Cultural Competency in Healthcare Policy:
Pursuing Elder, African-American Diabetics as Stakeholders in Successful Treatment

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Dissertation submitted to the faculty of the Virginia Polytechnic Institute and State University in
partial fulfillment of the requirements for the degree of

Doctor of Philosophy
In
Public Administration and Public Affairs

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April 20, 2010
Blacksburg, Virginia

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Abstract

Healthcare agencies and researchers identify several areas in which healthcare disparity affects elder, African-American diabetics including higher rates of diagnosis, higher limb amputation, increased kidney failure, and stroke. While the disparities have been documented, elder, African-American diabetics rarely have been invited into discussions concerning these disparities, research questions, project or program design, and results. They are not asked to be stakeholders in health care or health policy discussions. This study used grounded theory as a participatory action research method to invite elder, African-American, diabetics into the discussion using focus groups. The patient participants then suggested providers they believed to be "successful" in their care who were then interviewed. The analysis suggests that where patient/ provider communication has been peripheral that care and perception of care and patient suffer. Where successful communication was central to the patient/provider relationship, provider preconceptions lessened and patient compliance levels rose. This dissertation offers several downstream, midstream, and upstream recommendations using a patient-focused lens.

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Chapter One

Cultural Competency in Health Care Policy:
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Disparities in health care treatment and outcomes are significant across racial and ethnic groups. These disparities can be seen in numerous ethnic groups, most strikingly within the African-American community. In response, the U.S. national government and health care providers have looked to cultural competency to address the long-term issue of health care disparities. Yet, poor, partial, or nonexistent competency training and policy can result in degraded provider communication with and responsiveness to patients. The current strategies of cultural competency, especially given a diversity of definitions and application, actually may increase the problem. Inconsistencies in competency programming, definitions, and evaluation may be ameliorated by expanding evidence-based guidelines.[1]

Inconsistent programming can be seen in many policy locations outside of health care and in communities other than the African-American community. The area of diabetes management of elderly African Americans is only one context in which to increase effective, successful interaction that reduces health care disparity and negative outcomes. Public administration and public health administration may be more effective in reducing health and health care disparities by considering elder African Americans and other populations as stakeholder communities and incorporating their recommendations into tangible guidelines.

Purpose

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[1] Evidence-based guidelines are policy products constructed by small, sponsored groups of specialists for a generic, but prescribed patient population through an explicit, rigorous process with unclear effect. A fuller explanation of evidence-based medicine, evidence-based guidelines, and evidence-based individual decisionmaking can be found in Chapter Three.

I examined the perceptions of elderly, diabetic African-Americans of their "success" in interacting with their health care providers. I began with five themes, or "concepts," that emerged during a pilot study: patient perceptions of respect, of information availability, of intelligence, and of control, and provider preconceptions about their patients. The discussion is not limited to these five themes, but will begin there. These perceptual issues impact the nature and utility of care these patients receive. Successful patient-provider interaction increases providers' perceptions of compliance and patients' continuity of care.

This dissertation used a traditional grounded theory approach, relying on focus groups of elder, diabetic, African Americans, and interviews with patient-identified "successful" medical practitioners and with other medical practitioners. From these discussions came description, analysis, and critique of where elder, African-American diabetics and practitioners agree and disagree on definitions of "success." The findings may lead as well to prescriptions for health care providers and for public policy in the form of recommendations for evidence-based guidelines. As a stakeholder group, this population should provide important insight into current approaches, policies, and practices.

Diabetes in the African-American Community and Medical Disparity

Diabetes in the African-American Community

I focused on elder, African-American diabetics as stakeholders in successful care. Diabetes has reached epidemic status in the African-American population. In comparison with the majority population the numbers are grim. The American Diabetes Association (2005) presents these statistics regarding the prevalence of diabetes.

- 11.8 percent of all African Americans aged 20 years or older have diabetes compared to 6.6 percent of non-Hispanic whites.

- 25 percent of African-Americans between the ages of 65-74 have diabetes.

- 1 in 4 African-American women over 55 years of age has diabetes.

Diabetes has become a manageable, treatable disease for most. There are well-documented and successful treatment strategies, and the outcomes are consistent and reliable. Control of glucose, blood pressure, cholesterol, and lipids can cut damage percentages significantly. Preventative care of hands and feet can reduce amputation rates up to 85 percent.

Yet for African Americans, diabetes has more negative medical outcomes compared with the non-Hispanic white majority population.

- African Americans are 1.5 to 2.5 times more likely to have a lower limb amputated due to diabetes complications.

- African Americans with diabetes are 2.6 to 5.6 times more likely to suffer from kidney failure than non-Hispanic whites.

- As a group, African Americans with diabetes are 5 times more likely to suffer a stroke (ADA, 2005).

Some studies have looked into these issues, but mostly from a physiological perspective. In such work, among the measures of program outcomes were HbA1c levels, fasting glucose levels, and increased rates of cancer screenings (Davis et al., 1998; Erwin, Spatz, and Hollebert, 1999; Gilmer, Philis-Tsimikas, & Walker, 2005). None of these studies included patients as stakeholders[2] who may help define aspects of quality care. This dissertation used a participatory design as a means of addressing a specific need for dialogue with elder African American diabetics as stakeholders. Speaking with this community addresses "the relative lack of

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[2] McVea (2001) defines "stakeholders" as "any group or individual who is affected by or can affect the achievement of an organization's goals." This will be discussed in greater detail below.

involvement of diverse patients and communities in determining study issues, questions, designs, analysis, and dissemination of results" (Goode, Dunne, & Bronheim, 2006, p. xi).

Health and Health Disparity[3]

Medical disparities in U.S. minority communities have become more than conversation in recent years, and the U.S. federal government has become involved including the Department of Health and Human Services' Administration on Aging (AoA), Agency for Healthcare Research & Quality (AHRQ), Centers for Medicare & Medicaid Services (CMS), National Institutes of Health (NIH), the Office of the Inspector General (OIG), and the Office of Minority Health (OMH). Several studies have documented the connection between medical disparities and ethnicity, but few supply explanations of the environments, mechanisms, and interactions involved in propagating these disparities (AHRQ, 2003). Increasing cultural competency, or "the ability of health care providers and health care organizations to understand and respond effectively to the cultural and linguistic needs brought by patients to the health encounter," has been offered as one strategy to combat medical disparity (*Federal Register*, 2000, p. 80865).

Research Questions

The research here explored several questions:

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[3] Health disparities and health care disparities are different concepts. Carter-Pokras and Baquet (2002) give an excellent definition of health disparity. They describe the use of "health disparity" as exclusive to the U.S. context. Other countries (e.g., those in Europe and Africa) tend to emphasize "health inequality" or "health inequity." I use health disparity in this research and depend on their definition. "'Disparity' in the context of public health and social science, therefore has begun to take on the implication of injustice, but nonetheless may be distinguished from the general term 'inequality.' A health disparity should be viewed as a chain of events signified by a difference in: (1) environment, (2) access to, utilization of, and quality of care, (3) health status, or (4) a particular health outcome that deserves scrutiny. Such a difference should be evaluated in terms of both inequality and inequity, since what is unequal is not necessarily inequitable" ("What is Health Disparity?", *Public Health Reports*, (117). p. 427). Health disparities, simply stated, are the differences between one identified group and another. Health *care* disparities, on the other hand, focus on those differences in "provision of preventative, diagnostic, rehabilitative, and/ or therapeutic medical or health services to individuals or populations (health care services)" that impact the "degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (quality of care) (*ibid*). More specifically, the *Unequal Treatment* study defined health care disparity as "racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of interventions" (2003, p. 32).

1. What motivates/ hinders elder, diabetic African-Americans to increase interaction with their medical providers?[4]

2. Where do providers get appropriate cultural information?

3. What distinguishes successful interactions from unsuccessful interactions from the patients' and from the providers' standpoints?

Examining these questions leads to an increased understanding of both provider and patient as they interact while pursuing success in care. In the preceding definition of cultural competency, understanding and response are linked and increasing understanding should lead to an increasingly effective response for providers. Likewise, an increased understanding of patients should lead to an increase in effective response from the patient.

Organization of Dissertation

The next chapter describes the normative, legal, and federal agency connections between healthcare and public administration and policy. Then attention turns in Chapter 3 to reviewing several relevant literatures; the chapter concludes by describing the existing gaps in programming and policy developed without the input of those they are meant to affect and by identifying several impacts of this research. Chapter 4 details the study's methodological grounding. It discusses Forester's (1981) Critical Practical Rationality as an underlying theory for Kershaw's (2003) Scholar-Activist Approach as it is situated in participatory action research; these are complementary in that practical, culturally grounded communication is central to future action, practice, and policy. The subsequent chapter on research design details how the focus group participants and interview respondents were selected, the cities in which focus groups

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[4] Taking into account the Eurocentric, arbitrary nature of "old age" starting at 65, the World Health Organization defines old age at 50 (http://www.who.int/healthinfo/survey/ageingdefnolder/en/index.html). Although this number is also arbitrary and subject to many social, personal, and political dynamics, WHO emphasizes that chronological time is not the most important indicator of old age.

were held, and how the focus group and interviews were conducted; it also discusses the

limitations of the research. Chapters 6 through 9 present the ideas and perceptions collected from

the focus groups and interviews. Lastly, in Chapter 10, I discuss emergent recommendations and

their implications for cultural competency, evidence-based guidelines, and future areas of

research.

Chapter Two

Is This Public Administration?

In chapter 1, the current challenges surrounding type-2 diabetes are presented. Part of that discussion included just where responsibility for addressing health disparity lays. The patients have a complicated relationship to their care. They share the burden, but to focus on the patients' behavior alone would be to ignore several other important relationships. Providers also share in the burden in health disparity, but it is not simply a matter of finding and outing racist or biased individual providers. Health and healthcare disparity are complex, systemic issues that require community, state, and federal interventions.

With each national crisis, cultural expansion, and technological shift, the instrumental boundaries of public administration seem to shift. Public administration in the Unites States is involved in the classification and care of "enemy combatants," the organization and deployment of defense contractors, and the search for and isolation of possible public health risks. Each of these produces tensions that public administration must navigate. Public administrators must decide how to deal with persons that are classed outside Constitutional bounds, work with those not bound by an oath to uphold the Constitution, and discern when to constrain or limit an individual's freedoms to protect the public good. Public administration seems to respond to challenges continuously, including in the sphere of public health. Throughout U.S. history, public health has been a matter for the Departments of the Treasury, Defense, and now Health and Human Services.

Herbert Finer (1925) wrote that the civil service "acts on the theory that the good of the individual and of society may be discovered by the processes of social reason and action, and be implemented through statutes" (as quoted in Spicer, 1995, p.27). Concerned about the effect of

faction and instability in government, James Madison in *Federalist 10* wrote of administration balancing the whims and passions of the citizenry as faction moves to restrict the Constitutional freedoms of other citizens. It is in this position that public administration retains its legitimacy.

Just as public administration is steeped in achieving the general welfare through state agency, the origins of public health are no different. The Blacksburg Perspective (1990) might add that there is a normative requirement as well – that the general welfare also is present in the public administrator's reliance on and protection of the U.S. Constitution. Gostin (2006) and the Manifesto authors would include establishing justice, providing for the common defense, promoting the general welfare, and securing the blessings of liberty as applicable to and necessary in the arena of public health. Wamsley et al. (1990) link this normative responsibility to an expanded interaction with the people.

> It may be, however, that just as the judicial agents of the king developed their reputation by going out among the people and visibly demonstrated the superiority of their practice, The Public Administration's assertion of legitimacy will need to be founded on more direct linkages with the people, in order to win their trust (p. 43).

In this view, public administrators – as researchers and subject area specialists bound by a duty to the U.S. Constitution in service of the public interest – should do the work of governance that involves the people as stakeholders, while increasing their trust as citizens participating in this administrative system.

According to McSwite in *Legitimacy in Public Administration,* "Ultimately, the bureaucracy problem is simply the practical question of how we are going to live together, of the extent to which we are going to rely on the devices of cooperation in working out our national destiny" (p. 13). In similar fashion, *Health and Health Care 2010* provided three "scenarios" for

living together in a way that reduces health care disparity.[5] Only the first envisions cooperation among public health agency directors, private health care providers and organizations, and community-based organizations and leaders as a viable response to changing social needs and responsibilities.

Scenario One: Public-Private Community Partnerships

In this scenario, the medical services now provided by most government agencies are shifted to the private sector through a variety of public-private partnerships. The public health principles – especially those of prevention, shared standards and objectives, and community-based participation – potentiate this partnership. Public health agencies maintain a watchdog role to assure that vulnerable populations are served, but their focus returns primarily to assessment, policy development, and population-level interventions, such as health systems monitoring or monitoring or food and water sanitation systems (IFTF, 2003, p. 182).

The key to the kind of interaction Scenario One describes is dialogue between legitimate stakeholders. The ability of the medical community and public health agencies to converse and cooperate continues to be a key concern. A legitimate position for public health and public administration includes being able to speak to all partners.

Public Administrations Relationship to Medical Practice

I do not argue for public administration's or public health's introduction into medical practice as a substantive expert presence. Public administration and public health administration

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[5] Scenarios Two and Three are public health forecasts that paint a successively gloomier picture. Scenario Two describes a system where dynamic competition is the means of control. Public sector agencies provide the major services, while the private sector provides competition only in the provision of medical services. This scenario assumes that the goals and motivations of public sector agencies mirror those of private entities. Also, Scenario Two does not consider other significant portions of health care and whether those also would be driven by market factors. Scenario Three describes a national public health system that is in complete disarray due to an inability to compete with the private sector or establish state and local relationships. In this scenario, public health processes become "visible" in the form of breakdowns in the provision of basic service (IFTF, 2003, p. 182).

are not concerned with medical technique per se. They are concerned with access to and

provision of those services at the levels of individual, local community, and patient population.

The medical community produces a wealth of public health data through the application of its

techniques. Public administration and public health administration share a responsibility for

turning those data into useful information. They are charged with adding value to "fact." But, the

medical and public health communities have not been able to institute conducive or cooperative

exchanges with each other. They continue to work separately toward common goals (IFTF,

2003). Denhardt and Denhardt (2007) argue that this is part of the very nature of governance.

They write that in valuing citizenship "government will be required to monitor the interplay of

networks to ensure that principles of *democracy and social equity* are maintained within specific

networks and the relationships between and among the different networks" (p. 87). Through

evidence-based guidelines, cooperation and exchange may be more fruitful and services more

available.

 Health and Health Care 2010 presents four reasons for this gulf in cooperation when the

concerns of public health and medicine seem so similar.

  1. The disproportionate allocation of public health resources to publicly funded medicine

  drains capacity and attention from community–wide public service, assessment, and

  policy development functions.

  2. In both the public and private sectors, there is limited cooperation and coordination

  across public and personal health services for the provision of essential disease control

  functions.

  3. Opening Medicaid and Medicare reimbursements to the private sector has reduced the

  resources available to state and local public health agencies.

4. As the [federal] government's public health agency became increasingly involved with the provision of medical care, the general public came to confuse public health with publicly funded medical services with welfare (IFTF, 2003, pp. 178-179).

With these shifts in funds and understanding, the core of public health activities has been restricted. Funds and political attention have moved into the realm of terrorist health threats and away from basic domestic concerns. Hurricane Katrina and increased terror concerns have impacted the manner in which the U.S. Office of the Surgeon General (OSG) allocates resources. In 2007, the OSG listed five public health priorities – disease prevention, health disparities, public health preparedness, health literacy, and organ donation.

This summary of the OSG's priorities demonstrated that although most of the rationales for each priority reflect values (what Americans should be experiencing in public health), the only response that emphasizes funding initiatives and systemic change focuses on preparedness and response to terror. All of the others were aimed at the family unit or community without overt links to federal funding. At least for a time, public support diminished for public health responses reflecting collective responsibility (IFTF, 2003, pp. 178-179).

Since the campaign and election of President Barack Obama, health care reform has gained a more prominent position in public discourse. The current administration has emphasized several points that remain relevant to chronic disease management and, more specifically, diabetes care.

- Insurance reforms to protect consumers from insurance company worst-practices – like denying coverage based on pre-existing conditions, capping total coverage, and dropping or watering down coverage when you get sick and need it the most
- Making preventative care completely free – with no co-payments or deductibles

- Lowering the cost of health care for our seniors[6]

For elder, African-American diabetics, secondary preventive care would reduce adverse outcomes significantly.[7] Removing economic barriers to care would also provide positive incentive to pursue preventative care. Yet, political discussions must be supported by good policy and consistent, critical administration. By looking closely at the nature of patient interaction with providers and health/ health care disparity, administrators and educators may be able to expand and better inform the discussion.

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[6] "Organizing for America," BarackObama.com/Health Care, http://www.barackobama.com/issues/healthcare/. Accessed March 17, 2010.

[7] There are three levels of prevention: primary, secondary, and tertiary. Primary prevention includes "specific practices for the prevention of disease or mental disorders in susceptible individuals or populations" (National Library of Medicine (NLM), 2009, N06.850.780.680). Secondary prevention includes "the prevention of recurrences or exacerbations of a disease that already has been diagnosed. This also includes prevention of complication or after-effects of a drug or surgical procedure" (NLM, 2009, N06.850.780.750). Tertiary prevention includes "measures aimed at providing appropriate supportive and rehabilitative services to minimize morbidity and maximize quality of life after a long-term disease or injury is present" (NLM, 2009, N06.850.780.800).

Chapter Three

Review of Relevant Literatures

Wamsley et al. in "Public Administration and the Governance Process" write that "The Public Administrator should be committed to (1) praxis, critically conscious action or pursuit of goals; and (2) reflectiveness, thoughtful and critical assessment of action taken, in order to learn from experience" (p. 50). The authors connect praxis and reflectiveness to the goal of realizing transcendent purposes. Overcoming health care disparity may well be considered a transcendent purpose. This review of relevant scholarly, governmental, and historical materials attempts to be critically conscious and reflective by drawing together several literatures with the goal of providing a multidisciplinary background for the study. This chapter begins with an overview of how national government agencies have conceptualized public health. Then, I present a summary of communication research and patient perception. After introducing the agency summary and communication, the patient is introduced as a possible and necessary stakeholder in health care. A discussion of the challenges of defining cultural competency follows. The chapter ends by presenting the frameworks of evidence-based medicine and individual decisionmaking.

Public Health through National Government Agencies[8]

This section summarizes how U.S. national government agencies became involved in issues of public health. It is important to see how federal attention has considered economic, national defense, civil rights, employment, and research concerns with regard to public health. Table 1 provides a legislative overview of how national agencies began with the broad issues of

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[8] The legislative timeline is a selective overview. Its purpose is to present a history of public administration created in the production of federal agencies specializing in health and health care. It draws largely in the agency histories contained within the Department of Health and Human Services: The Office of the Secretary, Administration for Children and Families, Administration on Aging, Agency for Healthcare Research and Quality, Agency for Toxic Substances and Disease Registry, and the Centers for Disease Control and Prevention.

national defense and social welfare, and then focuses on diabetes disease management, research

and education among others.

Table 1: Selected Summary of National Agency Health Care Legislation[9]

Year	Legislation
1798	An Act for the Relief of Sick and Disabled Seamen (1 Stat. L. 605)
1870	(16 Stat. L. 169)
1878	Federal Quarantine Act (20 Stat. L. 37), (30 State. L. 976)
1890	26 Stat. L. 31
1902	32 Stat. L. 712
1935	Social Security Act (PL 75-244, 50 Stat. L. 559)
1944	Public Health Service Act (PL 78-410)
1958	Mutual Security Act (PL 85-477)
1964	Civil Rights Act of 1964
1965	Social Security Amendments (PL 89-97)
1965	Older Americans Act of 1965
1965	The Heart Disease, Cancer, and Stroke Amendments of 1965
1970	Health Training Improvement Act (PL 91-515)
1971	Comprehensive Health Manpower Act of 1971
1971	Nurse Training Act of 1971
1974	National Research Act (repeals and reestablishes HTI, CHM, and NR)
1974	National Diabetes Mellitus Research and Education Act (PL 93-354)
1976	Arthritis, Diabetes, and Digestive Diseases Amendments (PL 94-562)
1977	Health Planning and Health Services Research and Statistics Extension Act
1977	Biomedical Research Extension Act
1977	Health Services Extension Act
1992	Public Health Services Act defines "health services research" (PL 102-321)
2004	Pancreatic Islet Cell Transplantation Act of 2004

A federal interest in public health began in a 1798 statute, "An Act for the Relief of Sick

and Disabled Seamen," which established the Marine Hospital Service and created a hospital tax

on merchant seamen's salaries as a means of providing medical care to servicemen in the United

States through the Department of the Treasury. In 1878, the "Federal Quarantine Act" was

created as a matter of national defense – "to prevent the introduction of contagious or infectious

disease into the United States." In 1890, the Marine Hospital Service was given interstate

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[9] This chart does not include all health care legislation. It is a legislative history of federal health care at the agency level.

quarantine authority. These acts are important because they brought the issue of public health into the federal realm. Previously, states retained the right of quarantine and accountability for public health concerns.

Congress then furthered its involvement in public health issues as a matter of national defense. In addition to the quarantine acts, Congress directed the Marine Hospital Service to investigate leprosy in the United States. This represents the first mention of congressional direction regarding a specific disease. In 1902, the Marine Hospital Service was renamed the Public Health Service (PHS) and expanded in mission to include the "diseases of man," information dissemination, and pollution. "The law authorized the establishment of specified administrative divisions and, for the first time, designated a bureau of the Federal Government as an agency in which public health matters could be coordinated" (32 Stat. L. 712).

Although states retained great power with regard to public health, Congress created federal agencies as well as incentives for the states in the form of block grants. In 1935, for example, the Social Security Act established health grants for the states to take more prominent roles in reducing the spread of contagious disease. This act provided a substantive, cooperative, administrative link from the PHS to state and local health services. In 1944, the PHS Act expanded and specified the powers of the Office of the Surgeon General (OSG). It also divided the PHS into the OSG, Bureau of Medical Services, Bureau of State Offices, and National Institutes of Health.[10] A flurry of legislation created the National Institutes and tasked them with specific disease genres to study. Also of note, in 1947 federal appropriations began supporting these agencies.

PHS was placed under the new Department of Health, Education, and Welfare in 1953. At the same time, appropriations increased for interstate cooperation, matching grants to public

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[10] The National Institutes of Health became plural in 1937.

and nonprofit institutions, and research grants. In 1958, the Mutual Security Act gave the president the authority to form agreements with friendly nations to use foreign currency in the production, acquisition, and dissemination of scientific information overseas. This law brought U.S. health services and research into an international conversation and returned public health to its national defense and treasury roots.

With the Civil Rights movements in full swing (producing, for example, the Civil Rights Act of 1964), Congress authorized the National Institute of Child Health and Human Development to support research with a focus on mothers and children. In 1965, Medicare and Medicaid entered public law in the Social Security Amendments, and the Older Americans Act of 1965 was passed. Also, the 1960s saw an increase in direct federal government intervention in health care personnel development. The Heart Disease, Cancer and Stroke Amendments of 1965 "provided for establishment of regional cooperative programs in research, training, continuing education and demonstration activities in patient care among medical schools, clinical research institutions and hospitals so that the latest treatment methods for the three diseases may be more widely available to patients" (NIH). This push to increase the training opportunities for both public health and health care professionals continued into the 1970s with the Health Training Improvement Act, the Comprehensive Health Manpower Training Act of 1971, and the Nurse Training Act of 1971. These training acts were repealed and reestablished in 1974 under the National Research Act as block grants restricted to address subject area shortages.

Also in 1974, the National Diabetes Mellitus Research and Education Act passed. This act provided a coordinating committee and an associate director for diabetes in the National Institute of Arthritis, Metabolism, and Digestive Diseases. The 1976 Arthritis, Diabetes, and Digestive Diseases Amendments added a national diabetes board and commission for long-term

research. In 1977 an example of programmatic efforts authorized in public law extended federal

health care administration into the patient/ stakeholder realm. The Health Planning and Health

Services Research and Statistics Extension, Biomedical Research Extension, and Health Services

Extension Acts of 1977 established various disease control population research and counseling

programs.

It was not until 1992 that "health services research" was defined in national public law

with the addition to the Public Health Services Act. Health services research was defined as

"research endeavors that study the impact of organization, financing, and management of health

services on the quality, cost, access to and outcomes of care" (NIH). This effectively extended

the National Institutes of Health areas to include program analysis, organizational study, and

behavioral studies as matters of agency mission and administrative concern.

The September 11, 2001 terrorist attacks and the subsequent USA PATRIOT Act

refocused health care funds and priorities for a time on biological warfare and preparedness and

linking funding priorities to the Department of Defense and then later to the new Department of

Homeland Security. The laboratories and grant structures of the National Institutes are dedicated

to homeland security concerns. But passage of the Pancreatic Islet Cell Transplantation Act of

2004 illustrated the response to recommendations for legislative and administrative action from

public administrators associated with diabetes research at the federal level, the Diabetes Mellitus

Interagency Coordinating Committee. Clearly, government attention has been on specific

healthcare issues and populations for some time.

Diabetes disparities federal research summary

Attention next narrows to diabetes research at the federal level as it focuses on

disparities. In July 2003, the Agency for Healthcare Research and Quality (AHRQ) released the

first annual *National Healthcare Disparities Report* (NHDR). Public Law 106-129 (1999)

mandated that AHRQ produce the NHDR as well as the *National Healthcare Quality Report*

(NHQR). Section 903(a)(6) of the Public Health Service Act requires AHRQ to collect data on

"prevailing disparities in health care delivery as they relate to racial factors and socioeconomic

factors in priority populations" annually. [11]

AHRQ reported that the level of diabetic services received was connected with levels of

care and access. "Patients of lower socioeconomic position are less likely to receive

recommended diabetic services and are more likely to be hospitalized for diabetes and its

complications" (AHRQ, 2003, p. 6).

The 2004 NHDR presented a starker vision of healthcare disparity, specifically with respect

to race, ethnicity, and socioeconomic status. All dimensions – including quality of healthcare,

access to care, levels and types of care, many clinical conditions, many care settings, and among

many subpopulations – showed significant disparities.

In 2002, by congressional mandate, the Institute of Medicine (IOM) released *Unequal*

Treatment: Confronting Racial and Ethnic Disparities in Health Care., which attempted to

provide insight into the procedural, behavioral, and professional factors contributing to these

well-documented disparities. Its summary findings are comprehensive in nature Racial and

ethnic disparities in health care exist, are associated with worse outcomes, and are unacceptable.

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[11] The 2003 NHDR included seven findings: Inequality in quality persists; disparities come at a personal and

societal price; differential access to care may lead to disparities in quality; opportunities to provide preventative care

are frequently missed; knowledge of why disparities exist is limited; improvement is possible; and data limitations

hinder targeted improvement efforts (p.5).

- The broader American historical and contemporary contexts harbor racial and ethnic discrimination and have direct and pertinent bearing on health care.

- Health care systems, providers, patients, and managers may contribute to disparities.

- Bias, stereotyping, prejudice, and health care providers' clinical uncertainty may be a contributing factor, but more research is needed.

- A small number of studies offer patients' refusal of treatment as a mitigating effect, but – while a small number of patients refuse treatment – it does not fully explain these disparities (p. 19).

These findings suggest that programs and policies should be evaluated and standards created. Public health agencies and policymakers face an increased challenge in balancing public health crises, the business of health, and the practice of encouragement in healthcare communities. But several studies outline a crucial concern: the cultural competency definitions used to drive policy creation and educational curricula are not in agreement.

Summary

This overview has highlighted the entrance of public administration into public health – and more specifically into medical disparity in diabetes disease treatment and management – through congressional action. Public administration, by pursuing the public interest, has an interest in eliminating health care disparity. Attention turns next to research as a means of increasing the success of federal and state public health programs, particularly in the area of coping with diabetes.

Communication Research and Patient Perception

At the meta-level, public health and public health administration research and policy focus on communication research.[12] Forester provides a useful definition of "communicative action."

> Communicative action is a contingent, skilled, practical performance, and when it breaks down, two options arise. Either actors give up the attempt at mutual understanding and cooperative interaction (perhaps to resort to coercion), or they may momentarily step aside from the stream of action to participate in "discourse": a forum in which they may attempt, respecting only the force of the better argument, to resurrect and sustain the conversation – to test a factual claim against the evidence or to justify a normative claim with reasons, so that non-coercive communicative action may proceed (1993, p.72).

Communication is rational action, according to Forester, and practical evidence supports this claim. Better communication between health care providers and patients reduces lawsuits and impacts risk management strategies. "Studies document that the patients of physicians who are frequently sued had numerous complaints about communication. Physicians who had never been sued were likely to be described as concerned, accessible, and willing to communicate" (Goode, Dunne, and Bronheim, 2006, p. 27). While the Goode et al. study connects the perception of the patients to their willingness to file suit, it also notes a direct need for research into perception and communication. "Regretfully, none of the methodological approaches referenced patient, community, or key stakeholder participation in the research other than as subjects" (Goode et al., 2006, p. 30).

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[12] "Communication research focuses on how people use messages to inform, persuade, manage, relate, and influence each other in various contexts and cultures, using a variety of channels and media" (NCA, 2002, p. 4).

Perloff et al. make a case that agencies at the federal, state, and local levels should demonstrate an interest in communication and its importance to national health care outcomes and cultural competency. They list the following research needs.

- Carefully conceptualize and operationalize the concept of cultural competency;

- Define cultural competence from the lens of the recipients of health care;

- Determine whether there are a set of skills that create cultural competence for all groups of patients and whether there are more specific elements that need to be learned for specific cultural groups;

- Make greater use of qualitative research methods, given the ability of this methodology to capture the rich texture of health discourse;

- Examine the stereotypes that clinicians carry into the clinical encounter;

- Explore ways in which minority patients' beliefs unwittingly influence the trajectory of doctor-patient communication;

- Examine how physician appreciation of cultural norms (for African Americans, role of family and friends, strong sense of the present, spirituality) can enhance doctor-patient communication;

- Pinpoint the ways that race, as opposed to class, influences patient –physician communication, as well as effects of class/ raced interactions; and,

- Systematically study connections between doctor-patient communication and key health care outcomes, such as satisfaction, compliance, and wellness (Perloff et al., 2006, p. 849).

As a means of increasing systemic competence, tailored interventions are coming into vogue. "Message tailoring is the process of developing a specific, behavior-focused

communication based on an assessment of individual characteristics" (Campbell & Quintiliani, 2006, p. 776). Message tailoring may be as simple as changing the "Resident" portion of a health mailing to the actual name of the intended recipient. It may be more complex as more and more demographic information is added.

But, while the benefits of tailoring are growing, setbacks do occur that reverberate through communities. For example, a recent spate of news articles and broadcasts (e.g., CNN, Fox News) has alerted those taking the diabetes drug Avandia that there is a 43 percent increase in heart attack and stroke associated with the drug. This drug was heavily marketed to African-American diabetics, with television commercials including individuals like poet Maya Angelou. For a population historically skeptical of government, medicine, and medical practitioners, these kinds of incidents are disheartening at best.

In this contemporary example, the power of communication and the intersections with patients' perceptions and doctors' justifications are life-impacting. [13] Recommendations from government officials, researchers, and doctors come into direct conflict with an informed, suspicious, fearful patient base. The former's expectation seems to be that patients should continue to follow a medical regimen that, according to some evidence that has not been discredited either directly or through subsequent recommendations, may be putting them at great risk. The only proof of harm that a medical institution will respond to is an actual heart attack – no small requirement – even with the presence of an effective alternative.

Discussions about Avandia send many mixed messages. The tailoring seems successful in its ability to reach a targeted community – the African-American community. The tailoring has had an unforeseen, but strong negative effect in that it effectively placed a possibly detrimental drug in the African-American diabetic community. The discussion also highlights the privilege

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[13] For further discussion, see Appendix 3.

of definition and expectation of the medical community above patient communication even in ethically murky instances. According to the FDA, researchers and doctors, it is "good" for these patients to remain on Avandia. Avandia is considered successful – due to its FDA-approved status – until there is a preponderance of evidence otherwise. For the patient, this can support a continued mistrust and fear of medical providers and experts at all levels – federal, state, and local. It may well be that an ability to view patients as lesser participants in care facilitates an ability to ignore or minimize their concerns.

The Patient as Stakeholder

I maintain that patients are stakeholders in care. Freeman and McVea (2001) define a stakeholder as "any group or individual who is affected by or can affect the achievement of an organization's goals" (p. 2). Taking cues from both systems theory and organization theory, these authors write that identifying stakeholders is very important. "From a systems perspective, problems can only be solved with the support of all the members, or stakeholders, in the network. Systems theory emphasizes the development of collective strategies that optimize the network. … Individual strategies would simply result in sub-optimal network solutions" (p. 6). A stakeholder, once identified, becomes an integral concern in the development of collective strategies with the purpose of optimizing the network. According to this definition, stakeholders may be individual, but the focus is on strengthening the network by utilizing stakeholder input.

McVea and Freeman (2005) revisit three assumptions traditionally associated with stakeholders. In a corporate model, the customer, manager, employee, shareholders, and suppliers are distinct. Each role has a department dedicated to its concerns. Patient care attempts to follow a similar model. Stakeholders have been identified economically politicallyas medical providers, community health educators, and state and federal government health administrators.

Doctors, insurance carriers, state and federal government officials, and pharmacies endeavor to deal with each through distinct functions. But, McVea and Freeman argue, the model is far too simple to account for the stakeholder as defined above.

- Customers may play a significant role in designing, not simply just purchasing, innovative products and services … Employees who are direct shareholders may act differently from employees who are not shareholders and differently again from those who may hold shares only through their pension funds.

- Second, these role assumptions fail to capture opportunities for integration, that is, designing innovative entrepreneurial strategies and products that satisfy multiple stakeholders simultaneously.

- After all, if stakeholders and customers are just roles, not real people with names, faces, and families, then one may easily rationalize taking from one group and giving to another (perhaps to which one belongs) as just business (p. 58).

McVea and Freeman present stakeholder theory as both normative ethics and social science. They suggest that viewing patients as stakeholders presents an opportunity for greater mutual success. McVea and Freeman argue that ownership, and perceived distance from ownership, matter in the behavior of those who are participants in this system. Also, the patient may be a competent contributor to successful strategies. Lastly, McVea and Freeman contend that treating stakeholders as separate from their humanity (e.g., names, faces, and families) opens the opportunity for ethical challenges including moving services from one group to another in a biased fashion.

Ferguson and Candib (2002) write that provider participation at the patient level directly impacts outcomes and sets the tone for issues of compliance.

Minority patients, especially those not proficient in English, are less likely to engender

empathic responses from physicians, less likely to establish rapport with physicians, less

likely to receive sufficient information and less likely to be encouraged to participate in

medical decision making. These characteristics have all been linked to patient

satisfaction, patient compliance, and care outcomes in the general literature on the doctor-

patient relationship (2002, p. 359).

Viewing and interacting with patients – here, elder, African-American diabetics – as

stakeholders offers an option that does precisely what providers, state and federal officials, and

insurers all pursue: improved patient compliance and positive care outcomes, with the added

benefit of patient participation and satisfaction. The next section examines attempts at

stakeholder strategies, including cultural competency intervention.

Cultural Competency in Medical Practice

Cultural competency has become a strategy in the battle against disparate practice in

several fields including medicine. Medical schools are including more overt and covert

competency training within curricula, and "cultural competency brokers" are creating databases

of those consultants who offer linguistic services. But the definitions of competency continue to

multiply. Collectively, the definitions of cultural competency deal with multiple levels of

change, including those of individual interaction, practice, and organization. "There is no single

definition of cultural competence. Definitions have evolved from diverse perspectives, interests,

and needs and are incorporated in state legislation, federal statutes and programs, health and

mental health organizations, and academic settings" (Goode, Dunne, and Bronheim, 2006, p. 2).

Across those definitions one thing is clear: the patient is not treated as a stakeholder.

The definitions of cultural competency seen in Table 2 also provide a window into current views of cultural competency as a strategy. Scott and Backman (1990) write that "the professions rule by controlling belief systems. Their primary weapons are ideas. They exercise control by defining reality – by defining ontological frameworks, proposing distinctions, creating typifications, and fabricating principles or guidelines for action" (Scott and Backman, p. 290).

Table 2: Selected Definitions of Cultural Competency[14]

Definition	Source
An awareness of, sensitivity to, and knowledge of the meaning of culture	Dillard et al, 1992, p. 72
People who have moved from being culturally unaware to being culturally sensitive to their own issues and to how their values and biases affect racially different patients/clients	Pope-Davies et al, 1993, cited in MacDonald and Rowe 1995, p. 287.
Cultural Competence includes an awareness, understanding and acceptance of behaviors, attitudes, and beliefs of other groups. It also includes implementing policies in the health care systems or agency that enable staff to work effectively in cross-cultural situations.	Hodge et al, "Achieving Cultural Competence and responsive Health Care Delivery," 1998
Cultural competence is defined as a set of values, behaviors, attitudes, and practices within a system, organization, program, or among individuals and which enables them to work effectively cross culturally. Further, it refers to the ability to honor and respect the beliefs, language, interpersonal styles and behaviors of individuals and families receiving services, as well as staff, who are providing such services. Striving to achieve cultural competence is a dynamic, ongoing, developmental process that requires a long-term commitment.	Toni Brathwaite-Fisher & Susan Bonheim, National Center for Cultural Competence, U.S. Dept. of Health and Human Services. "Cultural Competence and Sudden Infant Death Syndrome and Other Infant Death: A Review of the Literature from 1990 to 2000," 4 (2001).
Cultural competence is defined simply as the level of knowledge-based skills required to provide effective clinical care to patients from a particular ethnic or racial group.	Bureau of Health Professions, U.S. Dept. of Health and Human Services, "Other definitions of Cultural Competence," http://bhpr.hrsa.gov/diversity/cultcomp.htm
Cultural competence in health care describes the ability of systems to provide care to patients with diverse values, beliefs, and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs.	Joseph R. Betancourt et al. The Commonwealth Fund. "Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches Field Report," 2002
Cross-cultural competency includes the ability to interact with others and to have knowledge of information that is specific to each culture	Chan, 1990, cited in Gujral, 2000
Cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations.	The Lewin Group, Inc. "Indicators of Cultural Competence in Health Care Delivery Organizations: An Organizational Cultural Competence Assessment Profile," 2002.
Cultural competence is defined as a set of congruent behaviors, attitudes, and policies coming together in a system or agency or among professionals that enables effective interactions in a cross-cultural framework.	Shams-Avari, "Linguistic and Cultural Competency," Radiologic Technology, 2005

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[14]This is a sampling of cultural competency definitions drawn from the health care literature. These definitions give an overview of how this concept has developed. The list is not meant to be comprehensive.

The selected definitions contain clues to the beliefs and values of the medical community. It is possible to see both what cultural competency is worth to those participating in these discussions and the present focal institution(s) beliefs. I have culled the "beliefs" and "truths" presented in Table 3 and 4, respectively, from the definitions in Table 3. They are snapshots and provide initial insight into the normative aspects of cultural competence as it has been defined.

Table 3: Beliefs Illustrated in Analysis of Cultural Competence Definitions

- It is a skill, ability, or practice to be possessed by medical providers.

- It can be defined and evaluated.

- It is about providing care (provider focus).

- It focuses on the needs of staff to accomplish care provision.

- Effective care remains highest priority

- The provider does not exist within a culture (professional/ acultural).

The definitions are based on the assumption that cultural competence is isolated to the provider's skill set and is a way of mitigating the inefficiencies in treating and interacting with the patient. The message becomes that effective care can still be given *in spite of* the barriers or complications of the patients' culture. Ikemoto (2003) outlines three themes :

- They (the definitions) acknowledge that health care has a culture of its own and that cultural competency requires adjusting that culture.

- They demonstrate that cultural competency goes beyond awareness and sensitivity; it requires effective use of that knowledge and awareness in situations.

- They acknowledge that health care is a social construct consisting of different values and beliefs about central concepts such as the body, wellness, illness, and decision-making.

Yet, at the same time, the definitions of cultural competence focus on the provider's skill development without balancing that with commensurate attention to the patient. My main criticism of cultural competence as it is generally defined is the orientation of the definition. The definitions, as Table 2 suggests, emphasize the medical provider. The "truths" about culturally competent care taken from these definitions outline what providers do or do not see as valuable (Table 4).

Table 4: Truths Illustrated in Analysis of Cultural Competency Definitions

- Culturally competent care is accomplished separate from self (acultural).
- Partial success is possible.
- Culturally competent care is not about receiving care (not patient focused).
- Culturally competent care does not focus on effective care relationships.
- The provider defines effective care.
- Culture is an external hindrance to effective care.

Ikemoto (2003) writes that "generally, the prime social and political fact behind efforts to implement cultural competence in health care is that the patient population is diverse in the United States, but health care, at the organizational, structural, and clinical levels, is not" (2003, p.98). The medical provider community has experienced continuous challenges with regard to the racial, ethnic, and gender diversity of medical staff (Hodge, Toms, & Guillermo, 1998; Sanchez-Hucles & Jones, 2005; Wilson, 2004). These challenges are reflected in the embedded truths in Table 5. The medical provider remains inviolate so long as cultural competency is an external process – a skill set. If the focus is on the comfort and efficiency of the provider, the interaction is in jeopardy. If (the patient's) culture is viewed as a hindrance, there is bias and cultural incompetence.

During medical training, doctors and nurses experience a training method that, in times when they cannot understand or trust the patient, encourages them to rely on other information –

e.g. patient history, cultural knowledge, statistics – instead of on potentially unreliable information from the patient.

> Doctors must depend on inferences about severity based on what they can see about the illness and on what else they observe about the patient (e.g. race). The doctor can therefore be viewed as operating with prior beliefs about the likelihood of patients' conditions, "priors" that will be different according to age, gender, socioeconomic status, and race and ethnicity. When these priors – which are taught as a cognitive heuristic to medical students – are considered alongside the information gained in a clinical encounter, both influence medical decisions (AHRQ, 2003, p. 9).

Ferguson and Candib (2002) write that "subconscious bias occurs when a patient's membership in a target group automatically activates a cultural stereotype[15] in the physician's memory regardless of the level of prejudice the physician has" (pp. 624-25). Doctors have been trained to respond to extra-verbal information (Ferguson & Candib, 2002; ARHQ, 2003).

> In practice, however, culture is more often assumed that assessed. For example, race and ethnicity are often used as proxies for culture. Such variables may be important – even central – parts of a given culture but are not, in and of themselves, culture. All African Americans, for example, do not share a single monolithic culture. Rather, many cultural subgroups may exist, and any African American may belong to one, none, or several (Kreuter et al, 2003, p. 134).

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[15] "Stereotyping can be defined as the process by which people use social categories (e.g., race, sex) in acquiring, processing, and recalling information about others. The beliefs (stereotypes) and general orientations (attitudes) that people bring to their interactions help to organize and simplify complex or uncertain situations and give perceivers greater confidence in their ability to understand a situation and respond in efficient and effective ways" (AHRQ, 2003, 10).

In addition, patients evidently respond to socio-historical or experiential promptings (Shams-Avari, 2005). Between these two understandings, the provider's and the patient's, disconnects may occur that contribute to health care disparities.

Currently, cultural competency is measured by the doctor's ability to effectively manage the patient's care, but there is little discussion of what patients perceive as respect or even "effective care." The focus rests on manipulating behaviors, diagnosing illness, and avoiding insult/confrontation. The patient is accommodated, but not has yet to be understood or addressed.

Medical providers and patients respond to social, historical, and cultural signals. At some level – conscious or subconscious – they are aware of cultural norms. This web of social assumption influences the patient/provider interaction including diagnosis and self-care. El-Kebbi et al. (1999) demonstrate this as they tracked the frequency of treatment intensification. If patients were perceived by nurses as noncompliant with some aspect of self-care, they would not be considered for treatment intensification although other indicators might suggest it. These treatment strategies are associated with the providers' assumed knowledge of the patients' racial, ethnic, and social backgrounds.

In these cases, the providers' levels of competence– at provider-focused reading and manipulation of patient behaviors – may be increasingly ineffective at achieving desirable care outcomes. In order to meaningfully affect health care disparities and foster more positive patient/ provider interaction, greater information is needed to supplement existing cultural competency standards and indicators. At the most fundamental level, this diversity in definition, practice, understanding, and implementation of cultural competency from the provider perspective presents a significant issue when one looks critically at evaluation and reporting of patient behavior, design of provider training, and basic assessment of patient compliance. Many research

efforts focus on the provider as source and authority. The study here focuses on assessing competency and success from the patients' perspective.

Challenges of "blame" regarding health care disparity

I have presented several criticisms of providers' cultural competency. But, there are significant disagreements about whether health care disparities are usefully defined and whether responsibility is rightly assigned. Klick and Satel (2006) take issue with two aspects of disparity research. One presents possible discrimination within the "biased-doctor model" where the intent of the doctor is to treat patients differently. The second revolves around "'third factors' correlated with race" (2). Klick and Satel argue that the entire discussion is stilted and inflammatory. They present a different reading of numerous studies and contend that the over-emphasis on race obscures other more salient indicators of population distribution, population density, provider density, and provider availability. The authors highlight three reasons for differences in health care if there is to be a practical policy response. Those explanations are found outside of the doctor's office. "Indeed, for answers to the race-related differences in health care, it turns out that the doctor's office is not the most rewarding place to look" (2).

1. White and Black patients do not visit the same population of physicians – making the idea of preferential treatment by individual doctors a far less compelling explanation for disparities in health.

2. Doctors whom black patients tend to see may not be in a position to provide optimal care.

3. Because health care varies a great deal depending on where people live, and because blacks are overrepresented in regions of the United States served by poorer health care facilities, disparities are destined to be, at least in part, a function of residence (2).

Due to these factors, Klick and Satel contend, "bias" should be replaced with "difference." Also, according to these authors, uncertainty and stereotyping must not be confused. Difference, they write, is dependent on other things. Bias is not an institutional issue, according to Klick and Satel. It is a matter of individual doctors adjusting their behavior and not a matter of bias in the medical system.

> Negative stereotypes, in the end, may be best addressed through the self-correction that comes from calling attention to their existence. Journal clubs (weekly gatherings of medical professors and trainees to discuss newly published research) and bedside teaching rounds are good venues to develop the habit of being mindful of the complexity and subtlety of clinical discretion and assumptions made within the doctor-patient relationship. … To our knowledge, there exist no systematic, prospective evaluations of physician decision-making in relation to patient race, let alone of the clinical results of such decision-making (25).

Although Klick and Satel disagree with the basic arguments that would make providers a point of interest in the disparity discussion, they do agree that studies focusing on the perspectives of doctors and patients should be completed. "To perform an accurate assessment of the complex relationship between race and medical care, we need many more prospective studies that ask doctors and patients about how they make decisions to offer and to accept, respectively, particular treatments" (10). Klick and Satel ask for further study, but they pair this need with a request for sensitivity to the medical community. They ask for studies, and researchers, that do not assume a racist stance on the part of providers.

Klick and Satel's three points outline major historical arguments about racism in any American institution. They argue that minorities experience segregation both in location and in

the quality and proximity to physicians seen by the majority population. Due to this segregation, doctors and patients experience reduced quality of care because of restricted care networks. Klick and Satel link these arguments to the decisions of doctors to operate in sub-optimal regions in the United States. Perhaps, the two outline factors that Freeman and McVea would label "system" issues. Medical schools and federal programs have been created to help individual doctors change clinical behaviors, but there also is a need to effect change at the system level.

The HHS Office of Minority Health writes that "because of the large number of potentially confounding variables it is very difficult to show a direct link between a cultural competence intervention and health status improvements and/ or cost savings" (Fortier & Bishop, 2003, pp. 4-5, as quoted in Perloff et al.). Nonetheless, there have been very compelling community and cultural interventions at the level of community programming and within hospitals. In a Manhattan example, the community interventions were successful at changing patient behaviors and increasing compliance with physician recommendations (Urbina, 2006).[16] There are examples of success at multiple levels. Patients discuss their needs being met and providers are operating in ways that reduce risk of suit. Evidence-based medicine, a way of taking the weight of omnipotence from the provider such that other avenues of information and strategy are available, gives providers and patients new opportunities for interaction and treatment.

Evidence-Based Medicine, Guidelines, and Individual Decisionmaking

Evidence-based medicine (EBM) is "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (p. 9). The term came into vogue after researchers began to look more closely at the variation in doctors' patterns of practice. Beginning in the 1970s, researchers discovered that doctors were treating illnesses in

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[16] For further discussion, see Appendix D.

vastly different ways with no increased success. "When different physicians are recommending different things for essentially the same patients, it is impossible to claim that they are all doing the right thing" (Eddy, 2005, p. 10). EBM became a means of correcting basic, expensive, and incorrect assumptions within the field.

David Eddy coined the term "evidence-based" to combat pervasive myths about patient care and physician capacity.[17] He took issue with "global selective judgment," depicting an all-knowing medical field; "consensus-based," a non-evidence based understanding among practitioners; and "preference-based," traditions of care held by individual doctors. He argued that "guidelines and related types of policies should be based on evidence, not subjective judgment or consensus" (Eddy, 2005, p.11). But, although he coined the term, he has come to consider its use too restrictive because the definition is being used to exclude myriad applications. Table 5 summarizes Eddy's discussion of the challenges preceding EBM and the considerations necessary to create lasting change.

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[17] D.M. Eddy, (1990), "Practice Policies: Where Do They Come From?" *Journal of the American Medical Association*, 263.

Table 5: Definitions and Assumptions of Evidence-Based Medicine, Evidence-Based Guidelines, and Evidence-Based Individual Decisionmaking

	Evidence-Based Medicine (EBM)	Evidence-Based Guidelines (EBG)	Evidence-Based Individual Decisionmaking (EBID)
Level of Analysis	Meta-level All of medicine with respect to all individual, generalized patients	Population level: Policies or guidelines concerning circumscribed, distinct, generalized, patient groups	Individual level: Concerning the decisions of individual doctors and patients.
Definition	"The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (14).	Small, sponsored groups of specialists creating generic, population-targeted, policy products through an explicit, rigorous process with indirect effect.	"Done by individual physicians, using implicit and personal methods, to make decisions about individual patients and directly determine their care" (14).
Previous Schema	"Art of medicine" and "clinical judgment" allowed for complete synthesis of all contributing research, medical history, professional history, and patient factors.	The "if-then" rigidity of medical decisions suited most if not all situations and created a reliable standard.	An individual doctor's decision is based on clinical research.
Fallacy prompting EBM	Variation in practice patterns regardless of patient or treatment shows that universal judgment and synthesis is not happening.	"If-then" decision matrices shown to be based on beliefs/ traditions of patient load and not evidence.	Key study demonstrated that only 15 percent of practices were based on clinical trial and when examined "taken for granted" practice was shown to be ineffective during trials.

Adapted from David Eddy's (2005) "Evidence-Based Medicine: A Unified Approach," *Health Affairs*, Vol. 24, Number 1.

EBM is a meta-level concept that includes the entirety of modern medicine. It is concerned with patients as generic individuals in numerous arenas: for example, evidence-based coverage, evidence-based performance measures, evidence-based medical necessity, evidence-based benefit design, evidence-based disease management, evidence-based quality improvement. EBM becomes evidence-based guidelines (EBG). EBG are generic policies targeted at a specific clinically identified population, or grouping, of patients. EBG affect physicians, and indirectly, the care given to patients. "That is, they (EBG) are intended to enable, guide, motivate, or sometimes force physicians and other types of providers to deliver certain types of care to people; they do not directly determine the care provided to a particular patient" (p.13). EBG are necessary due to the increase in influences on medical providers including political interest groups, advertisers, patient preferences, insurance providers, culture, environment, economy, time constraints, litigation, and personal factors. They also provide patients with a standard by which to judge their available care and options, both of which are integral to the production of informed stakeholders.

Swinglehurst (2005) offers a discussion of clinical practice guidelines (CPG) that demonstrates the presence of old assumptions even as EBGs are held as a step forward. CPG are "systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances" (p. 308). Eddy writes that physicians once believed that guidelines were only for communicating with uninformed lay people. "Guidelines were merely a way for experts to pass occasional pieces of advice to nonexperts" (2005, p. 10). Swinglehurst presents a rubric with which EBG's should be evaluated by individuals. Swinglehurst argues for what Eddy has described as evidence-based individual decisionmaking (EBID).

EBID is "done by individual physicians, using implicit and personal methods, to make decisions about individual patients and directly determine their care" (14). EBM and EBG both depend on the individual practitioner or patient being able to access and distill appropriate, generic evidence available in hopes of making an informed decision for individual care. EBID is a means of educating providers and patients on how to identify what is appropriate and how that evidence may apply to their situation. EBID is the conduit between theory, policy, and practice. It does not provide an "if-then" statement or a decision tree that may ignore salient factors. It does, however, provide insight into how administrators and policymakers may aid doctors, care providers, and patients without trespassing within the boundaries of provider care. EBID identifies areas in which training, guidelines, and information may be provided so that the use of EBM realizes its potential. Swinglehurst identifies several potential benefits: improved efficiency, reduce wasteful practices, improved quality, reduced economic burdens, improved health outcomes, improved consistency of care, normative standards for care, empowerment for patients, directions for public policy, and the promotion of social justice and equity (2005, p. 309).

The major impact of EBID for elder, African-American diabetics is a significant lack of directly relevant evidence. As has been mentioned, "noncompliance" is decided based on the personal beliefs of individual doctors.

Conclusion

U.S. public law and agency action have outlined the presence of medical disparity in health care. The reasons for these disparities and their impact on minority populations are difficult to discern, but bias and provider behavior have been identified as contributing factors. Patient communication, stereotyping, and disagreement on key definitions constrain the ability to

understand and mitigate these factors. But unless patients are included as stakeholders in their care, in research surrounding that care, and as partners in developing health care strategies, future attempts to reduce health care disparity may be jeopardized. This dissertation addresses the gap in these literatures, policies, and practices by approaching elder, African-American diabetics as stakeholders in successful care. This research may have the following impacts.

- Provide insight into a patient-focused definition of cultural competency.

- Produce information that may be used to examine existing cultural competency rubrics.

- Identify stereotypes that patients perceive within the patient – provider interaction.

- Identify stereotypical patient behaviors/ responses that providers perceive.

- Explore ways in which patient beliefs influence the trajectory of care outcomes.

- Understand patient and provider viewpoints with regard to satisfaction, compliance and wellness.

- Suggest key areas in which information is being misperceived.

Once definitions are addressed, and areas of misconception and misperception identified, further steps toward dismantling health care disparities may well become apparent as recommendations for guideline generation with the elder, African-American diabetic population and direction with regard to individual decisionmaking.

Chapter Four

Methodological Grounding

Health and healthcare disparity has been discussed on the level of the individual (patient and provider), community, and agency (state, federal, third-party stakeholder). I suggest that patients – elder, African-American, diabetics – be invited into their personal care and policy discussion as stakeholders. Authenticity in this research depends on patients participating in the design and implementation. This chapter discusses the assumptions and guidelines inherent in this research. First, I discuss the distinctions between action, participatory action, and participatory research. Next, critical practical rationality and the scholar-activist approach suggest guidelines for keeping the process grounded in the experience of the participants while engaging the process as an analyst. Finally, I present a pilot study as an example of how interdisciplinary research allowed this present research to emerge.

Action, Participatory Action, and Participatory Research

Action research (AR), or participatory action research (PAR), is a natural, group, planning process made deliberate. Kurt Lewin was foundational in operationalizing and coining the term "action research," which described a cyclical process of reconnaissance, planning, action, monitoring, analysis and evaluation (Tripp, 1990, p. 159). The hope of action research is that as the cycle continues there will be motion toward more strategic action based in evidence instead of habit and opinion. But there are several ways to consider AR or PAR.

Action research is an umbrella term with many facets. Tripp (1990) offers three kinds of action research: technical, practical, and emancipatory. Technical AR describes the ability to perform a task. Practical AR describes the normative assumptions within an action. More specifically, AR/PAR was developed to help organizations in industrialized nations increase

efficiency and task accomplishment through consensus (Zannetti, 1997). The reigning

assumptions are that solutions can be found that satisfy a consensus of stakeholders, and that

resource distribution as well as authority are considered legitimate within the applicable

stakeholder groups (*ibid*). The assumptions within AR/PAR are key. When there is inequity in

resource distribution and legitimate authority, PAR must be reassessed. To deal with this

challenge, Tripp argues for emancipatory action research as a critical arena within AR.

Emancipatory AR examines the social assumptions (about, for example, power, justice)

supporting the technical and practical versions. Tripp distills emancipatory action research into

Socially Critical Action Research (SCAR) as a melding of social critique and action research.

"The important point in socially critical action research is that neither social critique nor action

research are adequate without the other" (p. 161). SCAR contains five characteristics:

participation, direction, consciousness, constraint, and outcomes.

 Zanetti (1997) agrees with Tripp with regard to the need for critical practice and begins

to examine the need for a form of SCAR in public administration. By tracing the intellectual

traditions underpinning critical theory, Zanetti argues that the pursuit of critical theory in the

Marxist and Habermasian traditions produced a gulf between theory and practice that the

application of participatory research (PR) may bridge. Participatory research is to public

administration what SCAR is to education. PR is a means of reinvesting in the legitimacy of

disempowered stakeholders' experience in times when resources seem scarce and legitimate

authority elusive.

> The starting point is the lived experience of people, usually oppressed and powerless,
>
> with the purpose of producing knowledge and action that is directly useful to a particular
>
> group. … Additionally, participatory research seeks to empower the individuals in these

groups by helping them discover and understand the ways in which the "establishment"

monopolizes the production and use of knowledge for the benefit of its own members

(Zannetti, 1997, p.159).

PR, in acknowledging and examining social assumptions, seeks to produce action that impacts

the situations of the group involved.

In this dissertation, the objective was to aid elder, African-American diabetics to become

more successful in managing chronic illness. For this group, the assumptions of AR/PAR are not

consistently present. The lack of equitable resource distribution and the illegitimacy of their

authority within their care have not been addressed. The research was firmly situated in

participatory research and socially critical action research.

Tripp and Zanetti have provided key distinctions within AR/PAR and PR. Forester's

Critical Practical Rationality offers a more pointed approach for keeping the researcher/

administrator/planner's sights on the people as well as the process. Kershaw's Scholar Activist

Approach adjusts the researcher's lens in a way that privileges the socio-cultural experiences of

the elder, African-American participants with whom I worked in a legitimating way.

Critical Practical Rationality and Kershaw's Scholar-Activist Approach

If bureaucracy is concerned with how we do live together, then normative public

administration is concerned with how we ought to live together. More specifically, normative

public administration is concerned with balancing Constitutional rights, political concerns, and

general welfare. Habermas reminds us that the normative values behind rational decisions and

goals are important (Forester, 1981). Forester offers the term "critical practical rationality" as a

means of bridging the gap between theoretical considerations and those administrative activities

and decisions that are made at the ground level. Critical practical rationality allows practitioners and theorists to come together.

> [Critical practical rationality] preserve[s] and enhance[s] processes of interpretation and value formation, dialogue and political discourse; thus it promotes critically reconstructive decisions gathering together instrumental know-how and systems knowledge to explore and formulate responses to questions of right action, good design, and good planning in specific cases. As it considers action fundamentally communicative, socially constructivist, so does the practical-rational model extend beyond and overcome the systematic inadequacies of instrumental and systems rationalities (Forester, 1981, pp.165-166).

For Forester the key question is "To what ought I pay attention?" This question, and those like it, allow for systems to be examined in their technical aspects, but also bring forward actors' consideration and understandings. Forester connects the act of attention building as a skill set that public administrators must develop in order to communicate in a fashion that produces right action, good design, and good planning. "As the planning analyst's questioning shapes diverse activities of response, so does the administrator's or planner's analysis shape design" (Forester, 1981, p.170).

In order to assess impacts, interactions and meaning, the context of those experiencing a particular process is important. For example, designing all diabetes intervention programs alike without accounting for demographics (e.g., income, sex, age), geographic location, and accessibility age likely would be less effective than some consideration of the target audience(s). In this example, communication becomes more than a benign activity. Practical communication

opens the way for creative inputs, advice, support, relevancy, legitimacy, and increased civic engagement and response.

Public administrators can shape attention by adopting or introducing a normative framework that allows for numerous foci of attention and voices, in addition to the attention paid to the technical aspects of job performance and goal completion. Without this type of consideration, Forester draws a dismal picture. "This leaves planning practitioners all too often as frustrated Machiavellians, technicians, or rulemongering bureaucrats; what we are missing, and what we in the planning and policy fields anxiously, if not desperately, need, is the illuminations of questions of 'how-to' with a politically and ethically articulate and critical sense of 'what-for'" (p. 165).

National trends and percentages, as discussed previously, have given an impressive to-do list with regard to minority populations and chronic illness, specifically in the African-American community. Forester's view of purpose here is emancipation." 'Emancipation' must be intimately tied to practice overcoming those distortions of communications shaping our knowledge of one another, ourselves, our possibilities – including feasibilities and strategies" (p. 194). Forester's application of emancipation provides an opportunity to appreciate this "positive" definition. He has taken great care to create a definition that does not abandon anyone to an inescapable sense of blame or guilt. Instead, it allows for a critical glance at history and its effect on the greater systems in which public administrators must move. He ties the activity of reconciliation to the activity of administration through communication. Future, possibility, and strategy are all linked in the strength of attentive administrative communication and critical practical rationality. This is a critical challenge in minority communities with regard to health care. There is a need to uncover a strategy that enables agencies and practitioners effective

communicative access to these communities. Terry Kershaw's "Scholar Activist Approach" is one method of keying in on a particular community in order to discover a better way of communication that may lead to a more responsive community.

Perception and communication are growing areas of interest in the medical field. For elder, African-American stakeholders, the ability to hear and understand is one consideration compounded by a need to be heard and understood. "None of the methodological approaches used participatory action research models, and patient, community, or key stakeholders were involved only as subjects" (Goode et al., 2006, p. x). Patients are experiencing situations where there is troubled communication. Within action research, Kershaw's Scholar-Activist Approach is one perspective that allows the researcher to shift the privilege of communication to a different group.

I used the Scholar-Activist Approach to center and focus this study on how the focal stakeholder group considered success in their interactions with health care providers. It will be necessary to respond to the expectations assumed in some academic work. The research makes no claims of "objectivity," but focuses on the experiences and emergent definitions of elder, African-American diabetics from their perspectives. It did not, and indeed could not, discover any "universal generalizations," but endeavored to see actions and events within specific social contexts and interactions. As a centered, qualitative study, I strove to be driven by context-specific evidence in a way that can be repeated by other scholars and recognized by the participating communities. Kershaw offers five assumptions that guided this kind of research (see Table 6).

Table 6: Assumptions within the "Scholar Activist Approach"

Assumptions	Implications
1. Reason for Research	Relocating African people to their "African" center(s).

	Describing and explaining the agency of Africans in the shaping of their life experiences. Empowering Africans to positively affect their life chances and experiences. Generating "authentic" knowledge.
2. Nature of Human Beings	Acting from a cultural center and in own best interest.
3. Role of Common Sense	Consisting of intuition and individual and group understandings based on historical and cultural context.
4. Theory as an Approach and Orientation to Data	Connects African people to their common heritage. Rejects the agenda of any oppressor (historical and cultural specific). Seeks to ensure harmony throughout humanity. Searches for "truth."
5. Place of Values	All research begins with a value position. The research must reflect an understanding of the subject group's value system.

Source: Kershaw (2003), p. 34

The Scholar-Activist Approach identifies the context in order to gain a deeper understanding of a focal group in response and in conversation with national statistics regarding cultural medical disparities. It was important that the research be conducted and presented in a way that is authentic and meaningful[18] to the elder, African-American community.

Perloff, Bonder, Ray, Ray, and Siminoff (2006) bring Kershaw's approach directly into the patient/ provider relationship by identifying levels of meaning within their communication. They highlight places within this communication where misinformation and assumption may damage the care relationship and outcomes. (See Table 7).

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[18] I use the words meaningful and authentic here to invoke two specific thoughts. In order to be authentic in the Scholar-Activist setting, this research must be centered in the African-American experience in the sense that it is "entitled to acceptance or belief because of agreement with known facts or experience; reliable and trustworthy" or "conforming to fact and therefore worthy of trust (*i.e.* an authentic account by an eyewitness)." Meaningful is defined as "full of meaning, significance, purpose, or value; purposeful; significant"; it has a more generic connotation. Significance could be drawn vicariously from any number of locations without contributing to or citing the African-American experience.

Table 7: Levels of Meaning in Patient/Provider Communication

Levels of Meaning	Patient	Physician
Ideological	In some cultures, communal or familial interests take precedence over the interests of an individual	The individual interests of patients supersede those of families or related communities
Sociopolitical	Patients with limited education and/ or English skills do not want to appear stupid or waste the doctor's time, so many do not ask a lot of questions. Even so, they would like to know what is wrong and how it can be fixed.	The more questions patients ask, the more they wish to know about their condition.
Institutional/ Professional	People should be suspicious of medical research because too often they have been used as guinea pigs.	Medical research is good and necessary. It expands clinical knowledge and improves patient care.
Ethnocultural/ Familial	Doctors may know the best prescription medicines to take, but other people can advise sick people on other ways to feel better.	Home remedies are often dangerous. Even if they do no harm, they have no scientific basis.
Interpersonal	Whether voiced or not, patients make their own choices regarding their bodies.	It is important for physicians to control, or at least have a significant role in, medical management.

Source: Perloff et al., 2006, p. 837.

From a Western medical and policy standpoint, voice becomes a battle of privilege. The patient's

choice, voice, and perception are pitted against the authority and institutional values of the

physician. The "Physician" is to be engaged for information, ceded control of the patients' body,

and unencumbered by patients' cultural comforts and identifiers. But through the Scholar

Activist lens, which focuses on the value and importance of the patient's interaction with the

physician, the patient becomes a participant instead of a possible danger to him or herself. The

patient exists in many different locations and calls upon different webs of information,

affirmation, and decision. Communication becomes more important as these webs of

understanding widen. Policymakers and medical providers need a richer understanding of these interactions. The patients' words and experiences in combination with the providers' input provide a basis for understanding and definition. The next section summarizes five perceptions that give increased insight into the patients' perspective.

Blood Glucose Monitor Pilot Study and Five Emergent Patient Perceptions

In line with the principles of action research, this dissertation began through an associated exploration and analysis within the "Use and Design of Blood Glucose Monitors" pilot study conducted by Dr. Tonya L. Smith-Jackson, Sharon Dwyer, Lisa Tabor, Ying Hu, and Yu Hsiu Hung. The purpose of the study was to examine and compare the interaction of diabetic, elderly non-Hispanic Anglo-Americans and African Americans with blood glucose monitors in order to examine the design assumptions of these monitors. Design assumptions are those things that are assumed in the production of medical devices including users' vision, dexterity, and technological awareness.

Participants in the pilot study were identified through advertisements in area newspapers, churches, community centers, diabetes support groups, newsletters, and personal recommendations. After initial contact, each individual was screened through phone interviews. Initially, the participants were limited to those over the age of 65. Due to limited availability and participation, this age was adjusted to 55 years old**.**

Respondents participated either in individual interviews or in focus groups. The interview and focus group samples were distinct and did not overlap with each other. Individuals in both completed demographic information sheets and the Multigroup Ethnic Identity Measure (MEIM) cultural relationship inventory.[19]

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[19] J. Phinney. (1992). The Multigroup Ethnic Identity Measure: A new scale for use with adolescents and young adults from diverse groups. Journal of Adolescent Research, 7, 156-176. This tool was readjusted for age group. The

The interviews were conducted with European-American participants and African-American participants. These interviews were audio recorded. Applied focus groups were conducted with African-American and Anglo-American participants. The African-American groups were facilitated by an African-American woman, Dr. Smith-Jackson. The Anglo-American groups were facilitated either by an Anglo-American or by Dr. Smith-Jackson. The focus groups were given specific tasks to perform with two different sets of glucose monitors, after which each participant completed a questionnaire about the monitors' ease of use, weight, feel, shape, and understandability. After each questionnaire was completed, the group was asked to respond orally to questions about their experiences with each of the monitors. Several members of the research team were present to read documents and to assist when necessary, but they did not aid the participants during the specific activities. The participants' hands were videotaped as they performed the individual tasks. No other part of the focus groups was recorded. Field notes were employed to record participants' actions and responses during the entirety of the focus groups. Included in the prescreening, individual interviews, and focus groups were questions designed to explore the participants' relationships with health providers, daily use of monitors, diabetes history, and support networks.

Through basic content analysis, five themes emerged that suggested a need for further investigation:perception of respect, perception of information availability, perception of intelligence, perception of control, and preconceived perception. These issues of perception impact the nature and utility of care these patients receive. "Certain cultural traditions can lead to critical misunderstandings with dire consequences. These misconceptions contribute to a distrust of the health care system, potentially resulting in people avoiding medical care" (Shams-Avari,

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survey provoked an interesting response in that some of the African-American participants objected to being so specifically reminded of their race. One participant refused the instrument.

2005, p. 439). The patient's understanding of their provider's response can affect the quality of their provider interaction and relationship. When the patient's perception of care and the provider's perception are at odds, the relationship and effectiveness of care will be hindered, and disparity across individuals and groups may result.

> Physicians rated African Americans as less likely to be the kind of person they could be friends with, as being less likely to be free of substance abuse problems, and less likely than Caucasians to be interested in an active lifestyle and cardiac rehabilitation. Finally, physicians rated African Americans as less intelligent and less educated than Caucasians. All of these relationships were stronger if the patient was from a lower socioeconomic class (Ferguson and Candib, 2002, p. 354).

Although not all providers fit this mold, these responses inform the patient's ability to interact, understand, and trust information given by their provider. At the same time, patients and providers will have difficulty discerning what information is needed but not given. With regard to cultural competency, attention also must be paid to what information is given but unnecessary.

Theme 1: Perception of Respect

U.S. history in its entirety provides an ever present backdrop for elderly African Americans in their interactions with medical providers. As discussed earlier, historical precedent and national health care disparities serve as catalysts for prolonged patient concern. But here the concern is two-fold. Not only is the patient concerned that the provider has little respect for them or their opinions regarding care, but the patient also expresses concern for their self-respect within cultural boundaries. Many of the African-American participants in the pilot study preferred to ask trusted friends and family about monitors and care before asking their doctors.

Some even considered the doctor to be a last resort. Respect and control seemed closely linked in participant responses.

Theme 2: Perception of Information Availability

To the patient, the ability to seek and understand information from their provider is complex. If respect is not perceived, the patient will rely less on their provider and more on information from third-party sources, including friends, family members, printed/Internet/electronic resources, and bodily indicators. In some cases, all other available sources were signaled as being of higher priority and exhausted as options before contacting the doctor except in extreme circumstances.

Some participants considered the doctor to be infallible, but did not request information from him or her. Others saw doctor contact as a sign of personal failure. A portion of participants waited for the doctor to communicate necessary information or updates.

Theme 3: Perception of Intelligence

African-American participants strongly asserted their intelligence during interviews and within the focus groups. Intelligence and ability to understand technology and/or the doctor's instructions were considered to be closely linked. Not being able to understand was tantamount to admitting "stupidity." Participants communicated that telling their doctor these things would change their doctor's opinions of them.[20]

Theme 4: Perception of Control

Issues of control rose as important to participants in both ceding control and avoiding reliance on their care provider. Lacking control over their health and behaviors increased stress

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[20] All of the Blood Glucose Monitor pilot study participants were proficient in English.

and produced reactions ranging from embarrassment to helplessness to anger. Having to rely on a medical provider produced the same types of reactions. Trust and reliance would likely be placed on loved ones and friends before the care provider.

This theme also may be associated with financial concerns. As costs of diabetes medications continue to rise, an inability to continue or even begin drug treatment regimens can adversely affect the efficacy of patients and their willingness to communicate this to physicians. One physician gave an example that reduced cost concerns for at least one patient. The HbA1c test is a test measuring blood glucose carried within the red blood cells. Some diabetics call this the "cheater's test" as it enables physicians to monitor glucose levels for a three-month period. It involves the consumption of an unpleasant substance and an average two-hour wait. This physician, cognizant of the cost, sends clients to a local ice cream shop and tells them to return at a specific time in order to perform the test. This change, while unorthodox, is less taxing on the patient, relieves the pressure of some costs, clears the doctor's office, and provides an instance where compliance is almost completely assured without embarrassing the patient or exposing sensitive financial information.

Theme 5: Preconceived perception

African Americans in this pilot study showed either extreme deference or extreme self-sufficiency with regard to doctors' advice. This seemed to be a function of how they perceived the doctors' social responses to them. If they felt the caregiver respected them, they would defer. If there were doubts about the levels of trust or perceptions of the patient's intelligence, they might distance themselves from care. Anglo-American participants differed. They expressed greater confidence regarding their interaction with healthcare providers, including a different

level of expectation regarding professional treatment, preventative care, and ability to change providers, as well as less concern about costs.

Perceived levels of cultural understanding were an issue for the African-American participants. They spoke of inconsistencies between their culture and the doctors' understanding. Anglo-Americans also mentioned communication issues, but attributed none to culture; the communication issues mentioned were related to technology and instances of care management.

Perceptions: Summary

These five kinds of perceptions are a starting point for balancing the definitions and applications of cultural competency. They point to a more complex interaction between these patients and their providers than has been discussed widely in the research and training literatures. These perceptions may allow us to see health care disparities more completely. Patient perception, in concert with provider perception, is important.

The pilot study demonstrated that valuable information was being ignored from the patients. In the following chapter, Research Strategy, I describe how the focus groups were produced and vetted within the groups' communities. For the interviewed providers, the process was just as important. Grounded Theory, and its application in this research, is defined in Chapter 5 as well.

Chapter Five

Research Strategy

The pilot study stimulated my interest in finding out more about what patients perceived as "successful care" and in comparing these views with those of medical providers and educators. In exploring the lived experience of patients, caregivers, and providers in coping with diabetes in the elder, African-American community, his study endeavors to increase understanding of how elder, African-American diabetics and care providers interact.

This chapter describes the methods used in the research including the generation of focus groups and provider interviews and the application of grounded theory methods. First, I describe the process of creating the focus groups generally and, more specifically, the circumstances under which the individual focus groups were assembled. I look as well as at the provider interviews. Next, I explain how grounded theory methods are applied with examples of the generated analysis. Lastly, I discuss the limitations of this research. Table 8 provides an overview of the research methods, participants, and locations. Each will be discussed more fully in subsequent sections.

Table 8: Study Participants

Focus Groups		
• African-American men and women of at least 50 years of age diagnosed with Type II diabetes. Diagnoses were self-reported by participants.		
5 Focus Groups • Mean Age: 65.9; Median: 64.5 • 17 women; 10 men (1 not reported) • Mean level of education: 13 years.	**28 participants** • Group A: 10 participants • Group B: 3 participants • Group D: 1 participants • Group E: 9 participants • Group F: 5 participants	

Diabetes Summary
• 21 with diabetes
• 5 without diabetes (caregivers or relatives)
• 2 status not reported
• 9.9 years since first diagnosed
• 5 currently on insulin
	Insurance Summary
	• 24 insured (4 not reported)
	  o 10 Medicare
	  o 1 Medicaid
	  o 7 privately insured
	  o 9 insurance not specified	

"Successful" provider interview group (4)
• 18 total recommendations
• 12 contact information available through internet search
• 10 available for interview (1 number disconnected; 1 refusal due to unavailability)
	Providers selected and defined by focus group participants as "successful."
	• 3 Doctors (Male)
	  o 2 General Practitioners
	  o 1 Endocrinologist
	• 1 Registered Nurse (Female)	

Comparison providers (1/4)	Randomly selected from same geographic area as "successful" providers	Contacted through colleagues (other physicians, chaplains) within focus group areas.
	Lack of availability and access limited this group to one interview. That interview was not included in this study.	
Areas of Recruitment	**Proposed**	**Actual**
	Hampton, Virginia Richmond, Virginia Roanoke, Virginia Staunton, Virginia Washington, D.C.	Suffolk, Virginia Roanoke, Virginia Washington, D.C.

The recruitment strategy for the focus groups included contacting Diabetes Centers in

Virginia and Washington, D.C., health departments, state and local community health educators,

local churches, and community centers to find participants. I used snowball sampling, a form of

purposeful sampling (Patton, 1990), by asking those who volunteered for referrals of others who would be eligible to participate in the focus groups. The recommended providers were another purposive sample. As a comparison group, I tried to produce a sample of providers whom patients did not identify, but was not successful.

Focus Groups and Unconventional Researcher Vetting

My evidence comes from five focus groups of elder, diabetic, African-American patients, and interviews with practitioners whom patients considered "successful". As discussed earlier, "elder" here draws on the World Health Organization's definition of elders as those 50 years old or older. Originally, participants in this study were to be drawn from Richmond, Virginia; Hampton, Virginia; and Washington, D.C. These sites were chosen because of the perceived population density of both patients and providers. This strategy was amended due to lack of participation in several areas and economic constraints affecting my ability to travel to those sites. Actual participants were drawn from the Suffolk, Virginia; Roanoke, Virginia; and Washington, D.C.

I used focus groups to collect data from a specific kind of patient. This research emphasized patients describing their understandings of "successful" communication with providers. There are no relevant archival data as these stakeholders have not been queried in a consistent fashion. Surveys also were not an appropriate choice since they would not provide data rich enough for meaningful interpretation to emerge.

Through focus groups, I facilitated discussion of how the individuals were diagnosed with diabetes, their health care histories, strategies for provider selection, strategies for self-diagnosis, descriptions of visits, and support networks. Focus groups are the best method for this research for several reasons. First, they tap into human tendencies and promote self-disclosure (Krueger,

1994, p. 10).

Second, the research questions required an analysis of perceptions garnered from in-depth data. Individual interviews of patients also would have provided such material, but such individual experiences might have been too idiosyncratic. With focus groups, patterns in perceptions were more likely to emerge (Krueger, 1994). Also, exaggerations and other forms of community play should be more obvious.

In addition, with the focal community of interest, having knowledge of each other may or may not help increase comfort with disclosure. In my prior personal and research experience, elder, African-American diabetic open up to one another about health issues because of their commonalities in experience and health. They also appreciated being "heard." The focus groups consisted of people who knew each other socially. But the participants did not always know of each other's being diabetic.

Focus groups create an atmosphere where discussion may be guided with the understanding that the researcher is there to be informed by the group. My status as a young African-American minister and doctoral candidate was useful for gaining access, increasing trust, and clarifying my intentions.

Recruitment details and group description

In this section I describe how each focus group was advertised and assembled. After receiving approval from the Virginia Tech Institutional Review Board, advertising in several cities began. Initially, the cities included Washington, D.C., Richmond, Va., Hampton, Va., Roanoke, Va., and Staunton, Va. I contacted area churches known for having substantial African-American memberships, area diabetes clinics, hospital systems, and community centers. Each location was repeatedly called and contacted by email. I received no participants through

this method. Additionally, several interesting responses came from each type of location, which are presented in Table 9.

Table 9: Responses to Study Request by Type of Location

Types of Locations	Response
Community Centers	Committed to posting a flyer.
Hospital Systems	Refused to participate at all, including posting a flyer, unless the project was approved through the hospital's IRB.
Diabetes Clinics	Committed to posting a flyer; several did not respond due to not having filled their director's position.
Churches	Committed to adding an announcement to their church bulletin. This may or may not be read each Sunday. If the church had a health initiative coordinator or senior's group coordinator, information was forwarded and calls attempted.

In an attempt to increase response rates, I returned to the VT IRB in order to offer compensation to focus group participants. A $50 gift certificate to a local store was given to one participant in each focus group. The gift certificate came from a local store with a grocery department. Participants saw this more as beneficence rather than a contest. Most were glad to see the gift card go to someone they considered deserving by either financial need or strength of character. In one instance, one participant said, "I am glad X got it. She took off work to be here and she needs it." The rest of the group happily agreed. The recipient was chosen by giving each participant a number. Then, I or another non-participant drew the number, and the card was delivered to that participant.

Repeating the same strategy with the addition of the gift card did not immediately change the response rate. Since compensation did not seem to be the issue, I altered my recruitment approach. I began to look for an individual who would act as a coordinator within each community since I could not recruit on-site due to financial restrictions. When I located these

individuals, I began to find participants. The concern evidently was not about compensation. The participants responded to someone they trusted from within the community. I was an unknown to them at the time. Each group addressed me its own way. As I attempted to find focus group participants, several experiences became standard. For the first five months after Institutional Review Board approval, I contacted institutions including community centers, hospital systems, diabetes clinics, and churches throughout Virginia and Washington, D.C. The contacts were made primarily through phone, mail, and e-mail. I received no prospective participants during this time. I attributed this non-response to a lack of tangible incentives for participants. In August, I was able to offer an incentive for each group – a $50 gift card to a local store. This modestly improved contacts, but participants were still slim. The most successful strategy, consistent with recruitment strategies used in the pilot study, was physical presence and a trusting organizing contact in the local community. If I showed up for vetting and someone from the local community vouched for me, then I was able to secure a focus group. Consistently, however, groups could not be assembled if I did not present myself prior to the group in some form and have a local contact.

Individual patient interviews would have been useful for gathering information, but the group interaction itself is just as important. The interplay of focus group members enlivened and enriched the discussion. They literally called each other out. Frequently, one participant would share a practice and another would say "That's not right. You're not supposed to do that." They also would ask questions of each other and vocalize their appreciation of the opportunity to talk to one another about diabetes. One focus group included a healthy discussion of recipes and small changes that could be made to beloved, but contraband foods to make them healthier.

Without the group interaction, certain information would not have been communicated because of the perception that I, as researcher, already knew the information.

Characteristics of Individual Focus Groups

Focus Group 1 – Suffolk, Va.

This group met at an area African-American church. A Virginia Tech student put me in touch with her grandmother who is a member of this church and diabetic. I did not call the grandmother directly, but the student contacted her on my behalf. After that introduction, I was given a number and told to call.

I spoke with the grandmother several times. I described the project and its purpose. I was asked about my own background and interests, including church affiliation, ordination, education, and marital status. She asked that I mail her a project description, flyer, biography, and picture. After she received this packet, she set up a group. I later found out that she asked for the picture because she was unsure of my ethnicity over the phone.

The group was to meet after a regularly scheduled prayer meeting. At first, I was to be present at the prayer meeting. At a later time, I was asked to present a lesson. The focus group itself consisted of diabetics and non-diabetics. I discovered this as we began to do paperwork. I decided to include the non-diabetics to reduce disruption and maintain the level of comfort. I found out during the focus group that the non-diabetics were family members of the diabetics who gave consistent information regarding their loved one's medical care and experience. If I had excluded those members, I would not have gotten a full picture of their experience.

Focus Groups 2 and 3– Washington, D.C.

These groups, like the first, would not have happened without a local contact. A staff minister who is diabetic agreed to participate and encourage others to participate. The contact also asked about my background. She appreciated my student status and was willing to help for that reason. She organized two groups that would meet on the same day. The first group consisted of three people – two women and one man. The second group had only one individual. The rest of the possible participants were relying on one other for transportation, but the driver had emergency dental surgery the prior evening. This interview was difficult in that without peers being present, it was very hard to discern when he was in "storytelling/ entertainer" mode. His recollections seemed fantastic in some ways so that I was somewhat suspicious of some of the details he provided. Having other group members present may have provided clues to any possible exaggerations or validated his experiences.

Focus Group 4 – Roanoke, Va.

For this group, I was invited to participate in a church service and deliver my plea for participants personally. The group was held after a service with a significant turnout. There was a retired researcher present who "observed" the focus group. Interestingly, his presence was very supportive. He did not comment during the group, but encouraged those participating as they were leaving about their participation. The group dynamic was interesting as there was a man with significant speech impairment who was a stroke survivor. Speaking was difficult, but he could sing perfectly. The group was extremely comfortable with aiding each other in filling out forms and giving time for all involved to speak freely.

Focus Group 5 – Roanoke, Va.

This group also was facilitated by a staff minister who is diabetic. Actually it took two meetings in order to facilitate this group. The first time the group was scheduled to follow a church service. I participated in the service including adding an appeal during the announcements. At the end of the service, several people assembled in a conference room. I noticed an unease in the room as I described what we were about to do. Spontaneously, but in complete agreement, they began to reschedule the focus group. They were not prepared to fully participate this Sunday, but the following Sunday was agreeable. With that decided, we talked more about the project and its purpose. This first meeting dealt with all fears and concerns. Because of their concerns, I allowed them to read through the list of questions. They left the first session much calmer than they arrived. The second meeting was richer for this. Everyone was comfortable with the purpose and their level of participation. They aided each other with paperwork. After the focus group, they stated that they felt a higher responsibility for each other than before. They considered the focus group a type of intervention that made their diabetic status less of a secret.

Surveys

At the beginning of each focus group, I asked the participants to complete a short survey that asked if they would recommend their provider as "successful," The respondents also filled out a survey providing basic demographic information (age, sex, income range, and educational level attained). I informed all participants of Institutional Review Board procedures, confidentiality, informed consent, and the need for audio recording for project analysis. The recordings were transcribed. I used recordings because I conducted interviews and focus groups as a lone researcher. By using audio recordings, I could make note of non-verbal cues, highlight conversations, and more fully facilitate the group. (See Appendix for draft focus group and

interview questions.) I used Atlas.ti for content analysis of the transcribed focus group and interview comments. Grounded theory was the method of analysis (see below).

Provider Interviews

I conduct provider interviews with those who were recommended. Providers were not compensated. Each focus group participant was asked whether they considered their provider successful at dealing with elder, African-American diabetics. They wrote those names on a sheet and circled "yes." If they did not consider their doctor successful, they circled "no" and were instructed not to provide a name. Some patients were ambivalent about whether they considered their doctor successful or not. In those cases, I asked them to provide a description of why they felt that way on the provided sheet and not to give a provider's name. I only added this option if the focus group participants raised the issue.

I contacted the recommended providers – general practice physicians, specialists, and nurses – for individual interviews after completing the focus groups. Patients recommended a total of 18 practitioners. I identified 12 of the 18 through internet searches. One doctor declined due to scheduling conflicts, and another's telephone number had been disconnected. The remaining 10 were contacted for interviews; four accepted. (See Table 9) I informed them that they had been recommended as "successful" with this particular community. It was my hope that this "recommendation" would allay fears of racism or litigation. In these interviews, I asked about their experiences with this population, any pitfalls they had encountered, strategies they used, perceptions of compliance, how they thought clients perceived them as providers, whether and how their thinking had changed since beginning practice, and how they defined success in patient interactions.

The comparison providers initially were to be chosen from an Internet-generated list of

providers in the same geographic areas as those recommended by patients. Due to a lack of

response, hospital chaplains, retired physicians, and other physicians were asked for contacts.

That list was checked against the list of patient-selected providers to avoid any overlap.

Comparison providers were informed about the nature of the study without comment about

whether they had been recommended or not. Two providers responded to telephone solicitations,

but only one submitted to an interview. That interview was not included in this study because I

was concerned about the level of conceptual density in the comparison provider group.

Analysis using Grounded Theory and Kershaw's Scholar-Activist Approach

Analyzing the focus group transcripts requires that Kershaw's Scholar-Activist approach

be revisited. This dissertation research was designed to privilege the patients' voices as opposed

to the researcher's or the health care providers'. From this perspective there are several

expectations/assumptions, including that discussions will be "authentic" to the community from

which they are generated, that analysis will work to explain the agency and shaping of the

participants' life experiences, that participants will describe their own best interests within their

cultural setting, that rejection of oppression is acceptable and expected, and that an

understanding of the subject group's value system will be reflected. This return to the Scholar-

Activist Approach is key so that the participants' experiences, definitions, and contradictions

may be heard and so that, through grounded theory, the themes that emerge are true to their

thoughts – at least as reflected in discussion and interaction.

With these assumptions in mind the grounded theory process began. Glaser and Strauss

(1967) offer the analytic strategy of constant comparison. This means that the research questions

guide coding and that coding was consistently defined so that it could be applied to the analysis

of each transcript. Some categories were consumed within more appropriate categories or where

repetition or overlap was present. Categories formed in the pilot study were explored, but not to the exclusion of new ones. Also, those categories were not exempt from dismissal. This method of coding and categorizing continued until "saturation," the point at which coding more transcripts produced no new categories.

Application of grounded theory concepts

In "Remodeling grounded theory," Glaser summarizes and defends grounded theory against recharacterization as a sub-theory within qualitative data analysis. He writes that "the goal of GT (grounded theory) is conceptual theory abstract of time, place, and people. The goal of GT is NOT the QDA (qualitative data analysis) quest for accurate description." I will use Glaser's article as a frame for describing how I applied grounded theory methodology. I will discuss these elements of GT: theoretical sensitivity, getting started, all is data, use of the literature, and coding.

Theoretical sensitivity

Theoretical sensitivity, according to Glaser (2004), describes the researcher's capacity for conceptualization and theory development. "The ability to generate concepts from data and to relate them according to normal models of theory in general, and theory development in sociology in particular, is the essence of theoretical sensitivity." Glaser describes two preconditions for a researcher interested in developing theoretical sensitivity: 1) a particular temperament that allows for emergence, patience, and trust with regard to the data, and 2) an ability to develop and utilize insights developed within a given research area. "He/she must have the ability to conceptualize and organize, make abstract connections, visualize and think multivariately." Glaser suggests that the researcher enter the research with as few preconceived notions as possible including research questions.

My theoretical sensitivity was tested and developed throughout the dissertation process. My temperament and insightfulness will be evident in the resulting work. As for preconceived notions, when the germ for this dissertation began I had none. During the pilot study, I was a short-term, graduate research assistant in public administration hired for a human factors engineering project. My job was to interview and help convene and facilitate focus groups with elderly, African-American diabetics. The project was to evaluate the usability of hand-held blood glucose monitors. This involved allowing participants to interact with several brands of monitors. This project was novel to me. It allowed me to view the research population with "new eyes." In this mode I began to see that when asked if they could perform specific actions, the focus group participants would verbally affirm their ability, but then could not manually complete the tasks. During the interviews, the participants would say things like "No one ever asked me that" and be genuinely surprised that someone would want to know how they worked through their disease management including their concerns about the process.

I began to wonder about other aspects of diabetes management, physician interaction, and patient concerns. I began to take health care policy courses and look into the statistics surrounding African Americans and diabetes only to discover that the statistics were well developed in order to define the impacts. Yet, the qualitative explanations for the statistics were not as well developed. There was a hole there. I began to wonder, with the current advancements in diabetes care, why this population was still experiencing this level of negative outcomes. Through the pilot study, statistical, and study data, the research setting and initial interests emerged. Because of this prior exposure and experience, I was able to satisfy the dissertation process requirement of research question generation.

Getting started

Glaser identifies several blocks to getting started. These include specific parts of the dissertation process: preconception of a problem, creating a methods chapter, and producing a literature review. His argument is that in doing these things that one is building a cache of preconceptions about the research and may seek to force the data to fit them. Yet, as discussed previously, working with the blood glucose monitor project allowed conceptualization to begin prior to the formal dissertation proposal process. According to Glaser, "the focus and flow [should be] immediately into conceptualization using the constant comparative method" (2004). My emergent questioning and interest predated the dissertation process and allowed subsequent investigations to become part of the data and method. My goal was to see "why there was a discrepancy in outcomes" by focusing on two key players – the patients and medical providers. Glaser's mandate is "to remain open to what is actually happening and not to start filtering data through pre-conceived hypotheses and biases to listen and observe and thereby discover the main concern of the participants in the field and how they resolve this concern" (2004). Focusing on elder, African-American diabetics as central to discerning the main issues as well as the resolutions to those issues was the means by which I remained open. Kershaw's Scholar-Activist Approach is a grounding method that allows the patient's perspective to be the hub around which the discussion turns. The concepts and their definitions emerged from the patient participants and their experiences.

All Is Data and Use of the literature

Glaser truly means all is data. Grounded theory as a methodology can be utilized in both qualitative and quantitative research. Classic grounded theory appreciates that all data are viewed through a "human" lens, but resists the application of additional restriction. "The data may be

baseline, vague, interpreted, or proper-line. The data may not be discounted as 'subjective,' 'obvious,' 'constructed,' etc, as we find in QDA critiques" (2004). In this dissertation, each chapter is a summation of several types of data. As a chapter, the literature review is another way of allowing the problem to emerge in several contexts in patient-provider interaction and communication.

Coding

Coding, in grounded theory, is a way of examining every line and incident for what that piece of text is communicating. Beginning with substantive codes, those codes that are most immediate to the text, and then developing theoretical codes, those codes that represent the relationships surrounding substantive codes, the writer works toward forming theory. Glaser writes that "coding gets the analyst off the empirical level by fracturing the data, then conceptually grouping it into codes that then become the theory that explains what is happening in the data" (2004). Open coding is where the process begins.

In the open coding phase, each line or incident is examined for a code. As coding continues, general groupings become relevant. When coding the focus group transcripts, the large, vague categories of codes emerged like "doctor-patient interaction." Although I used Atlas.ti to code, I printed out the major code area and recoded it. I looked for sub-themes within doctor-patient interaction, and it became a theoretical code with several themes. I then returned to Atlas.ti to construct new codes. Doctor-patient interaction initially contained 112 substantive codes, codes linked directly to an incident in the text.

An example of this coding and then recoding can be seen with the following quote. First, this quote was included in the category "doctor-patient interaction."

At first the doctor didn't say much to me and I would have-because-- You know, my

mother was a diabetic. And, I know what happened to her. And at first I thought the

doctor was just brushing me off. During that first visit, because she was busy doing

something else, and that's when I got a little angry, a little impatient with her, and I told

her that, no, she had to talk to me. And, after that, it was easy.

This quote represents an incident between a patient and her doctor, generally. As I recoded,

looking more specifically at the substance of the initial code, other codes emerged. Privileging

Experience, Attention, and the Patient-Doctor Feedback Loop were associated with this incident.

Privileging experience, when the patient's personal experience is used to evaluate their current

experience with their doctor, is evidenced when she says, "You know, my mother was diabetic.

And, I know what happened to her." Attention, the ability of the patient to feel like the focus of

the visit, comes out when the participant describes feeling brushed off due to the doctor's

multitasking. The feedback loop is demonstrated by the patient's vocalization of anger and

impatience to the doctor and the doctor's change in manner toward that patient. When the patient

says, "And, after that, it was easy," she is referencing a shift in behavior as well as a shift in her

level of communication with the provider. The initial coding of doctor-patient interaction is a

substantive code describing concretely the content of the incident. Privileging experience,

Attention, and the Patient-Doctor Feedback loop are theoretical codes that allow a conceptual

view and patterns to emerge.

Theoretical sampling

The process for data collection began to define itself through my participation in the

human factors engineering study. That study, including interviews and focus groups, along with

the quantitative and research data described in the preceding chapters all aided in defining the

data collection process used in this dissertation. Glaser (2004) defined two requirements for data

collection emergence: what categories and their properties are to be sampled further, and where to collect the data. For this study, both patients and doctors would be sampled. More specifically, African-American patients who are 50 years of age or older were interviewed in a focus group setting. Also, medical providers who were recommended as successful by the participating patients were interviewed individually. Initially, another group of non-patient recommended providers was to be interviewed. The points of data collection were those locations most comfortable to the participants. Participation, from either group, about this topic hinged familiarity and comfort. Patients did not participate in a process wholly foreign to them. Providers did not participate in a process they did not trust. Through a semi-structured question strategy, I was able to follow the lead of the group or individual as they communicated what was important within our discussions.

Atlas.ti, qualitative analysis software, designed with grounded theory in mind, allows all transcripts to be drawn into a single hermeneutic unit. As a hermeneutic unit all codes can be systematically applied to each transcript consistently. Once the coding is completed, the codes are further categorized to identify larger themes. Atlas.ti allows codes and quotations to be grouped spatially, connected visually, and categorized uniformly. This is very useful as information from all transcripts is available and can be considered from a centralized, emergent code sheet without moving between individual transcripts.

Limitations

Addressing the limitations of this study presented a continual challenge. Doing this research at all was a challenge in that the focal population – elder, African-American diabetics – is not accustomed to being a part of research. They are skeptical, fearful, and anxious in a way that mainstream researchers sometimes overlook. Elder African-Americans – especially those

who live in southern regions of the United States – do not normally share their illnesses with others. I have been to many funerals where the dominant statement among the deceased's peers is some version of "He/She was never sick a day in their life." They may not share illnesses with family members and abhor having their infirmities broadcast to the community. I, as a researcher, was constantly vetted by elders as they navigated my background in order to discern my level of trustworthiness. As a scholar-activist, I have a burden and a responsibility to be true to this community in all its facets while attempting to tell their secrets to an academic and ethnic population they have learned to distrust. I am trusted and treacherous in the same moment. One participant waited until the digital recorder had been turned off to deliver a whispered warning about racist social behaviors and what personal behaviors were necessary to receive respect in a broader, majority context. Whether he "liked" his doctor's was irrelevant, he said; whether he could cause them to respect him was much more important.

Also, I was the only researcher on this project. I did not have the resources to employ another to validate codes or attend focus groups. But this project acknowledges a certain level of subjectivity within the method, which is not uncommon with qualitative, constructivist-based methods.

My pilot study experience had shown that there was a chance that this research might contain a large percentage of people who would describe themselves as "church attending" or "religious." This held true for the groups relied on for the dissertation research. This may be for several reasons. Many elder African-Americans may rely on religious organizations as social environments as well. Faith can be an integral factor in their daily health and healthcare decisions. Historically, this has been the case; the African-American faith community has been and is historically significant. Although I tried to recruit outside of the church, its community

importance (real or perceived) evidently meant that participants were still "church folks" or involved in faith communities regardless of their recruitment environment. At the beginning of recruitment, I sought neutral environments for focus groups to avoid excluding those who would participate, but would not be comfortable in a religious setting. When it became obvious that the groups would be organized around church communities, the group chose the locations most comfortable and accessible for the group –their local church. A consideration for future research in this area would be how to get participation from a wider population.

I also needed to be careful not to overreach in my analysis of collected data. Because I may share some cultural experience with the groups, whether in terms of familial, social, heritage, religion, or educational background, some interpretations are invisible to a majority community. I only include these types of interpretations if they are validated by the patient community.

This study stayed within the lived experience of elder, African-Americans with the intent of presenting their perspectives. Although this research can and should be extended to other racial, ethnic, gender, chronic disease, and age communities, I limited the scope of this study to elder, African-American diabetics. For my purposes, this community is identifiable, visible, and relational. Given my position as student, clergy, and youth (to most), my levels of access were enhanced in this community. I anticipate widening this study in future research.

I expected some challenges with regard to the medical provider interviews. Several circumstances occurred. Despites multiple "recommendations" from the focus groups, other factors whittled away at the number of recommended providers interviewed. I did not anticipate that written recommendations would be illegible. Also, several patients could not recall the spelling of their provider. At least one provider retired during the time of the study. For the non-

recommended provider interviews, there also were several challenges. When contacting physicians' offices, I had to convince the administrative and nursing staff that the project was necessary and worthy of the doctor's time. Staffers told me that the doctor was busy and could not participate. In some instances, this was prior to any message being left for the doctor. The staff's duty as gatekeeper was interesting and had significant effect on access to medical providers. Also, for at least one non-recommended provider a lack of compensation was a significant barrier. For the recommended providers, the idea that a patient had recommended them seemed to be compensation enough.

Chapter 6

Focus Group Analysis of Physician Manner

The research questions guided how I approached the data. In the analysis of the focus groups, I concentrated on those questions that linked directly to the focus group participants, elder, African-American diabetics:

- **What motivates/ hinders elder, diabetic African-Americans to increase interaction with their medical providers?**

- **What distinguishes successful interactions from unsuccessful interactions from the patients' standpoints?**

This analysis arises from the patients' perspective with regard to their health care experiences. Focus group participants identified two meta-level interactions to which other interactions are related. In this study, these interactions are called "Physician Manner" and "Patient Manner." Physician Manner and Patient Manner are meta-level codes for the web of behaviors and interactions that the patient perceives as related to the physician or to them as the patient, respectively. As a means of organizing these data, analysis will be organized using the strength of groundedness. Codes and concepts will be discussed in order, from highest to lowest level of groundedness. For example, Physician Manner compared to Patient Manner has the higher level of groundedness. This chapter will focus on Physician Manner, and Chapter 7 examines Patient Manner.

Table 10: Meta-level Codes from Focus Groups

Meta-level Codes (Density*)	
Physician Manner (77)	Patient Manner (34)
Super codes under **Physician Manner**	**Super codes under** **Patient Manner**
Physician Behaviors (39)	Patient Self-Management (71)
Communication (36)	Discovery of Diabetes (18)
Compliance (25)	Family Influence (7)
Diabetes Education (19)	Patient Self-Perception (5)
Process (6)	
*Meta-codes are ordered by density , or how many connections they have to other codes.	

Using Physician Manner as a focusing code is one way of conceptualizing how patients perceive their experience with health care. Each of these codes describes how patients ascribe characteristics to their provider, and meaning to the health care system in ways that the provider may or may not be aware. Using Patient Manner in the same fashion is one way of conceptualizing how the patients consider themselves after being diagnosed as having diabetes and encountering their health care provider networks as diabetics. These concepts and categories arose from analysis of the focus group discussion. The patients did not use this language in our discussion; I have provided summary codes based on these discussions. In the tertiary codes, those codes most directly linked to the focus group transcripts, more of the patients' language is present. **Error! Reference source not found.** presents an overview of primary and secondary codes derived from the patients.

Figure 1: Patient-derived Meta-Concept Overview
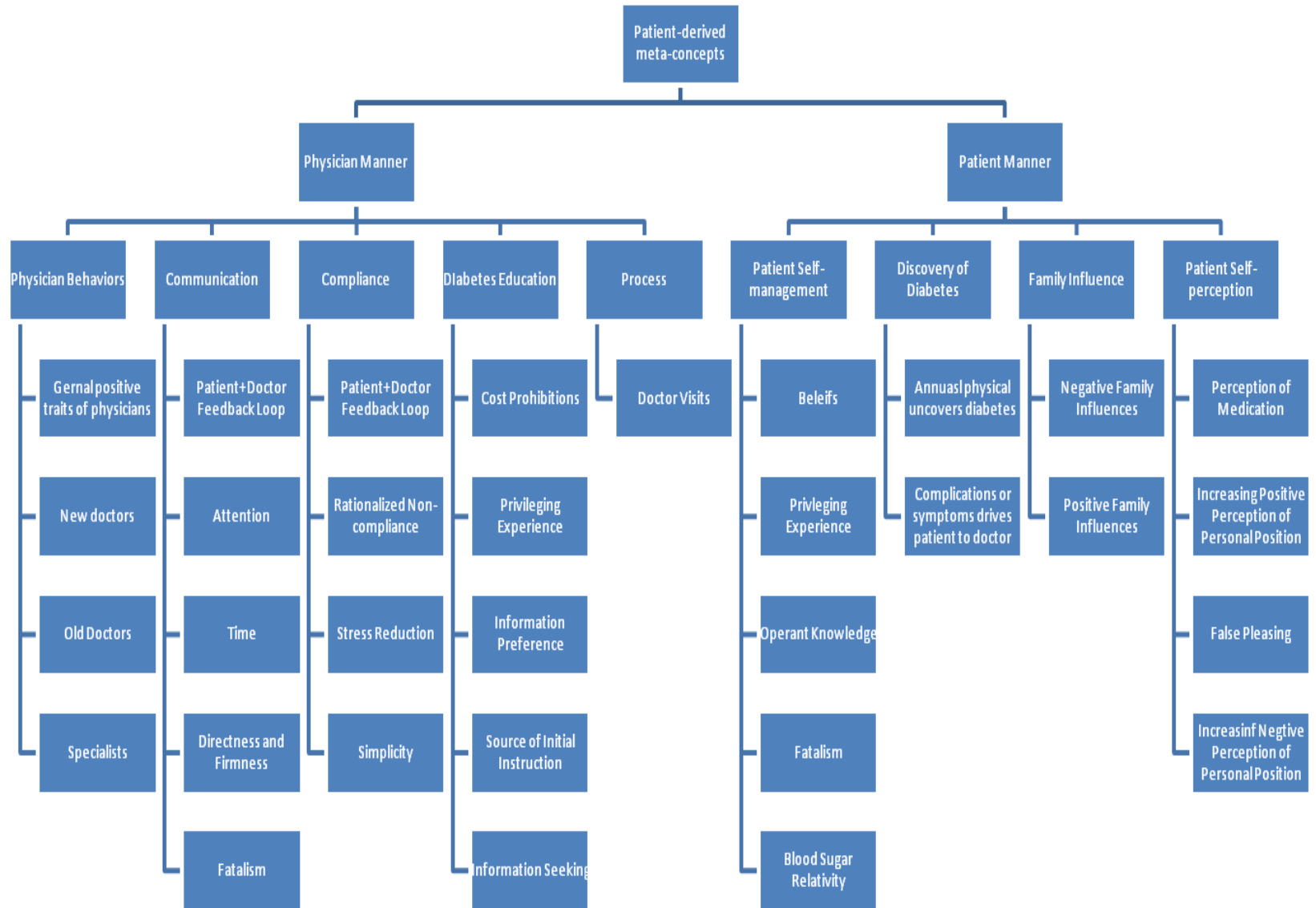
Physician Manner is a meta-level code that encompasses how focus group participants perceive physicians in a system of interactions. Within that system, patients see physicians as linked to a variety of other elements including Physician Behaviors, Communication, Compliance, Diabetes Education, and Process, and as influences on their own Patient Manner. (See Table 10). Each of these summary concepts contains a nested set of activities and descriptors that individually and collectively add flesh to the patients' understanding of this system. These definitions emerged from the focus group discussion, but I summarize them. After providing an initial summary I will provide an overview of each of the concepts under Physician Manner, I then describe them more fully.

Physician Behaviors

These are descriptions of how patients perceive physicians' actions. The focus group participants referenced these actions as a means of identifying positive traits in physicians. They made a distinction between old doctors, new doctors, and specialists. Major considerations for these patients were encouragement, time spent with the patient, whether the doctor was concerned about the patient's understanding, and whether they felt supported and included in their care.

Communication

Communication deals with how social and medical information is conveyed and received by the patient. It taps not only the giving and receiving of information, but also the connotations associated with that giving and receiving. The way in which the patient processes medical information is impacted by several factors, including the Patient+Doctor Feedback Loop, Attention, Time, Directness and Firmness, and then Fatalism in order of groundedness. The

patients may adjust their response to a treatment strategy based on Communication. They also may assume their doctor's level of concern for their well being based on their communication.

Compliance

These components influence whether a patient will pursue the physician's advice. This term was not used by the patients in the focus groups. The patient+doctor feedback loop, rationalized non-compliance, stress reduction, and simplicity of instruction were important to the patients. Having credible information, being involved in decisionmaking, understanding the doctor's advice, and having their personal experience considered strongly influenced their reported levels of compliance.

Diabetes Education

This term does not refer to the formal definition of diabetes education. The American Association of Diabetes Educators defines diabetes education as;

> Diabetes education, also known as diabetes self-management training (DSMT) or diabetes self-management education (DSME), is defined as a collaborative process through which people with or at risk for diabetes gain the knowledge and skills needed to modify behavior and successfully self-manage the disease and its related conditions (http://www.diabeteseducator.org/DiabetesEducation/Definitions.html).

For this study, the patients referenced all the locations from which they receive information. This discussion included those things that blocked their receipt of information. Concepts that emerged in diabetes education were cost prohibitions, privileging experiences, preferred ways of receiving information, and ways of seeking information.

Process

This concept describes ancillary interactions that are filtered through the patients' interactions with their doctors. Process includes cost prohibitions, insurance, numerous doctors who are not constituted as a team, private and managed care, and the mechanics of the actual office visit. The way the visit is conducted can create a cooperative atmosphere or inspire worry and fear, thus interfering with the patient's ability to participate fully. Physician behavior, communication, compliance, diabetes education, and process were all associated with Physician Manner according to the patient participants.

Physician Behavior: General Positive Traits

Patients watch their doctors' actions for clues regarding the depth of their relationship and quality of care. During the focus group discussions, the participants spoke positively about their experiences with physicians. But at times, surprising moments of anger and anxiety emerged that were triggered by group discussion of physician behavior. This section explores the concepts contained within physician behavior, including being encouraging, taking time with patients, instigating contact to discern patient understanding, bringing current research into the visit, acknowledging of knowledge gaps, providing coaching, giving immediate referrals, being perceived as thorough and having medications available onsite. Table 11 presents the set of characteristics associated with doctors, new doctors, old doctors, and specialists.

Table 11: Super codes within Physician Behavior*

General positive traits of physicians	New Doctors	Old Doctors	Specialists
Encourages patients (22)	Seemed more thorough (5)	Lacked attention (7)	Unless referred, some patients are not aware of access to specialists (4)
Takes time with patients (13)	Listened to patient experiences (3)	Didn't search for the unknown (2)	Specialists identify and discuss "good" and "bad" days (3)
Instigates contact to discern patients level of understanding (13)	Associated with increased survivability (3)	Seemed more confident (2)	They address the entire system (2)
Brings current research and new ideas (5)	Did more tests (2)	Confirm what is known regarding current diagnosis (1)	Receiving a referral to a specialist increases patient's perceived quality of care (1)
Acknowledges limitations in knowledge (5)	Challenged standard testing timelines (2)	May miss possible diagnosis (1)	
Provides coaching (5)	Sought new diagnoses (1)	Work from written history without including previous conversations (1)	
Gives immediate referrals (4)			
Is Thorough (4)			
Has medications present or gives samples (3)			

*Numbers in parenthesis indicate direct links to focus group responses

Encourages Patients

Encouragement is something that patients seek, but rarely receive from their providers. Encouragement, as defined from patient discussions, is the web of interactions that enable the patient to perceive self and care in such a way as to continue beneficial actions and stay engaged in diabetes management. When encouragement comes from the provider, patient motivation increased for these participants.

With your age, with your weight, and your eating habits, if your cholesterol stays the way it is, if it's this good, then all you have to do is just take the medicine for the diabetes. Those readings could beat it. He said, "Do it! You can do it."

Lose some weight, you can come off of everything. He told me that. It will come off, he told me that. Lose weight and your problems will disappear.

My doctor told me if I lost weight I would notice that my blood sugar was going down. Once you get to a certain place, then I could come off of the medication. I had to keep on exercising and keep on the diet.

Positive goal setting linked to an outcome that a specific patient valued was effective for these patients. They recalled their doctor's words, and intent, and were motivated by the process as well as the goals. In most cases, the patients valued being taken off their medication. Linking their goals to that possibility was motivating. Tailored interventions, those that were associated with a specific patient's goals instead of generic advice, were recounted more positively. The patients could talk about their successes and challenges more specifically and felt more in control of their care and themselves.

And so I was encouraged to take 10-15 minutes, two or three times a day, and walk to get

some exercise. Walking I was told and lots of water for some reason-they didn't know

why-that exercise lowers blood sugar. And I did do that. I guess the first two weeks I

must have walked a total of a couple hours a day. And, just doing little things to help

bring your blood sugar down. Rest. And that was it.

This patient in response to an exercise plan that was specific to her found a way to incorporate

some changes into her day. To her, the suggestions were simple and accessible.

When encouragement through research and treatment strategies is absent, patients begin

to wonder about their providers' quality of care.

And I've met other people who have been diabetic and it …- and everything and they

were on pills, but because of the exercise and everything, they did come off even the

pills. So I know it's possible, but the doctors don't encourage you toward that end.

This patient found herself in conflict with her provider in that she was receiving encouragement

from other sources about improvement possibilities. She was disheartened that her provider was

not giving her the same types of encouragement. It was important for her to reduce the number of

pills she was taking, but her doctor was not moving her in that direction. Hearing about these

possibilities from sources other than her doctor was disconcerting.

For another patient participant, the negative approaches were discouraging. Reading

literature, or being told only about negative outcomes including death, were off-putting.

I don't want to read medical stuff---that's not me. I don't want to read it. I really don't

really want to know probably. You know, there are people like that who don't really

want to know; they don't want to know that they're going to die from something. And so

I would like to be in a group setting, maybe even once a month with people who have

issues like mine and we can talk about it. And then I could take those thoughts to my

doctor after I sit to discuss it with those people. Because I'm just not going to read the

pamphlet. I'm not going to read the brochure. How many thousands of people die-- I'm

not going to read this. It's depressing, it's scary.

Encouragement, for this patient, was in being able to mitigate fears through personal interaction.

She needed not only a tailored support program, but also a strategy to deal with associated fears

and anxieties. Because encouragement reflects each patient's specific circumstance, participants

felt as though they were being treated as individuals and that the doctor was invested in them.

Encouragement was also a factor in how the patient perceived him/her self – promoting a

positive self-perception. When encouraged, patients felt supported, included, and were less likely

to engage in fatalism.

Takes time with patients

Spending time with a patient, like encouragement, was a significant factor for elder,

African-American diabetics. Time, also related to Communication, was a way of demonstrating

respect and care for the patient.

… she'd talk to me a long time, why did you come to see me. And she'd sit there and

somebody would come, she'd say "No, I'm with my patient right now." She didn't rush,

but unfortunately, she moved someplace else. So when you find a good doctor, most of

the time they've moving on.

This patient felt that her doctor valued her time and at the same valued her as a patient. Feeling

rushed added distance to the patient's relationship. It also impacted whether the patient felt

respected by the doctor.

Rush, being harried. OK…Here's your prescription. I don't take kindly to that. I think if you're going to pay $160, there ought to be some time spent with you.

I just didn't like him. To me, he just came into the room, another day, touch me here, touch me there, you know—just a quicky-quick thing, ask me a couple of questions, I'll do this and whatever. Just went out of the room. It just didn't happen. No interest whatsoever in my well being.

The "quicky-quicky thing" translated to some patients as a lack of interest in them and their circumstance. It reinforced, for some, beliefs that physicians were interested in generating repeat clientele and not in patient care.

Instigates contact to discern patients level of understanding

But, if a physician took the time to probe for patient understanding, the time factor was satisfied for some patients.

Sometimes you just want to hear it. If it's not good news then I don't want to know. I don't want to know that I've got to do this. So you kind of tune them out, but I think for me at first it was just… it shouldn't have been a shock because it's in my family, but I didn't want to hear it was me. Then after the instructions, whenever my doctor, particularly, gets new information he calls me and says… He gave me the instructions based on what he knew then, then when the blood tests came back and he called me on the phone and said "You gotta do this, this, this and that." He asked me did I understand. He's very good. My doctor is very good about that. So I knew I could trust him.

This patient essentially is telling two stories at once. He is discussing his initial diagnosis as well as the developed relationship he has with his physician. During his initial diagnosis, this

participant speaks about the shock of being declared diabetic – that it wasn't supposed to be him. But, his doctor breaks through and checks the patient's understanding, perhaps knowing that the patient had stopped listening and tuned out due to this shock. For this patient, trust was established and increased. The patient felt cared for with this physician.

Brings current research and new ideas and provides coaching

Introducing new ideas and current research to the patient was important to some patients. It was taken as an acknowledgement that the patient can make informed decisions regarding changes in their behavior and care.

> Well, I'm thinking about all the latest things that have come out. The pamphlets write-ups or those kind of things and sort of coach you along the way. The sort of coaching you need to control your diabetes-you know, to provide those kinds of things. As you go along, you know, have them give you a call from time to time. I mean see how it's percolating and that kind of thing.

Part of the process, for this patient, was being given information to consider and then being drawn into further conversation with his provider about what strategies were most successful for him. "Coaching" here refers to a partnership that improves on past successes by incorporating the patient and current research more directly. Providing coaching was a means for the patient to take ownership and demonstrate their personal success in managing diabetes.

Acknowledges limitations and provides referrals

Patients do understand that all physicians are not experts in diabetes care. It was a detriment to the patient's trust in their physician for them to act as if they were.

Well, I think just regular MD's that are diagnosing you, I think they should refer you to someone. If they aren't up-to-par on, you know, diabetes, or even if they think they are, like I said, mine never said to me, you know, anything about a diary or anything. They need to be made aware, they need, you know, to address those issues or refer someone who can.

Well he explained but he also sent me to someone else, who could tell, explain it better to me, and showing me different things about diabetes, video, talked to me about the different types of diabetes. There's a Type II. And I was on insulin so they showed me how to do the insulin—and about the insulin, what the insulin did. They sent me to__who explained, but they also sent me to someone else.

In the earlier quotation, the patient participant felt betrayed by his physician's lack of knowledge and lack of referral. He found out from other sources that there was information he needed, but did not get, from his provider. The second statement references a beginning conversation with the diagnosing provider that led to a referred conversation with a specialist. This combination of care reduced the patient's anxiety and deepened his relationship with his provider. In the earlier example, the patient eventually changed providers. Being given a referral, for some patients, was a sign of care.

Now if it's something that he doesn't think that he can help you with, he will refer you to someone who can ____ who has a better knowledge of it probably than he does. But he will take the time to listen to what you have to say about that.

Again, being knowledgeable and referring the patient to a specialist increased the patient's sense of being cared for.

And see my doctor is I'm doing well and I'll go back and ____ a week before I go, I go

have the blood work done. Then when I come into this office he has all of that. And he

has the chart and he has all the before and everything. And he goes over all that with me.

And then we discuss where we are and what we need to do. And I know what I should

do. And I take my… And I was not the best one ____ not good about taking before

different times of the day. But now that I'm no insulin, boy do I ever do it. So also I

bring it to him. The sheets. And he looks at it and he sees where your sugar level has

been, what you've done, like I take it before breakfast, I take it before dinner. At night I

take it at least 2 times __ sheet before lunch and all that. But he goes though. He has

everything there and he's going to talk to you about that. And you have another problem

he's going to make you discuss that. He's going to get to the chart and everything about

that. And the other thing he'll say he's willing to help you give whether he can give you

something or not. Like my allergies, I continue to talk about them and we can talk about

that. "I've given you medicine for that but now I'm going to refer you to somebody else

so they can check it out a little further," which I did. But he goes through… and he's

kind of very serious and when you can get him to laugh it's a good thing, and he will

laugh. And he's not going to give you anything at the time you cry wolf because he's not

one who believes in a lot of medication. He's an internist. He's a specialist.

Again, this patient is discussing his specialist's ability to manage the medical and the

psychological aspects of his treatment. There is security for the patient in the thoroughness of his

doctor's practice. All information, blood work and history, is present and being reviewed with

the patient. The specialist speaks with him about ongoing issues (allergies) as well as anything

that has emerged recently. The patient received referrals, but also has an understanding of when

the specialist will not respond to with medication. The patient talks about needing to see

emotional feedback from this provider as well. Receiving samples from the specialist as well as

a referral increases the patient's trust in the physician's quality of care.

"Old," New," and Specialist Doctors

After discussing the general positive traits of physicians, the patient participants got more

specific about the differences between "new" doctors, "old" doctors, and specialists. "New"

doctors were doctors who may be just out of medical school, but who rely on research and

testing more than experience and patient history in their practice. "Old" doctors relied primarily

on patient history and their personal experience. Specialists are those to whom the patient is

referred. This includes endocrinologists, internists, and diabetes educators.

New doctors were not always distinguished by age. They were described as those who

seemed more thorough, listened to patient experiences, did more tests, and were associated with

increased survivability. They were perceived to challenge standard testing guidelines and to seek

new diagnoses.

> Yeah, and they'll do that. It's like a totally different work-up. They'll ask, "When was
>
> the last time you had …? You should have this and you should have that." And that's
>
> how, I believe, I was able to survive two cancers. You know, I could tell the doctor I felt
>
> a lump. And, he didn't feel it. He said, "Well, you felt it?"   And I said, "Yeah," and he
>
> said, "Go get the mammogram." They found it on the mammogram, so …

This patient attributed her cancer survival to having a doctor who listened to her experience and

trusted it. He trusted her initial evidence and ordered the test. Old doctors, according to the

participants, lacked attention, did not search for the unknown, were very confident in their

experience, tended toward verifying known diagnoses, may miss things, and worked primarily from written histories and disregarded patient conversations.

> From the mammogram, they did a scan and that's when they found it. Because it was outside of the normal area of the mammogram. They found it and two weeks later I was in the operating room. And, two weeks after that, I had to go back because it was malignant and I had to go back and have another surgery to remove more and more. And I noticed that something was wrong with my stool. And the doctor said, "Well, let's go ahead and give you a colonoscopy." And I really wasn't due for that until the following year. And that's when they found the colon cancer. 'Cause some doctors, they miss it. They're not paying attention. And, that's why I don't mind a younger doctor.

This patient's experience validated her claim that new doctors were better for her than old doctors. The new doctor did routine tests out of their yearly sequence, was willing to see something new, and listened to her concerns. In this example, the physician's age was a factor.

> Specialists had another set of characteristics. For these patients, they were more successful at identifying and discussing "good" and "bad" days.

> I mean, I go into the examining room when it's time to go, the doctor comes in and checks the eyes, he does the feet with the little machine-with the little thing that he uses. He does the feet. And he does the eyes and does my ears, and then we go into his office and he talks to me about how am I doing for the past 30-90 days. … So, he really is a diabetic doctor. So, he does talk about it. That's why I'm there. And then I go and take my lab. And then he calls me back, or he'll write me a letter and say it's good. Well, if it's not good, he'll write me a letter. And if it's good, then everything is okay because

> I've had my better days and my bad … And, he tell me to change medicines or gives me
>
> new prescriptions.

They were concerned about the entire body and thought more systematically. The specialists

communicated well and were able to adjust the patient's medications.

Table 12: Incidents that hinder or increase patient interaction

Hinders increased interaction	Motivates increased interaction
• Rushing or creating distance between patient and provider. • Relying solely on charted patient information to the exclusion of newer complaints. • Avoiding referrals.	• Tailored strategies that tap into individual patient motivations • Adjusting time strategies to increase perception of respect and doctor investment. • Listening for, and responding to, patient cues that signal lack of comprehension or need for fear mitigation • Communicating current research developments • Utilizing referrals

Physician behavior influenced whether these patients trusted or acted upon their physicians'

advice (See Table 12). At times, physicians had to deal with other concerns before they were

able to educate the patients about diabetes management. From the patient's perspective,

behaviors that signified a generic or detached response became barriers to their relationship with

their provider. Feeling rushed or unattended to created a situation where the patient worried that

their provider did not care about their well being. But, if the physician employed strategies that

connected a patient's treatment to their goals and concerns, then the patient's sense of being

cared for and respected increased. They were more likely to employ the advice of their

physician.

Communication

Patient participants delineated several important components of the concept of

Communication. These included the patient+doctor feedback loop, attention, time,

directness/firmness, and fatalism. (See Table 13). Communication is defined through patient

discussion as a means of conveying social and medical information. Information on importance,

social relationship, care, success, and failure are processed by patients in several ways outside of

the clinical setting. It is not only the content of the message, but also how it is conveyed for these

patients.

Table 13: Super codes within Physician Manner - Communication

Patient+Doctor Feedback Loop	Attention	Time	Directness and Firmness	Fatalism
Instigates contact to discern understanding (13)	Is encouraging (22)	Respect (4)	Sensing immediacy in care (2)	Presenting detached physician manner (8)
Uses medication as primary treatment strategy (10)	Takes time with patient (13)			Negatively influencing family (4)
Involves family (9)	Increases positive perception of personal position (5)			Is self-discouraging (4)
Restricts information if patient cannot verbalize complaint or question (7)	Remembering patient history increases perceived level of caring (5)			Depression (2)
Alters patient behaviors due to fear of rejection or change in doctors opinion of patient (2)	Sensing immediacy in care (2)			

	Uninformed about costs associated with diabetes education (1)			

Patient+Doctor Feedback Loop

This loop is more than basic communication between a source and a receiver. The patients' perception of their relationship to the doctor, fear of rejection, anxiety regarding their condition, and/or the presence of family members can influence how the patient and doctor may interact. The Patient+Doctor Feedback loop is a mechanism by which the patient and doctor verbally negotiate the boundaries of their relationship. This loop, for the patients, was connected to both Communication and Compliance.

Instigates contact to discern understanding

When the doctor rather than the patient instigates discussion, the patient is reassured that the physician is invested in his or her care.

> I think it should be something when the doctors come out to you at least quarterly to let you know that things was alright—at least at the time that I checked it. But these are things you should look out for before I see you again. And I think that's… I mean people when people go to the doctor they should follow up with you, not that you have to follow up with them.

Depending on the patient's attitude toward medical care, elder patients may have an expectation that the doctor should provide information versus being asked. Doctors, to the patient, have access to a wealth of information as well as the patient's chart. If there is information to share, some patients believe it is the doctor's responsibility to share.

Uses medication as primary treatment strategy

Medications fall under the same expectation. Two categories were associated with how medication is given – with and without explanation.

I would have nearly died of diabetes. I mean, he gave me no instructions, not when he gave me the prescription. Nothing. I was getting the pills, the prescription, but no instruction. You know, nothing dietary. . .not that.

For this patient and others, medication was prescribed without description of side effects, other drug or food interactions, dietary changes, or other diabetes education. Giving medication without explanation, length of necessity, or alternative led to fatalistic attitudes about diabetes care, increased fear and negative self-perceptions for patients.

Involves family

In order to mitigate fear and increase understanding and control, several of the participants spoke of family involvement as a means of support and increasing success.

My mom can sit there saying she doesn't have any symptoms, but I can sit here and I can look at her and I can tell if she has symptoms. I can see it in her eyes, And I'll ask her "Did you take your medicine today?" and she'll answer sometimes yes, sometimes no. And I can see it in her eyes. … she's saying she's OK, and I'll look at her and I'll say "you didn't take your medicine." And I'll know she didn't.

For this participant, being involved in an elder parent's care was crucial to consistent care. Various problems affect elder, African-American diabetics in ways that interfere with cognition, dexterity, and personality. Challenges increase when glucose levels are not controlled. Without family, or a non-relative advocate, successful diabetes management may not be possible for

some as this type of support helps with routine visits, medication, third-party paperwork, and continuity of care.

Restricts information if patient cannot verbalize complaint or question

The patient may have reasons for withholding or not verbalizing a complaint. This creates a challenge as many physicians' responses are provoked by voiced complaints. Information may be lost if the patient or their caregiver does not vocalize it. In the following focus group discussion, patients spoke of disrespect as a way of shutting down discussion.

Woman: May I say something? I've gone to the doctor and I've told him certain things that I feel and he says, "Well I'm the doctor. You're the patient." "You're going to tell me what I'm supposed to be doing? Thank you sir, I appreciate it." Next week he was not my doctor. He can't tell me how I feel. I have to tell him.

Man: That's another problem. A lot of doctors think that just because they're doctors they're not on your level so you can't ask them a question or talk to them about anything. And no communication—one way or the other. So you [are] saying to yourself. He treated me and I leave … like back in the day when we didn't have no doctors. That's why a lot of black people [don't go] to doctors, because of being mistreated.

LT: Because they were being mistreated?

Man;   Yes. Like if you can't… Like my wife was saying, she asked the doctor a question and he's telling her that he's the doctor and you're the patient, but you know your body better than he do. I mean you should anyway. That's

because you ask him a question ___ for him to say it to her "I'm the doctor"…You know he's the doctor, that's why you came. But at least give an answer for your problem.

LT: So it's disrespectful.

Man: Exactly.

Woman: I said to him, "You are a doctor, but not mine."

Patients perceived that barriers of expertise, education, and power were communicated by their doctors. Being mistreated, or treated as unworthy of communication, was deeply problematic and insulting. At this point, the patient is not engaged in a medical discussion, but is forced into the position of defending him- or herself. For the patient, a health problem cannot be addressed because of a lack of respect and dignity.

Alters patient behaviors due to fear of rejection or change in doctors opinion of patient

For other patients, the opinion of the doctor is just as important. But, instead of having to overtly defend their sense of self, the patient withholds information or self-censors in order to maintain a positive relationship with the physician. Fear of rejection by the physician becomes a barrier to the patient due to the belief that the physician will change their level and quality of care.

You know what I realize – that I used to not be truthful. Let me just tell the truth. I wasn't truthful all the time. And I've come to the conclusion that my medications are not right because I haven't been honest. You know, if I don't tell him I'm not taking the medicine it shouldn't keep going up because it's making my insulin go up. The worst part is that I have to go in there to tell him that I did not do what he said. My fear is that he's gonna

say, "I cannot be your doctor anymore." I mean seriously. I would not want to be your

doctor.

Appearing to be in control or compliance when in consultation with the doctor was important to

this patient. The patient in this statement is actually re-negotiating her belief with the group. She

is convincing herself that she should be truthful while divulging the barrier to the corrected

behavior. In this instance, the patient is drawing a sense of agency from the group to combat her

fears of being rejected by the doctor.

Attention

Attention is related to the patient's ability to feel like the focus of the visit.

Encouragement, as discussed earlier, was one way to increase attention. Specifically, if the

encouragement is not tailored to the patient, elder, African-American diabetics may feel as

though they cannot accomplish their health goals or get things right, leading to fatalistic

behaviors.

Turning away, multitasking, and lack of eye contact were all barriers to attention. The patient

began to feel angry and impatient when seemingly ignored during a visit. Another patient

described lacking attention as being a "soap opera doctor."

> XX: Actually I had a …my first primary care physician when I first moved here was
>
> like one of the soap opera doctors, but anyway.
>
> LT: "Soap opera doctors": what does that mean?
>
> XX: They don't work, they just stand around and look good. That's what I call a …if
>
> you ever watch soap operas, how they never work, they're always talking to the
>
> nurses or whatever. But anyway, so I changed doctors because I felt really, really

bad and my other doctor was not doing anything for me. I don't think he even ever read my chart or anything. And when I changed doctors and they got my chart, he saw my family history _____. Just saw my history.

LT: So you were feeling bad and the soap opera doctor wasn't doing anything.

XX: He would come in the room, say a few words and he was talking to you as he was walking out of the room. And so I changed doctors and he actually read my chart the history. Saw that my father had diabetes and my brother had diabetes … so he just said, I'm going to do a diabetes test to just check. He did all kinds of tests. Stuff that I should have had done years ago. And he actually called me to give me the results personally.

The "soap opera doctor" didn't pursue any diagnoses. The patient came to the visit with complaints, and the doctor gave the appearance of not treating her at all. The doctor was non-communicative, did not engage her as a patient, and left the session in much the same detached fashion. When she changed doctors, she found a level of attention that suited her as a patient. Family history, her chart, and an engaged physician helped her receive correct treatment. A more positive feedback loop between patient and doctor, with the advent of an engaged physician, had been established.

With attention, through encouragement, patients combat the depression and anxiety associated with being diagnosed with diabetes.

Like I said, I went into a little depression when I found out I was a diabetic. I was not supposed to be a diabetic. I was going to be different from my mother. Out of seven children there are only two who are not diabetic.

This patient spoke about the impact of being diagnosed. She hoped that she would avoid diabetes, but came to think of it as inevitable. This had a negative impact on patients' ability to be active in their care. Some patients believe that being diagnosed as diabetic is a mark of failure. Depression accompanies the diagnosis of diabetes for some patients. Diabetes is a medical condition, but it also has a psycho-social component in that for some patients it has been a lifelong dread. They have been fighting to be the one member of their family who does things right and avoids the curse of diabetes. To be diagnosed with diabetes is evidence that one has failed significantly. This will be discussed more fully below.

> II: My doctor gave me instructions… I was in like shock because they always say it would skip a generation … But I just knew it because ____ I wasn't feeling the best but I never thought that I would be become a diabetic. It's been 10 years now.
>
> LT: And you said you were in shock.
>
> II: Yeah. Because I just could not believe that I was a diabetic. I didn't want to believe it because I felt I was doing well. But the tests came back showing something totally different.

This patient describes how she had been quietly trying to avoid diabetes through behavior and diligence. She says, "I thought I was doing well." She described what several other participants voiced – that diabetes is a consequence you bring upon yourself. But, her experience, like others, is conflicted. She was being diligent, but still the diagnosis appeared. The same applied to this participant.

> Because when I was in good shape, there…I wasn't having no problems; and all of a sudden the diabetes jumped on me. I was neat and trim. Because a lot of people think

that if you're a large person you're supposed to have diabetes, but I know some people just as skinny as a rail and got it, and they're in worse shape than I am.

Finding a way to help the patients maintain a positive self perception increased their sense of control and reduced fatalism. Physicians may then hear beliefs held by patients that encourage or discourage communication and active participation in care. One example of this is patient considerations of insulin.

… the form of the pill is better for you than the insulin. Taking the pill is better than taking the insulin.

Because I was put on insulin, but then through the grace of God I was taken off. And now … but that was about 17 years ago. … . I was blessed by God not to have to take the insulin.

What it does more for me is when I have to do the insulin. If I have to get up and go to the bathroom… I guess the whole idea of… Well, first of all, I was afraid of people seeing me with a needle and people thinking I'm using drugs. That was the first thing. Because I have a pin. I didn't want people to think I was shooting up.

A doctor did tell me ___ or somebody else—I don't know --someone told me that once you're on insulin... and I'm so glad she told me to get off because once you are on it you can never get off. And now that I know that… It's like you said, if you think you can't get better, you're almost doomed in a sense. And so I'm glad …

Patients associated insulin with an inability to manage blood sugar levels in public places, fear of

being labeled a drug user, being doomed, and a type of curse. These perceptions of insulin affect

a significant aspect of their psychological, social, and medical experiences. Feeling doomed and

or isolated encouraged fatalism. Fatalism is discussed more fully below.

Directness and Firmness

Directness and Firmness refer to the doctor's style in delivering information about

causes, effects, and consequences of diabetes. If these things are communicated directly and

firmly, the patient's sense of immediacy with regard to behavioral changes and medicine are

affected.

> I don't need him to be fun, fun. I need him to be "If you don't do this, this is going to
>
> happen." I need somebody to be on me because I'm very weak.   I   check   my   sugar
>
> when I feel bad. And every now and then I won't check it if I know I've been eating the
>
> wrong food because I know it's going to be high, which I probably should. After lunch—
>
> no. I'm not going to take it two times.

> I wish they would say to me "Now I'm going to tell you what I would like for you to do.
>
> And if you don't follow this you might be really deathly sick or you might really wind up
>
> dead." I think they have to put a little fear in it.

The vaguer or the more general the information delivered, the less urgent it seems. "Just tell me

what I need to do. Be straight with me." These patients wanted a more direct conversation that

linked actions and outcomes in a direct manner. As mentioned earlier, they did not want to be

flooded with negativity. They did want a straightforward presentation.

Fatalism

Falling too far into negative communication precipitates fatalism. Fatalism is a belief that only negative outcomes are possible after a diabetes diagnosis. Both the physician and the patient can communicate fatalistic themes. Focus group participants connected fatalism to a doctor's detached manner, negative family influence, self-discouragement, fear, and depression.

> You know, there are people like that who don't really want to know; they don't want to know that they're going to die from something. And so I would like to be in a group setting, maybe even once a month with people who have issues like mine and we can talk about it. And then I could take those thoughts to my doctor after I sit to discuss it with those people. Because I'm just not going to read the pamphlet. I'm not going to read the brochure. How many thousands of people die-- I'm not going to read this. It's depressing, it's scary. And I think if it's in the gene pool, my mother never went to the doctor. I never understood it, but maybe I got that from her. She didn't like seeing all that stuff. She only went when it was an emergency situation and she had no choice. And maybe I inherited some of that fear.

This patient describes a generational response to medical care with fear. Considering her mortality was a source of anxiety. Diabetes management, when linked to death, became a hardship to even hear about outside of a supportive environment. Finding family or social support also could be a challenge.

> What I think would be helpful in the classes is how to help you maintain your diet while your family is eating other things. [Agreement]. That's the most difficult for me. … I've got to watch the cholesterol for my husband and the sugar for me. It's difficult when you've got two people with two different problems.

You know, if I'm eating a plate of food and then I grab a diet soda, people will laugh.

People will laugh at me.

If other non-diabetic family members are not interested in changing household habits, the diabetic faces the prospect of providing for those who are not reciprocally concerned. One patient commented specifically about cooking for a non-diabetic mate who has other health concerns. Even for those patients who participated in formal diabetes education courses or met with nutritionists, nothing has helped with this. Also, many felt that non-diabetics have little empathy for diabetics.

Self-discouragement is also a factor in those who are not achieving goals or seeing present success. One participant said, "I just say that I'm disappointed with what I can do." The patient eventually comes to believe that they are not capable of making or sustaining change in order to see success. They are always going to "mess it up."

Compliance

The patients in the focus groups did not use the term Compliance. But the concept includes components that seem to influence whether a patient will pursue the physician's advice. The main components are the patient+doctor feedback loop, rationalized non-compliance, stress reduction, and simplicity. The patient+doctor feedback loop has been discussed previously and the others are examined below. (See Table 14).

Table 14: Super codes within Compliance

Patient+Doctor Feedback Loop	Rationalized Non-compliance	Stress Reduction	Simplicity
Instigates contact to	Privileges experience		

discern understanding (13)	(14)		
Uses medication as primary treatment strategy (10)	Perceives medication negatively (9)		
Involves family (9)	Generates unrealistic Goals (4)		
Restricts information if patient cannot verbalize complaint or question (7)	Uninformed about costs associated with diabetes education (1)		
Alters patient behaviors due to fear of rejection or change in doctor's opinion of patient (2)			

Rationalized Non-compliance

In rationalized non-compliance, the patient has a reason or justification for not following the physician's advice. Some categories of justification include privileging experiences, having particular perceptions of medications, being subject to unrealistic goals, and being uninformed about or unable to meet monetary costs.

Privileges experience

Privileged experiences are a patient's personal or relational experiences that they treat as being equal to, and compared with, the doctor's advice. In some cases, these are generational experiences or experiences with family members who have diabetes. It may be family members or friends who have had memorable experiences with health care systems.

You know my mother was diabetic. And, I know what happened to her.

... and if it had not been for my mother being a diabetic I would have nearly died of diabetes.

I got two sisters, two brothers. One sister is on insulin and two brothers [are] on insulin. The other sister is on it, too. So I'm aware of diabetes right in my family. Thank God I'm not there yet.

Each of these experiences relates to a patient's family experience with diabetes. Some are good experiences and help the patient cope with disease management. Other experiences reinforce uncertainty and fear for the patient.

Yet, privileging experiences are not restricted to family history. A privileging experience can be any experience that gives the patient another option to consider against the doctor's advice.

Man: And, I kept checking my blood sugar-I do that regularly-and, nothing went up. So, I stayed [off the medication]… and it never went up.

LT: So, your blood sugar numbers?

Man: Yeah. It never went up, so I was satisfied. [Chuckle] So, I went back to the doctor for my check-up and he asked me "how was that [the medication] going?" I told him that I had stopped.

In this instance, the patient's evidence trumped the doctor's prescription. He found success and later, when asked, informed the doctor about the change. He was satisfied with the outcome and would not be convinced to restart the medication.

The patient's responses also suggest that if the doctor does not answer the doubt that they have, they will find another source to deal with that uncertainty.

Woman: I've taken the cholesterol pills, I also do the research on the Lipitor and it seems to be the best one. But also they gave it to some mice; they lost their hair and it also gave them cancer. So now because of that Lipitor, I think I can also alternate a medicine that's called the Omega 3and take that and walk and do the ___ juice. And when I was doing that before… now I'm guilty of not doing what I was supposed to do, but when I went back to the doctor—oh man, your cholesterol is down. But I only took 6 of those pills.

Woman;   Did you go back [to taking the pills]?

Woman: No.

To this patient, being prescribed medication was wasteful and suspicious. She considered medication a means of keeping money flowing to and the body dependent on the doctor. Without alerting her doctor, she stopped taking the medication and began other naturopathic remedies to address her health problems. She prayed about her options, did other research, and followed another path. She allowed the doctor to see the outcome (cholesterol was reduced), but did not attribute that success to him (only took six pills). Complying with the doctor's prescription was not agreeable. Privileging experience will trump the physician's advice if the advice does not address the patient's fear.

Perceives medication negatively

This leads to the second category of rationalized non-compliance. Perception of medication describes the patient's cognitive and emotional responses to being prescribed medication. Although medication is a tool, its meaning is complex for the patient. In an earlier example the patient said, "I might feel ok, so I'll go and buy some pills. Sometimes I think it's a

waste." Wasting money was a consistent concern for the patients, but especially when they lacked understanding about the way that medication worked. Also, the physician's motive for prescribing was questioned. "Oh, he doesn't want me to make all these other changes. Because he wants me to keep coming back so he can keep getting that kickback on that prescription."

Generates unrealistic goals

Unrealistic goals were a third reason for rationalized non-compliance. Unrealistic goals include those things that the patient cannot conceive of themselves doing.

Going to the classes helped. The only thing about the classes which really bothered me, the lady who was teaching, she wanted you to measure every single thing that you ate. And I felt that was unrealistic for me. Now I do watch my labels, and I do watch the content, but to measure every single thing—your snacks and everything … in a realistic world, you've got three children and a husband and a job. I mean that's really….My life is…I mean I have to schedule everything—but that's really going way beyond what I want to do. So I don't agree with that. I didn't agree with that.

This patient outlined unreasonable expectations that were present in the diabetes education classes. She was not prepared to measure all of her food intake. It violated the rhythm of her life and interrupted her personal and family schedules. This became a point of conflict for the patient as she continued the class.

Another participant thought that personal blood glucose testing was unreasonable.

Stick yourself each and every day to find out that your sugar went up. And then it goes down. I think it's ludicrous except to the fact that your body … you'll feel it within,

inside. You'll know if you get dizzy or not get dizzy just tell you your blood sugar went up 10 degrees. Or 5 degrees lower.

Daily testing, according to this patient, was unnecessary if the physician was going to run his or her own test. His symptoms, if present, were more important indicators than the testing. Other participants argued with him, in an attempt to correct his thinking concerning the testing. But, he believed that testing was the doctor's responsibility.

Is uninformed about costs

Being uninformed about costs hurt patient follow-through as well. Several participants used costs associated with diabetes education classes as an example.

Man: That's another issue… My doctor, he scheduled me to go to diabetic class and I went. And when I got there the lady gave me a form and she said "Well you have to fill out this form." I said, "Well what is it for?" She said it was for your insurance. I didn't have any insurance at the time. "I don't have any insurance," and she said OK. I said, "Is there a fee?" She said well yes, you gotta do it for insurance. Well how much does the class cost? $8. I can't afford that.

Woman: He should have told you.

Guy: Yeah, he didn't tell me that there was a fee, and I needed insurance. I mean I was seeing him because I didn't.

Woman: Right, right.

Being put in a socially and economically challenging position by a medical provider impacts trust, dignity, and compliance. This patient did not attend the course. Having to leave after engaging the staff was a source of embarrassment, shame, and anger. He was angry with his physician for putting him in that position. He was ashamed of having to leave because he could not pay.

Stress Reduction

Stress reduction involves providing the medical and social support necessary to reduce the ambiguity of diabetes management. Ambiguity breeds stress, and patients tend toward more familiar patterns that may contradict the physicians' advice.

> But in the meantime when you do get in there to talk with them it shouldn't be a rush. Set away some time for the patients, because most of the time it's in your head anyway. If you don't talk to a person, at least I heard it from a lot of doctors, most time if you just talk to a person you get well.

This patient wanted more time to understand what was happening to him. To him, if his doctor would take the time to talk to him – educate him – he would be able to handle his challenges better.

Simplicity

The final component of compliance that patients mentioned was simplicity, or making advice understandable and accessible to the patient. "If it's simple, let's just keep it simple. You know, let's not complicate it. And, let's not do a lot of dancing. Just tell me what it is, what to do and I'll do it." Keeping it simple was connected with encouragement as well as compliance.

In order for the patient to comply with advice, it had to be personally relevant, connected to a goal that the patient was interested in, and presented in a way the patient could understand and implement.

Summary

Compliance, for the patients, depended on several needs being met. The patient+doctor feedback loop helps the patient remain engaged in the process in a manner that bolsters their self-perception. Rationalized non-compliance is a means of comparison and self-protection. The patient will follow the advice that most reduces anxiety, makes the most sense, and is the most straightforward. If the physician's advice does not meet those needs, the patient may choose other treatments or philosophies to follow.

Diabetes Education

Diabetes education, as discussed earlier, describes the concepts and interactions that influence the practical behavior of the patient: cost prohibitions, privileging experiences, information preferences, the source of initial instruction, and information seeking. Diabetes education for the patient is as much an informal process as a formal one. Table 15 lists the concepts associated with diabetes education.

Diabetes education as a means of conveying information can have positive and negative effects on how a patient considers themselves and their health prospects. Of the participants who had attended classes, most felt the classes were helpful. Having a group of people who shared in their experience was positive. Still most participants favored a one-on-one educational approach to formal education.

> Well he [primary physician] explained but he also sent me to someone else, who could
>
> tell, explain it better to me, and showing me different things about diabetes, video, talked

to me about the different types of diabetes. There's a Type II. And I was on insulin so

they showed me how to do the insulin—and about the insulin, what the insulin did. They

sent me to__who explained, but they also sent me to someone else.

This patient doctor provided an overview after her diagnosis along with prescribing medication.

Then she was sent to a specialist as well as to diabetes education classes. Within the group, she

was the most confident about her educational experiences, knowledge, and self-care. Others

spoke of the more confusing aspects of the type of education they received at their diagnosis and

their experience with diabetes education classes.

Diabetes education for another patient was dominated by negative experiences. From her

perspective her emotional and medical needs were disregarded.

With me, I think the very first time … was upset when he told me. At the same time, the

only thing I got from him is "You need to exercise and watch your diet." And you

know… because mine was the diabetes and the blood pressure together. And he said,

Well we can wait. I knew that my body was saying you're not feeling right.

Emotionally, she was unsettled, but the doctor did not address that or the way she felt physically.

She changed doctors and was met with a fatalistic attitude concerning her condition. To her the

presence of relationship was as important as the advice given.

The second doctor, the internist I had to get used to his mannerisms the first time, I will

say that. He is one of the best doctors in _____, I do know that. But I felt like he was kind

of detached, which bothered me. It interfered with trying to develop a relationship

between a patient and a doctor. So think they need to notice that. The other thing is that

when I left there the first time, with him, it bothered me. He made me feel like I would

always be diabetic—it would just probably get worse versus getting better. I didn't like

that.

This patient needed to feel good about herself and her future. Neither of her initial physician

experiences supported that.

Table 15: Super codes within Diabetes Education

Cost Prohibitions	Privileging Experience	Information Preference	Source of Initial Instruction	Information Seeking
Barriers to Communication (13)	Rationalized non-compliance (10)	Expert with Diabetes (10)	Diabetes Educator (6)	Nurse (4)
Insurance (8)	Operant Knowledge (8)	Mailings (10)	Primary Physician (5)	Current research on positive and negative behaviors sought (4)
Negative of personal position increased (supercode)	Crisis Response (5)	Internet (9)	Nutritionist/ Dietician (3)	Other successful diabetics (1)
Routine care covered(2)		Doctor (8)	Endocrinologist (1)	
Costs associated with diabetes educations hidden(2)		Pharmacists (1)		

Cost Prohibitions

Prohibitive costs were a consistent concern with these patients who mentioned several difficulties.

Barriers to communication

The ability to afford care acted as a barrier to getting credible information from professional sources.

I don't know if Blacks who may not have insurance will not necessarily know this, but it appears that the internist, which is a specialist, is [able] to spend more time with a patient than a family practitioner. And most people who don't have insurance or are on limited income will probably go to a family practitioner. And I'm thinking even senior citizens.

… But in the scheme of things I'm looking at African Americans, think about it and the reality of how many really go to a specialist. Of if they end up in the hospital, that's when they see the specialist, when it's probably too late, sometimes.

This participant was concerned about access for those African-American patients who were uninsured, elder, or without access to necessary care. She speaks to the heavy reliance on emergency care or hospitalization for access to specialists and the inadequacy.

Insurance and increasing negative perception of personal position

For those elder, African-American diabetics who are insured, challenges remain These patients, mostly through trial and error, discovered that becoming successful in diabetes management meant that their bills may increase.

But my only concern is now that my insurance provider they want to drop me off their diabetes letter because I'm not taking any medicine. But, yet I go to get my supplies, the last time I had to go back to see the doctor. And the doctor ordered. … It's crazy.

According to several patients, if at one point you were listed as insulin-dependent and then were not, then you would not be covered for blood glucose testing supplies. This patient had to return to his doctor and get a prescription for his monitor and testing supplies in order for those supplies to be covered. If patients do not know that their doctor can write that kind of prescription, then blood glucose testing may move out of their budget quickly.

And I think too insurance companies make it difficult for…and this again would be African Americans, seniors, people who can't afford it—make it difficult for them to even get those specialized services because they've got to be in pretty bad shape diabetically-speaking. Even though we're both diabetic if you don't have to take insulin, the insurance is just not going to pay for certain things. And you have to be in a place in

your diabetic whatever to get certain procedures and medical attention. They're not going

to…or send you to a diabetic or a diet specialist if you're on a pill, but if you're on

insulin they may. And just like any other medical thing, they're not going to approve

certain things if you've done this first, this, this, this. … because you can get a lot of

supplies free, but what about the care itself? If I got the meals and the insulin and all

that, but I don't know how to use it, I don't know what to do with it. I don't know how

it's affecting me because I can't afford …

For this patient, it did not matter that he could get certain supplies free if he did not have the

education necessary to make the best use of them. He was concerned about the conflict between

health coverage and health care. It seemed that he was being penalized by his provider for not

being in worse condition. The better he maintained his health, the more difficult it seemed to be

to deal with his insurance provider.

Insurance decisions also affect the medications taken and education regarding

medications.

Woman: I'm on a generic brand of medication and it's cheaper for the insurance

company. Whenever I take my prescription in everything … when the new

Medicare came through, though I got Welfare, so when I get my medications

it's always zero. I don't have to pay anything for it. Once they ran out of the

generic kind and that one tablet, and I had to pay the extra difference, but they

finally got the extra. And I still don't have to pay for the _____.

Woman2: I think that's terrible – I'll tell you what. Not for you, for me. I couldn't take

the generic and I tried it. And sometime when you try a generic and it does not

work for your body, _____. So I can't take a generic ___insulin pill that you

take _____ the generic costs $2.00; the actual pill costs $9.00. What does that

say…So now I'm taking a pill that costs $9.00 and made it into a $2.00 pill.

Are you actually getting the ingredients that the former pill had before?

These two women are discussing the pharmaceutical decisions that are being made by the

insurance company on their behalf. Insurance companies may decide that they will pay for the

generic before paying for the non-generic. While the generic fits a patient's budget there is a

concern that the generic does not accomplish the same goals as the brand-name drug.

Information Preference

Patients had definite preferences for receiving information about diabetes. Uppermost in

their discussion was speaking with or having access to diabetic peers who were successful in

managing their diabetes. They longed for positive contacts, but especially with those who could

show them how to cope with diabetes without casting aspersions and making them feel deficient.

I'd like to get it from somebody that it has worked. You know, someone who is, you

know, 102 and still in their right-you know, still have the mind and they can tell you that

you can live that long and be a diabetic. And, you know, every once in a while you fall

off the wagon and tell you how to get back on.

For this patient it was about the reality, and not the theory of living with diabetes including how

to deal with "falling off the wagon" and getting back on.

For a male participant, there was a gendered aspect.

When I was a kid growing up in North Carolina, if someone was not doing well and

someone [else] is doing well, I try to figure out what is the person [who is] doing well

doing and what the one not doing well doing or not doing. And I try to learn from it.

Never watch women talk. That's my wife's job. I don't know that many diabetics. So, I just don't.

It was important for him to have role models –almost silent partners – that he could observe or listen to in the course of doing other things. He was not necessarily going to approach an individual on his own, but he would watch and learn. He would not watch women, but might glean that information from his wife. His challenge was the lack of identified role models or experts to observe.

Other information sources the participants mentioned included mailings, the internet, their doctor, and pharmacists.

We need more literature coming from the doctor's office or insurance company. That's just my opinion. Anything that's up to date or what did somebody else try that helped them out that maybe it could help me out.

Patients were very open to receiving information. But they were still conscious of costs.

You know, they have that available to you. You can sign up and you can get the magazines and so forth. It costs you. But I mean, there's a clearinghouse that will give you information on a monthly basis or a 40-day basis and that kind of thing and so forth. You'll be helped.

A key frustration for some patients was an inability to know what information was valid or current at the time. The internet, for those with access, was a preferred source for keeping current. Patients were frustrated by quick changes in what should and should not be done and wanted a way of learning of the most recent advances on a regular basis. For most, their primary care physician or specialist was the preferred choice for keeping abreast of credible changes, but they acknowledged the physicians lack of availability as a barrier to this kind of communication.

Women: I would like to get that from a doctor. I would like to get newsletters. You know, current research. Maybe everybody is not interested in research, but they're improving on different types of insulin and medications all the time.

Man: Well for me, I would like to get it from the doctor because even though there may be improvement, I do like to know the effects of the medicine I'm taking, the side effects, you know because all the underlying problems, the risks. Some of those commercials you see on TV you after they tell you about it _____ the side effects [laughter]

For most, their primary care physician or specialist was the preferred choice for keeping abreast of credible changes, but they acknowledged the physicians' lack of availability as a barrier to this kind of communication. Several patients mentioned pharmacists excellent, but seldom used resources. They appreciated pharmacist's knowledge of drug, food, vitamin, and herb interactions.

Source of Initial Instructions

Upon being diagnosed as diabetic, initial instructions are the first informational experiences for the patients. Sources and types of information given in that moment were varied. Some recalled that they were informed of their diagnosis, but information was given initially by the diabetes educator. Some patients remembered their doctor giving a diagnosis with no or spare explanations regarding how they were to behave from that point forward. Overall, four sources were discussed: the diabetes educator, primary physician, nutritionist/ dietician, and endocrinologist.

When discussing the diabetes educator, nutritionist, and dietician, the discussion centered around dietary challenges. Specifically, patients were unhappy with generic, abstract dietary

recommendations. For the patient, once diagnosed, everything they have eaten is now suspect. Diet management becomes a matter of excluding foods with little discussion of what can be consumed. One patient said, "You know, there are certain things you take out, like I said, when you become a diabetic." Another told the group that he was told, "If it tastes good, spit it out." He was serious about the statement and had been governing his diet by it.

For the patients, foods suggested by the educators and nutritionist may be unfamiliar, unrecognizable, and undesirable. The patient's response is then to practice food consequence management, They would eat the foods they wanted (cakes, sweets, etc.) and then try to find other means of avoiding the consequence.

And then sometimes if I know for sure I've got to eat a piece of cake, I find out the hard way, I check my sugar, it's up to about 280, I never get to 280. My range is between 125 and about 150 after a meal. 280—I would get downstairs and exercise real fast and _____. I mean, it brings me down a little bit __ work it off, work it off, work it off. So I cheat. I try to follow what she tells me, but it's just hard.

Managing crises becomes a proactive strategy. Examples of this include responding to food induced crisis with exercising in close proximity to the consumption of food to counteract the surge in glucose. Another patient manages his crises with creative insulin application.

Well if my sugar stays high for so long then I just go up and I'll take the 70-30 insulin, and then I got the fast-acting insulin to go along with it on the scale. So what I do… like I was taking about 30 units; I went up to 35 units and then take the fast-acting insulin on the scale. Sometimes when my sugar gets up around 300, I take about 10 units of that fast-acting insulin and it brings it back down.

For him, since he had the option to make changes to his insulin doses, it became part of his strategy for living his life according to his own wants.

In addition to finding different ways to adjust glucose levels while eating familiar foods, working around food scheduling conflicts were largely left to the diabetics to discover.

It's hard. They tell you to be consistent when you eat and consistent when you take your blood sugar. And it's easier for me now, believe it or not, that I'm out of school. When I was in central office, if I had to be somewhere I didn't eat at the same time every day. There was just no way you could do that. And so it was very difficult for me.

This patient's work schedule did not lend itself to consistent meal scheduling according to the educator's recommendations.

Other challenges for these patients included adjusting a lifetime of food history and dealing with circumstances that make dietary changes difficult.

What I think would be helpful in the classes is how to help you maintain your diet while your family is eating other things. [Agreement]. That's the most difficult for me. When it's two people in the house… it's already…I don't know if it's easier if it's more people around or if it's two people it's more difficult. Because it's already hard to cook for one, so if you cook for two you want to fix something that both of you can eat and then even though it may be good for that person to eat the same thing, ___ so it seems to be a diet-friendly thing where you both could maybe enjoy the dinner and not have to eat separate meals.

This patient presents the difficulties of preparing separate meals to satisfy differing scenarios in the same household: medical requirements and family preferences.

When attention turned to formal classroom settings, two versions were discussed. Patients had experience with both individual sessions and group sessions. They much preferred the individual sessions; group sessions had some detrimental effects. Patients in group educational sessions found it difficult to be grouped with those who were experiencing drastically different circumstances.

> the class instruction, for me what was difficult was the people ___ not the people but they scheduled for those really overweight with people who are smaller in weight. I had a problem understanding how mine could be that bad. They kept telling me that the people that were overweight—their sugars were like 500 and mine was only 150. Why was I in this class? It wasn't a good mix of people, because then I started thinking, well mine can't be that bad if, no matter what anybody says. If they got 500 sugars, I only have 150…

Because her circumstances were different, this patient became confused about whether the advice being given was applicable to her situation. To her, there was little urgency to make changes because these suggestions were all for people in much worse condition than she. Group members spoke of comparing glucose levels, glucose control, and body type.

Information Seeking

Although the patient participants had preferences for how they desired to receive information, they spoke differently about how they actually obtained information. Their primary sources for seeking information were contacting the nurses in their provider's office, surfing the internet, and interacting with other diabetics. As mentioned earlier, interactions with other diabetics were complex in that unsuccessful diabetics seemed more prevalent than those experiencing success. That raised the possibility of being negatively influenced.

Summary

Diabetes education, for the patients, is a web of satisficing. They desire information and sources that support them and encourage positive disease management. They will take the information they can get with as little deprecation as possible from the sources available to them.

Process

Process refers to those interactions that patients consider ancillary to the doctor's visit. These include cost prohibitions, insurance, and the mechanics of the medical visit itself. I discussed cost prohibitions earlier with compliance and diabetes education, and insurance was addressed as restricting coverage based on the patient's level of diabetes management. But patients highlight third party suppliers as a process concern, viewing them as opportunistic and aggressive toward elder diabetics.

> … what happens is that somehow these people that supply the diabetic products get your name and you get flooded with phone calls from all different kind of companies. …. You know, and what's bad about it is that a lot of our senior citizens gets those phone calls and they're real forceful and trying to get them to sign up for. And my brother gets a lot of calls and he had to hang up on people.

Patient participants agreed that companies were taking advantage of elders and interfering with their lines of provision.

Doctor Visits

An important feature of process concerns revolves around visits to health care providers. Patients valued and were comforted by a predictable process when visiting the doctor. But due to that predictability, the physician may be performing routine diabetes care without the patient's knowledge.

Man: I usually get there a little bit early and sign in to let them know I'm there. If I need to fill out some insurance information, if they inquire about that, I give it to them. And, when it's my turn, the nurse just takes me into the examining room [to] check out my vitals. Fine. And then the doctor comes in and he does what he normally does and he tells me what's what. And he checks stuff out. He'll ask me how things have gone. Do I have any questions [or] concerns? And the diabetic thing never comes up.

LT: You're saying the diabetic thing never comes up?

Man: No, unless I bring it up. He doesn't bring it up.

The patient has the burden of initiating conversations regarding diabetes during some visits even though the doctor may be monitoring the disease at within each visit.

Conclusions for Physician Manner

Participants were generally positive about the professional characteristics of doctors. But they were specific about those things that motivated them to greater interaction with their providers or hindered such interaction. Communication was the greatest contributor and hindrance to patient interaction with their doctor. Patient participants desired substantive feedback from the doctor in a way that allowed them to feel cared for and attended to as an individual. It was important to feel as though their provider was invested in a positive outcome for their specific case. When the participants began to feel ignored, disrespected, or uninformed, their participation and information sharing with their providers were negatively impacted. The patients were not necessarily being recalcitrant by ignoring the provider's advice. In several cases, they had good reason to deviate from that advice. Due to a perceived lack of concern the patient engaged their own experience and researched competing methods of self-care to compensate. Successful interactions, with increased patient compliance, involved increased

communication in a manner that allowed the patient to feel informed, respected, attended to, and

cared for within their provider's system.

Chapter 7

Focus Group Analysis of Patient Manner

Patient Manner, as discussed previously, is one way of tapping how patients conceptualize themselves, their actions, and their circumstances after having been diagnosed with diabetes and encountering their provider networks as diabetics. Patient Manner is a meta-level code focusing on how patients consider themselves as systems within systems. Within it are several concepts including Patient Self-management, Discovery of Diabetes, Family Influence, and Patient Self-perception. Like the previous discussion of Physician Manner, I will provide an overview of each concept under Patient Manner and then describe each more fully. (See Table 16).

Table 16: Super codes within Patient Manner

Patient Self-management	Discovery of Diabetes	Family Influence	Patient Self-perception
Beliefs (16)	Annual physical uncovers diabetes (9)	Negative family influence (4)	Perception of medication (9)
Privileging Experience (14)	Complications or symptoms drives patient to doctor (9)	Positive family influences (3)	Increasing positive perception of personal position (5)
Operant Knowledge (8)			False pleasing (3)
Fatalism (7)			Increasing negative perception of personal position (0)
Blood Sugar Relativity (5)			

Patient Self-Management:

Patient self-management describes the collection of mechanisms that patients use to make decisions regarding their day-to-day self-care. Self-management considerations included personal beliefs, privileging experience, patient philosophy, diet, fatalism, and blood sugar

relativity. These patients spoke about what they considered true and, in turn, true for them. Balancing their experiences with those of others experiences formed an atmosphere in which patients defined their decisions and compliance with physicians. Self-management for the patient was influenced by whether they believed the burden of care was theirs or resided with the doctor.

Discovery of Diabetes

Discovery of diabetes, being given a formal diagnosis, describes a patient's initial awareness of themselves as diabetic. Patients in this study seemed equally split in how they discovered they were diabetic: by having an annual physical or by being driven to their physician by symptoms. But patients who were symptomatic seemed to have been managing those symptoms for some time prior to their diagnosis.

Family Influence

Family influences, for these patients, seemed either present or absent with little space in between. When present, those interactions were described as having a positive or negative influence on the patient. Positive interactions were characterized as supportive and increased the patient's sense of will power. Negative interactions lessened the chances of a patient successfully managing their diabetes by increasing fear, introducing barriers to care, and increasing fatalistic attitudes. Patients were concerned that formal diabetes education did not address the challenge of dealing with a lack of familial support.

Patient Self-Perception

Patient self-perception describes those things that support or detract from a patient's view of him- or herself as a diabetic. Patients described being a diabetic as differing from other diagnoses because it is perceived socially as almost entirely brought on by poor decisionmaking. Patient discussion focused on those actions and activities that positively influenced their senses

of self and those that negatively affected them. Positive impacts produced dignity, developed trust in a provider and in oneself, and fought stereotypes. Negative impacts produced fear, isolation, shame, and misconceptions in care.

For these participants, patient manner influenced their potential for success. If they understood themselves as having a potential for success, as well as being surrounded by supportive people and circumstances, then they practiced more successful lifestyles. If they did not perceive themselves as managing their diabetes well, then fatalistic attitudes prevailed and successful behaviors were limited.

Patient Self-management

Patient self-management, as a sub-concept of Patient Manner, is a complex mix of several perceptions. Beliefs, privileging experience, patient philosophy, diet, fatalism and blood sugar relativity all affect the patient's choices while complicating their perceived ability to maintain chosen strategies. (See Table 17).

Table 17: Super codes within Patient Self-Management

Beliefs (16)	Privileging Experience (14)	Patient Philosophy (13)	Diet (9)	Fatalism (7)	Blood Sugar Relativity (6)
Burden of care rests with doctor (11)	Rationalized non-compliance (10)	Patient opinion (5)	Food preferences and strategies (10)	Encouragement (22)	Lack of support (11)
Burden of care rests with patient (8)	Operant knowledge (8)		Exclusion of foods (9)	Detached manner of doctor (8)	Glucose levels (10)
Control (7)	Perception of medication (9)		Food consequence management (5)	Negative family influence (4)	Diabetes diagnosis (7)
Respect (4)	Crisis response (5)		Food scheduling conflicts (5)	Self-discouragement (4)	Level of control (7)
Fear of rejection/altering the doctor's opinion of patient (2)			Conflict with lived experience (4)	Depression (2)	Body type (4)
Dignity (2)			Modifying diet (2)		Sense of urgency (4)
Trust (2)			Permanent dietary shifts (2)		
			Unrecognizable foods (1)		
			Undesirable foods (1)		
			Diabetic craving (1)		

Beliefs

Belief, or the acceptance of an alleged fact or body of facts as true without supporting evidence, describes the underlying convictions that patients have about health or health care. Key

concepts within belief include whether the patient believes the physician is responsible for their

care or that they as the patient are responsible, positively or negatively affecting the patients'

sense of control or agency, communicating respect, dealing with the patient's fears of rejection

by the provider, affecting dignity and trust, and discerning whether patients associate certain

symptoms with diabetes or claim knowledge of what affects their glucose levels.

Locating the *burden of care* was significant for some patients. When patients believed

that certain duties were the providers' responsibility, they were less likely to perform those tasks

themselves as part of daily self-care. Whether the doctor does or does not perform actions like

measuring blood pressure or glucose levels, the patient does not perform them. The expectation

is that the doctor should perform the tests.

> Most of the time I don't check my sugar like I should. Because I don't think… I think
>
> it's the doctor's job to tell you the truth. If you go to the doctor and you walk in with all
>
> your things on a sheet of paper, what are you paying him for?

Some patients believe that the burden of care rests with the doctor. In this sense, checking blood

sugar, keeping records, and alerting the patient of any changes or problems are thought to be the

responsibility of the doctor, and the patient refrains from doing anything the doctor should be

doing. This also applies to discovery of new complications. The doctor is supposed to "figure it

out."

But, when the patient accepts the burden of care, behaviors and thoughts toward the

provider shift. When patients take on the burden of care, there can be several motivations and a

spectrum of responses. At one end, the patient does explicitly what the doctor recommends,

keeps records, examines documentation for changes, and treats the doctor as a health care

consultant. The other end of the spectrum includes a more jaded view of the doctor as fallible,

worthy of suspicion and uncaring about patient care.

> Man:　… When I need to know something about diabetes, I just make some adjustments on my own diabetes myself.

> LT:　Give me an example.

> Man:　Well if my sugar stays high for so long then I just go up and I'll take the 70-30 insulin, and then I got the fast-acting insulin to go along with it on the scale.　So what I do… like I was taking about 30 units; I went up to 35 units and then take the fast-acting insulin on the scale.　Sometimes when my sugar gets up around 300, I take about 10 units of that fast-acting insulin and it brings it back down.

This patient makes adjustments to medications based on his own perceptions and needs

according to the tools available.

> Being in control of some aspect of care reduced stress and provided comfort for some

patients.

> Woman:　I've gotten to the point that I have a list of questions that I write down and I ask them every question, and if he doesn't answer somebody is going to answer before I leave.

> Woman:　Excuse me, are you a hypochondriac?

> Woman:　Yes I am.　I write my list down and I'm like… did you check my weight. What are you going to do for my leg? What are you going to do for this? What are you going to do for that?　And if I don't, and I still have these questions, I'll call back and they'll say, well we'll ask her.　They're used to me asking questions now.

Making lists of questions and pursuing answers, for one patient, increased communication and

reduced uncertainty and anxiety concerning her condition. But, another participant was unsettled

by the patient's aggressive behavior toward her doctors. She asks her, "Are you a

hypochondriac?" Yet, using the term, neither of the women was talking specifically about

hypochondria, a health phobia including a preoccupation with the presence of disease regardless

of diagnosis. The question could be re-presented as "Aren't you being aggressive?" The response

of "Yes, I am," again was not in response to being a literal hypochondriac. The patient is

claiming her right to be assertive with her health care and knowledge of her medical self. This exchange between participants highlights the different levels of understanding involved in control. For one set of patients, this level of assertiveness is considered normal and necessary. For others, it is seen as aggressive and problematic.

The need for control, respect, and dignity often are present simultaneously. One patient described a situation in which his need for all three clearly contrasted with the wishes of staff while hospitalized.

> Man: The nurses, they don't want to do nothing but…last time I went in the hospital, I was feeling bad. I went in the hospital ____. The lady put a catheter on. You know what a catheter is? And she made sure it was short enough so I couldn't get too far from the bed. And then they put this thing on me and it was short. If I moved my head like that it was tight. So they do that to keep you locked down on that bed. So I told the lady, I said, "Well look here, let me loose of this thing; I got to go to the bathroom to do #2. And she come with a bucket. And I said "Lady, don't bring me no bucket. I can go to the bathroom."

> LT: Did they let you up?

> Man: No, she said I had to use the bucket and I said well I won't go to the bathroom.

> LT: Who won?

> Man: I won. I said to the doctor get me out of here. I don't need no nurse here because they ain't doing nothing. I call the nurse in and I told 'em I needed to go to the bathroom and she came about three hours later. I don't need nobody to put me in jail.

While the staff was operating according to their orders and guidelines, the patient was experiencing a significant assault on his levels of control and dignity. His movement and ability to take care of his own needs were restricted in ways he found intolerable. He could not go to the bathroom at the time he needed or in the manner he needed although he felt capable of doing so. He would sacrifice necessary medical care in a hospital environment to maintain control and dignity. For him, it was very much a fight he needed to win. Asking his doctor to intervene set up a situation where the doctor had to choose whether to affirm the patient's dignity or not. In this case, the patient "won" as his dignity was affirmed.

Privileging Experience

Although privileging experience was discussed previously in Diabetes Education, it is relevant also to the patient's self-management. Again, where there is uncertainty, privileging experience may trump a physician's advice. Rationalized non-compliance occurs when the patient decides to follow their own plan as opposed to the doctor's.

Operant knowledge

Operant knowledge differs from rationalized non-compliance. Operant knowledge refers to information, correct or incorrect, that a patient is using to guide behavior, and rationalized non-compliance is a system of explicit comparisons between the patient's needs and the physician's advice.

One patient described the effect of not eating on blood glucose. In her example, blood glucose levels rise when fasting. Although her explanation is contrary to common understanding, she uses this understanding to enforce appropriate eating.

> The thing about diabetes is that you cannot <u>not</u> eat and your blood sugar will go up. And, that's because your body has a defense mechanism, so if you're hungry, then what your body will start doing, is start eating on the fat that's there. And, the next thing you know, it's over-eaten; it's over-eating. The longer you wait to eat, the higher your blood sugar could go. And that's the way the doctor explained it to me. So it's just as important, you know, you got to eat, you got to eat, you got to eat.

With operant knowledge, it makes no difference if the information used is correct or incorrect. The patient orders their behavior according to the information.

> Another patient used operant knowledge to direct his use of pain medications:
>
> I don't take a lot of medicines because I don't want to mask something that maybe is happening and I don't know about it because of pain medicine. I know friends of mine that just pop, even if they're not hurting, they'll take a pain pill every day. How do you know if something is hurting or if something is bothering you if you're constantly on pain pills? I will take medicine when I absolutely have to because of that reason--I don't want to mask something that may be going on with my body and I don't know about it because of a pain pill or something.

Masking useful information is a concern for this patient. He is taking from his friend's lived experience and creating operant knowledge for himself. Pain and other symptoms are useful information for this patient. Creating a scenario where he is hiding useful information from himself and his doctors is problematic and drives his personal restriction on medication.

Perceptions of medication

Operant knowledge affected how medications were perceived. Insulin, and the avoidance of it, was a large concern.

The form of the pill is better for you than the insulin. Taking the pill is better than taking

the insulin.

This participant used this piece of information to motivate himself to do what was necessary to

avoid being prescribed insulin.

Crisis response

Several participants seemed to assume that their primary mode of operation was in

response to crisis events. These included anything from the appearance of symptoms to

emergency situations. Patients adjust medication from a position of crisis and not disease

management. Emergency room visits are commonplace.

I did go out of Virginia one Saturday and I stopped off at Boston Market because I knew

I needed to eat something. And the next think I knew I woke up in an ambulance. I told

'em just give me something to eat and I'll be all right. And they let me get something to

eat and I was all right.

At this point the patient is accustomed to emergency situations. He knew he needed to eat, but

his response did not match the severity of his situation. Once emergency personnel were called

he was still able to control the situation according to his own experience with crisis management.

Patient Philosophy

Whether managing crises or engaging in disease management, the participants had

overarching philosophies that could positively or negatively influence their behaviors. Some

philosophies were more developed than others.

Nobody tells me! I try to minimize anything I do because it's <u>my</u> health, not the doctors-

and--we were talking about my uncle, I think he lost-he's diabetic-I think his legs

because he didn't do [what he was supposed to]. And so, like if we had, I think of my

daughter who cooks me Splenda cake. And if they have a piece of cake that looks very

good, I'll let her cut off a little bitty sliver and taste that. So, no I don't do everything,

but I cut it back to the point where I don't think it will be--and if it shows up, I take that

as seriously. Because I do not want to be--when I'm ready to die, I want to die. I don't

want it to linger on, and on, and on, and on. And, if you don't do what you're supposed

to do, you'll be lingering on and that's all you're doing. All the damage. It all depends

on your philosophy.

This participant's philosophy included his decisions on his quality of life and death. He wanted

to determine how he both lived and died. His response to his doctor's advice was connected as

well. He would adhere to the advice so long as it did not negatively affect his quality of life or

keep him alive past a point he would tolerate (lingering on and on).

For another patient, her philosophy changed as she experienced successes and setbacks

with disease management.

I'm sorry, he's giving me instructions and I know I should be obedient but now I'm ready

to live. And I have to change my ways with the instructions he's given.

Being ready to live was a major transition for this patient. The physician's advice and her

obedience were now linked to her survival. Patient opinion speaks to those beliefs that are

unfounded, but may have an emotional component.

Definitely, that's why I'm in my trouble now. I eat a lot of what I'm not supposed to eat.

If I could just … January was A+, no regrets. … the rest was a mess because I thought he

was wrong. I know what I have to do-just change my eating habits. … I want to do just

what I want to do. [Laughs]

For this patient, part of her deviation from the doctor's recommendation was because she thought he was wrong. This is after she achieved a measure of success following his recommendation. She emphasizes this by saying, "I want to do just what I want to do." Emotion and opinion were in conflict with advice and evidence.

Another participant attributed the doctor's resistance to her self-management to his economic interests.

> Oh, he doesn't what me to make all these other changes. Because he wants me to keep coming back so he can keep getting that kickback on that prescription.

There were continued conversations within groups demonstrating patient opinions about doctors receiving benefits from pharmaceutical companies in a way that dissuaded treatments. Some patient's were of the opinion that the doctor desired them ill instead of well. Patient opinions were offered to the group for clarification or challenge.

> Man: I just didn't like him. To me, he just came into the room, another day, touch me here, touch me there, you know—just a quicky-quick thing, ask me a couple of questions, I'll do this and whatever. Just went out of the room. It just didn't happen. No interest whatsoever in my well being. …

> Man: And ___ the room, half hour, 45 minutes. You know why _____ ___ don't you? So they can bill you for an hour of their time. So they bill you. You go in there…you go in and they seat you in that room, the doctor is coming in within 10-15 minutes; how can they justify billing you $200-300 for that visit and you isn't in there but 10-15 minutes. They've got to leave you sitting in there to bill you for the time.

Woman: Well the bill is being in a hospital setting. The billing is not for the time he spends with you.   Each visit has a certain price. So whether he spends 10, 25, 30. [minutes] Because my doctor spends as much time as I need. They allocate way more [time] than most doctor's office. For you to come. The nurse will say…she will let the person know that he's running behind.

Guy: _____per se…I mean you get billed for more than just the doctor's time.

…

Woman2:   No I mean I'm saying that in the financial part of hospital billing, the doctor billing, there's a fee step for everything, whether you're in there 10 minutes, 15 minutes, or an hour. It's the type of visit that you come for, so if you come for a physical, that's a price. They're supposed to allot time for the visit based on what you came for. So if you came for … what I found on and depending on your doctor, if you come in there…let's say you make your appointment today for a physical – that's not a good example. You hurt your toe, you cut your toe, you went into the doctor to see about it. The doctor is really only supposed to talk about your toe. Because the insurance company's got a lot of issues with him going outside of what your visit was. So if you're in there for the toe and then while you're in there you say "You know I've been having headaches and this and that.." and it's not related to the toe they're not going to talk about it with you because they don't have that time. And they have to allot so much time because the insurance company only pays for …every visit has a code, everything they do has a code, and if that's not what you went in there for, they can't code a headache if that's not what you went in there for. In all fairness to the doctor, the

insurance companies have their bylaws. They ___because a lot of things they

don't do it's not because of them it's because they're not allowed to do it at that

particular visit. You can make another appointment and see about your head. You

can make another appointment to see him about your whatever.

In this exchange, one participant is explaining medical billing to another who is voicing an

emotion-based opinion. The latter's concern stems from feeling disrespected and unattended to

in connection with time spent in face-to-face contact with his physician. His opinion about

billing caught another participant's attention, and she spoke with him about it. By addressing his

assumptions with information she removed the venom from that opinion and corrected the

information contained within it. As a researcher, I was able to see him relax as she explained the

difference in understanding.

Diet

Diet describes how patients interact with food and recommendations made by educators

and physicians. Diet, for the participants, was emotionally and experientially complex. As

discussed earlier, a diabetes diagnosis makes every dietary behavior suspect. Diet becomes an

exercise in exclusion. Socially, diet is an isolating factor, and the patient may be left to fend for

themselves in family and social situations.

These participants were interested in positive food strategies that fit their preferences.

They wanted to know, from other diabetics, what worked for them, what tasted good, what

modifications could be made to the foods they liked, and what didn't work.

Woman: I'd like to get it from somebody that it has worked. You know, someone who

is, you know, 102 and still in their right—you know, still have the mind and

they can tell you that you can live that long and be a diabetic. And, you know, every once in a while you fall off the wagon and tell you how to get back on.

Man: You know, that's what I do with everything else. I don't do that with diabetes. When I was a kid growing up in _____, if someone was not doing well and someone [else] is doing well, I try to figure out what is the person [who is] doing well doing and what the one not doing well doing or not doing. And I try to learn from it. Never watch women talk. That's my wife's job. I don't know that many diabetics. So, I just don't.

Woman2:   There are a lot of people who are--who are diabetics. And it's working for them. I want to know: is it true? I'd like to think so. I'd like to think so. I don't drink sweet or sugar soda, though. So, I drink the diet Doctor Pepper, the diet root beer, you know. But I just like to be able to talk to a diabetic and establish their success with it. You know, doing all of those things that everybody else tells you when you sit down with the consultants. You know, if I'm eating a plate of food and then I grab a diet soda, people will laugh. People will laugh at me. You're just cutting sugar, but I'd just like to talk to one.

These patients would like to talk to expert diabetics, know there must be those who are successful, but do not seem to be able to identify those resources. For one participant in this exchange, there was a gendered complication. His experience was to look for community role-models to emulate. But, he would not attend to female role models. He would get information from his wife about those models, but considered it outside of his realm. It was important to be

able to connect and discover useful tactics. It also was important to avoid ridicule and embarrassment.

Fatalism

Fatalism is discussed in detail under Communication. But with regard to self-management, key influences continue to be encouragement, physician engagement, positive/ negative family influences, self-discouragement, and depression.

Blood Sugar Relativity

Blood sugar relativity refers to the patient's understanding of the uniqueness of their case including, but not limited to, the blood glucose targets that are suitable for them as individuals. Before going further, it is important to understand the guidelines associated with diagnosing, classifying and treating type 2 diabetes. The criteria for diagnosis of Type 2 diabetes, according to the American Diabetes Association's "Diagnosis and Classification of Diabetes Mellitus," include one or more of the following.

1. Symptoms of diabetes plus casual plasma glucose concentration ≥200 mg/dl. Casual is defined as any time of day without regard to time since last meal. The classic symptoms of diabetes include polyuria (excessive urination), polydipsia (excessive thirst), and unexplained weight loss.

2. Fasting Plasma Glucose (FPG) ≥ 126 mg/dl. Fasting is defines as no caloric intake for at least 8 h.

3. 2-h postload glucose ≥ 200 mg/dl during an oral glucose tolerance test (OGTT). This measure is not recommended for routine clinical use (ADAa, 2007, p.S47).

The ADA position statements include a lengthy caveat concerning the treatment strategies for older patients with diabetes.

> The care of older adults with diabetes is complicated by their clinical and functional heterogeneity. Some older individuals developed diabetes in middle age and face years of comorbidity; others who are newly diagnosed may have had years of undiagnosed comorbidity or few complications from the disease. Some older adults with diabetes are frail and have other underlying chronic conditions, substantial diabetes-related comorbidity, or limited physical or cognitive functioning, but other older individuals with diabetes have little comorbidity and are active. Life expectancies are also highly variable for this population. Clinicians caring for older adults with diabetes must take this heterogeneity into consideration when setting and prioritizing treatment goals (ADAb, 2007, p. S27).

This statement is significant given the following recommendations for treatment. After diagnosis, the ADA recommends that those patients who are 65 years of age or older, "who can be expected to live long enough to reap the benefits of long-term intensive diabetes management (~10 years) and who are active, cognitively intact, and willing to undertake the responsibility of self-management should be encouraged to do so and be treated using the stated goals for younger adults with diabetes" (ADAb, 2007, p. S27). The goals for younger adults (13-19 years of age) with diabetes include a PBG of 90-130 mg/dl before meals, 90-150 mg/dl at bedtime/overnight, and A1C of < 7.5 %. For those who have comorbidities, are less active, and –presumably – less inclined to undertake the responsibility of self-management, tight glycemic control takes a secondary role to management of hypertension and complications. Given the heterogeneity of older adults with diabetes and the differing physical, emotional, and social landscapes they

inhabit, recommending the goals of a much younger group seems to provide a challenge even to the most fit of elders.

For the participants, the assumption is that generic goals and guidelines are unhelpful. Patients considered the guidelines, but also considered their own personal ranges for perceived wellness.

> They said my range was from 90-130. OK, but when it drops down to like 100, and I think maybe one time it's dropped down in the 90s, but if drops down to 100-something, I begin having headaches and not feeling good. So I don't know if I totally agree. And then my range can be higher than 130. And I'll stay within range for awhile, but then it'll go back up. So I work to have to get it back down, but at the same time it may be 145 or 150 and I feel perfectly fine.

This patient explored the recommended blood glucose range, but found that she felt ill within the recommended range. She accepts that her range is different than the recommended range. Others had the same experience.

> … I've heard different things about what the range is, what the good range is. Some say it's 80-110. I've heard 90 to 120. But for me, I found out that if my sugar is 90 or below, then it makes me jittery. My hands actually start shaking and I thought, you know, OK 80 to whatever is in the good range, then why is this happening. And I don't know if it's because I'm not taking enough of the medicine ___ it's allowing my sugar to go low, I don't know. I don't understand that part. Or is it just because me individually as a person, maybe my range is different from the norm. The doctors or whoever came up with this range decided "OK, this is the normal range for everybody.

This patient admits to being anxious about why her range seems different from the norm. For her, achieving the goal of inhabiting the lower end of the blood glucose scale produces negative results. It sets up a conflict for her that doctors would set a goal that seems detrimental.

In the previous example the patient is concerned with how her glucose levels compare to what is considered normal. This contributes to blood sugar relativity. Patients compare themselves to the recommended guidelines without direction. They also compare themselves to other diabetics with regard to glucose levels, weight, and level of control.

> I had a problem understanding how mine could be that bad. They kept telling me that the people that were overweight—their sugars were like 500 and mine was only 150. Why was I in this class? It wasn't a good mix of people, because then I started thinking, well mine can't be that bad if, no matter what anybody says. If they got 500 sugars, I only have 150.

For this patient, the goal of the educational opportunity and the urgency of changing her own habits were lost due to these kinds of comparisons. She later said, "It didn't give me a sense of urgency, I guess, because I still looked at me versus them."

> Again __ the meal situation, they gave us these portions of the meals and everybody the same portion, I just don't believe that someone who could weigh 600 should eat the same portion I should eat. You know what I mean? I just had an issue with the class part of it. I thought it was too simplistic with that group of people. Too general. That's the word. Everything can't be general; it doesn't work for everybody.

Without the chance to look more closely at her situation, or gain more appropriate perspective in her comparisons, this participant experienced setbacks in self-management. The strategies that

applied to her circumstances were not obvious. By sticking to generic standards, participants felt unsupported.

Patient self-management is a complex category that largely hinge on the participants' levels of efficacy as supported or undermined by their interactions with providers, family members, and their own personal belief systems. When the participants felt supported and informed, they considered themselves able to manage their disease and were motivated to perform the associated tasks. But, when participants felt isolated and unsupported, the motivation lessened, while levels of fatalism went up. Self-management and discovery of disease are related in that the seeds for success or fatalism can be planted at discovery of diabetes.

Discovery of Diabetes

The way patients formally discovered their diabetes generally was split between two possibilities. Either their diabetes was diagnosed as a part of an annual physical, or the patient was driven to their physician by a variety of symptoms. The patients were not surprised by the diagnosis, but they were shocked nonetheless.

> I guess you might say I had all the classic signs: I had the frequent urination, but I started losing weight. So, I thought I had discovered a diet. And, I got a boil in my groin and then it got to the point that I could hardly walk. And, I started treating it myself. You know with the warm bath soaks. Finally, one day it came to a head and it burst. I decided to go to a doctor because it was just so awful. And I went to the doctor and the doctor asked me: are you diabetic? And I said, "No." And they found out my blood sugar was 500. They treated the wound—they gave me insulin that night. They sent me home and the next day they told me to come in and see my medical doctor. So, that's when it started.

This patient was convinced she was not diabetic. She declares that she had all the classic signs. She is aware of the symptoms now, but at the time of her diagnosis did not associate her symptoms with having diabetes. In her account, the doctors measured her insulin levels while treating the immediate wound. She was not formally diagnosed until the next day by her personal physician. In this case, she initially did not go to the doctor anticipating a diabetes diagnosis.

Another participant's complaints were overheard by an occupational nurse while at work.

> Yeah, I found out from work. You know, I kept complaining about being tired all the time. And then one day the nurse was on the dock and she just said let me check the blood sugar. And she took it and it was like [can't decipher]. . . over 400. … and she said, "You go to the doctor right now."

His workplace complaint prompted an on-the-spot response. The nurse's directive compelled him to visit the physician where he received a formal diagnosis.

Among some of those compelled to visit a physician by symptoms, several seemed not to connect the symptoms experienced to the possibility of diabetes.

> Yeah, well, I found out when I was on vacation and I was straggling a little. And just got dizzy and vision got blurry. And didn't think nothing about it. My head started hurting. And then that night I got up to use the bathroom four or five times [it was] unusual. And then told my wife I need to make an appointment to go see the doctor. And then I went to the doctor …

Not thinking anything of symptoms was typical for several participants. Others associated their symptoms with something else. Sometimes the re-association is optimistic. Sometimes the symptoms were associated with other ailments.

> So, I thought I had discovered a diet.

And my vision-during the day it was fine but at night my vision was very poor. I just

thought I needed my glasses changed.

And I just thought it was an age thing.

For other patients, even though there was no formal diagnosis, there was disease

management.

A symptom: before I found out I was diabetic I cut out a lot of stuff from my diet that I

knew wasn't good for me. And I was exercising long before I found out. Ah, I would go

to work--that was before I retired-and by 10:00 I would just start shaking, I would

become disoriented, I couldn't think straight. And I kept a package of peanut butter

crackers and I could eat a couple packages of those. I would settle down and I'd be okay

for work. And, that went away. I don't have that phenomenon any more. That was

something pretty bizarre.

Experiencing hypoglycemia, disorientation, and frequent urination, this patient had been

managing his diabetes symptoms for years. He made changes to diet, increased his exercise, and

began to plan routes around available restrooms in response to his symptoms.

Family Influence

For the participants, family influence was either present or absent. While examples of

positive and negative family influence were given, negative influences were more prevalent.

Negative family influences lessened the chance of a patient's successful disease management.

All I know is my family. And aside from Michael the rest of us aren't doing well. So I

can't ask another person who is doing bad or worse than I am. Up until today, I didn't

really know anybody else that had diabetes that I felt comfortable …you know, because

it's personal and everybody doesn't want to talk about their personal business. ____ I just didn't know who I could talk to because it is personal.

Being surrounded by uncontrolled diabetics was a problem for this participant. She felt isolated in her experience and unsupported. Isolation and fear can stem from long-held beliefs and negative generational outcomes.

Positive family influences were those that encouraged the patient in successful self-management.

My daughter and my wife, when first she had her stroke, would get mad at him, because-- "Well, did you ask him about this?" "No, it didn't come up. Why would I ask him when there was nothing came up that was related?" They would beat up on me! And, one girl would threaten to go with me … [*chuckle*] if I would tell her when I was going.

He enjoyed the interaction with his wife and daughter. It showed their concern for his wellbeing and reinforced his self-care. There was a sense of accountability – if something was amiss his daughter may follow through on her threat to accompany him to his doctor's visit.

For one of the caregivers, being able to visibly interact with her mother enforces a positive influence.

My mom can sit there saying she doesn't have any symptoms, but I can sit here and I can look at her and I can tell if she has symptoms. I can see it in her eyes, And I'll ask her "Did you take your medicine today?" and she'll answer sometimes yes, sometimes no. And I can see it in her eyes. … She's say she's OK, and I'll look at her and I'll say "you didn't take your medicine." And I'll know she didn't.

As caregiver to an elder parent with diabetes as well as cognitive challenges, this participant's intimate knowledge of her mother's habits and diligence in observation helps to maintain her mother's health and wellbeing even if her mother is unable to respond appropriately.

Patient Self-perception

Patient self-perception describes those things that support or detract from a patient's view of him- or herself as a diabetic. Most patients described being diabetic as differing from other chronic illness diagnoses because some others perceive diabetes as being brought on almost entirely by poor decision making. The patient's perception of medication has been discussed previously. Here, I will focus on the positive and negative perceptions of personal position and false pleasing.

> Like I said, I went into a little depression when I found out I was a diabetic. I was not
>
> supposed to be a diabetic. I was going to be different from my mother. Out of seven
>
> children there are only two who are not diabetic.

For this participant, being declared diabetic was a defeat. She was attempting to make different decisions with the specific goal of being different form her mother with respect to diabetes. Two of seven siblings were able to avoid diabetes; it was her intention to be part of that group. The depression she experienced was associated specifically with her diabetes diagnosis.

Although several patient participants mentioned fear and depression as part of their response to their initial diagnosis, they also spoke of things that helped or hindered their move away from depressive mental states and negative self-perceptions. (See Table 18).

Table 18: Super codes describing Patient Self-perception

Increases positive perception of personal position (5)	Increases negative perception of personal position (0)

Encouragement (22)	Cost prohibitions (15)
Attention (16)	Diabetes diagnosis (7)
Support (10)	Control (7)
Personal sense of will power (6)	Social mischaracterization of diabetics (6)
Stress reduction (4)	Self-discouragement (4)
Avoidance of Insulin (4)	Fear of rejection/ altering the doctor's opinion of them (2)
Dignity (2)	Classroom education (1)
Trust (2)	Specialist as evidence of being out of control (1)
Release from the specialist as a positive (1)	Repeat crises with uncontrolled glucose levels (1)
	Rationalizing lack of care from provider (1)

Increasing positive perception of personal position

Acknowledging the patient's understanding of themselves as a diabetic increases their ability to see themselves as having available positive outcomes. "Personal position" refers to the patient's relationship to their own possible outcomes. Having a positive perception of personal position means that the patient sees the possibility of successfully managing their diabetes. As mentioned previously, encouragement impacts self-perception by providing external evidence that positive outcomes are possible.

Woman 1: You know the way I'm going, he's probably worried. He told me, you know,

even as much as 20 pounds..

Woman 2: Lose some weight; you can come off of everything. He told me that. It will come off, he told me that. Lose weight and your problems will disappear.

Woman 1: With your age, with your weight, and your eating habits, if your cholesterol stays the way it is, if it's this good, then all you have to do is just take the medicine for the diabetes. Those readings could beat it. He said, Do it! You can do it.

For these two women, the outcomes were visible and attainable. They were supported by the doctor's declaration for their particular cases. Attention, an intense focus on the present patient's case and person, opened avenues of communication and participation.

Support, as given by family, friends, and providers, reduced the patient's isolation. In combination with encouragement and attention, support reduces stress and increases agency by giving the patient a clear sense of where they were with their care and what they can do to maintain it. In the following example, the patient expresses frustration about the level of communication during his exams.

Man: I would say that … I only go, like I said, twice a year to the eye doctor and she telling me everything is ok. I mean they don't give you the reasons. Like I said they're going to give you the reasons why it's good or why it's not good. So but if it's good, you're good to go. But come back in another 6 months. But if they don't tell you that something is wrong in between that time, how are you supposed to know? Until the ___ I think that's misleading. Because ____ I go to my doctor in Chesapeake and she said to me "Are you OK Mr. ___ you're finished." And then she'll say "I'll see you in 6 months." What

did you do that will cause me to come back in 6 months? Just say I'm good and that's it?

LT: So at least at this point you're not getting much actual feedback during your visits?

Man: Exactly. I think it should be something when the doctors come out to you at least quarterly to let you know that things was alright—at least at the time that I checked it. But these are things you should look out for before I see you again. And I think that's… I mean people when people go to the doctor they should follow up with you, not that you have to follow up with them.

He complained that, after an exam, he was given insufficient information about his present condition. He was not told what he was doing correctly, what had changed if anything, or what he should be aware of concerning his future care. His desire was for a more consistent communication with his providers. The lack of communication was producing anxiety.

For the participants, avoiding insulin was a priority. Insulin was negatively conceived as evidence of unending treatments with inevitable, negative outcomes. It could be a source of shame, anxiety, and an outward marker of an inward lack of self-control. Avoiding insulin was seen as a kind of success.

Because I was put on insulin, but then through the grace of God I was taken off. And now …but that was about 17 years ago. … I was blessed by God not to have to take the insulin.

The relief that this participant had about avoiding insulin was echoed by other participants. Being "diet-controlled" was considered a much better position – even a source of pride for the patient.

The positive effect of maintaining dignity and trust within care relationships has been discussed previously. But the relationship with specialists was complex. The participants appreciated a referral to a specialist, seeing it as signaling increased attention and care from the primary doctor. With regard to increasing a positive sense of personal position, being released from a specialist back to a primary care physician was seen as an improvement in the patient's ability to care for him- or herself.

> Well, I was thinking about this going to my primary doctor. Like for my diabetes, because it's been all right. And the primary doctor checks things, too. And he could kind of work it just like the independent diabetes doctor. So, I was just thinking, if nothing is making me uncomfortable, I was just thinking then maybe I could even go to the primary doctor 'cause he takes these tests also. And he can tell me about it, 'cause it's, like, more normal than it has than when I first got it. I can say it's more steady-it <u>was</u> more steady until the last six months, I've been eating out a lot [*voice goes to a whisper*]… and, I thought I could say-it's really my fault what's going on now. So, if I go back to what I was doing last year, eating correctly, 'cause he told me to keep up what I was doing--I went in January and had to see him, the primary doctor--that I wouldn't have to go to the independent doctor any more, just the primary.

This patient has had a period of successful management based on the advice and support of her primary physician and her specialist. She sees some redundancy in the process, but attributes any setbacks to her own choices. She was able to identify successful strategies and challenges to her progress. Yet she has created a goal and assigned a value to being released from the specialist. Seeing only her primary doctor, as a diabetic, was preferable. For her, it represented an increase in her self-control as well as a return to better control of her diabetes.

Increasing negative perception of personal position

For the participants, negative perception of personal position was easier to reach than positive perception. It was easier to believe – based on formal and informal education along with other experiences – that only negative outcomes were possible. Several of these notions have been mentioned previously as behaviors and practices that led to decreased communication, increased fatalism, and decreased active participation in care.

Cost prohibitions had an impact on patient's pride as well as producing a fear that an inability to pay would negatively impact the doctor's level of concern and quality of care. The diabetes diagnosis itself brought feelings of guilt, shame, isolation, and embarrassment which hindered any supportive relationships. Lacking a sense of control increased a sense of helplessness. Discouragement contradicted a patient's sense of agency and increased fatalistic attitudes. Fearing rejection by the doctor inhibited communication. Formal classroom education made some patients feel confused or worse about their situation. Having repeated blood glucose crises undermined agency and control and increased self-discouragement. Additional factors reinforced negative perceptions. For example, social mischaracterizations of diabetics enforce the belief that Type 2 diabetes is a consequence rather than a disease.

> Because a lot of people think that if you're a large person you're supposed to have diabetes, but I know some people just as skinny as a rail and got it, and they're in worse shape than I am.

> Because I just could not believe that I was a diabetic. I didn't want to believe it because I felt I was doing well. But the tests came back showing something totally different.

… Well, first of all, I was afraid of people seeing me with a needle and people thinking I'm using drugs. That was the first thing. Because I have a pin. I didn't want people to think I was shooting up.

In the first instance, the participant referred to a common belief that overweight or obese people are supposed to have diabetes. He observes that the common belief is untrue, but registers the stigma of others believing that he had earned his diabetes due to his size. In the second instance, the issue is still behavior. The participant had assured herself that she was doing well enough in her behaviors to avoid a diabetes diagnosis. It was a shock to her to be diagnosed as diabetic. The third instance is both similar to and different from the first two. The similarity is in its relationship to outside opinion and misconception. The difference is in the assumption of criminality. The participant is worried that, when she has to take her insulin shot in a public place, others will think she is taking illicit drugs. This concern leads her to avoid situations where she may be forced to take her insulin shot in a public manner. In some cases, she may not take her shot at all for fear of other's opinion.

Man: … I have other problems because I was having….I don't know where that problem comes from; I'm still having a little slight problem. I get a boil down in the groin area. And they won't bust it, but it'll start messing around and I can feel it start getting uncomfortable. And the next thing I know, I can pop. And then it'll go away, and then it'll come back. So I can't get no doctor to tell me exactly why that's happening.

LT: So they don't think it's important or they don't know.

Man: They don't know. I guess they don't want to be fooling around down there on my man no way.

When the patient was unable to get a response from his doctor about a pernicious problem, he rationalized his doctor's seeming lack of concern or care. He attributed it to the symptom to the location of the problem and a person's reluctance to engage that location.

False pleasing

False pleasing is a way of maintaining a positive relationship with providers. The patient has a desire to seem compliant even if their behavior does not suggest actual compliance.

> No, they'll [the doctors] tell her, you know you need to stop this. And she says, I know. They cry on each other's shoulders and then she comes back out and he'd drop her off- she's in a nursing home now--and that's why I give her this little story. But well, when we were young we lived to eat and now we have to eat to live. She doesn't want to hear it. But, that's life. You can't do what you used to do. She would have me drop her off at a place where she could get what the doctor told her not to do.

The participant's wife is also diabetic. He described his wife's interaction with her doctors. They will give her direction about what she should and shouldn't do. She will agree with the doctors while in their presence. She receives the emotional and social involvement in that moment. But, according to her husband, she resists their advice when out of their office. She rejects their advice as well as her husband's philosophy of life.

> For other patients, false pleasing comes with the anxiety of being in the doctor's office. After the nurse takes my pressure and does other testing and she says "C'mon follow me." And I go into an examining room and the doctor walks in. Speaking really nicely. "How you doing?" "FINE!" (laughter).

Worry about what the doctors may find, anxiety over the patient's levels of compliance, and "white coat syndrome" all contribute to false pleasing. This patient, with agreement from other

participants, describes blurting out an affirmative response and being unable to adjust that response as the interaction moves forward.

Conclusion

Patient manner is complicated as it includes influences more numerous than the patient's opinion alone. In relationship to what motivates elder African-American diabetics to increase interaction with their medical providers, patient manner suggests that providers compete with many other influences. These influences include the patient's beliefs, experiences, family influences and self-perception.

Understanding this competition may provide insight for the provider and for the patient. The challenge for both is to address beliefs, fears, misconception, and misinformation in a way that makes disease management goals visible and accessible to the patient. According to these participants, hindrances to interaction with providers are present and easily instituted. Negative family influences are more numerous than positive influences. Diabetics have immediate and continual access to fatalistic attitudes from family and providers. Successful interactions, for these patients, are those that deal with fear and fatalism by building communication and agency. The patient wants to feel that goals are specific to their case and attainable through their choices and behaviors, and that they are personally capable of successfully contributing to reaching those goals.

Chapter 8

Analysis of Interviews with Recommended Providers

Attention turns now from the patients to selected providers. This chapter focuses on individual interviews with medical providers whom focus group participants recommended.. I asked the providers a series of questions about their interactions with elder, African-American diabetic patients. The chapter will focus on two of the three research questions:

- **Where do providers get appropriate cultural information?**

- **What distinguishes successful interactions from unsuccessful interactions from the providers' standpoints?**

Leading into this distillation of provider discussions it is important to consider the space in which they occurred. This subject matter is sensitive as it deals with providers' abilities within interactions and their response to ethnicity. Focusing on medical interaction with an emphasis on individuals of a particular ethnicity and age range asked providers to openly discuss areas they may or may not explicitly consider. Part of the interview process was dedicated to discerning the providers' willingness to have this discussion and helping them acknowledge thoughts that were a source of discomfort. The providers, while speaking with respect and concern for their patients, answered candidly. It is my hope and goal as a researcher to present their honest comments as respectfully as they were given. Overall, the interviewed providers were honored to be recommended by their patients.

Table 19: Provider Demographic Information

Participant	Age	Ethnicity	Sex	Length of Practice	Profession/ Specialty	Location of Practice
S01	61	European American	Male	32 years	Family Practice	Blacksburg, Va.
S02	47	Hispanic American	Male	17 years	Endocrinologist	Silver Spring, Md.
S03	47	European American	Male	17 years	Endocrinologist	Roanoke, Va.
S04	60	African American	Female	37 years	Nurse Practitioner in Family Medicine	Suffolk, Va. Wakefield, Va.

The providers inhabited different specialties, ethnic locations, and experiences. (See Table 19). The analysis generated from the interviews reflects their differences and similarities in thought and practice. The providers' discussions yielded two meta-level concepts: affective communication and technical communication. Affective communication includes any information transmitted that may be technical, but expresses or deals with emotion. Technical communication expresses "technical" information in its most appropriate and understandable form, including HbA1c, weight changes, blood pressure, cholesterol changes, and other medical and behavioral needs. For the providers, affect and technical concerns are bound together. At the same time, the providers' comments suggest a continuum between the two kinds of communication as seen in Table 20.

Table 20: Affective, Shared, and Technical Communication Provider Super Codes

Affective Communication (42)	Shared Affective and Technical Communication	Technical Communication (19)
Style of Diabetes Education	Physician Support	Compliance – Provider Defined
Fatalism	Time	
Informal Diabetes Education	Feedback	
	Formal Diabetes Education	
	Art of Practice	

Considering these concepts of affective and technical communication is one way of viewing how providers experience themselves within the health care system. The super codes listed in Table 21 describe these experiences with elder, African-American diabetics. The providers did not use these words in our discussion. These concepts arose from analysis of the interview transcripts. I first will summarize the super codes presented in Table 21. Then, I will present a more detailed description of each. Lastly, I will return to the relevant research questions.

Affective Communication

Affective communication is a meta-level code that describes communicating with or about the effect of emotion or feeling. From these providers' perspectives, patients were more or less responsive given their experience with the provider. Compliance could hinge on how the patient received the information from the provider. Also, treatment options were impacted by the provider's perception or experience with patients or communities. Affective communication included the following super codes: style of diabetes education, fatalism, and informal diabetes education. Each is summarized below.

Style of Diabetes Education

A provider's style of diabetes education might include 1) positive, accessible statements, 2) negative, fatalistic statements, or 3) a combination that depends on context. Providers spoke of perceptions that impacted their style including whether they perceived the patient holistically,

perceived their own personal assumptions as providers, addressed the patients'

conceptualizations of medication and care, were able to increase a patient's positive awareness of

compliance, and/ or educated patients in a manner that linked prevention and consequence

avoidance. Style of diabetes education played as well a role in informal diabetes education.

Fatalism

Fatalism includes the provider as well as the patient. It is characterized by the attitude

that actions are futile and that negative outcomes are inevitable. From the providers' perspective,

their personal assumptions about patients are factors. These assumptions can be based on

experience with a population that now has been generalized, history, fear, or some unexamined

source. Providers' believed that fatalism in patients stems from a lack of education and

expectations of negative outcomes.

Informal Diabetes Education

Informal diabetes education, while related to style of diabetes education, also includes the

provider's inclination to provide a wider education regarding diabetes. Providers were at a loss to

explain why patients were uninformed about their needs and care. At the same time, providers

spoke of barriers to informing patients including the impact of time and a lack of understanding

of patient contexts.

Shared Affective and Technical Communication

Affective and technical communicationoverlap a great deal. According to the providers, there are things they learned to do and manage that were not necessarily covered in a formal education process. The five areas that emerged were physician support, time, the art of practice, feedback, and formal diabetes education.

Provider Support

Provider support refers to those behaviors that aid the patient in negotiating care. This is not exclusive to medical care. Negotiating care encompasses the system-oriented experiences that the provider may help direct in order to facilitate greater compliance. This can include charting patient economic data to facilitate support and patient comfort; moving according to the patient's timeline to avoid discouragement and increase understanding; and helping the patient work through the actual administration attached to their care including paperwork and reimbursements. Individualizing patient goals, situations, and care strategies as well as using the system to the patient's benefit also are part of provider support.

Time

From the provider's point of view, time available to communicate with patients, varied in amount and nature. The presence of time, lack of time, and use of time all carried different meanings. In some cases, time was a measure of respect. If a patient was compliant, then the provider felt that the time spent with the patient was reciprocated. Providers also spoke of timing pressure to avoid non-medical communication. Administration challenges were problematic to providers as well. Time was needed, but time was limited. Older patients require time that may not be available. At the same time, providers understood that spending time was necessary to build trust and establish relationships.

Art of Practice

The art of practice describes the characteristics of care that providers attribute to style, personality, discernment, and challenge. Some discussed whether interpersonal skills can be taught. Possible lessons include developing how advice is given, cultivating a community reputation, incorporating changing medical knowledge into patient care, and dealing with personal and patient challenges that skew their interaction with each other.

Feedback

Feedback includes those interactions and behaviors that communicate more than technical information between patient and provider. Providers outlined several situations that could act as barriers to feedback, including patient/ provider dialect, medical students and staff who are not native English speakers, and provider assumptions about patients' vocabulary and concept knowledge. Feedback also includes a mechanism for weeding out patients who may not comply with provider recommendations.

Formal Diabetes Education

Providers were polarized in their use of formal diabetes education. Here, formal diabetes education includes incorporating or recommending diabetes educators and/ or periods of time specifically designated for educational purposes. Either providers integrated formal diabetes education into their practices, or they delegated it to diabetes educators or nurses.

Technical Communication

Technical communication is "concerned with conveying information in an appropriate and maximally understandable manner for an audience while presenting it in the most appropriate format to meet the audience's needs."[21] Providers seemed to agree that technical information could be treated as an exchange of facts. Yet, further conversation uncovered that how technical communication happened was significant and carried more information than providers thought they were relaying.

Provider-defined Compliance

Compliance was not part of the original series of provider interview questions. As each provider mentioned "compliance," it became part of the discussion. Generally, compliance focused on whether the patient achieved the provider's goals by performing the given tasks, which included lifestyle changes, blood glucose monitoring, weight loss, and diet maintenance. For these providers, compliance had other associations as well. Compliance, or perceived compliance, was a means of considering the patient's worthiness and could be laden with preconceptions about the patient that impacted care. Rates of compliance could be skewed by the weeding out process.

Affective Communication: Style of Diabetes Education, Fatalism, and Informal Diabetes Education

Affective communication describes the emotional content of the patient-provider interaction. Patient and provider each carry a collection of assumptions and experience into their interactions. This affects what information is given, how each receives information, and how each perceives that information as reflecting the patients' decision making capacity and the

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[21] "Technical Communication: Professional Communication Society," http://ewh.ieee.org/soc/pcs/index.php?q=node/194, Dec. 8, 2009.

providers' inclination to provide quality care. Affective communication also plays into the kinds

of information that is omitted in the interaction. Table 21 further disaggregates style of diabetes

education, fatalism, and informal diabetes education, and the following sections will discuss each

super code more thoroughly.

Table 21 Affective Communication Expansion

Style of Diabetes Management	**Fatalism**	**Informal Diabetes Education**
Developing positive awareness as part of overall compliance (3)	Expecting negative outcomes (3)	Producing knowledge of family medical history, decision making, and prioritizing is a challenge (3)
Changing conceptions of medication and care (3)	Reducing fear through education (3)	Positions physicians at a loss for why patients are uninformed concerning their needs and care (2)
Cultivating providers' holistic viewpoint (3)	Generating catch 22: Fear is a barrier to medical contact which, in turn would reduce fear (2)	
Linking prevention with consequence avoidance through education (3)	Checking Attitude: If the patient won't work with their provider, they won't be successful with another intervention (1)	
Restricting assumptions connected to patient (2)	Assuming by provider (Supercode*)	
Supercodes contain several codes that will be explored more fully in the text.		

Style of Diabetes Education

The style of diabetes education applies to both formal and informal education. Providers

spoke of developing a style that included using positive, accessible statements, while at the same

time avoiding negative, fatalistic types of communication. Incorporating patient concerns while

dealing with the providers' own assumptions and concerns presented a continual challenge.

Developing positive awareness as part of overall compliance

Several providers thought it necessary to help their patients develop a positive awareness of themselves and their care. Encouraging positive awareness was a response to what the providers perceived as a lack of personal awareness or the production of a negative awareness. The patients had to be taught to attend to all of their health/physical information and not just in moments of crisis or failure.

> Well, they tend to have more medical problems than other populations, for example, hypertension, diabetes, obesity, cholesterol problems. And all these problems translate into more morbidity so they tend to have a lot more problems: heart attacks, strokes, renal failure. Like I would say that there's an issue of allocation [resources], how to take of themselves, the importance of knowing what happened in your family will happen to you too. You know there has to be more awareness developed among this population that they have all these problems so they need to be proactive-not wait until the end.

This endocrinologist spoke of the need for positive awareness as a means of avoiding negative outcomes by addressing the entirety of medical care. Because of the higher incidence of specific medical problems, he lists three areas of awareness: 1) defining resources so that health care is a priority, 2) increasing knowledge of self-care, and 3) knowing the health history of family members. Waiting until the end or the onset of physical consequence, according to this provider, entails waiting until disease occurs. Positive awareness describes having knowledge of more than medical failure or ineptitude. Patients are encouraged to have a full knowledge of their medical histories, priorities, and decision making.

This provider then discussed his response to the complexity of his patients. For him, diabetes is the connecting feature. Building awareness of just how connected diabetes care is to the entirety of their health is one strategy for increasing positive awareness.

> Probably what ties all this together is the diabetes. I try to use that as my point of reference and I tell them-listen, these will make these other problems bad or worse, so we need to deal with the diabetes and everything else will fall in place. And as I tell them a lot of the medication we give you for high blood pressure will also help your potential diabetes complications, like renal failure. And the ____ blood sugar control with help with the others. So and I try tie it up together around that.

Connecting diabetes to positive and negative effects made diabetes care more of a priority. Developing positive awareness is a strategy for threat mitigation and fear reduction.

Changing perceptions of medication and care

Providers are aware that certain treatment options give patients pause. For elder, African-American diabetics insulin therapy is highly problematic.

> Insulin was like the kiss of death. And you had to change that concept. To change that mindset, I'd say "If you are a diabetic, and you were an early diabetic, you *may* eventually be on insulin. But insulin is not a bad thing. The type of insulin that we have now is actually a good thing. And you can actually …. I keep saying actually, but you can do better on insulin than you can on several oral medications. In the long run, it's actually cheaper than several oral medications.

This nurse practitioner describes patient thoughts regarding insulin therapy. With this understanding she has institutionalized a response in her practice. She acknowledges the patient's fear, but moves to change the negative perceptions surrounding insulin by attaching it

to positive outcomes. Instead of the kiss of death, insulin becomes associated with a reduction in medications for some and reduced costs. Changing perceptions is connected to the provider's ability or inclination to view their patient holistically.

Linking prevention with consequence avoidance through education

Motivating patients to higher levels of participation and prevention, for the nurse practitioner, meant understanding the fears of the patient and working from there.

> So with the men it is decreased sexual function. And with the women and men both, it is
> the threat of losing their limbs. They're afraid that they're going to lose their feet, toes.
> You know, that kind of thing. It's only because they don't know what causes this to
> happen. And once you teach them, this is how this can be prevented, then the fear of that
> is lessened. Because then they know this is how I don't want to be. This is what I can do
> to prevent it.

The patient is motivated to avoid experiencing future complications or repeating an experience. She uses that fear and connects the avoidable outcomes with preventative behaviors. The patient is empowered to prevent his or her own negative outcomes.

Restricting assumptions connected to patients

Providers' assumptions about the patients' understanding can be counterproductive. One provider does not assume dietary knowledge. Instead she focuses on what everyone needs to know.

> Everybody needs to know the answers to why. Everybody wants to know why. If I say
> "Listen, you need to eat less carbs." You know, the best way to control this is …What
> did you eat? Did you eat? Well I ate spaghetti. Well, there's a lot of carbohydrates in

spaghetti. You need to cut back. Eat only one cup of spaghetti. You take for granted that people know things. You take for granted that they know what carbs are. You take for granted that they know carbs are converted to sugar. You take for granted that they know they know the difference between… they know what a cup is. You know, a cup is not a cup is not a cup. So you take all of those things for granted. But if you say, this is how much spaghetti I want you to eat and a cup of spaghetti contains 4 carbs, and a carbohydrate is this, and this carbohydrate is converted to sugar, and sugar is what raises your glucose level. The word glucose and the word sugar are the same. You know, there's so many things that we just take for granted because we're medicine people. So you need to really talk to the person as if he knows *nothing*.

Speaking as if the person knows nothing is not the same as speaking with a condescending tone. The provider is giving available, necessary knowledge. The provider is not judging the patient on what they should already know. If the patient does not have basic knowledge, there can be no expectation of control or compliance. By acknowledging the gap between the provider's assumption of knowledge and the patient's real understanding, the provider avoids frustration and increases the opportunity for compliance.

Fatalism

Fatalism describes the patient's or the provider's perspective that nothing can change and that negative outcomes are assured. In essence, there is no point in participating fully or expending effort as there is no hope. Several providers linked education to a reduction in fatalism.

Expecting negative outcomes

Both providers and patients can have fatalistic expectations concerning behaviors and outcomes.

> You know, sometimes there's a lot of fatalism. You know, if it happened to my mother, she got kidney failure, it will happen to me too. So that's going to happen.

This provider acknowledges that fatalism is present. He expects some level of fatalism to be present among patients. Another provider acknowledges fatalism in the area of insulin therapy.

> Everybody is trying to not get on insulin because it's always been the myth that if you ever progress to insulin usage, that you would eventually lost your limbs or end up on dialysis, or you would be close to death.

For the diabetes patient, providers acknowledge that thoughts of eventual death, limb loss, and organ failure are fears to be contended with.

Reducing fear through education

As mentioned previously, education, helped give patients more control over their circumstances. Education changed the emotional content of the diabetes diagnosis. Providers, as a means of recharacterizing diabetes, spoke of what they wished was more commonly understood.

> That the diagnosis of diabetes is not the end with all. That it's controllable. In some instances the diagnosis itself is probably saving your life. That if you would keep on the same path that you're on, without the diagnosis you would probably die a lot sooner than you would knowing that you're a diabetic, because knowing is a way to help control the process.

Knowing is a method of control in itself, according to this provider. Recasting the diagnosis as life-saving is important.

Generating catch 22

After the initial diagnosis, education can remove barriers to continual care. For one diabetes patient, fear kept him from addressing an obvious issue.

One of the first men that I ever saw with diabetes was a male that was not circumcised. And he came in with THE worst-I don't think I've ever seen worse case of candidiasis. It's a yeast infection around his penis. And it was **awful**. Because his foreskin was pulled up, he had all of this yeast coming out of the foreskin all down into the shaft. He could not even pull the shaft of the foreskin back. And he was just pitiful. And when I diagnosed him with the diabetes and that finally went away, we sent him to get a circumcision. And he was saying, "You know, [name removed], I actually thought that this was really the end. And I thought that they were going eventually have to cut it off because I thought the diabetes had messed me up."

The patient had to overcome a significant fear in order to pursue medical care. His fear was greater than the embarrassment of his immediate condition, but was based on a life-changing negative outcome. "I thought the diabetes had messed me up" became a springboard for patient motivation. The provider took the opportunity to increase the patient's education and address fears.

Checking attitude

Fatalism in providers can be just as present as among patients. Like the patient participants, providers discussed things that cause limits in care.

I don't think we as physicians, and certainly I probably don't push patients hard enough

to do. It's ___ diabetic education classes. They're particularly for new diabetics, but I

think that in retrospect something I ____push harder, and I don't plan to push harder to

help them. Again, getting the client to be ____ back with the problem, because if they're

not going to comply with you, going to some classes taught by a stranger is also going to

be difficult.

In this setting, the provider is saying several seemingly contradictory things. He thinks that

formal diabetes education classes are a useful resource, thinks providers should push patients

toward them, but has no inclination to do so himself. The controlling factor, for this provider, is

whether the patient is complying with him. If the provider doesn't see compliance, then there is

no need for further effort or outside recommendation. This assumption is almost entirely based

on the physician's authority. If the provider has discouraged the patient's participation in some

manner, non-compliance may be a self-fulfilling prophecy. Physician assumption will be

discussed more fully below in Art of Practice under Challenges for Doctors.

Informal Diabetes Education

Informal diabetes education deals with the messages sent and received within the patient-

provider relationship concerning diabetes and care that is outside the bounds of formal diabetes

education opportunities. Informal diabetes education may be impacted by attitudes and feelings

of the patient and the provider.

Some providers were at a loss for why patients were uninformed concerning their needs

and care.

The other concern I have is that there's a lot of lack of education. You talk to people

about how to eat… about ___ how prevalent they [diabetes and related complications are

within this population] are. People don't … I don't know if it's a lack of interest, or maybe society hasn't developed an awareness of all these problems happening.

Here, the provider offers two ways of reacting to the lack of education: patient's lack of interest or societal lack of awareness. Neither option includes the provider as a requisite source of education. The provider's expectations were that patients would be knowledgeable about their personal health history as well as the health history of their family. They also expected the patient to know positive decisions strategies and have, or set, appropriate priorities. Generally, the providers implied that they were waiting for the patient to become more empowered with regard to care and information pursuit.

In the affective-only group of concepts, style of diabetes education, fatalism, and informal diabetes education interact in important ways. Providers spoke of the need to develop positive awareness within their clients with the understanding that it may not be present. At the same time, there is an expectation that the patient already possess the structures for success including knowledge and understanding of personal and family medical history, decision making skills, and appropriate medical priority setting. The providers' discussion of fatalism within themselves and their patients presents a challenging background to the voiced expectations for both provider and patient. For some providers and patients, the expectation of negative outcomes and the presence of fear make the expected utilization of internalized success strategies problematic.

Shared Affective and Technical Communication

Shared affective and technical communication involves those concepts and activities that combine information transfer with emotional and psychological aspects.

Table 22: Shared Affective and Technical Communication

Physician	Time	Art of Practice*	Feedback*	Formal

Support				Diabetes Education*
Individualizing patient care including drug therapy, patient goals, education, and situation (6)	Reciprocating of patient value with expectation of return (5)	Developing how advice is given (6)	Simplifying, information exchange (9)	Integrating provider's formal feedback (super code)
Charting patients' economic situation to facilitate support and increase patient comfort (4)	Communicating (4)	Cultivating community reputation (2)	Weeding out (3)	Acting in isolated medical system (super code)
Moving according to the patients' timeline to avoid discouragement and increase understanding (3)	Refraining from non-medical discussion (4)	Changing medical knowledge (1)	Increasing cooperation thought technical education (3)	
Refrain from overemphasizing patient failure (2)	Challenging administration (3)	Challenging for doctors (super code)	Providing positive feedback (1)	
Help patient negotiate system (2)	Trust (3)	Empowering patients(super code)		
Understanding visible and invisible support network (2)	Effort (2)	Modeling patient support (supercode)		
Reteach priority setting (1)	Understanding (2)	Practicing realistic objective setting (supercode)		
Enforcing support: Provider can control change in patient through medication		Teaching patient priorities (supercode)		

alone without patient behavioral change (1)				
Use system in patients' favor to increase trust and compliance (1)				

* Where concepts contain super codes (art of practice, feedback, and formal diabetes education), tables will be provided to expand underlying codes.

While all concepts discussed by the providers contain some affective content, physician support, time, art of practice, feedback, and formal diabetes education occupy a more central position on the continuum between more strictly affective and more strictly technical communication. These concepts include physician support, time, art of practice, feedback, and formal diabetes education (Table 22).

Physician Support

Physician support encompasses those behaviors that help the patient negotiate their care. This may or may not be medical in nature. Physician support can include administrative, economic, and pharmaceutical considerations. Each component is discussed below.

Charting patient's economic situation to facilitate support and increase patient comfort

Several providers spoke about the costs associated with care. The conversations differed in the individual provider's felt need to adjust their care strategies based on the patient's need. Adding patient economic status information was one way providers could consider a patient's position while supporting that patient in compliance.

And I had to give so many free medications initially because their income was so low they could not afford the medication that I had prescribed. So initially, to even get them interested in controlling their diabetes, I had to first make the medications free.

This provider saw her goal as getting the patient interested in controlling their diabetes. One strategy was to remove the economic block to her patient's compliance until the importance of the medication was established. The patient's income level made it difficult for the patient to take on a new expense. It was in this provider's power and in the patient's best interest to think about costs when writing prescriptions. Without that level of consideration, the provider may be sabotaging some patients' ability to comply.

> What they would have the most difficulty with… With people just not being able to afford what they need. You may think that $10 is not too much. $8.00 is not too much. I can go to Wal-Mart and spend $4.00 and get my metformin. But some people really don't have $4.00. If you take time and look at their chart and see what their monthly income is, and you would see that $4.00 from $200 is a lot of money. So I think it is … because I have a new doctor and sometimes I realize that he doesn't take into consideration the cost of the prescriptions that he writes. And this is what I'm saying, it could be a problem.

This nurse is describing the provider's level of perception. Also, she is describing whether the provider wants to perceive. The problem is twofold. First, the patients may have an economic challenge that hinders their medical compliance. Then, the providers may be reducing patients' ability to comply by writing prescriptions that are outside the patients' economic reach. Both of these scenarios impact the patients' ability to trust their providers, become complicit in their own care, and avoid being labeled non-compliant.

If a patient cannot afford medication, dietary changes, insurance, or co-payments, some providers pursue other avenues. As suggested above, some providers take economic factors into account when writing prescriptions. Others provide samples when available. Others may code

down visits or provide visits that have no co-payments to encourage patients to return for follow-up visits.

Moving according to the patient's timeline to avoid discouragement and increase understanding

Pursuing compliance was foremost in the providers' minds. Yet, several thought it important to consider how quickly they attempted to bring the patient into compliance. The patient's emotional, physical, and financial ability to make the behavioral or medical changes their provider suggests may not be consistent with the speed the provider chooses.

> Don't move them too fast. Don't move them too fast. Go and take your time and teach them because the older population already has a concept about diabetes. It's a re-teaching thing. It's a change thing, and it's going to require some time. Don't just expect them to fall right into it right away. Some of them are really good; some of them take more time. Everybody wants to go right in. If your hemoglobin A1C is 11 or 10, they want to get you right down right then. They want you to change your diet; they want you to takes your medicines just right. They want you to do everything just right. But give them a few more frequent visits, and maybe code down the visit a little. But most of them are on Medicare anyway, but you need to get them in a little more frequently, and move them a little slower.

This provider made several suggestions for slowing the expectations timeline for elder, African-American patients that were positive. Moving more quickly reinforced the patient's failure and frustrations.

Refraining from overemphasizing patient failures, as a provider behavior, is related Acknowledging the changes that the patient does make will encourage continued progress while

highlighting a lack of movement emphasizes fatalism. Providers suggest that slowing down

progress markers makes them more achievable. One provider noted that the patient did not

become diabetic overnight, so interventions and expectations cannot be rushed either.

Helping patient negotiate the health care system and using the system in the patient's
favor

At times, patients are unsuccessful in dealing with administration. They may experience

difficulty with paperwork and receiving reimbursements. Providers can offer help. Others

perceive that type of help to be outside of their responsibility even though it impacts the patient's

ability to seek care.

> I happen to do more things than the than the average doctor will do for a patient. For
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> example, they tell me that their Medicare Part A is not working; they're not getting the
>
> reimbursement. So I happen to do know where they can get drugs less expensive than
>
> most of these programs will provide to them. Some of them bring me the paper they get
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> from Medicare, from Medicaid, that they don't want to pay. So I, more or less, do a little
>
> more so I can give them some guidelines.

This provider acknowledges that his relationship with his patients extends outside of the medical.

He extends himself as a resource in dealing with patient-side paperwork as well as locating

helpful programs to reduce the cost of medication. Other providers relate these types of

behaviors as promoting the patient-provider partnership.

Using the system in the patient's favor was a nuance offered as an incentive for trust,

participation, and continuity of care. "Coding down the visit" was one way of using the system to

the patient's benefit.

> When I say "code down the visit" it really doesn't matter that much because they're all on Medicare. But you know, say, I'm not going to charge this much; it should be covered without too much… anything that you have to pay over. That's what I'm saying. And maybe even give a free visit sometimes. You know, sometimes if you just give a free visit, no dollar co-pay; no this… Because then they know that you're interested in helping them.

In this scenario, the point is to build the patient-provider relationship. Dealing with the administrative system becomes a point of cooperation and care and not an antagonism.

Understanding the visible and invisible support networks

Providers were interested in any means of increasing patient success. In some areas, several providers felt restricted.

> I think that for a lot of African Americans, their church is important, and their religious faith is very important. And that's an area that usually doesn't come up in a medical encounter. But that's also trans-ethnic because you have the ____ across all ethnicities. It is important to their social structure, family and church are important. So again I'm circling back to a point that what I wish I could say is "What in your experience as an African American is unique and what do I need to know about that in order to be a better doctor to you?" And that's a question I cannot ask.

This provider listed church, faith, social structure, family, and culture as important factors. At the same time, culture, ethnicity, and social structure were areas this provider felt prohibited from exploring in order to support the patient due to his own ethnicity – European American.

Other providers did not feel the same restrictions. For one, connecting church and other community support was part of their standard approach.

Because a lot of them are over the age of 50 or 60, a lot of times they think they're

beyond exercising. I try to introduce to them: "Well why don't you get your church

interested in starting an exercise program?" Or "Why don't you…" We have a new

community exercise gym now, and I ask them to go and join that because that is about…

I think it's $5.00 a month. So I say, "Do you know about that? Could you please go and

join that."

For this second provider, the importance is on finding any available encouragement or

opportunity for community involvement and exercise. The challenge of referencing church was

not present.

I introduce things that they can do. Why don't you go out with your grandchildren and try

to hula hoop. Or if you look at the stories during the day - Search for Tomorrow, Days of

our Lives--whatever you look at, for one of those 30-minute times that you're looking at

that show, I want you to do some form of exercise. I don't care if you're just exercising

your upper body, but I want you to move that entire time. And just little things that you

put in that they can learn how to move again… just that little bit helps.

Church and community centers are at one end of the conversation, but the provider quickly

moves to even more local and individualized activities. She suggests exercise that includes

playing with grandchildren and incorporating movement into seemingly sedentary activities –

moving during the daytime soap operas.

Re-teaching priority setting

Due to several factors, providers commented on the need to re-teach priority setting to

their patients.

So, that would be one thing-is just really trying to appreciate that for some of those people being here, taking care of themselves, purchasing medications, taking ownership for their health, is just not a priority until we have to try to help make it one.

Providers had to recast care such that taking care of self was important to maintaining other life areas and not a selfish act or hindrance. This was especially problematic with patients who were caregivers to others. Their health would suffer because caring for another was their highest concern.

Enforcing support

When a provider causes and controls changes in patient through medication alone, without patient behavioral change, this is enforced support.

I tell people, you don't even have to even follow my advice, and even now if the medications have changed to the extent that they have, then we can force people to get better whether they actually are actively participating or not. If they just take medications. We have ways of determining success-one of them is through the blood work we do.

This approach, providing the patient will take medication as directed, seemed reserved for those patients who were not capable of compliance in some other way.

Individualizing patient care including drug therapy ,patient goals, education, and situation

Individualization refers to helping each individual patient see his or her particular situation and respond to it. Individualization applies to testing drugs for patient suitability and generating patient goals and educational strategy.

I'll start off with a metformin or actrose or avantia--one of those. And tell them why I

chose this particular medication for them. And let them try the medication. And we give

them 2 weeks. I give them 2 weeks; I get them back after 2 weeks. After I get them back,

and I also write a prescription for their monitors, and they learn how to stick themselves

and how to get their ___ checks. How often. The first two weeks I want them to do only

one a day, but at different times during the day and I tell them what times.

Here, the provider's strategy includes choosing a medication, explaining why the medication was

selected, and letting the patient try the medication for a short period of time. After two weeks,

the patient returns, the medication is re-evaluated, and a new phase begins with the introduction

of the blood glucose monitors.

The same pattern is used to introduce the monitor: instruction and then two weeks of a

specific testing regime. The provider designed these periods to make the new behavior normal,

set an expectation of continued use, and generate continued evaluation. The patient is learning

according to their own timeline, with specialized attention to their learning process.

So I say, "At different times during the day I want to take your glucose level. I want you

to take it before breakfast one day, the next day I want you to take it two hours or an hour

after your breakfast, and next day I want you to take it before your lunch, an hour before

your lunch. But only once a day - and write all of that down for me. Once you do that,

then I will know what your sugars are running on this particular medication." And we

can determine from there what we need to do. Whether we need to up that medication

and you have to determine the tolerability-especially if you put them on metformin. I try

only to put them on 500 mg a day of metformin once a day, especially if their

hemoglobin A1C is less than 8. I will put them on 500 mg of metformin, plus their diet

control, and I sit down and do the diet teaching and arrange for them to have classes-

diabetic classes, for dietary teaching. And we just work from that point on.

Each patient is given a mandate, and specific directions on how to report and respond when they

return for evaluation. The process is broken down into specific tasks to avoid overwhelming the

patient with daily interruptions and higher costs. Education is central to each process.

Time

Time, as a concept, carried a variety of meanings for the providers. It was a measure of

value and respect, measured by the provider's conception of patient worth according to patient

compliance. It was an administrative limitation to practice. It also was also a measure of required

and consumed effort. The concepts within time included reciprocity between patient value with

an expectation of return, communication, restriction to medical discussion only, administrative

challenges, trust, effort, understanding, and positive feedback.

Reciprocity between value and the expectation of return

Providers saw time as a commodity. They considered themselves as having been

respectful of the patient's time, but felt slighted when the patient did not reciprocate

appropriately. The slight was connected to patient compliance.

Well yeah, they keep coming to the office. I will say that about 90% of them are fairly

compliant. And they know, I try to emphasize - I'm here to help you, but if you don't

want to help yourself, don't come to see me because it's a waste of time for you and your

money. I try to give … there's a value here. And then I make an emphasis to provide a

value, but if you don't do anything for yourself….

The provider connects his provision of value directly to the patient's participation. Wasting time

(non-compliance) was a resource drain for both the provider and the patient. If the patient is

unwilling, then the value or effort demonstrated by the provider is misplaced. There is an opportunity for frustration for the provider if the patient does not accomplish what was agreed upon prior to the current visit. For the provider, time spent without return was time wasted.

This provider connected time to progress for the patient. Because he dedicated larger, unconventional portions of time to each patient, they were able to progress much more effectively.

And usually my patients take me a long time-at least 20 minutes. I lot of them I spend 40, 60 minutes. Initially it takes me longer because I try to do more education once they get used to my style, to the things I like to address. So then the communication is a lot easier. It's more constructive because they already know what's happening, so they're educated, so we can move forward.

Moving forward, for this provider, is a consequence of time and education. Patients are better able to understand because they have been participating in their own educational process. In this example, the provider invested time in the patient. Patients who can move forward are providing a return on that investment.

Communication

Providers found communication generally to be time-consuming. Communication included taking time to explain concepts or terms as well as exploring and discerning needs.

You know, there's so many things that we just take for granted because we're medicine people. So you need to really talk to the person as if he knows *nothing*.

This provider was not speaking out of a disdain for patient knowledge. She was acknowledging the gap in specialized knowledge that is present between providers and patients of any educational background. She is describing the need for "medicine people" who will assume that

the patient needs to know everything. For her, the method of giving advice is as important as the advice given.

> It depends on how the advice is given. If the advice is given with an explanation, then they usually follow it quite well. If the advice is just given, they usually don't.

She related how advice is given directly to levels of compliance. Advice given with explanation and without the assumption of knowledge was more like to be followed.

> LT: So with no explanation there's...
> S04: Very little, very little cooperation.

Taking for granted that patients understand dietary terms or have a clear understanding of measurement sets up a series of false expectations, leading to provider frustration at non-compliance and patient frustration at unmet goals. Taking time to discern patient understanding positively influenced cooperation.

Communication was seen as necessary, but would change over time depending on the patient's response. If the patient responded well, collaborative communication would continue. If the patient was perceived as non-compliant, the communication would be more dictatorial and rely on the provider's assertion of authority.

Refraining from non-medical discussion

Providers felt pressed for time given the type of work they needed to do. They focused on the technical aspects of care – meeting guidelines for diabetes care – because of this pressure.

> Another big factor is that the doctor doesn't have a lot of time because if you have a diabetic coming in and they have high blood pressure, cholesterol, diabetes and they usually have something else, then it's very difficult to give the time that you need to issues of compliance and education.

The complexity of an elder, African-American diabetic's condition left this provider with several different challenges to address. Each individual malady demands attention so that education and compliance are secondary concerns.

> You're looking, the doctor is looking at, you know, the medicine ____ OK, this patient is not under control. He's on 2, 3 medications. And he may be on insulin. OK, what do I do next? I've been working on this for 10 years and fine-tuning the medication, and so that takes some time for me.

The puzzle becomes the focus as the provider tries to meet the client's many needs and shifting targets. Fine-tuning the medication becomes the consuming focus.

> By focusing on the technical aspect, the providers were able to concentrate on what they considered important. Several considered any discussion outside of their specialty as someone else's work entirely.

> If you want to pursue that through [name removed] diabetes education, they may be able to give you some real good insights into what their perceptions are in terms of ethnic differences, in terms of needs, and how they approach the education of people. Quite honestly, they probably deal with it more than I do, or appreciate it more than I do. Because again, we only get so much time together, and I prescribe medication and check blood pressures, and try to make cholesterol and blood pressure and sugar and all those things right. So we're not really talking about beliefs as much as they are, and diet, and home remedies, and things of that sort. That probably all comes out a little bit more in an environment where that's intended to sort of extract that information and try to mold that into something that helps people.

> But I cannot do all that work for them. I have enough dealing with the medical problems.

Prescribing medication, checking blood pressure, and monitoring cholesterol and blood sugar were the focus of some providers. Education and compliance were supplemental discussions handled by diabetes educators. Dealing with beliefs, diet, and molding people was outside of some providers' realm of expertise.

Administrative challenges

Several providers described administration negatively. It consumed their already scarce time.

> Well you know it's complex; it takes time. And the profession is getting more complicated every day. Paperwork, regulations, lower rate of reimbursements. I happen to do more things than the than the average doctor will do for a patient.

> So you know I said that younger people will see that as a deterrent because it takes time. And unfortunately I would say younger people coming into medicine they see these are complications, so they want an easy way around things. And there's no easy way around it. You just have to deal with it the way it is.

Meeting increasing administrative requirements is problematic. The complexity may drive newer, younger doctors out of the field. Providers discussed several things that increase administrative stress. Elder patients require more administrative help. Lower Medicare and Medicaid reimbursement rates and increased regulation provide little incentive for extended provider administrative effort.

Trust and Effort

Providers acknowledged that trust within the patient-provider relationship increased with time spent. Without trust, the patient had little to draw on when deciding whether to pursue the provider's advice.

> How you do it specifically, I think first of all they have to appreciate that yes you know what you're telling them is correct. And then they have to trust you in a sense that you have their best interests in mind, and that takes time. It's not like we can fix these issues overnight.

These providers understood that they had to build trust with their patients. Trust happened as effort was expended. Effort was associated with those things that were "above and beyond" aspects of the provider's care. These things included helping with patient-side administration and taking time to explain outcomes, expectations, rationales, and interventions to the patient.

Understanding

Understanding is a concept that describes spending time that allows the patient to grow in appreciation of the provider and vice versa. For the provider, it may be important to have knowledge of why the patient may make a particular decision or behave a certain way. With this knowledge, the provider can adjust their strategy or work to educate the patient.

> Well in terms of their understanding and the reason behind doing things, I think you have to spend a little more time with the African American population, just kind of going over- this is what we're doing; this is the **reason** that we're doing it; and this is what we expect as an outcome. And then again, you can do that with everybody, but I think in terms of getting people to really be more participatory-in other words… obviously in our business the patients have to be part of the solution.

Expending the time and effort to develop the patient's understanding increased the level of participation and mutual expectations. Providers expressed several caveats concerning ethnicity that might interfere with increasing understanding. The following section discusses these caveats.

Art of Practice

The "art of practice" describes the characteristics of care that physicians attribute to style, personality, discernment, and personal challenge. Several disagreed over whether some of these skills may be actively taught. Table 23 includes the concepts within the art of practice.

Table 23: Art of Practice Code and Supercode Expansion

Developing how advice is given	Cultivating community reputation	Changing medical knowledge	Super codes contained within Art of Practice				
Active listening (9)		Heart disease kills diabetics, not blood sugar (1)	**Challenges for doctors**	**Patient empowerment**	**Provider models for patient support**	**Realistic objective setting**	**Patient priorities**
Acknowledging that trust is not compulsory (5)		Prescribed medications have collateral effects that compromise long-term care (1)	Provider learns not to trust verbal assertions from patients (1)	Health is not a social priority due to other life issues (4)	Encouraging affective social support	Charting patient's economic situation to facilitate support and increase comfort (4)	Women with chronic illness sabotaged by family's shift in needs (martyrdom) (5)
Cultivating buy-in (5)		Disregarding/ invalidating patient-instigated neuropathy may invalidate patient attempts at self-care (1)	Providers need to deal with mental health issues before endocrine can be addressed (1)	Provider sees self as a help to patients acting on own responsibility (3)	Developing self-proposed, informal guidelines for patient interview and exploration	Assume patient is trying to comply (2)	Socioeconomic level impacts priority setting (3)

			Table 24 (continued)					
Developing how advice is given	**Cultivating community reputation**	**Changing medical knowledge**	**Super codes contained within Art of Practice**					
Patient agenda precedes physician agenda (2)		Provider may not adjust strategies and end up supporting patient non-compliance (1)	**Challenges for doctors**	**Patient empowerment**	**Provider models for patient support**	**Realistic objective setting**	**Patient priorities**	
Refrain from hyping patient failures (2)			Provider uses medical knowledge to confirm suspicions regarding medical compliance (1)	Increased awareness could lead to patient proactivity (2)	Adaptation model	Appreciate and address patient agenda (1)	Barrier: Lack of patient's understanding seriousness of disease (2)	
Mutual expectations established (1)			Tests are not for information only, they discern patients' integrity as an information source and potential for compliance (1)	Provider sees patient as driver, but family has some benefit as a partner (1)				

Table 24 (continued)							
Developing how advice is given	**Cultivating community reputation**	**Changing medical knowledge**	**Super codes contained within Art of Practice**				
			Challenges for doctors	**Patient empowerment**	**Provider models for patient support**	**Realistic objective setting**	**Patient priorities**
			History of negative experience with doctors (1)	In order to be empowered about own medical issues, patient must ask, read, and become involved (1)			
			Dealing with same issues, but different people means strategies must be adjusted (1)				
			Super codes under Challenges for Doctors Caveats concerning ethnicity, Physician assumption, Double-edged sword, and Personality disorders				

Developing how advice is given

The manner in which information is given can help or hinder how a patient receives the information, responds to the provider, and makes self-care choices. Active listening seemed to be used most often by these recommended providers. According to Lang, Floyd, and Beine (2000), physicians practice two types of listening: active listening and active diagnostic listening. Active listening is "a skill for recognizing and exploring patients' clues" (p.222). Active diagnostic listening (hypothetico-deductive processing) is distinct from active listening. In active diagnostic listening, the provider is listening for what he or she needs to hear according to their medical training. Active listening, on the other hand, employs a search for what the patient is trying to communicate in addition to what the standard approaches are telling the provider. From the providers' perspective here, active listening was linked to reducing threats and mitigating fear, exploring patient decision making, expanding positive feedback, and communicating values and benefits.

Threat reduction and fear mitigation reflect the ability to deal with a patient's fear in a way that gains trust and cooperation. Providers who deal adequately with patient anxiety were able to address deeper issues and felt they had higher rates of compliance from those patients.

And what I do is when they are first are diagnosed with diabetes-from that point on, I always mention insulin as a mainstay in diabetic control so they will know that it is something that we can incorporate without it being such a threat to them. And if they know from the beginning that insulin is not a threat, then they progress better when it's time to go on insulin.

As discussed previously, insulin therapy remains a source of fear for patients. This provider begins to deal with insulin-related fears from the point of diagnosis by including it in all

conversations.Hearing and responding to underlying fear reflects active listening. Providers were clear that if they did not establish trust and deal with fear, their patients would find relief and support elsewhere. One provider labeled this phenomenon "neighbor-said."

"Neighbor-said" is community-based advice that competes with the providers' advice. These sources may include neighbors, friends, relatives, and mass media sources.

> I was in Richmond at the time. And I was examining this African American lady and examined under her breast and she had bread there. Slices of bread. And so that was very confusing, so of course I asked her "Why do you have bread here?" Well, she actually had kind of a yeast infection in the skin and someone had told her this was a way to resolve that problem because the bread would absorb the moisture. Never seen that before or since. But I think what tells you is that … and I have come to call it neighbor-said. That is people will often trust what their neighbor tells them, or their friend tells them, or their family member tells them, well ahead of what they'll… the sort of importance or validities that they give to what their doctor tells them. And it humbles you.

This provider describes being humbled by the realization that patients seek the sources that meet their needs the best. For the patient, dealing with fear and anxiety was as necessary as the actual diagnosis.

Because the source had the patient's trust, the information given was trusted above the provider's information regardless of the validity of the source's information. Trusted misinformation would trump physician advice if the relationship to the information giver was of a better quality. Similarly, if neighbor-said information was more familiar, it may trump a provider's unfamiliar advice. This was a source of continual frustration for some providers.

And a perfect example is here's a prescription for medication for cholesterol. This is important because it'll reduce your risk for stroke and heart attack. And they go "oh." And neighbor, Charlie, across the street says… Well I took that kind of stuff and it almost killed me. Well all of sudden here's somebody who's been told to do something by their doctor, but they talk to their neighbor, who probably was on something completely different that didn't lower his cholesterol, that had nothing to do with… didn't relate in any meaningful way to what was going on between the physician and the patient, but I can tell you more often than not, what the neighbor said to them wins out in terms of their decision-making. That fascinates me. Again, that's not .. but you have to appreciate that that sort of thing is very prevalent and its ability to impact on that individual's care is profound. And so you have to take time to explain to them… Charlie's situation is different. And yes maybe it does make some people have some side effects, but you know what, it beats dying from a heart attack, at least in my view.

For this provider, the response to his information delivery was underwhelming from his perspective. Yet, the patient's response to "Charlie" had far greater effect on the patient's choices. The physician describes the process as "fascinating," but downplays the patient's concerns at the same time. "And, yes, maybe it does make some people have some side effects …" could be seen by the patient as not taking his concerns seriously. When Charlie addresses those concerns, the patient feels vindicated and responds. The patient's motivation revolves around dealing with fear.

Providers worked to develop the patient's positive awareness as part of overall compliance and care.

You know there has to be more awareness developed among this population that they

have all these problems so they need to be proactive-not wait until the end. And that goes

with changes in lifestyle, education, taking their medication.

This means that the patient is taught to attend to their medical history, their family history,

current decision making and prioritization in order to circumvent negative outcomes. This is a

way of mitigating fear.

Active listening is a strategy that can illuminate why patients make some decisions.

We need to figure out why you're not making better decisions and what we can do to

help you make better decisions. Is it because you don't know what you're supposed to

do…and if you do, which of course is the other issue, if you've got the appropriate

education, you know what to do, why aren't you doing it? Let's try to figure that out.

I'm about 9/10 psychiatrist and 1/10 endocrinologist. I think diabetes requires so much

of… more than any other disease in the world, it requires so much in the way of lifestyle

modification that it's just very difficult to do it always and consistently.

This provider suggests that the thoughts behind the actions are as important as the actions. A

significant portion of his skill set is dedicated to discerning his patients' motivations. As

mentioned earlier, positive feedback and education play a role here.

Feedback and active listening are linked. These providers took steps to incorporate their

patients as partners in care. They requested and utilized blood sugar records from their patients

as a way of monitoring participation and continuing education and partnership.

When they come the next time, they bring me their blood sugar records. They bring me

the complications they have, the list of their medication and the interaction's a lot more,

you know, informative for them; it's a lot more successful to me because I get the results

of what I'm trying to do and that translates into success in their medical care.

This provider connects successful medical care to the patient's ability to communicate with them about their behaviors and experiences. When the interaction is well developed, both patient and provider experience success.

Feedback lessens the need for neighbor-said. But, while the providers were frustrated with other information sources, the providers acknowledged the patient's right to make informed, bad choices.

They do, I tell them if you want to try it it's up to you. If it doesn't work, then you have

to go back to what I told you. I can give them the opportunity to try; if it doesn't work

then, well, come back. People have to convince themselves of what they're doing. So I

would say this is a free country. This is a good thing about this society. You can do

anything you want, but if it doesn't work, then you know where to look for advice.

And I tell them-you have to buy into this. You have to agree with me that you see that

this is important. And sometimes it works and sometimes it doesn't work. Some people

say "I hear what you're saying. I believe it's true, but I choose not to do it." And you

know what, that's your right. You have to make the right to make a bad decision if you

want..at least what I perceive to be a bad decision.

You know they tell me that other people tell them what they heard from other relatives,

other patients, friends. They tell me what they see in the news. They tell me about home

remedies or natural stuff that they happen to get in contact with. And mainly I tell them

my honest opinion, what I think about it; if it's supported by technical medical research; or this is just something that is just out there. "They say that but there's no evidence to support what they're saying."

For these providers, knowing where to find credible advice is the key. The providers are aware that the decision rests with the patient. But, at the same time, these providers give the patient a way back into their interaction with their providers.

Neighbor-said as a concept was one provider's opportunity to acknowledge that patient trust was not compulsory. This meant that a provider could not count on their authority alone to influence a patient.

So I think that when I'm successful I think (a) you make people comfortable, (b) you have to have their confidence that you can actually give them what they need, because medicine is one of those things where you're sort of accepting people's recommendations somewhat blindly because you don't know if they're right or they're wrong. Of course that's true with lots of things, but people have to be comfortable and confident in the advice that you give them, and the medication that you prescribe and those kind of things.

Comfort and confidence are building blocks to establishing trust. The recommendations of providers were supported by an established relationship. Some providers realized that their advice competed with other trusted sources and that developing trust was important. Trust is an affective need that precedes the technical/ physiological need.

The providers understood that cultivating "buy-in" from the patient promised to increase a patient's likelihood to follow the provider's advice and wider behavioral suggestions.

I'm not sure that there's one strategy that I employ in a thoughtful way when I see someone. I just want them to understand and that can only happen through time. I mean

words will only carry you so far. I want them to understand that I am genuine, I'm very

down to earth, that I want them to trust that what I tell them is right for them. And that I

understand that… And I tell them-you have to buy into this. You have to agree with me

that you see that this is important.

"Buy-in" meant that the patient was an active partner who would pursue positive health choices

along with their physicians. From this provider's standpoint, it was his responsibility to establish

and build the expectation that what he tells them is in their best interest - especially, if the patient

is coming out of a history of bad provider interactions.

Creating buy-in meant that the patient's agenda often preceded the provider's agenda.

Providers acknowledged that unless the patient's agenda was met, they would not be able to

address the physiological issues.

And it's interesting. They come to me for … usually because they have an endocrine

problem. And my perception is you're here because you have an endocrine problem and I

need to work on that. But the patient's agenda may be completely different. They may

have something else on their mind that they want to discuss. So oftentimes you'll spend

a whole visit sort of getting that out of the way so you can move on to really, from my

perspective, what really is most meaningful and that is dealing with their endocrine

problems. But they may want to talk about the fact that their mother's living in their

house and driving them crazy. And that may be more of a pressing issue and you sort of

have to work on that and then move on to the next thing because you're not going to get

to the next thing until you deal with it.

This can be perceived as inconvenient; but it is a necessary impediment as time and effort can

translate into trust and compliance. In this example, the provider has to get things "out of the

way" as he acknowledges what is important to the patient in the moment. This provider has one perspective about what is really meaningful, but is willing to hear the patient in order to reach his own medical goals.

At the same time, the providers emphasized the need for mutual expectations in this relationship. Setting the rules for mutual engagement between provider and patient, at an early stage, reduced anxiety and increased communication.

It's just based on our exposure to one another and developing certain levels of comfort and in some ways letting each other know what we expect and what we want and what we anticipate, and making reasonable adjustments and working it out. It's a 2-way street.

Establishing mutual expectations and goals requires time and effort from patient and provider.

Cultivating community relationships

One provider's reputation precedes her in the community. Her reputation for partnership and cooperation allowed her patients to come in with a set of expectations and trust.

And when you've worked as long as I've been working you get the reputation that "She's not so bad when it comes to getting you controlled." And they come in looking to be helped. And they come in knowing that we're all partners-that we're going to be … This is a partnership and we work together.

Her patients understood her goals from the onset of their relationship. They also understood her method would involve active participation on their part. This provider used her knowledge of community, church, and social networks and resources to aid her patients. But, it was her reputation through the local diabetic community that allowed a more immediate access to her patients. She expected them to know what she does; they expected her to help them become more controlled as diabetics.

Changing medical knowledge

Introducing new understandings in medical knowledge was a challenge for several providers. Changing the diabetic's knowledge bases was challenging. For example, patients may focus on glucose control as a primary factor, but heart disease is as great a threat to diabetics.

> And so I'm kind of looking back seeing what I did 30 years ago and what I do now differently. I think to…In terms of the doctor, there's increasing the things that doctors do look at now is… We now know that diabetes--blood sugars don't kill most diabetics; it's heart disease. So paying attention to blood pressure and cholesterol is just as supportive.

These providers preferred to connect aspects of care instead of focusing on one factor at a time.

As understanding of diabetes care grows, providers are becoming more aware of the contradictions inherent in their treatment strategies. Prescribing drugs can produce negative effects in patient behavior and physiology.

> I stay away from them [sulfereas] because they will work the pancreas beta cells a little bit harder, and it's weight gain; it causes weight gain. You will find that a patient will learn how to manipulate them too. Take one or take two to help control the blood sugars. And it really isn't always a good drug to use because in the long run the patient is going to have to end up sooner on insulin because this drug is going to work the beta cells, put out this much more insulin, and then eventually they're going to get more insulin resistance, which is what Type II diabetes is anyway. And so if you put out more insulin and the person is still insulin resistant, you're not going to get the results that you want. And the patient is going to still eventually going to have complications from diabetes. So

> I try to put them on the metformin first. And then progress from there, and just try to leave out the sulfaureas altogether.

This provider recognized the issues associated with a particular drug. There were two problems. First, it would lead to weight gain and increased insulin resistance. Secondly, patients could game the drug instead of changing their behaviors. Instead of putting herself, and her patients, in a less effective situation, she chose to avoid this drug.

Standard treatments for diabetes can actually put patients into seeming non-compliant spaces.

> I wish I knew how I could say the right thing to motivate and to guide people to lose weight. And diabetics, unfortunately, a lot of the diabetes medicine, including insulin, have weight gain as a side effect. So you're basically asking people to starve.

Weight management is a consistent recommendation by providers. But, the medications prescribed may increase appetite and water retention. Asking the patients to work against the effects of the medication is a contradiction that is hard to avoid.

Providers may inadvertently stymie patients' efforts at self care. Most providers showed disdain for unproven naturopathy and communicated this to their patients. But patients may not be able to separate the disdain for the offered strategy from themselves.

> You know they tell me that other people tell them what they heard from other relatives, other patients, friends. They tell me what they see in the news. They tell me about home remedies or natural stuff that they happen to get in contact with. And mainly I tell them my honest opinion, what I think about it; if it's supported by technical medical research; or this is just something that is just out there. They say that but there's no evidence to support what they're saying.

Providing a solely technical response may not solve the patient's problem or address their underlying concern. The patient may or may not have been searching for a different type of response to meet their specific needs.

Challenges for providers

Providers and patients have an internal landscape that impacts how they see and interact with the world. For providers, their own thoughts and behaviors can become challenges to their interactions with patients.

> There are people who don't comply; who don't do well; who maybe tell you that they do, but I tell people we have ways of knowing whether you're telling the truth or not. And you know, I have as many Caucasians as I do African Americans who… say, yeah, my sugar is great-and they're not.

When compliance rates are low, providers can learn not to trust the verbal assertions of their patients. "I tell people we have ways of knowing whether you're telling the truth or not" is a statement that addresses the patient's behavior, but not their reason for providing incorrect information. Here, the provider uses the threat of their medical knowledge to confirm suspicions regarding medical compliance. In these situations, medical tests are not only a means of gathering diagnostic information; they become a tool for discerning the patient's integrity as an information source as well as their potential for compliance.

> Interactions can be complicated by the patient's prior history with providers. I mean that's the toughest thing I deal with is people who have personality disorders who just are tough and they're difficult, and they're antagonistic and they're always very defensive. And that's their nature. I mean it's just the way they are; they're difficult to … often they're people either ___ or been dismissed by multiple previous physicians. And

they wind up on your doorstep. Then you have to change your approach a little bit with those people, and that's what I mean by tweak.

In this instance, the provider may be dealing with diagnosed personality disorders or those who have been treated badly by different providers. He does not provide a distinction other than to acknowledge the emotional context of the patient and the effect it has on him as a provider. For this provider there is a skill in dealing with the human variation while working on the physiological issues many diabetics experience.

Within the general discussion of challenges, several caveats emerged. Providers offered caveats when pushed to speak about issues of ethnicity. These types of statements preceded commentary about ethnicity and provided space for contradiction.

And that again is not… it's not something I would say was particularly applied to African Americans. There are no specific recommendations that I would say when applied to African Americans that you don't apply to anyone else.

I don't know that I approach African American individuals any different than I do anybody else. You know, I love my African American patients; they're appreciative; they've very kind; they're sweet,

Care, this provider emphasized, was not different for one group over another.

For some providers, personality was a greater consideration than ethnicity.

And that again sort of is certainly the artistic part of it is trying to figure out what that individual needs from you to feel comfortable and to get the information. And it's a little bit different from one person to the next. And I'm not sure that's an ethnic thing necessarily, so much as it is just a personality thing.

The provider would rather think in terms of individuals and their personalities. It was important for this provider to avoid ethnicity, but the exchange is taxing. Dealing with antagonistic, defensive, and difficult patients was draining as well.

Once the conversation was allowed to include ethnicity, some providers acknowledged the adverse history and context for African Americans.

> I would certainly be interested to hear what your focus groups say they wish doctors WOULD say. That might give me some insight. And I think that is … that may be a problem in terms of if there is a specific sub-cultural or a value phenomenon with the African Americans that physicians like myself don't pick up on and could utilize. That would be good, but there is a double-edged sword because I'm very aware of the historical context and the need to see someone when they come in the office as not belonging to any particular ___ group. In order to not convey any of the deeply cultural ingrained prejudices that I know are there, and so to focus on specific African American subculture, brings race into the equation, which creates some angst and discomfort.

This provider was torn between his desire to know more about what might be culturally relevant and his place in history as a white male. His wish for insight and his need to dispel personal angst and discomfort were at odds. More specifically, he wanted to avoid provoking some sort of cultural confrontation with his patients.

Ignoring ethnicity was a way to avoid conflict. It also may create a blind spot regarding useful personal and cultural information. Colorblindness, for this provider, is a means of preemptively assuaging the patient's innate sensitivity. The provider assumes that he is capable of an untoward judgment. His only recourse is to avoid the subject entirely. By enforcing the

taboo, he acknowledges that useful information may be lost including methods of support: social structures, theology, cultural history, and experience.

The provider must find other ways to categorize the patient that excludes, and is safer than, ethnicity. Some patients were classified as "just more interested in participating in care" as discussed below in "Weeding Out." Verbal communication was acknowledged as a challenge, but ethnicity was excluded as a reason.

> So, I would say that doesn't apply necessarily to the African American population or the Caucasian European population or whatever, communication is just very, very important. I mean I can't underscore that enough and people who struggle with the English language, foreign medical graduates, that kind of thing-they have a tough time and patients have a tough time. And of course depending on where you are from, in southwest Virginia, if you've got a big accent, it's tough for people to understand what you're telling them.

More acceptable reasons included providers and student-providers who struggled with English language mastery as well as rural or regional accents.

Yet, one provider offered that s/he spent more time with elder, African-American patients. While spending extra time with all patients was possible, this provider highlighted this strategy for elder, African-American diabetes patients. Increasing the patient's understanding of the treatment process, the rationale behind the process, and preferred outcomes was a way of expanding participation.

Providers also acknowledged that, there seemed to be no recommendations specifically for African-American patients, there were differences in exercise habits and diet due to ethnicity.

> I'm not sure that necessarily that applies differently to ethnic populations, but we do see some differences in dietary habits and exercise habits and things like that, that you really have to try to address. But that's done more by the diabetes educators and dieticians, which by the way may be a group that you'll want to think about talking to…in terms of how they educate people. They may have some real good insights into whether there are ethnic differences that they appreciate, and whether they sort of uniformly apply those to the population they see.

Seeing differences, according this provider, is left up to the diabetes educators and dieticians. For this provider, there is a difference between himself and the dietician and diabetes educator that allows them to go where he cannot in the patient relationship.

Assumptions and caveats are related concepts. Assumptions are statements that describe the provider's thoughts and logics concerning their patients. Providers' thoughts on socioeconomic status led to speculation about levels of support and ability to comply.

> So, I guess there may be in my mind a correlation between socioeconomic status and social support. Those two [patients]are very poor to not have social support as those are not. And possibly because the functional families do better economically than dysfunctional families - maybe. That's beyond the medical.
> And the lower they are on the socioeconomic ladder, the more time you have to spend getting them to appreciate, yeah, buying these medications is an important thing and you need to do it. Because they [are] having to make choices and it's not necessarily a priority.

For some providers lower economic status was connected to dysfunction and lower health care priorities. Lower SES was also an assumed indicator of poor decision making.

> They're usually wind up being people who make bad decisions about a lot of things in their lives. It's a sort of a pattern. People don't ignore their health and do things that are bad for their health independently of a lot of other things. They are usually not succeeding in a lot of areas in their life. So that's a whole different-that's a psychology/psychiatry issue, not something that we can necessarily resolve here.

Success in health care was associated with success in other life areas and was assumed to be reflected by socioeconomic status and vice versa. Fatalistic attitudes may emerge from the connection of bad decision making, poor health, and lack of socioeconomic success as the sole common denominator in patients' personal failure without consideration of other factors.

Providers had several means of considering patients and assessing value: by compliance, by ethnicity (African American), by socioeconomic status, by medical statistic (morbidity, disparity), by profession, by age, by educational level, and as a human being. Compliance will be discussed under Technical Compliance. Depending on the context, African American patients can be preconceived as non-compliant.

> And again, when I was a resident, for instance, and we went to diabetes clinic, we had a different population. A lot of those patients were African American, very low on the socioeconomic ladder, very little money, a lot of those people not working and getting some sort of government assistance in terms of health care benefits and food stamps, and where they live-that sort of thing. And that was a horribly non-compliant population. I mean you just couldn't get them to do anything right. And again, I think our approach had a lot to do with that because … I think it was just of well this is a population that is never going to do anything you tell them to do. And so why bother?

Unemployed, African-American, diabetic and on government assistance almost guaranteed non-compliance. The non-compliance was attributed, in this instance, to the person and not the circumstance.

> When the other categories were considered, the representation was less fatalistic.
>
> I happen to be lucky. I practice in a suburb: Silver Spring and Clinton. So a lot of my African American patients, they're people that work for the Federal government. A lot of them. So they had a steady job. They have retirement. They have Medicare. They have secondary insurance. And most of them are married. So you see that they have that support. They have a steady job, finished their career. They're married, now they're enjoying retirement. So you see that among them.

This provider is relieved to have a patient pool that is well supported in income, family structure, and work experience. Insured and educated, his patients are prepared to participate more fully in their care.

Patient Empowerment

Patient empowerment deals with the degree that patients take control of their own health care. The providers see themselves as aiding patients who are taking the initiative regarding their own health care. At the same time, providers see health being pushed aside as a priority due to other life issues.

> They're part of the problem and they have to be part of the solution. You have to get people to really appreciate that this is something that's really important, because I think there's a lot of other issues that sort of press on them in terms of … .gotta be at work every day and providing for a family, and so health becomes something that's not really focused nearly as much probably as it needs to be.

Providing for their families and meeting day-to-day needs were immediate patient concerns. Providers recognized the challenge of pushing health care to a primary position in a patient's life. Socioeconomic status plays a role as household income will reshape patient priorities.

Providers recognized empowered patients as those who asked questions, read about their conditions and medicines, and were actively involved in their own care.

Well you know that they need to empower themselves with knowledge and education about themselves, about their medical problems. That's key in order to enjoy a healthier existence. You know… to ask questions, to read, to be involved in their medical care. Not just expect to go to a doctor and the doctor give me things, [they] just take them, and there you go.

This provider was frustrated by patients who did not pursue information from him or other sources. Just receiving medications was not sufficient. For this provider bring knowledgeable about themselves as patients was essential.

The providers understood the prevalence of diabetes and diabetes complications in the African-American population. They did not understand how their patients could be uninformed about them.

You know there has to be more awareness developed among this population that they have all these problems so they need to be proactive-not wait until the end.

Waiting until the end, or waiting until there were negative impacts from diabetes, was symptomatic of a generalized lack of awareness in the community regarding diabetes. The provider intuits that increasing awareness of diabetes and its complications would impact patients' choices.

An example of the lack of awareness related to patients' knowledge of their own medication.

> You know when they come back to you, you want them to tell you what they're taking in terms of medication. Half of my patients don't know what they take, which to me is hard to understand. They all know how much money they have in the bank, or which car they're driving, or how much they owe in the loan, but which pill they put in their mouth every day-they don't. So I think that they need to take more … get more involved in their care and knowing what they're doing. At the end it's their health. The benefits are for them, it's not for me. I'm trying to be a facilitator. And then, you know, the patient-physician relation is a two-way relation. It's not just one way. They're the one who will benefit from it.

The provider is effectively rating the patient's interest in their care and preparing the ground for his response as a provider. If the patient doesn't know his or her own medication, the provider perceives a violation of the two-way relationship in that the patient isn't interested in being involved in their care. Or, worse, they don't care at all, which impacts the provider's understanding of their current and future compliance.

The providers would like the patient to be a major driver in their own care. Secondarily, they recognize a benefit of family as a partner. For the provider, the patient's family's involvement may or may not be a positive. Several providers viewed family involvement as a resource drain with little return.

> So, what is important - and again we probably don't involve the family nearly as much as time would allow or money would allow, I mean somebody winds up having to pay for these things. In a perfect world you'd have the whole family come in and you'd do a

family intervention and __ getting everybody on board in terms of why it's important that

everybody in the house participate. But in the real world that doesn't happen. But

hopefully the patients involve their family and when family members are here I tell them,

you know, everybody in the house has got to participate in this. And if you care about

this individual, you'll make some changes too so that those temptations, the food and

other things are not constantly there. But do they involve their family? I think that

depends on the individual, I guess. I encourage them to get family members to be

involved, particularly with diet and that sort of thing. But whether that actually happens I

couldn't tell you. They don't bring their family with them. That's not typical. Most

people come by themselves, maybe with a spouse. Occasionally you get an older parent

who's either widowed or has a spouse that's not able to bring them and they're brought

by a child. And that's pretty much it.

It takes time to educate an entire household, according to this provider. There is an option here,

but the resource questions make the likelihood of family education low. The provider encourages

the patient to involve family members. But, there is little follow up on that encouragement.

Provider models for patient support

In order to increase patient success and rates of compliance, providers report that they

used several methods: encouraging social support, developing self-imposed, informal guidelines

for patient interview and exploration, and creating adaptation models. One provider gave s

several examples of trying to establish connections between the patient's neighborhood, current

economic situation, family connection, and leisure practice. She acknowledged the concerns and

fears of the patient – they are beyond exercising. Then she begins to make suggestions along

positive lines in their lives. With regard to community, she highlights opportunities for church

connection and inexpensive local options. In the arena of family, she suggests playing with the grandchildren –a non-threatening option. In the leisure arena, she suggests adding movement to an activity that is sedentary like watching the "stories," or afternoon soap operas. This provider increases rapport, suggests community connections, as well as restores confidence in attainable motion. These strategies perform numerous functions; they propose to increase the physical activity and mobility of the patient while establishing avenues of community and family support.

Another provider has his own internal model for supporting the patient. This approach has four goals: get to know the individual, assess medical challenges, explore the socioeconomic location, and then develop an individualized care strategy for the patient.

I need to know the individual. Are they retired, what they do for a living, their education, so you more or less can position yourself as you're going to approach that patient. And then their socioeconomic needs, you know. Are they married? Do they live by themselves? Do they have more economic means to deal with their medical problems? No family support? And they the medical problems and then I try to look at this individual as a diabetic with all these potential problems and then these are the complications. And you ask them how long have you been a diabetic so you can put that patient in a framework, and then you know __ range of diabetes and you more or less will know the complications and what to expect about that patient's care and complications down the road. So I would say that try to have a scheme and order in your head what you're doing here.

Knowing the individual, and all that entails, is this provider's way of tailoring care for the best patient results. By using his active listening skills in concert with his diagnostic skills, he has information concerning employment, education, retirement, medical history, family presence,

and financial support. In this way he positions himself to deal with abundant or lacking social support, economic challenges to care, medical complications, and other impacts to the patient's care and his own timelines.

Although providers agreed that family had a significant role to play in whether the patient would be more or less successful, they disagreed over whether family involvement was always positive. One provider does not recommend familial support because they assume that the patients in the worst positions have little available support.

> I think having a family member… to the patient, I would say, bring a family member with you. If you're over 65 it's really better to have a family member. They can be your advocate; they can be another set of ears and they can be _____ source of support. Interestingly, I don't do that myself because the paradox is that the ones that need it the most, the family members are hardest to find and to get there.

The provider acknowledges the paradox. He believes it is better for elder patients to involve their families, but does not recommend that course to some because he believes they do not have available support.

Another concern is that family members may be a negative influence on their diabetic relatives by producing an atmosphere that sabotages success.

> I tell people…You can try your best to stop smoking, but if everybody in the house is smoking it's not going to happen. You can try your best to follow a diet, a diet meaning a way of eating, not something that's intended to cause weight loss, although many of our patients do need to lose weight. But if you're trying to follow a diet and everybody else in the house has a horrible diet, the odds are pretty good you're not going to succeed.

Lifestyle changes are extremely difficult to make if the family is not making changes also. Several providers considered family support at this level an unrealistic goal. But there were exceptions. Marriage provided some support in specific circumstances. (I will discuss these exceptions below in "Patient Priorities.")

These strategies combine with others to form a type of adaptation model. The adaptation model combines affective and technical communication with the goal of meeting the patient's need.

> And that's the challenge to take a person who has the same problem as the last person you saw, but a very different personality, a different agenda, a different set of expectations and make it work for them. And that's the difficult part of what we do. So that's only something that I think you develop a skill with over time (S03).

For the provider it means developing the capacity to adapt the standard approaches with the individual patient in mind. Adaptive practice impacts compliance as well.

Realistic objective setting

Realistic objective setting contributes to treatment strategies and goals that make sense both to the provider and the patient.

> First, the individual as a human being, then the socioeconomic circumstances, and then whatever has happened with their medical problems and where you are going to position them in the natural history of this condition. And then you can develop strategies. Every patient is different. So no two patients are the same so you need to change your cookbook every time you see a patient.

Here, the provider considers humanity, economy, and then condition as precursors to treatment. "Changing the cookbook," or adjusting the standard approach, to fit the patient includes

considering those things that make success possible. Realistic objective setting includes charting economic situations, assuming compliance, and appreciating the patient's agenda.

Assuming compliance was one way for providers to avoid applying their own preconceptions and generating fatalism in the patient.

I think looking at a realistic objective, and then don't put guilt trips on the patient for non-compliance because most people will do their best given their circumstances.

You have to doctor… how do your patients comply and then you actually find out how many of them comply. There's a world of difference. But if I don't walk into the room assuming that people are not doing what I'm asking them to do, I assume they do. I give them the benefit of the doubt. And because if you're ___ people get on the defensive, they do worse in my view.

Creating realistic objectives means that the provider has to continually understand the fallibility of the patient, while at the same time promote the notion that the patient is concerned about and participates in their own care. This provider understands that "people will do their best given their circumstances." As a provider, he is leaving the door open for the patient's continued compliance. By staying aware of the patient's circumstances, the provider may be more attuned to the patient's agenda and enrich their buy-in and trust.

Patient priorities

Patient priorities and patient empowerment are closely related. Both of these codes suggest that socioeconomic status impacts health care as a priority, decision making, and forced non-compliance when medications, diet, insurance, and co-payments are not affordable. But these providers emphasized that patients may not understand the seriousness of their disease.

The patient may downgrade their diabetes care in order to address those life issues they consider more important or more pressing.

> And then I think with some there is the __ a lack of understanding of the seriousness of
>
> diabetes that leads to inconvenience.

Patients, according to this provider, may characterize their diabetes care as inconvenient if they do not understand the consequences. Inconvenience does not mean that diabetes care is not important. It means that circumstances have caused the patient to adjust their priorities in a way that does not allow their diabetes care to be primary. The patient's priorities may be counterproductive with regard to their own health.

> From the providers' perspectives, the type and intensity of family support can contribute

to whether the diabetic is successful in setting priorities or not.

> Usually if they happen to be married, there's the family structure so they help each other,
>
> the husband and wife.

Issues of power in the household may hinder the success of patients. Creating the changes necessary involve making decisions that affect the entire household and not just the diabetic. Specifically, women with chronic diseases can be significantly sabotaged by a family's shift in needs. One provider called this "martyrdom."

> And so trying to get them to really take ownership of their health and to appreciate that
>
> even though they sort of adopt this martyrdom, and females in particular, who are raising
>
> grandchildren and children and providing for it seems like everybody…that that
>
> martyrdom, that is certainly respectable, from a health stand-point winds up backfiring on
>
> you because if you don't take care of yourself something bad happens and they all wind

up taking care of you. So that's really I think something that you really have to drive home, you know, for people.

For such women, the priority is taking care of others at the cost of their own health. This can happen within marriages as well. If the wife is diabetic and the husband is not, there may be social challenges to the wife asserting changes to further her health and health care goals.

LT: And so do you find in that situation where the husband is not diabetic, but the wife is, is the husband providing any other kind of support?

S04: Very little. Because you're talking about the older people. You know he is used to not being in that role. He's used to not worrying about cooking. He's used to just sitting back and she knows what I like to eat. It's an established relationship by that time. She knows what I like to eat, she's going to fix it. And why is she changing? She knows I'm not going to eat that - that kind of a thing.

Pressures from within the relationship may make it difficult for the wife to make significant lifestyle changes on her own behalf. But the scenario changes if the husband becomes diabetic and the wife does not. Because of established household roles, the wife may be in a position to impact the household more effectively if the husband becomes diabetic.

And I had someone on the other hand whose wife completely took control over cooking. She went to classes; she bought books. She's not a diabetic; only her husband is a diabetic. But everyone in the house went on the diet. She has since lost weight, she walks with him; she is most successful one that I've had. So, when the wife… when it's the husband and the wife usually is not a diabetic, but when she gets involved, you get better outcomes than you do if it's the wife who is the diabetic and the husband is the one who does not have diabetes. Because she still has to cook for him. And she neglects

herself. So she usually does not stay on the diet because she does not want to cook two

meals.

The challenge, in these two scenarios, is in the level of priority. In both situations, the wives are involved in cooking for the household. In the first, the wife is not diabetic, but asserts dietary and lifestyle changes for her husband. In the second, the wife is diabetic and the husband is not. She views her choices as either cooking separate menus for herself and her husband or cooking one menu according to his wants. She does not perceive the third option of creating a healthful diet for the household. It is her problem alone to deal with.

One provider offered an example of how she dealt with a situation where the wife felt powerless to make changes in her household to support the health of the family.

I have a family that the husband is a diabetic, the wife is a diabetic, the son is on his way

to becoming a diabetic. But the son has autism. The man just doesn't follow his diet at

all. The woman cooks for the man, so therefore her blood sugar is not controlled well,

even though she WANTS to do better. She excuses it by saying that "I have to cook for

them." So when I talk with her just last week, I said: "What you need to do is that you

are the person that's doing the cooking, then you should cook the right foods for

everybody. If you don't want your son to become a diabetic.. he may, and I expect that

he will because you and your husband are. But if you want him to have a life free from

diabetes longer than what you have had, then you need to cook to save both you and your

husband." So even though she knew what she should do, she needed that extra push , and

so she got up and she said, "From now on, I am going to cook what we're supposed to

eat."

This wife and mother had to be convinced by the provider that her prioritizing was damaging her family. The provider, within the established relationship, exposed the real issue and solution – the diet was a problem and the woman was the only individual cooking. With that, the provider was able to promote a new solution with an important re-prioritization. Because she trusted her provider, the call to save her husband and son through her usual role transcended the family's wishes. Previously, there was only a battle of wants. The wife wanted to be healthier as a diabetic. The husband and son wanted to eat as they always had. To save her family, she (as wife and mother) could control the family's diet. Healthy eating became a priority.

Feedback

Feedback includes the interactions and behaviors that both providers and patients use to exchange information. This information can be technical or affective. But, even simple information exchange can be challenging. Providers discussed the inaccessibility of some types of information for some patients. Feedback, when it is successful, helps both provider and patient.

> I think it means that to be successful one has to be able to gather and convey information so that people give you what you need and get what they need. And I think that sort of crosses all cultural barriers. … I can get the information I need to help them; and I can give the information back to them in a way that they understand it. And that may change a little bit from one person to the next depending on the level of education and their backgrounds and their ethnicity and those kinds of things, but not very much.

This provider described feedback as skill development and links it directly to his success as a provider. He highlights the ability to adjust to education levels, background, and ethnicity. At the same time, he downplays the need to do it. Linking successful feedback to successful practice

seemed important to this provider, but the implication that his style of feedback may change under some circumstances made him uncomfortable enough to qualify his comments.

Another provider claimed responsibility for making information accessible. This included reducing knowledge assumptions. Terminology like carbohydrates, sugar, glucose, and measuring units may or may not be common knowledge for patients. As this provider suggests, these terms may be quite relative depending on the patient's knowledge and experience. Introducing basic terms and interactions, for this provider, was a way of avoiding damaging assumptions, educating the patient, and increasing education without denigrating the patient's knowledge. She assumes that the patient lacks medical knowledge and works to continually educate.

While concepts and terminology may present challenges, providers mentioned other barriers to successful feedback. Language barriers included educational levels, regional dialects, and patients/providers/ medical students whose primary language is not English. Because of the differences in understanding, language, and style, there can be significant breaks in information transfer. Both patient and provider have numerous chances to misunderstand each other.

Several providers used similar strategies to reduce misunderstandings and capitalize on educational opportunities. An example follows.

> Yeah probably the first 3,4 visits I try to tell patients "This is the point that we need to emphasize. This is your medical care. This are these key points that you need to follow." And then after that people go into the… And it's just a process of education that they get introduced into a style of health here so they know what happened. … When they come the next time, they bring me their blood sugar records. They bring me the complications they have, the list of their medication and the interactions a lot more. You know,

informative for them; it's a lot more successful to me because I get the results of what

I'm trying to do and that translates into success in their medical care.

This provider emphasizes that the patient is being introduced to a "style of health." The style

includes the manner, opinion, and actions of the physician as much as it includes the medication,

testing, and behavioral changes of care. He extends his educational timeline in order to ensure

participation and long-term results. By establishing this style of care, he is able to verify the

information that his patients receive and act upon.

While introducing the style of care to a patient, there was an associated weeding out

process. This process begins when the provider lets the patient know the conditions under which

they might remain a patient with that provider. If the patient does not think they can meet the

provider's expectations, they will leave the provider's care.

And they know, I try to emphasize - I'm here to help you, but if you don't want to help

yourself, don't come to see me because it's a waste of time for you and your money.

And you know I'm in a practice where I tend to collect people who are interested in

doing for themselves what they need to do to get better.

This is a group that if they're not interested in doing the right thing or having demands

placed on them or getting advice, they don't come. So already that makes my job a little

bit easier because they have…they know that there are expectations when they get here.

And that it's not something that can be dealt with without their full participation. It just

doesn't work out very well or at all.

In these statements the emphasis is on individual and group time, inclination and resources. The patient is given the option of self-selecting out of the process with this provider. From the provider's view, there is a single rationale for self-selection out of care: the patient is not interested in doing what they need to do to get better. While it may seem to make the provider's job "a little bit easier," one may question whether this process skews the provider's conceptions of collaboration and rates of compliance.

 As discussed in earlier, providers emphasized that education and feedback take time and resources, but increase cooperation with patients. Tying the patient's diabetes care more directly to other complications also increased understanding and patient buy-in to the care process.

> It's just like disciplining your children. If you say "you need to do this" but there's no repercussion, people don't really sense that there are repercussions and they don't happen. So everybody's the same whether they are kids or adults, you have to say look… These are the repercussions and you really have to get them to buy into that and have that be the motivating factor. I think those are some of the strategies I've employed. And just really, I think… People come and really have a sense of trust and understanding and know that what I'm telling them is for no other reason is to help them be healthier and live longer and healthier lives. That's really the goal.

> Establishing trust in the provider's care, fear of negative repercussions, and direct communication are factors in increasing patient participation. The goal for providers is patient health. The means to increased patient health is through established relationships built on communication and trust. Positive feedback, discussed earlier, was one means of increasing trust, using active listening and time.

Formal Diabetes Education

The interviewed providers were polarized in their views toward formal diabetes education. Either the providers saw themselves as isolated from formal diabetes education and educators or there was strong integration of formal education into their practice.

Those providers who acted in isolation felt more comfortable prescribing medications. Their understanding of time, comfort, and authority were associated with remaining in their familiar medical practice. For one provider, it is not just time, but appreciation that drives his separation from diabetes education. For him, formal diabetes education is not his domain. His realm is technical medical practice – medication, blood pressures, cholesterol and glucose monitoring. Technical compliance will be discussed in depth later, but includes a focus on controlling patient behavior and following recommendations. Behavioral and non-medical support is left to diabetes educators.

The providers who integrated formal diabetes education into their practice tended to be nurses and specialists. In these cases, frontloading education preceded successful collaboration. One provider mentioned that patients who had great education early could be moved into more advanced treatment strategies.

> And usually my patients take me a long time-at least 20 minutes. I lot of them I spend 40, 60 minutes. Initially it takes me longer because I try to do more education once they get used to my style, to the things I like to address. So then the communication is a lot easier. It's more constructive because they already know what's happening, so they're educated, so we can move forward. And I would say to go further in their medical care, I don't have to be reminding them about taking their medicine, what happened, here, so there's a point where they come to me and they tell me "This is what I'm doing," so I can move on and do other more advanced intervention with them.

Educating the patient first led to a less frustrating interaction with the provider as unnecessary repetition in care was avoided. He did not have to remind them about their medication and past interactions. The patient would take initiative and begin to bring him information concerning their case and become a partner in care. Advanced interventions may be encouraged for those who meet the provider's criteria of initiative.

Frontloading education was associated with several positive aspects of care. When the patients were involved in formal diabetes education, their fears were addressed more directly. As discussed previously, the fear of insulin therapy and other complications were redefined as motivators for more proactive care instead of becoming barriers to care. By exploring why patients were making particular decisions, providers could discern blocks to progress like insulin therapy. Also, formal diabetes education led to increased explanation of expectations, outcomes, and interventions. Formal diabetes education also presented opportunities for feedback and coaching to assure that correct information was being given and received in an effective manner for both patient and provider.

Formal diabetes education could have detrimental effects according to the providers. Without appropriate feedback and coaching, patients may retain information selectively. They may return with increased fatalism and depression concerning their condition. For one provider, the danger of the patient returning with untrue information and misconceptions was reason to avoid formal diabetes education courses. It took more effort to address the misconceptions learned than to do one-on-one instruction.

Yet, formal education in several areas remained effective for these providers. Prescribing medication in combination with formal education increased compliance and reduced fear. Also, teaching diabetes technology, including the blood glucose monitor, allowed patients to be more

successful in their personal testing and achieve glucose control. Those who were not instructed in using their monitor did less testing and remained uncontrolled.

> And you would ask them to bring in their monitors and you would see different days that they would have such high levels. And you would say, "Well, what happened this day?" "Well I didn't take the medicine that day. It was running low, so I know that I wasn't going to see you until two weeks from that so I just didn't take it, or I took it every third day instead of every day." That kind of thing.

Because this provider provided instruction on the monitor, she was able to use the patient's monitor to generate feedback concerning self-care. She asks, "well, what happened this day?" and discovered the patient's approach for adjusting their medications. The patient wanted their medication to last until the return visit and experienced fluctuations in blood glucose because of the shift in medication timing. Without a reliable blood glucose regimen, the provider would miss that information.

> Formal diabetes education can provide information that impacts communication, feedback, and participation.

> And then of course from a diabetes educational standpoint, we have classes that really assess initially people's educational levels, you don't obviously take things for granted, but can people read, can they write, can they understand what we're telling them. They're very good to sort of triage those individuals into the right educational programs that will fit their needs.

Classifying individuals to find programs that fit their needs is relegated to formal diabetes education, but providers see it a positive practice. . The provider appreciates this process, but considers it to be separate from medical practice.

While leaving formal diabetes education to others, some providers were more focused on controlling behaviors. The mechanism for this seemed to be patient compliance with authority. Authority compliance pursues a behavioral response based strongly on the provider's authority.

> Well, I think in the strictest sense it means if I tell you to do A, you do A. It means taking medication, following your diet, checking the blood sugar, generally following the advice that we've given them, the strategies that we recommend they employ to achieve good glucose, good blood sugar control. And you know, that involves a lot of things-diet, exercise, taking medications, checking blood sugar, those kinds of things. And people who … compliance to me is if you know you're supposed to be doing something, and you're not doing it, you're making a conscious decision not to do it, that's a lack or non-compliance. That must means you've made an active decision not to do what time has told us is an appropriate thing to do to achieve what you need to achieve with regard to your health.

"If I tell you to do A, you do A" is characteristic of authority compliance. The provider in some cases may link compliance with authority to other types of support.

Formal diabetes education can be impacted by authority compliance. Some providers said that if a patient will not comply with the provider, that provider will not connect the patient to community resources. The rationale is that if the patient will not work with the provider, they will not be successful with another, outside intervention.

A provider explained why he does not involve formal diabetes education classes with his patient. He believes it can be useful, acknowledges that he and other physicians do not push it, but then says he will not offer it to patients. The difference, for this provider, seems to be in the relationship. The challenge is between the doctor and the "stranger" who may or may not

influence his patient. In this conflict, the patient does not get a choice; the provider has decided to restrict patient access to community resources.

Authority compliance suggests that compliance is more than technical. There is meaning applied that depends on whether the patient is compliant or not.

> … compliance to me is if you know you're supposed to be doing something, and you're not doing it, you're making a conscious decision not to do it, that's a lack or non-compliance. That must means you've made an active decision not to do what time has told us is an appropriate thing to do to achieve what you need to achieve with regard to your health.

Non-compliance, for this provider, means the patient is purposefully choosing against his or her own best interest and the doctor's actions. From this perspective, non-compliance may increase fatalistic responses from the provider.

Provider belief contains some contradictions. Providers were concerned about their patient's "blind faith" in untested, natural remedies.

> People want to go to the supplements store and want to treat themselves using things that really… I mean that's a whole other psychology that doesn't apply to one ethnic group, but the psychology behind supplements and self medicating-it's just fascinating to me because people do it with a lot of blind faith and yet are very skeptical of something that is heavily scrutinized and raked through with a fine tooth comb.

Blind faith is contrasted with earlier statements that providers may be asking for this type of faith and trust when making demands upon patients before appropriate trust or rapport is established. Several providers commented on the patient's pursuit of natural remedies as a departure from the provider's advice and a possible challenge to the provider's knowledge and authority.

When the provider's authority is challenged and the patient's perceived capacity to comply is compromised, several providers reconsidered their approach to the patient. While experience demonstrated that compliance and levels of education were not related, some providers reserved collaboration and negation of medical care for more educated patients. A more directive approach (authority compliance) was used with less educated patients.

> With the more educated, I tend to be more collaborative, meaning I'll make a suggestion and it's like a negotiation strategy. Then they'll make a counter-suggestion and then we wind up with a plan that may or may not be followed up.

> And with the person of the lower educational status, I'll tend to be more directive, and relying more on medication.

Since educational status may or may not be an indicator of likely compliance, the broader consideration is the provider's perception of a patient's rationality as measured by education and economic status, and income level. Directives are then given to those who demographically are assumed to be less able to contribute to the patient/ provider partnership.

In this the provider attaches several factors to a population's non-compliance: ethnicity, SES, job status, and government assistance (health care and housing). Marked non-compliance seemed, to this provider at the time, evidenced by the patients' external circumstances. "I mean you just couldn't get them to do anything right" implies a characteristic that gives the provider a reason for sub-standard care. "So why bother?" becomes a rationalized response to a perceived attitude within the population.

For some providers, resisting community-based resources is a means of protecting resources, effort, and time from a population preconceived as non-compliant. For others, the

patient has not met the threshold of compliance that could make other valuable resources available. But, for other providers, formal diabetes education is the means by which compliance, trust, and authority are produced.

Shared affective technical communication demonstrates that how a provider feels about a person, situation, or circumstance can impact their professional response to a patient. This includes recommending treatment options, encouraging positive behaviors, or propagating fatalistic attitudes.

Technical Compliance – Doctor- defined

Doctor-defined technical compliance focuses on the definitions of compliance delineated by providers. As mentioned earlier, compliance as a term was not part of the original series of provider interview questions. Each provider used the term independently during the interview. It was discussed with each provider at that point.

As discussed previously, compliance is a complex term. For providers, technical compliance included taking prescribed medication, increasing exercise, monitoring glucose levels and cholesterol, losing weight, following dietary recommendations, returning for follow-up visits, having ordered tests performed, and following provider recommendations. Two other considerations included preconceived non-compliance and forced non-compliance. Non-compliance carries a negative connotation and may affect the effort, time, and resource providers spend on patients. Forced-non-compliance seemed a special category that allowed for consideration of patients' environments.

Pre-conceived non-compliance involved a provider assuming non-compliance prior to the patient exhibiting actual non-compliance. Categories that could trigger preconceived non-compliance included being African-American, receiving government assistance, being

unemployed, or occupying a lower socioeconomic status. These assumptions originated from past experience or physician expectations.

One provider gave an example several classes of non-compliance. Forced non-compliance included those who cannot afford medication. For those patients, the provider is moved to provide samples and aid. "Hard-headed" individuals pose a problem for the provider. He considers them willfully non-compliant as they have the means to comply and choose not to follow the doctor's recommendations. He applied the following generalizations to these patients. In general, the provider considers them habitual bad decision makers. If they cannot make positive health decisions, there must be failing in other life areas as well. The provider, while he hopes for compliance, has built a rationale that allows him to shift effort once non-compliance is established.

Conclusion

The providers were candid in their responses and revealed patterns of thought and assumption that likely influence medical practice. For some providers, gaining cultural information was taboo – as was any overt discussion of ethnicity or culture. Gaining appropriate cultural information, then, was that much harder for them. Affective, shared affective and technical, and technical communication all contained undercurrents of assumption and belief that changed how the providers considered their patients, what treatment strategies were offered, how directive or collaborative the advice, and whether patients would return or be weeded out. Locations where cultural information might emerge included family and community interactions, but in many cases providers did not encourage their use for reasons apparently associated with both assumption and belief. Providers spoke of very few methods for gathering or assessing

cultural information. Also, little pushed providers to assess or challenge their assumptions or beliefs as they interacted with the patients.

And yet these were the providers that patients recommended as successful. Success, from the providers' perspective, was demonstrated in establishing trust, relationship, and participation that resulted in positive health outcomes. They recognized the need to communicate effectively as well as to acknowledge the flaws in practice and communication that may be present. While the providers may not completely understand the motivations and experiences of their patients, they were concerned about the economic barriers their patients may be facing. Overall, the providers seemed able to facilitate connections between proactive care and behavioral consequences while reducing anxiety and fear in their patients. With their fears addressed, the patients were able to hear and participate in their own care. The following chapter will link the patient discussions in chapters 6 and 7 with this chapter's examination of providers.

Chapter 9

Agreements between Patient and Provider Meta-concepts

Chapters 6 and 7 presented the patient participants' data, including the analysis drawn from their collective statements, while the last chapter focused on the medical providers' perspectives on their practices and their interactions with elder, African-American patients. This chapter brings the two discussions together to highlight where patients and providers agree and where they depart from each other. **Table 24** sets the meta-concepts generated from the patient participant data next to the comparable meta-concepts from the providers. The chapter is organized according to the focal patient meta-concepts.

Table 24: Conceptual Pairings using Patient Meta-concepts as Focus

Focal Patient Meta-concepts	Related Provider Meta-concepts
Physician Behavior	Fatalism Physician Support
Communication	Time Art of Practice Feedback
Compliance	Style of Diabetes Education Informal Diabetes Education Formal Diabetes Education Compliance – Provider Defined
Diabetes Education	Style of Diabetes Education Informal Diabetes Education Formal Diabetes Education
Process	Fatalism Art of Practice Feedback Formal Diabetes Education
Patient Self-Management	Fatalism Informal Diabetes Education Physician Support Art of Practice Compliance – Doctor Defined
Discovery of Diabetes	Fatalism Informal Diabetes Education Formal Diabetes Education
Family Influence	Fatalism Informal Diabetes Education
Patient Self-perception	Style of Diabetes Education Fatalism Physician support Art of Practice Compliance – Doctor Defined

Each of the focal patient meta-concepts is compared to provider meta-concepts by listing

challenges, responses, and rationales. The challenges emerged from the patient and provider

discussions and the responses are answers to the challenges put forth by patients and providers.

The rationales are my summary synthesis based on the emergent challenges and responses. The

tables are general guides, elaborated on in the text.

Physician Behavior

Physician behavior is a patient meta-concept that contains those behaviors that affect the patient's ability to relate to their provider positively or negatively. Many patients voiced concerns about their interactions with their providers including trust, care, and communication. The patients used the physician's behavior toward them as a barometer of the physician's levels of respect and interest in their case. When the patient perceived negativity, they disengaged from the provider and tended to disregard the provider's advice or become increasingly suspicious of that advice. **Table 25** highlights physician behavior.

Table 25: Focal Patient Meta-concepts: Physicians Behavior (Patient)

Physician Behavior (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Built trust Engaged understanding Detachment	Take time. Attend. Listen. Tailor education.	When trust is high, the patient is more likely to follow the given advice. When trust is low, the patient will rely on other sources or be suspicious of given advice.
Related Provider Meta-concepts to Physician's Behavior			
Major Concepts (Provider Perception)	Provider Challenges	Provider Response	Analyst Rationale
Fatalism	Provider and patient expectations of negative outcomes. Fear as barrier to pursuing care. Provider assumptions concerning patient populations. Reduced treatment options based on assumptions of patient behavior.	Reducing expectations of negative outcomes. Increasing patient education to reduce fear. Utilizing patient education more than authority to motive patient. Presenting all available patient options.	Dismantling fatalistic assumptions and behaviors increases the availability of treatment options. While fatalism fuels fear and creates barriers, reducing fatalism increases patient efficacy which positively impacts outcomes.
Physician Support (Provider)	Generic patient care. Lack of economic knowledge or support. Hurried timelines. Hyped patient failure. Unsuccessful negotiation of system. Lack of clarity regarding patient support networks. Unfamiliar patient priorities. Directive, authoritative care without patient participation.	Attach care to patient's specific medical situation. Chart patient's SES. Adjust care timeline for patient success. Avoid fatalistic promotion. Discern patient support networks. Assess patient priorities. Use directive care in a collaborative manner.	By allowing patients to perceive their personal situation, move according the most encouraging timeline, and utilize support networks, providers establish trust, provide encouragement, and build rapport.

The provider concepts associated with physician behavior were fatalism and physician

support. From the provider discussion, fatalism, aligned with patient concerns about changes in

attitude and care from their providers. Providers spoke of offering different treatment options

based on their preconceived notions about a patient population or about an individual patient. Assumptions led some providers to avoid suggesting behavioral changes rather than medicinal interventions for those they thought less capable of compliance. Providers acknowledged that patient fears also affected whether some patients would pursue care.

Physician support describes how the provider aids the patient in negotiating the health care system. For the patients, feeling supported in the provider interaction increased their possibilities for success outside of that interaction. Conversely, a lack of physician support undermined their success and motivation outside of that setting. Being treated as a number or in a hurried fashion left the patient feeling that their condition or presence did not matter. Increased levels of disenfranchisement contributed to fatalistic attitudes in patient and provider. When providers presented themselves in ways that patients perceived as disrespectful or dismissive, the patients were less able to perceive success or enact successful interventions.

Communication

Patients voiced a need to be involved in their care. Communication was a means of involvement. The patients expected providers to respect them and to help them understand their illness and its treatment. When they understood, patients then made better decisions about their day-to-day self care. When they felt included and respected, they were more likely to attempt compliance. Table 26 describes communication and its related provider concepts of time, art of practice, and feedback.

Table 26: Focal Patient Meta-concepts: Communication (Patients)

Communication (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Patient involvement Encouragement. Complexity Distraction Vagueness	Use plain speech. Maintain eye contact. Explore the patient's motivations.	Engaged communication gives respect, seeks understanding, and focuses on the patient's goals. The patient's need to comply was complicated by whether they believed that any good could come of these changes.
Related Provider Meta-concepts to Communication			
Major Concepts (Provider Perception)	Provider Challenges	Provider Response	Analyst Rationale
Time	Lack of return on investment. Diminished non-medical discussion opportunities. Reduced trust, understanding. Reduced extended effort by provider.	Vocalize expected returns on investment. Explore non-medical investigation opportunities. Establish trust and understanding. Aid patient in negotiating system.	As a measure of respect and participation, time spent seemed to effect whether the provider perceived the patient as worthy of continued effort.

Art of Practice	Suspicion of patient assertions Collateral medication effects Invalidated patient self-care attempts Contradictory patient priorities Provider reluctance to adjust strategies to increase compliance Seriousness of disease misunderstood Negative impact of socioeconomic level and family situation	Reduce assumption of common patient/ provider priorities. Assume patient is trying to comply. Understand and validate patient attempts at self-care. Empower patient to investigate medical care. Pursue patient trust. Appreciate and address patient agenda. Establish mutual expectations. Expose and deal with assumptions and biases concerning ethnicity, education, and socioeconomic status.	Style of practice, combined with medical information, has an effect on how advice is given by providers and received by patients. Provider assumptions change/ restrict offered interventions. Patients may be encouraged in their self-care efforts or hindered by their providers response to those efforts.
Feedback	Complex information delivery Weeding out process	Simplify information delivery. Establish mutual expectations Address physician assumptions	Feedback, with time and education, increased cooperation with patients. Tying care to complications improved patient buy-in.

Patients and providers defined Time similarly. Patients considered time a measure of effort, respect, and attention. If sufficient time spent was not perceived, the patient felt slighted by and detached from the provider. Providers viewed time as valuable. Patients who were perceived as compliant could be afforded more time as they demonstrated that there would be a return on previously invested time. Patients conceived as non-compliant might find their time reduced as well as not engaged in any exploratory conversation. This was a challenge because disrespected patients were less likely to comply.

The art of practice was similar in that provider assumptions seemed to affect the types of care offered to patients and the support given to patient self-care. The art of practice describes the style, personality, and discernment of a particular provider. Providers spoke of being, or becoming suspicious of patient assertions as well as the negative impacts of socioeconomic levels on patients. While providers may have knowledge of patient circumstances, it remains the providers' prerogative to adjust treatment strategies for a patient in order to increase compliance. Providers acknowledged that patients may have different priorities for their own care and concerns as well as different understandings of the severity of their disease. Because of these differences in understanding, providers may inadvertently invalidate patient attempts at self-care, which in turn may increase fatalism in the patient. In the art of practice, the providers' overall conceptualization of their patient contributes to their treatment of their patients. Patients seem to pick up the negative aspects while actively searching for encouragement from their providers.

Time, the art of practice, and feedback are connected. Feedback includes the communication of perceptions and assumption as well as the more technical exchange of information. Patients considered feedback to be at times complex and inaccessible. Providers considered feedback a time-intensive activity. Feedback was adjusted by providers at times, depending on the patients' levels of compliance, actual or preconceived. As mentioned previously, if the patient provided a good return on investment, feedback could be increased. If not, the provider tended toward an authority-based, dictatorial communication style. Feedback also included language that could weed out uncooperative patients early in the dialogue.

Communication, or the control of it, seemed heavily weighted toward the provider. The provider had medical knowledge, patient knowledge, and experiences or assumptions that controlled the release of information about treatments strategies and education options. The

patient may or may not have the same types of access, and experimenting with self-care could be detrimental to their relationship with the provider. More collaborative, educating styles of communication addressed the concerns of both provider and patient.

Compliance

Patients considered compliance a matter of whether they would, wanted to, or could follow provider recommendations. Several factors came into play from the patient's point of view: economic concerns, education, familiarity, fear, and trust. If the provider's recommendation did not allay anxiety or increased it, the patient was less likely to pursue the given advice. The provider's advice competed with the patient's fear and experience. Table 27 describes compliance and its related provider concepts of style of diabetes education, informal diabetes education, formal diabetes education, and doctor-defined compliance.

Table 27: Focal Patient Meta-concepts: Compliance

Compliance (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Little education Rationalized non-compliance Patient stress.	Explain advice clearly. Avoid assumptions in understanding. Seek reasons for non-compliance. Address fears and concerns directly.	Patients seemed more inclined to follow the advice that best dealt with their major concerns and fears. Physicians who practiced engaged communication tended to deal with these fears through effective education and listening.
Related Provider Meta-concepts to Compliance			
Major Concepts (Provider Perception)	Provider Challenges	Provider Response	Analyst Rationale
Style of Diabetes Education	Lack of positive awareness in patient community. Negative perceptions of provider care and medications Provider assumptions concerning patient population. Disconnection between behavioral consequences and preventative care.	Developing positive, overall awareness in patient. Identifying and addressing negative perceptions. Integrating and communicating consequence avoidance and education. Identifying and addressing provider assumptions.	Building positive awareness allows both patient and provider to focus on goals and compliance while reducing fatalistic behaviors and attitudes. A holistic viewpoint integrates care strategies and can reduce opportunities for provider assumption.
Information Diabetes Education	Patients lack knowledge of family history. Patients have modes of decision making and prioritizing that conventional contradict provider thought. Providers do not know why patients are uninformed concerning their care and needs.	Connecting knowledge of family history to preventative care. Discover patient decision making and priority setting rubrics. Explore patient-side impediments to care.	Unearthing the differences between patient and provider understandings provides opportunity for clearer communication and more effective patient education.

Formal Diabetes Education	Selective information retention Increased fatalism, misconception, and depression Generic programming Not included in medical practice Behavioral control emphasized Challenges to provider authority	Check class effectiveness. Intervene with educational evaluation. Assure patient class according to need and education level. Include educational evaluation at provider level. Collaborate with patient. Examine provider conception of authority challenges.	Educational structures produced a complex effect for some patients. Addressing the integration of formal diabetes education into provider care in terms of direct education and educational evaluation may aid patient understanding. Dealing with provider sentiments regarding formal diabetes education would help integration.
Compliance – Provider Defined	Discerning between technical, preconceived, and forced non-compliance Negative connotations associated with non-compliance Environmental considerations of forced-non-compliance	Identifying assumptions leading to preconceived non-compliance. Increasing education on consequence avoidance and preventative care. Utilizing physician support to discern environmental effects that produce forced non-compliance.	Non-compliance affects how providers respond to patients as well as patient's future care. Increased levels of fatalism bring negative consequences for providers and patients.

Patient misinformation and challenging personal or familial experiences were problematic for providers. Providers spoke of the lack of positive awareness in the patient population, including the patients' conceptions of care and medication, as harming a provider's ability to communicate and educate. Again, provider assumptions affected how they choose to educate patients. For example, conversations that connected patient behavior and larger consequences were often lacking. Providers tended to manage the immediate symptoms without addressing the larger issues. Compliance, for the patient, became a numbers game that was disconnected from broader concerns.

Informal diabetes education was sparse and challenging as it occurred in the spaces between patient, family, provider, community, and media. The patient's thoughts and decisions concerning their care can contradict provider thoughts, and the provider may not discern the reason for the difference. These underlying rationales can cloud patient attempts at compliance. Formal diabetes education may not be as effective for the same reasons, providers agreed. Providers hesitated to incorporate formal diabetes education because they were saw negative effects including greater misconceptions and depression. At the same time, many of the providers had no way of evaluating the effectiveness of formal diabetes education. They considered the classes external to their practices and their patients' care.

Doctor-defined compliance and patient-defined compliance did not align completely. Both patients and providers agreed with the definition of technical compliance (e.g., medication, diet, glucose control), but providers presented a host of connotations associated with non-compliance. Providers agreed that, for some, environmental factors made compliance difficult if not impossible (forced non-compliance). Presumed non-compliance was a challenge for providers. This fatalistic attitude affects treatments offered and effort put forth. For the patient motivation to comply decreases.

Compliance involved both patient and provider attitudes and assumptions. If useful communication was not established, assumption ruled. Neither patient nor provider would accomplish their goals.

Diabetes Education

For the patient, diabetes education was as confusing as it could be clarifying. Often, after their initial diagnosis, the patient's education about their diabetes was delayed. The provider would give a prescription, a rudimentary discussion, and tell them to pursue diabetes education

classes and/ or consult with a dietician. In this scenario, there may be several days or weeks

between the diagnosis and formal education at a cost unknown to the patient. The patients'

beliefs may or may not be addressed. Also, the patients considered the classes and other

educational opportunities generic and inapplicable to their situations. Table 28 describes diabetes

education and its related concepts.

Table 28: Focal Patient Meta-concept: Diabetes Education

Diabetes Education (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Financial concerns Errant patient beliefs Delayed and inaccessible information Delayed education Generic, inappropriate class referrals	Disclose all costs. Inquire about insurance. Provide human and text-based community resources. Standardize information and directions given at diagnosis. Group like cases.	When information sources were restricted, patient's personal or familiar experiences fill the vacuum. The patients build their own systems of knowledge and crisis response. These may be networks based in fear and fatalism.
Related Provider Meta-concepts to Diabetes Education			
Major Concepts (Provider Perception)	Provider Challenges	Provider Response	Analyst Rationale
Style of Diabetes Education	Lack of positive awareness in patient community. Negative perceptions of provider care and medications Provider assumptions concerning patient population. Disconnection between behavioral consequences and preventative care.	Developing positive, overall awareness in patient. Identifying and addressing negative perceptions. Integrating and communicating consequence avoidance and education. Identifying and addressing provider assumptions.	Building positive awareness allows both patient and provider to focus on goals and compliance while reducing fatalistic behaviors and attitudes. A holistic viewpoint integrates care strategies and can reduce opportunities for provider assumption.

Information Diabetes Education	Patients lack knowledge of family history. Patients have modes of decision making and prioritizing that conventional provider thought. Providers do not know why patients are uninformed concerning their care and needs.	Connecting knowledge of family history to preventative care. Discover patient decision making and priority setting rubrics. Explore patient-side impediments to care.	Unearthing the differences between patient and provider understandings provides opportunity for clearer communication and more effective patient education.
Formal Diabetes Education	Selective information retention Increased fatalism, misconception, and depression Generic programming Not included in medical practice Behavioral control emphasized Challenges to provider authority	Check class effectiveness. Intervene with educational evaluation. Assure patient class according to need and education level. Include educational evaluation at provider level. Collaborate with patient. Examine provider conception of authority challenges.	Educational structures produced a complex effect for some patients. Addressing the integration of formal diabetes education into provider care in terms of direct education and educational evaluation may aid patient understanding. Dealing with provider sentiments regarding formal diabetes education would help integration.

Some providers did not suggest formal diabetes education classes or considered them detrimental. At the same time, the providers voiced concern about their patients' lack of knowledge surrounding diabetes and related illness. For some providers, diabetes education, , was not necessarily about increasing knowledge or understanding, but about behavioral control that helped meet certain compliance goals.

Process

Process, for the patient, included those actions and mechanics that support their actual interactions with providers. (See Table 29). Overall, the process was a source of anxiety for the patient. They were concerned about the lack of information and confusion about fees and payment structures. The patient felt they could become lost in the activity of being seen by their

doctor, negotiating coverage and bills, and being harassed by third-party suppliers, ultimately

never addressing the reasons that brought them to the provider in the first place.

Table 29: Patient Meta-concepts: Process (Patient)

Process (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Communication barriers Vague, rushed, routine practice. Prohibitive costs	Engage understanding. Inform patient of each procedure. Attend and listen.	Patients sometimes saw the routines as a means of masking problems that they, or the physician, did not wish to discuss.
Related Provider Meta-concepts to Process			
Major Concepts (Provider Perception)	Provider Challenges	Provider Response	Analyst Rationale
Fatalism	Provider and patient expectations of negative outcomes. Fear as barrier to pursuing care. Provider assumptions concerning patient populations. Reduced treatment options based on assumptions of patient behavior.	Reducing expectations of negative outcomes. Increasing patient education to reduce fear. Utilizing patient education more than authority to motive patient. Presenting all available patient options.	Dismantling fatalistic assumptions and behaviors increases the availability of treatment options. While fatalism fuels fear and creates barriers, reducing fatalism increases patient efficacy which positively impacts outcomes.

Art of Practice	Suspicion of patient assertions Collateral medication effects Invalidated patient self-care attempts Contradictory patient priorities Provider reluctance to adjust strategies to increase compliance Seriousness of disease misunderstood Negative impact of socioeconomic level and family situation	Reduce assumption of common patient/ provider priorities. Assume patient is trying to comply. Understand and validate patient attempts at self-care. Empower patient to investigate medical care. Pursue patient trust. Appreciate and address patient agenda. Establish mutual expectations. Expose and deal with assumptions and biases concerning ethnicity, education, and socioeconomic status.	Style of practice, combined with medical information, has an effect on how advice is given by providers and received by patients. Provider assumptions change/ restrict offered interventions. Patients may be encouraged in their self-care efforts or hindered by their providers response to those efforts.
Feedback	Complex information delivery Weeding out process	Simplify information delivery. Establish mutual expectations Address physician assumptions	Feedback, with time and education, increased cooperation with patients. Tying care to complications improved patient buy-in.
Formal Diabetes Education	Selective information retention Increased fatalism, misconception, and depression Generic programming Not included in medical practice Behavioral control emphasized Challenges to provider authority	Check class effectiveness. Intervene with educational evaluation. Assure patient class according to need and education level. Include educational evaluation at provider level. Collaborate with patient. Examine provider conception of authority challenges.	Educational structures produced a complex effect for some patients. Addressing the integration of formal diabetes education into provider care in terms of direct education and educational evaluation may aid patient understanding. Dealing with provider sentiments regarding formal diabetes education would help integration.

Fatalism and process are linked by the patient's and the provider's practice of using routine to hide concerns. If no one brings up the concern, then it can be glossed over. If the

patient believes it will not help to voice a concern, or the provider thinks it will do no good to address an issue, then the visit can occur without significant comment from either. The process can then be used to discourage patient participation and negatively affect patient efficacy. The provider's art of practice can either reinforce or discount fatalistic attitudes. If the provider values education and patient collaboration, the process can be used to educate, comfort, and encourage. If the provider is working from a palate of unexamined assumptions, the process can foster non-compliance, misunderstanding, and ill will.

In some cases, the process benefits the provider as it can discourage continued interactions with those who do not fit the provider's compliance profile. Patients, after hearing from the provider, may self-select out of that provider's care. Providers discussed this as a matter of necessity. Non-compliant patients waste time with little or no return on the provider's investment.

But patients conceived of the process differently. For the patient, how the provider interacted with them mattered. If the patient felt the provider lacked faith in them or their condition, their ability to think positively about their care diminished. If their interaction was negative, they were less likely to continue care with that provider. Weeding out, or selecting for compliance, may not be as simple as providers characterize it. It is unclear who is being weeded out as providers and patients have different needs within the relationship.

The process of formal diabetes education was problematic for both patients and providers. For both, formal diabetes education was separate from their medical care. Patients were sent into a confusing, generic, hard-to-apply educational experience. They were unsure of what was relevant to their situation. Physicians considered formal diabetes education the arena

of nurses, diabetes educators, and dieticians and did not include it in their practice. In some cases providers also seemed to view it as a challenge to their authority.

Patient Self-management

Between the provider visit and after the formal diabetes education courses, the patient is responsible for any care that occurs. According to the patients, the success of patient self-management revolved around whether they believed the weight of management rested on them, the types of information/beliefs they operated under, and whether they believed their personal actions would have positive effect. If fatalism and negative personal/ family experience informed their perspective, their attempts at self-care would be less consistent with regard to medicine, diet, behavior, and consistency of care. (See Table 30).

Table 30 Focal Patient Meta-concept: Patient Self-management

Patient Self-management (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Discerned burden of care Challenges to patient's sense of control, respect, and dignity Alternate information sources or false information. Differing patient philosophy on quality of life. Lack of dietary changes that make sense within the patient's experience. Self sabotage and fatalism. Generic application of guidelines regardless of patient circumstance.	Create specific connections between patient self-care and more general guidelines. Investigate patient operant knowledge and opinion of care.	Success at self-management seemed connected to what the patient thought him or herself capable of as well as the strength of the information that they applied.
Related Provider Meta-concepts to Patient Self-management			
Major Concepts (Provider Perceptions)	Provider Challenges	Provider Response	Analyst Rationale

Fatalism	Provider and patient expectations of negative outcomes. Fear as barrier to pursuing care. Provider assumptions concerning patient populations. Reduced treatment options based on assumptions of patient behavior.	Reducing expectations of negative outcomes. Increasing patient education to reduce fear. Utilizing patient education more than authority to motive patient. Presenting all available patient options.	Dismantling fatalistic assumptions and behaviors increases the availability of treatment options. While fatalism fuels fear and creates barriers, reducing fatalism increases patient efficacy which positively impacts outcomes.
Information Diabetes Education	Patients lack knowledge of family history. Patients have modes of decision making and prioritizing that conventional provider thought. Providers do not know why patients are uninformed concerning their care and needs.	Connecting knowledge of family history to preventative care. Discover patient decision making and priority setting rubrics. Explore patient-side impediments to care.	Unearthing the differences between patient and provider understandings provides opportunity for clearer communication and more effective patient education.
Physician Support	Generic patient care. Lack of economic knowledge or support. Hurried timelines. Hyped patient failure. Unsuccessful negotiation of system. Lack of clarity regarding patient support networks. Unfamiliar patient priorities. Directive, authoritative care without patient participation.	Attach care to patient's specific medical situation. Chart patient's SES. Adjust care timeline for patient success. Avoid fatalistic promotion. Discern patient support networks. Assess patient priorities. Use directive care in a collaborative manner.	By allowing patients to perceive their personal situation, move according the most encouraging timeline, and utilize support networks, providers establish trust, provide encouragement, and build rapport.

Art of Practice	Suspicion of patient assertions Collateral medication effects Invalidated patient self-care attempts Contradictory patient priorities Provider reluctance to adjust strategies to increase compliance Seriousness of disease misunderstood Negative impact of socioeconomic level and family situation	Reduce assumption of common patient/ provider priorities. Assume patient is trying to comply. Understand and validate patient attempts at self-care. Empower patient to investigate medical care. Pursue patient trust. Appreciate and address patient agenda. Establish mutual expectations. Expose and deal with assumptions and biases concerning ethnicity, education, and socioeconomic status.	Style of practice, combined with medical information, has an effect on how advice is given by providers and received by patients. Provider assumptions change/ restrict offered interventions. Patients may be encouraged in their self-care efforts or hindered by their providers response to those efforts.
Compliance – Provider Defined	Discerning between technical, preconceived, and forced non-compliance Negative connotations associated with non-compliance Environmental considerations of forced-non-compliance	Identifying assumptions leading to preconceived non-compliance. Increasing education on consequence avoidance and preventative care. Utilizing physician support to discern environmental effects that produce forced non-compliance.	Non-compliance affects how providers respond to patients as well as patient's future care. Increased levels of fatalism bring negative consequences for providers and patients.

Expressions of fatalism in self-care emerged in both provider and patient discussions. Patients may believe that they cannot accomplish certain things, including blood glucose control, behavioral changes, and weight loss. They may believe that they cannot avoid negative outcomes including kidney failure, amputation, and death. Performing consistent self-care becomes extremely difficult under those circumstances. Providers also can believe that patients are not committed to change. In those cases, providers discussed treatments that require little

cooperation from the patient. If they could get them to take their medicine, that would be the extent of treatment.

Fatalism combined with informal diabetes education and the art of practice to negatively impact how successful patients believed they could be. Patients spoke of having few examples of positive disease management in their families or within their peer group. They experience more impediments to success and decision making. Providers who have little cultural experience and little time for social discovery may confuse a patient's lack of knowledge about personal care or family history as a lack of investment and evidence of future, or current, non-compliance.

Physician support that avoided overemphasizing failure and attended to patient understanding and circumstances encouraged patients in their self care. Providers were able to link guidelines to patients' specific circumstances. Connecting the patient's circumstances to prevention and treatment strategies gave the patient a meaningful goal for which to strive. The providers who made their recommendations meaningful for their patients also seemed to increase compliance.

Discovery of Diabetes

Discovery and management of diabetes were two distinct issues. Patients spoke of managing their diabetes symptoms for a significant period of time prior to their formal diagnosis. Fear of the disease motivated the patients to recast the symptoms even if the patient suspected they were diabetes related. In some cases, the patient did not actually know the symptoms of diabetes. Table 31 displays the challenges and responses to patients discovering they have diabetes.

Table 31 Focal Patient Meta-concept: Discovery of Diabetes

Discovery of	Patient Challenges	Patient Response	Analyst Rationale

Diabetes (Patient Perception)	Patients managing disease symptoms without acknowledging disease. Unknowledgeable about symptoms (Patient).	Formalize symptom education prior to disease onset.	While providers understand that diabetes diagnosis happens much later than actual disease onset, patients are both fearful of the diagnosis. How the disease is discovered impacts the patient's response to the diagnosis.
Related Provider Meta-concepts to Discovery of Diabetes			
Major Concepts (Provider Perception)	**Provider Challenges**	**Provider Response**	**Analyst Rationale**
Fatalism	Provider and patient expectations of negative outcomes. Fear as barrier to pursuing care. Provider assumptions concerning patient populations. Reduced treatment options based on assumptions of patient behavior.	Reducing expectations of negative outcomes. Increasing patient education to reduce fear. Utilizing patient education more than authority to motive patient. Presenting all available patient options.	Dismantling fatalistic assumptions and behaviors increases the availability of treatment options. While fatalism fuels fear and creates barriers, reducing fatalism increases patient efficacy which positively impacts outcomes.
Informal Diabetes Education	Patients lack knowledge of family history. Patients have modes of decision making and prioritizing that conventional provider thought. Providers do not know why patients are uninformed concerning their care and needs.	Connecting knowledge of family history to preventative care. Discover patient decision making and priority setting rubrics. Explore patient-side impediments to care.	Unearthing the differences between patient and provider understandings provides opportunity for clearer communication and more effective patient education.

Formal Diabetes Education	Selective information retention Increased fatalism, misconception, and depression Generic programming Not included in medical practice Behavioral control emphasized Challenges to provider authority	Check class effectiveness. Intervene with educational evaluation. Assure patient class according to need and education level. Include educational evaluation at provider level. Collaborate with patient. Examine provider conception of authority challenges.	Educational structures produced a complex effect for some patients. Addressing the integration of formal diabetes education into provider care in terms of direct education and educational evaluation may aid patient understanding. Dealing with provider sentiments regarding formal diabetes education would help integration.

Informal and formal diabetes education seemed deficient both to the patient community and from the provider's perspective. Provider and patients discussed educational efforts that began at or after the initial diagnosis. At the point of diagnosis, the patients talked about experiencing a host of negative emotions including fear, shame, defeat, and shock. The provider's response, at the moment of diagnosis, matters with regard to the patient's self-care. A successful discovery experience put the patient and provider in position to hear and respond to each other. Unsuccessful discovery experiences encouraged fatalism and depression.

Family Influence

Patients in this study reported either negative family influences surrounding diabetes management or no influence at all. If they knew their family's history, it was a lineage of mismanagement, secrecy, and death. For the few patients who could point to positive influences, those experiences acted as a lifeline in supporting their own self-care. (See Table 32).

Table 32 Focal Patient Meta-concepts: Family Influence

Family Influence (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Overwhelmingly negative family influence including unsuccessful diabetics and generational, negative outcomes.	Explore past experience with diabetes and outcomes. Address fear.	Patient understands provider position on care, but may have experiences that promote fear and disillusionment. Addressing these fears may increase success.
Related Provider Meta-concepts to Family Influence			
Major Concepts (Provider Perception)	Provider Challenges	Provider Response	Analyst Rationale
Fatalism	Provider and patient expectations of negative outcomes. Fear as barrier to pursuing care. Provider assumptions concerning patient populations. Reduced treatment options based on assumptions of patient behavior.	Reducing expectations of negative outcomes. Increasing patient education to reduce fear. Utilizing patient education more than authority to motive patient. Presenting all available patient options.	Dismantling fatalistic assumptions and behaviors increases the availability of treatment options. While fatalism fuels fear and creates barriers, reducing fatalism increases patient efficacy which positively impacts outcomes.
Information Diabetes Education	Patients lack knowledge of family history. Patients have modes of decision making and prioritizing that defy conventional provider thought. Providers do not know why patients are uninformed concerning their care and needs.	Connecting knowledge of family history to preventative care. Discover patient decision making and priority setting rubrics. Explore patient-side impediments to care.	Unearthing the differences between patient and provider understandings provides opportunity for clearer communication and more effective patient education.

Providers spoke ambivalently about family influences. Family could be helpful,

according to the providers, but it was a drain of resources to identify and train them. For those

reasons, if a family were to be involved, that participation had to be initiated by the patient or the

family member. It was beyond the provider's scope to expend that kind of effort. But providers acknowledged that family involvement in care enabled better compliance and self-care. Providers spoke of the contradiction inherent in the situation: if doctors were willing to spend resources on educating families and other support structures, then patients would be more successful.

Patient Self-perception

The stress of chronic disease management has a continued effect on the patient. A type-2 diabetes diagnosis impacted how patients saw themselves socially and individually. Defeatism and depression often accompanied the diagnosis as many consider diabetes to be a self-inflicted disease of personal health mismanagement. The diagnosis becomes a failure in itself. If the patient considers themselves negatively from discovery, then a strategy must be established to deal with self-perception and affective challenges if successful management is a goal. As Table 33 summarizes, patients sought increased opportunities for success and support within their communities as a boost to self-perception.

Table 33 Focal Patient Meta-concept: Patient Self-perception

Patient Self-perception (Patient Perception)	Patient Challenges	Patient Response	Analyst Rationale
	Defeatism and depression. Moving patient into a positive self-perception.	Increasing positive, family or community support for patient. Accentuate personal successes in self-care.	Self-efficacy was negatively impacted by negative self-perception. Without visible success, patients may be unmotivated to continue a heightened level of self-care.
Related Provider Meta-concepts to Patient Self-perception			
Major Concepts (Provider Perception)	Provider Challenges	Provider Response	Analyst Rationale

Style of Diabetes Education	Lack of positive awareness in patient community. Negative perceptions of provider care and medications Provider assumptions concerning patient population. Disconnection between behavioral consequences and preventative care.	Developing positive, overall awareness in patient. Identifying and addressing negative perceptions. Integrating and communicating consequence avoidance and education. Identifying and addressing provider assumptions.	Building positive awareness allows both patient and provider to focus on goals and compliance while reducing fatalistic behaviors and attitudes. A holistic viewpoint integrates care strategies and can reduce opportunities for provider assumption.
Fatalism	Provider and patient expectations of negative outcomes. Fear as barrier to pursuing care. Provider assumptions concerning patient populations. Reduced treatment options based on assumptions of patient behavior.	Reducing expectations of negative outcomes. Increasing patient education to reduce fear. Utilizing patient education more than authority to motive patient. Presenting all available patient options.	Dismantling fatalistic assumptions and behaviors increases the availability of treatment options. While fatalism fuels fear and creates barriers, reducing fatalism increases patient efficacy which positively impacts outcomes.
Physician Support	Generic patient care. Lack of economic knowledge or support. Hurried timelines. Hyped patient failure. Unsuccessful negotiation of system. Lack of clarity regarding patient support networks. Unfamiliar patient priorities. Directive, authoritative care without patient participation.	Attach care to patient's specific medical situation. Chart patient's SES. Adjust care timeline for patient success. Avoid fatalistic promotion. Discern patient support networks. Assess patient priorities. Use directive care in a collaborative manner.	By allowing patients to perceive their personal situation, move according the most encouraging timeline, and utilize support networks, providers establish trust, provide encouragement, and build rapport.

Art of Practice	Suspicion of patient assertions Collateral medication effects Invalidated patient self-care attempts Contradictory patient priorities Provider reluctance to adjust strategies to increase compliance Seriousness of disease misunderstood Negative impact of socioeconomic level and family situation	Reduce assumption of common patient/ provider priorities. Assume patient is trying to comply. Understand and validate patient attempts at self-care. Empower patient to investigate medical care. Pursue patient trust. Appreciate and address patient agenda. Establish mutual expectations. Expose and deal with assumptions and biases concerning ethnicity, education, and socioeconomic status.	Style of practice, combined with medical information, has an effect on how advice is given by providers and received by patients. Provider assumptions change/ restrict offered interventions. Patients may be encouraged in their self-care efforts or hindered by their providers response to those efforts.
Compliance – Provider Defined	Discerning between technical, preconceived, and forced non-compliance Negative connotations associated with non-compliance Environmental considerations of forced-non-compliance	Identifying assumptions leading to preconceived non-compliance. Increasing education on consequence avoidance and preventative care. Utilizing physician support to discern environmental effects that produce forced non-compliance.	Non-compliance affects how providers respond to patients as well as patient's future care. Increased levels of fatalism bring negative consequences for providers and patients.

The provider's style of diabetes education contributes to the patient's self-perception and, by extension, to their sense of efficacy concerning self-care. Providers spoke of having little time to discuss diabetes education or concerns outside of glucose, weight, blood pressure, and cholesterol issues. Links between preventative measures, consequences, and patient-side strategies frequently were excluded due to time constraints. As a consequence, compliance and success were filtered through these overt measures of blood glucose control, weight, blood

pressure, cholesterol levels, and HbA1c. In many cases, the measures served only to highlight medical and behavioral failings on the patient's part.

To combat fatalism providers widened their views of time and success to find ways to support their patients. Providers spoke of verbalizing and charting smaller victories for the patient so that motivation and self-perception would increase. Slowing strategic timelines increased opportunities for success and allowed the patient to acclimate to changes in lifestyle. Provider awareness of psychological stresses and economic circumstances also produced occasion to enhance compliance. Patients were able to see their successes as well as areas needing change. They were better able to comply as their levels of understanding and trust increased with their positive interactions with their providers and their treatments.

Conclusion

This analysis reveals that there are significant gaps in communication, understanding, and meaning between patient and provider. At times, providers make decisions for the patients. There also are times when patients make decisions that are invisible to providers, but important to care. It is important to reiterate that both patient and provider act in ways that erect barriers to care. In the concluding chapter, I will revisit how this analysis responds to the guiding research questions and identify prescriptions at the level of individual, community, and policy.

Chapter 10

Conclusions

This analysis has used what Forester (1981) calls critical practical rationality as a means of understanding the interaction of elder, African-American diabetics with their healthcare providers. As chapter 4 discussed, critical practical rationality asks that public administrators and policy analysts move beyond solely technical discussions and seek to shape the attention of policymakers. This involves expanding the palette of voices allowed into the discussion and exploring technical and social/ affective aspects of public challenges, an effort aimed at emancipating the public as stakeholders from systemic and social distortions that impact policy and strategy.

The context for this study were the challenges of health and health care disparity affecting elder, African-American diabetics, who had not been drawn into the discussion of their own health at the level of policy and strategy. As the introduction discussed, significant health and healthcare disparities between African Americans and non-Hispanic whites, with negative outcomes including kidney failure, blindness, amputation and death for elder, African-American diabetics. The technical aspects of diabetes diagnosis, care, and intervention are well documented. The social and affective facets have not been as fully explored. In the research examined here, communication – technical and affective – emerged as central to both the problem and the solution. Chapters 6, 7, and 8 described several significant barriers to understanding in the broader communication practices of patients and providers. Chapter 9 highlighted several points of agreement – where patient and provider are both aware of and participants in successful communication – as well as several points of conflict – where patient and provider miscommunication is high. This chapter will revisit the research questions, discuss

policy prescriptions and implications using McKinlay's downstream, midstream, upstream framework, and suggest avenues for future research.

Revisiting the Research Questions

Forester reminds administrators and policy makers that the questions they pose will direct attention. This dissertation focused on three guiding research questions:

- What motivates/ hinders elder, diabetic African-Americans to increase interaction with their medical providers?

- Where do providers get appropriate cultural information?

- What distinguishes successful interactions from unsuccessful interactions from the patients' and from the providers' standpoints?

The dominant theme in the underlying responses to all three questions involves communication. For these patients, the technical information they received from their provider meant little if it was not delivered in a way that invited trust and lessened fear.

What motivates or hinders elder, diabetic African-Americans to increase or decrease interaction with their medical providers?

For the patients, communications through personal experience, friends, family, providers, and media impacted their behavior toward and responses to their providers. If their provider was the most consistent, positive source of communication, the patient was more likely to become compliant and ignore other sources of information. If the provider was not consistent, or communicated disregard and negativity, the patient was likely to be suspicious and elevate another of communication to replace or compete with the provider's recommendation, according to focus group participants. Patients picked up on verbal and non-verbal cues to discern the

provider's level of concern or care. They actively looked for support or disregard in their provider's manner.

The source of patient information, treatment, and self care is important. While the patient participants spoke of several resources, they tended to trust those sources that allayed fear and resolved suspicion. This happened whether the non-provider source was accurate. Also, the patient's personal and familial experiences with diabetes were mostly negative. If communication with the medical provider sours, the patient is not in a good position to receive accurate information or realistic direction.

Where do providers get appropriate cultural information?

Providers asserted that they had few if any opportunities to acquire appropriate cultural information. European-American providers believed that culture and ethnicity produced personal anxiety for themselves. The providers acknowledged that they made assumptions about their patients' responses since the patients had not communicated any anxiety related to ethnicity or culture. With the lack of sources for appropriate cultural information, my conversations with providers turned mostly to assumptions.

For most of the providers I interviewed, assumptions were ways of considering the patient that centered on their possible compliance. This was important because the providers adjusted their recommended care strategies, effort, and manner based on these suppositions. Economic status, reliance on government assistance, educational level, and a provider's experience with similar patients or members of similar groups were areas in which providers had significant preconceptions. Providers spoke of expecting compliance and collaborative care from those with higher levels of education and who were not on public assistance. They spoke of negative compliance assumptions about those with lower incomes and less education. It is

important to note that when providers assumed non-compliance, they consistently spoke of altering the range of treatment strategies available to the patient.

What distinguishes successful interactions from unsuccessful interactions from the patients' and from the providers' standpoints?

Patient participants acknowledged success when they felt included and respected by their care provider. More specifically, success happened when their provider helped reduce fear, anxiety, and fatalism about diabetes management. Patient efficacy increased when they believed they were meeting their provider's expectations along with their own personal goals. Unsuccessful interactions were characterized by rushed, inaccessible, disrespectful visits that left the patient confused, unsure, or angry. For the patient, compliance and success were tied to clearer communication and more positive relationships with their providers.

For the providers, success was signaled by technical measures of compliance including HbA1C levels, glucose levels, diet and weight control, and cholesterol levels. Affective effort from providers seemed reserved for those patients who could demonstrate initial and continued compliance. This is problematic as patients may have several reasons, some unavoidable, for non-compliance.

Overall, the research questions highlight communication as the center of what is successful and what is not. Ineffective or harmful communication is the source of systemic and social distortion from which patients and providers should be emancipated. Although the discussion and analysis here cannot be generalized, they do point to several prescriptions and public policy implications.

Policy Prescriptions

McKinlay (1995) suggests examining three levels of analysis when seeking to reduce health disparities: downstream, midstream, and upstream. A "downstream" emphasis involves interactions at the level of individuals (e.g., between patient and provider). A midstream focus concerns a patient's geographic relationship to community organizations (e.g., hospitals, churches). An upstream stress examines where policy is created to support reductions in health disparity. This includes state and federal governments and for- and non-profit organizations, including third-party payers and advocacy groups. I will use McKinlay's model to organize the recommendations that emerged from this research, beginning with downstream prescriptions.

Downstream Recommendations

These prescriptions focus on the individual and those things that affect individual behavior and choice. Patients prioritized several suggestions (summarized in Table 34).These recommendations cover both opportunities to increase positive patient interaction with providers and to reduce barriers to those interactions.

Table 34: Downstream Recommendations

- Researchers and program specialists should prepare for community vetting.
- Written documentation, while useful, is not an optimal, first-line information source for elder, African-American diabetics.
- Personal documentation motivates patients.
- Patient and provider should establish explicit mutual expectations.
- Providers should establish explicit definitions of compliance and non-compliance.
- Providers should identify – or educate the patient to identify – false, but comforting sources of information.
- Providers should be aware of challenges to patient dignity, control, and respect.
- Providers should understand and validate patient attempts at self-care.

Researchers and program specialists should prepare for community vetting.

Based on my interactions with patients as a researcher, it would appear that researchers and outreach coordinators should be prepared to establish themselves as trustworthy in the

community prior to their planned interventions. They will have to cultivate and maintain trust to become a primary source of information and direction. This is consistent with how the patient participants considered the providers as well. Trust was important to cooperation and participation in their own health management.

Written documentation, while useful, is not an optimal, first-line information source for elder, African-American diabetics.

Information exchange is one means of trust production as well as a point of collaborative contact between patient and provider. When the provider selects written information and connects that information to the patient's position, the patient was able to elevate that information above the generic information. In addition, the patient felt directed and cared for by the act of selection and explanation. Patients were more likely to refer to and follow the information.

Personal documentation is motivational to patients.

A take-away sheet confirming their vital signs for the visit, reminding them of goals, confirming prescriptions, and listing new recommendations would give patients a reference point from which to ask questions and to begin an ongoing reference of their own health. Family members could also refer to these reports to keep track of care.

Patient and provider should establish explicit mutual expectations.

While hospitals and providers offices often post variations of the "Patient's Bill of Rights and Responsibilities" throughout their premises and give them to patients prior to certain procedures, more explicit discussions also are necessary to detail how the patient can respond to

their provider. If the provider asks for feedback from the patient, the patient may feel less restricted in verbalizing concerns and fears. Allowing the patient to make their priorities and concerns explicit gives the provider clues about the patient's motivations and the difficulties they may confront.

Providers should establish definitions of compliance and non-compliance.

Providers may assume that a patient knows how to comply with the providers' recommendations. They also may assume that their recommendations are a life-priority for the patient. Connecting compliance to larger patient goals and possible consequences allowed providers and patients to expose fears and misunderstanding. Unearthing barriers to compliance from the patient's perspective produced higher levels of compliance as those challenges could be addressed.

Providers should identify, or educate the patient to identify, false, but comforting sources of information.

Education about experimental procedures, media advertisements, and drug side effects are a significant part of diabetes education. If the provider helps the patient avoid informational pitfalls by highlighting current trends and changes in diabetes care, the patient is more likely to consider the provider a primary source and remain compliant. Patients discussed their need for fear mitigation as part of their care regimen. When the provider ignored their affective need, the provider's status as the primary information source suffered. Given that patients discussed having few family or peer relationships that they would identify as successful, the odds of their finding other positive sources of diabetes care information seemed low.

Providers should be aware of challenges to patient dignity, control, and respect.

Patients who felt slighted or disrespected would withhold information from their providers due to lack of trust. They also might be suspicious of the advice and information given. They would not be likely to pursue pertinent information or question their provider. When they are able, they change providers in silence. If they are not able to do so, they suffer in silence. Periodically, there should be ways to examine the customer service aspects of the visit and administrative process. This might be done in exit interviews for patients leaving a provider or after selected office visits.

Providers should understand and validate patient attempts at self-care.

Success for the patient may not look to the provider like immediate technical compliance. But it may be a supporting step toward such compliance. Recognizing small changes in diet, exercise, and glucose control provides encouragement and support to patients who may underrate their ability to accomplish the provider's goals. Patients were more likely to think they were capable if they believed their provider agreed they were indeed capable.

Downstream recommendations focus on building the patient's relationship with their provider as well as building their relationship with the disease management process the provider offers. The providers I interviewed acknowledged that although they, as providers, disagree with the faith patients put in untested outside opinions and products, they are asking the patient to maintain a level of faith in them as providers as well.

Midstream Recommendations

Midstream recommendations happen at the community level. Patients discussed having very little available to them in their local, residential, or religious community. They travel for

their care; they may travel for diabetes education classes. They yearn for community-based peer

information or availability. They also want to see the recommendations and advice work for

someone who is accessible. Previous midstream recommendations have not been especially

successful for these patients as the groups they rely on – churches and social groups -- are not

focused on their health care needs. They did make several suggestions (see Table 35).

Table 35: Midstream Recommendations

- Motivate patients with their own personal summary documentation.
- Develop electronic records management for continuity of patient information including SES.
- Standardize information and direction given at initial diabetes diagnosis.
- Institute diabetes education evaluation for patient efficacy and provider reference.
- Budget for the development of positive communication between patient and provider, in addition to outreach and publication materials, in diabetes research and programming funding requests.
- Create an incentivized, protected structure for evaluating preconceptions and bias in care organizations.
- Group patients according to case needs and educational levels in formal diabetes education courses.
- Seek out "peer" representatives for newly diagnosed diabetics.

Motivate patients with their own personal summary documentation.

Patients valued summaries of their vital signs, records of compliance for the provider,

medications, and changes in their status or blood work. A take-away sheet confirming their vital

signs for the visit, goals reminders, confirming prescriptions, and listing new recommendations,

would give the patients a reference point from which to ask questions and to begin an ongoing

reference of their own health. This recommendation is a downstream prescription, but it is an

upstream concern as well. Family members could also reference these reports to keep track of

care if they were not able to accompany their family member to the provider visit. Being able to

create this type of summary would require a community-level move to electronic medical

records management, itself being encouraged for numerous other uses.

Develop electronic records management for continuity of patient information including SES.

Electronic records management, including whether the patient has received formal diabetes education, could allow the patient's care team to see trends in patient behavior, discussion notes from nurses and educators, and visit-to-visit summaries of his or her progress. Education level, literacy, and annual household income information would to allow the organization to discern possible placement in drug or community programming. Also, managers and/ or administrators – health care organizations (e.g., U.S. Department of Health and Human Services, Office of Minority Health), insurance managers (private, Medicare, Medicaid), and advocacy groups (American Diabetes Association, National Partnership for Action to End Health Disparities) – could track exit rates and "weeding out," treatment strategies offered, and treatment escalations. Currently, measures of healthcare disparity include complication and mortality rates. Electronic records management would allow the tracking of factors that *precede* adverse events like end stage renal disease, blindness, amputation, and death.

Standardize information and direction given at initial diabetes diagnosis.

After their initial diagnosis, patients spoke of being left on their own to cope with their despair, fear, and depression. They often were told that they would be scheduled for an educational class at a future date. Postponing education until classes can be attended left patients unsupported and vulnerable. It negatively impacted levels of trust and self-efficacy by leaving the patient in a place of failure. By standardizing the type of information given – technical and affective – the patient's foundation for future care may be less fatalistic.

Institute diabetes education evaluation for patient efficacy and provider reference.

Patients and providers discussed formal diabetes education classes as being detached from regular care. Providers refrained from recommending them, and patients who attended sometimes came away confused or misinformed. Creating a system for evaluating the information patients receive, their level of knowledge acquisition and perceived relevance, and feedback for their medical provider would increase utility and enable communication. This also could be tied into the electronic records system.

Budget for the development of positive communication between patient and provider, in diabetes research and programming funding requests, in addition to outreach and publication materials.

Developing constructive communication between patient and provider is essential to successful care. Providers spoke specifically about communication with patients and families as a drain on resources. Unless funding is included to mandate training and evaluation, these issues will remain peripheral as time requires both effort and money.

Create an incentivized, protected structure for evaluating preconceptions and bias in care organizations.

Providers worry about labels or bias and racism and litigiousness. For an organization to examine the ethnicity assumptions present in its history and practice will require that it protect its providers during the self-examination while still mandating the process. A systemic review would include monitoring rates of escalation of care strategies, tracking care strategies offered

across patient income levels, educational levels, ethnicity, age, and sex. This also could include examining patient exit rates from providers across similar categories.

Group patients according to case needs and educational levels in formal diabetes education courses.

Being in courses with people of differing circumstances caused patients to second guess their own circumstances. For example, they were concerned about weight and portion control in a class where there was a 300 pound range in weight. They were frustrated by a lack of discussion of food options that matched their lifestyles. They were bothered by the generic nature of the courses themselves. Being grouped with those who were experiencing similar challenges, with similar lifestyles seemed to increase comfort levels with the changes confronting them.

Seek out "peer" representatives for newly diagnosed diabetics.

In connection with establishing community trust, patients wanted to see how someone would successfully live this new life that educators and providers suggested. They wanted to be reassured about their quality of life while managing diabetes. With overwhelming negative family experiences concerning diabetes and few successful friends with the disease, patients needed to see someone in their community who was living successfully with the necessary lifestyle changes. This could be accomplished through educational and research partnerships with seniors' organizations, religious groups, and other social groups.

These midstream recommendations reflect the needs the patients discussed at the community level. Most of the recommendations could be incorporated into the work of diabetes educators, but that is a danger as well. The work of diabetes educators seems separate from direct

care. The prescriptions here focus on creating integrated streams of information that benefit the patient, their providers, and diabetes educators.

Upstream Recommendations

Upstream recommendations are at the level of state or federal public policy, but also deal with public health concerns. (Table 36summarizes six such prescriptions.) Several upstream recommendations also are midstream recommendations, because policy, funding, and programming for midstream impacts would need to be put in place upstream.

Table 36: Upstream Recommendation

• Develop electronic records management for continuity of patient information including SES.   • Standardize information and direction given at initial diabetes diagnosis.   • Create an incentivized, protected structure for evaluating assumption and bias in care organizations.   • Institute diabetes education evaluation for patient efficacy and provider reference.   • Add depression screening to the routine care of diabetes – especially for those without significant support.   • Budget for communication development, in addition to outreach and publication materials, in diabetes research and programming funding requests.

Develop electronic records management for continuity of patient information including SES.

Although electronic records management could positively impact patient relationships at the mid- and downstream locations, several considerations need to be addressed. The Health Information Technology for Economic and Clinical Health (HITECH) Act, a part of the American Recovery and Reinvestment Act (ARRA) of 2009, creates incentives for health care organizations, hospital systems, and individual providers implementing health information

technology.[22] For smaller self-owned practices, state or federal funds will be available in 2011. System standards have not been defined by the Secretary of Health and Human Services regarding system compatibility for patients who move between hospital systems or self-owned practices. HIPAA sanctions for violations in electronic records management have already shifted as patients will be able to request a listing of disclosures going back three years after Jan. 1, 2014. (Waldren, Kibbe, and Mitchell, 2009, p. 22). Also, a tiered system of violations penalties will be in place (p. 23)

Standardize information and direction given at initial diabetes diagnosis.

Providers rely on their own experience, availability, and preconceptions in negotiating an initial diabetes diagnosis. Some are thorough. Some are cursory. But that initial experience was crucial for elder, African-American patients being diagnosed. Designing and implementing a guide for the "discovery" experience that bridges and standardizes the initial diagnosis and follow-up educational opportunities would further reduce fatalism.

Create an incentivized, protected structure for evaluating assumptions and bias in care organizations.

As policy conversations about healthcare reform continue, providers and systems need to evaluate themselves for competencies. At the same time, resources should be directed to evaluating bias and preconceptions about patients in health delivery systems and in individual practice. Providers spoke of working from assumptions about their patients in ways that

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[22] Waldren, Steven, David Kibbe and Jason Mitchell. (2009) " 'Will the Feds Really Buy Me and HER?' and Other Commonly Asked Questions About the HITECH Act." *Family Practice Management.*

negatively impacted care. This may mean adjusting medical school curricula or creating certificate/ continuing education programs.

Institute diabetes education evaluation for patient efficacy and provider reference.

Elevating diabetes education and integrating it into patient/provider record keeping relationship would require a high level intervention. Educators would be better able to help their patients if certain medical and cultural information was made available to them. At the same time, providers could better assess their patients understanding if a mechanism for feedback from the diabetes educators was present in their system.

Add depression screening to the routine care of diabetes, especially for those without significant personal and family support.

Patients spoke of becoming depressed after first being formally diagnosed with diabetes or becoming so as fatalistic attitudes increased over time. Providers did not mention, or evidently recognize, the emotional toll of being diagnosed. Adding a depression screening to routine diabetes care may positively impact patient/ provider relationships and increase overall compliance rates.

Budget for communication development, in diabetes research and programming funding requests, in addition to outreach and publication materials.

This research demonstrates that the way something is communicated greatly impacts whether and how the message is received or acted upon. Patients refused credible advice due to the manner in which it was conveyed. Ineffective communication hindered their pursuit of health. Assessing the effectiveness of provider communication in conveying accurate

information should be included in treatment budgets as medical organizations pursue cultural competencies.

These upstream recommendations emphasize creating priorities in policy and budgets that support downstream and midstream initiatives. Effective upstream interventions also create standards, incentives, and enforcements that are consistent.

Thinking more broadly about these recommendations, several upstream issues need to be considered. As more payers and providers expand their services nationally, regulations that concern interstate commerce and consumer protections should be considered. Waste has been identified in the third-party payer system already. As contracts change and networks become more formal, there are implications for health networks that begin to exclude Medicare and Medicaid patients as shifts in state reimbursements make patients unprofitable. Bundling, an umbrella term for a range of payment systems, is gaining momentum. Hurwitz (1991) suggests that bundling drugs and services presents an antitrust issue. Linking drugs and services is one form of bundling, linking physician and hospital payments to positively affect quality of care and reduce waste is another (Alexander, 2008, p.40). The Centers for Medicare and Medicaid Services (CMS) saw Medicare cost savings and major changes in select hospital/ physician practice patterns in an early bundling demonstration from 1991-1996. Although the participation criteria were stringent, Medicare saved about $50.3 million from four participating heart bypass centers (p. 41).

The CMS demonstrations suggests a useful way to examine bundling – not as a blanket option, but where most efficacious. Alexander (2008) presents the demonstration scenario where not only the larger institution buys into the payment system, but hospital medical staff and consulting physicians as well. While the consulting physicians balked at being restricted in

billing Medicare directly, other parts of the system adjusted to absorb the contention. To support

the medical staff, the hospitals took care of all billing and collections costs. Patients had the

benefit of receiving a single copayment billing. For larger healthcare organizations, staff

physicians may have a measure of assurance regarding administration. But, bundling is more

challenging for smaller groups or individual practices as margins are much slimmer concerning

provider-to-provider payments. Unexpected hospitalizations, or inappropriate payment amounts,

could cause a smaller practice significant harm by underproviding care or creating financial

hardship (Miller, 2009, p. 1423-1424).

Future Research

Using grounded theory methods, this study identified and defined several concept areas

that seemed important to the patient/ provider relationship as well as to nuances of compliance.

In future studies it would be worthwhile to repeat this kind of study to attempt greater conceptual

density and establish more causal links for fuller theoretical description and analysis. Mixed

method, collaborative projects would be appropriate as well. Examples of this might be in using

established tools to assess patient/ provider communication in combination with interviews or

focus groups for a more robust analysis.

In addition, with regard to the concept of "weeding out," further comparison of patient

exit rates with provider discussions of necessary compliance evidently would be useful in

understanding the movements of elder, African-American diabetics and the rationales of the

providers. There seemed to be a difference between the reasons the providers supplied for their

exiting patients and those of the patients themselves.

As mentioned previously, the measures of healthcare disparity that are used to highlight

its dangers are adverse indicators – for diabetics, amputations, kidney failure, blindness, and

death. Identifying the factors that precede disparity – which, in an electronic system, could act as flags for bias or for intervention – would pave the way for dismantling disparity at its roots in systems and in practice. Also, more recently created systems could be examined for possible inconsistency in care escalation, given education, consistent preventative care, and weeding out. In addition, there is room for scholars to explore the continuing evolution and implementation of the HITECH Act and its effects on patient care, patient privacy, corporate cooperation, and issues of federalism.

Lastly, this research should be expanded to include diabetes educators, whose perspective is missing here.   In my recent conversations with area diabetes educators, the issue of access to patients was raised. The diabetes educators spoke of being unable to get a foothold in African-American communities. Exploring issues of vetting and developing trust between this population and community health organizations would be worthwhile to researchers, diabetes educators, and elder, ethnic populations.

Conclusion

This study suggests that elder, African-American diabetics are aware of their physiological issues, their challenging provider interactions, and how those play a part in their success in chronic disease management. The analysis indicates that the problems of health and health care disparity in this community reflect more than individual behavior alone. When informed and respected, patients were willing to share their problems, their enacted solutions, and their successes. They were willing to be stakeholders when they understood how to advocate for themselves. Likewise, the "successful" providers were candid about their reticence to work with elder, African-American diabetics as stakeholders in care. They were forthcoming about their successes and flaws as providers.

But the discussion does not end with the patient's or the provider's individual response. I, as a researcher, have a responsibility. As stated in the methodology discussion, with participant action research, I will return the community's words and suggestions to the community – their downstream and midstream claims and recommendations. For the providers, I will supply an executive summary of the patients' and their own recommendations. I will also distribute these recommendations upstream through publication and direct interaction with agency representatives. More immediately, I have established a connection with area diabetes educators to develop community programming that uses the recommendations for the elder, African-American community. In this way, this research may have immediate impact on practice for patient, provider, and educator as well as continued effect in the larger health care policy and cultural competency discussions.

Appendices

Appendix A: Focus Group and Interview Scripts

Tentative Focus Group Script:

Items in each folder:

Informed consent form (2 copies)- white
Demographic - yellow
Provider Recommendation - green

Brief Introduction(s)

Purpose: Focus groups are used to encourage group discussion and decision-making about topics of interest. Today, we will be discussing experiences, preferences, and problems with doctor/ patient interactions. The focus group will last about 1.5 hours and we will take a break halfway through.

Before beginning, I would like to read the informed consent document to you, and then will ask you to sign it after you have indicated that you understand the information.

Review informed consent. Ask for signature. Mention that they will be <u>audiotaped</u>.

Demographic sheet: This is a form that asks for some basic information about you such as age, gender, ability, etc. Let me know if you need assistance.

Process: I will raise several questions related to your experiences with your providers and ask you to discuss these issues openly. **Please feel free to jump in whenever you are ready**. This is sort of a brain storming session so please feel free to say whatever you think is important. Also, please be considerate of other's opinions.

Are there any questions before we begin?

Focus Group Questions

1. How did you first find out you were diabetic?
    a. Who gave you instructions at that time?
    b. Were they easy to understand?
2. How your doctor, or nurse, or diabetes educator support you when you were first diagnosed?
3. What were you told about diabetes?

4. Do you receive on-going or routine medical care for your diabetes? In other words, do you meet with a doctor, nurse, or other healthcare provider on a regular basis?
5. What kind of doctor do you see m most often? Prompt: General practitioner, nurse, emergency room?
6. When is the last time you changed providers?
    a. Was there any reason for the change?
7. Who do you ask if you have questions about your diabetes?
8. How do you prefer to receive information about your diabetes?
   (Prompt) pamphlets, booklets to read, verbal with pictures etc., videos
9. Do you have friends who are diabetic?
    a. Family who are diabetic?
10. A normal blood glucose level is 80 to 140. If you were told your blood glucose reading was 150, what would that mean to you?
11. Do you consider your diabetes "under control"?
12. Can you describe a regular visit to your doctor?
    a. What are some of the first things he or she does?
    b. What stands out to you about your doctor?
    c. What makes you comfortable?
    d. What makes you uncomfortable?
13. Do you do everything you doctor asks?
14. What do you wish your doctor would say to you?
15. What do you wish he or she would not say to you?
16. What's the most encouraging thing the doctor has done?
17. Would you consider your doctor successful at dealing with African-American patients? Prompt: Would you recommend him to someone else?
18. What would it take to make this person successful or more successful?
19. Is there anything you would like to add?

Please make sure that the yellow and pink documents have been returned to your folder. Make sure that one signed copy of the informed consent document is also in your folder.

Thank you for participating in this focus group. The information you have provided is very valuable. I can provide information about this study when it is completed. You can use the information on your copy of the informed consent document to contact me if you have further questions or wish to remove yourself from this study at any time.

Thanks again.

"Successful" Provider Interview Script

Thank you for agreeing to meet with me. This interview should last about an hour. I will be audio recording for research purposes.

Review informed consent and confidentiality statement. Ask for signature. Mention that they will be <u>audiotaped</u>.

Demographic sheet: This is a form that asks for some basic information about you such as age, gender, ethnicity, and length of practice. Let me know if you need assistance.

You have been recommended by a patient as successful at dealing with African-American patients – particularly elder diabetics.

1. What do you think about this recommendation?
2. In you tenure, how many elder, African-American, diabetic patients have you had?
3. What was your first elder, African-American patient like?
4. What have you learned about this population over time?
5. Has your way of working with them changed over time?
     a. Can you describe a typical visit?
6. What have you noticed to be most successful?
7. Least successful?
8. If you had a student on rotation in your office, what would be the most important thing for them to know?
9. What would you expect for new doctors to have the most trouble with?
10. Do your patients tell you about home remedies or other therapies they may try?
11. Do your patients involve their families in their care?
     a. How often?
12. Do these patients follow your advice most of the time?
13. Are their any pieces of advice they are more reluctant to follow?
     a. Why do you think that is?
     b. What would you like them to do more of?
     c. Less off?
14. Have you ever experienced something with this population that confused you?
     a. How did you work through that?
15. If you could change something that would lessen the negative outcomes for this population, what would it be?

That's all the questions I have. Thanks again for your time and responses.
Please make sure that the yellow and pink documents have been returned to your folder. Make sure that one signed copy of the informed consent document is also in your folder.

You can use the information on your copy of the informed consent document to contact me if you have further questions. Thanks again.

Comparison Provider Interview Script

Thank you for agreeing to meet with me. This interview should last about an hour. I will be audio recording for research purposes.

Review informed consent and confidentiality statement. Ask for signature. Mention that they will be <u>audiotaped</u>.

Demographic sheet: This is a form that asks for some basic information about you such as age, gender, ethnicity, and length of practice. Let me know if you need assistance.

1. Do you remember your first, elder, African-American patient?
2. What were they like?
3. In you tenure, how many elder, African-American, diabetic patients have you had?
4. What have you learned about this population over time?
5. Has your way of working with them changed over time?
    a. Can you describe a typical visit?
6. What have you noticed to be most successful?
7. Least successful?
8. If you had a student on rotation in your office, what would be the most important thing for them to know?
9. What would you expect for new doctors to have the most trouble with?
10. Do your patients tell you about home remedies or other therapies they may try?
11. Do your patients involve their families in their care?
    a. How often?
12. Do these patients follow your advice most of the time?
13. Are their any pieces of advice they are more reluctant to follow?
    b. Why do you think that is?
    c. What would you like them to do more of?
    d. Less off?
14. Have you ever experienced something with this population that confused you?
    e. How did you work through that?
16. If you could change something that would lessen the negative outcomes for this population, what would it be?

That's all the questions I have. Thanks again for your time and responses.

Please make sure that the yellow and pink documents have been returned to your folder. Make sure that one signed copy of the informed consent document is also in your folder.

You can use the information on your copy of the informed consent document to contact me if you have further questions. Thanks again.

Appendix B: Normative Public Administration and Public Health

Normative public administration did not spring full-grown and self-conscious. The values associated with classic public administration have varied. William West (2004) gives a useful overview of concepts imputed to public administration. From 1921-1961, the value of accuracy held sway. The character of the public administrator was emphasized as a reaction to the corruption evident in political offices. Next, public administration moved toward the techno-rational and the value of efficiency. This was marked by an increase in the sophistication of budgeting models and a need for precision and objectivity. In 1974, with the nation-changing events of the Vietnam conflict, Watergate, and the Civil Rights movements, policy making became an administrative focus. Outcomes, goals, and consequences were the ruling attributes.

The 1980s pushed public administration into the overtly political. Ronald Reagan mandated a responsive public administration especially as he moved to restrict its abilities. The watchwords were accountability and agenda. Moving into 1991, new public management, GPRA, and the hunt for "waste, fraud, and abuse" refocused public administration on budget indicators, cutbacks, and resource management. Public administration was pushed toward mechanistic efficiency, but the purely techno-rational personality of the 1960s was gone. Public administration retained strong inclinations toward policy making and political interaction. All three branches of government have struggled for control of the administrative apparatus, with no clear-cut constitutional supremacy of any branch (Aberbach & Rockman, 1988). Interestingly, the U.S. Census Bureau provides a definition that brings public administration into the work world.

The Public Administration sector consists of establishments of federal, state, and local government agencies that administer, oversee, and manage public programs and have

executive, legislative, or judicial authority over other institutions within a given area. These agencies also set policy, create laws, adjudicate civil and criminal legal cases, provide for public safety and for national defense. … Establishments in this sector typically are engaged in the organization and financing of the production of public goods and services, most of which are provided for free or at prices that are not economically significant (U.S. Census Bureau, 2002).

This definition provides concrete actors, activities, and outcomes as well as room for normative concerns within public arenas. Public administration includes federal, state, and local agencies that are enabled through statute to wield executive, legislative, or judicial authority within restricted bounds. Within these positive and negative powers, public administration provides for public safety and for national defense while engaged in organizing and providing public goods and services.

Public health and public administration have been a matter of national defense, agency activity, and public law. In the U.S. context, public administration has authority through legislation, delegation, and the Constitution. It is through these same gates that public health is connected to public administration.

According to Gostin (2006) five characteristics are essential to public health law:

- Government's responsibility to advance the public's health

- Population-based perspective

- Relationship between the people and the state

- The discrete set of services and scientific methodologies

- The role of coercion

In Gostin's framework, governmental intervention in public health is one important means to ensure citizen participation in core democratic systems. "Without minimum levels of health, populations cannot fully engage in the social interactions of a community, participate in the political process, generate wealth and assure economic prosperity, and provide for common defense and security" (p. 8). The isolation of public health and related concerns from other realms within public administration is impossible. Public health policy and law rely on the same foundations supporting public administration.

Appendix C: Avandia Example

A May 25, 2007 CBS News.com article "Calm urged for Avandia Patients" reads: "There's no urgent need for type-2 diabetes patients to stop taking Avandia, even if the drug really does increase the risk of heart attack, some experts caution."[23] The article goes on to say that although the study's findings are valid, further study is needed. This didn't make much difference for many patients who immediately halted the medication. Luigi F. Meneghini, M.D., director of the diabetes treatment center at the University of Miami, said, "Patients have stopped taking their medications. They don't want to be on this medication anymore" (ibid). In the midst of patient panic, it has been reported that the FDA had been aware of this increased heart attack risk since 2005 (ibid).

Neither the FDA nor the leaders of the major diabetes centers focused on what scared patients were telling them following the study's release. They concentrated instead on getting those patients' compliance with their recommendations.

- If you are taking Avandia, do not stop taking the drug.
- If you are taking Avandia and have already had a heart attack or heart trouble, call your doctor to schedule an appointment as soon as possible.
- If you don't already have a heart problem, the risk from Avandia – if there truly turns out to be one – is not so great that you have to see a doctor right away. But, do make an appointment to discuss the issue (ibid).

The major response of the FDA and *The Lancet* has been to criticize the alarmist tone of the study. They have rushed to reassure those participating in clinical trials that their health is of

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[23]DeNoon, Daniel. "Calm Urged For Avandia Patients: Some Experts Say There's No Urgent Need to Stop Taking Diabetes Medicine; More Study Needed". May 25, 2007.
http://www.cbsnews.com/stories/2007/05/25/health/webmd/main2851556.shtml

primary concern and that the alarm is overblown. The point emphasized by the *Lancet*, a British medical journal, the FDA, and the diabetes centers is that patients' sense of panic should be managed; they openly and repeatedly chastise the *New England Journal of Medicine* for inciting panic. The reason for patients' concern is downplayed. This illustrates a systemic behavior regarding patients. Their communications are subjugated by the need for compliance and financial success – even when the patients' perception of their risk is great. The support for Avandia also is suspicious given the presence of a pharmaceutical alternative. Another drug, Actos, lowers the risk of heart disease and occupies the same class as Avandia. Meneghini identifies the issue as a liability decision. "It may be hard to justify continuing to prescribe Avandia if there is an alternative, Actos, that does not have the same risk profile," said Meneghini (ibid). This also may be evidence of challenges within the medical and pharmaceutical communities. In this example, patient and peer compliance seems to come before responding to the concerns of the patient.

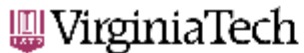**Appendix D: The Shut Down of Successful Diabetes Centers**

Four hospitals created diabetes centers that focused specifically on preventative measures and education. Seven years later, the institutional initiatives were considered to have "failed" due to financial concerns – a lack of high-cost surgeries reduced the hospital's income from insurance payments rendered the centers unable to support themselves. The failure of the institutional expeditions into diabetes prevention and management do not hinge on the ability to save money. They were able to achieve cost reductions in significant areas. The failure was in an inability to satisfy the income requirements produced by the reduction in major surgeries. Insurance organizations would pay a diminished fee (in one class $25 for a single nutrition class session with multiple participants) for an educational class and balk at the cost of that class. But, these companies would not hesitate to pay for a $30,000 amputation.

> They did not shut down because they had failed their patients. They closed because they had failed to make money. … Insurers, for example, will often refuse to pay $150 for a diabetic to see a podiatrist, who can help prevent foot ailments associated with the disease. Nearly all of them, though, cover amputations, which typically cost more than $30,000. Patients have trouble securing a reimbursement for a $75 visit to the nutritionist who counsels them on controlling their diabetes. Insurers do not balk, however, at paying $315 for a single session of dialysis, which treats one of the disease's serious complications (Urbina, 2006).

The program was closed because its success at reducing adverse outcomes for low-income, minority, and inner-city populations severely reduced the insurance funds in a way that the larger hospital structures found untenable. This is an example of patient outcomes being subverted by fiscal concerns. At this point, these fiscal concerns also echo normative and ethical concerns.

Here, because insurance payments are skewed toward negative surgical outcomes such as amputations, the increased positive patient outcomes – disease education, management, and prevention – were disregarded.

Appendix E: IRB Documentation

VirginiaTech
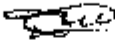
DATE: April 10, 2008

MEMORANDUM

TO: Karen M. Hult
       Lisa Tabor

FROM: David M. Moore

Approval date: 4/10/2008
Continuing Review Due Date:3/21/2009
Expiration Date: 4/9/2009

SUBJECT: **IRB Expedited Approval:** "Cultural Competency in Healthcare Policy: Pursuing Elder, African-American Diabetics as Stakeholders in Successful Treatment" , IRB # 08-200

This memo is regarding the above-mentioned protocol. The proposed research is eligible for expedited review according to the specifications authorized by 45 CFR 46.110 and 21 CFR 56.110. As Chair of the Virginia Tech Institutional Review Board, I have granted approval to the study for a period of 12 months, effective April 10, 2008.

As an investigator of human subjects, your responsibilities include the following:

1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.
2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.
3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.
4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects.
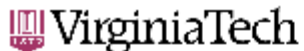
Important:
If you are conducting **federally funded non-exempt research**, please send the applicable OSP/grant proposal to the IRB office, once available. OSP funds may not be released until the IRB has compared and found consistent the proposal and related IRB applicaton.

cc: File

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Virginia Tech

Office of Research Compliance
Institutional Review Board
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540/231-4991 Fax 540/231-0959
e-mail moored@vt.edu
www.irb.vt.edu
FWA00000572(expires 1/20/2010)
IRB # is IRB00000667

DATE: August 18, 2008

MEMORANDUM

TO: Karen M. Hult
          Lisa Tabor

Approval date: 4/10/2008
Continuing Review Due Date: 3/21/2009
Expiration Date: 4/9/2009

FROM: David M. Moore

SUBJECT: **IRB Amendment 1 Approval:** "Cultural Competency in Healthcare Policy: Pursuing Elder, African-American Diabetics as Stakeholders in Successful Treatment" , IRB # 08-200

This memo is regarding the above referenced protocol which was previously granted approval by the IRB on April 10, 2008. You subsequently requested permission to amend your IRB application. Since the requested amendment is nonsubstantive in nature, I, as Chair of the Virginia Tech Institutional Review Board, have granted approval for requested protocol amendment, effective as of August 18, 2008. The anniversary date will remain the same as the original approval date.

As an investigator of human subjects, your responsibilities include the following:

1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.
2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.
3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.
4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects.

cc: File

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