations at Iowa State University Digital Repository. It has been accepted for inclusion in Retrospective Theses and Dissertations by an authorized administrator of Iowa State University Digital Repository. For more information, please contact digirep@iastate.edu.
INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

Bell & Howell Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48108-1346 USA
800-521-0600

UMI®
What influences patients to change?
A qualitative exploration of health decision-making factors among diabetes patients

by

William Ralph Garris, Jr.

A dissertation submitted to the graduate faculty in partial fulfillment of the requirements for the degree of
DOCTOR OF PHILOSOPHY

Major: Human Development and Family Studies (Marriage and Family Therapy)

Program of Study Committee
Harvey Joanning, Major Professor
Mary Jane Brotherson
Charles Link
Sandra Sellers
Ron Werner-Wilson

Iowa State University
Ames, Iowa
2002

Copyright © William Ralph Garris, Jr. 2002. All rights reserved.
Graduate College
Iowa State University

This is to certify that the doctoral dissertation of

William Ralph Garris, Jr.

has met the dissertation requirements of Iowa State University

Signature was redacted for privacy.

**Major Professor**

Signature was redacted for privacy.

For the **Major Program**
to wanda
TABLE OF CONTENTS

ABSTRACT vii

CHAPTER 1. INTRODUCTION 1
  Overview of the Study 1
  Research Question 3

CHAPTER 2. LITERATURE REVIEW 4
  Overview of the Chapter 4
  Diabetes 4
    Diabetes: One disease in three forms 4
    Epidemiology 5
    The costs of diabetes: Physiological and financial 7
  Compliance in Context 11
    The semantics of compliance 11
    A review of how “compliance” has changed over time 13
    An overview of the literature on noncompliance 15
  Research about Adherence, Patient Decision-making, and Diabetes 21
    Quantitative studies 21
    Qualitative studies 29
  Why Marriage and Family Therapy 34

CHAPTER 3. METHODOLOGY 36
  Why Qualitative Inquiry Was Chosen 36
  Researcher as Instrument 39
  The Generation of Data 42
    Selection Procedure and Description of Informants 42
    Access to the Field 44
  Data Collection and Analysis 46
    The generation of data 46
    The analysis of the data 50
    Strategies to Ensure Trustworthiness 55
  Summary 59

CHAPTER 4. RESULTS 60
  Description of Participants 60
    Evan, age 42 61
    Ted, age 29 61
    Betty, age 65 61
    Sam, age 59 62
    Christine, age 72 62
    Kelly, age 45 62
<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stan</td>
<td>79</td>
</tr>
<tr>
<td>Debbie</td>
<td>48</td>
</tr>
<tr>
<td>Mary</td>
<td>56</td>
</tr>
<tr>
<td>Quinn</td>
<td>53</td>
</tr>
<tr>
<td>Denise</td>
<td>59</td>
</tr>
<tr>
<td>Kent</td>
<td>44</td>
</tr>
<tr>
<td>Theresa</td>
<td>63</td>
</tr>
<tr>
<td>Bernice</td>
<td>71</td>
</tr>
<tr>
<td>Sally</td>
<td>65</td>
</tr>
<tr>
<td>Krista</td>
<td>56</td>
</tr>
<tr>
<td>Kendrick</td>
<td>58</td>
</tr>
<tr>
<td>Steve</td>
<td>49</td>
</tr>
<tr>
<td>Nora</td>
<td>61</td>
</tr>
<tr>
<td>Kurt</td>
<td>63</td>
</tr>
<tr>
<td>Olive</td>
<td>63</td>
</tr>
</tbody>
</table>

Map: A Visual Overview of the Categories

Description of the Categories, Properties, and Dimensions

Overview: Disentangling interrelated ideas

Category 1: Disequilibrium

The central category: Health decision-making

Category two: Knowledge

Category three: Purpose

Category four: Self-agency

CHAPTER 5. DISCUSSION

Explication of Relationships Among the Variables

The theoretical overview and backdrop

Disequilibrium

Knowledge, self-agency, and purpose

The theory summarized

The Place of this Theory within the Broader Body of Knowledge

Juxtaposed against the propositions from chapter two

Situating this research among other social science theories

Implications for Clinical Practice

Limitations of Grounded Theory Methodology in this Study

Directions for Future Research

CHAPTER 6. CONCLUSION

APPENDIX A. HUMAN SUBJECTS REVIEW BOARD APPROVAL

APPENDIX B. APPROVAL FROM HOSPITAL IRB

APPENDIX C. INFORMED CONSENT
ACKNOWLEDGEMENTS

It seems unfair that only one person is awarded the doctorate. This project has been the work of many people, all of whom have earned this degree, sacrificing and contributing in different ways.

I would like to begin by thanking the professors who have seen me through this endeavor. Mary Jane Brotherson, Chuck Link, Ron Werner-Wilson, Sandy Sellers each played a vital role in seeing this project to its fruition. Notably, I would like to thank Harv Joanning for his tremendous encouragement throughout the years. Harv is a cultivator of dreams.

I would like to thank Mom and Dad McGuirt who allowed me to take their daughter to Iowa to pursue what, at times, seemed like an interminable education. Thank you for believing it could be done. Mom and Dad Garris, who helped at every turn: this would not have been possible without you. I am grateful.

Most of all this is for my family; they have sacrificed the most. Lauren and Sarah: I love you both so much. May the word “dissertation” never cross my lips again. Wanda, thank you for tolerating my unavailability. You have been a wonderful mother, friend, and support, particularly when I have not lived up to my end of the deal. I love you. As I put the final touches on this effort, I have four words for you: your husband is back.

Thank you, Father, Sustainer, Provider, God. “O sovereign Lord, you are God! Your words are trustworthy, and you have promised these good things to your servant.”

2 Samuel 7: 28
ABSTRACT

The United States’ aging population increasingly requires the medical community to address chronic disease management, rather than the treatment of acute conditions. Management of long term health concerns relies heavily on the active participation of the patient, yet insight into patient motivations is lacking. A review of the literature revealed that most medical research into the patient as a person has addressed factors related to non-compliance, such as demographics, compliance with specific therapeutic regimens, and external factors such as pill shape and color. Research into the health decision-making process from the perspective of the patient was found to be generally absent in the literature.

In an effort to reduce that void, 21 people diagnosed within the past six months with Type 2 diabetes met with the researcher three times over a period of six months and were interviewed as to the factors that were influencing their decisions to make changes to their lifestyle in response to diabetes. Analysis of the data generated by these interviews revealed four categories that influenced health decision-making. These factors that emerged were (a) the degree of emotional upset, termed disequilibrium following their diagnosis with diabetes; (b) varying knowledge about their illness that could be described as factual knowledge, emotional knowledge, and experiential knowledge; (c) differing perceptions of empowerment over their illness, broadly categorized as self-agency; (d) and the sense of purpose that inspired their efforts toward change.

The interrelationships among these categories are presented as a theory of health decision-making, grounded in the perspective of the patient. The new theory is compared with existing explanations for health decision-making. The paper ends with a discussion
about the implications of these findings for healthcare professionals, the limitations of
naturalistic research, and suggests directions for future study.
CHAPTER 1: INTRODUCTION

Overview of the Study

Despite advances this century in understanding disease processes, treatment that requires significant lifestyle changes on the part of the patient often fails. Nowhere is this more true than with the diabetic patient. Although new medications help people manage chronic illnesses, many physicians, medical sociologists, and third party payers remain puzzled over how to facilitate healthy lifestyle changes. Frequently these concerns are discussed in terms of "compliance" and "non-compliance."

A widespread problem, non-compliance wrecks personal, economic, and societal consequences. Although it varies widely by medical condition, treatment regimen and drug type, it is generally accepted that between one-third and one-half of all patients do not comply with doctors' directives (Donavan & Blake, 1992). Non-compliance with treatment for diabetes ranges from 65% to as high as 93% (Cerkoney & Hart, 1980; Venter, Joubert, & Foukaridis, 1991), depending largely on how one defines "compliance." The costs of non-compliance are staggering, not only in financial terms, but also in human lives. Greengard (1990) reported that patient non-compliance costs 22 billion dollars a year. Expenses are incurred from medications going unused, unnecessary hospitalizations and nursing home admissions, and lost workdays.

In the endeavor to understand and modify adherence behaviors, a vast body of literature on non-compliance has accumulated. Much of the compliance research consists of
connecting demographic variables with patient “defaulting.” Additionally, there is a body
of literature that describes compliance rates quantitatively with specific treatments.
Moving from the strictures of the “compliance” debate to the broader concern of how
people make health-related decisions, it becomes evident that the role of the patient in
health care has been disregarded (Ary, Toobert, Wilson, & Glasgow, 1986; Chubon, 1989;
McClean, 1997). Research seems to support the myth of the patient as a passive recipient
of medical advice (Stone, 1997). Relatively few medical studies consult the patient on their
experience as an active agent in managing their health concerns. The consequences of not
understanding how patients come to experience lifestyle change have been costly in both
personal and economic terms (Betteridge, 1997; Clark, 1998; Giardino & Brownlee, 1997;
Goldberg, 1995; Gu & Cowie, 1998; Harris, 1998; Herman, 1994; Johnson, Doll, &
Cromey, 1986; Moss, Klein & Klein, 1991; The National Institutes of Health, 1999;

Only recently has there been a call to explore how the patient, as an active agent,
constructs a narrative out of the medical information they receive (Stone, 1997; Vanderford,
Jenks, & Sharf, 1997). Fueling this present movement toward patient-centered research is
an increasing value placed on multi-method approaches to healthcare research (Roter &
Frankel, 1992; Stange, Miller, Crabtree, O’Connor, & Zyzanski, 1994), with medical
researchers adding ethnographic methodologies to their inquiries (Searight & Campbell,
1992; Searight & Young, 1994).
**Research Question**

The purpose of this study was to develop a theory of health decision-making rooted in the experiences of type 2 diabetes patients. Type 2 diabetic patients were selected because, unlike juvenile onset diabetes, Type 2 adult patients' illnesses were often related to poor health practices, habits that needed to be reformed as a matter of treatment. Examples of grand tour questions that guided the research included:

1. How would you describe the nature of the change required to adhere to the diabetic regimen prescribed by your physician (sudden, gradual, in stages, affective, cognitive, experiential, other)
2. What factors persuade you that these changes needed to happen?
3. What factors keep the changes maintained in your life?

Other questions may be found in the section on methodology. Descriptions of these experiences were elicited using qualitative approaches. Because this study used an inductive approach, no formal hypotheses were proposed a priori (Bogdan & Taylor, 1984; Glaser & Strauss, 1967; Lincoln & Guba, 1985; Spradley, 1979, Strauss & Corbin, 1990). Biases and beliefs of the researcher, however, will be addressed under the chapter on methodology.
CHAPTER 2. LITERATURE REVIEW

Overview of the chapter

This chapter begins with an overview of diabetes, providing a definition, delineating its forms, its costs and consequences. Following this will be evidence that lifestyle changes do reduce symptoms and mortality. Next I will review the notion of "compliance" because it has been the traditional lens through which patient health behavior has been understood. After exploring compliance and demonstrating the extreme consequences of noncompliance to medical advice, the focus will be narrowed to the state of the field in terms of theory and the newer literature describing patient behavior, particularly as it relates to diabetes.

Diabetes

In 1992 Glaxo published a periodic overview of medical specializations based on surveys of physicians. Their surveys identified that the illness that family doctors found most challenging to treat was diabetes ("Pathway Evaluation," 1992). This is not surprising as Cerkoney and Hart (1980) found that only 7% of diabetics are fully adherent to their required treatment regimen. Although other researchers defined adherence more loosely and offered more optimistic figures of 35 - 50% compliance (Venter, Joubert, & Foukardis, 1991) enlisting the active participation of diabetic patients in their own treatment constitutes a significant challenge for practitioners.

Diabetes: One disease in three forms

"Diabetes mellitus is a group of metabolic diseases characterized by hyperglycemia resulting from defects in insulin secretion, insulin action, or both" (The Expert Committee
In healthy individuals, the body derives its energy from glucose, though to a lesser extent proteins and fats also provide fuel. This glucose, broken down from the more complex sugars in the diet, circulates in the bloodstream where it is carried to cells for metabolism. Ordinarily, the beta cells of the pancreas secrete the hormone insulin, which facilitates the glucose's uptake from the blood into the cell. In the diabetic individual, this system fails. Either the beta cells do not create enough insulin or the body's cells ignore the insulin that is produced. In both situations, the result is an excess of glucose in the blood which is passed out of the body with urine. Even though the blood may be loaded with glucose, cells are unable to access it for fuel and forfeit a primary energy source. There are three primary types of diabetes: insulin-dependent diabetes mellitus (IDDM) or type 1 diabetes, noninsulin-dependent diabetes mellitus (NIDDM) or type 2 diabetes, and gestational diabetes.

Though the disease pathway for type 1 is not clearly understood, scientists believe a genetic or viral trigger, combined with age, seasonal variation, and chemicals, causes a misguided autoimmune response, whereby the immune system turns on itself and destroys beta cells of the pancreas (Diabetes Overview, 1996; Tsalikian, 1990). The pancreas then produces little or no insulin. It is a chronic disease that typically afflicts children and young adults. Type 1 represents about 10% of all diabetes cases (Diabetes Overview, 1996).

Type 2 is far more common, developing in adults who are over age 40 and often overweight (Goldberg, 1998). In this disease, the pancreas functions normally; it is the body's cells that fail to acknowledge the presence of insulin, and thus the presence of
glucose, in the bloodstream. As with type I, scientists do not know the exact cause of type 2. Risk factors that have been identified include (a) being a minority in the United States, (b) age, (c) obesity, (d) waist to hip ratio, (e) low birthweight as an infant, (f) family history of diabetes, (g) history of gestational diabetes, and (h) physical inactivity (Goldberg, 1998).

Finally, gestational diabetes is diagnosed in 3 to 5 percent of all U.S. pregnancies. According to the Diabetes Sourcebook (1994), gestational diabetes generally does not cause birth defects, is usually temporary, and disappears after the pregnancy concludes. Nonetheless, women who have had gestational diabetes are at higher risk for developing type 2 later in life.

**Epidemiology**

Diabetes mellitus is a growing problem throughout the world. Considered a disease of affluence, the prevalence of diabetes has risen steadily with the United States' prosperity. The increase of diabetes has been particularly notable over the last 40 years. In 1948 roughly 1.5 million Americans had diabetes. Current estimates are that 10.5 million people in the U.S. have now been diagnosed with the disease (Harris, 1998), a seven-fold increase. Worldwide, it is predicted that the number of type 2 patients will increase from 100 million to 200 million over the next 15 years (Cruikshank, 1997) as industrialization results in longer life expectancies, reduced physical activity, and an over consumption of foods in developing third world nations.

Yet the diagnosed cases of diabetes do not fully explain the growing problem facing healthcare. The Third National Health and Nutrition Examination Survey, that took place between 1988 and 1994, collected medical data from a sample of the U.S. population aged
40 to 74. Their findings revealed that the prevalence of undiagnosed diabetes is significantly greater than had been realized, with about 1/3 of the diabetic population living asymptomatic, undiagnosed and untreated (Harris, et al., 1998). Estimates of the total number of diagnosed and undiagnosed cases of diabetes have risen to around 16 million (Center for Disease Control, 1998; Reiber, Boyko., & Smith, 1995). Many people do not learn of their diabetic condition until a routine physical exam or as part of evaluation for another known medical problem. Although this may not immediately seem like cause for concern, these asymptomatic and undiagnosed people can still suffer the consequences of diabetes (Zimmerman, 1990).

**The costs of diabetes: Physiological and financial**

The inability to breakdown glucose has severe consequences. Prior to the development of insulin in 1922, a diagnosis of diabetes constituted a death sentence, executed after a short but harrowing existence. McFarlane, Bliss, Jackson, and Williams (1998), in an effort to describe the diabetic's deterioration, suggest it would be analogous to the suffering currently associated with an advanced cancer or the late stages of acquired immunodeficiency syndrome (AIDS). However, as insulin treatments grant a medical reprieve from the most acute metabolic consequences of diabetes, attention is shifting from the primary causes of diabetes to the long-term complications of the disease. It is this myriad of secondary effects that is principally responsible for today's diabetes high costs in terms of personal suffering, economic burden, and death.

The long-term health consequences of diabetes are sometimes divided into two categories, microvascular and macrovascular complications, with an array of other ailments not neatly
fitting either category. Microvascular changes refer to the increasing constriction of the blood vessels (Giardino & Brownlee, 1997). The primary cause of this narrowing is prolonged exposure to hyperglycemic conditions, though certainly some other factors contribute to the problem. However it occurs, the result is the same; blood is insufficiently delivered to the affected organs and they begin to fail.

The list of potential harms that can occur because of microvascular degradation is extensive. Damage to the retinal capillaries leads to swelling, exudate, increased risk of cataracts, and blindness. In fact, among the broad 20–74 year old age group diabetes is the leading cause of blindness in the US (Harris, 1998.) Damage to capillaries in the kidneys can result in chronic renal failure. Nerve tissue can become demyelinated, ultimately leading to sensory and motor control dysfunction. This diabetic nerve damage is believed to be the most common cause of neuropathy in the Western world (Johnson, Doll, & Cromey, 1986) and frequently leads to amputation. Data from the U.S. National Hospital Discharge survey indicate that diabetics are 15 times more likely than the general population to have a lower-extremity amputation. Roughly 50% of all non-traumatic leg amputations are the result of diabetes (Reiber, Percoraro, & Koepsell, 1992). Additionally, neuropathy results in problems for the autonomic nervous system that include poor night vision, heat exhaustion, orthostatic hypotension, constipation, diarrhea, fecal incontinence, bladder dysfunction, and sexual dysfunction (Giardino & Brownlee, 1997; Harris, 1998; Herman, 1994; Tsalikian, 1990; Zimmerman, 1990).

Macrovascular disease refers to the constriction of larger blood vessels caused by fats and blood clots sticking to the vessel walls. Although the disease pathway is somewhat less
clear (Harris, 1998), it can be said that people with type 2, and consequently hyperglycemia, have more frequent lipid abnormalities, leading to hypertriglyceridemia and higher rates of vascular disease (Betteridge, 1997). This causes increased mortality from ischemic heart disease and stroke. A follow-up of earlier NHANES participants uncovered that the rate of death from any cardiovascular disease was 12 per 1,000 person-years for men without diabetes, whereas it was 30 per 1000 person-years for diabetics. The rate of death due specifically to ischemic heart disease was more than 3 times higher for diabetics (Gu & Cowie, 1998).

Hypertension also poses a serious health-risk for the person with diabetes. Exacerbating the normal risks associated with high blood pressure, a diabetic patient may experience increased blood pressure rushing through already compromised nephrons, accelerating the destruction of the kidney’s filtration abilities. The result is end-stage renal disease (ESRD). Treatment for ESRD includes hemodialysis, peritoneal dialysis, and kidney transplantation. ESRD can also result in death. As diabetes has increased, so to the problem of diabetic ESRD has worsened. Between 1982 and 1996 diabetic ESRD as a percentage of total ESRD from a variety of causes has worsened from 22% to 42% of the cases (US Renal Data Report, 1998). The advent of insulin in 1922 may have mitigated the immediate metabolic consequences of diabetes, but there remain many grave complications to the long-term effects of hyperglycemia.

Despite the fact that death rates from type 2 diabetes are more difficult to assess than one might ordinarily expect, many statistics, estimated and inferred, all support diabetes as a significant contributor to early deaths. Death certificates are commonly used to determine
mortality rates and cause-of-death. Although this may seem unproblematic, Geiss, Herman, & Smith (1997) cite and describe various ways in which all cause-of-death data, and especially deaths from diabetes, can be recorded incorrectly. Of primary concern is that fact that long-term hyperglycemia leads to other fatal conditions. Frequently this obscures the causal role of type 2 in mortality (Geiss, et al., 1997).

One of the largest sources of morbidity data is the National Center for Health Statistics. Its National Mortality Followback Survey (NMFS) tracks not only the immediate causes of death, but also some of the broader medical conditions of the decedents at the time of their demise. It indicates that among the deceased in 1993 411,000 people had been diagnosed as having diabetes. This represents about 18.6% of all deaths, an increase in proportion of 1.4% from seven years earlier (The National Center for Health Statistics, 1998). Using the 411,000 diabetic deaths from the NMFS and dividing it by the 7.8 million diagnosed diabetics in 1993 (National Center for Health Statistics, 1994) there is an annual rate of death for this population of 5.27%. This is consistent with other smaller, longitudinal cohort studies that also found a death rate of 5.7% (Moss, Klein & Klein, 1991). An overview of the literature by Geiss et al. (1997) determined that individuals with diabetes are twice as likely to die as people without diabetes. This elevated risk remained even when controlling for other risk factors such has smoking, hypertension, and cholesterol levels.

Not only are the consequences of uncontrolled diabetes medically insidious, they are expensive. According to the American Diabetes Association (as cited in Clark, C.M., 1998) about one-sixth of health care dollars in the United States are spent on diabetic care. Of the medicare budget, one quarter of their medical expenditures are for diabetic treatment (Clark,
Although only 3.1% of the US population is diagnosed with diabetes, they are responsible for 11.9% of the health care dollars spent in the U.S. The cost of diabetes to the U.S. is around $100 billion (Goldberg, 1995; The National Institutes of Health, 1999). This figure combines the indirect costs, such as disability payments, lost work time, and premature death, with the direct costs of diabetic care, including hospitalizations, medical care and supplies.

Compliance in Context

The semantics of compliance

Compliance is a sticky and contentious idea both in the literature and in practice (Playle & Keeley, 1998; Trostle, 1988). In one of the more widely cited definitions, progenitors of the term, Sackett and Haynes (1976, pp. 2-3), explain that compliance is “the extent to which a person’s behavior (in terms of taking medications, following diets, or executing life-style changes) coincides with the clinical prescription.” This was intended to be interchangeable with “adherence” and was set forth as a nonjudgmental alternative to “recalcitrance” and “insensitivity” (Lerner, 1997). Yet a fundamental problem with “compliance” remains. It retains connotations of “obedience” with more implicit notions about power, appropriate roles, and value judgments upon people who fail to comply (Donavan & Blake, 1992; Lutfey & Wishner, 1999; Playle & Keeley, 1998; Ross, 1991). Trostle (1988) states:

Compliance is an ideology based in theories about the proper relationship between physicians and their clients. Yet its assumptions, definitions, and manifestations have been studied and reified as quantifiable categories of human behavior. Though
compliance can be called a non-judgmental concept, it is rarely used or studied in this way (p. 1303).

Equally problematic, "compliance" often functions as blinders on researchers, constraining them to simplify the patient's role as "direction follower." Contextual factors, such as the role of the family, the cost of medicine, concern about treatment side effects, the effect of treatment on quality of life, cultural issues, and the thinking processes of the patient are obscured. Indeed, Donovan and Blake (1992) conclude that much of what is termed "non-compliance" is in fact not merely forgetfulness or disobedience, but the result of a thoughtful and reasoned-out process whereby the patient weighs benefits of treatment against the risks of side-effects and concerns about medication dependence.

Other less value-laden terms, such as "adherence, obedience, cooperation, concordance, collaboration, and therapeutic alliance" are offered in place of "compliance" (DiMatteo & DiNicola, 1982). However, as each term reflects a differing, and sometimes opposite, construct about the roles of patient and physician, there is no consensus for which word to use. The role of language in such a politicized discourse is critical. The Sapir-Whorf Hypothesis asserts that "the structure of a human being's language influences the manner in which he understands reality and behaves with respect to it" (Carroll, 1956, p. 23). Social constructionists complement this by stressing that language includes an ontological dimension that ultimately "generates the sense of what is real" (McNamee & Gergen, 1999, p. 19). The terms selected to frame the discussion of patient decision-making and compliance have social, political, and even ontological implications for both the researcher and reader to consider.
A review of how “compliance” has changed over time

Regardless of the vocabulary used, issues of non-compliance have been in existence as long as society has had formalized roles for its power structures. Indeed, Hippocrates is reported to have said, “The physician should keep aware of the fact that patients often lie when they state that they have taken certain medicines” (as cited in Lasagna, 1973, p. 217).

According to Treue’s study (as cited in Koltun & Stone, 1986) the sharp witted 17th century French playwright Moliere was queried by King Louis XIV about the medical care the writer was receiving. Moliere records the following exchange:

The King: You have a physician. What does he do?

Moliere: Sire, we converse. He gives me advice which I do not follow, and I get better.

In the days before effective medication, the consequences of non-compliance were minimal and perhaps even saved a few lives. But recently, compliance has become a more pressing issue for healthcare professionals. There are at least two reasons for the heightened concern about compliance. Some researchers posit the rise in compliance literature is linked to the advent of antibiotics, stating that prior to the 1950s physicians did not have access to many effective medications and it was not as critical that medications were taken. The second reason is more cynical: economics. Trostle (1988) believes that the ideology of compliance is part of a historical collusion between the medical and pharmaceutical industries to reduce the people’s reliance on folk remedies and direct them toward the healthcare industry.
Although Trostle raises interesting points and extensively documents his argument, changes in medical-consumer behavior renders it somewhat less relevant. Issues surrounding compliance and the “active-passive” model of medicine (Szasz & Hollender, 1956) have greatly changed in the last 40 years. Consumerism has eroded physician respect and authority (Haug & Lavin, 1983). Drug companies, in addition to persuading physicians to offer their products, now engage in expansive television and print media campaigns to promote medicines among the public. Thus prescriptions and hospital budgets are increasingly driven by consumer demand. The availability and accessibility of health information has been dramatically increased by the media, notably the internet. In 1997 Restino and Ratzan reported that 11 million Americans sought out medical information on the World Wide Web through resources such as the National Library of Medicine’s (NLM) “PubMed,” a variant of the popular MEDLINE compilation. Illustrating its exponential growth, Morris of the NLM states that 12 million searches are now conducted monthly, more than the library used to do each year (personal communication, May 30, 1999).

Other notable shifts include the advent of physicians as salaried employees of for-profit hospitals and health maintenance organizations limitations on treatment. All of these changes serve to diminish the physician’s control over health care technology, and, in due course, their power (Trostle, 1988). Therefore, with the issues of power in medicine disappearing, old notions of compliance seem less relevant. In this new medical environment that deals increasingly with chronic health issues that depend patient action to ameliorate, it becomes increasingly pragmatic to drop the former discussion on “compliance” and to re-explore how it is people come to choose healthy behaviors.
An overview of the literature on noncompliance

The patient compliance literature is vast and continues to grow exponentially. Before 1960 there were only 22 English-language articles published on the subject. By 1978 there were 850. Between 1978 and 1990 it is believed that 8000 papers were published (Donovan & Blake, 1992; Trostle, 1988). A short-lived *Journal of Compliance in Health Care* in the 1980s also provided a venue for research and discussion (Ulmer, 1989). These efforts helped researchers develop models for patient behavior, and identify rates and consequences for non-compliance.

Models used to explain patient behavior.

Although no theories of patient decision-making behavior have originated from diabetes research, there exist many models to explain patient behavior, some of which have been applied to the diabetic patient. These more general health decision-making theories offer some insight into how diabetic patients come to make health-related changes to their lives and may come to adhere to a treatment regimen. Three major theories are the Stages of Change Model (SCM), the Theory of Reasoned Action (TRA), and the Health Belief Model (HBM).

Created in 1982 by Drs. Prochaska and DiClemente of the University of Rhode Island, the SCM views behavior change as a naturally occurring and dynamic process. Prochaska and DiClemente studied individuals who managed to quit smoking on their own, apart from any formal cessation program. To describe their observations, a five-step process of change was created, including the stages of (a) pre-contemplation, (b) contemplation, (c) preparation, (d) action, and (e) maintenance. The original model has been expanded to
explain a broad range of behaviors, including, among others, weight loss and injury prevention.

The TRA also has been used to explain and predict a variety of human behaviors since its creation by researchers in 1967. Theory originators Ajzen and Fishbein assumed that people are rational creatures who make systematic use of the information they have. Second, they believed that people thought ahead to the consequences of their actions before committing to engage in a certain behavior (Ajzen & Fishbein, 1980). Consequently, people are presumed to take certain actions if they believe that these behaviors will lead to outcomes that they find desirable. Behaviors explored by the TRA include the use of contraceptives, dieting, the use of safety devices such as seatbelts or helmets, exercising, voting, breastfeeding, smoking, and drinking (Fishbein, Middlestadt & Hitchcock, 1994).

One of the theories more commonly used to explain patient compliance is the Health Belief Model (HBM). The HBM originated during the 1950s as part of a public health effort to explain why people were not taking advantage of disease preventives and screenings, particularly for asymptomatic diseases such as tuberculosis (Rosenstock, 1974). It was later extended to include other similar screenings for polio, influenza, cervical cancer, and dental disease (Rosenstock, 1974.) Those working on this project (Dr.s Hochbaum, Kegeles, Leventhal, and Rosenstock) were trained as social psychologists (Maiman & Becker, 1974) and were significantly influenced by the theories of Kurt Lewin.

Kurt Lewin, a pioneer in social psychology, is regarded for his development of field theory. In it, he argues "that our behavior is purposeful" (Tesser, p. 340) and proposes that individuals exist within what he termed a cognitive "lifespace" (Lewin, 1936). This
lifespace represents the social environment, relationships, and one's place in society (Lewin, 1936). It also contains both negative and positive regions that compel movement away from distressing stimuli or toward goals. Arguing that behavior is related both to one's personal traits and to the social situation in which one finds oneself, field theory borrows from behavioral psychology, but then uses phenomenology to delve into the "black box" of the mind which Skinner ignored.

Rooted in the "phenomenological behaviorism," of field theory, the HBM presumes that diseases are negatively valued (negative valence) and exert a force that moves a person away from that particular region. Health is, of course, seen as a positive region of the lifespace. Each day's choices are seen as part of a process in which a person is being pulled by positive forces and repelled by negative valences. Derived from these premises, the HBM offers five postulates about health-related behaviors: A person will modify their behavior (a) if they believe they are vulnerable to a particular illness, (b) if the consequences of acquiring the illness are believed to be severe, (c) if the benefits of reducing their perceived or real susceptibility exceeds the barriers to or costs of the treatment, (d) if the availability of internal or external cues to trigger the preventive health behavior, and (e) according to what are described as modifying social psychological, demographic and structural variables. Many other less popular models for health-decision making behavior exist, including transference (Blum, 1985) and cognitive dissonance theory (Coffield & Buckalew, 1988). Except to acknowledge that they exist, there will be no effort made to cover them at this time.
Although the purpose of this research is heuristic and not confirmatory, it was decided that the later chapter of discussion would be aided if some basic tenets of these theories were distilled here and reevaluated at the research's conclusion:

1. Change occurs naturally in biological systems (SCM)
2. Change is incremental (SCM)
3. Change is rooted in a rational decision (TRA)
4. Change can be facilitated by education (TRA)
5. Change will be facilitated by people viewing themselves as vulnerable to an illness (HBM)
6. There are triggers for change that can be either internal or in the social environment (HBM)
7. Change in health behaviors occurs when the perceived benefits outweigh the perceived costs (money, time, effort) to engage in the activity.

Rates of nonadherence

Buckalew and Buckalew (1995) sought to estimate the prevalence of non-compliance with medications among a larger and generally healthy population, to explore what demographic variables may be related to compliance, and to identify if there were preferences for the form of the medication, such as tablet or liquid. The researchers recruited a sample of 148 persons, stratified by race, age, and gender to be consistent with the 1980 U.S. census data. Next, they altered the simplistic categories of “compliance versus non-compliance” into “failure to fill, filling but not taking, taking only a portion, or not following frequency or dose instructions of a prescription” (p. 316). After the
administration of a short (five minute) survey, they researchers found that only twenty-five percent of their subjects were fully compliant. Thirty-three percent of the respondents even failed to satisfy the more forgiving criterion of taking the medicine seventy-five percent of the time. Ley (1983) reported that fifty percent of patients do not follow the simplest of their doctor’s instruction and the Schering Report’s (1992) interview of 2000 consumers revealed that 8.7% of respondents failed to have even their initial prescriptions filled.

Rates of adherence also vary by disease, demographic variables, and treatment. Only sixty percent of hypertensive patients are compliant with their medications (Clark, 1991; Morisky, 1986). Other studies have reported that 30-40% of patients do not adhere to preventive treatments, while 20-30% neglect to complete “curative (relief of symptoms) medication regimes” (Segal, 1993, p. 90). It is generally accepted that between one-third and one-half of all patients do not adhere to their treatment regime (Buckalew, 1991; Conrad, 1985; Donovan & Blake, 1992) and that adherence increases with the presence of symptoms and decreases with longer term regimens (Sackett, 1976).

**The costs of nonadherence**

The urgent need to understand the patient’s perspective is underscored by the high costs of non-adherence. The consequences can be measured two ways: financial and personal. Researchers have offered different measures of the economic costs of non-compliance. Levy, Mermelstein & Hemo (1982) studied admissions to Israeli hospitals and reveal that 2.9% were primarily the result of noncompliance. Col, Fanale, and Kronholm (1990) reviewed the hospital medical records of 315 elderly patients admitted to an acute-care hospital. They later interviewed the patients and determined that 11.4% of the
admissions were the result of noncompliance. Each admission cost an average of $2,150. A literature review estimated that two million hospital admissions annually in the US are the result of non-compliance (Sullivan, Kreling, & Hazlet, 1990). Further, the March 25, 1992 Wall Street Journal (as cited in The Task Force for Compliance, 1994) offered that these increased physician visits and hospital admissions cost 8.5 billion dollars. Although true economic expenses, direct and indirect, of nonadherence cannot be determined, the costs are high. An aging population with increasing needs for health care will only amplify the costs of noncompliance.

Nonadherence also has personal costs. Eight percent of people taking birth control pills have some measure of noncompliance (Jones & Forrest, 1992), that can result in an unplanned pregnancy. People who fail to manage their hypertension, about forty percent (Clark, 1991; Morisky, 1986), are at increased risk of stroke or other cardiovascular mortality. Eighteen percent of people who have had organ transplants fail to maintain their treatment regimen which can lead to organ rejection and death (Rovelli et al., 1989). The need to understand and modify patient behavior and lifestyle change is high.

Yet despite the explosion of research on non-compliance and the urgent need to understand how to facilitate health change for people, satisfactory explanations for non-compliance remain elusive. Stimson (1974) stated:

The answer to the second question, what are the characteristics of the people who do not follow their doctor's instructions, has met with little success. The results of the studies are inconclusive and contradictory. Few significant differences between
defaulter and compliers have been found despite the testing of numerous variables.

(p.98)

Though Stimson’s work is from a generation ago, current researchers report that the situation has not changed. There is wide agreement that noncompliance remains poorly understood (Bucklew & Sallis, 1986; Donavan & Blake, 1992; Lo, 1999; Schoenberg, Amey, & Coward, 1998).

**Research about Adherence, Patient Decision-making, and Diabetes**

In defining “adherence,” researchers have come to recognize that it is not a singular concept, particularly in the case of the diabetic patient. Rather, managing the illness requires incorporating into their schedule a complex set of instructions. Diabetics may be required to follow a meal plan, take up exercising, follow a foot-care plan, regulate blood glucose levels, manage other diabetes-related symptoms, and take insulin or an oral hypoglycemic (McNabb, 1997). Each of these different components requires a different skill set or belief system and consequently a person may be adherent with certain portions of the regimen and not others (Ary, Toobert, Wilson, & Glasgow, 1986). Individuals with diabetes indicate that the more difficult components of treatment to manage are diet and exercise (Christensen, Terry, Wyatt, Pichert, & Lorenz, 1983; Glasgow, McCaul, & Schafer, 1987), incidentally facets of the regimen that require the largest time commitment and change in lifestyle.

**Quantitative studies**

As stated previously, the majority of the adherence literature has consisted of quantitative studies. The quantitative research ranged from identification of rates of non-
adherence and theory testing, to surveys designed to understand what patients believed about their illness. Perhaps most notable among the quantitative research was a landmark demonstration that behavior change did indeed affect mortality for diabetes patients.

**Rates of Nonadherence**

Pineiro et al. (1997) performed a surprise pill count on 107 Type 2 diabetics and found that less than half were within 80-110% of their targeted compliance. Forgetfulness (40.7%) and lack of knowledge (29.5%) were the two most frequently given explanations for failing to adhere to the regimen. Other factors this study found associated with low compliance were length of time having the disease. Those who had been diagnosed with diabetes more than four years were less likely to be in adherence than the more recently diagnosed. Cerkoney and Hart (1980), in their study on locus of control and compliance, found only 7% of diabetics were fully compliant to regimen that combined using the right dosage of insulin, foot care, diet, and urine testing.

**Theory-based Diabetes Adherence Research**

Several studies used the HBM to investigate diabetes regimen adherence behaviors. Alogna (1980) used survey research to examine the connection between adherence and the HBM component “perceived severity of the illness.” A significant relationship was found to exist. The dependent variable of retrospective adherence was divided into two categories, adherent and non-compliant; thus it was impossible to evaluate how “perceived severity” accounts for different degrees of regimen adherence.

In 1980 Cerkoney and Hart used the HBM to study compliance with a diabetes regimen. Employing an HBM-based health belief measurement tool adapted from the
Standardized Compliance Questionnaire, which the authors briefly described, they found a 0.5 correlation between overall compliance scores and their responses on this HBM measure. Thus, only 25% of the variation among respondents' compliance levels was explained by the HBM, suggesting a constellation of other factors in health behavior change not yet recognized by researchers. The results for this retrospective study also found associations between HBM components and adherence. However, as with the previous research, only the correlation between “perceived severity” and adherence achieved statistical significance.

Finally, Harris, Skyler, Linn, Pollack, and Tewksbury (1982) applied the HBM to 50 males from a Veterans Administration hospital. Compliance was determined using both physiological measures and patient recall. Health beliefs were obtained using a 71 item questionnaire which had been derived from earlier compliance research. The researchers found significant correlations between “susceptibility” and dietary adherence, “benefits” and exercise, and “barriers” and the taking of medicines. Additionally, the investigators found relationships between these health beliefs and certain demographics. Married subjects were more likely to feel susceptible to the complications of advanced diabetes and were concerned about its potential implications for family members. It was also found that African-American patients viewed themselves as less susceptible to diabetic complications, but perceived medical care as being more helpful than other subjects.

Heiby, Gafarian and McCann (1989) began with three different theories of compliance: an operant model, the HBM, and a Health Compliance Model. Each of these theories presumed a slightly different set of skills or factors are involved in compliance behaviors.
Based on these theories, hypotheses were generated. Finally, a 67 item Likert-type questionnaire in which diabetic patients provided a self-report of their habits and attitudes was developed, with the purpose of identifying elements of the theories that were actually being used by diabetics. Their study found that compliers were characterized by using positive self-talk to encourage adherence to exercise, diet, medication, appointment keeping, and blood/urine monitoring. Second, compliers reported intending to be more compliant in the future, important because of theories that posit people perform health behaviors that they intend to do. Third, they learned that the adherent persons had a higher internal health locus of control, assuming more responsibility for their health. Finally, being knowledgeable about diabetes, skill at managing a busy schedule, and enjoying exercise and the diet were correlated with compliant behaviors.

Schlenk and Hart, (1984) using a non-probability, convenience sample, interviewed and surveyed 30 Type 2 diabetes patients during their diabetes clinic visits in order to elucidate the relationship between health beliefs and compliance. The independent variables, health locus of control, perceived social support, and health value, were measured using questionnaires, while self-report and observation were used to determine compliance. The researchers reported a statistically significant relationship between compliance and perceived social support (p > 0.001) and a locus of control that resided within the individual (p > 0.05) or powerful others (p > 0.01), but is not consigned to chance or fate.

**Studies That Seek to Find Other Correlates to Adherence or Nonadherence**

In 1988 Schatz recognized that theory-based research proposing to understand patient compliance yielded results that were not predictive of actual patient behaviors and at times
even conflicted with the theory. Schatz studied 98 adult diabetes patients to investigate the variables that might be affecting compliance in this patient population. Her research revealed that compliance was positively associated with the length of time since diabetes diagnosis (more adherent patients had been aware of their diabetes longer), knowledge about diabetes, higher scores on a measure of the HBM, and use of home glucose monitoring. In her study 100% of the adherent participants utilized home glucose monitoring, while only 1/3 of the non-adherent patients tested their blood at home. Schatz concluded that the real difference between the two groups lay in their response to feedback or cues in their environment that they used to shape their everyday choices. It should be noted that her findings about “years diabetic” being positively correlated to adherence contradicted the later findings by Pineiro et al. (1997).

Belgrave and Lewis (1994) explored what role social support played in compliance and other health behaviors for African Americans with Type 2 diabetes. Through the administration of simple questionnaires, researchers found that social support is positively correlated with keeping medical appointments and significantly associated with following through with diet and foot care regimes. Similarly, Glasgow and Toobert (1988) purposed to extend their Diabetes Family-Behavior Checklist–II (DFBC-II) from its previous administration on Type 1 patients to Type 2 diabetes patients. Their study also sought to examine the relationships between multiple measures, such as the Perceived-Stress Scale, the Medical-Care Satisfaction Questionnaire, the DFBC-II and regimen adherence as measured by self-report on the Summary of Diabetes Self-Care Activities. The research
found that family-support measures were the most powerful and consistent predictors of compliant behavior.

Lo, (1998) attempted to take a broader view of the patient’s life in order to understand what factors were associated with adherence and what constituted barriers to compliance. She administered a 19-paged, 298 item questionnaire to 387 respondents. The survey was created to gather information from people about their response to being diagnosed with Type 2 diabetes and the physical, emotional, and ecological issues affecting people who live with diabetes. In her statistical analyses, factor analysis and multiple regression, the dependent variable she measured was “intention to carry out self-care behaviors to medical regimes.” Her survey produced the following discoveries: factors that significantly influenced the dependent variable included (a) the effects of stress, (b) accessibility to social support, (c) locus of control, (d) self-esteem, (e) coping skills, (f) health beliefs, (g) perceived obstacles to adherence, and (h) difficulties following diet regimes. The most salient relationship the researcher found was the relationship with compliance was with the independent variables “intent” and the quality of the relationship between the HCP and the patient. Again, this was meaningful because of research showing “intent” leading to compliance behavior (Heiby, Gafarian, & McCann, 1989).

Ary, Toobert, Wilson, and Glasgow (1986) re-examined the rates of nonadherence for Type 1 and 2 diabetic patients, as well as the reasons they gave for nonadherence. To accomplish these two goals, 208 qualified subjects completed a self-care assessment and then answered both standardized and open-ended questions about their reasons for noncompliance. With the standardized portion subjects responded to one of five researcher
provided reasons. The open-ended questions, which were later coded, allowed subjects to explain why they did not adhere to specific regimen components. Their study found that the vast majority of subjects reported taking their medications on time (87%). Glucose testing was less common at 67% for type 2 patients. Subjects reported adhering poorest to prescriptions for dietary and exercise change, with type 2 patients providing self-reports exercise regimen compliance only 53% of the time. The authors noted that these two components were similar in that they both require the most time and alteration in lifestyle. Reasons for nonadherence varied across different components of the regimen, but included situational factors such as eating out in restaurants and failure to refuse inappropriate offers of food from others, both of which required assertiveness on the part of the patient.

The study was limited in many respects. There were no explicit references to theory and it was set up inductively or as a heuristic inquiry. The exploratory nature of the study was evident in the principal questions they asked, such as “what is the patient perspective of factors that contribute to nonadherence?” Yet the methods they used were quantitative. Even when they used open-ended questions, it was not clear that the researchers did not bias the responses by having the respondents answer the standardized questions first.

Why is adherence so important in managing diabetes? In 1983 the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) embarked on a landmark Diabetes Control and Complications Trial (DCCT). This project was to be the largest, most comprehensive diabetes study ever, with participation from over 1400 subjects and 29 medical centers. Using an experimental and control group, the research compared the physiological effects of standard diabetes treatment against a more intensive, tight control
on diet and exercise. After 10 years the researchers found a 75 percent reduction in eye disease, 50 percent reduction in kidney disease, and a 60 percent reduction in nerve disease. A position paper from the American Diabetes Association (ADA) states it this way: "it appears there is a direct relationship between blood glucose levels and the risk of complications," (s24, 2000) though the organization recognized this relationship was somewhat mediated by genetic factors. Although the DCCT study was on Type 1 diabetics, current medical convention holds that the results apply to people with Type 2 diabetes as well (ADA, 2000).

Finally, Anderson, Nowacek, & Richards (1988) researched the effects of diabetes education. Patient education programs typically focus on affecting physiological improvements by offering knowledge and training in skills believed to contribute to better self-care behaviors. However, casual feedback from participants led the researchers to wonder if there were not also some less tangible benefits to diabetes education. More specifically, the researchers hypothesized that diabetic education also influenced how patients felt about their diabetes and the personal meaning they attributed to being a diabetes patient. Using a pre-test post-test design and 54 subjects they found that diabetes education did indeed have a positive effect on the patient's personal meaning of having and treating diabetes.

**Summary of Quantitative Studies**

In summary, there has been much research about patient behaviors from a quantitative perspective. The research has described rates of adherence for specific regimen components and identified demographic correlates to diabetic patient behavior. Many researchers have
asked good questions, trying to understand the beliefs and perspectives of the patient (Ary, Toobert, Wilson, & Glasgow, 1986; Glasgow & Toobert, 1988; Lo, 1998; Schatz, 1988; Weller et. al., 1999), but their examinations have been subject to the limitations of survey research (Playle & Keeley, 1998). Finally, there has been strong evidence from the ADA (2000) that tight control of blood glucose does matter. Moreover, how people construe the sick role and the personal meaning of diabetes is subject to intervention (Anderson, Nowacek, & Richards, 1988). Put another way, quantitative research has shown us that it is possible not only to educate people about diabetes management, but to also change how they approach the illness. The DCCT underscored that changing their approach would have dramatic benefits.

**Qualitative Studies**

In contrast to the vast body of quantitative research into the life of the diabetic patient, there have been relatively few studies using open interviews with the patient as their data source (Ary, Toobert, Wilson, & Glasgow, 1986; Chubon, 1989; McClean, 1997), despite calls for increased exploration of patients’ experiences (Vanderford, Jenks, & Sharf, 1997) and the qualitative evaluation of treatment (Altman & King, 1986; The National Long-Range Plan to Combat Diabetes NIH Pub. No. 88-1587). There were, however, a few exceptions.

One such exception was a genre I term “rhetorical literature.” The purpose of these publications seemed to be to heighten the reader’s awareness of the patient role, without actually interviewing patients. Stone’s 1997 article “In Search of Patient Agency in the Rhetoric of Diabetes Care” was a good example of the sensitizing, rhetorical literature. In
this piece she unpacked the terms “compliance” and “adherence” and examined how these terms affected patient agency in the realm of diabetes care. Many others have written similar articles (Lutfey, 1999; Playle & Keeley, 1998), with Vanderford, Jenks, and Sharf (1997) arguing for the centrality of the patient’s experience in health care research. They posited that it was the patient who “constructs meaning, devises strategies, and modifies life choices in response to information and changes in and about health. All of these issues require a focus on the patient as a central construct of research” (p. 14). The same authors also noted that “although the range of issues to be explored in patient-centered research is broad, we find patients’ decision making to be a potentially rich field of inquiry” (p. 22).

Other researchers (Altman & King, 1986) have also argued for an increased utilization of qualitative methods to understand prevention and compliance because qualitative methods provide “richly detailed descriptions of people and situations and a depth of understanding of process usually unattainable by other evaluation methods” (Patton, 1980, p. 67).

Another exception to the dominance of survey research was the short biographical narrative which may be found in journals. Maria L. De Alva (1998) discussed the challenge of having diabetes during brief remarks at an Amylin Pharmaceutical Incorporated sponsored symposium. Her lament about the travail of the diabetic patient was recorded in an issue of Diabetes Care. Similarly, Chubon (1989), who had roles as both an educator and a spinal cord injury patient, described his experience of daily life with this injury.

Finally, there was some patient-centered research that used qualitative methodologies. Chubon (1989), noting a paucity of research on the experience of living with a therapeutic regimen from the patient’s perspective, created an ethnography of rural southern Blacks’
experiences with managing their health. Her grand tour questions led her informants to address their views of health, how they managed life with a chronic illness and what things did to improve their health. The resulting ethnography painted a picture of people enveloped by folk knowledges about health and physiology, confused by medical explanations, and guarded about sharing vital health information with their physician.

More pertinent to diabetes, Schoenberg, Amey & Coward (1998) sought to find a relationship between dietary adherence and the patient’s personal story of how they acquired diabetes. After conducting ethnographic interviews with 51 older (65) participants, five stories for etiology emerged: (a) eating a poor diet, (b) genetic tendency toward diabetes, (c) improper bodily functioning, (d) being overweight, and (e) personal risk factors such as being a woman or a certain age. Informants who explained their type 2 diabetes by way of diet, obesity, improper bodily functioning were found to be more adherent to the prescribed dietary regimen.

In 1999 this researcher sought to understand adherence from the perspective of five individuals who were self-reporting to be following their regimens. These informants also had corroborating evidence, such as documented weight loss and recognition from significant others about their change in lifestyle. The study yielded five different themes. First, the informants tended to understand their eating and exercise programs as having a direct causal effect on their disease management. This relationship was described in both cognitive and affective terms. Second, these informants had good relationships with a HCP. Third, a renewed sense of health or energy related to weight loss motivated the informants to stay with their regimens. Fourth, none of the informants participated in a support group.
The informants tended to describe managing their health in rather solitary terms, and the role of relationships was not emphasized. Finally, the "super-adhering" informants experienced a radical change in their orientation toward nutrition, sometimes "throwing the liter of Pepsi I had down the sink" (Garris, 1999, p. 15). This was in sharp contrast to the conventional approach of coaxing people into slower, incremental changes. These informants appeared to experience some sort of epiphany about their health that most other patients missed.

O'Connor, Crabtree, and Yanoshik (1997) also designed a similar qualitative study to determine if people who respond well to diabetic treatment differ in attitude and perspective from those who do not. The researchers had access to graduates from a diabetes care program. Subjects were divided into one of two groups: so-called "positive responders" who experienced a 20% or greater improvement in glycemic control and "negative responders" who had less than 20% improvement. The study posed the following grand tour questions to focus groups and individuals:

1. How has your life changed since learning you have diabetes?
2. How would you describe the social and psychological impact of having diabetes?
3. How are others around you involved in your diabetes and its care?

Analysis of informant responses resulted in four major themes. First, adherent patients viewed their diabetes more seriously than did the negative responders. This may be seen to support the earlier quantitative research in which "perceived severity" was correlated with
adherence (Alogna, 1980; Cerkoney & Hart, 1980; Harris, Skyler, Linn, Pollack, & Tewksbury, 1982). Second, positive responders viewed the lifestyle changes required by the diabetic regimen as a normal part of their new daily routine. In contrast, the negative responders described life as a daily struggle. Rather than having the regimen seamlessly incorporated into the day's activities, the non-adherers wrestled with the timing and necessity of each task and resent its intrusion into "normal" life. Third, the authors reported that around 25% of the adherent informants described a "conversion experience" whereby they underwent some sort of paradigm shift, resulting in a radical re-orientation toward health management. O'Connor, Crabtree, and Yanoshik (1997) noted that little is understood about this "conversion experience" and that it might provide a useful augmentation to the current theories about health decision-making. I would also add that these conversion experiences are not immediately reconcilable to the more incremental and rational models presently proposed. Finally, the two groups differed in their perspective of medical providers. Negative responders reported higher satisfaction with their providers. In general the informants rated satisfaction with their HCP as high, except for one group: those who had experienced a "conversion." These patients indicated that their physicians were treating diabetes management too casually and wanted their provider to address diabetes with the same sense of urgency that they, the patients, were now doing.

In summary, qualitative research, though increasingly finding an audience among medical researchers (Playle & Keeley, 1998; Searight, & Campbell, 1992; Searight & Young, 1994; Stange, Miller, Crabtree, O'Connor, & Zyzanski, 1994) is still in its infancy. The issue of adherence, left mostly unanswered by quantitative research (Buckalew &
Sallis, 1986; Donavan & Blake, 1992; Lo, 1999; Schoenberg, Amey, & Coward, 1998), is being revealed through the stories told by individuals. The voice of the patient in health decision-making is only recently being heard.

**Why Marriage and Family Therapy?**

How is this a sphere of study for a marriage and family therapist? In short, the fields of therapy and medicine have been intertwined for 50 years, since marriage and family therapy’s inception (Broaderick & Schrader, 1981; Nichols & Schwartz, 1991). Physicians and therapists occasionally collaborate in medical settings (Coyne & Anderson, 1988; Minuchin, Rosman, & Baker, 1978; Seaburn, et al., 1993). Frequently, both have as their objective behavior change, though the presenting problems are usually different. Because medical concerns are normally traced to a physical etiology, physicians have the bulk of their training in the biological sciences; marriage and family therapists are trained as behavioral scientists. Though diabetes is a problem of metabolism, diabetes care is essentially a social-psychological concern. From an extensive overview of diabetes management issues, Glasgow, et al., (1999) concurs that “developments in biology, genetics, pharmacology do not diminish but rather expand the importance of behavioral science” (p. 832). Similarly, the editor of Diabetologia adds,

Lifestyle drugs… do not interfere with the disorder as such but delude patients into thinking they can continue to maintain their detrimental hedonistic habits… There is no doubt that reduction in the prevalence of Type II diabetes will come mainly from changes in lifestyle (Waldhausl, 2000, p.1-2).
Equipped with multiple lenses, family therapists are trained to examine phenomenon from multiple angles, particularly cybernetics, patterns, and language (Anderson & Goolishian, 1988; Becvar & Becvar, 1996; Hoffman, 1990; Keeney, 1984; White & Epson, 1990), and have brought unique perspectives and solutions to such diverse issues as business environments (Curtis, 1988; Keough & Joanning, 1996), hospital management (Angera, 1997; Kerber, 1997), spirituality (Joanides, 1997) and agricultural pest management (Mayhew, 1997). Consequently, this cross hybridization of disciplines is not new and is expected to yield benefits for both medical and therapy practices.
CHAPTER 3. METHODOLOGY

This chapter reviews the methodology of the study. Because of gaps in the literature on the patient's perspective and, more specifically, the nature of the patient decision-making, I decided that a qualitative inquiry would be most appropriate. Following guidelines recommended by Creswell (1998), I will offer a brief rationale for qualitative research in general and the grounded theory approach in particular. Following this will be a sketch of the principal investigator and discussions about data collection and analysis.

Why Qualitative Inquiry Was Chosen

In order to answer the question "what is the process of health decision-making like for newly diagnosed type 2 diabetes patients," I chose to use a qualitative research methodology for this project. There were several reasons for this decision. The first reason was the imbalance between the use of hypothetico-decutive theory testing versus exploring the perspective of the patient (Altman & King, 1986; Ary, Toobert, Wilson, & Glasgow, 1986; Chubon, 1989; Lutfey, 1999; McClean, 1997; Playle & Keeley, 1998; The National Long-Range Plan to Combat Diabetes NIH Pub. No. 88-1587; Vanderford, Jenks, and Sharf, 1997). Bednar, Burlingame and Masters (1988) argued that maturation of understanding progresses through five steps. The first two steps were qualitative: careful observation and the formation of descriptive taxonomies. The remaining phases were quantitative and sought to verify the accuracy of the earlier qualitative work. At times quantitative work preceded the establishment of good qualitative descriptions. In this situation, theories about the phenomenon can be divergent from the participants' own explanations for phenomenon.
Considering a review of the literature, it seemed reasonable that this had occurred in understanding patient decision-making. However, even if one embraces a more recursive, mutually informing model of knowledge development (Creswell, 1994; Sells, Smith, & Sprenkle, 1995), a review of the literature suggested that the majority of adherence studies have used quantitative methods and that our knowledge of the patient’s perspective needed bolstering (Altman & King, 1986; Ary, Toobert, Wilson, & Glasgow, 1986; Chubon, 1989; Lutfey, 1999; McClean, 1997; Playle & Keeley, 1998; The National Long-Range Plan to Combat Diabetes NIH Pub. No. 88-1587; Vanderford, Jenks, & Sharf, 1997).

Other justifications for a qualitative approach included its strengths in studying complex phenomena that are not well understood or scientifically immature (Huberman & Miles, 1994; Joanning, Newfield & Quinn, 1987; Moon, Dillon & Sprenkle, 1990; Sells, Smith, Coe, Yoshioka & Robbins, 1994). Second, qualitative inquiry offered the researcher discovery oriented design. This flexibility allowed the researcher to go where the informants led and to uncover other facets of a phenomenon that may have gone undetected by a rigid, predetermined approach. Again, this freedom proved useful when the phenomenon was not well understood and the variables not easily identified by social scientists (Creswell, 1998; Denzin & Lincoln, 1994; Huberman & Miles, 1994; Lincoln & Guba, 1985; Mastoukas, 1994; Moon, Dillon & Sprenkle, 1990; Searight & Young, 1994; Sells, Smith, Coe, Yoshioka & Robbins, 1994, Wolcott, 1994). Third, following the discovery of new information, qualitative research allowed for the creation of interrelated propositions and new theoretical models for these phenomenon (Creswell, 1998; Denzin & Lincoln, 1994; Glaser & Strauss, 1967; Lincoln & Guba, 1985; Strauss & Corbin, 1990;
Wolcott, 1994). Finally, the research question had as its goal not experimentation, prediction, and control, but description and understanding (Creswell, 1998; Denzin & Lincoln, 1994; Lincoln & Guba, 1985; Searight & Young, 1994).

The particular type of qualitative inquiry I undertook was grounded theory with the collection of data occurring longitudinally over approximately six months. Grounded theory offered a methodologically rigorous tool for creating explanatory theory about "common social life patterns" (Annells, 1996, p. 380) and was unique in allowing the theory to systematically emerge from the basic social processes or phenomenon being observed. This inductive approach led to the generation of major categories or constructs, the relationships among these categories, and context and processes. The finished product was a theory of a phenomenon or social process that projected beyond a simple, descriptive account (Becker, 1993).

Grounded theory derived its theoretical and philosophical underpinnings from symbolic-interactionism and the American pragmatism movement (Annell, 1996). Symbolic-interactionism was a micro-sociological theory that addressed how people created meaning individually and in social life through the exchange of symbols, principally language. Epistemologically, symbolic-interactionism hailed from a Kantian position on knowledge, that knowledge was created by the knower rather than an essential quality of the outside world. Out of symbolic-interaction research arose a need in social science inquiry to find patterns and commonalities among meaning-oriented, "privatized" experiences. Highlighting this need to merge phenomenological and positivist traditions, two University of California (UC) sociology professors united to write *The Discovery of Grounded Theory*. 
and argued for new strategies for conducting qualitative research in the social sciences. Over the subsequent 30 years, these professors, Barney Glaser and Anselm Strauss, explicated these strategies and promoted what has become detailed and systematic procedures for collecting data, analyzing it, and theorizing. It should be noted that as Glaser moved on from the UC system, and the pair separated, two divergent approaches to grounded theory developed. One is described as more formulaic and programmatic (Melia, 1996) “forcing” the data to speak and the other, with fewer rules, is said to allow theory to emerge from the data (Glaser, 1992).

**Researcher as Instrument**

In qualitative research the researcher may be viewed as a measuring and analyzing tool, capturing rich depictions of the phenomenon and responses otherwise left unrevealed by a static survey. Further, this “tool” was enabled with processual immediacy and quickly assimilated data into meaningful hypotheses and testing out these ideas (Lincoln & Guba, 1985). Not a detached transcriber of the experience, the qualitative tradition also posits that the researcher creates a knowledge of the phenomenon through the act of writing (Denzin, 1989). Since “objectivity” was impossible, it is required that the researcher consider his biases and disclose them to the reader so that a complete evaluation of the text is possible. To this end, a self-description of the researcher follows.

I am a 32 year old white male, married for 11 years and with two young children. I have undergraduate and graduate degrees in psychology and marriage and family therapy. Since earning a master of arts degree in 1992 I have worked variously in counseling and post-secondary education. This is my second foray into a research project. For
approximately seven years I have had an increased interest in health care issues and at one time took prerequisite classes for medical school. However, as most of my schooling is in the social sciences, I have decided to train my attention on a more psychological aspect to the medical profession: patient adherence and, in particular, the health decision-making process.

My interest in diabetes stems from father’s family. The paternal side of my family has a tendency toward obesity and a history of diabetes. I personally feel vulnerable to developing type 2 diabetes. Insofar as this may influence the research, I think I bring a personal interest to the subject matter. My concern about my own health, reflected in diet and exercise choices, varies depending on stress level, busyness, and even information gathered in the process of writing this dissertation. Certain pieces of literature and interviews motivated me to noticeably change my patterns, though it’s not clear how durable these changes are.

I personally balk at the notion of “non-compliance,” believing it to be a simplistic, mechanistic, and value-laden view of how doctor and patient interact. “Adherence” may be a slightly more value-neutral, but still seems to place unnecessary blinders upon researchers and strictures upon patients. I favor the phrase such as “health decision-making” because it assumes the patient is an active agent in the process and is less directional.

As an epistemology forms the foundation for how things are known, it also influences the worldview of the researcher and it seems relevant to offer a few remarks about my epistemological assumptions. Broadly speaking, there are two different views on epistemology or the nature of knowledge. The first holds that “fact” is in the world around
us, waiting to reveal itself to the examiner. The second position is that knowledge is the creation of an organism or culture and is invented by the “knower.” The former, “objectivist,” position argues reality is exogenic (Gergen, 1982) or external to us, but is apprehended as the external etches into the investigator’s mind a true representation of itself (Efran, Lukens, & Lukens, 1988). Thus “factuality” is a property of outside world, irrespective of the observer (Sutton, 1993, p. 411).

In recent years there has been a forceful shift from positivism toward a postmodern view of the social sciences (Berger & Luckman, 1967; Gergen, 1984; Shotter, 1993; Shotter, 1997). The re-cognition of knowledge as constructed, not discovered, is not new, but a reemergence of an endogenic (Gergen, 1982; Gergen, 1984) perspective on knowledge. Rooted in the writings of Kant, Spinoza and Nietzsche, it posits knowledge is the invention of an active organism that is interacting with an environment” (Efran, Lukens, & Lukens, 1988, p. 28).” In other words, knowledge is not based so much on the qualities of our physical world, but upon the way in which humans process that information. This antinomy is variously characterized as a dichotomy between objectivists and constructivists (Efran, Lukens, & Lukens, 1988), Lockeans and Kantians (Becvar & Becvar, 1996), realists and antirealists (Held, 1995) and exogenic and endogenic perspectives on knowledge (Gergen, 1984). The most recent incarnation of the Kantian epistemology includes the divisions of constructivism and social constructionism. Although some would argue there are not meaningful distinctions between the two (Efran & Heffner, 1998; Efran, Lukens, & Lukens, 1988), it is widely accepted that constructivists subscribe to a more individual creation of reality, while social constructionists stress the social, public, and linguistic
nature of knowledge (Buirs & Martin, 1997; Gergen, 1985a; Mills & Sprenkle, 1995). These differences are due in large part to their respective theoretical origins. According to Mills and Sprenkle (1995), “constructivism claims roots in biology and the physical properties of individual perceptions, whereas social constructionism is grounded in a philosophy of community” (p. 369).

I came to identify with postmodernism after struggling to reconcile several different family therapy theories that were purporting to define norms and accurately map the social world. When it became evident that these irreconcilable theories were less like miniature model representations and more like lenses through which phenomena were viewed, my modern worldview experienced a breakdown or deconstruction (Combs & Freedman, 1994). This postmodern shift has been called the most significant change in clinical thinking since family therapy’s inception (Hoffman, 1988). It tends to be less concerned with etiology and strategic interventions, but emphasizes reflective listening and language which opens up possible solutions (Hoffman, 1998). Its presence is evidenced in the work of therapists who focus on meanings, stories, and searching for solutions (Anderson & Goolishian, 1988; Combs & Freedman, 1994; deShazer, 1994; Furman & Ahola, 1994; O’Hanlon, & Weiner-Davis, 1988; Miller & Sprenkle, 1995; White & Epston, 1990). The postmodernism has two implications for this project. I tend to be more interested in people’s stories, not just “the facts” of a situation. Second, I do not believe improving patient adherence requires finding a “cause;” it may be that social scientists are able to improve patient adherence simply by focusing on patterns of what works.
The Generation of Data

Selection Procedure and Description of Informants

The 21 informants who participated in this study were selected using convenience and criterion sampling techniques. First, for reasons of logistics and convenience the researcher selected participants that were geographically close to where he had a base of operations. Consequently, 13 of the participants were from metropolitan and rural areas in a midwestern state where the dissertation was being completed. The remaining eight informants were from metropolitan and rural areas in the Southeastern United States, where the researcher had family that he visited regularly. Twenty-seven individuals expressed interest in being in the study and were involved to various extents ranging from signing a “Consent to be Contacted” by the researcher form (entry point) to completing the first interview. Not all 27 informants were full participants in the study. In addition to comprising a convenience sample, participants in this study also were sampled according to two criterion (Creswell, 1998; Lincoln & Guba, 1985; Luborsky & Rubenstein, 1995; Patton, 1980). The first criterion was that the informants had to have been diagnosed by a physician as having Type 2 diabetes within the past 6 months. The reason for this was that the researcher purposed to conduct a prospective study about the factors that influenced the patient’s decision-making process. Rather than a retrospective recreation of events and choices from years ago, the researcher wanted to capture an “en-vivo” process, a description of the storm from someone presently embattled by the elements. Second, because the nature of this inquiry was grounded in interviews, it was necessary that informants be sufficiently articulate and capable of describing thoughts and events that were shaping their health choices. Out of the
27 possible participants, three were deselected because they were unable to sufficiently explain the factors that influenced their health decisions or because their interviews did not contribute any diversity to the budding category development. Another three informants dropped out of the after learning more about the time-consuming process of the research. This number provided sufficient data for category development and saturation and was agreed to by the committee as the data collection – analysis phase of the research was in process. Patton (1990) reminds us that Piaget’s contributions were made studying only two subjects, his children, and demurs that “sampling size adequacy, like all aspects of research, is subject to peer review, consensual validation, and judgment” (p. 186).

**Access to the field**

Access to the field proved to be one of the more challenging aspects to this project, as the researcher did not have ready contact with people recently diagnosed with type 2 Diabetes. As a first step, the researcher sought permission from various institutional review boards. Prior to contacting and interviewing the respondents, a description of the study and potential interview questions was submitted to the Iowa State Human Subjects Committee. The Committee approved this research, contingent upon the participants’ signed consent form (see Appendix A) and approval by the respective hospitals’ Institutional Review Boards (IRB) (see Appendix B). Maintaining the confidentiality of the research participants was a primary concern. Consequently, information that could be used to identify the informants, such as names, ages, and employers, and locales, was removed from the transcripts. Further, audio tapes of the interviews were kept in a locked filing cabinet in the researcher’s office. The research was not anticipated to produce any harms for participants
and may have provided some minor benefits by increasing the client’s awareness of their decision-making processes and sensitivity to health issues. Studies have shown that external cues, such as phone calls, have had positive effects in increasing compliance with exercise and medication taking regimens. More details about the steps taken to protect the informants’ rights can be located in the consent form (see Appendix C). In the months that followed the ISU Committee approval, the researcher presented his project to three different IRB’s representing six different area hospitals that treat people with diabetes. He also created memoranda of agreements with two other rural hospitals that did not normally participate in institutional research and had less formalized, or nonexistent, IRB processes (see Appendix D). For institutions that did not have unique IRB procedures, it was agreed that the approval of research methods by the ISU Human Subjects Committee offered a sufficient measure of oversight. These memoranda detailed the researcher’s and hospital’s responsibilities and referenced the informants’ rights to informed consent. Finally, the researcher developed working relationships with various hospital administrators, diabetes educators, dieticians, two endocrinologists, and participated in two organizations that were addressing diabetes at a local level: the Wellmark Diabetes Task Force and the Iowa Department of Public Health’s “Healthy Iowans 2010” workgroup on diabetes. It was through these workgroups and relationships that most informants came into contact with the researcher.
Data Collection and Analysis

The generation of data

In order to protect informants' rights not to have their medical condition disclosed without their permission, patients recently diagnosed with type 2 diabetes were given a tri-fold brochure (see appendix E) explaining the purpose and methods for this research project by their diabetes educator or endocrinologist, the "gate-keepers" to this population. On the last page of the brochure was a "Consent to be Contacted" form. This form, which only granted permission for the researcher to contact the patient, was separated from the informational part of the brochure collected back by the healthcare provider as necessary. The response rate from diabetes education classes was approximately 15 percent and, by agreement with the various institutions, there was no information, including demographic details, about the people who elected not to inquire further about the research.

After the patient initiated lowering the veil of confidentiality, the investigator then contacted the individual, first by telephone and then in person, to describe the research to them in greater detail and review with them an Informed Consent form. Over a period of nine months the researcher had 27 persons sign "Consent to be Contacted" forms. There are two important comments that need to be made about this number of informants and the way in which they came to participate in the study. First, of the twenty-seven people the researcher had contact with, three declined after learning more details about the research and three were deselected as participants after a first interview because they failed to meet the criterion required to be quality informants. Second, because the enlisting of informants took place over nine months, as different institutions' approvals were granted and new
relationships and referral networks were established, the researcher began interviewing
people as they became available to him. Consequently interviews conducted early in the
process tended to be more exploratory and generative, with nearly all of some initial two
hour interviews being transcribed. Inquiry conducted with informants later in the process
reflected increasing maturity, both of the researcher and of the project. The lead questions
may have begun the same way, but the researcher did not seek to elicit as much descriptive
detail about already completed categories.

The primary means through which data for this project was generated was the semi-
structured face-to-face interview. The interviewer conducted these sessions with a list of
open questions designed to guide the conversation with the informant toward certain key
areas of interest. Examples of opening questions included the following:

1. How is your life different now that you have the diagnosis of Type 2 diabetes?
2. What decisions have you made relating to your life (health) in response to the
diagnosis?
3. How did you come to decide upon these choices? That is, what led you to make
these choices?
4. What factors are currently influencing whether or not you follow through with
your decision?
5. How would you describe the nature of the changes you have made (sudden,
gradual, in stages, affective, cognitive, experiential, other)?
6. What factors keep these changes present in your life?
7. How do you see your life/health differently since being diagnosed?
8. How would you try to affect the changes you experienced in another person (i.e., a friend or child)?

9. What is the biggest challenge you are facing in managing your diabetes? What are you doing about this challenge?

10. How has your identity (sense of self) changed/stayed the same as you have come to live as a person with diabetes?

Again, as alluded to earlier, the researcher did not know exactly what questions to ask to access the process of health decision-making, or what factors influenced health behaviors. These early questions and sessions proved to be something of a fishing expedition. These questions did provide a beginning point, however, with the researcher asking follow-up questions for clarification, better understanding, and more microscopic inquiry in a manner that would be viewed as conversational. Once it seemed the vein had dried or the conversation had quieted he then returned to these ten questions. This process was recursive in nature, with the data provided by the informants and the researcher’s analysis leading to further questions as the interview took place. The investigator listened attentively, made notes of interesting remarks and themes, and conscientiously avoided leading statements.

Interviews with informants, the first two of which occurred face-to-face occurred at least once every eight weeks through the six months of their participation in the study. Interviews number three, and in some cases four and five, were conducted over the telephone. These interviews were primarily for purposes of rounding out properties among dimensional lines and establishing the relationships among variables and the questions were
shaped by these needs. Some interviews also repeated the initial questions, looking for changes in informant responses over time.

In this project the researcher decided which portions of each interview were to be transcribed from audio soon after the interviews occurred. Filler words, such as “uh huh” and “you know” were not included, as well as the portions generally considered “joining” or “small talk.” In the early stages of this project almost complete interviews, up to two hours in length, were transcribed. At this point it was not at all clear what relevant categories were going to emerge. However, as the project matured, the researcher became sensitized to the more salient information in the interview and only the portions of interviews relevant to explicating theory were transcribed. The researcher listened to the interview one to three times to understand the nuances communicated by the informants and to gain an overall sense of the whole database (Agar, 1981; Guba, 1981; Spradley, 1979). Finally, having a great sense of familiarity with the interview, the researcher created a new tape for transcription, with the irrelevant portions deleted. This was done as a reflection of improved capabilities as a research, as well as for reasons of efficiency and economic necessity. The field acknowledges a diversity of opinion regarding how much tape to transcribe (Weiss, 1994). The researcher or a transcriptionist, depending on time and financial constrictions, transcribed the tapes. The outside transcriber was informed of the confidential nature of the research and her obligation to protect the informants’ rights. She was familiar with these requirements, as she is similarly bound in her regular work as a legal secretary. The transcripts had all identifying geographical and occupational markers modified to protect respondents’ anonymity and were reformatted with a 4.5 inch right
margin for the researcher's subsequent coding and memoing. The researcher is an efficient
typist and found it practical to type memos alongside the transcripts while they were still in
electronic form. The transcripts were then printed and maintained in a three ring binder.

**The analysis of the data**

Data analysis followed the guidelines offered by the grounded theory approach (Glaser
approaches are divided as to the degree of methodological rigidity to apply to data.
Followers of Glaser support a looser, more emergent research approach, not wanting to
"force" the data. Their views have merit, but for the purposes of this dissertation the
clearly state that research is a fully integrated and recursive process with coding slipping
into memoing, and analysis being enhanced by writing, which may then direct the
researcher back to the data or the informants. Indeed, this was truly descriptive of the
research and analytic process. However, despite this acknowledgment of emergent
processes, *The Basics of Qualitative Research* (Strauss & Corbin, 1994) provided a detailed
and highly methodical approach to research. Their style of grounded theory methodology
was selected because of two distinct benefits: the detailed guidelines offered the novice
researcher a high degree of "instruction" on how to do grounded theory research and the
more enumerated process seemed easier to defend. The following description outlines the
different ways in which the data were analyzed and coded, but does not fully account for the
intrinsically recursive nature of this research.
In grounded theory methodology, the coding and analysis processes are referred to as open coding, axial coding, and selective coding (Strauss & Corbin, 1990). The early stages of inquiry focused on “open coding.” Initially, the researcher carefully read through the transcripts and fractured the data into tiny meaning units that became the basic units of analysis. This was done as underlining and brief notations and markings written within the transcripts themselves. The purpose was to call attention to certain words and concepts that would, upon further analysis, constitute important elements in the developing theory. These meaning units were subsequently analyzed and written about in the 4.5 inch margin on the right as part of an intensive process of memoing. Memos were simply “written records of analysis” (Strauss & Corbin, 1994, p. 217) that were more like prose than the initial underlining and marking of the transcript. Memos fell into one of several categories, such as code notes, operational notes, or notes about theory, depending on their content. It was through the writing process of memoing that the researcher was able to explicate the theoretical elements of a grounded theory. These basic elements took form when meaning units were grouped together and then collapsed under cover terms called categories and subcategories, depending on their level of specificity or abstraction. Categories and subcategories had different attributes or characteristics, termed properties. The density of the categories and properties was further developed when the researcher elaborated on the degree of presence of a property. A quick illustration clarifies the use of these different terms. If the research project involved an examination of the process of patient interactions in the social world, patient-physician relationships might be one category, patient-pharmacist relationships could be a second category, and patient-family relationships might
be a third category. Each of these categories could be subdivided into subcategories. Depending on what emerges as theoretically salient, each of these relationships could be subcategorized as male or female, or the role of the patient in these relationships could be subcategorized as superior, egalitarian, or subordinate. Each of these subcategories would have different properties, possibly frequency of contact or level of self-disclosure. Finally, each of these properties could be dimensionalized along continua that describe the amount of contact, ranging from high to low, or describe different forms of self-disclosure ranging along some continua. Exactly how one categorizes and what variables one chooses to dimensionalize all depends on the research context, which is central in determining the relevant angle to consider.

A second aspect to my analysis was known in grounded theory methodology as “axial coding” (Straus & Corbin, 1990). Strauss and Corbin (1990) described the process this way:

The actual process of axial coding… is complex because the analysis is, in fact, performing four distinct steps almost simultaneously. These are: (a) the hypothetical relating of subcategories to a category by means of statements denoting the nature of the relationships between them and the phenomenon,… (b) the verification of those hypotheses against actual data; (c) the continued search for the properties of categories and subcategories and the dimensional locations of data indicative of them; (d) the beginning exploration of variation in phenomena, by comparing each category and its subcategories for different patterns discovered by comparing dimensional locations of instances in the data. (p. 107)
Thus, whereas open coding fractured the data into meaning units, which developed into categories, subcategories, properties, and dimensions, axial coding helped the researcher systematically relate categories to subcategories and explicated links among categories at the level of properties and dimensions. Although, as Strauss and Corbin (1990) described the process in "four distinct steps," like the other parts of the analysis, this aspect was also recursive and required a constant shifting between inductive and deductive thinking.

After the data had been "opened up" and links among the categories, subcategories, and properties were becoming established at a dimensional level, it became appropriate to attempt to articulate and refine a theory that would integrate these components. This level of analytical coding was known as "selective coding" (Strauss & Corbin, 1990). Strauss and Corbin (1990) outlined somewhat abstractly the five stages to this goal. The first step was to generate or make explicit the story line. In grounded theory "story" referred to a descriptive narrative about the central phenomenon under investigation. The "story line" was then a conceptualization of this story as abstracted from the categories and becomes the study's central category. Strauss and Corbin (1990) described it metaphorically as "the sun, standing in orderly systematic relationship to its planets." (p. 124.) The second step consisted of relating subsidiary categories to the core category or story line. Continuing the metaphor, it was the formation of planets rotating around the sun, the purpose of which was to help the researcher think systematically about the data, and to move beyond asking questions and toward proposing linkages among the categories. The third step was to relate categories at the dimensional level. The fourth step involved validating these relationships...
against the data. The final step required filling in categories that may be insufficiently
developed (Strauss & Corbin, 1990).

As the researcher reviewed all of the categories revealed in the data, one theme seemed
to be particularly important: agency, sometimes described in other literature as self-
efficacy. For a time agency was considered as the central category. However, a central
category should have analytic power, drawing together the other categories into an
explanatory mosaic (Strauss & Corbin, 1994). Although agency clearly was a key element
in diabetes management, the researcher believed that it failed to meet all the criteria of a
central category (Strauss & Corbin, 1994). Moreover, there was a sense in which agency
was actually pointing to another concept that united the categories together better. This
concept was “health decision-making.”

The researcher used three specific tools to integrate and refine the theory. First, he put
outlines of his categories, subcategories, properties, and dimensions on cards and tried to
conceptualize the emerging theory visually, demonstrating with proximity and distance how
the categories interacted with one another. This practice of “diagramming” proved
somewhat helpful in clarifying the researcher’s analysis. Second, the researcher sought to
aid integration by writing the storyline. In the first attempt, three single spaced pages of text
led to of the creation of a central category, and a clarification of how the other categories
related to it and to one another at different dimensional levels. A follow-up effort of seven
pages further detailed these relationships and improved the precision of categories and
properties. Finally, writing the results chapter of the dissertation, while being mindful of
the purposes of selective coding, also proved to be something of an analytic exercise. The
researcher listened to the story for internal consistency and logical development. He sought
to make sure the categories were fully developed with salient properties and dimensions
identified. When the development of properties and dimensions were found to be lacking,
he returned to the memos or to the raw data of transcripts to review for data that might have
been missed. Occasionally he returned to the field and selectively gathered data from
theoretically sampled participants. Improving the “density” of categories helped ensure
their precision and enhanced the explanatory power of the theory.

The final product of this analysis is a theory, grounded in empirical data, of how
patients make health-related decisions following a diagnosis of Type 2 diabetes.
Additionally, the categories, subcategories, properties, dimensions, and or linkages among
them are illustrated graphically. Such a representation was considered important for valid
analysis because they allowed all the data to be viewed at once, albeit in reduced form, and
organized so that they address the research question (Huberman & Miles, 1994). Huberman
and Miles (1994) suggested data displays were analogous to the output of statistical
programs because (a) they promoted data analysis occurring near to the data, (b) helped the
investigator to see if other analysis is needed, (c) allowed for easy comparability of the data
and (d) increased the credibility of the research findings through their inclusion in the
chapter on discussion.

**Strategies to ensure trustworthiness**

The scientific value of any research findings depends upon the trustworthiness of the
research. (Stones, 1985) and consumer of research will want some verification that (a) the
data accurately reflected the phenomenon studied, (b) the findings can be applied to other
like situations, (c) the results demonstrated stability or consistency, and (d) and that the influence of the experimenter is minimized (Guba, 1981; Lincoln & Guba, 1985) or at least identified. Within qualitative research these issues are known as credibility, transferability, dependability and confirmability. In both quantitative and qualitative research these concerns are addressed by accepted canons in their respective methodologies.

Credibility occurs when there is congruence between the realities of the informants and the descriptions written by the investigator (Denzin & Lincoln, 1994; Guba, 1981; Lincoln & Guba, 1985). In social sciences this congruence is achieved when the phenomenon is examined from several different vantage points, rather than from a single source (Bogdan, & Biklen, 1982; Denzin, 1978; Guba, 1981; Lincoln & Guba, 1985). This is referred to as triangulation. In this study, credibility was created by through the inclusion of member checks and peer debriefing.

During member checks the researcher returned to participants and asked them to review and comment on the investigator’s initial findings arising from his analysis of the data, their stories. In particular, the researcher requested clarification on areas in which he was unclear. Informants were asked to make corrections, additions, and deletions of sections that did not accurately reflect their experience. This process of verification served to ensure an accurate description of the informant's experience and strengthened the truth value of the research.

A second data source for triangulation came from peer debriefing. The peer debriefer served several vital functions: (a) keeping the researcher "honest" and aware of his influence on the project, (b) acting as a sounding board for newly emerging hypotheses, (c)
serving as a partner in testing subsequent steps in the methodology, (d) and as a therapist, allowing the researcher an opportunity to vent frustrations (Lincoln & Guba, 1985). The peer debriefer was a colleague at the college where the investigator teaches. Following Lincoln and Guba’s guidelines (1985), the debriefer was approachable, spoke frankly, and had previously conducted qualitative research. She had an interest in the field of health psychology and served the College as Chair of the Department of Health and Human Performance. Additionally, she had expertise in qualitative research and had served as the presider of The Qualitative Research Interest Group Conference. The researcher met with the peer debriefer eight times over a span of eight months, approximately one hour each visit. Together they looked at the transcripts, memos and developing analysis of the principal investigator, and discussed other possible meanings in the data as well as the process of interviewing.

A third method of triangulation will be achieved by getting data from additional sources. Because interviews were audio taped and then later transcribed, the researcher was able to maintain eye contact with informants and observe body language without being distracted by the need to take notes on the conversation. This broadened the types of data observed and recorded. Finally, subsequent to each interview the researcher jotted field notes describing his experiences with the informants, thoughts about the conversation and impressions and hunches about the developing story. These notes were integrated into memos about the transcripts, once transcribing was completed.

Transferability is concerned with enabling readers to determine how well the research findings will transfer to other similar situations (Denzin & Lincoln, 1994; Guba, 1981;
Lincoln & Guba, 1985). Two methods were used to establish transferability. First, the informants were selected using the purposive sampling. Beyond the criterion previously discussed, when the researcher had the option of selecting participants that were demographically dissimilar (age, education, sex, income, location, marital status) he selected the one who is least like the others in the study. The reader will need to ascertain how well these findings apply to other context, but the researcher aided this through the inclusion of thick descriptions that richly detailed the people, context, and findings of the study.

Dependability concerned the stability or consistency of the data (Denzin & Lincoln, 1994; Guba, 1981; Lincoln & Guba, 1985). Dependability was established by the collection and analysis of data from multiple sources as previously described. Additionally, the researcher organized all the data, analysis, and research notes into an audit trail (Huberman & Miles, 1994; Rodgers & Cowles, 1993). Specific sources of data for this audit trail were: (a) the research proposal (b) raw data from audio tapes, (c) transcripts (d) transcripts that had been coded (e) memos, and (f) data displays. A colleague with an extensive background in experimental psychology examined the research proposal, transcripts that had been coded, memos and the data display to verify that the findings of the research plausibly reflected the data.

Confirmability sought to ensure that the data emerges from the informants' stories and that the researcher does not covertly influence the data and findings (Denzin & Lincoln, 1994; Guba, 1981; Lincoln & Guba, 1985). To accomplish this, the researcher uses the
previously described triangulation procedures and the external audit to verify that the findings reflect the phenomenon shared by the informants.

Summary

This chapter detailed the reasons why a qualitative methodology was chosen, the role and person of the researcher, the selection of participants, and the collection- and analysis of the data. The following chapters will include the results of this study and a discussion of those results.
CHAPTER 4. RESULTS

What were the factors that newly diagnosed Type 2 diabetes patients identified as influential in their health decision-making process and how did these different elements interrelate? In seeking answers to this question, chapter two examined the literature on diabetes, adherence, patient decision-making, and contained overviews of the dominant theories seeking to explain patient behavior. However, despite developing some familiarity with the current explanations about patient behavior, the goal of this research was to create a theory of health decision-making that was grounded in the voices of the participants and not some preexisting explanation. Therefore, once collection and analysis commenced this researcher purposed to set aside these explanations in favor of letting the data “speak for itself.” This chapter is the results of this inquiry and is divided into three sections. The researcher provides (a) brief sketches of research participants, (b) a graphical representation of the categories, and (c) a detailed delineation of the categories indicated by the data.

Description of Participants

Because the goal of grounded theory methodology is the creation of a theory the focus is on the building blocks of theory, categories and their properties, rather than the narrative of the characters, as might be true of a biography or case study. However, because the categories are supported by the stories from various participants, the researcher thought it would be helpful to at least have a thumbnail sketch of the research participants. Names have been changed and descriptive information has been made unspecific in order to protect the participants’ right to confidentiality.
**Evan, age 42**

Evan was referred by the diabetic counselor at a small hospital and first contact was made in the month following his diagnosis. He was married and had two young adolescent children. Evan lived in a small mid-western town with a population of less than 5,000, though he moved around and previously lived in larger cities. He had earned his GED and his work experiences were primarily limited to positions requiring manual labor. His work history was irregular and, in fact, over the six month span of the interviews, Evan changed jobs twice and spent some time as a stay-at-home father. Finances were a regular concern for Evan.

**Ted, age 29**

Like Evan, Ted was also referred by the diabetic counselor at the local hospital and first contact was made in the month following his diagnosis. He was divorced and had one child. He lived in a small, Midwestern town, though he too had moved all across the United States. He had some college education and an irregular work history as well. Ted was a very large man, weighing around 360 pounds, and was very well-read, opinionated, and talkative about many different areas, ranging from religion and sex to military strategy.

**Betty, age 65**

Betty was referred in her first month of diagnosis by the diabetic counselor at the hospital in a small mid-western town. She was a healthcare provider and had several close family members who were also in the medical profession. In contrast to the previous informants, she had a very stable work history and was something of a fixture in this small community. She was well read and highly knowledgeable about physiological processes.
Sam, age 59

Sam was an acquaintance of the researcher who agreed to participate when approached by the researcher. He had been diagnosed with Type 2 diabetes six months prior to entering the study. Sam was a professional with a graduate degree and a very steady employment history in larger southern city. He lived with his wife of 30-plus years; two children and grandchildren lived in other states. Sam presented as thoughtful and articulate.

Christine, age 72

Christine was a widow who lives by herself in an apartment. Looking out the window of her home, she could see a nursing home that served to regularly remind her of the consequences of unmanaged diabetes. She had four adult children and many grandchildren. She entered into the study two months after her diagnosis with diabetes. An active woman, she worked several days a week and, in widowhood, has discovered an interest in traveling.

Kelly, age 45

Kelly was a healthcare provider in a mid-western city of more than 250,000 people. The nature of her work led her to be very familiar with not only the physiological processes surrounding diabetes, but also provided her intimate knowledge of its consequences. More than professional exposure, she also has a lot of personal experience with diabetes. “Both of my parents are type 2 diabetics, most of my aunts and uncles are, so it was just a question of ‘when.’” She was married with two adolescent children. Her diagnosis occurred six months before she first interviewed with the researcher.
**Stan, age 79**

Stan was a retired farmer who was referred by a diabetic counselor who led a diabetes education class. He was within one month of diagnosis when he entered into the research, though he had “suspected” he had diabetes a year earlier. Stan lived on a farm in a rural mid-western state. Although he was retired, Stan had many “break-even” businesses, the real intent of which seemed to be to give him a reason to connect with other people. Stan enjoyed meeting people and talking with them. Stan was married, with adult children and grandchildren.

**Debbie, age 48**

Debbie worked in healthcare and was six months removed from her diagnosis with diabetes. She came into the research by word of mouth. She was a single woman with no children, but was very involved with her nieces and nephews and volunteered extensively in various community projects. Debbie was from a mid-western town of more than 250,000 people.

**Mary, age 56**

Mary was diagnosed with diabetes six months before entering into the study and the referral was made by word-of-mouth. She lives in a large city in a large southern state. She lives alone, was recently divorced, and had three adult children. As a consequence of her divorce, she had recently entered the job market. She was articulate and knowledgeable about diabetes, in part because her former spouse was a healthcare provider who dealt routinely with Type 2 diabetes.
**Quinn, age 53:**

Quinn had been diagnosed with diabetes three months earlier, when he entered into the study. He was referred by the diabetic educator who was teaching the diabetes class he attended. At over 300 pounds, Quinn was a very large man and a ready smile regularly revealed a good sense of humor. He was married with two adult children, and had been professionally employed with the same company in a mid-western town of about 50,000 people for most of his adult life.

**Denise, age 59**

Denise had been diagnosed two months earlier and learned of the research through a common acquaintance. She was an articulate and thoughtful woman who worked as a public health nurse in a rural mid-western community. She lived alone, having been widowed twelve years earlier. She had lived in large urban centers, such as New York City, but returned to the countryside, in part, to care for an aging mother.

**Kent, age 44**

Kent had been diagnosed two months earlier and referred through a common acquaintance. In many respects, Kent embodied success. A businessman, he was very involved in the community and served on the boards of several local organizations. His office, where we visited, was adorned with numerous awards and images of achievement. He was married, with one elementary aged child. Kent hailed from a large southern community of more than 250,000 people.
**Theresa, age 63**

Theresa had been diagnosed three months before she began to participate in the study, her involvement encouraged by a mutual friend. Theresa lived in a very small community in a southern state. She had no children herself, but enjoyed being involved with grandchildren she acquired through marriage to her husband. In addition to watching grandchildren play football, she also maintained an active social life centered on church and small-town activities.

**Bernice, age 71**

Bernice’s healthcare provider encouraged her to participate in this study and she entered into the research one month after being diagnosed. Bernice lived in a mid-western city with 250,000 or more inhabitants and had lived there with her husband for her entire adult life. She had adult children and grandchildren with whom she had regular contact. Of particular concern to Bernice was her husband, who in recent years had shown mild dementia suggestive of Alzheimer’s and had also begun to have heart problems.

**Sally, age 65**

Sally was also referred by her healthcare provider six weeks after having been diagnosed with Type 2 Diabetes. Sally had grown up in a larger city in the southern United States. Relationships provided motivation for her to stay healthy, with children grandchildren, and great, great grandchildren yet unrealized, giving her reasons to watch her diet.
Krista, age 56

Krista had been diagnosed five months prior to her participation in the study and was referred by her healthcare provider. Krista worked among diabetics as a nurse. Interestingly, she did not recognize the early symptoms in herself, but was unofficially diagnosed by a coworker. Although knowledgeable about the illness from a medical perspective, she expressed significant ambivalence about being diagnosed. “Just that denial thing, you know. I’m saying I’m not a diabetic, and I know I am.” Krista was married, with adult children.

Kendrick, age 58

Kendrick learned about the study from his spouse and entered into the study in the same month he was diagnosed. He was from a larger city in the southern United States, had finished high school, and worked in a trade. Except for the diabetes, Kendrick appeared to be fit and had begun to exercise with weights when he learned that his body was not metabolizing glucose correctly. His family and his faith encouraged him to do the right thing, but his wife described him as an “icecream freak.”

Steve, age 49

Steve decided to participate this study after he encountered the researcher making a presentation. He had been diagnosed two months earlier. Steve, a businessman in a larger mid-western city, was married with two children. Several graduate degrees complemented his measured, articulate speech. Steve particularly valued health because he had recently overcome through surgery what was believed to be a chronic condition he had endured
since childhood. However, this was balanced against work stress, as he sought to keep his new business expanding.

**Nora, age 61**

The diabetic educator at the local clinic recommended Nora consider participating in this study, following her involvement in a diabetes education class. Nora had been diagnosed earlier that month. She is married, with three grown children, and had lived most of her life in a mid-western city with a population of around 50,000. She had recently retired as a chef, but still loved cooking and volunteered to cook for different people and events.

**Kurt, age 63**

Kurt decided to participate in this study after the dietician at a rural hospital described the project to him. He was a divorced farmer in a mid-western state and lived on an acreage. Although he lived alone, he had a very close relationship with his father, who also farmed with him. Kurt was one of the more disciplined participants, taking advantage each day of an exercise room he had set up in his basement. He also addressed diabetes sans emotions, but with a very articulate awareness that steps had to be taken now in order to prevent problems later. Talking to this farmer, one got the sense that he had seen how little problems, although nothing to become anxious over, needed be addressed to prevent more calamitous events later.

**Olive, age 53**

Olive was diagnosed five months before entering into the study, her participation recommended by her physician. Although diabetes ran in her family, because she was
otherwise healthy she did not imagine she would get diabetes until her 60s or 70s and was quite surprised by the diagnosis. She was married with adult children.

**Map: A Visual Overview of the Categories**

This research revealed a central category, four primary categories, and two subcategories. Because this present chapter, Results, is devoted to identifying and describing the categories in rich detail, supported by quotes from the informants, it is easy to quickly become lost in the minutia. Offered below is an overview of the categories revealed in the data. Though it is introduced here to help the reader conceptualize the categories, the map will not be significantly developed until Chapter 5, Discussion (see figure 1).

**Figure 1.** Overview of the research categories
Description of the Categories, Properties, and Dimensions

Overview: Disentangling Interrelated Ideas

A unifying central category and four primary categories were identified from the data. The central category of health decision-making (HDM) both served as a focus of the research and came to function as an axis for the other categories. The category, “disequilibrium,” preceded HDM temporally, and operated as a causal condition. Orbiting about the process of HDM were three other categories: knowledge, purpose, and agency. These categories not only influenced the HDM process, but also mutually influenced one another. For example, as a person had more, or certain types of, information about diabetes, this enhanced their sense of control over the illness. Conversely, having a sense of agency or control over the events in one’s life increased the likelihood that one would seek to acquire helpful medical information. Because the concepts interrelated, the researcher sometimes struggled with the how to categorize them. Dividing the categories in this way was at least partly the result of the constrictions of language. However, even though the categories were closely tied together, there were reasons for separating them. Certain indicators for each concept were not interchangeable. A person could have a lot of knowledge about diabetes, but may feel powerless affect the course of the illness. Although connections among categories make it difficult to completely postpone commentary, the primary explication of linkages and theory will occur during the chapter on Discussion. Consequently, what follows is primarily, though not exclusively, a description of four variables involved in HDM.
Category 1. Disequilibrium

As participants described the process of being diagnosed, the choices they made in response to the illness, and how they made those choices, nearly all experienced a disruption to their normal routines. They were variously concerned, shocked, afraid, and angry as they were reconciled to being newly diagnosed with a chronic illness, one which would require many lifestyle changes of them. The degree of disruption varied depending on the amount of prior knowledge they had about diabetes and the extent to which other concerns already claimed their attention. Disequilibrium, and the two mediating subcategories of prior diabetes knowledge and concurrent challenges marked the participants’ entrances into a more deliberative HDM process.

Disequilibrium had two distinguishing features: (a) an emotional response, ranging from mild to distressed and (b) a shift in cognition, particularly surrounding how participants viewed themselves, and is experienced variously as shock or confusion.

Illustrating the emotional aspect of disequilibrium, Sally exclaimed:

Sally: “SUGAR?!” [incredulity]. Then after that they [sic] was telling me about you have to be so careful. And then I was pleased that, I don’t want sugar at all, but I was glad that it was not any worse, then what, as taken the needles. You know, [sic] givin’ yourself needles everyday. So I was thanking God it wasn’t that. I wasn’t pleased with it, but my reaction was you have to be so careful now, now that I know that I have it...

New patients were typically inundated with an extraordinary amount of new information that provides directives for exercising, an entirely new method measuring food intake, information about physiology and disease processes, and often a new identity as “patient.” Addressing the confusion Steve remarked:
Steve: My wife didn’t know what to do. We were all just sort of in a whirlwind.

**Two subcategories affecting disequilibrium**

**Prior diabetes knowledge.**

The amount of disequilibrium was mediated by two subcategories: the amount of prior diabetes knowledge and the other stressors a person may have had in their life. Most people had some knowledge of diabetes which framed their response to the diagnosis. This understanding came typically came from personal experiences, such as watching friends or parents work against the illness, but also derived from their work or studies. No participant mentioned media as having a role in prior diabetes knowledge, though after their diagnosis participants were more sensitive to media images.

Only 3 of 21 participants had almost no prior awareness or knowledge about diabetes. Not having any context in which to understand their diagnosis, their reaction was somewhat muted and tentative. Numbers, in particular, were not meaningful, and the diagnosis presented only a small amount of upset in terms of emotions and their self-image:

<table>
<thead>
<tr>
<th>Int:</th>
<th>What were your initial numbers?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stan:</td>
<td>I had a friend that had it about two weeks ahead of me. So I went to his place and I tested my blood and it was 253 or 243 – I don’t remember.</td>
</tr>
<tr>
<td>Int:</td>
<td>Were you alarmed by this?</td>
</tr>
<tr>
<td>Stan:</td>
<td>I had talked to other people and they said, one gal said “mine was 800.” She had been taking insulin shots for years and was getting along [sic] good.</td>
</tr>
<tr>
<td>Int:</td>
<td>So relative to her and some other numbers you had heard, 240-250 did not seem like that big of a deal</td>
</tr>
<tr>
<td>Stan:</td>
<td>No.</td>
</tr>
</tbody>
</table>

Kent also had no context for understanding diabetes. Consequently, he did not have much distress, but was rather nonplussed.
Kent: I was kind of surprised, but I didn’t think it was that big of a deal because of the fact that I didn’t feel bad... I didn’t have a clue. ... He [the physician] said that I was a diabetic, and what can you say. There’s nothing you can really say. You don’t know how serious being a diabetic is, not ever [sic] bein’ one.

Quinn echoed a similar response. Despite using an expletive, the mood is clearly lighthearted and he draws a very clear link between prior knowledge of diabetes and upset:

Int: Your reaction was...?
Quinn: Shit! [laughter]. Well, I didn’t know anything about diabetes. I’m learning quite a bit. I went to the first four hour class at the clinic and then Monday I go to the next one. So I’m learning quite a bit more about it. If I had known all about this and then found out, I probably would have been a little more upset that this had happened.

Illustrating the influence of an increasing amount of prior diabetes knowledge we encounter Kendrick, whose wife had been diagnosed four months before him. In contrast with Kent, Kendrick was more familiar with how diabetes was going to change his life, though he did not yet realize the long term costs of hyperglycemia. He is more chagrined by the diagnosis and describes it as “[sic] devastatin’ a little bit” before backing off somewhat to diabetes being a “negative.”

Int: And what was your first reaction to being diagnosed?
Kendrick: It was weird. You’re trying to be, trying to do some of the things you’re supposed to do because you know someone else who has it. And you’re trying to stay away from some of the things that they [sic] be talking about. So it was [sic] devastatin’ a little bit. It was a negative, I’ll put it like that.

People with a fuller understanding of diabetes tended to voice more surprise and a more emotional response. Mary had been married to a healthcare provider who worked regularly with people diagnosed with diabetes. Moreover, she had known a few friends to be diagnosed with the illness, and one of her parents had diabetes. Being more familiar
with both the changes required and the consequences to her health, she voiced an even

stronger reaction to the diagnosis:

Int: What in the world was your response to that [being
diagnosed]?

Mary: Well, I was afraid of living alone. You don’t want to feel
vulnerable. I was a little bit angry. I didn’t think I deserved that. Just a
little afraid, a little bit angry about it.

Similar to Mary, Sally had a higher level of knowledge about diabetes. She had

watched a close co-worker’s health deteriorate in response to diabetes and had been recently

reading about the illness.

Int: How did that [the diagnosis] come about?

Sally: I was having some strange symptoms. One day I got up and it felt like I
had stockings on. Then another day I was looking at something, children
in the street playing ball, and I was seeing double. I was reading some of
the literature on diabetes and these two things struck my mind - that
these were the symptoms I had been reading about. So I called about
coming in for a check and this is when he told me that I had diabetes.
When he told me it was just like someone pulled a stool from me. It
can’t be [sic] happenin’. … He [the physician] saw the look on my face
and he reassured me that it didn’t have to be all bad. …So that was
some relief. I said, “well maybe it’s not as bad as I think it is.” But it
just worries me. It frightens me.”

Olive knew something of the course of diabetes; her father had been
diagnosed years before, as had a first cousin:

Olive: And it was a shock. And for a couple of months I was [sic] kinda
depressed.

Several participants did not seem to experience disequilibrium following their
diagnoses, but accepted the changes very matter-of-factly. These participants were similar
in that they possessed a “fuller” knowledge of diabetes. This more complete and cerebral
understanding of diabetes appeared to reduce the fearful component of disequilibrium.

Kelly, a 45 year old healthcare practitioner, was intimately familiar with diabetes both from her personal life and from her professional experience. There was a flatness as she described the following:

**Int:** How did you come to be diagnosed with diabetes?

**Kelly:** I diagnosed myself, basically. I was doing a screening program through [the hospital]. And 2 years in a row my fasting blood sugars came in a little high and that I could possibly have diabetes. It was running right around 130. So I went to my physician both times and she poo poo’d it. The second time she took an A1C and it was 6.9 and she said they didn’t worry about it unless it got over 7. So I went a bought a glucometer and did 27 blood sugars over 1 week. Only 15 of those were over 200. Only 5 of the 27 were under 150. And they were an assortment. Some were fasting, some were before meals, some were 2 hours after meals, and some bedtimes. So I took that into the doctor and had her look at that and she said well, yeah, maybe I was right and she ordered the glucotrol XL and that’s how I got diagnosed.

**Int:** Good thing you were very attentive to that.

**Kelly:** Yeah, well, both of my parents are Type 2 diabetics, most of my aunts and uncles are, so it was just a question of “when.”

**Int:** It sounds as though you were not altogether surprised, that you were expecting it.

**Kelly:** Yep, pretty much, with such a strong family history and my own weight problem.

One might argue that such detachment could be related to the emotional distance achieved in the six months since her diagnosis. Challenging that idea, and supporting the link to knowledge was Betty. Like Kelly, Betty was a healthcare provider. She also had additional responsibilities as an upper-level hospital administrator. Also like Kelly, she had family members who had been diagnosed with diabetes. She differed in that she entered into the study in the same month she was diagnosed. Her reaction to being diagnosed is
marked by its near absence of emotionality. When prompted, she described her response this way:

Int: How did you come to be diagnosed?
Betty: I had no specific symptoms, except maybe frequency of urination. With my genetic background it was just a regular check and it hadn't shown up until October. My parents and my brother were... well my parents were type 2, my brother should have been a type 1. ... My maternal grandmother was an insulin diabetic and a double amputee and my paternal aunt was an insulin diabetic who also had a juvenile diabetic, so it was there.

Int: It sounds as though you come from a family of bad pancreases.
[laughter]
Betty: Yes. My goodness. So if anyone should have been stick thin their whole which I wasn’t, I’ve always been a little on the heavy side... because I was in denial and kept putting off changes. ...Well, he [the physician] said “you're official now.” And I said, “Yeah, I guess I can’t get around it any more.”

Int: He said, “you're official now?”
Betty: Officially diabetic. Oh, we know him real well. He’s part of the clinic. He anticipated that I would be diabetic, probably sooner than I ever thought I would be. So it’s there. It’s black and white and you can’t get away from it.

Concurrent challenges.

A second factor that appeared to reduce disequilibrium was the presence of other worries deemed greater than diabetes. Participants who had no other medical concerns and relatively fewer outside stressors tended to focus more on the diabetes. It upended their emotions and thinking to a greater extent because they had the time and “luxury” to worry about a health condition that is more feared for its long-term effects than its immediate consequences. Challenges, such as more acute health or relationship problems, concurrent to the diagnosis of diabetes tended to minimize, or perhaps masked, the disequilibrating effects of the diagnosis. Bernice, a 71 year old participant, was newly diagnosed at the time
of the first interview and had a background in healthcare. However, in place of diabetes, her
greater concern, as revealed throughout the interview, was her spouse who was living with
Alzheimer’s and would eventually suffer debilitating heart attacks over the six months of
this study. Instead of voicing fear, anger, or shock at being diagnosed, her muted emotional
response can be seen in the following exchange about being diagnosed.

Int: What do recall your response to diabetes being when the doctor said
"well, Bernice?" [you have diabetes]
Bernice: I wasn’t real, real happy about it, but I it’s just another one of
those things that you cope with in life. I seem to be doing pretty well
with it… I didn’t really ask to have the diabetes, but I’ve got it and I
accept that fact.

Demonstrating reduced disequilibrium, Bernice, who had been diagnosed
within just the past month described the diagnosis calmly as just one more hassle.

Christine, the 72 year old widow, also exuded calm when she talked about her
recent diagnosis. It appeared that her many medical complications this year mitigated the
disruption that a diagnosis of diabetes may have had. Indeed, as Christine recounted her
recent hospitalizations, there was a peculiar levity to her list:

Int: Tell me what life has been like living with diabetes… You had
mentioned that you had had a pretty rough year medically last year.
Christine: Well, I had my gall bladder taken out, so I don’t have that problem any
more. I had been on blood pressure medication that depleted the
potassium, so I am no longer on blood pressure medication. After being
fed potassium for a week in the hospital, I’m ok. I have fibromyalgia….
don’t have problems that much with it at all right now.

Int: What’s life been like living with diabetes?
Christine: Basically, the only thing is just watching what I eat.
After reviewing the various acute medical concerns of the past twelve months Christine had what she construed to be minimally invasive and relatively simple prescription: to watch what she eats.

In a somewhat extreme example, in the midst of this project Kelly began testing for some pulmonary problems that had made it impossible for her to draw a complete breath of air.

Kelly: It feels more like a complication instead of the main event. If I need to be on steroids for this lung disease, then the diabetes is more of a problem because of the blood sugar getting out of control with all the prednisone.

Int: So a lot of your attention is on breathing and the diabetes becomes something that all the other treatments have to work around or taken into consideration.

Kelly: Right. And it makes even the outside notion of trying to get an exercise thing going impossible. I can hardly walk across the room and breathe, let alone exercise or anything.

Kelly, who was experiencing a most acute challenge, did not describe the diabetes diagnosis as upsetting, but was instead necessarily focused on breathing.

Although the participants in this study represented a widely diverse group of people, each had one thing in common: at some point within the preceding six months they had been diagnosed by their physician as having type 2 diabetes. Diagnosis of a chronic illness was, for most, a life-changing event. This was no less true with diabetes, where the diagnosis not only was a statement about mortality, but also a challenge to radically overhaul one’s dietary and exercise patterns. Wrestling with mortality and the many needed changes led to a condition of upset for most, termed disequilibrium, reflecting that for a time things seemed out of balance. Confronted with this new information about their health and the requisite lifestyle changes, participants began trying out different behaviors, such as
modifications to their diet or exercise patterns. Multiple decisions and changes, only some of which were maintained by participants, also contributed to the sense of disequilibrium, unbalance, and change. It was these decisions, or more precisely the factors that influenced these decisions, which, through inductive analysis of the data, were organized into categories and became the focus of this research.

**The Central Category: Health Decision-Making**

After a careful examination of ways in which the various categories interacted with and affected one another, health decision-making (HDM) was selected as the central category in the data. The process that led to HDM being identified as the unifying theme began with data that had been open-coded being reorganized into semantically related categories or domains with various properties and then dimensionalized. Following this, the researcher examined the ways in which the categories interacted with one another by composing a storyline memo (Strauss and Corbin, 1994). However, the selection of HDM as the central category was not without some difficulty, primarily because it was the least developed of the categories. What would be the reason for its simultaneous centrality and conspicuous absence? People are not generally accustomed to describing this decision-making process. When asked “how” or “why” they decided to take a particular action, participants’ responses fell into one of three categories: (a) they would either state that they did not know, (b) they would provide a tautological response, such as “because I wanted to,” or (c) they would describe something that either motivated or constricted their behavior, such as Krista’s “I’m not ready to die” or Kent’s “because I don’t want to be a burden on my family.”
Strauss and Corbin (1994) expressed the results of qualitative research through the astronomic metaphor of the solar system. In this analogy the central category was represented by the sun, holding the other categories and subcategories to coherent and orderly, planetary-like orbits. I would modify their metaphor slightly in this case and suggest that Health Decision-Making as a central category was like a black hole. Black holes are invisible and not directly observable, yet astronomers agree to their existence theoretically because their presence and influence explains various actions of other heavenly bodies. Thus, while direct empirical evidence for black holes is lacking, their presence can be observed indirectly as they act upon other entities. Similarly, after I reorganized the data into semantically similar categories and subcategories, I examined how the concepts interacted with one another and assessed which category was the most integral and explanatory, and which categories represented casual or intervening conditions. After considering several different concepts as central categories, particularly "agency," I decided that Health Decision-Making was the crux of the change process.

In this research, the category of HDM, at its most basic level, described a choice. Expanding the idea of HDM conceptually, it is the nexus where a large and nearly unmanageable number of factors and forces (Lacy, 1981; Peers and Christie, 1984) converged and consummated into an action. These factors were important in shaping choices and, indeed, comprised the categories that follow in this chapter. However, they were the factors that influenced decisions, not choice itself. HDM as an organizing principle assumed the individual was the unit of analysis and presumed the locus of control rested within that individual. It also assumed some level of agency as the person responded
to various factors by choosing a health behavior from a menu of options. The following three sections describe categories that influence this decision-making process.

**Category Two: Knowledge**

One of the categories that influenced HDM was Knowledge. Knowledge referred to the information that the participants had about their illness. People’s understandings about diabetes varied immensely from person to person, and it was a variable that changed over time. In addition to noting how the amount of knowledge people possessed varied, it was theoretically clarifying to recognize that knowledge had different properties and to consider how the different properties interacted. The four different properties reflecting differing aspects of knowledge were factual knowledge, feedback, experiential knowledge, and affective knowledge.

**Factual Knowledge**

Typically, being diagnosed with type 2 began a long educational process that almost uniformly commenced with great intensity. Doctors provided their patients with pamphlets, clinics provided group classes and counseling, and hospitals hosted weekend-long seminars. Informants with a lower prior diabetes knowledge regularly commented about the steep learning curve required as they adapted to managing their diabetes. It was not difficult information, as several informants concurred with Steve, it "was not rocket science." It was, however, typically outside of the patient’s normal sphere of knowledge and required learning some new vocabulary and processes in order to address their illness. Most people craved more information about their illness at this time. As Steve remarked:

Steve: Because I found that if you have information, you get over your fears initially and you get something you can do about it. And once I found
something I could do about it, like exercise, I guess I just took it by the horns.... Let me say this. I wish that education would have started.... We had to wait a week I think it was for the round to start again...and I wish it would have started the moment I got out of the doctor's office because I was just like a sponge. I needed to know this stuff in order to change my life in order to put some control and shape on it that would be compliant with what the doctor recommended. And the doctor recommended diet, exercise and pills, and it was one step from there to insulin, and God knows I didn't want to go down that route. So I just learned as much as I could to try to put ...my control on it.

Ted also expressed a desire to learn more about his illness, a desire motivated by concern about the consequences and balanced against the belief that he could alter its course:

Ted: As soon as they diagnosed me I knew quite a bit about diabetes, but I didn't know all the ins and outs. I got on the net, I talked to a couple of my friends who are doing diabetic research, they got every type of information I could possibly use...what's the [sic] do's, what's the don'ts, everything down to the cellular structure, everything down to eyes, hands, feet. The impotency problem has really bothered me. I am not having any [sex] now and I would like to at some time, so I would like to continue a stiffy sometime. Be a little more careful. I used to go barefoot all the time. The doctor said "watch that," so now I wear shoes all the time. I've tried to be a little more cautious because you can get a sore on your foot, it fester and become gangrenous, you get decubitis ulcers, you get all these other things that are associated if you get diabetes.

Int: So you did some research, talked to some friends, you wanted to find out what's happening. [It] sounds like it spurred an interest in you and, ok "what does this mean, what are the consequences" and you educated yourself.

Ted: Yes

For many, acquiring information through these pamphlets and seminar proved instrumental in their taking steps to manage their illness. In particular, information about how the consequences of hyperglycemia and very practical steps to manage their
health was described as important decision-making factors by informants. Sally explained how factual knowledge influenced her choices:

Sally: I know it can go into a [sic] worser state and that I don’t want.
Int: How did you come to know things about the [sic] worser state?
Sally: [The doctor] and his nurse, giving me a little pamphlet or books or what not.
Int: So you’ve just been learning things, reading.
Sally: That’s it.

Four of the 21 informants emphasized the role of cognition to the near exclusion of other factors. In essence, they indicated that once they were diagnosed with diabetes, they learned through classes and readings what they needed to do and simply and without deliberation made the necessary changes. The researcher was a bit incredulous of the simplicity of their explanation and challenged them to consider other influences.

Nevertheless, they tenaciously held to their view that they only needed to be told they had the disease and educated about it in order to make different decisions. Sam was one such informant. At this point in the interview, the investigator had discussed with Sam what themes he had seen emerging in the data:

Int: What has your experience been with the category of “time?”
Sam: I don’t know that age really plays a role in it per se. It may be an educational factor more than age. ... I think it is more of an education perspective, than an age thing.
_Int: So it’s more of just understanding the consequences and understanding the processes.
Sam: Uh huh.

And further in the interview he held to his position that education and changes in understanding were paramount:

Int: What kind of a role has faith played in this, if anything?
Sam: Nothing really, nothing to really any extent [pause]. I think it is more of an educational thing than a faith issue.
Similarly, Kurt indicated that a change in cognition or understanding was an essential, though not the only, ingredient to changing his decisions about eating and exercising:

Int: What has been motivating for you of late?
Kurt: Still the same things. Just the fact that it’s been a warning and I need to take care of myself and the things that can happen to you if you don’t are pretty scary.
Int: ...You see the storm clouds on the horizon and you know what to do.
Kurt: If you get a warning, then you better take heed.... If you look at the facts, you [sic] got no choice in the matter.

Informants spoke of the need for good information about diabetes and health. In particular, early diagnosis was one important piece of information. For many it served as an early alert for potentially greater problems. Information about the disease process was also deemed useful. Participants desired to know how the disease functioned. Although diagnosis and pathophysiology were valuable in mobilizing patient resources, two other types of information proved to be highly activating. Information about the consequences of long term hyperglycemia served to be motivating and specific action steps recommended by healthcare professionals gave them some direction in which to channel their energies.

**Feedback**

Participants in this study also spoke frequently about the role of feedback in shaping their actions. Feedback took two forms: physical symptoms and quantitative data from tests. Betty, who had had a long career in healthcare, was particularly moved to action by her readings.

Betty: My A1C was 7 point something, so that’s when the props went out and the denial had to be faced up to.
Later the researcher sought clarification as to what helped end the denial. Betty responded:

Betty: Seeing it in black and white on paper. I saw my blood results back and there it was. ...You know, it's there. It's black and white and you can't get away from it.

Three participants described experiencing some early symptoms of hyperglycemia that were directly related to recent food choices. One symptom mentioned by two informants was that after they over consumed carbohydrate-rich foods their toes would tingle. Quinn described toe tingling as:

Quinn: A little sign that "hey bud, you've done something wrong."

In Quinn's mind this feedback served as a warning, but one which was benign and easily disregarded. He speculated, in somewhat facetious tone, that a more dramatic feedback mechanism would elicit a better response from him:

Quinn: If every time I ate pasta I threw up, it would be easier not to eat it, you know. But ever time I eat pasta nothing happens, except that I take my blood sugar it it's high. So, yeah, if I threw up ever time or went into convulsions or something like that, it would be easier not to eat it.

At other times the feedback would be positive, as in the encouragement a person would experience when efforts to change their diet and exercise patterns was rewarded with weight loss. Feedback in a variety of forms, weight on the scale, numbers from medical tests, and symptom presence or reduction served to inform participants decisions about health management.

**Affective Knowledge**

Although some people's health choices were directed by new education about
diabetes, others were motivated by a different type of knowledge: emotions. Does “emotional response” qualify as a type of knowledge? Two recent, influential writers, Howard Gardner and Daniel Goleman, laid the foundation for emotions as a property of intelligence. First, Gardner reintroduced the idea that intelligence is not a unitary property, but that there were at least eight distinct components to intelligence. One of these properties, intrapersonal intelligence, related to the ability to recognize one’s emotions (Gardner, 1983; Gardner 2000). Goleman further contributed to popular and academic discussion about the role of emotions in a schema of intelligence with his book Emotional Intelligence (1995). Goleman’s proposition of emotions as intelligence demonstrated academic longevity, as it represented an elaboration of E.L. Thorndike’s concept of “social intelligence” originally articulated in 1920 (p. 228). Participants regularly described having an emotional response to the diagnosis and these emotions seemed to have theoretical significance in the emerging theory. Given the recent discourse on emotions as knowledge, I elected to include them as a property of cognition.

All participants discussed having some emotional response to diabetes. Women, however, were far more descriptive than then men in articulating their emotional state, a feature which was reflected in the selection of informant quotes. This gender imbalance did not harm this research, but rather was consistent with other research on emotions. In 1992, Dindia and Allen published their findings from a meta-analysis of 205 emotion studies with more than 23,000 subjects and concluded that while men and women both experience a range of emotions, women are more likely to disclose their feelings to others. The properties of this knowledge included anger, sadness, and fearfulness. The extent to which
these emotions were recognized varied along a continuum of intensity. More significant theoretically, they also varied along a functional dimension I referred to as “mobilizing.” Certain emotions seemed to be more of a catalyst for behavior change than others.

**Anger.**

One of the more uncommon emotional responses was anger. This feeling may have stemmed from the belief that they were somehow entitled to good health or a general resistance to having to make changes in their life. Mary neither talked about anger as an impediment or a mobilizing factor in her health management:

Mary: I did get little resentful and that’s why I don’t exercise everyday because I think that I would probably rebel....And if you don’t have the ability to make choices, then you do feel resentful. You feel like you're trapped, like your body betrayed you, you don't really look at yourself as being the one at fault, but it's like you’re on the outside looking in. That's the way I felt. My body had betrayed me. How dare it allow this disease to come and to take over. I mean really, I know I've done it to myself and I had a tendency to get it, but you always want to blame somebody else.

Sometimes diabetes is perceived as an obstacle to one’s other goals, such as a healthy and active retirement. Describing her response to the diagnosis, Nora added:

Nora: I was upset. I was angry. I was just getting up to retirement age. And I was afraid because I had no idea what it involved. So that day when I left his office I just went to the mall and walked

Although anger was a distinct property of emotion, the researcher decided not to pursue dimensionalizing the variable along continua of intensity or ability to mobilize because of its infrequency and apparent lack of theoretical significance.
Sadness.

The data also occasionally reflected that people felt sadness in response to being diagnosed. It is widely accepted that sadness, or grief, is a reaction to an experience of loss, and people diagnosed with diabetes contend with many losses. Foremost among these changes, particularly for younger participants, was the loss of their sense of health and well-being. Several indicated that they understood diabetes was chronic condition, noting that it occupied a check-off box on most employment and insurance forms. For participants who had otherwise been healthy, diagnosis brought with it an understanding that they had crossed over a Rubicon, from a place of a care-free inattentiveness to health concerns, toward preoccupation about their health.

Sally: ...Yeah, I have always considered myself pretty healthy... And (so) it was a shock. And, for a couple of months I was kind depressed, you know. I don't think it was so much finding out that I was diabetic, but having to learn that I couldn’t eat certain things. [sic] Because I would go to a buffet every day. And that was my thing. I would get all the kids to school, to work,[and] I would go eat buffet. And I would eat until I felt stupid. I would eat, and eat, and eat. And when I found out, well, I have to cut back on this, and certain things, I couldn’t have, like a lot of cake, ice cream, I was devastated.

Sadness appeared to slightly diminish informants’ efforts to mobilize resources to manage their health.

Fearfulness

The most common emotional mentioned in response to living with diabetes was fear (17 of 21). Not only did “fear” frequently appear in the data, it was typically included in the context of “motivation,” a point which is illustrated in the quotes from Betty, Steve, and Mary. For these two reasons, its pervasiveness and ability to mobilize, it is the most
theoretically salient property of affective knowledge. Participants described the intensity of
the fearfulness variously, ranging from nonexistent to strong, and described its effect in
ways ranging from somewhat motivating to very motivating.

Betty: Part of my motivation is fear of what will happen if I don’t take care of
it. And I think fear is a good motivational factor. It’s in the back of my
mind because of my grandmother…

Sally: He (the physician) saw the look on my face and he reassured me that it
didn’t have to be all bad… So (not being required to take shots) was
some relief, I said, “well maybe it’s not as bad as I think it is.” But it just
worries; it frightens me.

Fearfulness emanated from a variety of concerns, but was most often attributed to very
specific consequences from diabetes, ranging from impotence, which was mentioned as a
significant preoccupation for the often brash, 29 year old, Ted, to the more commonly
articulated worries of amputation, blindness, and death. Mary illustrated what was a
primary concern for many:

Int: So what motivates you to combat, to not allow it to progress?
Mary: Well, a fear of dying. My own mortality.

Not all of the fears, however, were directly related to physical consequences. Some
took a more abstract form, as in fear of the unknown:

Steve: Just the fear of not knowing, I guess (was) the greatest fear that I had. So
I set about to get some more information. Because I find that once you
know stuff that those fears tend to go away.

Two female informants who were single because of divorce or the death of a spouse
spoke about a fear of losing independence because they had no partner to take care of them.
They indicated that although at one time they expected to have been cared for by their
husbands, they were reluctant to have their children shoulder this responsibility and were
therefore anxious that there was no one else on whom they could depend should their health begin to fail. There was a sense in which lack of spousal support removed a safety net and left them feeling more exposed.

Mary: I guess vulnerable is the word I would use because I feel as though I am at risk. Something might happen, and I don’t have anyone right here and I don’t want to be a burden on the children. So I want to keep myself in good shape.

Int: So if diabetes is allowed to progress, it could affect your independence. You could have to depend on someone for transportation because of the eyesight.

Mary: Or the limbs, you could lose legs, you could have dialysis. That would be a nightmare for me. I know that if you’re not healthy then you also have to call on people... I guess that’s pretty much what motivates me.

Men described a related, but contrasting fear. Theirs was not a fear of needing help and not finding it in a spouse, but simply needing help. Using the same metaphor, the fear is not the absence of a safety net, but falling and needing to depend on it. More than once they voiced concern about being a drain to their family financially and emotionally. Kent, a younger businessman and father, spoke for many men when he explained how fear was motivating him:

Int: What’s motivated you to make the changes, uh, thus far?
Kent: Well, I found out I was a diabetic.
Int: How come that’s, uh...
Kent: Well, I mean, again, I, uh, later on in life, like I say in the beginning, I don’t want to lose any limbs. I don’t want to go blind. And I don’t want to be a burden to my family. And I don’t want somebody to have to take care of me and be in a wheelchair and not be able to see where I’m going and have to depend on somebody to drive me everywhere I need to go. I don’t want to be in that situation.

Int: So, it’s ...
Kent: I’m 44 years old and that could be 20 years away at least. And I don’t want to do that. I don’t want to be a burden to my family.
Int: That’s really important to you. You’ve probably said that 4 or 6 times. Three times just recently.
Kent: Yeah. Because I’d just as soon be dead. As long as I’m ready
to go… I don’t want my son to have to take care of me. You know. I
don’t want my wife to have to take care of me. You know, I’m not
talking about something that you could recoup from… And from a
financial standpoint. I don’t, I don’t want to wipe my family out. You
know? That’s not what I’ve been [sic] workin’ all my life for, just for
something like that. … And not just financially, but, from a mental
standpoint … the stress. The mental stress involved and the physical
stress, mental and physical on my family.

One factor that influenced participants in this study was an affective or emotional
knowledge about diabetes. Anger, sadness, and fear were common, with fearfulness serving
as the most potent mobilizing emotion. For most, their emotions diminished into a more
sustainable sensitivity about their health. However, equipped with a new understanding
about their vulnerabilities to the long-term consequences of diabetes, participants did not
return to the blithe days before the diagnosis

**Experiential Knowledge**

A final specialized type of cognition is the understanding of diabetes that came from
having witnessed someone suffer through its consequences. This property, termed
experiential knowledge, was closely associated with another cognition property, affective
knowledge. However, because indicators for experiential knowledge did not always
coincide with the presence of affective knowledge indicators, there were theoretical reasons
to consider them as separate concepts. Indicators for the presence of experiential
knowledge were that someone had observed another with diabetes, particularly another
person who was manifesting some of the ill effects of long term hyperglycemia.

Additionally, experiential knowledge was marked by a lasting and disturbing visual image
of that person, though evoking fear or emotionality in the participant was not a necessary
feature. Experiential knowledge served as a reminder and motivator to participants, and
could be dimensionalized, like many other variables, along a continuum of "mobilizing" to "no effect."

Eighteen of 21 participants in the study had known of another person who had had diabetes. It may have been a close family member such as a sibling, a parent, or even both parents. At other times it was a co-worker or a client. The salience of the experiential knowledge was affected primarily by the degree of injury the participant witnessed in the other person. Needle sticks and amputations proved particularly memorable to participants. The biological closeness of a stricken family bore importance as well. Recalling a mother's struggle was more distressing than remembering that of a cousin's. In a case that was somewhat exceptional because of its intensity, Steve stated several times that his mother had had diabetes and that it was very hard to watch her in sickness. When prodded to clarify what he had observed, Steve effectively slammed the door on further discussion, suggesting that this was a particularly painful memory:

Steve: And I'm fine with that [taking medication] as long as the medication is not insulin.
Int: I remember that you were real clear that you did not have a needle phobia, but what was it about insulin?
Steve: I had to see my mom work through it and, uh, it's not a pretty picture
Int: Because [pause] I'm not following you.
Steve: The reason you're not following it is because I'm not being very clear about it. And I'd rather not be very clear about it, quite frankly. There were some situations that I saw her in that were very ugly, and I'll leave it at that. It was just very negative, I guess. And I don't want to go through that.

More typically, people discussed what they had observed with significantly less demonstration of emotion. These encounters left participants with strong impressions about the long term consequences of their disease. In the following interchange Sam does not talk
about fear in relation to his observation, illustrating the reasoning behind the researcher's
decision to maintain them as separate properties, but discusses it as illustrating what could
be long term consequences for him:

Sam: ...I had one client that lost feeling to diabetes and had peripheral
neuropathy. So he burned his foot and didn't know that he had burned
his foot. Another friend had some hot water on his foot and just about
lost his leg cause of diabetes. So there was a lot of effort so he could
keep his foot. So um, knowing those from clients and friends and can
really cause quite a change in your longevity and body parts and things
like that.

Int: It keeps it from being too abstract.

Sam: It's interesting. You see a person go blind because of diabetes. At one
time he was very active and everything else and then all of a sudden he is
totally dependent on everybody for everything. It is quite a change in
that person's life.

Int: And so, being dependent on other people, losing abilities, even a
livelihood...

Sam: Those would be very severe consequences if you don't address it.

In contrast, Sally was a bit more emotionally demonstrative as she described what she
had recently observed.

Sally: Hopefully I didn't wait too long to catch it. The man on TV
said "nip it in the bud." When I think about it, see these people out here
(in the doctor's waiting room) with no legs, some with one leg; boy,
that's the first thing that hits me. Then I see somebody taking a needle.
Lord, don't let it come to that.

Int: You have all sorts of visual images of people who let their diabetes go
unmanaged.

Sally: Yeah, either that or they didn't know they had it. One patient came here.
They almost had to drag the lady in. She had been going somewhere,
some other doctor when she found out she had diabetes. And it had just
about taken the best of her health. And it hurts me because she was one
of my co-workers.

Evan was easily able to recall others he had known who had suffered from more
advanced diabetes. Also, Evan, and two others, described symptoms that they felt after
deviating from their regimen. The sensations were usually described as “tingling” in extremities. This was also coded as experiential knowledge and served to make the participant very mindful of their health decisions. Evan’s symptoms were a little different:

Evan: I actually get sweats around my neck. I get sweats around my ears. You can feel it. You can feel it. At night I have real cold feet. My knees will turn purple. You can see right now there’s just no circulation. So I know someday they’ll be cutting and I’m not looking forward to that. I know two people, one has two titanium legs and the other died. They tried to take a vein out of one leg and put it in the other and he died from that. But like I said, I’m trying to keep my head up and not thing about those kind of things, still trying to support my family.

Experiential knowledge is a distinct property of cognition, differing qualitatively from “factual knowledge” and “affective knowledge” in its indicators and origination. Witnessing the long-term effects of hyperglycemia contributed to motivation in a manner similar to fear, though some participants construed the experience as something more detached, like a “warning sign.” In this way it was different from affective knowledge. It was also different from the property of “factual knowledge” in that it tended to evoke a more visceral response, such as seeing the contorted metal from a car accident may have more of an effect on speeding than noting a speed limit sign or reading the latest research on speed as a factor in vehicle deaths.

**Category three: Purpose**

As people talked about managing their health, they would often draw encouragement from a sense of vision, meaning, or calling about their life. This idea of “living for something greater than oneself” is summed up in the notion of “purpose.” Sometimes this purpose had spiritual underpinnings. Indicators for this would include talking about “God,”
"faith," or "plan." At other times the focus was on children or grandchildren. Indicators for this second property termed relationship might include references to "children" and "seeing them grow," and "influencing them," combined with talk about the "future." However, whether this calling was colored by religious or familial overtones, purpose, as discussed by the participants in this study, was nearly always in the context of relationships. Ultimately, people were not inspired to make healthy choices so that they could achieve personal milestones. People wanted to stay healthy so that they could contribute to the lives of others.

**Mission**

Mission was a property of purpose and was used taxonomically to capture the motivations derived from a personal faith. Eight of twenty-one informants indicated that they viewed health and faith as intertwined. Some participants were highly involved in church and found that the challenge to maintain their health was imbued with extra meaning when viewed from a theological context. As Kendrick reveals below, faith for him offered both the promise of longevity and comfort in the midst of a difficult time. He holds an interesting and seemingly paradoxical understanding that God is in control of his health and the number of his days, and yet he has a responsibility to actively manage his health. It may best be understood as a pact which God has pre-established whereby if he lives responsibly, God has an obligation to maintain his body to a certain age.

**Int:** What sort of things are motivating you to make these changes?

**Kendrick:** There are things that when we are born are already [sic] destined. But there are things I would like to see done and things I want to do. And I know when you play with diabetes, and being a diabetic and playing
around with that there is a tendency to be cut short. And I don’t want to be cut short....Let's put it like this. I have a great deal of faith. And the Bible says you're going to live 3 score and 10 and you hold the Lord accountable for what he says. He says this is what he does. And I believe what he says. He said it. He promised it. And I'm looking for it. I'm not cutting myself short [sic] none whatsoever. 3 score and 10 is 70 and anything that comes after that I will be thankful and grateful.

Int: You will have led a full life. Your body will have lived up to its potential to have lasted 70 years.

Kendrick: Exactly.

Int: So your faith is really instrumental for you in fighting this...

Kendrick: Like I said, all days after that I will be thankful. But until then I'm looking to hold him accountable. In the same process, I need to do the things that are right. If I know that certain things are causing me to be cut short then I'm praying to Him, and I can't do that.

Int: What stands out to me is that your faith plays a very, very central, a very, very important role in why it's important to stay on top of this.

Kendrick: ... Your faith has a whole lot to do with it. Even down to the point of accepting that you are a diabetic and not worrying about it. I think [sic] worryation causes you to have more problems than you normally would have. This is something that has come upon me and I'm not going to worry about it because somewhere down the line I feel we can overcome it.

Like Kendrick, Ted proffers a spiritual dimension to maintaining his health. Ted has had a range of faith experiences and purports to have read the Bible, Torah, and Book of Mohammed, among others. His spiritual sense of mission as he makes health choices is among the least dogmatic, but every bit as purposeful, as he explains here:

Int: What role does this [faith] have in your motivation with the choices you have made with your diabetes?

Ted: I believe it has kind of got me into the thinking that "ok, this body is a shell and I'll be in heaven and I won't have to worry about the diabetes and all that stuff. But God wants me to do something down here. He would have taken me a long time ago in certain situations if he didn't.

Int: He had his chances.

Ted: Oh, he had lots of them. So I kind of look at it like God wants me here, I feel kind of drawn to this church. Let's take care of myself so I can do what God wants me to do.
While living in this small Midwestern town for several months, Ted had quickly become involved in a local church and insinuated himself into its youth ministry and the lives of several of the community’s more troubled teens. The researcher knew from his work counseling in this farming community that adolescents who were having problems with parents or opposite-sex relations would commonly be over at Ted’s house and parents trusted him to offer guidance to their children. Consequently, from the context of Ted’s life it is evident that “doing what God wants me to do” is intertwined with being involved in these young people’s lives, intertwined with relationship. A sense of mission, as a property of purposes, was typically, though not always, associated with relationships.

**Relationships**

As mentioned, when people discussed the reasons they had for remaining healthy, they would frequently describe the important role that a sense of purpose played; commonly this was intertwined with relationships. 18 of 21 participants mentioned relationships when they described their motivation to remain healthy. Relationships fell into two categories, family and non-family, with family relationships recurring much more frequently and appearing more theoretically significant as a motivating factor (16 of 21).

**Family.**

The emergence of family as a factor, quite candidly, surprised the researcher. As a student of relationships, he had conducted an earlier pilot project that focused somewhat more on the role of the relationship between the patient and their healthcare provider. During those interviews he explicitly inquired as to the role of spouses and found that participants viewed their role was negligible or even antagonistic. As a result, as this
research first commenced there were no “grand tour” questions that pertained to relationships or family involvement and the significance of relationships emerged somewhat indirectly. Typically the researcher would open a series of questions with a very broad “what motivates you to take steps to remain healthy?” This was usually met with an equally broad and vacuous “because I want to have my health” or “because I don’t want to die.” Only after the researcher pressed them further as to what they had to live for or what made life worth living did purpose, and in particular family, come up repeatedly as a factor.

Husbands, wives, children, grandchildren, and even yet unborn generations, were all mentioned as offering potent reasons to remain healthy. The ways in which family members influenced the patient varied. If spouses were mentioned, they were depicted in one of two roles: partner/encourager, or, if ill, they functioned in a “care-receiving” capacity. This “care-receiving” capacity is a theoretically significant dimension that will be elaborated later. More frequently, participants spoke of children and grandchildren as providing a sense of purpose. Part of the reason for this may be because five of the informants were single, and yet either had biological children or “fictive kin” offspring. Younger generations, however, seemed to imbue participants, with greater resolve to stay healthy. Betty illustrated two different roles that family members can play, a theme repeated in other interviews:

**Int:** So what motivates you to make changes now, in contrast to just saying “well, I’ve got this so….I’ll just let the disease run its course and I’ll check out at a certain time.”

**Betty:** I’m not ready for that. My youngest [child] is only 24. I’m going to stick around a long time in good health. I want to be at his [graduate school] graduation. Walking! My husband is very good at complimenting me, especially from the exercising, how things are tightening up. And that’s always good.
Int: So sticking around to see children and having a spouse who is encouraging. Tell me a little more about that. He's complimentary. Are there other ways in which he has become involved?

Betty: No, he still eats the wrong things. But he's a good cheerleader. He encourages me. And he tells me he can tell my muscles are tightening up, firmer and all that. That's always nice to hear from your spouse.

Int: I'm hearing, tell me if I'm wrong about this, I'm hearing that family is important, that being around for children and watching them is important and I'm also hearing implicitly that the marriage is strong and important.

Betty: Yeah, very definitely. We have too much invested. It's been almost 43 years.

The researcher captured a similar exchange with Sally. Sally spoke at length about her "children" and her involvement in their lives through daily phone calls, weekly meals, and regular admonitions to live right. Her attachment to her "children" was so profound that it eluded the researcher for much of the first interview that she was referring to nieces and nephews.

Int: What motivates you to make these changes?

Sally: I want to be as healthy as possible. I want to live as long as I can.

Int: How come?

Sally: Cause I got some children around - that boy I was telling you about. I'd like to see them get off to a good start and see them through life and see them. You know, I go way back there. I got sisters there, my mother died and left them young. I dropped out of school to take care of 'em. I was 8 years old when my mom died. My step-momma died when her children, her twins were 8 years old. She died, the last wife Dad had, she didn't have any children...

Int: So the women you looked up to growing up, your mom and step-mom, passed away pretty early.

Sally: And I was paying the bills, I bought the groceries, I bought the clothes, I did everything. And they still kiss, they are in my house every Sunday and we eat dinner. They bought plates [so that they can take-out the food they don't eat at my house]

I try to tell them if you got good health you can enjoy life. There is nothing in running around, living dangerously I call it. It's more in taking care of yourself. An ounce of prevention is worth a pound of cure, I always tell 'em so take care of yourself. I'm trying to indoctrinate them it is so. I told them I won't rub it in, but I remind them from time to
time. But those are the things that really inspired me to live and I look at my Dad. He was really, really an inspiration to me because he showed me the right things...

Int: So your children are a reason for sticking around and your grandchildren and you want to see them and to help them and that’s important to you...

Sally: Yeah.... And it makes me so good to see them... [family]. makes me feel good to know they come from a long way [metaphorically]. And if it hadn’t been for me sometime I think would they have gone that far.

Int: You were the mother to your own children, the mother to your siblings as well...

Sally: I didn’t have any children.

Int: So all these are nieces and nephews?

Sally: Yeah, I don’t have any children of my own.

Int: But you talk about them as though they were your own.

Sally: They cling to me for everything, you know. If it doesn’t go right they tell me, R so and so... I just enjoy it. I love them all.

A few moments later in the conversation, Sally underscored how these “children” imbedded his life with a sense of mission. Sally had regular involvement in their lives, calling them daily. Faith and family were interrelated in Sally’s youth and as the conversation turned to matters of faith it becomes clear that these present relationships embodied more than close kinship ties. Sally had a vital mission to help the children succeed in life and choose moral paths, a choice that seemed particularly stark to her as she reflects on her “drug infested neighborhood.”

Sally: And it’s a funny thing. I call them. If they don’t call me, I call them. That’s the first thing we do in the morning. We call each other. [sic] And before going to bed. “What you doin?” And everybody seems to [sic] be goin’ to be about the same time.

Int: Do you really?

Sally: Uh hmm. Yeah. We’re just family oriented.... [Discussion about her family used to go to church — required by father]

Int: Tell me about how your faith affects your response to illness.

Sally: I believe that when you put your trust in God anything is possible. And I feel like you put him first in all things he will see you through. ...You don’t question anything that God does because he is supreme; He makes no mistakes. So you hang on to that point. And I try to lead them down
that road. To try to keep them [sic] goin’ the straightest.

Quinn and many others echo the same ideas. Children are very important. They are provide relationship, motivation, and inspiration to see the future. It is also worth noting in these following three excerpts, as with the previous two, how naturally “children” follow as an answer to the question of motivation.

Int: And Quinn, elaborate on the motivation.
Quinn: I guess you could say that it goes without saying - except you are asking me - but it goes without saying that I want to be around for my kids and I mean I enjoy their company and I enjoy our relationship and all like that. But further than that, beyond that, I don’t want to be a burden either... Not only do I want to be around to enjoy my kids and my family and I’m sure some day I’ll be a grandfather, but I also don’t want to be a burden during those years when I could be enjoying it. If you knew me, you would know that it goes without saying that I enjoy our relationship. I can wait to be a grandfather, mostly because of their age. I guess if you knew me, you would know that other part goes without saying: family.

Mary, divorced and a mother of three adult children, elaborated on the same theme as Quinn, that she was vested these yet unborn grandchildren. She extended his thoughts by elaborating the notion of grandchildren as legacy.

Int: And what motivates you combat, to not allow [diabetes] to progress?
Mary: Well, a fear of dying [laughter]. My mortality. I would like to be around to see my children and grandchildren, if I have those [in the future].
Int: So it ‘s relationships and caring about people and maybe some sort of curiosity about seeing children growing up?
Mary: I just want to be a part of their lives. I guess it’s kind of a vanity thing. I want to live, I want to be able to influence them, I want to be around as long as I can, and if there are grandchildren, I would like for them to know their grandmother, you know.
Int: So it’s a combination of giving love and receiving love and the vanity piece is so people would have a memory of you.
Mary: Well, since I’m not going to write the great novel or compose the great symphony, my legacy is going to be my children and it would be what I have taught them. Everybody wants to leave the world a better place and I would hope that they would carry on with what I’ve taught.
So it doesn't stop with them, but goes on to their children and so forth. That's what I would leave as my legacy, I guess.

Finally, Olive emphasizes in colorful idiom how children enrich her life with purpose and meaning.

Int: And you said you want to live a long time?
Olive: Sure, don't you? Don't you want to live a long time? We all want to live a longer. If you want to live longer you [sic] gotta try to do the right things. I want to be here to see my great, great grandchildren.

Int: So it's pretty important to you.
Olive: It is.

Int: What is it about children and grandchildren that is so powerful?
Olive: Well to me, if you look at them they are the children of tomorrow. The future children. If I'm there to set that example for them, then they're [sic] gonna carry the generation on. They are powerful. If I live to see my children grown, and I love my children and I definitely love my grands. Because, as I say, they are the children of tomorrow. And if we can be an example for them, then they can carry on the family, they can carry on the generation.

Int: Children of tomorrow. Something about the future you're excited about or holds promise for you?
Olive: Sure. Especially when you set a good example. Now when [sic] you a rotted type, you don't want your kids to learn that. But when you are teaching them the right way and having them to follow your footsteps, teaching them what's right and what's wrong, and when you do that, the majority of the time they'll follow in your footsteps. [sic] Gotta have someone to carry on. Cause when we've died and gone on, they'll still be here carrying on.

Int: And what if you didn't have children. What would motivate you then?
Olive: Myself. I have my companion. And I have my children. I have a beautiful husband. And if it wasn't him, you're always an example for someone. There's always someone. That's why you're a role model for someone, whether you have children or grandchildren. People are always watching

Int: Does your husband say anything to encourage or discourage you?
Olive: He asks did you take your medicine, but nothing [sic] dis-encouraging.

Olive's final remarks reflected the sentiment of many other participants. Spouses can play a positive role. One male participant talked about the crucial woman's involvement in diabetes management as his family's cook. It was his view that the typical male would eat
the food put before him and therefore educating the wife about the diabetic diet was vitally important. More often, however the effect of the spouse tended toward inconsequential, especially when compared to that of children or grandchildren. Quoting the somewhat taciturn Stan:

Int: Wife supportive or non-supportive?
Stan: I cook for myself and she cooks for herself. That's kind of the way we get along.
Int: Does she do some things to encourage you?
Stan: Well, she'll just say "you're doing a good job."
Int: Was she your walking partner this winter?
Stan: Nah, not very much. She walks too fast for me.

Non-family

The parent-child bond, however, was not the only important relationship, as Sally illustrated through her inclusion of "fictive kin." Informants without children told of involvement in the lives of their nieces and nephews in terms no less powerful than the parents above. Occasionally people described relationships with other adults, rather than children, as especially meaningful. Although not nearly as common, they certainly warranted a brief mention. Stan, above, was one such individual. Stan was 79 and officially retired when the researcher met him. Yet he was extraordinarily busy with all manner of work. Stan delighted to describe his petty jobs, raising plants, collecting and roasting nuts, and selling the product of his labors at farmers’ markets. As Stan detailed meeting all sorts of interesting people and further indicated that he was only breaking even with these efforts, it became evident that the purpose to his labors was, in fact, the opportunity it created to be in a public place talking with people. Christine, 72, had more distant relationships with her grandchildren and fretted about being a burden to her children.
Over the course of the interviews Christine disclosed that after her husband died, she moved from a small rural town to a larger city and had made many new friends. Contrasted with her confined existence in her small, Midwestern hometown, life in this new city, and, in particular, these new friendships, had expanded her world, quite literally, taking her many places she had never been. Interviews had to be scheduled around her frequent travels with other adult female friends.

Int: So you went to the Grotto last weekend... And you have a trip to Michigan coming up?
Christine: August, to see the “tall ships.” I don’t know anything about it, but I go to a single’s group and one of the ladies in the singles group wanted to see it. ...She said (she) was going to go alone and was probably going to sleep in (her) car. I don’t think that’s a wise thing and I have the money and the time and just thought it would be nice to let her have this opportunity to see it. She’s gone through a divorce in the last 3-4-5 years. And she and her husband traveled a lot and she misses the opportunity to travel. And I think it would be nice.

One further dimension to Christine’s friendship should be noted here. In traveling with this recently divorced friend, Christine helped to meet a need. This dynamic paralleled some of the familial relationships described earlier. It also appeared that, although meaningful, these friendships did not imbue Christine with the same degree of purpose that we saw in the other examples. Indeed, as we shall see, “need” or “caregiving” may be an essential relationship ingredient in purposeful relationships and living.

**Open hands: the tension of caring for others and receiving care**

A key property of purpose has been identified as relationships. From this research, the most salient dimension to relationships appeared to be “need” and relationships could be dimensionalized across this continuum. “Need” in this study was defined as contributing uniquely and vitally to the welfare of others. At its lowest level, “need” in relationships was
nonexistent or minimal, as in the case of Christine above. Its more modest presence could be seen in the words of Quinn, who enjoyed his children’s company and, as they are college age, was still contributing to their well-being. Yet because his children were grown and becoming established as adults, his role, although important, was not essential. Others, such as Sally, described relationships where they perceived they exercised a critical role in the welfare of others. Sally’s “drug-infested” world was filled with many dangers for youth. Because of these perceived risks, she had made it her responsibility to protect future generations from wayward living and to see them succeed. Children and motivation were explicitly linked for Sally and many other participants. More broadly, for many, helping others appeared to give purpose to life and emboldened and energized health-related decisions.

But the dimension of “need” in relationship had a second aspect. While participants commonly extolled the benefits of helping others, particularly family members, a few also volunteered a dread of being “in need” of others. Typically this was couched in terms of being “a burden” to the same family members they were presently helping. Evidently, it was purposeful and positive to give help to others, but unacceptable for the care to be reciprocated by the same. Kent, 44, married and with an adolescent, spoke poignantly of his fear of burdening his family in an excerpt included under the category of fear. Slightly less dramatically, Christine made the same point. She maintained her health because she did not wish to live a nursing home. Her apartment’s picture window overlooked a convalescent home, regularly reminding her of this possibility. Living with family was not an option in her mind:
Christine: My kids have got their own life. They don’t need to worry about a mother in a nursing home. And there’s no way I would go live with my kids rather than [a nursing home]. NO. Their lives are their lives.

And in a later interview Christine elaborated:

Christine: They [my kids] don’t need this. Their lives are busy. Why should I make them worry about me when I can do something about it…The kids are busy. My son will be 48 this fall. One’s got two jobs, by her own volition. And her kids will be in high school. Doesn’t have time to worry about me.

Similarly, a primary motivation for 63 year old farmer, Kurt, was to not have to rely on family members.

Int: How come you are making changes?
Kurt: Because of the fear of kidney failure, amputation, and blindness. Poor health. I don’t want to be in poor health. Don’t want to be dependent on someone else. Would just as soon to take care of myself. Being a burden on my kids.

Int: So it is a fear of long term consequences.
Kurt: Not wanting to be burden on someone else.

As people talked about what motivated them to make health decisions, the notion of purpose arose repeatedly. Frequently this would have theological overtones to it, though this was certainly not true for everyone. However, each time the idea of purpose was invoked it was in the context of relationships. The data from this research suggested relationships where a person was needed had particular salience for bolstering a person’s sense of purpose. But while it is meaningful to give help, many people were averse to the prospect of being in a “care-receiving” position.


**Category four: Self-agency**

The final category affecting health decision-making was self-agency, referring to a sense of empowerment over the illness. As reflected in the data, agency appeared to depend upon how a person thought about their situation. It was distinct from the earlier category of knowledge because the salient factor was not necessarily the information the patient had, but beliefs as it affected the perception of their role in relation to the illness. Self-agency was supported by three subcategories: 1) “possibility thinking,” in which participants perceived their future was undetermined and pliable; 2) “mindset,” which was reflected a mental resolve a person had in addressing their illness; and 3) “choice,” the extent to which a person felt capable to make decisions about their situation.

**Possibility thinking**

Participants who had a higher presence of agency tended to be optimistic about the future. They speculated that they could delay the onset of symptoms for a lengthy period. Some confided that they believed this would give medical researchers time to develop a better treatment, if not a cure. One commonality among the participants was an approach to life that I termed “possibility thinking.” This idea was observed in the frequent use of conditional statements that incorporated “if” and “may.” An open prognosis or even uncertainty about the future seemed to extend empowerment to participants. In contrast, forecasts and predictions seemed to foster passivity.

Other interviews also hinted at the importance of understanding the future as not yet determined, the basic idea of “possibility thinking.” Steve and others demonstrated this open, possibility thinking through the use of multiple, conditional “if” statements:
Steve: If I take care of myself, if I exercise and eat right, I can manage it and it’s not going to kill me. It isn’t going to prematurely kill me if I take care of myself.

Quinn also noted that he is in process and that things may change in the future. The indeterminable future, marked by the generous use of linguistic indicators “may” and “maybe,” was further by his lighthearted speculation at what changes the next year may bring to his 300 pound frame:

Quinn: Now, maybe in a year when I’m 170 pounds and who knows, weight lifting, and running, and jogging, and everything else, I may have a completely different attitude and may open up a gym or something. But right now I’m fleeing [poor health]… So maybe in a year from now and I’m a whole lot healthier, I may be completely different and start running towards it [health].

In a somewhat extreme illustration Debbie demonstrated the power of “uncertainty” as she described starkly contrasting interactions with two different healthcare providers. She began in this fairly lengthy exchange by describing what might have been a factually accurate, if disempowering, prognosis given by her first physician:

Debbie: My last check up I had numbness in one foot… So he [the doctor] tested it and he goes, “Well you’ve just got to be careful and not go barefooted and don’t check your water with your feet and stuff.” And then he said it looks like you are going to lose your foot.

Int: Did I hear you say that he said you were going to lose your foot?
Debbie: Yes. And it scared me. I left his office crying.

Following this appointment, Debbie went home, noticed a toe was causing her particular trouble, and then called the same physician’s office, speaking with his nurse:

Debbie: And I said you know I’m a little scared here. I said the toe that’s numb has a little crack and I said they put me on Neosporin” and I said “what can I do? “Oh nothing, you will probably get an infection in it and have problems.” And I said is there anything else that can cure? “Oh, just keep putting neosporin on it” [the nurse said].
Debbie decided to get a second medical opinion and relayed her experience to
this other physician.

Debbie: I told her the whole story. She goes,

"It’s not going to happen. Why did he tell you that?" I said I don’t know
but I was real upset when I left his office. And she said “it’s not going to
happen. You’ve got strength in your feet. You’ve got strong circulation.”
It sounds pretty good. It could be better but it’s not the worst she’s seen
or heard. And she said your feet are in pretty good shape outside of that
one spot. And so she had me walk and she had me do all kinds of things
and I said what’s going to happen now. She said it may stay in just that
one area the rest of your life. It may move to other areas. We don’t know.

Int: How did her message affect you versus [the other doctor’s message]
Debbie: A lot calmer.

Int: What did you want to do with your life or your health, if anything, after
the doctor said "Well you’ve got a little neuropathy here. You’re going to
lose your foot. Check in with the billing clerk on your way out."
Debbie: You know, I didn’t sleep that night and I kept checking my foot. I was
just so upset and everything and so I got to (the new doctor) and she told
me to change my socks twice a day and she gave me exercise and she’s
going to see me every two months so the 26th of this month I have an
appointment with her. …She gave me her own personal phone number if
I had a problem or anything with my foot or infection started, just call her
directly. I don’t have to go through an answering service to her or
nothing. When I left her office I was so relieved. She said the only way it
has to be really bad to lose your foot is your leg would not circulate. It
turns black.

This second physician did not promise a cure, but instead pronounced a therapeutic
uncertainty: it may or may not advance; we don’t know. With the end of the story not yet
written, Debbie responded in a much more empowered manner toward her illness,
eschewing the earlier tears and fatalism.

A key component of agency, or empowerment over illness, was “possibility thinking,”
a conviction held by the patient that the future was not already predicted, but that their
choices could influence the course of the disease. As a subcategory, it constituted a
component part of the category “agency” and was highly interrelated with the subcategory locus of control. Participants who believed the future was undetermined also believed that they held the power to affect how that future took shape. Finally, as Debbie turned from fear to fortitude we saw evidence that “possibility thinking” was a component of agency that could be positively influenced by the healthcare provider.

Mindset

Informants who demonstrated agency also tended to describe their approach to diabetes in terms of cerebration. They used words and phrases like “acceptance,” “how I see it,” and “knowing I can do certain things.” Further underscoring the perceptive or mental aspect of agency, and certainly the subcategory of “mindset,” was the paucity of distress articulated by people with agency. People who indicated higher rates of agency did not talk about the illness with any evidence of anxiety, but were very matter of fact. They described lifestyle changes and potential consequences in much the same way one might have describe being required to do chores. Bernice explained how she faces her illness, contrasting her approach with that of her husband’s:

Bernice: Don’t worry about it and it will go away. That’s the way he was brought up. Now I was brought up the other way...not to worry but to face life as it comes...and accepting what’s dealt to you. And I don’t think he [my husband] really at times accepts what he has.

Int: You have a much greater sense of agency or power where you realize that you are give some things to deal with or what have you, but that you have an important role in how that plays out.

Bernice: Yes. I didn’t really ask to have the diabetes, but I’ve got it and I accept that fact.

“Accepting the fact” of having diabetes was important. Kurt, too, evinced this resolute view of the illness when he described in making changes in his lifestyle as a necessary task.
He also captured the cognitive aspect of this subcategory through his use of the term “mindset,” an idea that would become the in vivo code for this concept.

Kurt: I guess I changed the next day, to be right truthful with you. It just needs to be done. ... Well, if it needs to be done, it needs to be done. That’s all you can do.
Int: Also, you were nodding a second ago. For you the change was mostly a matter of intellect?
Kurt: Mindset.

When informants spoke of “mindset” it had an axiomatic, constitutional quality about it; informants received the situation this way because that was how they (a) view life, (b) were brought up, or (c) were made. Although vacuous as an explanation, it did have some interesting features. These participants who evidenced agency did not identify the role they had in fashioning this perspective. None described any prerequisite summoning of courage or soul searching in which they identified necessary steps to take. Quickly moving to “acceptance” of one’s situation and then “doing what needs to be done” was an intuitive response for high agency individuals and one over which the informants proffered they exercised no control.

Choice

Following “mindset,” the second category that facilitated agency over the disease was “choice.” For participants to develop a sense of empowerment with their health, it helped to not only have gritty, determined resolve, but a course of action to take. The subcategory of “choice” broadly refers to this course of action, the perception that there is a decision to be made. Choice contained two important properties: locus of control and the perception of options.
Locus of control

The first property to emerge from the data was “locus of control.” The term is drawn from other research in the field (Wallston & Wallston, 1978) and reflected the extent to which an individual ascribed decision-making power to themselves or to other factors. Responses to this property fell along a continuum with some participants indicating their ability to make healthy decisions was overwhelmed by a variety of circumstances, typically time or money, or some combination of the two. Others, for gain or naught, believed that they were in utter control of every decision they made. Evan had a lower sense of empowerment over his diabetes, which was especially manifested in a more externalized locus of control. Over the course of nine months Evan voiced a desire to exercise, but complained that his circumstances would not allow it. Weather, finances, and time all conspired to keep him from exercising or eating healthy:

Evan: I think that in the wintertime it’s harder to lose weight because you just can’t get out to do anything. No jogging in 22 degrees snow and stuff. But I think that after we get our income tax back I’m going to buy us a family pass [to the recreation center] to go work out.

Even after the Midwestern winter thawed and the tax refund came Evan did not begin any regular exercise program. The idea that external factors prohibited him from making healthy choices was a general theme throughout his interviews.

Evan: They really need to process a book for a diabetic, like a 7-day planner where each day they would have different foods for you to eat the guidelines. And they didn’t give me that and that’s why I struggle with it, ‘cause I don’t know what I’m supposed to eat. So I go out and I’m hungry and I probably eat the wrong things.
At the opposite extreme, some participants demonstrated a highly internalized locus of control. Steve might be described as a “take charge” guy. At 49 years of age and with several graduate degrees, he was in his second career graduate and was in the early stages of starting a new business when the researcher met him. With few outside forces shaping his destiny, he demonstrated the concept of a highly internalized locus of control throughout his interviews:

Steve: And I guess just knowing that I can do certain things to make my life just as long as anybody else’s. If I take care of myself, if I exercise and eat right, I can manage it and it’s not going to kill me. It isn’t going to prematurely kill me if I take care of myself...It’s my life. I’ve got to live it out. And I overcame what was a very debilitating disease when I was thirteen years old I was in a car accident and I developed epilepsy from that. And when I was in my 40’s I finally found a cure, that is the surgery and I whipped it. And I wasn’t going to let diabetes get me down to the extent that I can’t whip it, too. I would say because I’m alive and vital I feel a power over these things. And I’m not going to let them put me in a box where - even a large wooden box - by my inaction. I’m going to do what I can like I did with my epilepsy to make sure that I’ve done everything I could. And diabetes, I know that there is lots to do. ...You have to take responsibility for it. And I have taken responsibility for it, to do what I can to fend off the time at which - if there ever arises the time - which I will be required to take insulin. Frankly, between you and I, I was watching a program on television the other day, I think they’ll have a cure for this thing in the next ten years.

Other participants with a strong presence of agency agreed with Steve. Although appreciating that external factors made goals more or less achievable and certain behaviors more or less likely, informants with high agency unequivocally agreed with Steve that each person controlled their fate. Regardless of circumstance, the way one spent their time and what they ingested were decisions over which the individual over which the individual
exercised ultimate control. Sam and Christine represented the views of many with an internal locus of control:

Sam: I think that a person determines the state of their health more than anything else. [sic] Obesity or anything else. And with this you optimally have a lot of control. It is something you really can work with.

Christine corroborated Sam’s view in remarks in two different interviews:

Christine: I just think it’s silly if you've got a problem and you don't do anything about it, it's nobody's fault but your own.

Christine: Well, why be an invalid or make yourself be an invalid if you can help it. ... If I can take care of it while it's still minor, why wait till it get major to start working on it.

Christine: When I see people on the street with these humongous bellies hanging over [their belt], some people say awww... They've done it to themselves. ... They don't they have any pride in themselves, when they get that second belly hanging over

Although typically ascribing an internal locus of control to oneself resulted in a person taking steps to improve their health, this was not always the case, as Christine later illustrated:

Int: How come you don't add regular exercise to your schedule?
Christine: [sic] ‘Cause I'm lazy. And I don't go to exercise classes. I used to work at the senior center and those ladies would come down there and boy, they didn't like it if a person didn't go right through the regular, they had it down pat... That's the way I felt, watching them. So, no, I don't go do exercises

With her admission of laziness Christine owns the decision not to exercise, though she later buffers this decision, and maybe her self-image, by mentioning other external factors.

Internal locus of control by itself may be a necessary condition for agency, if not a sufficient one.
One final note about locus of control: Participants with lower levels of agency and more externalized loci of control regularly mentioned "time" as the choice thief. Indeed, among employed participants, "time" was so reified and arose so often that early formulations of the theory included "time" as its own category. Mary describes how "time" keeps her from exercising:

Mary: I think realistically I can't do it because of time and scheduling.

Only after taking this theory back to the informants did they clarify that "time" truly did not limit their options. Rather, they believed "time" was a reflection of personal priorities, that it fit better under the subcategory of choice, and reflected the property of locus of control. Excerpts below showed that even though participants ultimately redefined "time" as an issue of priorities or choice, reifying their decision this way was so common for them that they regularly vacillated in their depiction:

Kelly: I know that I am young enough that if I don't keep it under control I'm going to have those problems. But the busy factor is the counter [balance] to that. I'm so busy that I don't have time to count carbs and I don't have time to find a regular exercise time...my busyness....

Int: [Establishing empathic rapport] And you are very obligated to many other people, your daughter coming in to steal you away for some homework or something [interview was interrupted earlier by daughter]

Kelly: Yes. And I'm sure it is a matter of priorities. I guess if I really put myself and my health first, then those would be the things that I did first. But I guess I have a hard time doing that with my family, my job, all the other demands, I tend to put the things that I need to do for me well if I have time I'll do that. And then oftentimes, every time I get to the place where I've got a few minutes, I'm tired. I'm exhausted. I don't have the energy to do what I should be doing....I mean there's probably these nights when I sit down and watch television for an hour when I should be riding a bicycle or walking or some sort of exercise. The time is there, but by the time I get to that hour of time I'm tired. I don't have the energy
Sam was like most others who spoke about busyness or time as a real impediment.

In nearly the same breath he also explained it as a matter of making one’s needs secondary to the demands of others. This opened the door for the researcher to receive clarification from Sam that it was, in fact, an issue of priorities or choice, and not a true obstacle:

Sam: I think you can get to a certain level [of busyness or preoccupation with work] and don’t care of anything and let things just sort of fall where they will. I think that can be a factor. You get so much going on in life that you put yourself second or third, as opposed to taking care of your own personal needs first....I think priorities is a better way of expressing it. You put your health above other situations. You take care of your own health needs first.

Time frequently arose as an obstacle to effective diabetes management.

Indeed, it occurred often enough to constitute a robust category as the theory was initially developed. However, further analysis and subsequent feedback from participants illuminated insufficient time as an issue of locus of control, rather than an actual property.

**Perception of options**

A second important property of choice was the perception of options. Whereas locus of control described an attribution of decision-making power, perception of options was a mental assessment of what choices could be made. It was a dimension with existential overtones in which a person construed that they had too many choices or perhaps no choice, with people between these two extremes. Mary appeared to be awash in choices.

Mary: But I haven’t given up everything, and really and truly they didn’t tell me that I had to. They told me that it was choices that I had to make. I could choose to have certain things for dinner. I might have to give up some other stuff. They spent a lot of time, the dietician, talking with us about choices. Some things I should never eat like fried foods. Some things you shouldn’t eat, but you’re not going to drop over dead if you eat a slice of cheese. So I think they were trying to say eat sensible, try to make choices… I guess the way the team at the hospital has approached
everything, they have tried not to be so... tried not to come down so hard, they've tried. Their big word is choice. And they have tried to do this because when you get into a thing like this you feel like your life is out of control. And if you don't have the ability to make choices, then you do feel resentful ...I think it's better that we have choices. It puts the responsibility on us when we have choices.

The hospital where Mary received her diabetes education emphasized that patients have choices. Mary described herself as naturally “stubborn” and “rebellious” and, consequently, warmly received this message that she had many choices to make. She believed that she would have resisted anyone rigidly prescribing change. Nine other participants, in contrast, indicated to varying extents that they believed they had no choice, but that they were compelled to make healthy choices. In concert with a more internalized locus of control, respondents powerfully described feeling compelled to change their lifestyle, and doing so:

Bernice: There was only one option for me. I mean, what had to be done.
Int: There wasn't this internal discussion of “do I or don't I?”
Bernice: It's “no, this is what has to be done.” ...There are certain things like law breaking and things like that when you have no choice. You have to do what seems right.

Steve forcefully asserted the same point:

Steve: And to answer your question, was I compelled? Yes, I was compelled. I didn't think I had a choice. I still don't. This is something I have and so I'll get over it. Just do what they say and you'll feel better.

The property “perception of choice” shared some common characteristics with the subcategory “mindset.” In both cases, whether they had many choices or no choices seemed self-evident to participants, parts of an invisible, presuppositional lens. Also similar to “mindset,” people who believed the only decision was lifestyle revision indicated
less emotional distress over their initial diagnosis and less torment over each day's choices. In contrast, people who perceived many choices tended to wrestle over their options, a deliberation which appeared to contribute to their anguish:

Evan: I'm sick of salads. And everybody wants a snack every now and then, as in something sweet. You go through urges where "God I would just like a Snickers bar, just to eat the whole thing." ... I walk up behind somebody [at the convenience store] an they'll sit there with their big drink and their sub sandwich and an order of onions rings and whatever else they've got and I just go (emphasis added) ARRRRRGH!! YUM! Wouldn't that be nice!

Although over the course of the interviews Evan did make changes to his diet, he also could imagine other possibilities. The previous excerpt suggested that entertaining the notion of eating fried foods or sweets made diabetes management more difficult for him compared with others who were able to rule out certain foods. Similarly, although Mary made some changes to her diet, her emphasis on choice, which she felt was necessary to accommodate her self-described rebellious nature, appeared to increase her angst.

Mary: But at least the clinic gives me a choice and I don't feel bad. Like today was teacher appreciation day and the PTA brought in little ice cream sundaes for everyone. Well, I went ahead and ate one because if I sat there like a martyr I would have been really miserable. And I really wanted it.

Mary invoked the powerful image of a martyr who suffered silently because sundaes were possibly not "off limits" to her. In a later interview she hinted at how she would entertain the prospect of eating a food that she should probably avoid. Rather than wrestle with this prospect all day long, she would go ahead it eat, albeit only one, a measure for success for her:
Mary: I’m pretty good. But if I really, really want a doughnut and they have them at school, I’ll eat one rather than think about it all day… I’ve decided that it’s better to go ahead and get it, just eat one and be done with it, rather than obsessing about it so I (sic) wanna eat five of something.

Participants varied in the extent to which they believed they had options in managing their health. It was not at all evident that the perception of choice led to more effective management. Although nine participants felt driven to make certain changes, five actually executed radical changes to their lifestyles, summarily eliminating certain foods. These individuals who made sweeping and even austere changes seemed more accepting of and less vexed over the new limitations. Others construed that they had many options, deliberated each decision, and anguished over what they denied themselves. At least in this sense, having a reduced perception of options appeared to be associated with more successful diabetes management.

Perception of options comprised one of two properties of choice, the other being locus of control. The conviction that one had no choice but to act, when linked with an internal locus of control, a calm determination to address the illness, and the belief that the outcome was not yet decided, imbued participants with a sense of power over their circumstances, the essence of “agency.” Agency, in concert with mobilizing knowledge about diabetes, and an overarching reason for living or purpose formed a triad of crucial ingredients that influenced health decision-making among participants in this study.

Decision-making about health is a complex process influenced by many factors including personality, beliefs and cognitive processes, and external factors. This research revealed certain patterns that were organized into four categories. Initially, all informants
experienced some measure of upset or disequilibrium, which appeared to vary depending on extent to which participants had prior knowledge about diabetes and the degree to which other concerns already commanded their attention. Following diagnosis and disequilibrium, participants became more actively engaged in an HDM process. Three factors prominently affected HDM: cognition, agency, and purpose. Regarding cognition, people responded to their health based on the information they had about the illness, emotional reactions, especially fear, and a more visceral knowledge derived from knowing someone with uncontrolled diabetes. Agency was second category that influenced HDM. Participants varied in how much control they perceived they had over their health. Factors that contributed to this variance were the ability to conceive of the future as not yet determined, a mental resolve or determination to address their illness, and the extent to which a person felt they had an array of options. Finally, informants usually spoke about having a "reason" for managing their health; these reasons were captured in the idea of purpose. The central category, four primary categories, and two subcategories are displayed graphically in Figure 2 on the following page.
Figure 2. The grounded theory of HDM. Categories Cognition, Agency, and Purpose each influence HDM as well as one another.
CHAPTER 5. DISCUSSION

How do the different concepts, disequilibrium, agency, purpose, and cognition, work together to affect health decision-making? This chapter attempts to answer that question by elaborating on the results developed earlier (Chapter 4, above). Specifically, relationships among the various categories will be explicated. After particular links among the categories are demonstrated, the researcher will present these categories and relationships as an empirically grounded theory of health decision-making. This new grounded theory will be situated within the larger body of patient behavior theory and research. Finally, the limitations of the grounded theory methodology used in this research and ideas for future study will be addressed.

The Grounded Theory Explication of Relationships Among the Variables

The theoretical overview and backdrop

Drawing from Strauss and Corbin's astronomic imagery it can be helpful to imagine the theory as existing in space and being affected by principles of gravitational attraction. The data from this research suggested a central category, health decision-making, with three other primary categories, agency, cognition, and purpose, revolving around it. Because of their close proximity and theoretical heft, these conceptual bodies also exerted influence on one another. Much farther away, disequilibrium constituted a fourth category with two subcategories, prior diabetes knowledge and concurrent challenges, mediating the amount of imbalance experienced by participants. Although a common occurrence and significant as a descriptive category, it lacked explanatory power for subsequent decision-making and thus is conceptualized as having a peripheral, outer orbit. Consequently, most attention will
be given to agency, cognition, and purpose. This following section examines how these categories interact with one another, but begins by addressing a basic premise common to the researcher, culture, and question.

Space is not a vacuum, but consists of widely distanced particles. As the concepts came into focus it became evident that the researcher, too, was not viewing them in a vacuum, but had ensconced the categories within some broader presuppositions about the patient, which, like space, had initially been invisible to the researcher. This backdrop is best summarized by the biopsychosocial model. George Engel formally proposed this more encompassing view of the patient by throwing down the gauntlet to “biomedical dogmatism” in the 1977 issue of the journal Science (Engel, 1977, p. 135). In contrast to what he depicted as a reductionistic, physical and biochemical approach, he proposed that a person operated at three levels or systems: biological, psychological and psychosocial. Explicitly referencing the ideas of theorist Von Bertalanffy, he described these systems as distinct entities that mutually influenced one another, such that change in one results necessarily in change in the others. From his view, and I would agree, this integration offers a more holistic view of the patient. Because of the social-psychological orientation of the researcher, the current zeitgeist for “holism”, and the nature of the research question, my emergent theory is inescapably embedded in this more ecological view of patients as psychological and social creatures.

**Disequilibrium**

The first category addressed in this study was disequilibrium, referring to the upset experienced at several different levels of abstraction experienced by participants following diagnosis with Type 2 diabetes. Participants’ reactions varied dramatically from intense
shock, fear, and anger, to acceptance and incomprehension. Psychological and, to a lesser extent, relational upset was a sequelae to the diagnosis regardless of whether one had been symptomatic or asymptomatic.

More important seemed to be the extent to which two other subcategories were present: concurrent challenges and prior diabetes knowledge. According to the data, people who had many other concerns on their minds, ranging from more acute health issues to urgent concern for a loved one, experienced less upset by the diagnosis. The more pressing the other problems, the more secondary and less distressing the diagnosis of diabetes was for participants. This could be understood in at least two different ways. First, from a biopsychosocial view the person-system was already in a state of disequilibrium and therefore the pronouncement of diabetes did not appreciably add to their upset. Addressing more narrowly the psychological aspect, consciousness and attention are sometimes depicted metaphorically as a spotlight which can only be directed to one item at a time. Accordingly, participants could either be preoccupied with diabetes or the other stressor, but not both. A second factor that had a relationship with the degree of upset experienced by participants was the amount of diabetes knowledge already possessed by the participant at the time of their diagnosis. Those who had little to no prior information about diabetes did not have a context in which to understand their illness and were generally unfazed by the diagnosis. Other participants had a detailed knowledge about diabetes, either from intimate personal experiences or professional work in healthcare. Their response to being diagnosed was muted. The group that demonstrated the most upset was a middle set who had enough information to be worried about the implications, but not yet cognizant of the treatment options.
As stated earlier, the researcher could identify no explanatory power in the relationship between this category and the others and therefore the role of disequilibrium is minimized in this theory. Figure 3, below, illustrates the relationships between disequilibrium and the two mediating categories of prior diabetes knowledge and concurrent challenges.

**Figure 3.** Disequilibrium is affected by the intervening subcategories of prior diabetes knowledge and concurrent challenges.
Knowledge, self-agency, and purpose

Health decision-making was affected by innumerable factors, described some as an "unmanageable level of complexity" (Regis, 1995, p.3). Although this is certainly at one level true, this particular data, when analyzed by the researcher, were found to coalesce around three primary categories: cognition, purpose, and agency. These categories influenced how people made health decisions. Each was important. No one seemed to be singularly powerful influence on the process, but like a troika they tugged at health decision-making in a synergistic fashion.

Knowledge

Knowledge described what the participants knew about diabetes and had four different properties: feedback, factual knowledge, experiential knowledge, and affective or emotional knowledge. These distinctions represented differences in how the participant came to acquire the knowledge and variations in physiological arousal. One property of cognition was feedback. Feedback referred to a special type of knowledge about the effects of diet and exercise on their health. Participants received feedback from a variety of sources which could be divided into two categories. First, they talked about the importance of meaningful physiological feedback. Blood glucose levels often guided particular eating choices early in the diagnosis, literally influencing specific decisions to eat a snack or refrain. The hemoglobin A1C served a slightly different role, taken more as evidence as how effective their overall management was progressing. Participants described weighing less on the scale as encouragement, but did not describe an increase in weight as discouraging. Rather, they were frequently befuddled about how they could have made the changes they claimed only to have it not affect the scale. A smaller number of participants
spoke about a different category of feedback, social feedback from friends or spouses noticing weight loss or improved health. Participants who were inclined, who had a higher sense of agency and purpose, would take this information and use it to guide their eating choices. Having high amounts of factual knowledge enabled a person to understand their role in managing diabetes, but did not necessarily lead a person to take action. On the other hand, lower amounts of knowledge appeared to serve as a slight impediment to the newly diagnosed who were motivated, but did not know what steps to take. Because of the numbers of informants who had extensive knowledge about diabetes, yet regularly admitted to lapses in their diabetes management (healthcare professionals Betty and Kelly), it is difficult to conclude that factual knowledge directly influences decision-making. It was as though knowledge created options, but did not compel participants to take one path or another. There was, however, evidence that factual knowledge was associated with a reduction in fear. Many participants described high states of anxiety in the early stages of diagnosis, that diminished as they learned more about their illness and, in particular, the steps they could take to manage it. In contrast to the anxiety reducing effects of factual knowledge, experiential knowledge tended to increase informant’s arousal or affective knowledge. Participants vividly recalled others’ experiences with diabetes-related blindness or amputations, which would usually lead to fear, an indicator of emotional cognition. Thus an increase in experiential knowledge contributed to an increase in affective knowledge. Among the properties of knowledge, affective knowledge may be the most important, bearing the most influence upon health decision-making. Although some theorists view fear and anxiety as negatively impacting decision-making (Bandura, 1977), this research revealed it to be a powerful motivator in consequence avoidance. Indeed, informants
explicitly described not being motivated to be healthy, but over and again
mentioned fear of blindness, amputation, and dependence as motivational. The greater the
amount of fear, the more motivated the participant appeared to be to take steps to change
the course of the disease. This link was very clear in the minds of many participants. Many
indicated they made major changes in their diet when they were fearful of the consequences
of not doing so. Later through the course of the interviews some of the same participants
who experienced early success in changing their diet indicated their efforts had become
more half-hearted and tolerant of deviation as their fear diminished. Subsequent A1C
readings rose, invoked fear, and led to a return to stricter management. Affective
knowledge, and in particular fear, appeared to be one factor that contributed to successful
diabetes management.

**Self-agency**

Fear alone was not sufficient to lead to change in health decision-making; participants
also required agency, a sense of empowerment over their health that stemmed from a belief
that they could influence the outcome of the illness. The amount of agency a participant felt
varied according to the presence of three properties: 1) “possibility thinking,” 2) “mindset,”
and 3) “choice.” As participants experienced greater indeterminacy regarding disease
prognosis, reflecting “possibility thinking,” and more resoluteness in their resolve to defeat
it (mindset), their sense of empowerment over the disease increased. On the other hand, the
notion that participants had many choices tended to diminish agency and consigned some
participants to fretting over their options. But agency alone was insufficient to induce
change; participants needed to have a reason or purpose for their efforts.
Purpose

Not only was it necessary for participants to have their emotions stoked and to be emboldened with a sense of empowerment, participants indicated they needed to have a reason for modifying their lifestyles. In a typical conversation, I would ask informants what was motivating the decisions they were making. Often the response was something which paralleled “I want to stay alive.” I knew from my counseling work that not everyone wants to remain alive. Therefore, it seemed natural to me to challenge what for most may have seemed obvious, and to press participants further on their reasons for wanting to stay alive. This deeper probing revealed the importance of purpose in undergirding health decision-making, a factor largely overlooked in health research.

Purpose emerged from two places. First, many participants viewed the world through theological lenses which imparted meaningfulness to their lives. This perspective justified hardship and consequently minimized perceived “unfairness” and the immobilizing anger that sometimes would accompany it. This perspective also offered them hope and courage through the understanding that God was in control of their circumstances, with them in the difficulty, and not presenting them with anything they could not handle. The qualities of this perspective remained equally true whether the faith was from a more structured church tradition or an open form of spirituality. What was relevant was the extent to which the participant embraced this worldview. Some participants indicated in their interviews that faith was irrelevant in their diabetes management. Others, when prompted, mentioned church involvement, but hesitated or were uncertain when describing how this actually influenced their life. They had fewer indicators for purpose haling from a
spiritual dimension, a dramatic contrast to certain informants who effused over the subject. Second, a sense of purpose emerged out of relationships with others, with dependence or being “needed” as the theoretically relevant dimension for this property. The more financially or emotionally needed the participant was by another, particularly a family member, the more intensely informants spoke about their need to manage their health. There was some evidence that as the dimension of need in the relationship decreased, that is as the relationship became more mutual, that the perception of purpose also diminished.

**The theory summarized**

In summary, the data revealed that the diagnosis of Type 2 diabetes provoked a state of disequilibrium in participants that ranged from highly upset to minimally upset, depending on the extent to which they had other worries and the amount of knowledge they already had about diabetes. As the number of other acute concerns increased, the amount of disequilibrium from the diabetes diagnosis decreased. In the case of prior diabetes knowledge, a little knowledge was indeed a dangerous thing and was related to higher amounts of upset. Lots of knowledge, such as a healthcare professional would have, or virtually no knowledge was associated with less disequilibrium. Following this initial reaction, informants were inexorably drawn into a health decision-making process that was influenced by the troika of agency, cognition, and purpose. These three forces wielded influence on health decision-making and on each other. Singly, their influence on HDM was negligible, but when they occurred together they appeared to explain HDM for participants in this study.
Chapter 2 reviewed what was known about patient adherence and decision-making and contained an overview of the dominant theories from health psychology that offered insight into health decision-making. The three theories reviewed were the Stages of Change Model (SCM), the Theory of Reasoned Action (TRA), and the Health Belief Model (HBM). Drawing from these three theories, six broad propositions about patient decision-making were predicted. These predictions are revisited in view of the findings of this research.

**Proposition 1: Change Occurs Naturally in Biological Systems**

It was first proposed that change occurs naturally in biological systems. This proposition comes from the Stages of Change Model (SCM, sometimes referred to as the Transtheoretical Model because of its integrative nature and atheoretical origin. Drs. DiClemente and Prochaska (1982) compared smokers who quit as a result of formal cessation programs with others who quit on their own. It came to be their view that change was a part of the natural order. The findings from this study and the corresponding theory supported this view. The research found that after participants were diagnosed with Type 2 diabetes they faced many decisions about their diet and exercise and were inexorably drawn into engagement about their health. Although further reflection about the generalizability of this finding will be addressed when the limitations of qualitative research are discussed, changes in eating and to a lesser extent exercise patterns proved to be common for the informants in this study. The new grounded theory, also, is supportive of this “natural change” claim. The new theory proposed is under girded by Engel’s biopsychosocial model (1977), which, in turn, applied Von Bertalanffy’s General Systems Theory (GST) principles
to the patient. The biopsychosocial approach understood health as a matter of homeostasis or balance among three different systems: the biological, psychological, and environmental. These systems are viewed to interact dynamically with each other in order to maintain balance and health. Change is indeed a natural part of this adaptation.

**Proposition 2: Change Is Incremental**

A second proposal from the SCM was that change occurred incrementally. The findings from this research neither validated nor refuted this assertion. As participants in this research described making changes to their diet, to their exercise routines, and to their thinking about their health, their depictions varied significantly. Some transformed their diets, completely eliminating sweet-tasting foods like cookies, ice cream, and candies. Sam illustrated the more transformation approach that might be popularly described as quitting “cold turkey:”

**Int:** How would you describe the nature of the changes you have made?  
**Sudden, gradual, in stages?**  
**Sam:** Dietary, but we just did those right then and there. There was no gradual or working into the situation. And I’ve had no candy since that incident or whatever. I knew this was causing problems, so why continue with it.

On the other hand, consistent with the proposition that change is incremental, some informants modified their lifestyles just enough to bring their blood sugar levels into line with their physician’s recommendation. Even as Sam provided evidence of change occurring in an instant, he also illustrated the more incremental, “just enough” approach to HDM. Sam exercised at a local fitness club one day a week which, along with dietary changes, managed to keep his blood sugar levels within a range that satisfied his healthcare providers. When I inquired as to why he did not go more often, Sam indicated he was
reserving bolstering his exercise routine for some future date when diabetes
management might require more effort. That a person could seemingly easily do more to
manage their diabetes, but did not, was an interesting finding and supported the idea that
change had an incremental aspect to it. Similarly, Quinn spoke of “fine tuning” his
behaviors to meet his understood blood glucose goal of 150mg/dl with 2000mg of
Glucophage. As a 53 year old man with adult children who lived away from home, Quinn
appeared to have the vigor, disposable time, and other resources to manage the diabetes
more through lifestyle changes such as exercise. Yet he seemed satisfied with just meeting
the goals set by him and his physician. In summary, this research neither supported nor
refuted this proposition, instead finding that not only did the process of change differed
from person to person, but that even the same individual might dramatically change some
aspects of their life, while more incrementally “fine tuning” other parts.

Prochaska and DiClemente’s SCM also proposed that change occurred in a six stage
process: (a) precontemplation, (b) contemplation, (c) preparation, (d) action, (e) and
maintenance. It was their view that change was not linear, but moved forwards and
backwards among the stages. Data from this research corroborated this aspect of the SCM.
Over the span of six months in which I conducted interviews many informants described a
common process of (a) making significant changes to their diet, (b) witnessing dramatic
improvements to their A1C readings, (c) feeling less anxious or vulnerable to diabetes, (d)
becoming less restrictive in their health management, which Betty described as “goofin’ off;
” (e) this was typically followed by a return to the regimen. This pattern would appear
consistent with the dynamic and nonlinear view of change argued for in the SCM.
Proposition 3: Change Is Rooted in a Rational Process

Ajzen and Fishbein, drawing from a larger body of research on the role of attitude in predicting a target behavior, formulated their explanation of health behaviors, the TRA, in 1967. Their theory proposed that beliefs about the consequences of the target behavior and beliefs about societal norms affected attitudes. Attitudes, in turn, affect intentions, and intentions led to the target behavior. Figure 4 below graphically represents these relationships.

Figure 4. The Theory of Reasoned Action: Beliefs lead to attitudes, which contribute to intentions and, ultimately, the behavior (Ajen & Fishbein, 1980)

There were several other relevant corollaries to Fishbein and Ajzen's model. First, it was their view that this was a linear and unidirectional process: beliefs led to actions, but actions did not lead to a change in beliefs. Second, they believed that as the immediate antecedent, it was intention that was the best predictor of behavior. Finally, they
emphasized that people were not controlled by unconscious pushes or overwhelming desires but instead were rational and systematically used information to guide their decisions (Ajzen & Fishbein, 1980).

The theory that emerged from the interviews is supportive of some elements of the TRA, but suggested that its emphasis on rational processes to the exclusion of other factors was an oversimplification and did not reflect the complexity of the HDM process from the patient's perspective. Despite these limitations of the TRA, there were nevertheless several points of resonance between the Ajzen and Fishbein's theory and the new grounded theory. First, the TRA emphasis on the systematic use of available information in informing HDM was reflected in the important role of knowledge in the grounded theory. Factual knowledge was a component of cognition, which was one of the three primary categories affecting HDM. Ajzen and Fishbein not only addressed the role of information, but also the importance of beliefs. In their model, beliefs referred to outcome expectancy, how an individual believed a certain action would affect their health. This research's theory also addressed outcome expectancy, though under category of agency. Specifically, my analysis of the data located this TRA construct as an indicator of "possibility thinking," a property of agency.

**Proposition 4: Change Can Be Facilitated by Education**

Because actions are governed by rational thought, the TRA proposed that change can be facilitated by education. Unquestionably, this was born out in the findings of this project. The category of cognition was one of three primary categories affecting HDM. Several informants, notably Sally, Sam, Steve, Kurt, and Ted, were very quick to acknowledge the role that education played in changing their behavior. However, the research also
suggested that factual knowledge was just one component of cognition; and even more broadly, cognitions were only one part of the triad affecting HDM. So while the findings corroborated the proposals from the TRA, it is my view that the new grounded theory which has emerged represents an improvement to the limitations of the TRA.

**Proposition 5: Change Will be Facilitated by People Viewing Themselves as Vulnerable**

Although this vulnerability was not identified a priori as a construct for study, the findings quite clearly supported the important role of perceived susceptibility. According to participants in this study, vulnerability was linked to fear:

Int: What was your response to being diagnosed
Mary: I was afraid of living alone. You know, you don’t want to feel vulnerable.

As several examples from Chapter 5 illustrated, fear was a powerful motivator for many, though not all, participants. In the process of analyzing the data and creating broad categories from similar bits of information, fear was conceived as a type of affective knowledge and one which was effective at mobilizing patient action. Consequently, in the newly proposed grounded theory, cognition, and fear in particular, played prominent roles, concurring with the HBM view of vulnerability as a critical factor in changing health behavior.

**Proposition 6: There Are Triggers for Change that Can Be Either Internal or in the Social Environment**

The HBM proposed that HDM was influenced by cues to action. These cues to action may include environmental cues such as messages in the media or they may include bodily cues such as a symptom. Evidence in the data pointed to environmental cues and
physiological cues as differentially affecting motivation. First, participants rarely
mentioned external cues as influential. Only two of twenty-one participants spontaneously
offered that media played a role in their choices. Quinn mentioned being encouraged to
manage his diabetes because of a glucometer commercial that starred Wilfred Brumley.
Because this theory was to be grounded in the patient’s voices and because media was
mentioned infrequently, I decided it did not warrant further investigation or development.

When prompted to speak about temptations or situations that caused them problems,
some participants mentioned certain scenarios that served as external cues, which affected
their eating choices, notably boredom and special social events such as birthday parties.
Yet again, these did not spontaneously appear with enough frequency in the data to justify
being developed into a category.

The findings and theory did corroborate the action cue component of the HBM,
however, when it came to internal or physiological feedback. This information took the
form of test results, including weight, glucometer and A1C readings, or symptoms, such as
tingling of the toes. Informants who also demonstrated a belief in their ability to manage
their health, agency, and a reason for doing so, purpose, tended to integrate feedback into
their decision-making.

**Proposition 7: Change in Health Behaviors Occur when Benefits Outweigh the
Perceived Costs (Money, Time, Effort) to Engage in the Activity**

This proposal suggests that people weigh the benefits and costs to potential actions
and then act accordingly. As a more generic decisional model, it has a long history in
research and its occasional reemergence at different times and in different fields is a
testament to its explanatory power and utility. It nearly occupied a central role in
this theory, as well.

Earlier in data analysis, after identifying multiple rudimentary categories, I
examined whether the constructs appeared to facilitate or inhibit effective HDM and
sketched out models where these positive and negative factors were balanced across a
fulcrum. Ultimately, this model was discarded because it appeared to presume that patients,
consciously or outside of their awareness, engaged in a deliberative, weighing process
which, although very appealing to a detached observer seeking explanatory mechanisms,
did not reflect the participants' experiences. A model of patient decision-making that
described a process buffeted by variations in knowledge, agency, and purpose, though
somewhat less parsimonious, seemed to more precisely depict the informants' complicated
experiences.

This is not to say, however, that the new grounded theory is contradictory of this
HBM tenet. Examined a different way, the same data could be formatted to an exchange
theory schema. A person with a low sense of purpose would have fewer perceived benefits
to the perceived costs of changing their diet. A person with greater agency would have
fewer perceived costs associated with change. Fear would be viewed as influencing change
because its reduction would be an important benefit perhaps worth significant effort. In
summary, the data from this study is supportive of this final proposition, though the new
model departs from this decisional model and is believed to represent a more patient-
centered view of the data.
Situating this research among other social science theories

This previous section integrated the new grounded theory of patient decision-making against what I had deemed twenty months earlier to be the dominant theories of patient behavior. Since that time it has become more evident that there are multiple models of decision-making, arising from many social science specialties. This newly emerged grounded theory was found to integrate well with three additional models or theories: (a) Albert Bandura’s construct of self-efficacy, (b) social constructionism and the perception of options, and (c) a postmodern systems view of a patient as a systemic organism requiring meaningful feedback to maintain health or balance. The following sections situate the new theory in relation to these other theories.

Self-Agency and Self-Efficacy

One of the most significant points of resonance with other theory occurred between the constructs of self-agency and self-efficacy as developed by Bandura in Social Cognitive Theory (SCT) (Bandura, 1977). SCT proposed that behavior emerges from the dynamic and reciprocal interaction of three elements: environment, personal factors, and behavior. Cognitions or beliefs figured prominently as one of Bandura’s personal factors, and one element of cognition that has received particular attention from public health researchers has been his concept of self-efficacy. Broadly speaking, self-efficacy referred to a perception of empowerment over a situation. It consisted of a personal sense of control and an optimistic, yet realistic, belief that one could change their situation by taking an adaptive action. What causes self-efficacy? Straddling the behaviorist and cognitivist schools of psychology, Bandura argued that the “can-do” cognition of self-efficacy emerged through an inductive process as a person interacted with their environment, successfully mastered
challenges, and then fashioned a theory or generalization about their capability to succeed over difficulties (Bandura, 1977). Further, he has classified these sources into four different categories and identifies the experiences that lead to these empowered beliefs (Table 1.). However, because people process information differently, perceptions of self-efficacy vary even as people appraise the same experiences (Bandura, 1977).

**Table 1.** The sources of self-efficacy expectations.

<table>
<thead>
<tr>
<th>SOURCE</th>
<th>MODE OF INDUCTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERFORMANCE ACCOMPLISHMENTS</td>
<td>Participant Modeling</td>
</tr>
<tr>
<td></td>
<td>Performance Desensitization</td>
</tr>
<tr>
<td></td>
<td>Performance Exposure</td>
</tr>
<tr>
<td></td>
<td>Self-instructed Performance</td>
</tr>
<tr>
<td>VICARIOUS EXPERIENCE</td>
<td>Live Modeling</td>
</tr>
<tr>
<td></td>
<td>Symbolic Modeling</td>
</tr>
<tr>
<td>VERBAL PERSUASION</td>
<td>Suggestion</td>
</tr>
<tr>
<td></td>
<td>Exhortation</td>
</tr>
<tr>
<td></td>
<td>Self-Instruction</td>
</tr>
<tr>
<td></td>
<td>Interpretive Treatments</td>
</tr>
</tbody>
</table>
The data I collected in many ways corroborated Bandura’s theory. Addressing Performance Accomplishments, many informants mentioned that early success with weight loss was highly motivating in the early stages of managing the disease. However, it was also found that easy early success sometimes lulled participants into complacency, which later led to an increase in blood sugar levels. The role of Vicarious Experience appeared negligible. Bandura proposed that people watching others successfully mastering a challenge inferred that they too could overcome, increasing their self-efficacy. However, in this study very only a small minority of participants mentioned good role models as enhancing their self-efficacy or affecting their health decision-making. More often by far, they mentioned lessons learned from watching others who failed to stay on top of their illness. I found significant overlap with his domain of verbal persuasion, perhaps because of my orientation toward narratives. Contrariwise, my categories and properties do not have the behavioral component (desensitization, modeling) that emerged from Bandura’s behavioral training. Addressing emotions in general terms, Bandura (1977) argued that social learning theory emphasized the “informative function of physiological arousal” (p. 199) and generally portrays fear and anxiety as diminishing a person’s self-efficacy. He also acknowledged, however, that from different perspectives emotions function to energize a person toward avoiding some consequence. It was this latter view, that fear was highly...
motivating, that was borne out time and again in my research. Finally, consistent with Bandura’s exhortation, some informants voiced gratefulness for the positive coaching offered by diabetes educators, while others lauded spouses. Under the theory I propose, this would probably constitute a type of social feedback, a form of knowledge that influences HDM.

**Agency, Reality and Social Constructionism**

Very early during the sequence of interviews the researcher noticed a phenomenon that seemed peculiar. Participants’ talk about health decisions seemed to fall into two different categories. Certain informants, notably Evan and Mary, spoke at length about the many temptations they faced and how they were challenged at every moment with choices. Others, particularly Kurt, Sam, and Denise, spoke with tranquility about being compelled to make changes. That is, once the doctor pronounced the diagnosis, told them of its consequences, and prescribed changes in their behavior, they accepted these limitations. When prodded, participants would explain that they had no choice; considering the consequences, adherence was the only option. The former position met with more anguish and perhaps poorer compliance. Theirs was much like the counseling problems described by Efran and Fauber (1995):

A linguistic *maybe* afloat in a sea of *yeses* and *nos*. The average client does not worry whether he or she will be asked to run for the presidency, to fly to work without an airplane, or to eat soup with a fork. For most people, those issues are settled and therefore out of mind. What keeps people up nights and sometimes propels them to the therapist’s door are their personal mights and might nots (p. 280).
Examining the idea of choice from this lens suggested that accepting limitations may produce far less consternation and, by extension, better health management than the present focus on options as a means of empowerment patients.

**Feedback**

Finally, the findings of this research underscored the importance of feedback, which directed near term choices and activated general rebalancing of behavior away from poor health. Participants described immediate eating decisions as being informed by glucometer readings, especially if they had been recently diagnosed. Alternatively, A1C readings or chastisement from the HCP tended to steer people toward tighter blood glucose control. Illustrating this more concretely, a person noting their glucometer reading of 140 mg/dl might refrain from eating piece of cake in the following moment. Someone with a reading of 100 might not be so restrained. An A1C of 11 typically resulted in the participant reevaluating their overall management strategy. It was easy to view participant’s use of feedback in decision-making as a system’s response to imbalance in a negative feedback loop, a perspective that linked this research to general systems theory and the writings of Bateson and Keeney.

If health can be viewed as a matter of biopsychosocial balance and people can be understood as linguistic systems trading in the currency of meaning and idiom, then it is essential that the person receive feedback that is meaningful to guide their choices. Clarifying the work of Bateson, Keeney wrote that in order for a system to register a perturbation in the pattern that leads to change, it must discern “a difference that makes a difference” (Keeney, 1983, p. 153). Indeed, not all differences in readings resulted in change for the person-system; certain types of feedback proved more meaningful than
others. Weight did not generally register as a meaningful difference for the system. Perhaps weight is too common or ambiguous a measurement to be perceived by most participants as noteworthy. In contrast, A1C’s, were generally received by the person-system as potent negative feedback that shaped overall health management.

The theory of health decision-making that emerged from this research shares many features in common with the dominant models that explain changes in health behaviors. It also finds resonance with other theories of change which did not originate from the healthcare literature. This new theory, however, grounded in the patient’s descriptions of change, deviates from the present array of theories in that it is not focused narrowly on a sequence of stages, cognition, or balancing costs and benefits, but instead takes into account the complex, interrelated influences of cognition, agency, and the generally overlooked construct of purpose.

Implications for Clinical Practice

Several implications for healthcare practitioners and therapists were suggested by the findings of this project. First, it was important for people to have a life infused with a sense of purpose. To be sure, people were motivated to avoid pain and people were motivated to avoid death. However, when pressed about their motivations to avoid death, informants spoke about the need to fulfill a calling, a mission that was usually enriched by, if not defined by, relationships. This emphasis on purpose, which may be largely overlooked by adherence research, is consistent with the narrative emphasis on man as a meaning-generating creature and Viktor Frankl’s writings about the powerful influence of purpose in Man’s Search for Meaning (1963):
A man who becomes conscious of the responsibility he bears toward a human being who affectionately waits for him, or to an unfinished work, will never be able to throw away his life. He knows the "why" for his existence, and will be able to bear almost any "how." (p. 127)

The role of meaning and relationships as a health motivator was also found to resonate with the demographics of suicide in the United States. The Morbidity and Mortality Weekly Report, published by the CDC (1996), indicated that the rate of suicide for divorced or widowed men was 2.7 times the rate for married men. Similarly, divorced and widowed women committed suicide at 1.8 times the rate of married women. Further, the CDC identified social isolation as a prominent risk factor for suicide among the elderly. Although a causal relationship is not indicated by these findings, when considered along with the consistent emphasis participants put on purpose and relationships as the ultimate motivator for their healthful behavior I believe it further reinforces that this is a critical domain.

In view of this, efforts to facilitate change in patients and clients may be improved by first understanding what imbues their life with meaning. Because patients in this study identified relationships as a principal source of meaning and motivation, healthcare workers may find it pragmatic to assess the social connectedness of their diabetes patients. Additionally, the findings suggested that HCP’s may observe greater motivation and adherence by ensuring that their patients are involved in vital relationships where they feel needed. This may include, perhaps, prescribing volunteer work, connecting with grandchildren, or social activities in addition to the regular admonition to exercise. Finally, changes required by the regimen or intervention can be grounded in this larger, energizing
vision. For example, a diabetes educator might say to a patient, "it sounds as though your grandkids really benefit from your wisdom. As they grow older and life becomes more complicated, you know they are likely to draw upon your experience more and more."

Purpose, and relationships in particular, were ultimately motivating for participants in this research. Present models of decision-making neglect this dimension. People charged with influencing the decisions of others may find it useful to tap into this resource when attempting to motivate their clients and patients.

A second clinical implication of these findings is the importance of the indeterminate nature of the future. Believing that the future was still malleable proved to be an important change element, feeding a sense of agency, optimism, and action. In contrast, pronouncing a particular outcome tended to foster passivity and resignation. Through my own professional counseling networks I have heard tales of clinicians who have told couples that there was no hope for their marriage, which effectively sounded the death knell of their union. As in the case with Debbie's first physician, this prognosis may be a medically accurate professional opinion. Yet the biopsychosocial approach, which emphasizes the dynamic interplay which the mind and environment can have on biological processes, suggests that it may be of greater benefit to our patients and clients to exercise humility over what we "know" about future events. If negative information must be given, it should likely be couched in tentative or "if - then" language.

This posture, however, raises an interesting ethical concern. Does this mean that in cases where someone has a terminal illness that healthcare professionals should withhold that information from patients, as is often done in Japan? Perhaps a measured approach is
to simply leave the future open and as Debbie’s physician told her: the neuropathy
may “stay in just that one area the rest of your life. It may move to other areas. We [itals added] don’t know.”

Finally, the findings of this research remind us of the importance of feedback as
intervention. People, as purposeful systems, require feedback to direct their steps. From a
systemic perspective clinicians must do more than simply hope to perturb the system by
prescribing behavioral change for the person, whether that be changes in marital
communication or diet. Clinicians are part of the patient’s system and must provide
meaningful feedback on how the system is responding. This calls attention to the important
and arguably difficult task of discerning what would constitute meaningful feedback for the
client. The findings from this research suggest that, for most, the A1C or some analogous
instrument is considered an important source of feedback. Counseling may also benefit by
more deliberately utilizing feedback. The penchant of participants in this study to ascribe
significant meaning or “difference” to numbers or, as Betty said, “seeing things in black and
white” suggests that counselors might devise some simple measures of therapeutic progress
that could be administered to clients throughout the course of therapy.

Limitations of Grounded Theory Methodology in This Study

Research adds to our constantly evolving body of knowledge. Science is never static
and definitive, but instead is dynamic, with all findings requiring additional verification.
Qualitative research has certain strengths, particularly the degree to which it seeks to
understand in detail a phenomenon without the constraints or coloring of an a priori theory.
This strength, however, contributes to its primary limitation. Although the researcher is
able to generate sizable amounts of information about a phenomenon, it is very time intensive and thus impractical or impossible to have a large sample size. Consequently, conclusions that can be drawn from this research are restricted to this study, and the ability to generalize, uncertain.

A second limitation also relates to the methodology and, in particular, the sample. Participants were not randomly selected. Indeed, the kind of person who volunteers three to six hours of their time to participate in a study is unusual. Based on my knowledge of the size of the diabetes education classes where many informants were drawn, it is estimated that only one in eight persons approached about participation chose to fill out a form consenting to be contacted by the researcher. What might prompt someone to participate? Information about the sample suggests they already had a keen interest in health issues. Nine of the twenty-one participants either worked in healthcare or had an immediate family member in healthcare. Although participants sometimes struggled with making healthful decisions, they were, however, engaged in the process. The findings suggest that the diagnosis of Type 2 diabetes inexorably drew them into an active HDM process. Other recent research suggests that this is not necessarily typical, with as many as one third of people who receive irregular blood glucose readings at public screenings not following up on this alert with a physician (Wellmark Diabetes Taskforce, 2001). This suggests that a significant number of people who learn they might have diabetes do not make changes to their lifestyle.

A third limitation of this research is the widely recognized tendency for people to imbue their interviews with positive self-presentation. Because for many people choosing healthful behaviors and, as the researcher learned, even health itself, carries moral overtones
of right and wrong, good and bad, the credibility of some of the informants' statements may be challenged. Although this is a concern in both qualitative and quantitative research, the latter has more tools to address this issue. Surveys or other measures used by quantitative researchers offer more anonymity. People or names are more easily separated from their data; collectors and analysts typically cannot identify who may have given particular response. Qualitative research also endeavors to offer participants confidentiality. To this end, names have been changed and other identifying information has been made more ambiguous. Yet interviews, an indispensable part of this research's data collection, are an inherently intimate and revealing enterprise. Confidentiality, at least in the moment of the interview, is patently impossible. Consequently, the goal of qualitative inquiry, accessing and communicating informants' experience, may prove elusive if the participants feel uncomfortable being honest with the interviewer. The quality and depth of information collected is bound by the rapport that the researcher has at that moment with the participants.

Generally speaking, appearances were that participants were forthcoming with the investigator. There were many instances where people in the study admitted to varying from their regimen, sometimes in dramatic and humiliating fashion. Betty apparently felt very comfortable disclosing to the researcher about a period of time when she was not adhering to her regimen:

Betty: But the second four months I was really goofin' off way too much... I thought I'd get chewed out. And I was thinking that one time I got over 200 and I was taking cough syrup and all this and that was a real shocker.

Int: This chewed out thing, would you tell me a little more about that?

Betty: Well, there's tact and then there's strong vocabulary, used by whoever I'm seeing, whether it's [the diabetes educator] or the doctor. And I really expected them to say, "Ok, kid, you've had your fun long
enough. It’s time to get down.” – Chew me out for not doing better than I was….Not shouting, but you know, “you crazy, look at what you’re doing to yourself.”

**Int:** You’d feel ashamed?

**Betty:** Oh, absolutely. I know better than that and I was being very aware of it myself. That’s why I expected to get criticized.

Similarly, a very candid exchange between Evan and his wife, Wendy, that occurred during the interviews suggests that there was a high comfort level with the researcher and a correspondingly high level of disclosure:

**Wendy:** You know, we’ve only gotten into one real good argument over food. He was to the point where he was mad. I was mad.

**Evan:** It was over popcorn balls

**Wendy:** He wanted to make those popcorn balls soo bad. And I told him, “Why do you want to make popcorn balls so bad when all you’re going to do is eat them?” “No, they’re for other people.” “Right” and I told him I’m going to give them all away. And he had this gnarled look on his face.

Wendy proved to be very candid during the researcher’s interviews with Evan, suggesting that spouses might be included systematically in future research for triangulation and corroboration of data. She added:

**Wendy:** He used to listen to me a little bit. And now it’s like – he gets this look in his eye. And it does like, “Ok, do what you want to do.” Because he’s always eaten the way he wants to eat forever. And it’s hard. We’ll go into the store and he’ll say, “The kids need this.” And I’ll say “the kids don’t need those” ‘cause when I go to the store I don’t buy that kind of stuff. And he’ll say “the kids need this.” Well, you look around the corner into the living room from the couch and there’s Evan standing over his Ho-Ho’s trying to sneak. It’s funny because he’ll sneak food and I feel really bad, because why should he feel like he has to sneak to eat something?

**Evan:** Because it has sugar in it.

**Int:** And you feel...

**Evan:** I kind of feel guilty when I eat it now.

Despite the willingness of participants to share their shortcomings in diabetes management, there were a few times when self-reports did not line up as expected with my
observations. For instance, one informant, Sam, would talk about how he was able to manage diabetes through significant changes to his diet, yet over the course of the interviews there was no concomitant change in his weight. This was perceived as a discrepancy until the researcher learned that while Sam had, as he had stated, nearly eliminated sweets from his diet, he was maintaining about the same number of caloric intake by eating more protein and other, less sweet, carbohydrates. Another participant talked about how she had been exercising more, though the researcher had observed from interview to interview that her weight and body shape had not appreciably changed. This incongruence led the researcher to press for details about her exercise:

Theresa: Also, I've been exercising a lot more... I have more energy and I exercise more because I haven't had the headaches.
Int: Right.
Theresa: And, um, not the tension up there in my neck and shoulders and back, you know. So there' in turn, that has helped the diabetes, you know.
Int: Having the pain go away you have felt more like exercising and you have been exercising.
Theresa: I have been.
Int: What have you been doing?
Theresa: Just working in this house. That type of thing, not exercise per se, but, I will once this house gets in order.

Similarly, Krista described increasing her exercise between the first and second interview:

Krista: You know what I've started doing now? I park my car across the street [from work].
Int: So you're walking about thirty yards then?
Krista: Yeah, I get a little walk in... With that [sic] walkin' 'cross that street that gives me a little pep. I'm trying to do little things that make a change.
Evidently, the definition of “exercise” describes dramatically different behaviors to people, as the researcher suspects most people do not customarily consider walking across the street or cleaning the house to be “exercise.” Yet, rather than an attempt to mislead, I believe that this is an example of “positive illusion” (Taylor & Armor, 1996), the tendency for people to exaggerate their abilities and what they have control over. The tendency toward positive illusion and the desire to present oneself in the best light is widely cited in other research and, given the personal nature of the interview, is a particular threat to qualitative inquiry. Laughter, the disclosure of failings, and the voluntary and uncompensated nature of the participants’ involvement all suggest an adequate degree of rapport with the researcher and argue against deliberate attempts at deceiving the investigator or sidestepping important issues. Nevertheless, social psychologists advise that unintentional, positive illusions self-report cannot be ruled out and, in fact, would be expected of most people (Taylor & Armor, 1996). Consequently, I would argue that this more benign view of is the most appropriate way to understand the exaggerated depictions of exercise and dietary change.

It must be made very clear, however, that this study sought to identify the factors that influenced health decision-making, not establish that these factors would produce certain outcomes. Therefore, specific changes participants made, while illuminating, are not as critical as understanding how they came to make those changes. As Wall (1999) stated, “Just because we do not know everything, that does not mean we do not know what we have learned and what we have learned is not helpful” (p. 154).
Directions for Future Research

The findings of this project suggest several directions for further research. Notably, opportunities exist for verification of this new HDM theory and, in particular, the roles of purpose and disequilibrium in affecting change. First, future inquiry may seek to validate the theory proposed here by creating and testing hypotheses derived from this tripartite model of HDM. Qualitative research’s strength lies in its ability to generate theory from data. Despite a constant comparative approach and repeated verification with informants, however, it was not possible to carry out a true testing of hypotheses given this research design. One recommendation for future research would be to create a scale from the theory and test high scores on mobilizing cognitions, agency, and purpose against tighter diabetes control.

Second, the category of purpose and relationship as motivation is of particular interest because of its general neglect as a motivating factor in HDM research. Now that this category has emerged from the data, I think it would be beneficial to validate purpose and relationships as elemental factors in HDM by creating scales for them and subjecting the purpose-compliance link to testing. In addition to conducting basic research on the role of purpose, healthcare professionals may find it productive to explore this relationship in an applied context. Medical professionals could take a cohort of people recently diagnosed with type 2 diabetes and, using an experimental research design, assign the control group to participate in some sort of relationship. The specific nature of the independent variable could vary along the continuum of need and range from participation in recreational social activities to something farther along the need continuum such as volunteering or participating in a youth mentoring program.
Further, purpose, relationships, and the needed-dependent continuum proved to be such a powerful motivator in this research that it would be interesting to examine these factors as they might relate to adolescent risk-taking behavior and gay male sexual behavior. Even more broadly, this construct might provide insight into the male disinterest in health that contributes to the nearly six year difference in life expectancy for men and women. That men access healthcare differently from women is a well-documented phenomenon that is usually ascribed to men being socialized toward independence and self-sufficiency. Perhaps the quality and nature of men’s relationships also play a role.

From a more heuristic perspective it might be beneficial to examine the role of disequilibrium in change. Keeney believes that “a change of lens always invokes a period of initial confusion or transition” (1984, p. 155). Participants in this study certainly experienced Keeney’s “change of lens” (1984, p. 155), stemming from a new knowledge about one’s vulnerability, understanding of the body as a metabolic system, and a new identity as a patient. My early clinical training as a systemic-strategic therapist inclines me to believe that this “out of kilter” period is extraordinarily ripe for transformation. However, by narrowing the study to the factors that participants reported influenced health decision-making, the research obscured a potentially relevant relationship between disequilibrium itself and change. Specifically, now that disequilibrium and two mediating subcategories have been identified as factors that accompany participation in health decision-making, it would be useful to know if greater upset was associated with more or less change.
CHAPTER 6. CONCLUSION

A review of the literature on patient adherence suggested that before healthcare professionals could see improvement in diabetes management, an illness in which patient initiated changes are central, patient decision-making needed to be better understood. Moreover, it was recognized that research which examined health decision-making from the patient’s view was largely absent from the medical literature. In view of these factors, this dissertation has explored how people with Type 2 diabetes make health decisions, and proffers a grounded theory into the factors that influence this process.

Toward this end, the researcher interviewed 21 people at least three different times, collecting this data from participants over a period of 6 to 8 months. All participants had been diagnosed with Type 2 diabetes within the previous six months. Participants represented a wide demographic spectrum: ages ranged from 29 to 79, education spanned high school to multiple earned graduate degrees, 5 African Americans and 16 whites were represented in this study. Interviews were transcribed and analyzed according to a prescriptive, yet accommodating, grounded theory approach which yielded five categories, and four interrelated subcategories, all with various properties. Peer review, member checks, and an audit were conducted to assure the trustworthiness of the findings.

The five categories that emerged in this study were (a) disequilibrium, (b) health decision-making and its three associated categories, (c) knowledge, (d)self-agency, (e) and purpose. This new grounded theory was set against the backdrop of Engel’s biospsychosocial model, which articulated a vision of the patient as a person who functioned in three different and interrelated systems: the level of the biological, the level
of the mind or psychological, and the social or environmental. All participants experienced some amount of upset, termed disequilibrium, following diagnosis with Type 2 diabetes. The amount of upset varied dramatically for individuals, with some registering shock and others noting it was just an additional burden. Two subcategories mediated the disequilibrium: prior diabetes knowledge and concurrent challenges. Patients who had lots of prior experience with diabetes tended to have muted reactions. Patients with no prior experience with diabetes also had muted reactions as they had no organizing schema through which to make sense of their diagnosis. Patients with little and moderate amounts of knowledge about diabetes, the majority of the participants, tended to respond with the most upset. Also, participants who had few other distractions in their life experienced the diagnosis to be more upsetting. In contrast, participants who were already combating other chronic illnesses, dealing with other acute health concerns, or involved in the critical care of others experienced less disequilibrium. Participants in this study seemed inexorably drawn into a health decision-making process that was influenced by three broad factors: cognition, agency, and purpose. Knowledge was a broad category that described the different understanding participants had about diabetes. The understandings could arise from physiological oriented feedback on their health, factual knowledge about the illness and treatment, experiential knowledge gained from witnessing someone else with the illness, or an emotional reaction such as fear. Self-agency referred to the amount of influence a participant believed they had on their health and was linked to mindset, participant perceptions about choice, and perceptions about the indeterminate nature of their future. Finally, participants indicated that a reason for staying a live was important, the idea of purpose. Participants found purpose from two sources, their faith and relationships. The
more they perceived they were needed in relationship, the more vividly participants
describe the sense of purpose that indwelt their life.

The seven propositions distilled from the existing theories of health decision-making
and introduced in Chapter 2 were restated and findings from this research were then
considered in view of these seven points. The new grounded theory and the theories from
previous research shared many points in common, such as the important role of information,
education and feedback, and the significance of vulnerability or fear in shaping behavior.
Points where the new and old theories departed were also noted and included the SCM view
that change was incremental and rational, the TRA over emphasis on reason and rational
decision-making, and the absence of the idea of purpose as a motivating factor for HDM, a
category that was clearly present in the data. The theory was then shown to integrate further
with other more general theories about change: Bandura’s Social Cognitive Theory, choice
as a matter of social construction, and General Systems Theory.

The clinical implications of this new theory were developed. Notable contributions to
the field included the attention drawn by this new theory to (a) purpose in motivating
change and (b) the importance of indeterminancy as necessary ingredient for agency, and (c)
the role of feedback as a critical source of information for the patient. This study’s
limitations were discussed, and possible directions for future study were suggested.

In conclusion, health decision-making is a complex process that includes many factors.
Participants in this project revealed that they were influenced by information, emotions,
experiential knowledge and feedback, constituting the category of knowledge; a resolve to
manage their situation, perception of their options, and the belief that the future was
changeable, defining the category of agency; and the largely overlooked role that a sense of
purpose played in inspiring people to manage their health. This research contributes to the field by presenting a grounded theory of HDM. This new theory includes elements of the other dominant decision-making models, which is understood as a testament to their utility and proximity to the phenomenon of HDM. However, this new theory, in capturing the experiences of 21 diverse participants, was more encompassing than any one health decision-making theory and is unique in the field in drawing attention to the importance of purpose.
APPENDIX A. HUMAN SUBJECTS REVIEW BOARD APPROVAL

Checklist for Attachments and Time Schedule

The following are attached (please check):

1. □ Letter or written statement to subjects indicating clearly:
   a) the purpose of the research
   b) the use of any identifier codes (names, #s), how they will be used, and when they will be removed (see item 11)
   c) an estimate of time needed for participation in the research
   d) if applicable, the location of the research activity
   e) how you will ensure confidentiality
   f) in a longitudinal study, when and how you will contact subjects later

2. □ Signed consent form if applicable:

3. □ Letter of approval from dozens, from cooperating institutions, or institutions of application

4. □ Date-gathering instruments

5. □ Anticipated date for contact with subjects:
   First contact: [ ] [ ] [ ] [ ] [ ] [ ]
   Last contact: [ ] [ ] [ ] [ ] [ ] [ ]

6. □ If applicable, anticipated date that identifiers will be removed from completed survey instruments and/or audio or visual tapes will be erased:
   [ ] [ ] [ ] [ ] [ ] [ ]

16. Signature of Departmental Executive Officer: [ ] [ ] [ ] [ ] [ ] [ ] [ ]

17. Decision of the University Human Subjects Review Committee:
   □ Project approved  □ Project not approved  □ No action required

Name of Human Subjects Research Committee Chair: Patricia M. Keith

Date: [ ] [ ] [ ] [ ] [ ] [ ]

Signature of Committee Chair: [ ] [ ] [ ] [ ] [ ] [ ]

http://www.grad-college.iastate.edu/forms/HumanSubjects.doc
TO: All clinical investigators

RE: Approval of protocol

Approval of protocol # has been granted by our Institutional Review Board on

It is the clinical investigator's responsibility to promptly report to the IRB changes in research activity, including any unanticipated problems involving risks to human subjects or others. All severe and fatal toxicities and outcomes will be reported to the IRB by the clinical investigator at the first convened meeting following the outcome. (See ECOG grades 4 and 5 in ECOG toxicity criteria, appendix II, Notification of Action. Appendix III.) Requirements for compliance include any unexpected toxicity or any grades 4 or 5 toxicity to be reported to the IRB Chair:

- by phone or facsimile within 24 hours of the event and
- in writing within 10 working days and
- presentation of a brief summary of the event at the next full IRB meeting

Any changes in the approved research may not be initiated without IRB review and approval except where necessary to eliminate apparent immediate hazards to the human subjects.
March 8, 2001

William R. Garris
425 Pearson Avenue
Ames, IA 50014

Dear Mr. Garris:

The Institutional Review Board of Methodist/Lutheran & Blank Children’s Hospital met on March 8, 2001 and approved the following protocol and informed consent:

**Type 2 Diabetes - The Process of Health Decision-Making for Persons Newly Diagnosed with Type 2 Diabetes**

Approval of a study should not be interpreted as a granting of any hospital privileges to any of its investigators participating in the study. Individual investigator participation in the study at a hospital site is restricted to only those hospitals where he she has been granted applicable privileges.

Your protocol has been given the following ID Number: IM2001-018. Please refer to this number when making inquiries regarding your research study.

The IRB shall review each approved study according to a schedule adopted by the IRB for each study, but not less frequently than annually. You will receive a report form when your study is scheduled for continuing review. Each investigator is responsible for notifying the IRB whenever approval of the study or investigator is withdrawn by the sponsor, FDA, or HHS. Additionally, each investigator shall notify the IRB in the event that the investigator discontinues the study at any time other than the scheduled completion date, and an investigator is required to report promptly to the IRB within 24 hours if possible, any fatalities and life-threatening or serious adverse events occurring in subjects enrolled in a protocol or variance from the approved protocol. At the conclusion of the study, the IRB may require such follow-up information and documentation of a completed or discontinued study as it may determine appropriate.

This IRB operates in accordance with all applicable federal, state and local laws and regulations.

Please contact me if I can be of further assistance.

Sincerely,

Thane J. Peterson
Administrator
APPENDIX C. INFORMED CONSENT

CONSENT FORM

READ THE FOLLOWING MATERIAL TO BE SURE THAT YOU UNDERSTAND THIS MEDICAL RESEARCH STUDY. PLEASE SIGN THE FORM IF YOU AGREE TO PARTICIPATE. YOUR SIGNATURE ON THE FORM CONFIRMS THAT WE HAVE INFORMED YOU OF THE NATURE AND RISKS OF PARTICIPATION AND THAT YOU HAVE MADE YOUR DECISION FREELY. YOU WILL GET A COPY OF THIS CONSENT FORM.

RESEARCH STUDY: THE PROCESS OF HEALTH DECISION-MAKING FOR NEWLY DIAGNOSED TYPE 2 DIABETICS

I. ________________________________, willingly agree to participate in this research study which has been explained to me by the undersigned physician. There may be approximately 30 participants invited to take part in this study.

PURPOSE OF THE STUDY

It has been explained to me that I have Type 2 diabetes. I have been invited to participate in this research study. This study involves participation in interviews, which will be conversational in nature about the choices I am making regarding managing my diabetes and what the factors are influencing these decisions. The purpose of this study is to increase our understanding of how people make health-related decisions.

DESCRIPTION OF PROCEDURES

Following the signing of the consent form, the researcher will contact participants by phone to arrange a convenient appointment to discuss how they are adapting to life with diabetes and what changes they have made in their life. Also, participants will be asked to inform the investigator how it is they make these decisions, that is what factors are involved. Particular questions used to initiate interview will include:

1. How is your life different now that you have the diagnosis of Type 2 Diabetes?
2. What decisions have you made relating to your life (health) in response to the diagnosis?
3. How did you come to decide upon these choices? That is, what led you to make these choices?
4. What factors are currently influencing whether or not you follow through with your decision?
5. How would you describe the nature of the changes you have made (sudden, gradual, in stages, affective, cognitive, experiential, other)?
6. What factors keep these changes present in your life?
7. How do you see your life/health differently since being diagnosed?
8. How would you try to affect the changes you experienced in another person (i.e., a friend or child)?
9. What is the biggest challenge you are facing in managing your diabetes? What are you doing about this challenge?
10. How has your identity (sense of self) changed/stayed the same as you have come
live as a person with diabetes?

The informants will be interviewed 4-6 times over a period of 6 months. The interviews are anticipated to last from 15 minutes to 2 hours and the total time commitment required from participants is estimated to be around 5 hours. The interviews will be audiotaped and may be conducted face to face or over the telephone. Participants will also be asked to make weekly entries into a journal about their experience managing diabetes and to consent to disclose parts of their medical records that specifically address the diagnosis and treatment of their diabetes.

RISKS AND DISCOMFORTS
There are no anticipated risks from these interviews, neither to consenting participants or their unborn children. There may be some benefit to participants in having someone in whom to confide about the new challenges of living with diabetes.

CONTACT PERSON
The principal investigator, Bill Garris, M.A. (ABD) may be reached the following ways:
515-232-7262 ext 330 bgarris@ames.net
515-296-0475
He may be contacted at any time if the participant has any questions regarding this study, if further information about the nature and conduct of the study is required, or if any problems result from participation, including a research-related illness. The chair of the joint institutional review board, telephone (515) 241-5790, may also be contacted for further information regarding my rights as a research subject.

FINANCIAL CONSIDERATIONS: COSTS AND BENEFITS
There are no medical costs that are anticipated to occur as a result of the interviews. Consequently, participation in this research will have no bearing on the patient’s financial responsibility for their own diabetes treatment.

Participants will not be reimbursed for their time. There is no guarantee of benefit from participating in this study, though it is possible that some participants will find it beneficial to talk with someone about the new challenges they are facing as they adjust to life with diabetes.

ALTERNATIVES
This study is not a treatment and will have no effect on the range of treatment options that may be discussed between the physician and the patient.

VOLUNTARY PARTICIPATION
Participation in this research study is voluntary. The participant may refuse to enter the study or may stop at any time. Refusal to join or continue will not affect the participant’s right to receive medical care that might help him/her now or in the future. In the event that the participant withdraws from the study, their decision shall be reflected in the data and no further information about the participant will be collected.

The investigator may stop the participant’s involvement at any time if it is in the participant’s best interest, if the participant does not follow the study requirements, or if the study is stopped.
Participants will be told of any changes in the study or procedures that may occur.

CONFIDENTIALITY
Although the study results may be published, confidentiality of participants will be maintained. Names of participants or information identifying participants will not be released without permission unless required by law. Medical records may be used to corroborate data supplied by participants, but will not be connected to the patient. That is, the records may be combined with others to create averages, but it will not be possible to link the data to a particular participant. Medical records, if obtained, will be requested under a separate release form. Audiotapes and transcripts from the interviews will be labeled with a code, not participants names, and will be kept in a locked filing cabinet which is in an office that is locked when the researcher is not present in the room.

I HAVE HAD AN OPPORTUNITY TO HAVE MY QUESTIONS ANSWERED AND THE QUESTIONS I HAVE ASKED HAVE BEEN ANSWERED. A COPY OF THIS FORM HAS BEEN GIVEN TO ME. I AGREE TO PARTICIPATE IN THIS MEDICAL RESEARCH STUDY.

(date) (signature of participant or parent or guardian)

(date) (signature of investigator obtaining consent)

(date) (witness)
In order to complete the research component of his doctoral studies at Iowa State University, William R. Garris has requested the cooperation of Greene County Medical Center (GCMC) in soliciting participants.

The process of requesting patient's participation occurs over two steps that are put in place to protect the patient's rights. The first step, designed to protect the patient's right to privacy, is the Consent for Contact form. As part of this GCMC - researcher agreement GCMC will have its patients who have been recently diagnosed with type 2 Diabetes (less than six months) view a form that briefly overviews the research. On this sheet potential participants will be requested to check one of two boxes indicating that they do or do not wish to be contacted by the researcher or their desire to not be involved in the research. Potential participants will also be asked to sign this sheet. If the GCMC patient marks the box indicating their wish not to participate, or if they check no boxes on the sheet, then no contact will be made between the investigator and the patient. If on this form the patient indicates their willingness to disclose their medical condition (diabetes diagnosis) and be contacted by the researcher, then the process of soliciting their participation proceeds to the second step.

In the second step the investigator will contact the patient. He will explain the purpose of the research and the protocol. The patient will also be informed of their rights as outlined on the Consent to Participate (CP) form. The patient will then be given the choice of signing or not signing the CP form and, subsequently, participating or nor participating in the research. If the patient chooses not to sign the CP form, they will thanked for their interest and time, and there will be no further contact with them.

The investigator’s role is to meet with the patients and to ask questions that will lead to an increased understanding of the health decision-making process that new patients undergo. The details of the investigator’s role may be found in the research protocol contained Chapter 3: Methodology of his dissertation. The investigator will not tell the patient what he should do, will not represent himself as a diabetes educator, will not provide information on diabetes management or standards of care, will not represent himself as an agent of GCMC, and will not dispense opinions that could be construed as medical advice. The investigator also has responsibilities to protect participants as required by the Human Subjects Committee at Iowa State University.

Although cooperating with the investigator in identifying potential participants, GCMC has no liability for this research and is not connected to this project financially. The agreement will last for 6 months from the date signed below.

investigator (date) hospital representative (date)
References


Bacon.


Carroll, J.B. (1956). *Language, thought, and reality: The selected writings of Benjamin

http://www.cdc.gov/diabetes/pubs/facts98.htm#appendix


Col, N., Fanale, J.E., & Kronholm, P. (1990). The role of medication noncompliance and
adverse drug reactions in hospitalization of the elderly. *Archives of Internal Medicine, 150*, 841-848.


Diabetes Overview (1996). NIH Publication No. 96-3873


*The Family Therapy Networker, 12*(5), pp.27-35.


qualitative research. Chicago, IL: Aldine.


*Educational Communication and Technology Journal, 29, 75-92.*


*Family Planning Perspectives, 24(1),* 12-19.


McFarlane, I.A., Bliss, M., Jackson, J.G.L., & Williams, G. (1997). The history of


analysis. *Family Medicine, 29* (6), 424-428.


of Compliance in Health Care,


