Negotiating Diabetes: Professional Diabetes Care Work in the U.S.

Melissa Marie Gesbeck

Loyola University Chicago

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NEGOTIATING DIABETES: PROFESSIONAL DIABETES CARE WORK IN THE U.S.

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN SOCIOLOGY

BY
MELISSA M. GESBECK
CHICAGO, ILLINOIS
AUGUST 2015
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To all those whose lives are touched by diabetes.
May greater understanding of what happens in diabetes care lead to improvements in wellness and quality of life for persons with diabetes and those who live, love, and work with them.
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<tr>
<td>A1C</td>
<td>Hemoglobin A1C blood test</td>
</tr>
<tr>
<td>AADE</td>
<td>American Association of Diabetes Educators</td>
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<tr>
<td>ACA</td>
<td>Patient Protection and Affordable Care Act of 2010</td>
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<td>ADA</td>
<td>American Diabetes Association</td>
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<tr>
<td>ANA</td>
<td>American Nurses Association</td>
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<td>AND</td>
<td>Academy of Nutrition and Dietetics</td>
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<td>BGSM</td>
<td>Blood Glucose Self-Monitoring</td>
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<td>CGM</td>
<td>Continuous Glucose Monitoring</td>
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<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
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<tr>
<td>DCW</td>
<td>Diabetes Care Worker</td>
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<td>DEAP</td>
<td>Diabetes Education and Accreditation Program</td>
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<td>DPP</td>
<td>Diabetes Prevention Program</td>
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<td>DPP</td>
<td>Diabetes Prevention Program</td>
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<tr>
<td>DSME/T</td>
<td>Diabetes Self Management Education (Training)</td>
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<td>EBM</td>
<td>Evidence-Based Medicine</td>
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<td>EMR</td>
<td>Electronic Medical Records</td>
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<td>GT</td>
<td>Grounded Theory</td>
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<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act of 1996</td>
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<tr>
<td>IE</td>
<td>Institutional Ethnography</td>
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<tr>
<td>LNG</td>
<td>Local Networking Groups (local AADE chapters)</td>
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<td>LNG</td>
<td>Local Networking Group (AADE local chapter)</td>
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<td>MAN</td>
<td>My AADE Network</td>
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<td>MD</td>
<td>Medical Doctor</td>
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<td>MNT</td>
<td>Medical Nutrition Therapy</td>
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<td>NIH</td>
<td>National Institutes for Health</td>
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<td>NP</td>
<td>Nurse Practitioner</td>
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<tr>
<td>Pharma</td>
<td>Pharmaceutical and Medical Device Industry, also Big Pharma</td>
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<tr>
<td>PMD</td>
<td>Personal Medical Device</td>
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<tr>
<td>RCT</td>
<td>Randomized Clinical Trial</td>
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<td>RD</td>
<td>Registered Dietitian</td>
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<td>RN</td>
<td>Registered Nurse</td>
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<tr>
<td>SA</td>
<td>Situational Analysis</td>
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<tr>
<td>SDM</td>
<td>Shared Decision Making</td>
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<td>SOP</td>
<td>Standards (or Scope) of (Professional) Practice</td>
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<td>SWT</td>
<td>Social Worlds Theory</td>
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T1DM       Type 1 Diabetes Mellitus
T2DM       Type 2 Diabetes Mellitus
VA         U.S. Department of Veteran’s Affairs
ABSTRACT

The rising incidence of diabetes mellitus (types 1 and 2) transcends national borders, creating a global pandemic. The U.S. leads the world in diabetes prevalence, despite its wealth and access to sophisticated medical technologies. Within health care, there is an increasing focus on lifestyle and behavioral interventions that research suggests may be the key to reversing this trend, but thus far their effectiveness in practice is uneven at best. In order to gain a better understanding of the other factors involved in professional diabetes care work that might support or inhibit effective diabetes management, this research treats diabetes as a social problem and investigates the question, “How is diabetes care done?”

This institutional ethnography is centered on frontline diabetes care workers, primarily from the standpoint of diabetes educators. I draw on data from in-depth interviews with 30 diabetes care workers in 2012 and approximately 150 hours of participant observation of professional associations, annual meetings, local networking events, and educational events conducted between 2012 and 2014. I also analyze the ways that texts coordinate their activities and provide context for them. Viewed through a negotiated care framework, the data show that diabetes care workers negotiate amongst themselves and other stakeholders to define professional diabetes care as it is practiced within the constraints of policy.
CHAPTER 1

INTRODUCTION

Diabetes treatment and prevention are high priority areas for public health research in the U.S., averaging over a billion dollars in research funding per year from the increasingly lean National Institutes for Health (NIH) budget, alone (U.S. Department of Health & Human Services 2015). There are long-established management protocols with demonstrated clinical success in reducing the severity of type 2 diabetes and preventing it. New diabetes drugs are in constant development, as this has been identified as a growth market by the pharmaceutical industry (Pharma). We live in an era where there are both unprecedented amounts of information about how to live longer, more healthful lives and that information is readily available to the public.

Frustrated health practitioners, policymakers, insurance companies, and other stakeholders are asking, “Why has this largely preventable disease become an epidemic and what can be done about it?” As diabetes has spread well past U.S. national and cultural borders into the rest of the industrialized/industrializing world, research on this growing pandemic is becoming all the more urgent.

This study contributes to these efforts by approaching the question sociologically: “How do we understand diabetes and how do our understandings shape the ways address it in our society?” Where the dominant biomedical and public health
discourses look for ways to change behaviors and health interventions within the existing system, inquiry into the social structure around diabetes necessarily shifts our focus to issues underlying the social organization of the disease. Diabetes is more than a chronic health condition; it is a social problem. By turning our attention to these questions, we can see how they are situated in a much larger structural context and possibly identify critical points of intervention beyond the dominant medical and behavioral strategies.

**Diabetes as a Social Problem**

The vast majority of medical research relies on quantitative methods and biometrics, data for studying problems that are defined in terms of discrete, quantifiable factors such as fasting blood glucose levels and hemoglobin A1c (HgA1c) test results (common metrics for diabetes control). What these data cannot speak to, however, is how attitudes and behaviors around the management of a chronic condition define the condition and shape its outcomes, i.e., its context. This becomes particularly salient to the management of chronic conditions that are caused by and/or managed through particular lifestyle behaviors—fundamentally social phenomena (Dressler and Bindon 2000). Sociologists have made substantial contributions to diabetes knowledge by focusing the lens on the social aspects of diabetes including the illness experience (e.g., Abubakari and al. 2011; Balfe 2007; Gingras and Aphramor 2010; Greenhalgh and et al., 2011, #7755; Nolan et al., 2011, #92927), lay experiences of diabetes care (e.g., Campbell et al. 2003; Wilcox 2010), psychosocial approaches to diabetes care (e.g.,
Peyrot et al. 2006; Peyrot and Rubin 2007), and social health disparities (e.g., Lutfey and Freese 2005; Martins and Norris 2004; Mendenhall et al. 2010). Furthermore, sociological qualitative research methods have been employed in a small segment of the health literature, particularly in nursing, where there has traditionally been a larger focus on patient experience and clinician-patient interactions in care settings (Diamond 1992; Graneheim and Lundman 2004; Rankin and Campbell 2006; Kean 2007; Speziale et al. 2010).

Although it is clear from the health care literature that diabetes is an individual health problem and that individuals are expected to manage the condition for themselves in order to live long, productive lives, the increasing prevalence of the problem and the ripple effects of diabetes into social life suggest there is something larger happening; diabetes is a social problem. A social problem is a public issue that is widespread throughout a society and acknowledged to be a negative condition in need of resolution, but one that individual actions cannot resolve (Mills 1959; Best 2007). In the public health and biomedical literatures, the social problem of diabetes is framed in terms of epidemiology and societal costs or by the issues that the disease state brings in terms of its effects on individuals social lives. From a sociological point of view, because social problems are constructed by stakeholders in a particular historical and political context, the potential for their resolution lies in understanding the differential power, resources and other contextual factors involved in shaping, framing and addressing the condition as a problem, or not (Becker 2003).
Despite widespread availability of health information, structural and cultural issues create and perpetuate the context in which the social problem of diabetes—and any other number of chronic health conditions—increase the severity of long-term negative social impacts (Glasgow et al. 1999; Watkins et al. 2000; Lloyd et al. 2001). By approaching diabetes as a social problem, we are able to draw connections between the larger social organization of health care in the U.S. and the social inequalities that it produces, contributing to an effort to understand and thus facilitate change of the context that creates the problem.

This dissertation is an institutional ethnography (IE) of diabetes care, fundamentally grounded in the question (problematic), “How is contemporary U.S. diabetes care done?” Taking the standpoint of frontline diabetes care workers, I have collected a substantial array of data from fieldwork observations (at least 150 hours), 30 semi-structured in-depth interviews with people involved in frontline diabetes care work, and the texts that coordinate their activities. Through a combination of qualitative analytic strategies, I present here what I have learned about how diabetes care work is done in the U.S., how diabetes care workers and others negotiate our cultural understandings of the disease, and how these understandings might shape the ways we address diabetes as a social problem.

**Introduction to Institutional Ethnography (IE)**

According to Dorothy Smith, “institutional ethnography’s modest proposal is to work from what people are doing or what they can tell us about what they and others
do and to find out how the forms of coordinating their activities ‘produce’ institutional processes, as they actually work” (2005:60). Beginning with the researcher’s experience and knowledge, we identify a problematic, or subject of study. A problematic is not a statement of a problem to be studied, but rather a technical term in IE that identifies the everyday, ordinary subject of the research. Campbell and Gregor (2004) explain:

The problematic can be understood as a conceptual research tool. Here is how it can be employed. A researcher finds herself in a setting listening to people talk about their lives. In any account of an informant’s own experiences there’ll be important clues about their social organization that the researcher can pick up. These are the entry points to a possible inquiry. They guide the researcher towards a discovery of relevant features of social organization that must be traced and understood to make sense of the setting. The inquiry associated with an institutional ethnography is an investigation of how things actually happen as they do – whatever the people who are involved might make of them. The problematic offers accounts of actual circumstances were actors in the situation participated in its social organization, often unknowingly. (P. 49)

The entry point into understanding a problematic is identifying a standpoint with whom the researcher will learn to identify. As they learn from their informants about their activity, they also observe structural power dynamics that are passed down from institutions to ordinary actors through texts. In this way, institutional ethnographers position themselves to draw overt connections between the local activity and its location within the ruling relations of the institution and society at large.

According to Smith (1999), ruling relations are not only the expression of the organization of power, but it is through the printed and electronic texts that ruling relations are enacted:

The material text creates a join between local and particular, in the generalizing and generalized organization of the ruling relations. It in the materiality of the
text itself that connects the local setting at the moment of reading into the non-local relations that it bears. Its technology, its system of distribution, and its economy are foundational to the peculiar property of abstraction that provides for forms of social relations that have no particular place or time in which they happen. (P. 79)

Furthermore, the substance of the text embodies and propagates cultural notions of valuable knowledge, appropriate language, areas of concern, and other organizing features. Texts coordinate the activities of different organizations and individuals across space and time in ways that are taken for granted as independent from other actors and activities. As Rankin and Campbell (2006) explain,

Finding them [actors], exploring what they do and how they are organized to do it is how and institutional ethnographer discovers ruling. Being ruled means that while actual people’s own participation remains integral to all forms of organization, their actions are being regulated, and their individual will and judgment are systematically superseded. and it is through this coordination that ruling relations play out. (P. 17)

Texts, then, are artifacts that we share across time, place, and our various contexts.

Each interaction with the text, direct or indirect, is part of the coordination of activities that serve institutional power. In a case where activity is directly textually mediated—health care delivery being chief among them—the study of the texts and the ways they are activated and co-created are generalizable across a much broader population than conventional ethnographic study allows.

Through standpoint theory, institutional ethnographers insert themselves into the problematic in order to bring their social scientific knowledge and experiences to make sense of questions that arise as a result of identifying the problematic. That is, once we look at the thing we want to study and observe the ways that actors are involved with
the thing, do their activity, or talk about it, a whole host of questions for further
research emerges. We are able to take the material reality that we witness/experience
(though observation and/or the storytelling of our informants) and use it to identify
where we see the coordination (activation of ruling relations) that our informants
cannot, due to their position in those relations.

Furthermore, IE is distinguished from general ethnography in that the research is
carried out in service of the subjects, and not the institutions involved in the research
process or the site of the activity of the subjects. The point of approaching research this
way is to learn on behalf of the subjects how their activities support ruling relations
through the activation of texts in order that they could be better equipped to change
the conditions of their activity when have the desire, will, and ability to do so. To engage
in IE is to necessarily take a critical approach to understanding the problematic and, by
extension, the world in which it is situated.

For example, DeVault (1999) studied public health nutrition from the standpoint
of nutritional science professionals, particularly focusing on their “negotiated
professional identities” as they relate to “the selves that form during professional
training, the curious mix of authority and deference that characterizes professional
identities in these fields” (Devault 1999:167). In the struggle for professionalization of
feeding work that has historically been the undervalued, “non-scientific” purview of
women—an attempt to create a meaningful, professional employment niche for
women—DeVault found professional “training often produces, structurally, a kind of
isolation from family and community,” making it necessary to “find networks of colleagues and create spaces—more or less formally—where we can work on reconciling our hopes and fears with the demands of professional work” (DeVault 1999:180). DeVault observed that the “field relied heavily on a science mediated by agricultural interests and the food industry,” to the point that the professionals believed they could not do their work without industry support (DeVault 1999:173). This produces a tension for the activist professionals who got into the field to work toward health promotion and equality between doing the public health work that motivated them to enter the profession in order and the economic conditions that prioritize the use of messaging from the food industry that misleads consumers into narrow understandings of good nutritional habits (e.g., the promotion of milk consumption even among populations who experience high rates of lactose intolerance because the nutritional education materials available to them are sponsored by dairy producers).

In another example, Rankin and Campbell’s (2006) IE of Canadian health care reform from the standpoint of nurses demonstrates the power of IE to uncover the ruling relations that have effectively reformed nursing practice. By examining the ways that the new managerial technologies organize information, they “analyse the text-mediated processes through which the big problems in health care are being defined, worked on, and apparently resolved” (Rankin and Campbell 2006:18). By taking the standpoint of nurses, they present a different type of evidence than is ordinarily used in evaluating the efficacy of managerial and clinical practices in health care. By learning
from those whose activities are coordinated by health care reform, Rankin and Campbell show that nurses’ “proximity to actual patients informs their practice differently, troubling their conversion into the new work practices that are guided textually, and, apparently, objectively” (2006:175).

Integrating the lesser valued experiential evidence of frontline health care workers into the larger discussion on health care policy and practice sheds light on the features and strategies that may work in theory, but not in actual practice—a standpoint far removed from those who have the power to define and enforce the ruling relations of health care. Different institutional ethnographies take different forms and approaches to data collection and analysis. What follows is an account of this IE.

**The Diabetes Care Work Study**

My research interest in diabetes care developed first from my experiences as the spouse, daughter, granddaughter, niece, and friend of several people living and dying with Type 2 Diabetes. Then, through my experience as a non-patient participant in a diabetes self management education class in 2008, I became aware of the specific field of diabetes education. Soon after, I conducted a small pilot study (unpublished coursework) of persons with diabetes and their closest support person to learn how they have coped with and adapted to the diagnoses. These interviews revealed to me the importance of diabetes education in incorporating new diabetes-related health behaviors into social life. I continued my PhD coursework and developed specialized knowledge in medical sociology, health care policy, and the professions. Meanwhile, I
also formed professional relationships with nursing faculty and a personal friendship with a dietitian, who were all generous in discussing the challenges of their work with me. When it was time to choose a dissertation topic, I realized I had enough background knowledge of the organization of health care and policy and significant personal motivation to study diabetes care, effectively building a long-term research program around it.

Beginning with the problematic of “How is diabetes care done?,” I adopted the standpoint of frontline diabetes care workers. I entered the field with the following assumptions:

1. The problematic (how diabetes care is done) can be understood as part of the ruling relations of the institution of U.S. health care;

2. The standpoint of diabetes care workers will show us how the ruling relations affect their work, including patient outcomes;

3. Increasing our understandings of ruling relations in diabetes care will help identify ways to change the context of the problematic; and

4. Changing diabetes care is a desirable outcome, given the personal and social costs of the disease and its increasing prevalence.

IE is exploratory in nature and typically does not impose a particular research question. For the sake of the format of the doctoral dissertation, I formulated basic research questions that apply my existing conceptual framework to the problematic:

How do diabetes workers and others negotiate our cultural understandings of diabetes
and how might they shape the ways we address diabetes as a social problem in our society? In the language of IE, these questions are the goals for understanding that I intended to come from the research.

I collected a wide variety of data and the more I learned about diabetes care and the organization of health care, the more future research questions I uncovered. Due to the time, budgetary, and institutional constraints, my focus throughout this dissertation is centered on the institution of U.S. health care and the ways that the activities of professional diabetes care delivery are mediated through texts. As a result, I include discussions of what professional diabetes care work is, its place within the institution of U.S. health care, and the ways that the transfers of data that occur in diabetes care among the various stakeholders both facilitate and complicate effective diabetes management.

Organisation of the Dissertation

In Chapter 2, Background and Theoretical Considerations, I discuss the theories and literatures that have been most influential in shaping my orientation to health care research and this project. These include Fundamental Cause Theory, Constrained Choice Theory, Shared Decision Making (SDM), and Social Worlds Theory (SWT). I introduce a Negotiated Care framework that gives greater power-structural nuance to our

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1 The phrasing differs slightly between my proposed research: In the original I ask “How do they shape the ways we address diabetes as a social problem in our society?” I changed the “do” to “might” because it implied an assumption that I did not intend to make—that we actually address diabetes as a social problem, as opposed to as a biomedical problem. As discussed in Chapter 2, I believe that we should treat diabetes as a social problem, not that we already do. This semantic change has had no effect that I am aware of on the way I conducted this research.
understandings of interactions between the various actors in health care, their organizations, and the larger health care system.

In Chapter 3, *Methods*, I provide an account of the production of this text. Beginning with my own, personal experience with diabetes, I describe the process of the development of my interest in diabetes care and the project. I then present the theoretical underpinnings and philosophy of IE that are central to the ways I identified the problematic, goals, standpoint, data collection methods, and analytic strategies. I then discuss the details and limitations of the technical aspects of the project that comprise its methods: data sources, participant sampling and recruitment, semi-structured in-depth interviewing, textual analysis, ethnographic fieldwork, textual analysis, grounded theory analysis, and situational analysis.

In Chapter 4, *Doing the Everyday Work of Professional Diabetes Care*, I introduce diabetes care workers and the ways they define/do their work at the intersections of the social worlds of diabetes care. Through negotiations and exchanges of information, DCWs work from their disciplinary knowledge and situational base in the hierarchy of health care, but these knowledges and resources are insufficient to supporting the actual work they do with patients. Through the key texts that govern and coordinate their activities in diabetes care (generally referred to as Scope of Practice (SOP) documents), I expose a major administrative-professional blind spot: invisible casework.

In Chapter 5, *Cornering the Market: The Professionalization of Diabetes Education*, I discuss the role of the American Association of Diabetes Educators (AADE)
in establishing the profession of Diabetes Educators and their ongoing efforts to expand the reach of the profession to increase its share of the health care market and to gain autonomy through their professional project. This expansion of Chapter 4 situates the DCWs in the U.S. health care system as a whole, including their relationship with the pharmaceutical industry, and shows the ways they organize for recognition and status through the apparatuses of SOPs, licensure, and accreditation texts.

In Chapter 6, *Technology, Data, and Power in Diabetes Care*, I problematize the use of patient data as a primary currency in health care by presenting the specific case of diabetes-related data. Patient-performed data collection and reporting are central to professional diabetes care, which is burdensome to patients. While personal medical devices such as downloadable blood glucose meters, continuous glucose monitoring systems (CGM), and insulin pump technologies have reduced some of the data work performed by patients (monitoring blood glucose, calculating insulin dosage, reporting the data), the pain and expense of the work remains. The main text that these technologies help to produce, the log book, is a site where patients have control over the validity and quality of the data on which clinicians depend for treating their diabetes, destabilizing the power dynamics between the provider and patient and presenting an opportunity to negotiate their care by the degree to which they comply with personal responsibility regimes in health care.

Finally, in Chapter 7, *Diabetes Care in the Era of the Affordable Care Act*, I introduce the ACA and discuss its implications for professional diabetes care work. This
landmark legislation presents an opportunity to change the work and compensation environments for DCWs and a changing political landscape for the work of the AADE. It also demands increased use of data in making health care decisions for all actors involved in the system, increasing the value of patient data. I conclude this analysis with policy recommendations for improving diabetes care quality and DCW job satisfaction.

By treating diabetes as a social problem and viewing the work of diabetes care through a negotiated care lens, these chapters expand our understanding of the context of diabetes care in the U.S. More importantly, the data also show us where professional diabetes care begins, a powerful vantage for locating sites for change.
CHAPTER 2

BACKGROUND AND THEORETICAL CONSIDERATIONS

For this dissertation, my primary concern focuses upon what we can learn from the activity of diabetes care. Methodologically, an institutional ethnography (see Chapter 3) requires limited use of preliminary literature review in order to allow the researcher to learn most directly from observation, conversations and locally generated texts. Instead, a conceptual framework is used in order to frame the area of inquiry and to situate the researcher in her field (Campbell and Gregor 2004:51). What follows in this chapter serves to orient the reader to a specific case (diabetes) to better understand the larger structure in which it is situated (contemporary U.S. health care). Since the topic of diabetes crosses disciplinary borders, I begin with a brief overview of the health care literature on diabetes with particular emphasis on the main treatment/management modalities and epidemiological data (the dominant ways it is discussed in health care). By framing the topic within this discourse, I highlight the larger public health concern around the rise of diabetes and give an overview of the clinical concepts presented by informants throughout the dissertation. Next, I discuss the sociological literature on the U.S. health care system and health inequalities that influence the assumptions that are embedded in this study. Finally, I propose a negotiated care framework for studying the
activity of diabetes care as it happens in the overlapping social worlds of health care stakeholders in order to best illustrate how we understand diabetes in our society.

**Overview of Diabetes and Diabetes Care in the U.S. from Health Sciences and Public Health Perspectives**

It is estimated that over 25 million (about eight percent) U.S. children and adults have been diagnosed with type 1 or type 2 diabetes mellitus (collectively referred to as diabetes) and that an additional 79 million people are “pre-diabetic”\(^1\) (Centers for Disease Control and Prevention 2011b). Diagnosed cases of diabetes have more than tripled between 1980 and 2010, from 5.6 million to 20.9 million, and half of that growth has happened in just the past ten years (Centers for Disease Control and Prevention 2011b). Type 2 diabetes accounts for 90 to 95 percent of cases and is often avoidable or manageable through lifestyle changes that include a prescribed low-carbohydrate diet (medical nutrition therapy) and regular physical activity (Centers for Disease Control and Prevention 2011b). Diabetes education, often cited as key to the management of diabetes, has focused on the aspects of care that can only be performed within the household in conjunction with regular physician visits, blood glucose monitoring, and medications.

There is an immense body of knowledge about diabetes in the health fields. Most of the research on diabetes can be found in public health, health education, \(^1\) It could be argued that “pre-diabetic” is a contested illness category. This is an important aspect of understanding diabetes, but it is outside of the scope of this dissertation since these data do not inform on first-hand experiences of the ascription of the label. The data do, however, demonstrate the relevance of the category to the larger discourse on diabetes.
nursing, and medical journals and focuses on the efficacy of medical interventions (e.g., Jendle and al. 2009; Nathan and al. 2009; Taskinen et al. 2011), best clinical practices (e.g., Handelsman et al. 2011; Mazze and al. 2012; Nolan 2011), disparities in diagnoses and outcomes (e.g., Bell 2012; Berggren et al. 2012; Ell and al. 2010; Mount et al. 2012), and diabetes education (e.g., Klein and Lippa 2012; Martin 2012). Taken from the health care perspective, in lay terms, the general consensus is that diabetes is a disease where the body is unable to use glucose (the nutrient necessary for energy in our cells) effectively, causing glucose to accumulate in the blood. This accumulation causes damage in the vascular system which affects all organs. Left untreated, it causes a variety of severe complications such as blindness, neurological problems, kidney failure, and infections that do not heal and lead to amputations (Engelgau et al. 2004).

**Diabetes Types**

There are three main categories of diabetes that differ in how they occur, the severity of the disease and the types of medications that are effective in lessening or controlling the symptoms.

Type 1 (T1DM) is believed to be an autoimmune condition where the pancreas does not produce insulin. Historically, T1DM has been referred to as juvenile diabetes because most cases are diagnosed as children.² It has also been referred to as insulin-

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² Researchers are presently engaged in identifying different variants of diabetes and metabolic disorders which complicate this division. For instance, recent research has drawn attention to a variant on T1DM, latent autoimmune diabetes in adults (LADA) which is sometimes described as “type 1.5” because while it involves the cessation of insulin production in the pancreas, it develops much more gradually, usually within six years of diagnosis. See Palmer and Hirsch 2003; Palmer et al. 2005.
dependent diabetes because it used to be the case that insulin was usually only used for this type. While T1DM is relatively rare (about 5% of cases in the U.S.), it has increased significantly. According to Hurley, T1DM is now “twice as common among children as it was in the 1980s, about five times more common than in the years following WWII, and perhaps ten times more common than 100 years ago, if early statistics are to be believed” Hurley (2010:xx). Patients with T1DM require insulin injections for survival and tight dietary control of carbohydrate (glucose) intake and the timing of meals to avoid life threatening complications from the diabetes (e.g., ketoacidosis) or the insulin (e.g., hypoglycemia). Frequent blood glucose testing is key to assisting the patient determine the ratios of carbohydrates to insulin for a given dose relative to a meal. Since this intensive management is difficult for patients in the long-term, the pharmaceutical and medical device industries have a healthy market for long-acting insulins, pumps, continuous blood glucose monitoring systems. There is no artificial pancreas on the market as yet, but there is a definite international race for its development (Hurley 2010).

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3 See Hurley’s 2011 book, Diabetes Rising: How a Rare Disease Became a Modern Pandemic, and What to Do About It (New York: Kaplan) for a thoroughly researched narrative of the history of the increasing prevalence of the diabetes and the evolution of its treatments.

4 Typically a patient pricks their fingertip to collect a drop of blood which is then analyzed in a blood glucose monitoring device to give a reading of their blood glucose level at that moment. The number of times per day that this is done depends on a number of factors that will be discussed in greater detail in Chapter 6. In order to gain a three-month overview of general glycemic control, the hemoglobin A1C (HbA1c) test is used.

5 At the time of this writing, a few personal medical device manufacturers and pharmaceutical companies have launched devices that attempt to adjust insulin doses through a pump with continuous blood
Type 2 (T2DM) usually occurs in adults and is believed to be the result of a combination of genetic predisposition for the disease and lifestyle factors. T2DM is commonly associated with obesity in adults and children, leading to a conflation of the conditions. There are three main mechanisms for excess blood glucose: the liver releases too much glucose into the blood stream, the pancreas does not produce enough insulin for the amount of glucose in the blood, or the pancreas produces enough insulin, but there is some other factor preventing the cells from using the glucose for energy, e.g., excess body fat inhibiting the effectiveness of insulin (insulin resistance).

The first line of treatment for a newly diagnosed patient is oral medications that reduce glucose output from the liver (e.g., metformin) and increase insulin production from the pancreas (e.g., glyburide) in combination with dietary changes to reduce carbohydrate intake in order to limit the amount of glucose in the blood that comes from food. New types of injectable medications have been developed in recent years (e.g., exenatide and liraglutide), but they are less widely used than oral medications due to cost and glucose monitoring. As impressive as these developments are, they still require patient intervention to confirm the device-suggested dosage and timing of the dose.

The term “diabesity” captures this conflation. While originally posited as diagnostic category for T2DM that results from obesity in laboratory studies of animals (see Leiter and Chapman 1994; Shafrir 1992), the catchy term has taken on other meanings in popular media and has entered the vernacular of practitioners as observed at professional conferences. The problem with the term is that it ascribes most, if not all, of the cause of type 2 diabetes to the patient’s obesity, a stigmatized condition within our society. Based on what I have learned from scientific papers presented at conferences, I believe a more accurate description of the relationship between diabetes and obesity is that they have a common causal mechanism and, as such, treating one often leads to the resolution of the other. That is, if both diabetes and obesity are caused by consuming more carbohydrates than the body can process, for example, then limiting carbohydrate intake will affect both diabetes and obesity. Blaming obesity for diabetes obscures that it is possible for diabetes to be a cause of obesity and that weight loss alone does not actually cure diabetes. Indeed, if the issue were as simple as balancing energy consumed with the energy expended, then reducing carbohydrates would singularly produce a cure for both conditions.
patient reluctance to do injections. As the disease progresses, the pancreas slowly loses its ability to produce its own insulin and insulin injections are used make up the shortfall. If T2DM advances to the failure of the pancreas to produce insulin, it requires the same management protocols as T1DM. There is mounting evidence that early, aggressive management of T2DM can effectively halt this progression (Gerstein et al. 2008; Holman et al. 2008; Duckworth et al. 2009; Rodbard et al. 2009).

What most distinguishes T2DM from T1DM is that T2DM is often preventable (Venkat Narayan et al. 2000; Crandall et al. 2008; Danaei et al. 2010; Robertson et al. 2010; Centers for Disease Control and Prevention 2011a). For decades, the category of “pre-diabetic” has been used to describe patients who have characteristics that are highly correlated with T2DM, but who fall below the clinical guidelines for diagnoses (Meigs 2010). Formerly referred to as “borderline diabetics,” the new diagnosis of prediabetes assigns them to a definite diagnostic category for which there are treatment protocols (Centers for Disease Control and Prevention 2011a; Colwell 2011). The 27-site Diabetes Prevention Program Study has been under way for more than a decade and has shown that at little as 5-7% weight loss yields a reduced risk of developing T2DM in participants already diagnosed with pre-diabetes. A curriculum based on the program that focuses on lifestyle change and weight loss is commonly used in community education settings and is available free of charge as a government

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7 The treatment of the risk of developing diseases as if the risk were a disease in its own right has been an active topic of discussion amongst sociologists of health and the body, particularly with respect to the idea of the risk society.
sponsored public health initiative, distributed through the Centers for Disease Control (National Center for Chronic Disease Prevention and Health Promotion 2012). Time will tell if it will be widely adopted and, if so, whether its behavioral/lifestyle approach or the prophylactic use of Metformin will make a significant difference in the prevalence of T2DM (The National Diabetes Information Clearinghouse 2008).

The majority of the literature focuses on T1DM and T2DM. However it is also important to recognize that occasionally diabetes occurs as a complication from other diseases or their treatment (Dispenzieri and Loprinzi 1997; Bendz and Aurell 1999). More commonly, gestational diabetes occurs in 2-10% of pregnancies in the U.S. While the causal mechanism is unknown, 5-10% are diagnosed with T2DM immediately after the pregnancy and the remaining have a 35-60% chance of developing T2DM within the next 10-20 years (The National Diabetes Information Clearinghouse 2011). In this condition, the disease is managed by daily blood glucose monitoring, insulin injections, and dietary control (Reece 2010; Cundy 2012). While it is generally a temporary condition, gestational diabetes affects not just the mother, but also poses risks to the developing fetus, including birthing injuries due to high birth weights, respiratory distress syndrome, and hypoglycemia after birth, and also increased risks of glucose intolerance, obesity and/or metabolic syndrome in childhood (Reece 2010).

Diabetes Management

The goal for chronic condition management is to allow patients to live as healthfully as they can for as long as they can—to avoid complications and to improve
their quality of life. This differs from the conventional disease model for which there is an acute illness and a medical cure. Chronic conditions are not curable and are often progressive, but they can be managed.\(^8\) For acute illnesses, the goal is to cure the patient, and the success or failure of a medical treatment is determined through laboratory tests—\emph{objective} biometrics. For chronic conditions, however, the success or failure of a treatment depends on a larger constellation of factors that include not only biometrics, but things that are much more difficult to operationalize and quantify, such as psychosocial well-being and subjective quality of life. Self-management requires that the patient be the primary participant in their own day-to-day care, and the success or failure of those efforts is constrained by the resources available to the patient and the priority of the self-care regimen in the patient’s life. There are factors that EBM cannot account for, though I argue that they are essential to effective chronic disease management.

Diabetes is a chronic, progressive condition for which there is no known cure.\(^9\) According to Mol, “in dealing with a disease that is chronic, the care process is chronic, too. It only ends the day you die” (Mol [2006] 2008:22). The treatment goal is to slow or reverse the progression whenever possible (preserving pancreatic beta cells and

\(^8\) Indeed, if there are treatments and self-management regimens available for a patient, they are charged with the personal responsibility to seek these out and to administer them.

\(^9\) This is accepted as biomedical truth in scientific circles around diabetes research, except in cases where the diabetic condition is iatrogenic (e.g., as sometimes happens during chemotherapy for some cancers), in which case, the resolution of the causal condition often resolves the diabetes. There is a counter-narrative around the assertion that eating in a particular way can cure type 2 diabetes, however those “cures” only work as long as the patient adheres to them—diabetes self-management.
cardiovascular health), and to enable the person living with the disease to avoid or minimize disability that could result from the disease. Regardless of the type of diabetes, its biomedical management requires a combination of medical and behavioral approaches with the desired outcome of glycemic control. Glycemic control, or the regulation of blood glucose levels within certain established parameters, is measured through standardized blood tests. Evidence based medicine relies on the results of these blood tests and other biometrics in setting the diagnostic criteria for the disease and the definition of successful treatment and management.

The parameters are set by a panel of medical experts within the American Diabetes Association\textsuperscript{10} who review research on relationship between glycemic control and other desired outcomes (i.e., the lessening or avoidance of comorbidities such as diabetic neuropathy). Occasionally, these parameters are revised based on new evidence. Changes to standards established by the ADA have long reaching effects since the organization has a strong influence on public health, health policy, insurance administration, pharmaceuticals, health education programs, and the training of health care professionals. When it comes to approaches used to achieve glycemic control in diabetes care, diabetes self-management protocols dominate clinical recommendations and practice.

\textsuperscript{10}The American Diabetes Association is so integral a part of understanding diabetes in the U.S. that it will be thoroughly discussed throughout the rest of the dissertation and will only be introduced here.
Initially used to describe the coordination of care activities and administration of
treatment protocols that happen in the day-to-day lives of asthmatic children, the idea
of self-management has expanded to encompass chronic disease care more generally
(Lorig and Holman 2003). The idea of disease self-management recognizes that
perpetual work of living with chronic illness and simultaneously places responsibility for
the activity (or inactivity) on the individual living with the disease. According to Lorig and
Holman (2003):

One cannot not manage. If one decides not to engage in a healthful behavior or
not to be active in managing a disease, this decision reflects a management
style. Unless one is totally ignorant of healthful behaviors it is impossible not to
manage one’s health. The only question is how one manages. (P. 1)

In this general view, even failure or refusal to actively engage in care activities around a
disease state is also management activity.

In diabetes care, *self-management* has a central role and a specific meaning.

Standards of Medical Care in Diabetes—2013 is the main document that establishes
best practices in diabetes care in the U.S. According to these standards, diabetes self-
management education (DSME) and diabetes self-management support (DSMS) are
essential to overall diabetes management and should be incorporated into diabetes
treatment practice (American Diabetes Association 2013). The AADE’s National
Standards for Diabetes Self-Management Education and Support defines DSME and
DSMS:

DSME: The ongoing process of facilitating the knowledge, skill, and ability
necessary for prediabetes and diabetes self-care. This process incorporates the
needs, goals, and life experiences of the person with diabetes or prediabetes and
is guided by evidence-based standards. The overall objectives of DSME are to support informed decision-making, self-care behaviors, problem solving, and active collaboration with the health care team and to improve clinical outcomes, health status, and quality of life.

DSMS: Activities that assist the person with prediabetes or diabetes in implementing and sustaining the behaviors needed to manage his or her condition on an ongoing basis beyond or outside the formal self-management training. The type of support provided can be behavioral, educational, psychosocial, or clinical. (Haas et al. 2013:S101)

Formal DSME has become such an integral part of diabetes care that it is generally covered by Medicare, Medicaid, and private insurance to varying degrees.

Adherence to the ADA protocol for DSME is generally a requirement for reimbursement and, as such, has created a market for health professionals trained specifically in administering these guidelines and delivering DSME to patients: diabetes educators.

Since DSME is central to our standards of diabetes care in the U.S., it is central this study and will be explored in depth in Chapter 4.

**Diabetes in the Context of Sociological Perspectives on U.S. Health Care**

The *Political Economy of Health Care*

The political economy perspective explores the ways politics and economics shape the health care system and their collective effects on society. Since the early 1980s, the U.S. health care system has been increasingly privatized and managed care organizations and other for-profit health services groups have gained the majority of the market share for the provisioning of health care services (Waitzkin 2000; Quadagno 2006; Mendel and Scott 2010). Over the past fifty years, we have seen health care increasingly privatized and marketized through the uncontrolled growth of the
insurance, pharmaceutical, and managed health care industries. With these changes, physicians have in effect become employees, and patients have become consumers in the capitalist health care marketplace.

Managed care came about in the early 1980s with the rationale that by centralizing purchasing for multiple sites and institutions into groups and overseeing the allocation of health care services through these managing corporations, they could contain costs and promote efficiency, passing the savings along to the patient-consumer. What actually happened, however, is the cost of health care has outpaced the cost of living index and general growth of the economy (measured by gross domestic product) for the past twenty years (Mendel and Scott 2010). Meanwhile, insurers and medical groups have experienced huge growth, in no small part because health care costs have been increasingly redistributed to the people who use health care services through rising premiums and co-pays. According to Waitzkin, “[s]ince 1989, all newly initiated managed-care organizations have operated as for-profit corporations, often under the control of private insurance companies” (2000:xii). The corporatization of the medical profession has necessarily compromised the notion that the goal of health care is to promote the health and well-being of the population—the majority of which is covered by managed care. Physicians and other health care professionals work and compete in a market economy where their work is increasingly specialized and their professional autonomy is restrained.
Before managed care, the patient-physician relationship was predicated upon professional authority (Freidson 1970b; Ritzer and Walczak 1988). This was problematic at times in that the self regulating field of medical practice was a protected market with little external oversight—a condition susceptible to abuses of the system (Light 2010).

According to Light (2010), the current model of health care delivery presents *countervailing powers* that challenge the authority of the individual physician in the name of *Evidence Based Medicine* (EBM) and the establishment of quality standards. In a managed care context, one of the most significant ways that the health organization reduces the autonomy of the physician is by limiting the diagnostic methods or course of treatment that will be used and the amount of time spent in the clinical encounter by what is covered by insurance (Bird et al. 2000). As Light states, however, there’s irony that the standardization of care delivery practices that was supposed to increase patient trust in health care has diminished it as “quality varies considerably, not only by insurance status and other market variables, but even after controlling for them” (Light 2010:282).

External oversight is not necessarily a bad thing, nor is specialization or conscientious efforts to reduce costs to patients and their families. However, the main concern is that decisions that affect people’s lives are being made with profitability in mind and, sometimes, without adequate expertise for making decisions about health care. As Light puts it, “[w]e cannot expect professionals to act too differently from the market structure and institutional framework in which they practice. Most will not be
very altruistic or civic in a system focused on generating revenues and profits” (2010:274).

The shift toward managed care ushered in a new era of outcomes-oriented medical practice: evidence based medicine (EBM). With physicians newly having to justify their diagnostic and treatment practices to third party payers, it became increasingly important to be able to demonstrate that health care services and products were effective uses of resources (Bird et al. 2000). For decades, physicians relied on the randomized clinical trial (RCT) as the gold standard for biomedical research, so it is not terribly surprising that they would try to apply this model to their assessments and standards for quality in health care despite the mismatch between objective measures of subjective phenomena. With the increased bureaucratization of health care, physicians have embraced the very method that, according to Cockerham, has contributed to their deprofessionalization (2001:11). Timmermans calls the move toward standardization a “two-edged sword: what begins as a tool for greater rationality and autonomy may ultimately undermine the foundations of the market shelter” (2010:312).

EBM has become standard practice in health care as a system-wide effort to demonstrate the value (and justify cost) of medical interventions (Timmermans and Berg 2003; Casper and Morrison 2010). However, due to the nature of health care as distinct from ordinary business and managerial practices and its risks, responsibilities, and system of professionalization, EBM and the related managerial models of
continuous quality improvement (CQI) and total quality management (TQM) are somewhat misapplied. Overreliance on these models, which have failed to diminish under- and over-use of medical services, puts the goals of the organization, the professions working within the organization and the patient-clients at odds (Mendel and Scott 2010; Timmermans 2010).

The development of health care as a profit-making enterprise instead of a public good or a professional services relationship between the patient and physician has necessarily led to the application of business models to the definitions of improvement and success within the system. Some of these themes are readily apparent in the earlier discussion of the public health and health care perspective on diabetes and diabetes care (e.g., the use of glycemic control measures to measure successful diabetes management).

Health Care Inequalities and Health Disparities

There are many sociological explanations for disparities in health and access to health care services, including social capital (Marmot 2004; Carpio 2006; Kawachi 2010), life course (Power et al. 1997; Beller 2009), behavioral models (Andersen 1995), and general susceptibility (Syme and Berkman 1976), among others. One way or another, these theories work together to explain the rates of illness/health or tendencies toward illness for disparate populations within our society in terms of social networks, material and cultural resources, and the cumulative effects of relative advantage/disadvantage throughout a person’s life—all of which are shaped by larger
social processes, usually having to do with inequalities of power, status, and material wealth within our society. The central distinguishing feature of sociological explanations of health disparities—as opposed to biomedical, public health, or epidemiological explanations—is that they look for explanations beyond the pathophysiology of the body to the context in which the body lives. Two theories that present this feature particularly well are *fundamental cause theory* and *constrained choice theory*. 

*Fundamental Cause Theory*

In public health, interventions are often aimed at changing “modifiable” risk factors (e.g., quitting smoking, not using lead based paints, eating a low fat diet, as opposed to biological predispositions such as race, sex, and genetics) with the rationale that if we can identify all of them we can create interventions that head these off, thereby eliminating health inequalities. There has been some degree of success with this approach; since it has been employed, we have seen huge declines in deaths due to infectious diseases in the 19th century and chronic diseases in the 20th century. Unfortunately, it is limited in “that it is difficult to decouple the identification of risk and protective factors and the deployment of knowledge and technology based on those factors from social conditions” (Link and Phelan 2010:4). Furthermore, while biotechnological innovation and communications infrastructure have boomed, putting much more of both into our society, they are not equally available to everyone. Health disparities that existed before new innovations in treatment and information are not lessened because the innovations are only available to those with the resources needed
to access and use them. According to Link and Phelan, “major health disparities by race, ethnicity, and socioeconomic status are social products, brutal facts that we create” (2010:4). Fundamental cause theory explains how it is that scientifically-developed interventions and strategies do not actually affect society the way they are intended. According to Lutfey and Freese, if the problematic phenomenon or condition is itself a “fundamental cause of an outcome, then the association cannot be successfully reduced to a set of more proximate, intervening causes because the association persists even while the relative influence of various proximate mechanisms changes” (2005:1328).

According to the model laid out by Link and Phelan, fundamental causes have four defining features: they are related to multiple disease outcomes; they operate through multiple risk factor mechanisms; pre-existing inequalities are reproduced with the introduction of new intervening mechanisms; and “they involve access to resources that can be used to avoid risks or to minimize the consequences of disease once it has occurred” (Link and Phelan 2010:7). Because social conditions predispose some people more greatly than others to the risk of developing a chronic disease, the fundamental causes of those conditions need to be addressed in order to reduce the chronic disease in our society at large. What makes this perspective especially useful in health care research is it provides a way to bridge research between the biomedical and sociological paradigms, by lending itself easily to the incorporation of biomarkers and disease outcomes in examining the effects of biotechnology and public health education campaigns. It raises questions about underlying social processes of inequalities in
society-at-large and can testify to the role of these inequalities in concordant health disparities, shifting the focus from the individual to the social.

*Constrained Choice Theory*

In a different vein, *constrained choice theory* asks the dual questions of “What keeps men and women from making health an everyday priority?” and “What factors contribute to the differences in men’s and women’s choices?” (Bird and Rieker 2008:54-55). Bird and Rieker (2008) start their analysis with these questions of personal choice and responsibility and effectively demonstrate through their analysis that there are structural forces that constrain the *range* of choices people have in making decisions about their health. Everyday decisions that come to bear on health choices such as which neighborhoods and housing they live in, their jobs, the use of household income, and how they take care of the support needs of their families (not limited to childcare) are constrained by larger social forces at the levels of family, community, and government.

In constrained choice, the most powerful force by far is the institution of gender. Expectations for the economic functioning of the family are predicated on the normative caregiver/breadwinner duality—regardless of social and economic changes in individual choices of women for workforce participation, political changes that have opened opportunities for women to work, and those changes that have *necessitated* the paid work of women for family survival for the middle class in addition to working class families. All of this change has happened without social and ideological changes that
should more equally divide reproductive labor in families, increase community support for families on the local level, or enact social policies that make it easier for adults to hold up their end of the American social contract—that we are productive citizens in the capitalist marketplace. Bird and Rieker (2008) take the rhetoric of personal responsibility head-on in their main suggestion for how to achieve better health for Americans:

> We contend that the greatest health benefit will be achieved by simultaneously increasing efforts to reduce constrained choice and to develop a health consciousness from the national level down to the individual. Although individual men and women still have a large role to play in maintaining their health, society can do far more to promote health by enacting social policies and regulations that limit poor choices and increase opportunities for people to pursue health, rather than relying solely on the platform of individual responsibility. (P. 244)

Link, Phelan, Bird, and Rieker (and many others) all take the biomedical measures of disease and outcomes that the health care system depends upon and demonstrate a way to productively problematize their measures and findings for further, deeper inquiry. By applying the same processes to the presumed factors of improving health care, the sociological perspective can help shape more effective policies and best practices. Regarding diabetes as a social problem enables us to engage with fundamental causes of health disparities and the ways that the health care system, and the structure of our society more generally, constrain our health care practices, both formal and informal.

This study of diabetes care presents an excellent opportunity to further examine the social conditions that inhibit the effectiveness of the prevention of chronic diseases in our society, to perhaps uncover the way that the U.S. health care system works for
and against its various stakeholders. With this historical background and sociological orientation in mind, I propose a negotiated care theoretical framework as a way to understand the complex relationships between policy, stakeholders, and everyday practice. Drawing on shared decision making (SDM) from health care delivery (Edwards and Elwyn 2009; Yin et al. 2012) and social worlds theory (SWT) from sociology (Strauss 1982), I look to the ways that care is negotiated at the boundaries, recognizing the ways that stakeholders variously exercise power over the activity.

**Toward a Negotiated Care Framework**

As health care institutions compete for market share, an emerging trend is the marketing of collaborative care, or a teamwork approach to providing health care that appeals to empowered, educated, patient-consumers to work with their health providers (Aita et al. 2005; Irwin and Richardson 2006; Edwards and Elwyn 2009). According to organizational theorists, collaboration is a process by which consensus is reached about the goals of the stakeholders and the ways that those goals will be achieved (Eden and Huxham 2001; De Dreu and Van Kleef 2004). In thinking about my own experience as a health care patient-consumer and the nature of medical and professional authority in our culture, historically and within the current political and economic context of the U.S. health care system, it occurred to me that patient-consumers negotiate care with their professional health care providers over what should be taken seriously as health problems and what should be done about them.

Furthermore, the balance of power (i.e., the ability to influence the actions of the
parties in the interaction) in medical-lay interactions depends on many factors, not the least of which are dependent on access to information and economic resources. Power imbalances do not necessarily preclude collaboration, but negotiations are a necessary first step. Before we can achieve collaborative care, we need to recognize the negotiations inherent in that care: a negotiated care framework.

Convinced that other health and social researchers would also be thinking along these lines, I began my inquiry into how negotiations of care are framed in the sociology and health literatures. Negotiations entail at least three dimensions: exchanges of information; claims of responsibility/locus of control; and cooperation/conflict between stakeholders. Surprisingly, the literature on “negotiated care” in health care is sparse and situated in the shared decision making literature where it refers to different methods/strategies for achieving a decision (Buetow 1998) or recognizing the importance of the family in children’s nursing practice (Smith 1995).

*Shared Decision Making*

In our market-driven health care system, extra-medical factors (e.g., policymakers, insurance companies, advertising, consumers) influence the discourse, shifting the burden of health care provisioning away from formal, professional health care providers to individuals and lay caregivers, such as family members. With this shift in responsibility, largely spurred by a combination of increased access to health information for lay persons, the rise in direct to consumer advertising for pharmaceuticals and health care services, and the increasing economic constraints
around health care (i.e., the efforts of managed care organizations to reduce spending
wherever possible by shifting care to unpaid caregivers (Ward-Griffin 2012), there has
also been a shift in power in the clinical encounter that requires a more collaborative
relationship between clinicians and patient-clients (Henry 2006; Newman and Vidler
2006). This collaboration is most often referred to as shared decision making (SDM).

While the idea has floated around the health literature for decades, Charles and
colleagues (1997) were the first to synthesize the literature into a more-or-less
comprehensive working definition of SDM. According to Charles et al. (1997), SDM has
four major characteristics:

(1) that at least two participants—physician and patient be involved;
(2) that both parties share information;
(3) that both parties take steps to build a consensus about the preferred
treatment;
(4) that an agreement is made about the treatment to implement. (P. 681)

The most important feature of SDM is that it requires the participation of
multiple parties. This recognizes the fact that often there are more parties than one
physician and one patient involved (e.g., multiple physicians, insurance companies,
family members, other caregivers). More importantly, though, it recognizes that at least
two parties must be involved for a decision to be shared. That is, if a patient refuses to
participate in the sharing of information, goals of treatment, or to agree to treatment
with the clinician—or vice versa—then SDM has not occurred. According to Charles et
al., for true SDM to occur, “there needs to be complementary role expectations and
behaviour between physician and patient around this issue. It is in this sense that we
emphasize that ‘it takes at least two to tango’” (1997:686). In discussing the limitations of their research and other SDM research to date, the authors problematize the assumption that SDM is necessarily something that should be implemented (i.e., SDM might not be the most beneficial goal for all patient populations or it might not be desirable to patients). However, now that SDM has been better defined, this is a good starting point to measure whether it is happening and, when it does happen, whether it has the desired positive effect that is presupposed by SDM proponents.

More recent research in SDM has sought to clarify the effects of SDM on the patient experience as a part of a larger agenda to improve patient experiences. Longo and colleagues describe shared decision making (SDM) as a “middle ground where information is exchanged and the nature of the decisional agency negotiated, allowing both patient and professional to decide their degrees of preferred influence on the process” (2006:36). Using discrete choice experiments, they engaged patients (N=584 across 20 clinical sites in Wales) who were already involved in a study of the use of risk communication tools in general practitioners. The researchers sought to evaluate the worth of SDM to patients, a matter of concern because it requires additional special communications training for physicians and its efficacy for improving health outcomes has been spotty. To do this, they presented the subjects with a series of scenarios that differed in terms consultation attributes, relative degrees of information and agency between a patient and a physician. For example, they described a health scenario and presented the subject with a choice of preferences such as “doctor decides” and
“patient decides.” In this sample, SDM was not necessarily as valued as other characteristics (e.g., a sense that the doctor listens to them), however they also found that patients are “responsive to changes in experiences of healthcare,” suggesting that “if healthcare professionals adopt [SDM] approaches, then patients may come to value the process further” (Longo et al. 2006:41). The researchers note that while their results do indicate that SBM brings about some changes in patient preferences, they recognize that their study design does not allow them to understand what happens in people’s minds to make the difference.

Picking up this thread, two members of the Longo et al. research team, Edwards and Ellyn (2006), published another paper focusing on a group of physicians within the larger study who trained for six months in communication skills. Of the 20 participant physicians in the earlier study, 12 physicians continued on to the qualitative phase of the study, collectively recruiting 68 patients to allow them to record their consultations. The researchers then performed follow up semi-structured interviews with 17 purposively selected patients with OPTION scale scores that indicated a high degree of patient involvement in decision-making about their care. Through content analysis of their transcripts, Edwards and Elwyn found that patients experienced two distinct types of consultations with communications skills trained physicians: “Some interviewees felt clearly that they had made or led the decision, thus perhaps fitting the “informed choice” model, whereas an equal number believed they had made a shared decision with their doctors” (2006:311). Edwards and Elwyn are careful to cite the limitations of
their study as they discovered that among the patients who felt their decision was patient-led, there was often uncertainty as to who actually made the decision, “reflecting firstly some different meanings attached to the concept of decision making from those in the literature, and secondly that preferences for decisional responsibility vary during a consultation” (2006:315). They suggest that a distinction between the process of involvement (presentation of options, preferences for decision making) and the actual decision making would be useful for further study since it seems that the process of involvement in making the decisions was more important to patient satisfaction than was making the decision, per se.

In another qualitative study, Evans and Robertson (2009) performed a grounded theory study to understand patient needs with respect to physician-patient interactions. The researchers conducted interviews with 11 elderly women living in one of two residential settings. Coding of the interview transcripts revealed that on the whole, patient satisfaction with physician interactions were rooted in the perceived attentiveness of the physician to the patient’s concerns and issues, often presented in written communication in the form of lists prepared ahead of the visit and patient letters—a unidirectional form of communication in the time-compressed contemporary clinical context. When it came to seeking new physicians for new health concerns or due to transportation issues (e.g., moving to another part of town and/or losing the ability to drive), the researchers found that the patients were on a quest of “finding Dr. Right,” a doctor who would listen to them and take their concerns seriously. Evans and Robertson
conclude, “Truly these elderly women were seeking participatory spaces in which to plan their health care” (2009:423). This study makes an important contribution in demonstrating the expanded use of qualitative methods for research into patient-client interactions, but the focus is limited to physician-patient relations and communication styles.

Overall, the literature on SDM focuses on physician-patient interactions, but when it comes to care for chronic conditions, it is other health care practitioners who interact most with their patient-clients. SDM as a concept is also limited in that it ignores differential power and ability to make informed decisions between all of the involved parties.

**Negotiated Care**

The existing definition that I found that most closely relates to my concern with power as an integral aspect of negotiating care was published by Polaschek (2003) in an article on nursing work in a renal setting. According to Polaschek, negotiated care involves “supporting clients’ attempts to negotiate the requirements of the therapeutic regime, in accordance with the dominant discourse, into their own personal situation that reflects the client discourse” (2003:357). In the case of health care, the dominant discourse is the biomedical model, which focuses on states of illness with treatment and/or cure as the objective.

In negotiated care, health professionals work with their clients to find ways to communicate information from the dominant discourse so that it is relevant to the
client’s experiences. As “complex interconnected webs of modes of being, thinking, and acting” (Gannon and Davies 2007) discourse becomes a story through which power relations are variously exercised, challenged, and reinforced by who has control over what is known about whom/what. The story (discourse) of primary concern for this study is that of diabetes as understood by stakeholders and communicated through their texts, observable behaviors, and the way they describe their overlapping social worlds as they relate to diabetes and the health care system more broadly.

Polaschek (2003) examined the nursing role in terms of the medical and nursing discourse and the actual work of nursing care in the renal setting. His essay, based on his own personal experience as a renal nurse contextualized in terms of the literatures on discourse, patient experience, and medical compliance, was able to uncover the ways that nurses bridge the expectations of the clinical role with the emotional and practical needs of their patients. Within Polaschek’s frame, renal nurses negotiate patient care within the technical, medical bounds of the treatment regimen to allow patients to live as “normal” a life that they can on their own terms. This does not mean that patients are encouraged to pick and choose from the therapeutic regimen according to what is relatively convenient, nor does it mean that nurses merely present technical information. Instead, renal nurses try to find ways to make treatment regimens work better for their patients and ensure that the patients are aware of the potential costs and benefits in well-being for their lifestyle and treatment choices. The case of nursing work in the renal care setting demonstrates the complexity of power
dynamics between the dominant medical discourse, the workers who interact most directly and consistently with patients, and the patients:

The dynamic interplay of authority and responsiveness in the relationship between nurses and clients in the renal setting mirrors the complex interrelationship of dependence and autonomy involved in living on dialysis. The caring quality developed in their relationships with clients can enable nurses to facilitate people living on dialysis in integrating the clinical requirements of therapy into their own personal situations, and to participate actively in the clients’ own negotiation between the dominant and client discourses. (Polaschek 2003:361)

As a theoretical essay, Polaschek’s work presents a way of looking at health care that bridges the social worlds of health workers and patients, engaging in social philosophy as well as everyday lived experiences. It cannot stand on its own, however, due to its limited scope and sparse empirical grounding—the N of one problem (Conrad 1990). This study expands the reach of negotiated care beyond the clinical health care setting as a framework for understanding the complex relationships between discourse and practice from the highest levels of public policy through everyday activities.

**Overlapping Social Worlds of Diabetes Care**

Social worlds theory (SWT) offers a way for us to approach the study of social life by recognizing the organization of actors, motives, and frames of reference. According to Anselm Strauss (1978):

In each social world, at least one primary activity (along with related activities) is strikingly evident, i.e., [...] researching, collecting. There are sites where activities occur: hence space and a shaped landscape are relevant. Technology (inherited or innovative means of carrying out the social world’s activities) is always involved [...]. In social worlds at their outset, there may be only a temporary division of labor, but once underway, organizations inevitably evolve to further one aspect or another of the world’s activities. (emphasis in original)
This way of thinking is useful in approaching diabetes as a social phenomenon because it allows us to look at the groups of actors that share the concerns for the care of diabetes, activities associated with diabetes, social relationships around diabetes, and allows us to examine power dynamics built into the organization within and among the social worlds. Tovey and Adams (2001) advocate for the use of SWT specifically in studying primary health care, modifying Strauss’s definition to allow for membership in a latent social world where membership is ascribed by an outsider (e.g., through a medical diagnosis). Three of Strauss’s particularly useful social world processes that Tovey and Adams point to for health research are segmentation and differentiation into sub-worlds, the “quest for authenticity or legitimacy and the sub-processes of boundary setting,” and the “process of intersection—the overlapping subworlds with a consequent transmission of knowledge” (Tovey and Adams 2001:697).

In her study of the controversy over the construction of Premenstrual Syndrome (PMS) as a diagnosable condition in the DSM III-R, Figert “use[s] the term ‘domain’ to locate and distinguish the multiple social worlds” because it “allows for spatial understanding of the location of the actors and distinguishes the multiple meanings of the controversial fact or artifact,” (i.e., whether PMS is a diagnosable condition that belongs in the guidelines for psychiatric diagnosis)(Figert 1996:64). At this point, the existence of diabetes as a diagnosable condition is not controversial, but rather the differences between the ways that people make meaning of the diagnosis (and what should be done as a result) depend on social world membership of the actors involved.
Stakeholders that occupy social worlds interact across social world boundaries in arenas of common interest in which the competing interests, knowledge claims, and agendas play out.

Building on Strauss’ and Figert’s definitions, I conceive of U.S. health care as the product of overlapping social worlds. Where I depart from Figert’s application of SWT is that instead of a controversy over the creation, legitimacy, and utility of a diagnostic category, I am investigating practices around the professional care of a condition that has largely been black-boxed,\(^\text{11}\) situating it within the larger political context that encompasses all of the stakeholders, and defining the arena of diabetes care work (the

\(^{11}\) Whether it should remain in the black box is a topic for a different paper.
problematic or object of inquiry) as both wholly within and distinct from its constituent arenas. According to Clarke, “social worlds/arenas theory offers particular advantages in terms of analytically tolerating the porous boundaries between and among various worlds specifically because of the openness and elasticity of its conceptual framework” (Clarke 1991:137). As I will discuss in Chapters 4 and 5, Situational Analysis (SA) mapping (Clarke 2005) of the data affirm that this organizing schema is far more accurate for capturing the fluidity of the content, motivations, contexts, resources, and power dynamics of the negotiations of diabetes care than can be captured in a more conventional, linear and hierarchical organizational chart such as Fisher’s depiction of the organization of clinical research (Fisher 2009:10).12 That is, all of these elements are relational in interactions between and among stakeholders, influenced by but not entirely governed by the texts (e.g., laws and formal organizational structures) that define the relationships in a contextual vacuum.

The practice of health care is a social process and framing it as a negotiation allows us to see the ways that the stakeholders in that process variously exercise degrees of power over the discourse (the way we think/talk about it) and praxis (what

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12 While there is overlap in pharmaceutical clinical drug trial work and diabetes care work (i.e., diabetes care workers are involved in clinical trials for diabetes-related drugs), DCW is not organized in such a clear top-down model, in part because it is organized within the profession itself and not tightly regulated the way that clinical trials are. Fisher’s model reads as if there is zero overlap between the parties of each category and with a top-down structure that suggests the most power resides with Pharma, not the coordinators or volunteer research subjects. Compliance, however, is the most significant factor in the usefulness of the study data and without adequate participant motivation and coordinator skill/commitment, Pharma is unable to meet FDA regulations. Human subjects volunteers are central to clinical trials, but situated at the bottom of the organizational chart. I believe the approach I am taking would further contextualize Fisher’s analysis of the work of performing clinical drug trials, demonstrating the murkiness of the categories and the work that is done despite such tight regulation.
we do about it) of the situation, depending on the constraints and interests of their respective individual experiences and their social worlds, more broadly. When it comes to the overlapping social worlds of diabetes care (see Figure 1), the stakeholders (and their social worlds) are numerous: individuals who use the health care system (patient-consumers), health care workers, several industries (medical, pharmaceuticals, medical devices, and health insurance), health care policy, and the special interests groups (e.g., professional associations, patient advocacy groups, lobbyists). I present this social organization of diabetes care as a complex Venn diagram because each stakeholder group engages with the others in one or more arenas. Special interest groups are too numerous to list and are important players in influencing the interactions between the stakeholders, especially the interplay of health care policy. I define health care workers broadly as those who deliver or perform care. Because they are the ones whose actions are most constrained and proscribed by the other stakeholders, they sit completely within the industry-policy overlaps. Finally, individual patient-consumers sit at the center where they fully experience the health care milieu. Where there is overlap, there are points of negotiation.

Negotiation certainly arises from conflict between the goals, roles, motivations, and understandings that each actor has in the system, but it is not necessarily contentious (e.g., not all patients wish to challenge medical authority and not all physicians wish to enact their power over the choices their patients make). The most productive negotiations in health care result from mutual respect and shared

To study diabetes as a social process—a negotiation of care—is to acknowledge the social nature of “disease” and to uncover power relations that we as a culture generally take for granted, cannot see, or are obscured. This is not to say that collaborative care is impossible, but rather that negotiation is a necessary precursor to collaboration and it is in the negotiations of care that we can see the social process of health care in action. Each group of stakeholders has their own social worlds that influence how they approach negotiations and what their desired outcomes are. I believe that if we can approach health-related social problems with a greater understanding of the ways a problem is constructed by the various stakeholders, we can find more comprehensive ways to approach the social problems associated with chronic illnesses in our society—an important task in reducing health-related social inequalities and improving healthcare more broadly.

By studying the social worlds of the stakeholders in the arena of diabetes care, we can better understand the negotiations of care in the terms of each stakeholder’s standpoint and find the ways in which social worlds overlap. It is in these places of overlap that negotiations have the greatest potential to be mutually beneficial. This research contributes to a greater understanding where the overlaps lie and the social worlds around health care will enable us to better identify common ground for
facilitating more truly collaborative care. One of the greatest strengths of the negotiated care framework is it allows us to see where the bridges are between social worlds. Each stakeholder is involved in the discourse and its praxis, with varying degrees of power, and their social worlds are not necessarily mutually exclusive. Boundaries are porous social membranes at best, roughly delineating areas of authority or responsibility for particular stakeholders. Not only is authority (or responsibility) in the treatment of chronic conditions not exclusive to professional health practitioners (or the patients), under the negotiated care framework it is necessarily inclusive. Negotiation is both/and, not either/or.

13 Assuming, of course, that is the actual goal.
CHAPTER 3

CONDUCTING THE INSTITUTIONAL ETHNOGRAPHY

Nancy\(^1\), a middle aged, white woman stands at the front of the small room, wearing a white clinical smock over a pastel green polo shirt and khaki Capri pants. She wears her hair in a neat, dark blonde bob and greets us all with a smile, reserving her introduction until we are assembled. Three couples\(^2\) sit around three sides of a group of narrow conference tables shaped into a rectangle. Behind Nancy, there is a shelving unit holding props to her left and a blank wall, reserved for the projector that’s connected to her laptop computer. Behind the rest of us, there is just enough room to pull out a chair to sit down at the table, and not much more. I know which people in the room are patients because I noticed that after my husband saw a nurse privately for his weight and blood glucose reading, he emerged with a folder bearing the hospital’s logo across the front. Two men had folders in front of them. I would learn quickly that the third folder was under the control of the wife of the patient with diabetes. Just as Nancy introduced herself, a woman rushed in to take her seat. As she settled in, Nancy welcomed us to Diabetes Self Management Education. I am ready to write down everything because this is *important*. Upon review of my notes, I noticed recurring

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\(^1\) This is a pseudonym.

\(^2\) I initially guessed that they were couples by observing their behaviors, but this was verified when we introduced ourselves to the group early in the class.
themes in the messages that were directed to the patients: It is hard to live with failure, and you will fail at some point. Failure means not taking your medications, eating properly, and managing your diabetes.

- It is your choice alone and nobody else can do this for you.
- What you eat is crucial to diabetes management.
- You must take care of yourself. There are no acceptable excuses for not doing so.
- Calories count, even if the food is sugar free.
- If you stick to the rules on the handout, you can still enjoy food in moderation.
- Your goal is to reduce your blood sugar.
- Your goal has to be written down in your own handwriting because the diabetes center is accredited and “they” make them do that.

* * *

In August and September 2008, I sat next to my husband Phillip in a diabetes education class for three consecutive Saturday afternoons. We were lucky he was diagnosed with Type 2 diabetes at a private hospital in an affluent suburb close to home because they directly referred us to their accredited diabetes education program. We had good health insurance and did not have to worry about the costs of his medications, changes in diet, or the expense of the course we were taking to help us adjust to his diagnosis. Since I was also a graduate student of field methods at the time, my diabetes class notes include all kinds of information in addition to pathophysiology and target
blood glucose levels, such as the fieldwork jottings that allowed me to reconstruct the scene above.

At 30 years old, Phillip and I were stunned and a little freaked out at the prospect of managing the disease that we had both seen ravage our loved ones through complicated insulin use, non-healing wounds, amputations, kidney failure, transplants, and death. I have a general tendency to intellectualize stressful or distressing experiences as a coping mechanism. In the process of writing down and thinking about the ways that the educators presented information and interacted with patients, I became curious about their work, training, and motivations. I was struck by clear messages of personal responsibility (week 1, nurse), the condescending tone of the dietitian who largely treated the class like we were ignorant children (week 2, dietitian), and the insights into the administrative side of diabetes care (week 3, nurse).

Regrettably, my focus on these interactional elements of diabetes education did not make me an effective supporter of a person with diabetes, but it did plant a seed that would become my dissertation project years later.

**Project Overview**

The primary goals of this research are to learn how diabetes workers and others negotiate our cultural understandings of diabetes and how do they shape the ways we might address diabetes as a social problem in our society. Ultimately, the point of conducting this research is to inform practitioners and policymakers in ways to improve care delivery, outcomes, and worker satisfaction. I use mixed qualitative methods (semi-
structured interviews, ethnographic observation, textual analysis) to develop an institutional ethnography of diabetes care work as understood from the standpoint of diabetes care workers.

Data

The original research proposal included:

• Membership in and observation of professional associations, professional meetings, discussion forums, and events.
• Interviews with diabetes care workers (target of 30 interviews).
• Observation of DSME group classes.
• Interviews with DSME group class participants.
• Textual analysis of professional texts, marketing materials, educational materials, and popular diabetes books and magazines.

While methodologically sound, the original plan was overly ambitious for a dissertation project. I made three major changes under the supervision of my dissertation director and the IRB:

1. IE requires adopting one standpoint at a time and there was not sufficient time to take the standpoints of both diabetes care workers and patients. I resolved this problem by not interviewing patients.
2. I obtained conditional IRB approval for group class observation, pending equivalent institutional support from the health care organization site. Due to events in my
personal life at that time, however, I decided to focus on the data from interviews, fieldwork, and texts.³

3. There were too many texts to include in this project, given the time and labor constraints. A sizable collection of diabetes educational materials, popular and professional publications, medical device samples and advertising/informational materials, and pharmaceutical advertising/informational materials awaits future analysis.

The data included in this project are from ethnographic field observations (Emerson et al. 1995; Kouritzin 2002) of professional association events and activities, semi-structured in-depth interviews (Weiss 1995) with diabetes care workers, and analysis of the texts (Fairclough 2003; McKee 2003) that coordinate the activity of diabetes care.

Professional Associations

Building on the knowledge I gained through personal experience and conversations with friends and acquaintances who work in health care, I was fairly certain that the bulk of frontline diabetes care workers were diabetes educators. In order to gain a sense of their concerns in diabetes care and to discover other types of diabetes care workers, I joined their leading professional associations, the American Association of Diabetes Educators (AADE), the American Diabetes Association (ADA), and the Academy of Nutrition and Dietetics (AND). As a student professional member

³ I would like to include this in future research.
I identified myself in my application for membership and my online profile as a sociologist who studies diabetes care and a doctoral candidate. I was required to provide proof of my full-time student status in an accredited program. The benefits of membership include online access to organization documents, annual meeting resources, discounts and advance notice of annual meeting details, access to networking and continuing education events, and access to online forums and member lists.

As a part of the development of my research proposal, I attended an ADA regional clinical meeting in 2012 that was advertised to nurses, dietitians, pharmacists, and physicians who do work with diabetes care. In order to get a sense of the breadth of possibilities for recruiting diabetes care workers and to develop some sense of the sorts of concerns that they have, I attended the sessions and wrote fieldnotes. As an observer, I was unaware of social functions and I did not initiate conversations with other meeting participants. When those conversations began, I informed the other party that I was at sociology student and writing a dissertation about diabetes care. This was received well and while I did not conduct any interviews as a result (because I did not yet have IRB approval), I left the event with a strong impression that my inquiries would be welcome and that I would find the most potential interview participants within the AADE.

In total, I attended one annual meeting of the ADA (June 2013) and three annual
meetings of the AADE (August 2012, 2013, and 2014). While there, I attended the sessions that pertained directly to diabetes care workers as I had come to understand their concerns through interviews and conversations (e.g., racial health disparities, insulin injection techniques, weight loss, professional credentialing). Attending the sessions and initiating conversations with other participants deepened my understandings and guided me toward aspects of diabetes care that I could only have seen from their standpoint. These conversations happened as we were packing up to leave a room at the end of a session, while standing in long lines to enter events or to receive various freebies, riding the shuttle bus between locations, and wandering about in search of the coffee stand. I attended at least one, and often two, major social events per evening during the conference, which helped me understand the role of the pharmaceutical industry in diabetes care as they interact with diabetes care workers.

Between conferences and local educational/social events, I estimate I have conducted at least 150 hours of observation.

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4 A rich description of the AADE conference environment and the data I collected at the meetings can be found in Chapter 5.

5 The cost of traveling to attend annual meetings was about $1,500-1,800 per meeting. This expense limited the number of meetings I could attend between 2012 and 2014. It was too late to apply for grants to support this part of the research by the time that I realized it would become as important and expensive as it was.

6 My conference fieldwork days started 1-2 hours before the first session of the day, during which I reviewed the notes I took and observations from the day before and planned which sessions I would attend based on what I learned the day/night before in terms of trends in participant interest or questions that occurred to me in the field. The workdays ended around 9:00-10:00 p.m., when I returned to my hotel room after social functions. I have learned to pace myself by allowing pockets of time in the day where I am in the field, but neither writing nor talking—just observing. I was occasionally overwhelmed by crowds of people and noise in the exhibition hall and I coped with that by stepping outside for 10-15 minutes.
I began casual conversations with other attendees by identifying myself as a graduate student researcher and explaining that I study diabetes care. All people I engaged in this way were willing to talk to me. Over the course of the conferences and local continuing education/social events, I have developed relationships with diabetes care workers that have led to interviews, resources and insights into the world of diabetes care, and their ongoing interest in my work as it develops. By the time I attended the 2014 AADE Annual Meetings (AADE14) in Orlando, Florida, I had become so comfortable there I made a personal inquiry into the educational requirements for becoming a certified diabetes educator in the event that I might pursue future embedded research as diabetes educator myself, as Diamond (1992) did in his study of nursing homes from the standpoint of nursing assistants.7 Over the course of three years, my identity with respect to diabetes care workers has gone beyond participant observation. I am becoming a non-clinician insider in the diabetes care work world and have developed empathy for diabetes care workers.

**Interview Participants and Recruitment**

Based on the assumption that we can learn about the problematic of diabetes care from the standpoint of diabetes care workers, I began with a recruiting participants from the AADE. According to Charmaz, theoretical sampling functions to distinguish the researcher’s emerging theoretical categories and is not about representing a population

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7 Note that this was not the first inquiry into the educational requirements for the professional certification for diabetes educators, but that this was with particular curiosity for my own career development and research.
Sampling this way is aimed at explicating the researcher’s categories so that “they reflect qualities of your respondents’ experiences and provide a useful analytic handle for understanding them” (Charmaz 2008:100). The category I am most concerned with is “diabetes care worker,” so I began with the most visible frontline care workers, CDEs, but wrote the recruitment prompt in a way that does not limit the sample to CDEs.

Beginning in July 2012, I distributed flyers and sent email invitations to participate in the Diabetes Care Work Study. Participants qualified if they answered yes to all three questions:

1. Do you work in diabetes care in the Metro area?
2. Would you like to help in the effort to improve diabetes care?
3. Are you at least 18 years old?

The invitation included the following study description:

Melissa [Gesbeck], a doctoral student in the Department of Sociology at Loyola University Chicago, is conducting a dissertation study on diabetes care to gather information about the work that goes into diabetes care and the people who do it.

You will be asked to participate in a confidential one-hour interview at a time and place that is convenient for you. You will receive a $20 Visa gift card for your time.

I distributed flyers (see Appendix A) and business cards with the same call for participants printed on the back during the course of informal conversations with

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8 In order to protect the confidentiality of participants, I refer to the large Midwestern metropolitan area where the research was conducted as Metro.
diabetes care workers at professional association meetings and networking events. I also posted the call for participants on the Metro diabetes educators group, a list I was able to access through my AADE membership. From these initial contacts, the call for participants spread across the network of diabetes care workers in the Metro area. In total, 41 people expressed interest in being interviewed and 30 completed the interviews, all conducted between August and October of 2014. Of those who did not participate in an interview, three cited conflicts of interest and nine were unresponsive to follow-up emails and/or phone calls for scheduling. All participants were offered a $20 Visa gift card in appreciation; two participants declined, stating that accepting it would be a “conflict of interest.” All personal and organizational names and identifying information has been changed to protect the confidentiality of the participants.

Interviews lasted about an hour, with a range of 45-90 minutes.

I specifically use the non-standard term “diabetes care work” in order to allow space for participants to self-identify and to define the range of their work. Framing the standpoint this way has helped me to maintain an open mind to activities and actors of diabetes care work I may not have known at the outset. Of the 30 participants, all but two were nurses or dietitians. Of the nurses (RNs) and dietitians (RDs), all but three were also certified diabetes educators (CDEs). The other two participants were an endocrinologist and a pharmaceutical sales representative without clinical credentials. An additional pharmaceutical employee was also interviewed, but she is counted as an RD, CDE because teaching diabetes education classes is a large part of her job. The
Interview participants were overwhelmingly white (87%), women (90%), and above the age of 40 (83%). As a mid-30s, white woman, I was able to avoid many of the difficulties that occur when interview subjects differ significantly from the interviewer. However, the lack of diversity in age, socioeconomics, gender, and race closes off several areas of research that I would have liked to pursue.

The only specific diabetes care workers I sought out were practitioners of color and pharmaceutical representatives, since those who were volunteering to be interviewed were proving scarce. From the initial recruitment posting on the AADE forum, three Latino participants volunteered. One of them referred me to two more participants who were Latino and African American, respectively. In my AADE conference fieldwork, I was struck by the overwhelming whiteness of the members in attendance and hoped to learn from DCWs of color how their activities and interactions might differ as a result. I also learned from the annual meetings and interview participants that pharmaceutical sales representatives have an active role in diabetes care. Unfortunately, my direct attempts to recruit them for interviews were unsuccessful and I was redirected to the pharmaceutical company’s public relations contact page on the website. It was through referrals from other interview participants that I was able to interview two Pharma reps.

After the initial contact from a prospective participant, I directed them to a Google Calendar that displayed my availability online. From there, I asked the participant to choose an available date and time block or to propose a different time
that would work better for them. In the cases where participants preferred to communicate by phone, I proposed dates and times by phone. I confirmed the date, time, and location with each participant by phone or email a few days before our meeting. A handful of participants needed to reschedule their interviews, and all but one did so successfully. In one case I needed to reschedule an interview and we were able to complete it at a later date without further difficulties. In the case of three practices, participants coordinated amongst themselves in order to allow me to conduct multiple interviews in one site visit and offered me dates.\(^9\)

When setting the interview location, I informed the participant that I would be glad to go to a location where they were most comfortable or it was most convenient for them. Several took place in their clinic offices and educational spaces, but just as many took place in cafés or coffee shops. When a participant asked for me to choose a location, I suggested a coffee shop near their work site. In one instance, the participant suggested an office space that I found was locked and empty of furniture and people. I soon discovered that she works out of her car as a contract RD, going between several facilities in the course of a day. She was familiar with the suburban office park where we met and I conducted the interview while we sat on the grass under a tree. In another case, the participant had developed a pregnancy complication between the time we scheduled the interview and the interview date. To accommodate her, I conducted the

\(^9\) Through this process I learned that I should not conduct more than two interviews in a day. The most I did in one day for this project was four.
interview in her home where she was on bed rest.\textsuperscript{10}

The varied locations created difficulties in transcription (variable audio quality), challenged my ability to focus as an interviewer, created physical discomfort at times, and subjected the interview to interruptions and interviewee distractions. However annoying these factors were at times, the choices of locations coincided with the degree of autonomy the participant had in their work environment and/or the facilities available to them. Participants who were more autonomous in their work invited me into their clinical work spaces, which afforded me a valuable glimpse into their world and allowed me to see some of their work in action, even if that work was not directly in contact with the patient at that moment. The participants who worked part-time did not have the sort of space they could invite me into, or the authority to do so without higher administrative oversight.

**Conducting the Interviews**

I conducted semi-structured qualitative interviews with 29 self-identified diabetes care workers and one pharmaceutical sales representative\textsuperscript{11} who was referred to me by one of the participants who regards him as important to her work in diabetes care. I chose an interview method that allows for adaptation to the story the participant is telling in the moment and for the focus of subsequent interviews to shift in response

\textsuperscript{10} I was acquainted with this participant through my professional network, so I was not concerned about my safety. I stressed to her that my feelings would not be hurt if she withdrew from the study, but she wanted to do the interview. She was happy to be talking with someone who was not her immediate family for the first time in over a week. She and her twins are doing well at the time of this writing.
to emerging patterns, themes, and synchronous data collection and analysis (Weiss 1995).

At the beginning of each interview, I explained the various parts of the consent form and provided them the opportunity to ask questions about the research. The most common questions I was asked were who else might hear the audio recording and why I was doing the research. To the first, I explained that I would probably work with a transcription assistant who would be held to the same standards of confidentiality that I hold. To the second, I let them know that as the spouse and family member of several people with diabetes, I am familiar diabetes care from the patient perspective and would like to help improve it. As I said in one interview, “I’m hoping that by looking more closely at what goes into diabetes care, we can change the conversation that we’re having about it in terms of health care reform as it has to do with diabetes.” I also told participants that I believe they were in the best position to tell me what actually goes into professional diabetes care and what might help them improve it. The question of my motivation was more likely to come up at the end of the interview than at the beginning. Participants who asked my motivation also seemed pleased that I wanted to hear their perspective. Once questions were answered to their satisfaction, we each signed the consent form and I gave a copy to the participant to retain in the event that they wished to follow up with me, my supervisor, or the Office of Research Services

\footnote{One of the participants is both a pharma rep and also a RD CDE who does DSME as her primary job function. Since most of the insights she offers are in the realm of DCW, I count her among DCWs primarily.}
after the interview. At this point, I offered a $20 Visa gift card to the participant and thanked them for their participation.

I digitally audio recorded the interviews using two different devices and software. The primary recording was done using the AudioNote app (Luminant Software, www.luminantsoftware.com) on an iPad 2. The backup recording was done using the built-in Voice Memos app on an iPhone 4. In only one case did the primary recording fail. Based on the best available recording (usually the primary recording), a verbatim transcript was done by myself or my transcription assistant. We documented pauses, false-starts, audible pauses, and verbal tics as they occurred. We also noted inflection and tone as well as descriptions of other sounds present on the recording, such as throat clearing and interruptions to the recording. To facilitate transcription, we used ExpressScribe (NCH Software, www.nchsoftware.com) with a USB foot pedal playback controller. I converted the audio files to mp3 format using Switch (NCH Software) and we saved the transcripts as Microsoft Word documents. Finally, I uploaded the transcripts into Dedoose (SocioCultural Research Consultants, www.dedoose.com) online analytic software. The transcripts and recordings are stored securely.\footnote{I do not disclose the storage locations or methods here because doing so would remove an important layer of security. The data storage has been approved by the Loyola University Chicago IRB. Contact me directly for more information.}

In preparation for the interviews, I developed an initial interview guide in order to develop a sense of who does diabetes care work, how they define it, how they train
for it, and their attitudes and beliefs about it (see Appendix B). I never read any of these questions directly as printed, shared the document with the participants, nor did I bring up the topics in any predetermined order. Instead, I used it to review my goals and the key words that I believed would elicit more detailed stories from the participants (in bold font). The actual questions I asked evolved depending on what I learned from earlier interviews, new leads that came up in the interview, and hunches that I followed in pursuit of emerging theory. I allow interviewees to tell me their stories as they wish to tell them, rarely interrupting and only doing so to ask for clarification. The only semi-standardized parts of the interviews are the first and last questions.

All interviews began with the question, “You have volunteered to participate in a study about diabetes care work. I was wondering what that means to you,” and its follow-up: “What is your role in it?” This question defined the field and situated the participant in it, giving me a sense of what direction the interview might take. All interviews concluded with some variant of, “Think about the time between when you first learned about the study and the scheduling leading up to it. Were there any questions you thought I might ask that I didn’t or any areas you think I’m missing?” Most participants took this opportunity to reiterate their beliefs about the problems in diabetes care and what they think should be done about them.

**Textual Analysis**

According to Fairclough, “[a]ll forms of fellowship, community and solidarity depend upon meanings which are shared and can be taken as given, and no form of
social communication or interaction is conceivable without some such ‘common ground’” (2003:55). Through the ethnographic fieldwork and interviews, I learned which texts constituted this common ground and their role in organizing diabetes care work through legal and professional governance, shaping discipline-specific understandings of diabetes and persons with diabetes, and coordinating the activities of diabetes care. I take McKee’s (McKee 2003:11) post-structuralist understanding of texts into the analysis:

It seems to me that we make sense of the reality that we live in through our cultures, and that different cultures can have very different experiences of reality. No single representation of reality can be the only true one, or the only accurate one, or the only one that reflects reality because other cultures will always have alternative, and equally valid, ways of representing and making sense of that part of reality. (P. 11)

Given this understanding, it does not make sense to approach the textual analysis as a way to quantify the content of the text, the way many analytical methods approach texts. Rather, I observe the texts and their activation in practice and use them as a way to learn about the sense-making processes of diabetes care. I interpret the texts based on my cultural understanding of the world of diabetes care and health care more broadly, and that allows me to make greater sense of the activity of the texts—what the texts do.

In addition to the collection of texts/artifacts I specifically cultivated (described at the beginning of the data section), from early 2012 until the time of this writing I have also regularly consumed educational, professional, and popular media information about diabetes and diabetes care through websites, blogs, web-based and in-person
seminars, television shows, product demonstrations, and other sources. As I study a text, I approach it with the questions:

- What can we learn about diabetes care from this?
- How was this text produced, by whom, and for which audience?
- What does this text do and how?

For the purposes of this dissertation, I explicitly engage with the texts that legally and professionally govern the work of Registered Nurses (RN), Registered Dietitians (RD), and Certified Diabetes Educators (CDE)—the primary professional DCWs. In order to understand differences in perspectives, attitudes, and activity among DCWs, I studied their disciplinary Scope and Standards of Professional Practice documents and position statements, and the ways that participants activate and co-construct texts in practice, including medical records, assessments, and diabetes log books. I have also read many practice guides and health sciences textbooks that give context to the ways practitioners from different disciplines are trained to interact with patients. These texts have allowed me to gain a greater understanding of the baseline common knowledge among DCWs and have also demonstrated the coordination of their activities—and the activities of patients—at a very high level.

While I engage primarily with key texts in nursing, dietetics, and diabetes education and the data work involved in diabetes care, all of the other texts I have encountered and analyzed over the past few years have contributed to my larger implicit understanding of the social space that diabetes occupies in our culture.
Grounded Theory and Situational Analysis

Traditionally, Grounded Theory (GT) analysis begins with the premise that theory emerges from data (groundedness) and presents itself through the systematic revelation of elements and patterns that come from the data. According to Glaser and Straus, “[g]enerating a theory from data means that most hypotheses and concepts not only come from the data, but are systematically worked out in relation to the data during the course of the research. *Generating a theory involves a process of research*” (1967:6)(italics in original). In its purest form, the researcher would approach the data with a blank slate and learn only from the data, inductively producing theory that comes only from the data and is not shaped by externally existing theoretical frameworks.

This position is antithetical to IE, which requires that our biases and experiences as researchers be explicit and not separated from the data or its analysis since we, ourselves, are a part of the research. With the stated aim of exposing ruling relations, IE’s reliability and generalizability “[r]ely on discovery and demonstration of how ruling relations exist in and across many local settings, organizing the experiences informants [talk] about” (Campbell and Gregor 2004:89). The goal of the research is to learn the social relations of the setting through accounts and observation of activity, not to learn about the setting or activity per se. While these are significant philosophical differences in the purpose of the research and its process, it does not preclude the use of GT analytical tools in combination with other qualitative methods. In this research, I follow the procedures of repeated close reading and iterative coding that are primarily used in
GT analysis, however instead of starting with a blank slate, I start with recognizing my assumptions and the frameworks that influenced the pursuit of this project.

Using Charmaz’s (2008) guidelines for GT coding and with the goals of my research in mind (to uncover the ruling relations of diabetes care), I began coding the first five interview transcripts uploaded in Dedoose (transcribed in the arbitrary order in which they were conducted) by identifying and labeling (coding) actions and activities that are demonstrated or discussed in the interviews (e.g., talking, learning, coordinating, testing). I then restarted the process, this time coding to contextualize the actions by identifying actors, resources, relationships, power, texts, and other elements related to diabetes care as presented by the interview participants. Soon, the code list had grown to the point where I could recognize common themes, a recognition based in my knowledge and experience of diabetes care. Based on these emergent themes and what I was learning from re-listening to the interviews and the concurrent textual analysis and fieldwork, I chose the thematic areas that I wished to explore in greater depth for this dissertation:

1. How is diabetes care work done? (Chapter 4)

2. How do professional associations affect diabetes care? (Chapter 5)

3. How do data work in diabetes care? (Chapter 6)

I repeated the initial coding process for each chapter, coding and re-coding each individual transcript based on the question at hand. I then identified emergent themes and selected all of the interview excerpts that were coded within the theme. From this
compilation, I engaged in textual analysis to answer the question that pertained to the chapter I was developing, and the analytic process introduced new questions along the way. The iterative processes of collecting data, coding, analyzing, and writing began simultaneously with a vague direction informed by my background knowledge and primary focus on the coordination of activities—ruling relations. To make sense of the data and emergent theories, I drew on Clarke’s (2005) adaptation of GT to map the ideas and social worlds I was observing: Situational Analysis (SA) mapping.

Through the process of creating maps that explicate the relationships between the ideas that emerge from the qualitative data, SA moves beyond the observable actions and discourses and connects those to the larger situation of the inquiry itself by literally drawing the connections, allowing for discovery for the boundaries and relationships between social worlds (and their porousness). Following Clarke’s (2005) SA strategy, I drew several iterations of maps in order to identify the actors, concepts, institutions, forces, texts, discourses, locations, and other elements that I observed from my earliest data collection/analysis through the time I was drawing the maps. After identifying these elements, I was able to organize them into maps that helped me to understand the social worlds of diabetes care and the relationships between the actors, institutions, and texts that operate within and between those worlds. My earliest thinking about the field I was entering was influenced by Social Worlds Theory, so I began there.
The earliest subsequent maps were the most difficult to draw because I was swimming in data and uncertain where to begin writing. I began by talking through my developing ideas about the ways diabetes care works and translating those discussions into lists, word clusters, diagrams, and flow charts. Through these various maps, I was able to focus in on specific areas and to examine them more closely, while remaining situated in the larger problematic. Throughout the process, I wrote about what I was learning from the maps and how I believed the social relations worked. Then, I started over again, building on what I learned the last time around, repeating the process until I arrived at a representation of the data that helped me tell its story.

The drawing process began on scrap paper and in my notebooks, but since it is an iterative process that requires revision, I soon transitioned to using a large dry erase marker board with different colored markers. Once I had a sense that the drawing on the board was close to right, I took a digital photo in order to preserve the drawing as it was in that moment. I then used Scapple (Literature & Latte Ltd., www.literatureandlatte.com/scapple.php) and Gliffy Online diagramming software (Gliffy, Inc., www.gliffy.com) to digitize the drawings in such a way that would allow me to move the elements of the diagram around and to change the types of connections between the elements as made sense for my developing understanding or in order to shift the focus of the analysis.

In the process of transitioning from paper to dry erase board to digital formats, I manually redrew the maps several times, each time refining them and discovering new
questions. By writing memos to narrate the maps, new questions occurred to me—many of which will be used for future analysis.

Limitations

I have discussed limitations and difficulties throughout this chapter. In summary, they fall into five categories:

• Generalizability
• Data homogeneity
• Project Constraints
• Institutional Constraints
• Messiness

Issues of generalizability are of perpetual concern for qualitative researchers, however for IE generalizability is not the goal. Instead, the goal is “seeking access to the extended or macro-relations organizing the society through an analysis of the micro-social” (Smith 1990:9-10). The focus on ruling relations and the ways they are enacted through textually mediated activities allows us to see the relationships between individual experience and social structure, an entry point to examining the processes of ruling that make up much of the social world that we take for granted. The limitation of generalizability does not impede the method, but rather the value placed on the ways of knowing that produce IE. In order to demonstrate the credibility of my research, I have provided a detailed account of the ways I have come to know the story that I tell in this dissertation.
My interview participants were mostly homogenous, which reflects the lack of economic, racial, and gender diversity in the field of professional diabetes care as a whole. This imposes disappointing limits on my analysis because I am troubled by the effects of this disparity between high prevalence of diabetes in communities of color and relatively few diabetes professionals of color. I have insufficient data to pursue this important line of inquiry. In order to gather that data, I would need to re-enter the field from the standpoint of DCWs of color, specifically.

This dissertation project was subject to constraints of time, labor resources, and budget. The part of the project I ultimately dropped included observation of group diabetes classes where I would have had a better opportunity to see the actual work with patients in action. I would also have liked to observe a broader range of professional associations with the degree of attention I have paid to AADE, however it was prohibitively expensive to do so. I also would have liked to conduct multiple interviews with each participant to have a stronger sense of the effects, if any, of recent health care reform on their activities.

Another way that this project has been constrained is in its purpose for fulfilling the requirements of my degree. As discussed earlier, I have adapted the format and ways of presenting the data so that its format clearly demonstrates that my research meets or exceeds the standards established by my university, department, and discipline. This limits the degree to which another researcher could use this research as a reference for how to conduct IE, however well I have documented my methods.
Finally, IE is messy. I am attempting here to present a narrow enough slice of the world of diabetes care that it is possible to shape it into a communicable order. To do so means that I am privileging some information over other information, and some stories over others, in the pursuit of my agenda to show the coordination and regulation of the way diabetes care happens in the U.S. Throughout the conception and execution of this project, I have attempted to mitigate the effects of my personal bias on the research by actively practicing reflexivity about my orientation to the subject and the ways my personal agenda shapes what I see. The truth of the experiences and understandings my informants shared with me was integral to developing the truth I present here as a medical sociologist who studies diabetes care and wishes to see improvements in that care for workers and patients.
CHAPTER 4

DOING THE EVERYDAY WORK OF DIABETES CARE

The everyday clinical work of diabetes care is a tangible manifestation of our ideas and understandings of diabetes in the U.S. In order to gain an understanding of the scope of this work, the Diabetes Care Work Study called for participants who “work in diabetes care in the [metro] area” who would “like to help in the effort to improve diabetes care,” through professional association membership and word of mouth. This approach yielded a variety of participants who were eager to share their experiences and ideas about diabetes and diabetes care. Most importantly, the participants defined the scope of activity that goes into the work of diabetes care—diabetes care work.

I begin with the story of Juanita’s experience as a diabetes educator (and my experience interviewing her) because it demonstrates the ways that her diabetes care work extends well beyond delivering Diabetes Self-Management Education (DSME), including the ways she tends to the material, emotional, and relational needs of her patients. Then, based on interview data for the study as a whole, I contextualize Juanita’s experience by presenting the ways that diabetes care workers (DCWs) define their work and how they negotiate patient care within the constraints of professional practice and institutional priorities, especially through invisible casework.
Juanita’s Practice

It is a brisk fall day, just wet enough to make the roads and leaves slick, and dark enough to make it feel much later in the day. I am standing alone in the atrium lobby of the Professionals Building associated with Leonard Memorial Hospital.\(^1\) As I entered the parking lot, I had noticed there were only a few parked cars—a fact that at first seemed odd for a Tuesday afternoon, but now makes sense as I look around the dim space and see that the lights are on in only two or three medical offices. I climb the stairs to the second level with the hope that I am in the right place, since the diabetes educator I am about to meet comes highly recommended in the metro diabetes care community and it took weeks to schedule the interview.

I double check the suite number against my scheduling notes since there is no signage to suggest this is the place to go for diabetes education. Connie, a middle-aged white woman dressed in an oversized sweatshirt and faded jeans greets me from behind the small reception window. She sounds a little apprehensive as she asks, “Do you have an appointment?” “I have a three-o’clock appointment with Juanita, but it’s not a medical visit.” Connie smiles and says, “Oh! I’ll let her know you’re here. She just went in with someone.” I am not surprised. I have learned to build waiting time into any interviews I conduct at clinical sites. By the nature of the work they do and their drive to help, most diabetes care workers tend to be flexible and generous with their time for patients.

\(^1\) All person and place names are pseudonyms.
I notice that there are many file boxes on the counter at the back of the reception area, packed, but not taped shut. Aside from that, the work surfaces are clear of the usual office supplies and equipment, suggesting perhaps that they were in transition—moving in or, more likely, out of the aging building. The waiting area has just a few chairs and a small cache of toys.

I take off my coat and notes out of my bag to make the waiting time productive. I hear a young child playing with Connie just before she runs into the waiting area giggling. She thinks my magenta trench coat is pretty. I thank her and attempt to return to my notes. She plays with a toy for perhaps 60 seconds before her attention returns to me. A harried young woman holding an infant comes out to retrieve her daughter. She apologizes and I assure her there’s no need.

A petite, middle-aged Hispanic woman wearing a white coat over a black pant suit is close behind, wrangling the family back down the hall. She pauses for a moment to say, “I just have to get a family started and I’ll be right out.” Juanita returns a few minutes later and introduces herself as she leads me down the hallway to her office. She stops abruptly outside of a consultation room where I see the mother and her children with a much older couple. An educational video plays on the small TV and Juanita confirms with the family that they’re all set, first in English and then again in Spanish.

When we arrive at her office, Juanita introduces me to her husband Raul who is using her computer. He volunteers so that she can see patients well into the evening, after Connie is gone. I try to stand out of the way as he finishes what he is doing and she
clears a pile of file folders off of a chair. It seems like every surface in the small room is covered in layers upon layers of paper, mostly diabetes educational materials and professional samples boxes. There is a desk and a round table with four chairs underneath it all, a typical furniture setup for a clinic-based CDE. Given the age of the posters on the wall, through fading ink and out-of-date dietary guidelines, I surmise it has been years since DSME was done in this office. While the rest of the facility feels like it is in transition, Juanita’s office feels thoroughly lived in. I balance the recorder on the edge of my tablet on my lap.

Juanita works in a unique environment where Leonard Memorial Hospital has donated regular meeting space for her community group, and the physicians and other health care professionals contribute to its bilingual educational programming. Before meeting Juanita, I had heard about her work from multiple participants because they look to her as a leader in setting up and running community-based diabetes education and support groups. While the community work is uncompensated and lacks steady financial backing, Juanita also works as a CDE/RN in the hospital’s accredited diabetes education center. Because of these credentials and the requirements to meet and maintain them, Juanita is able to bring clinical best practices and professional medical samples and educational materials into an underserved community. She tells us about a patient who approached her at a community meeting. He had recently been hospitalized for hypoglycemia, a common, dangerous risk of taking insulin and other diabetes medications.
He went [to a competing medical center], and they didn’t even give him strips. He’s on insulin. So I went to our stash and got them, because [she said to him] ‘you said you get low—you don’t know what you’re doing. You’re gonna [go] back in the hospital for under again.’ So, I should not—

Juanita’s cell phone interrupts her thought. She apologizes as she steps out of the office to take the call. When she returns, we resume the interview for a few minutes, discussing what has gone into creating the community group until her phone rings again. This time I hear the beginning of the conversation before she steps out; she is clearly coordinating care or services for a patient. With the door open, I hear the little girl down the hall whining and her mother explaining, in English, that they can’t leave just yet. Juanita returns and I restart the recording. Juanita says, “Thank God I got the number and I was able to—sorry about that. [...] I’m a case manager, resource manager, social worker—Sometimes a minister.”

When she returns to the patient’s story, I learn that the patient had an initial expectation that she would simply give him information that he requested. However, because of her training as a nurse and certified diabetes educator, Juanita values the formal assessment process and does not proceed with DSME until she has completed it.

Returning to the patient, Juanita says:

Even though he was a walk-in, I said, ‘We’ve got time. I need to do an assessment because I need to know where to really target.’ I’m not just gonna do insulin [education] if something else is critical. [...] So in this case, it turns out that his biggest thing is stress. Huge. And he didn’t want to tell me about it unless I stopped to do the assessment and I insisted on it. [...] I said, ‘Well, in the future visits you’ll need to bring your family.’ So, he says, ‘Well, can we come back and I’ll bring her?’ ‘Cause I said, ‘You want success? Or you just want mediocre? I’m just gonna give you the recipe for
success here. So, you know, it’s up to you.’ [. . .] So he went back, got his wife, she’s there. Daughter, granddaughter, grandson.

While Juanita describes the family, she nods in the direction of the consultation room we passed as I was walking in and I realize she is discussing that particular patient. I am suddenly more aware of the sound of the temper tantrum down the hall. In the vast majority of interview sites, even in clinical offices, I rarely have encountered patients directly or had the opportunity to see the participant doing their work, due to HIPAA regulations and the constraints of the university IRB.

The assessment is a central process in professional health care delivery. During the assessment, the practitioner asks the patient a series of standardized questions and records other important data such as vital signs and medications. The questions vary depending on the clinical subfield, but the purposes are fairly universal: to be sure that each patient is screened for potentially serious or complicating conditions, to record facts about the patient into the health record, and to ensure a universal starting point for all cases, regardless of the practitioner (i.e., the standard assessment that a CDE performs to the standards of care governed by the American Association of Diabetes Educators contains the same minimum information as those conducted by other CDEs). In DSME, the assessment is critical for tailoring the program for the needs of the individual patient. As Juanita says, “I’ve done it in the past when I’ve felt sorry for somebody and they really wanted ‘The Great [Juanita] Teaching’ and I said [to this patient], ‘It doesn’t work like that because what fits you may not fit somebody else.’”
Through the assessment process and informal counseling, Juanita learned that the major causes of her patient’s stress are related to post-traumatic stress disorder, which has recently worsened with his unemployment and conflicts within the family. In doing this, Juanita “connects the dots” so that her patients can see the relationship between their diabetes management (motivation and degree of success). In further conversations with the patient and his family, Juanita learned that the patient used to manage stress through his involvement with his church, but that he stopped attending years ago.

As part of her community outreach, Juanita speaks at churches in the area to raise awareness of her bilingual Latino-focused diabetes education and support program. Her Christian faith is important to her and her practice; she thinks of herself as a tool for God’s work and she is comfortable praying with her patients—an approach that has proven important in diabetes care for the Latino community. Juanita continues the patient story, turning to the faith-based component of her care work:

[The patient said,] ‘Well, could you tell us of a church nearby please?’ ‘I don’t know the churches nearby, but I did speak at one recently. I believe they’re bilingual and believe that the minister there speaks English, so you’re welcome to go to that one if you want. I think I have their number, but I don’t have their address and I don’t have their hours. But if she calls me back then you can talk to her.’ And she just called back.

It is a rare diabetes education center that does not bill for its services, even though it could. If they did, Juanita would not be able to attend to her patients as thoroughly as she does. In fact, Juanita is able to focus primarily on Latino patients, blending her clinical and community work, because Leonard staffs their diabetes center with two full-
time CDEs. The other CDE focuses on English speaking patients. I am unable to reach her for an interview, but I have learned from Juanita and other participants that she takes a more conventional approach to DSME. As I observe the ways that the staff at this clinic have interacted with the family in the other room and the ways that Juanita goes far beyond the standards of care specified in her nursing and diabetes education areas of practice, it occurs to me that I am uncertain whether I am meeting her at the Leonard diabetes center or a community program office. She explains the relationship between Leonard and her community work:

They deserve the biggest gold medal of any place in the whole city. Tell me of any hospital that’s providing a non—a free service with two CDEs, not one, of an accredited diabetes program. [. . .]

Somebody told us that it’s just that they haven’t gotten to us yet to—[Juanita laughs] to get rid of us. But it’s been ten years and I’ve been praying for ten years that they’d not, so— maybe my prayers are getting somewhere. But, yeah, we don’t charge. I’m hoping that they get a tax break ‘cause were a community service program, but they’re not a not-for-profit.

Juanita wishes there were some award that Leonard could win to raise awareness of the way they approach diabetes education and to help other organizations see the value of community-based work.

The sound of the escalating temper tantrum prompts Juanita to excuse herself from the interview again. She opens the door and asks Connie what the problem is. It turns the family is finished with the video and the little girl wants to leave, but they are waiting to say goodbye to Juanita. Juanita says, “Oh, is that all?” and disappears down the hall to see them off. When she returns, we wrap up the interview with just a few
more questions because she has a patient scheduled to come in to receive test results. I thank her, again, for the interview and she tells me to call her any time.

Back in the waiting area, I put my notes away and pull on my coat. Just then, the next patient walks in and Connie greets him warmly. Juanita comes bounding out of the hallway with his chart in her hand. I am mid-step toward the door when Juanita says, “No, please stay!” I make eye contact with the patient because I feel intrusive and will excuse myself if he seems apprehensive, but everyone is smiling. I step toward the group as Juanita announces “Raul’s A1C is 7! It was 13 when he started!” They applaud and I join in, awestruck by the openness of this diabetes care work practice. Raul beams with pride—he should, since this is no small accomplishment. As I leave, I realize I have just glimpsed the type of diabetes care work that most of my participants wish they could do for their patients.

**Health Care Organizations, Ideal Types, and Scopes of Practice**

DCWs work in a variety of settings, including hospitals, clinics, community centers, retail stores, pharmacies, pharmaceutical and medical device companies, universities, research institutes, and public health agencies (among others). All of these settings and the professional workers within them are part of the larger bureaucratic organization of health care, where each sector (social world) of the larger system intersects. DCWs work at the intersections of these social worlds (Figure 2) where they negotiate care through the exchange of information/resources from their positions within the larger patchwork health care system: a complex web of bureaucracies.
According to Weber, there are six major features that characterize modern bureaucracy ([1922]1978):

1. Designation of jurisdictional areas which assign official duties to the position and imbue the position with the authority to carry those duties out. Qualifications of the position are tied to extra-personal factors.

2. Positions are organized in a hierarchy where power relations are enacted through the positions.

3. The management of the organization is organized through written documents.

4. It is presupposed that the person occupying the position has thorough training in their field of specialization.
5. The work of the profession is a primary activity, superseding other roles and duties (e.g., complete focus on work tasks at designated work times).

6. The organization is managed by general rules that are more or less exhaustive.

These rules can be taught and this knowledge forms a technical expertise.

According to Smith, “bureaucracy is par excellence that mode of governing which separates the performance of ruling from particular individuals, and makes organization independent of particular persons and local settings” (1990:213). The texts that are produced through bureaucratic processes communicate the domain of responsibility and the requirements of a given position within the bureaucracy.

Because the practice of health care is tightly regulated, even independent contractor DCWs (e.g., self-employed diabetes educators) work within the professional-legal guidelines of legal statutes, licensure, professional association membership, and credentialing agencies. Ideal types are specified through documents (e.g., Scope of Practice, Medicare Reimbursement Guidelines) produced and maintained by these entities. According to Fairclough “Different texts within the same chain of events or which are located in relation to the same (network of) social practices, and which represent broadly the same aspects of the world, differ in the discourses upon which they draw” (Fairclough 2003). Focusing on the texts that most directly coordinate professional diabetes care work practice highlights the differences in discourse and structural power arrangements, depending on the position of each organization with respect to others in the system.
While the activities assigned to a position within the structure pertain to specific ideal types, the performed activities of work blurs those boundaries. According to Weber, the use of ideal types makes it possible to compare empirically observed activities to proscribed activities in order “[... ] to arrive at a causal explanation of the observed deviations, which will be attributed to such factors as misinformation, strategical errors, logical fallacies, personal temperament, or considerations outside the realm of strategy” ([1922] 1978:21). The ideal types in diabetes care work are defined by Scope (or Standards) of Practice (SOP) and/or Standards of Professional Practice (SOPP) documents\(^2\) produced by governing professional associations in accordance with statutory limitations of practice as specified in state professional licensure. The SOP for a given profession is a bureaucratic text that serves to specify the range of activities that are the purview of members of the profession and the educational and credentialing requirements to be included in the profession. The SOP communicates these requirements to outsiders to the profession, which serves to define and preserve the boundaries of spheres of activity:

Legal scopes of practice for the health care professions establish which professionals may provide which health care services, in which settings, and under which guidelines or parameters. With few exceptions, determining scopes of practice is a state-based activity. State legislatures consider and pass the practice acts, which become state statute or code. State regulatory agencies, such as medical and other health professions’ boards, implement the laws by writing and enforcing rules and regulations detailing the acts. (Dower et al. 2007:1)

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\(^2\) These types of documents will be collectively referred to as SOPs from this point forward.
In health care, these distinctions organize the professions into a hierarchy that is largely demonstrated through occupational prestige, interprofessional deference, and public and private payor reimbursement policies (i.e., which services are reimbursed, who may perform those services for reimbursement, and at what rate).

**Negotiating the Bounds of Diabetes Education: Registered Dietitians and Nurses**

The two largest groups in this study are Registered Dietitians (RD) and Registered Nurses (RN). Of these, the vast majority are also Certified Diabetes Educators (CDE).

One of the defining characteristics of an ideal type is the exclusivity of the domain of activity the professional performs. For instance, according to the Scope of Practice for the Registered Dietitian (Figure 3), it is the exclusive domain of RDs to perform Medical Nutrition Therapy (MNT), “an integral component of diabetes prevention, management, and self-management education” (American Association of Diabetes Educators 2011a:S23).

In contrast, the American Nurses Association (ANA) uses the “uniquely caring nature” of the nursing profession, in addition to clinical competencies, to position nurses in the larger health care system (American Nurses Association 2010b:32-33). According to the Nursing: Scope and Standards of Practice (American Nurses Association 2010a), the activities of nursing are more context-based than those of registered dietitians and are

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3 The study also includes one endocrinologist (MD), one nurse practitioner (NP, CDE), and one pharmaceutical company sales representative (without clinical credentials).
limited by barriers to practice such as state/commonwealth licensure and institutional attitudes regarding the role of nurses.

MNT is a cost-effective, essential component of comprehensive nutrition care. Diseases or conditions may be prevented, delayed, or managed, and quality of life improved in individuals receiving MNT. During an MNT intervention, RDs counsel individuals on behavioral and lifestyle changes that impact long-term eating habits and health.

MNT is an evidenced-based application of the Nutrition Care Process (NCP), including:

- performing a comprehensive nutrition assessment;
- determining the nutrition diagnosis;
- planning and implementing a nutrition intervention using evidence-based nutrition practice guidelines; and
- monitoring and evaluating an individual’s progress toward goals.

MNT services are provided by the RD for individuals and groups utilizing meal plans, medically prescribed diets and tube feedings, specialized intravenous solutions and specialized oral feedings, and the analysis of potential food and drug interactions. MNT involves in-depth individualized nutrition assessment; determination of the nutrition diagnosis; determination and application of the nutrition intervention personalized for the individual or group; and periodic monitoring, evaluation, reassessment and intervention tailored to manage or prevent the disease, injury, or condition. (Price et al. 2013:S18)

Figure 3. Scope of Practice of Medical Nutrition Therapy (MNT) for the Registered Dietitian

According to the ANA, “Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations” (2010b:3). This is carried out through the SOP, which comprises the nursing process (Figure 4).
RDs and RNs are both able and encouraged to pursue further training in areas of specialization that allow them greater authority and independence for reimbursement (i.e., some credentials allow the non-physician practitioner to bill directly for services instead of billing through the oversight of another provider) in those domains. Diabetes
care, in particular, further develops the skills and attitudes that are central to professional identities of nurses and dietitians, creating a complementary profession: Diabetes Educator. Most of the nursing participants have been in practice for more than 20 years, adding the diabetes specialization later in their careers. Lourdes (RN CDE), who works in a hospital-affiliated community health clinic explains how older nurses can better afford to do lower paid clinic work than younger nurses: “You tend to find us older nurses in clinics. We've done that, we've been in the hospital, you know we're done with the family business, and we're not needing as much money any more.” For Lourdes, the shift into diabetes care came directly from the need she saw in her patients:

I was their maternal and child health nurse, and that was a case manager position. [. . .] At the beginning I had no gestational diabetics and as the years went I started having them. So then I said to my boss, ‘You know I'm, I'm not—I need education in this area because I'm seeing more patients.' So I went, took a few courses, and that's how I got interested in the position. [. . .]

So the more I got involved in gestational [diabetes care] I liked it. I liked the education, the interaction. I'm a people person. So then we had a nurse practitioner who was our diabetes educator, she had left. Once she left [. . .] I went to my manager and I said, ‘I'm interested. You know, we're the highest diabetic clinic of all the 7 we have and I think we need to take care of our diabetics and I want you to give me the opportunity to create something here.’ And she did.

Juanita, too, was already working as a maternal and infant care nurse when she was inspired to pursue diabetes-specific training in order to help people with diabetes.

Throughout her interview, Juanita regularly mentions her “board certification” and credits it with the high quality care she is able to give her patients that practitioners and
community health workers, such as promotoras, who are not trained in this way are unable to give.

The Standards of Medical Care in Diabetes (American Association of Diabetes Educators 2011a) identifies eight key areas in which both RNs and RDs are cross-trained: patient evaluation, management, glycemic control, pharmacological treatment, MNT, Diabetes Self-Management Education (DSME) and Support. These are codified in the AADE Scope and Standards of practice, which position the CDE as both complementary and distinct in diabetes care:

Diabetes education is unique in that its practitioners come from a variety of health disciplines. Diabetes educators remain individually accountable to the standards set by the discipline and by national, state, local, and institutional regulations that define and guide professional practice. This document serves to guide diabetes educators’ practice regardless of their professional discipline. (American Association of Diabetes Educators 2011a:1)

**Defining Diabetes Care Work**

I began each interview with the following question: “You have agreed to participate in a study about diabetes care work. I was wondering, what does diabetes care work mean to you?” The use of a general, descriptive term as opposed to one that points to any specific mode of care, created a situation in which the participants often needed to pause and think for a moment before answering the question. Confirming my

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4 Promotoras are community health workers in hispanic communities who deliver health information and assistance to members of their community. Because they are a part of the community they serve and have shared language and culture, they often act as a liaison between the patients and health care professionals.

5 Other health care professionals are eligible to become CDEs (e.g., PharmD, MD), but since all but two participants in this study have RD or RN credentials, they are not discussed here.
assumption that this terminology, diabetes care work, was unconventional in their understanding, I occasionally needed to rephrase the question in order to generate a response: “What is the work of diabetes care?” Virtually all participants mentioned medications, diet, and behavioral/lifestyle skills development. The follow-up question, when needed, was either “So what specific work do you do?” or “What is your role in this?” The responses to this question reflected a diversity of work environments, patient populations, professional training, and attitudes regarding patients with diabetes.

On the whole, participants defined diabetes care work in terms of the areas of DSME that they cover as a part of their job. Linda (RN CDE) works in an affluent suburban setting, an outpatient diabetes clinic affiliated with a community hospital. She defines diabetes care work in this way:

So diabetes care work, to me, means the involvement that I have with the patients that I interact with when I’m at work. And maybe the way that I conduct myself with my patients and help them to better manage their own diabetes care. [...] I am a certified diabetes educator and I’m a nurse. And so, what I do is meet with people, both outpatient and inpatient, and give them the skills so that they can, learn how to take care of themselves better. We teach monitoring of blood sugars, we teach people insulin actions—the procedure of giving insulin—how medications work, behavior change, just the whole—kind of basic pathophysiology about what diabetes is, exercise—the benefits of that. We help people establish goals for their behavior change. Meal planning is huge. So those are the things that we incorporate, I’d say, into our practice.

Linda works as part of a team of four CDEs who coordinate to provide the parts of DSME that each member of the team is best qualified to do. As a nurse, Linda focuses most on the biological (pathophysiology), medical (medications and insulin), and behavioral
change elements. She notes the importance of meal planning, but does not speak at
length about it. Her colleague, Audrey (RD CDE), focuses on the nutritional education
and meal planning component of DSME, and this is clear in the way she defines diabetes
care work:

I think it’s a big—a myth out there about the management of diabetes and
people are going to listen to a lot of their friends and relatives. And so it’s very
rewarding when they come in here and we can present the basic facts and
management that’s according to basically proven care. So, I think that [Audrey
pauses] [the work is] to put it all in perspective for people understanding,
especially about what they can eat. And to negate a lot of the myths that are out
there is very important.

Audrey’s office feels home-like. Her small round conference table seems more
like a kitchen table. There are educational placemats and dishes and the wall next to it
features shelves that are well-stocked with clean, empty food packages and plastic food
models that Audrey uses to teach patients how to read nutritional labels, appropriate
portion sizes, and how to use that information to make healthier food choices. These
techniques help her to determine how well the patient is understanding and able to
apply the information. In contrast, Linda’s office, two doors down the hallway, has the
same furniture, but her table was plain and the shelves were stocked with boxes of
blood glucose meters. She demonstrates for me the way that she uses a blood glucose
log book and a highlighter to teach her patients how to log their meter readings and to
identify high and low values, basic pattern recognition that assists in achieving good
glycemic control.
Their hospital-based diabetes clinic bills for their services. Like the majority of DCWs, they are limited in what they can do for patients in terms of the time and resources they have available (including institutional support and insurance reimbursement). They work together to deliver DSME group classes and each sees patients individually as needed or allowed by insurance.6

Another major theme in the ways that DCWs describe their work is the importance of building rapport and trust with the patients and other members of the diabetes care team. Susan (RD CDE) focuses on the centrality of relationship-building in her definition of diabetes care work:

Developing a relationship with a person with diabetes or a person [with] pre-diabetes. Having them understand that it's a lot more than just taking your medications and checking your blood sugars and eating right. There’s a lot more information that you need to know. So, I think it’s trying be the liaison between a physician who [...] encouraged a patient to come see a diabetes educator, which is a plus. And then try to make them realize that as much as they can be overwhelmed, we’re going to make it a simple process—and try to fit it into their life instead of diabetes controlling their life.

As a liaison, Susan is able to share information in ways that are meaningful to the audience—patient or clinician. She works in an university hospital endocrinology practice with a dedicated team of physicians, dietitians, nurses, CDEs, and a clinical social worker. Susan is able to draw upon those resources to help her patients (mostly children and teens with Type 1 Diabetes) maximize their office visits by teaming up with

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6 Insurance is not a requirement for accessing these services, but a referral from a physician typically is. Between the cost of the physician’s visit and the sessions with CDEs and/or group classes, DSME is very costly and this deters uninsured or underinsured patients from using the services.
providers, minimizing patient’s out-of-pocket cost and the time between referrals and diabetes education services—effectively negotiating between the patient, physician, insurance, and other clinicians involved in the patient’s care. There are fewer limitations on the services that they are able to provide because of the university’s commitment to providing services for the underserved, but Susan’s skill at relationship-building aids her in negotiating for the most comprehensive care for her patients.

This is somewhat similar to Leonard Memorial Hospital’s commitment to expanding access to diabetes education to underserved Latinos, especially in the way Juanita is able to define her work more holistically than most DCWs. Because they do not bill insurance for her services, she has been able to use their resources to develop community programming. When asked what diabetes care work is to her, she replied:

Well, to me, as a diabetes educator, it’s what I do. But I know that I work within a team, so diabetes care work encompasses, number one: the patient. Then, secondly, my work that I do directly with them, both in teaching them, and also the work of physicians, psychologists, you know, everyone, social work—everyone that is part of the team network for that patient.

Juanita’s less specific definition is consistent with the scope of the work that she does that goes beyond the standards of practice and the requirements of the AADE accreditation. As we saw in the beginning of this chapter, Juanita involves many more aspects of a patient’s life than the diabetes and its immediate management, including the family, psychological issues, and spirituality.
The Value of the CDE

Juanita sees a big difference between what lay community health workers can give to patients with diabetes when compared to CDEs. In Latino communities, promotoras are community members who are trained in health information so that they can disseminate knowledge in their communities. They fill an important gap where health education programming is lacking, either through lack of Spanish-speaking professional DCWs or insufficient medical facilities in medically underserved areas. Promotoras have a role in delivering DSME, however their lack of broader clinical training limits how they can serve a patient’s needs. Juanita points to the assessment process as a distinct, necessary benefit of hiring CDEs:

If you don’t have a licensed person who knows, really, how to assess someone, you can’t just start teaching them when maybe they needed something else. So in this case, it turns out that his biggest thing is stress. Huge. And he didn’t want to tell me about it unless I stopped to do the assessment and I insisted on it.

Juanita is passionate about helping people live healthfully with diabetes, but her passion and good intentions are not enough. What differentiates her from a promotora is the way that she systematically approaches her patients through the nursing process as an RN and then draws on the deep diabetes knowledge she gained in her training to become a CDE.

Mandy (RD CDE), goes through a similar process from a dietitian’s perspective. She tells us about her most recent patient, who was diagnosed with diabetes whose blood sugars are so chronically elevated that it affects his vision. The patient was referred to her from his primary care provider, which is how most patients access DSME.
It was an assessment in combination with a medical nutrition therapy visit because his insurance only allows three total visits, [and] we wanted to try to lump some together so he could get the most benefit and education out of the sessions. [. . .]

[The doctor] started him on meds and sent him here. He was put on metformin and Januvia and was in my office. So, [long pause] the assessment is an information gathering exchange. I am sitting at a computer, I am typing in information from, you know, name, address, phone number to referring provider, the insurance, measurements such as anthropometrics, blood pressure. [. . .] I ask him, ‘When was your last dilated eye exam? When was your last foot exam?’ Well, he never had a foot exam, so I proceeded to do a comprehensive foot exam. [. . .] So I did quite a bit of education on caring for [his feet] and gave him some samples of some moisturizers to use on there and to try to get [the callouses] softened up and sloughed off.

Continued on with the medical management, then developed a plan of care and talked with him through two goals. ‘What do you wanna learn by coming here?’ And then, of ‘What you know about diabetes, what do you feel needs to change?’ And this particular patient set an activity goal, ‘I need to get back to the gym three days a week.’ And ‘I wanna learn whatever you can share with me so that I don’t—I can feel better.’ His vision was a real concern for him.

So we—I finished the assessment, we proceeded on with the meal plan component. [. . .]

When I do a meal plan, medical nutritional therapy visit, the first thing I do is I get a diet history. I wanna know what a typical day is. What time do you wake up in the morning? Um, do you eat right away? If you eat, what time's breakfast? What do you have? About how much? Do you do any snacking? What time is lunch? Dinner? Bedtime snack, and so on.

In this two-hour visit, Mandy uses the assessment process for MNT as the basis of the initial visit and adds diabetes-specific elements, such as educating the patient about foot care while conducting/demonstrating a foot exam—a critical practice for avoiding infections and amputations. In this visit, she also instructs the patient in proper use of his blood glucose meter, evaluates his dietary habits, and sets him up with a basic meal plan. Since the patient’s insurance coverage is limited to three visits for diabetes
education (a very common limitation), the physician also included MNT (a second billing category) on the referral so that she could use additional time to do the most she could in one visit for this patient.

Another way the CDE complements RN and RD practices, is by motivating practitioners to learn new information and techniques for managing diabetes. In my field observations at the AADE annual meetings, I have spoken with countless DCWs who look forward to coming together to spend days learning and being in the company of others who are as passionate about the work they do as they are. Vivian had been working as a dietitian and encountered an increasing number of patients with diabetes. Her supervisor saw Vivian’s interest and experience in diabetes care growing and encouraged her to pursue the CDE certification, which has changed her practice as an RD:

I think the certification really makes you focus and I can say from—from my experience, [. . .] it changed me because, like I said, I focused in more on it and I’m glad she was able to see in me that there was a skill and a talent for being able to take something complicated and make it understandable to the layperson, so to speak, the non-medical person. [. . .]

Everything you learned in school the first time, guess what, you gotta re-learn it because there’s new science. There’s new information that needs to be translated and given to people with diabetes. So, I came—it was, it was the timing was right. And like I said, then there was so much information to try to absorb and make sure that you were getting the new [emphasis] information out correctly to your peers as well as people with diabetes.

Vivian’s connection to the community of CDEs in the metro area and its importance to her professional development and growth in clinical skills and knowledge fuels her interest in the work. Juanita, Lourdes and others have also shared this
experience. CDEs gain scientific diabetes knowledge while they prepare for the certification exam, but they gain practical knowledge in the field and amongst their peers. This is critical, because there is much more to diabetes care work than SOPs can define.

**Beyond the Scope: Invisible Casework**

Throughout their definitions and descriptions of diabetes care work, CDEs regularly refer to labor that is beyond the SOP for their discipline and/or the CDE. While all participants who delivered DSME refer to the AADE- and ADA-approved curriculum, they necessarily have to work it into the bigger picture of their patients’ lives, which are complicated by other health, social, psychological, and economic conditions. In order to deliver the care defined by their credentials, licensure, and job descriptions, CDEs must engage in activities beyond their health care training.

As indicated by Juanita earlier in this chapter, “I’m a case manager, resource manager, social worker. Sometimes a minister.” We see this in the way that Juanita works with her patient to get to the psychological underpinnings that led to his recent hospitalization due to poor diabetes self-care. As a RN CDE, Juanita draws on her experience as a practitioner and as a fellow human as she shows compassion for her patient and goes so far as to put him in touch with a pastor who might help him. While Juanita’s involvement with her patients might be deeper than most other CDEs, owing in part to institutional support for her doing these activities without concern for billing, she is not unique in going beyond the scope in order to be able to do the work that is in-
scope. Bonnie, a CDE and RN who works in an outpatient cardio-pulmonary rehabilitation clinic sees a disconnect between health care professional education and the needs of the patients:

We’re asking people to almost do the impossible. And I have a certain set of rules that I was taught are important to deal with, but what actually happens in the human being’s life is quite different. And so I had to learn to individualize my plan of care based on what that patient was receptive to. So that’s a real change from what you learn in nursing school or medical school and what actually happens in real life. This is a chronic illness that requires a lot of support and intervention, and also I find it has a lot of stigma, usually—the diabetes does—because people look at it as bad or good. And I think healthcare professionals also do the same thing—[patients] are compliant and non-compliant. And I think that we may miss an opportunity to really engage in what the person actually needs to make those changes. And unless you look at that, it’s two people talking at each other and nothing will ever be resolved. And I see that a lot.

Issues around patient readiness are a strong theme throughout the interviews. DCWs see the timing for DSME as one of the greatest barriers to successful diabetes self-management. Lourdes (RN CDE) has come to a similar conclusion about the difference between the goals she was taught for patient care and the ones she actually practices.

My goal is to find out from them what they want, because I’ve learned the hard way that if you don't give them what they want, or what they need at that time, then they don't build that relationship with you. And I think you'll have them in the palm of your hand if you, if you do that. And I think they probably figure, too, then that ‘she's listening to me.’ And just 'cause the doctor says, ‘teach her all about food’ or whatever, but they're not ready [. . .] They're not gonna do anything, so then you're gonna send them off, bring them back at 3 months for a doctors visit and in 3 months they did nothing. We wasted everybody's time and nothing got done.

The DCWs generally take issue with the ways that patients are categorized as compliant or non-compliant, depending on how closely they follow doctors’ orders. Just as Bonnie
sees the connection between labeling the patient this way and their stigmatization, Lourdes also turns a critical eyes to physicians who seem to be out of touch with the realities of the challenges their patients face. She says:

I think people don't realize sometimes all the other stuff that comes into play in the life of a diabetic that affects the management of the diabetes. They don't take into account, all that other stuff, [ . . . ] you have to take all that into consideration when it comes to taking care of their diabetes. You have to manage their lives, you know, outside that office. And then that becomes hard when you add something else, now, that they have to take care of in addition to everything that's going on in their lives. And I think that's the part a lot of people on the other side forgot. You'll hear from doctors, [condescending tone] ‘Oh, she's a non-compliant patient.’ ‘Do you know why? Do you know why she's not doing whatever she should be doing?’ Sometimes it is all that other stuff that's going on.

Some DCWs invest more of their time and energy into helping their patients identify and remove barriers than others. Throughout the interviews, it has become apparent that the ones who feel more empowered to help their patients in these ways are the ones who are in settings where they are not subject to the limitations of payors. That is, they do not bill for their services and their institution supports their work. It is far easier for Juanita, for example, to take the extra time for her patient when her performance is not judged based on billings. Lourdes is in a similar position; her clinic is not accredited, so she is unable to bill directly for DSME. As a result, her patients are able to schedule as much time with her as they need and she regularly does joint medical appointments with physicians so that diabetes education is incorporated into their follow-up. Her sense of empowerment and responsibility for helping her patients
address their barriers to diabetes management is apparent in her description of diabetes care work:

What it means to me, diabetes carework? Well, I would say to me—carework would mean [. . .] taking care of the patient. I see it as the care that, whatever care that patient requires, we should be able to provide and there [are] many areas. That doesn't necessarily mean just the disease process itself, because if they have barriers like they don't have a job and can't buy meds, I think we still need to get involved in that aspect of their care, to see if there's things that we can do to help them take care of the disease. So, to me it would entail everything. (Lourdes RN CDE)

CDEs spend a lot of time helping patients gain access to medications, negotiating with physicians and pharmaceutical companies to change to more affordable medications and to get free samples or patient assistance program enrollment for their patients. Mandy explains what she does for patients who cannot afford medications:

Well, we do have an indigent drug program here in our center. [. . .] We require an order from a physician [and] we will dispense one [prescription for insulin] time. At the time you come in to get your medication, you'll sit down with a clinician and we assist them in filling out paperwork for ongoing support. A lot of these companies—there's a lot of companies out there that now have drug assistance, but if people are health illiterate, they may not know, or just illiterate in general, filling out the forms can be very cumbersome, so we sit down with them. We help them fill out their part. We say, ‘Okay, you need to take this to your doctor. They need to fill out these parts.’ And then oftentimes if it's done here we'll fax it, or the physician's office will fax it for them. And then it allows them to get their insulin. [. . .]

[Even for patients who do not use insulin], I'll have somebody come in and they're just down and out, they don't know what to do, and I'll just say, ‘Bring your list of medications. I'll sit with you. And it doesn't even have to be just your diabetes drugs. I'll go through the whole list and see if you’re not already on the $4 Walmart ones. Let's compare and see how we can get you to—to save the most out of your pocket.’ So, medications is a huge, huge thing.
The time that DCWs spend with their patients helping them secure access to other services, medications, or just listening to their worries is a necessary component of DSME, even if it is neither recognized nor reimbursed. From the DCWs point of view, the information that they give a patient to manage their diabetes is of limited value if they lack the means to apply that information toward making the necessary lifestyle changes. Another value that I see in their narratives is just how worthwhile this part of their job is, not just for the patients, but also for the DCWs. Mandy talks about what she gets out of doing the work she describes above:

And we don’t get paid for that hour and a half that I was with this person, but it was just the coolest thing ever. Because I gave somebody that had no hope, hope. And I gave somebody that felt they had nobody on their side, somebody on their side. I mean it’s just awesome. And so I leave work feeling—did I make any money for the center? No—but, boy I impacted this person’s life, probably more than I’ll ever know.

In addition to being a RD CDE, Mandy is also the administrator for her hospital-affiliated outpatient diabetes education center, so the way she prioritizes tending to the patient’s needs that are beyond the scope of her job over doing the work that generates revenue is significant. Since these are skills she did not learn in school, she mentors the staff in her clinic through assisting patients in filling out paperwork and in developing their listening skills.

The underlying desire to help people that the participants expressed as a motivation for doing DCW is most clearly seen in the ways that DCWs talk about how they assist their patients with addressing the psychological, social, cultural, and
economic barriers to embracing DSME and taking personal responsibility for their diabetes management. Case management is certainly included in the SOP for nursing:

Nursing Case Management is a dynamic and systematic collaborative approach to providing and coordinating healthcare services to a defined population. It is a participative process to identify and facilitate options and services for meeting individuals’ health needs, while decreasing fragmentation and duplication of care, and enhancing quality, cost-effective clinical outcomes. The framework for nursing case management includes five components: assessment, planning, implementation, evaluation, and interaction. (Llewelyn & Leonard, 2009, p. 12)

However, the work the DCWs in this study described goes far beyond the American Nurses Credentialing Center approved definition and is more aptly described as invisible casework.

As I observed and learned about the ways that DCWs often coordinate with outside agencies it occurred to me that they were engaged in activities better understood within social work, social casework:

The process, named “social casework” to denote its center of attention and its individualized aspect, is a progressive transaction between the professional helper (the caseworker) and the client. It consists of a series of problem-solving operations carried on with a meaningful relationship. The end of this process is contained in its means: to so influence the client-person that he develops effectiveness in coping with his problem and/or to so influence the problem as to resolve it or vitiate its effects. (Perlman 1957:4-5)(italics added)

Of the 30 DCWs I interviewed, none were licensed social workers and none of them cited a background in social work, social services, nor clinical psychology. Nonetheless, several cited key aspects of their work that fall outside of their clinical purview, including coordinating public services (e.g., Medicare/Medicaid, transportation
subsidies, food assistance), enrollment in Patient Assistance Programs for free medications, and informal counseling.

If these services were performed outside of the context of the professional-clinical relationship, they might more appropriately be called “community service” or “helping a friend.” However, as the DCWs have shown, it is a part the job and, therefore subject to the rules and boundaries of professional practice. Because it is out-of-scope, this important work goes largely professionally unnoticed, unrecognized, and unrewarded within the larger health care system. Furthermore, there is already a licensed profession—social work—which has claimed this type of work within its domain, granting its members access to jobs that require its credentials. As long as this is the case, the SOPs and requirements of certification will not require education or supervised clinical hours in these areas. As a result, DCWs will not universally receive the resources they need to ensure that their patients receive these services at the best possible quality and without burning out the DCW, due to lack of training and other social work resources.

In order to do their professional work, DCWs begin with the SOP of their base practice. In this study, that is overwhelmingly from nursing or dietetics. From there, they draw on their additional knowledge, skills, and relationships with other practitioners, patients, families, and community members (e.g., pastors), to exchange information and resources in order to lead their patients down the path to medical compliance—one of the primary goals of DSME. Not only do DCWs negotiate between the interests of the
stakeholders in health care to do this, they also act as a liaison and *advocate* between the health care system and their patients. As with the development of other professions, the CDE credential gives them legitimacy in their work, measured by their authoritative voice in diabetes care research and the increasing opportunities to bill payors for their services. Expanding the scope of the CDE would increase the visibility of the profession, which, in turn, would increase its market share for professional diabetes care work and its autonomy. As I discuss in the next chapter, these are all elements of the professionalization of diabetes education.
CHAPTER 5
CORNERING THE MARKET: THE PROFESSIONALIZATION OF DIABETES EDUCATION

As we saw in Chapter 4, the profession of diabetes education overlaps with other established professions, primarily nursing and dietetics. The texts that govern and guide their practices and that establish their legal and social authority over those practices, however, are products of processes that establish and maintain the status of an occupation as a profession and its workers as professionals. As such, the meanings of profession and professionalism are dynamic and depend on several more factors than the achievements professional diabetes care workers cite.

In this chapter, I introduce the AADE and my narrative of its shifting organizational priorities as I have observed them. Then, I present a background overview on the sociology of the professions to orient us to the meanings of professions and professionalism in our culture. I then draw on data collected through participant observation, textual analysis, and interviews with diabetes care workers in order to examine what it means to be a professional diabetes educator. By examining the role of the American Association of Diabetes Educators (AADE) and the pharmaceutical industry in the professional project of diabetes education, we can locate the place of diabetes education—a central process in diabetes care—in the context of the health care industry.
“Diabetes education is a right, not a luxury.”

I am standing at the entrance of the Orange County Convention Center in Orlando, FL, suddenly chilled after walking a few blocks in the hot, humid August morning. A large fuchsia banner welcomes me to AADE14, the 2014 annual meeting of the American Association of Diabetes Educators. The banners overhead announce the conference theme, “Refresh. Recharge. Renew.” Up front, I see a banner directing me to the exhibition booth for Sanofi, a major pharmaceutical company and corporate sponsor of the conference (see Figure 5).

Figure 5. AADE14 Conference Entrance (Orlando, FL, August, 2014)

This is my third AADE annual meeting and between that and my Metro area observations, I expect to see a few familiar faces. I also expect to find:

• Thousands of diabetes educators who are excited to be together among their tribe;
• Informative sessions on pathophysiology, behavioral interventions, clinical recommendations and guidelines, billing, professionalization, and clinician self-care (to avoid burnout);

• General sessions intended to be informative and/or inspirational;

• A large Exhibit Hall packed with elaborate booths and representatives from the pharmaceutical and medical device industries, publishers, other professional associations, food manufacturers, and other niche products targeted toward diabetes care workers and their patients;

• “Product Theaters” where industry representatives discuss their newest technology and how to incorporate it into diabetes care practice, with a catered lunch;

• Social events as a part of and in addition to the conference, such as dinner presentations, cocktail receptions, and lavish customer appreciation events hosted by pharmaceutical and medical device companies.¹ As a participant observer, I have participated in all of these types of activities, including the industry sponsored social events.² This time around, I am registered to attend a performance of Blue Man

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¹ I will refer to pharmaceutical and medical device companies collectively as Pharma.

² During the registration process for these events and at their entrances, the sponsoring corporations post the following statement: “Several states have enacted state regulations prohibiting sponsoring companies from providing any food, beverages and/or meals to healthcare professionals practicing in those states. Please consult your state regulations and ethics laws to see if such prohibition would apply to you” (http://aade-365.ascendeventmedia.com/aade14-preview-news/product-theaters/ accessed January 26, 2015). This relieves their liability in the event that laws designed to prevent coercive influence from the pharmaceutical industry over health care providers are violated. Indeed, I found these events much more plentiful at AADE than ADA meetings, possibly because there are fewer regulations around these practices regarding non-medical health care practitioners.
Group (Asante), a cocktail reception at Ice Bar (Asante), a Dancing Among the Stars performance and reception (Tandem Diabetes), the huge annual customer appreciation dinner reception (BD/Lilly), and the Irish coffee dessert social/fundraiser (AADE Foundation, Sanofi, Novo Nordisk, Topricin, and Galen). The social events are where I have had some of my most interesting and revealing conversations with diabetes workers.

I follow the tide of people to the registration area and pick up my badge and tote bag (sponsored by Janssen) containing a printed program and Pharma flyers. I enter the large, dark general session room that is set up to accommodate a few thousand participants and move toward the bright, magenta and orange lights spotlights at the far end of the room. The large screen behind the wide stage and two smaller screens repeat the welcome greeting and theme. A slide show cycles through the names and professional portraits of AADE leadership and major award winners, and thanks the many corporate sponsors—all recognizable names in pharmaceuticals.

The loud pop music dies down and handsome emcee takes the stage. He welcomes the participants, thanking them for “all the hard work they do in the fight against diabetes,” starting an enthusiastic round of applause. After some more congratulations, corporate sponsor recognitions, and some meeting announcements, AADE President Joan Beardsley comes onto the stage. She steps behind the podium and reads a carefully prepared speech from a translucent teleprompter with the skill and poise of an experienced public speaker. From past meetings, I expect to hear about the
strength and importance of the organization, more congratulations to the attendees and sponsors, and a pitch to support the AADE Research and Education Foundation. Before getting to any of that, however, Beardsley leads with “Diabetes education is a right, not a luxury.”

I am intrigued by such an overtly political statement to an audience that had heretofore seemed to me oddly under-politicized given the direct relationship between health care policy and their day-to-day work. Over the course of the next 15 minutes, Beardsley spells out AADE’s vision for the ways diabetes educators should work toward increasing access to diabetes education for their patients. She states that they should:

• Demonstrate the value of DSME by tracking outcomes and reporting on data;
• Develop leadership skills and practice leadership in their organizations;
• Be involved and practice leadership within Local Networking Groups3 (LNGs);
• Increase the growth and visibility of CDEs as a profession within health care and among the public;
• Recruit new AADE members to further larger political goals, including reimbursement for implementing Diabetes Prevention Program (DPP) interventions, expansion of state licensure to guarantee reimbursement for DSME, and expansion of the scope of practice for DSME to include “all functions of DSME.”

I had noticed rumblings of these themes in sessions at earlier AADE meetings, however those sessions were not as well-attended as those that were focused on

3 Local chapters of AADE.
specific clinical skills or knowledge building. Here, the president of the organization is calling to the membership to advocate for the expansion and protection of the work of their profession: “We need to prove our value.” AADE is attempting to politicize its base and to assert authority over the terms of their work. Their professional project has just taken a major turn. Is diabetes education becoming a profession distinct from nursing and dietetics?

**Becoming a Profession(al)**

As professionals and experts in their field of study seeking legitimacy themselves, inquiries specifically about the professions were of particular interest to sociologists and educators in the early 20th century. One of the most often cited early examples of this work is Abraham Flexner’s *Medical Education in the United States and Canada* (1910), a report to the Carnegie Foundation for the Advancement of Teaching. Through his harsh critique of the unevenness of medical training and lack of unified standards for practice at the time, Flexner highlighted the absence of professionalism from the field of medicine by proscribing major reforms to the medical education system. By 1915, his criteria for professionalism become more cogent and he applied them to professions more generally:

> [P]rofessions involve essentially intellectual operations with large individual responsibility; they derive their raw material from science and learning; this material they work up to a practical and definite end; they possess an educationally communicable technique; they tend to self-organization; they are becoming increasingly altruistic in motivation. (Flexner 1957: 156)

Flexner’s writings established the criteria for measuring the relative
professionalism of a given occupation and set a an enduring bar for occupations seeking recognition as professions (e.g., social work) (Austin 1983). Indeed, Flexner’s report was responsible for the investment of unprecedented sums of private foundation funding into the implementation of his recommendations for the improvement and standardization of scientific medical education, a move that irrevocably changed the course of modern medical education and professionalization (Larson 1977; Starr 1982).

Definitions and Classifications

Carr-Saunders and Wilson agreed that members of a profession have a set of techniques and knowledge in common for their work, however, they added that “[a] profession can only be said to exist when there are bonds between the practitioners, and these bonds can take but one shape—that of formal association” (Carr-Saunders and Wilson 1964:298). That is, a professional is not simply a person who has skills and credentials to perform a specialized task, but one who also does this work in the context of a professional associations. Goode (1957) described the professional association as the “community of profession,” where a community exists by virtue of several characteristics including a shared sense of identity, continuity of membership, shared values, shared understandings of roles and obligations, a common language that is not fully understood outside of the community, collective power over individual members, clear social boundaries, and the ability to reproduce its members (through control of information and social networks needed to gain entrée).

The process of professionalization of the individual, then, must involve the
socialization into the community of a profession. The socialization process, including the enforcement of community norms, is somewhat obscured from the outsider; the community protects its own and mediates the relationships the professional practitioner has with the state and clients. Legal regulations limit who may participate in the market for a given occupation, and associations add a structure of accountability for members and present a public face of the profession. According to Carr-Saunders and Wilson (1964), Instead of diminishing the power of the formal associations to determine professional status for practitioners, increasing government regulation (licensure) made membership more desirable because it signals to the community of practitioners and the public at large that a member not only has completed the education and training requirements, but also has the respect and acceptance of their peers as a competent, trustworthy professional.

With a general description of the characteristics of professions in place, theorists turned to the task of defining a process by which an occupation becomes a profession. To this end, Wilensky (1964) studied a wide variety of occupations and observed the following sequence of professionalization:

1. Focus on the activity of the profession full-time
2. Establish a course of training;
3. Form a professional association;
4. Define boundaries for professional tasks and establish a pecking order for delegation;
5. Advance a political agenda to ensure protection of the revenue stream and exclusivity of the right to perform the activities of the occupation for members of the profession;

6. Establish a formal code of ethics to eliminate the unqualified and unscrupulous from practice, limit internal competition, and to protect clients and practitioners.

Given these broad criteria and the expanding push of occupations to achieve the status of profession, a new question emerged in the 1960s: Is what we have in our culture actually a professionalization of everyone (Wilensky 1964; Haug 1973)? This is an important question because if this is true, then professionalization itself would become meaningless and professional work would lose its special status among occupations.

Wilensky’s conclusion is that there have been fundamental changes to the organization of work that have created a class of semi-professions, program professionals. He stated, “End products of broad movements of social reform, these men [sic] combine professional standards of work with programmatic sense and constitute an important link between professional culture and civil culture, the man [sic] of knowledge and the man of power” (Wilensky 1964:158). The field of professions, then, remains limited because there are very few that can achieve the monopoly of authority needed to stake out sufficient jurisdiction over professional activities.

Hierarchies of Professions

By the 1960s and 1970s, with increasing bureaucratization of traditionally (largely autonomous) professional work, the shrinking of manufacturing and other blue
collar job markets, and the increase of access to higher education for the general population, the philosophical questions about the value and status of professions came into sharp focus. Emerging theorists contended that the power dynamics are more complex and contingent upon the larger political and economic context of the site of professional work and conditions of achieving professional status. For example, Freidson suggests “that what is critical for the status of medicine and any other profession is its ultimate control over its own work”—professional dominance (1970: 185). This means increased social power to not just exercise autonomy over its own work, but to also delegate work to other professions and further differentiate semi-professions within health care. Freidson asserts that the professions are a special category of occupation because they have worked to create and sustain the idea that this is so. This raises an question: If professionalism, then, is a social construct, then would this not lead to the professionalization of all work, a deprofessionalization, in essence?

Larson (1977) responds to Freidson’s work, further problematizing the notions of professional power by analyzing it explicitly in its capitalist context. According to Larson, there are two inseparable dimensions to professionalization—market control and social mobility. These conditions create a proletarianization of highly skilled, highly educated labor that ensures the cooperation and loyalty of the professionals to the increasingly market-oriented and hierarchical bureaucratic organizations in which they work (Marx 1967; Gramsci 1971). Professionals experience the bureaucratization of their labor differently from other workers because its hierarchical structure preserves the notion of
the professional’s special status apart from other workers while at the same time subjugating them.

With the rise of information technologies and expanded access to technical and scientific information that was once controlled by the professions, in order to maintain the specialness of professions, they have needed to appeal to their markets based on the value that they add through their work. According to Haug (1973), the value of a professional is not just in the knowledge they store, but in their ability to draw upon it to solve problems. In the present age, the public still relies on factors of cultural legitimacy in discerning which claims to believe and what to do with the information. We turn to people who “should know what they’re talking about”—experts (Collins and Evans 2007: 2). Competition in the market for professional dominance hinges largely on convincing the public of the appropriate boundaries and status of a profession relative to other professions: jurisdiction.

Through his system of professions concept, Abbott (1988) takes the view that jurisdictions of work are in perpetual flux—including the degree of autonomy in work—the jurisdictional view highlights the fact that these processes of degradation of professional work are not new; they are a part of the rhythm of occupations. Fights for jurisdiction, then, are not restricted to the academy or the degree to which one gains entrée into the right associations or institutions, though these are still valuable, but they also occur in public—drawing on their professional cultural resources (special knowledge, associations, codes of ethics, etc.) to sway popular opinion of legitimacy.
over jurisdiction. As Abbott observed, “That demonstrable legitimacy protects jurisdiction should be obvious. Societies have little time for experts who lack cultural legitimacy, irrespective of their success rates” (1988:54).

Since the professions have usually been separated out from the rest of the capitalist labor market, it was not until the discussion of the professions recognized the erosion of this distinction in the organization of professional work that sociologists applied countervailing powers theory it to the professions, particularly building on Larson’s (1979) and Johnson’s (1972) works that emphasize the use of the state to gain and maintain professional market control through monopoly powers. The pervasive influence of capitalism on medical practice in the U.S. and its implications for the processes of professionalization and the status of professionals (Navarro 1988) creates what Light (2000) describes as countervailing powers. According to Light, “the model of countervailing powers also takes into account the social roles of the state in forming, training, institutionalizing, and employing professions” (2000:203). Medicine provides an excellent case for demonstrating countervailing powers. Light (2000) states:
The central idea is to regard the medical and other health professions as one of several major countervailing powers in society, consisting of the state and employers as payers of health care, patient groups and enrollees as consumers of health care, the medical–industrial complex as producers of products and services for profit, alternate modalities or schools of healing and wellness, and perhaps other parties depending on the country and is sociological character (Light 1995). These parties have different interests, cultures, and goals that are in tension with each other, though significant alignments are possible. Each seeks, to a greater degree or less, and a more organized way or less, and with greater resources or less, to fulfill its interests. These too change over long periods of time. Thus, the rise of dominance of the American medical profession can be analyzed in terms of its alignment with cultural and institutional development in American society and with other major parties’ interests. (P. 203)

The medical industrial complex is but one example of the ways that professionals have become actors in a much more complex story where their power—along with the power of corporations, government, and consumers—has become contingent on several interconnected interests outside of the profession (Waitzkin 2000). What, then, is the special value of a professional occupation in our society when it is so stripped of the elements that defined the professions for so long? According to Light, the key is trustworthiness (Light 2000: 211). In the rest of this chapter, I draw upon these theories and perspectives on professionalization to illustrate the professionalization of diabetes education.

**AADE and Diabetes Education’s Professional Project**

As theorized by Larson (1977), a professional project transforms an occupation or group of practitioners of an occupation (labor) into a profession by way of three major processes: the production of professional producers (i.e., the making of new professionals who produce services for the market); monopolization of the certification
of competence; and monopolization of opportunities in the market, with the goal of monopolization of status and work privileges in an occupational hierarchy (Larson 1977:50-25). I describe these processes as phases of the larger professional project because while the activities that support them are not mutually exclusive, the achievement of the goals of one phase support the achievement of the subsequent goals (Figure 6).

![Diagram](image)

**Figure 6. Professional Project of the American Association of Diabetes Educators (AADE)**

These processes are supported by ideologies that begin in ethical and moral claims around the activities of the would-be profession—a *calling*—and progress through rational-scientific claims to expertise and cognitive exclusiveness (Larson 1977). In Larson's analysis of several professions, including those that are traditional and well-established (e.g., medicine and law) and more recent, emergent professions (e.g., engineering), she describes a pattern for the ideological progression through stages of the professional project. Phase 1 is characterized by the production of professional producers, which is enacted through organizing for the public good (Stage 1) and Standardizing Knowledge and Training (Stage 2). Phase 2 is characterized by the monopolization of the certification of competence (Stage 3). Finally, Phase 3 is
characterized by the monopolization of opportunities in the market, which is supported by securing licensure (Stage 4), expanding access to entering the profession (Stage 5), and achieving autonomy (Stage 6, enacted through stages 1 and 2).

**Stage 1: Organizing for the Public Good**

The profession begins with the rationale that organizing the activity of the occupation is for the public good and is not self interested. It is the position of AADE that diabetes education is important in the effective management of diabetes and that it is an advocate for diabetes educators and their patients.

**AADE Mission:** Empower healthcare professionals with the knowledge and skills to deliver exceptional diabetes education, management and support

**AADE Vision:** Optimal health and wellness for all people with diabetes and related chronic conditions (American Association of Diabetes Educators 2013a:3)

As Beardsley said in her opening comments that day,4 “Diabetes education is a right, not a luxury.” Throughout general sessions at AADE14, the speakers reiterated time and time again that it is because diabetes educators have a uniquely holistic understanding of the issues facing patients with diabetes that if they will organize, they can demonstrate holistic solutions for population-based health problems. Most importantly, they should do so.

**Stage 2: Standardizing Knowledge and Training**

In order to best serve the public interest, standardized training is necessary and leading members of the emergent profession are those who should determine the

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relevant knowledges that pertain to the activity of the occupation. This is achieved through universities where research, curriculum development, and programs of training establish the minimum base knowledge that professionals in the field should be expected to have. Furthermore, training socializes students into a shared understandings of the occupational hierarchy, cognitive superiority and exclusiveness, and establishment of personal identity as a professionals (Larson 1977; Abbott 1988; Apesoa-Varano and Varano 2014).

The relevant knowledge for a profession is heavily influenced by the structure and conditions of the professional market, which directs areas of research as well as the contents of the curriculum. As discussed in Chapter 4, the disciplinary underpinnings of professional diabetes education are nursing and dietetics, for which educational programs are plentiful. Research and curriculum specifically promoting and establishing best practices in diabetes education come from these academic programs in coordination with AADE. The relationship between these elements is stated in an AADE presentation:

AADE is the standard-setting body for the practice of diabetes education and creates guidelines, competencies, curricula and position statements. We also manage the advanced level diabetes management credential (BC-ADM) and accredit diabetes education programs. (American Association of Diabetes Educators 2014c)

AADE is thoroughly involved in diabetes education research through the AADE Research and Education Foundation and their peer reviewed research and practice publications.

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5 See Steering a New Course: 2013 Annual Report, American Association of Diabetes Educators
giving them direct influence over what qualifies as professional knowledge in diabetes education—the production of professional diabetes educators.

**Stage 3: Monopolizing the Certification of Competence**

With the standards and content professional knowledge established, certification would ensure the quality of services delivery and competence is best certified by organized members of the profession. It is in this way that members of the profession communicate to outsiders that an individual professional has the knowledge and skills required to perform the work with competence. Certification is a way for the profession to vouch for one of its members in a way that does not rely exclusively on social ties, which is useful to the client (at least in theory) for discerning whether they should trust the opinion of a given professional (Fontanarosa 2014). As certification develops, so does the educational system supporting it, establishing and maintaining a monopoly on the determination of relevant knowledge for the profession, its transmission to members of the profession, and controlling access to becoming a member of the profession.

AADE has achieved a monopoly on the certification of competence in diabetes education. AADE has over 14,000 members, of whom 63% are certified as CDEs or BC-ADMs (American Association of Diabetes Educators 2014c). The National Certification Board of Diabetes Educators (NCBDE) administers the examinations and maintains the registry of CDEs (including the collection of exam and application fees and tracking of
continuing education credits for periodic recertification). As of January 2015, there were 18,806 CDEs made up of 51% nurses, 40% dietitians, 6% pharmacists (National Certification Board for Diabetes Educators 2015).

While they are a separate organization from AADE, the exam contents are based directly on best practices and DSME/T curriculum published by ADA and AADE. Recently, another diabetes educator professional association has partnered with NCBDE, the Academy of Certified Diabetes Educators (ACDE). Started in 2012, ACDE was founded with the mission of providing resources specifically for the needs of CDEs. They are not in competition with AADE, stating “The Academy of Certified Diabetes Educators is focused on the needs of the Certified Diabetes Educator, whereas ADA and AADE membership, although open to CDEs, does not necessarily focus on meeting the unique needs of the CDE” (Academy of Certified Diabetes Educators 2014). Time will tell if ACDE will gain the membership and support to compete with this function of the AADE, however it appears they will continue to defer to AADE and ADA for research and publications.

Since 2009, AADE has been the sole accreditation agency for diabetes education programs that are eligible for reimbursement through the Center for Medicare and

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6 AADE also requires that applicants for the CDE complete their training requirements, which costs several hundred dollars in addition to the cost of sitting for the exam.

7 I only learned of this organization while researching the relationship between AADE and NCBDE; no participant or other professional association publications, materials, or presentations I observed refer to it. I joined the organization as an affiliate member in order to see what it was and as far as I can tell, it is a forum for CDEs to share information outside of AADE.
The American Diabetes Association recognizes programs, however they rely on AADE’s Diabetes Education Accreditation Program (DEAP) certification criteria (based on national standards\(^9\)) and the certification is the sole purview of AADE. Given the occupational hierarchy that generally gives medicine priority over nursing and dietetics, this is a major shift. Since the site certification program began in 2008, AADE has certified over 600 programs and 1500 sites (American Association of Diabetes Educators 2013c:10). Site certification requires staffing by at least one CDE, the use of the AADE7 curriculum, and record keeping and data reporting to AADE\(^{10}\) (American Association of Diabetes Educators 2013b). Susan explains the value of program certification from her perspective as a dietician (RD CDE) working in a hospital-based endocrinology practice within an interdisciplinary team. She states:

> I know this sounds really bad and I shouldn’t be repeating, but it’s kind of like a Good Housekeeping seal. ADA is the oldest certification or recognition to be approved. We have to turn in data. We have to keep this up. Any day they can audit us. It shows that we are teaching these nine areas of diabetes management. It’s showing that there is goal setting, that communication is open. When we get a contract from this patient, they’re signing it and it also goes to the doctor.

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\(^8\) While not all U.S. health care consumers are eligible for Medicare, its coverage is often used as the baseline for commercial health insurance coverage. Medicare is the single largest payor in the U.S. health care market, making certification attractive to health care organizations.


\(^{10}\) See *Diabetes Self-Management Education Core Outcomes Measures* (Mulcahy et al. 2003) for details on the AADE7 guidelines and the data that are used to measure its efficacy.
When I asked Susan what the nine areas of diabetes management were, she named the areas listed in the AADE7 curriculum. A part of the program is to engage the patient in setting goals related to the curriculum and writing them down in an agreement that becomes part of their patient medical record. The data they are required to report include de-identified biometrics (e.g., weight and blood test results) and the ways that the program content is delivered to patients. Susan continues,

> It helps our reimbursement, so that’s a plus! Especially if you are on Medicare, [. . . ] it ups the reimbursement rate. A lot of times private insurances follow Medicare [. . . ] Maybe what will happen is American Diabetes Association will put out a list and maybe those lists will be only recognized programs.

It is a costly process for her hospital, which is partially justified through automatic inclusion as a CMS-approved site (ensuring revenue), professional membership for one staff person in AADE (ensuring access to CEUs, publications, and other AADE resources), and the online AADE7 patient education management system\(^{11}\) (which facilitates the use of the AADE7 curriculum and provides a venue for data collection for AADE) (American Association of Diabetes Educators 2014a).

**Stage 4: Securing Licensure**

State licensure, depending on competence established through certification, is necessary to ensure that only recognized professionals perform the activities of the profession. According to Hodge, “the law directly impacts professionalism in patient

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\(^{11}\) I have access to this system as a member and went through the process of setting up fictitious patients in order to gain an understanding of how the system fits into the curriculum. There is room for some customization, but it is designed for delivering AADE7 curriculum and collects data used in EBM to demonstrate efficacy.
care by authorizing licensure of practitioners and entities, defining practitioners’ scope of practice, setting the appropriate [legal] standards of care and assessing liability” (2014:113). By establishing the exclusivity of the domain of their work, the supply of workers who achieve professional certification and meet the requirements of licensure is limited. The scarcity of expertise, in turn, supports the perceived value of the certification, elevating the profession in the hierarchy of health care work. In addition to regulating Medicare payment eligibility through site certification, AADE is actively engaged in lobbying and political advocacy to create independent licensure that would ensure that CDEs could practice outside of the purview of a medical provider or as an add-on to another service, such has MNT delivered by an RD (American Association of Diabetes Educators 2012, 2013d). However, they are clear that the definition of a qualified diabetes educator is that of the AADE:

> Without this “legal” definition, diabetes educators will continue to be self-defined. While payors may reimburse for the diabetes education service (DSMT), they may not recognize (reimburse) the provider of these services – the qualified diabetes educator.

> Diabetes educator licensure is intended for the healthcare professional that has a defined role as a diabetes educator, not for those who may perform some diabetes-related functions as part of, or in the course of, other routine occupational duties. (American Association of Diabetes Educators 2015e)

AADE certification represents not just a difference in area of focus or specialized training, but also functions as a boundary object in the world of diabetes care. According to Star, “boundary objects are a sort of arrangement that allow different groups to work together without consensus” (2010:602). Artifacts, tools, and ideas that distinguish a
group “become an object only in the context of action and use; it then becomes as well something that has force to mediate subsequent action.”

In considering the texts of diabetes care (e.g., SOPs, assessment, blood glucose log book), it is only when they are activated by use that they delineate roles and jurisdictions of the categories of actors that use them. The CDE certification and licensure, then, are intended as objects that arrange the diabetes care workers who hold them in a position that is superior to other non-physician and lay diabetes care workers in the occupational hierarchy.

The distinction between workers who happen to do some diabetes education in the course of their work and those who make diabetes education the center of their work is important to the CDEs I spoke with. According to Ella (RD CDE), another distinguishing feature is the role of bringing diabetes care from the various practitioners together in service to the patient. She states:

Certified diabetes educators are healthcare professionals that specifically focus on diabetes self-management, helping to create behavior change that can—along with the medical treatments, which is the responsibility of the physician to provide as far as prescriptions and medicines and adjusting doses and all those kinds of things—help all of those work. [..] So a certified diabetes educator is that individual to pull that package together. [Patients] may receive instruction about care from other healthcare [..], but it’s not as focused as what they get from a certified educator.

Ella clearly expresses deference for the activities that are outside of her legal and professional scope of practice (i.e., the management of medications is explicitly left to

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12 Italics in original.
doctors), however she is equally clear about the activities that are not only the domain of the CDE, but that can be done best by a CDE. Susan also underscores the difference having a CDE performing diabetes education makes in differentiating CDEs even from other dieticians: “If you’re seeing a dietician who’s not looking at a log book or if you’re seeing a dietician whose not even aware of your medications, then that’s not a diabetes educator. So I’m looking at the whole package.” These practices are codified in the standards of care, AADE7, the certification exam, and reporting requirements for site certification.

The diabetes workers that I spoke with universally expressed frustration with the non-professional diabetes care advice their patients receive in their communities and from their families. For example, Juanita (RN CDE) tells the story of a patient who is resistant to formal diabetes education:

Even though she's in denial, she's taking advice from everyone else except her medical team. "My neighbor, my friend said to do this." She's putting vinegar in lemon juice, and somebody told her that. So she's doing all this other stuff, but yet she doesn't do the medical part of [. . .] The doctor only wanted me to talk to her about nutrition because she thinks that that's the problem.

In this case, Juanita is frustrated that the patient takes the misinformed advice of a lay person over medical advice. She is also frustrated that the referring physician is undermining her efforts to help the patient understand the importance of adhering to the medical treatment by limiting her expertise in the eyes of the patient. Misinformed lay advice is so common that diabetes educators coach their patients through how to resist it. Janice (RD CDE) suggests that patients who are confronted with “food
policing”¹³ tell people, “I’ve been through education. I understand what I can and can’t do. And there really are very few foods that are out of bounds.” In doing so, she invites her patients to draw on the authority of formal diabetes education to assert their own autonomy.

According to Ella, misinformation from non-legitimate sources can complicate long-term diabetes management.

The misinformation that’s there can create barriers to the new direction or the new treatment plan for that patient. You have to overcome those in order to move forward. [. . .] With all that’s printed and all that’s available for diabetes, it still amazes me that people don’t reach out often—it’s very rare when a person says, ‘I visited already the ADA website.’

Because of the availability of diabetes information on the Internet, I was surprised to learn from the interviews that only a minority of patients do Internet research to learn about diabetes. Those who consulted ADA’s extensive patient education website¹⁴ or the variety of brochures they have available (either accessed online or through their doctor’s office) were fairly rare. If the patients lack buy-in that the “official” information sources are superior to what they learn watching daytime television programs (e.g., The View, The Doctors), their friends and family, or books claiming to hold the secrets to curing diabetes, then it is difficult for CDEs to assert authority based on their expertise alone.

¹³ Food policing is giving unsolicited commentary on what another person should or should not be eating. This is a very common issue for people with diabetes.

¹⁴ Http://www.diabetes.org
Licensure that enables greater CDE autonomy might be a step toward increasing CDE legitimacy with patients, but only if it is coupled with a public information campaign that increases visibility of the profession of diabetes education with both physicians and patients. As Jenny puts it, “doctors don’t refer and even if doctors do refer, patients may not go because they don’t understand the value of [diabetes education].” Susan echoes this concern and works as a part of a diabetes policy coalition to try to address it: “We go down [to the capitol] once a year, and of course we couldn’t beg for more money, but what we did say to our congress people is ‘Your constituents aren’t taking advantage of what’s being offered to them [through Medicare].’ [. . .] People don’t know what CDEs are.”

With the organization of health care work as it stands, CDEs who have conflicts with physicians are limited in what they can do when they disagree with them regarding patient care. Theresa (RN CDE) shares the story of her elderly patient whom she did not think would gain significant benefits from the increased complexity of adding insulin to her treatment regimen:

I didn’t tell her just not start insulin. I said, ‘You got two weeks [until your next appointment], talk it over with [your doctor], and he’ll tell you why you need it.’ So she goes and sees him, has a little [log] book, and she says, ‘I just saw the educator and she wanted me to show you these numbers to see if I really need insulin.’ She gave him the book. He threw it on the table. He says, ‘I told you to start insulin.’ She says, ‘But I saw the educator and—‘. ‘I don’t care what the educator says, I told you to start!’ He pounded the table and said, ‘I am your doctor and I told you to start insulin. They have no right of telling you not to start insulin.’ He says, ‘You come back in a week. I’ll have your A1C again.’ And he needed A1C to determine if she [even needed insulin] because she hadn’t had one for 6 months. What is he basing it on?
Theresa was careful to mind the boundary between her scope of practice and that of the physician. Instead of challenging it herself, she empowers her patient to ask questions of the doctor regarding her treatment. Theresa was shocked at the physician’s outburst and pressed her patient to seek another doctor. When CDEs make medication recommendations, they cross the boundary into the physician’s area, what between the CDE and the prescribing physician. Apesosa-Varano and Varano call “transgressing the diagnostic line” (Apesoa-Varano and Varano 2014:111). How well the transgression is received depends on the relationship between the CDE and the prescribing physician.

A physician conflict that particularly stood out to Mandy was when the physician ordered her to change the ways she was doing diabetes education. She states:

We use these forms for our patients who are on intensive insulin therapy. We teach them advanced carb counting where [. . .] they’re using an insulin-to-carb ratio and a sensitivity factor—there's a lot of math that goes on in there. [. . .] Because the [patient’s] education level is not there, we have what we call a cheat sheet. [. . .] Well, this endocrinologist called and said, ‘There's this form that you’re using. I don't want them relying on a form.’ I said, ‘You know, there are some that—‘I don't want them relying on a form. Don’t use that form again.’ And I said, ‘But there's patients—‘I don't want you using that form on my patients.’ I said, ‘Fine.’ I didn't win the battle. Unfortunately, because of that, it's required so much more intensive sessions. All for one piece of paper.

In this conflict, the physician crossed the boundary into diabetes education and pulled rank in dictating to the CDE how best to teach a math-intensive treatment protocol.

Furthermore, he did so, in the view of the CDE, without regard for the particular patient challenges she was addressing through use of the cheat sheet tool. Mandy, whose diabetes clinic relies on referrals from the physician, acquiesced to the demand, even though it made her diabetes care work more difficult and potentially less effective for
the patient due to their lack of numeracy. Lourdes (RN CDE) faces similar constraints when she disagrees with physicians. She notes:

I go and investigate and I may come back and present those other obstacles that they may not be aware of but I don’t say anything because I gotta work with them every day. I have to have a good relations. I need them, just as much as they need me. Because without them, I can’t get free samples.

The participants who had the most cooperation with physicians worked in team environments where physicians understood and respected their work and regularly referred patients to diabetes educators. Susan (RD CDE) works in an endocrinology practice that is staffed by physicians, nurses, dietitians, CDEs, and a clinical social worker. According to Susan, her ability to successfully challenge a physician comes down to her developing relationships with them. She notes:

There are some doctors that feel that they know more nutrition than I do, but when I develop a relationship with the doctor I can usually overcome it. I’ll just say, “You know you asked one question. I got a full diet history. That’s a formula [for caloric goals]. I [am] dealing with a person,” and I’ve never had a problem. I guess it’s just developing relationships. So, any educator who feels that they’ve [had conflict], then they haven’t developed a relationship with their doctor.

Mandy has had a similar experience. While she lost the battle in the cheat sheet tool example above, other physicians in her hospital-affiliated diabetes education center seek out her professional expertise: “One doctor said, ‘You know what you’re doing. That’s why I send them to you.’ They’re general practitioners. They know a little bit about a lot of stuff.” Even in interdisciplinary, hospital-affiliated clinics, it takes some time for physicians to recognize the value of CDEs. As Janice (RD CDE) puts it, “I’ve been
there 15 years. And I would say over the last five years we finally have our doctors on board. They love us because we do a good job."

At this time the CDE certification is voluntary for doing the work of diabetes education and “does not confer any permission to manage diabetes beyond the limitations of the individual’s professional practice” (National Certification Board for Diabetes Educators 2012). Independent licensure that depends largely on the CDE certification and/or compliance with national standards for diabetes care and curriculum would further the professional autonomy of diabetes educators and legally restrict the market for who could receive payment for these services to those who hold the diabetes educator license. By establishing a health care profession outside of nursing and dietetics, diabetes educators could be in a better position for negotiating the boundaries of their work and expertise with physicians and other providers.

Consistent with AADE’s position on what it means to be a qualified professional, NCBDE has also issued a position statement expressing their concern that lesser (by their definition) certification standards would diminish the quality of diabetes education. They suggest that the CDE certification supersede other examinations or pathways to licensure (National Certification Board for Diabetes Educators 2014). This would protect the monopoly that AADE (through NCBDE) has on certifying competence for diabetes education.
Step 5: Expanding Access

Clarifying the career path and revising the certification process and requirements of certification have been high priorities for AADE since 2011 (American Association of Diabetes Educators 2011b, 2013a). In addition, there are now numerous workshops and textbooks available for exam preparation that were not as readily available to the more experienced CDEs I interviewed. When asked about how they became diabetes educators, most described a process where their work in dietetics or nursing had become increasingly occupied with diabetes care as a result of patient demand. The stories are varied since there has not been a clear path to becoming a diabetes educator until recently.

If the new career path as proposed by AADE at AADE14 (described at the beginning of this chapter) goes according plan, there will be different points of entry into the field of professional diabetes education, a more clear set of requirements and avenues for achieving them, and additional opportunities for recognition for those who became CDEs before these changes. The most significant changes are the addition of a certification category that recognizes lay diabetes educators (i.e., diabetes educators without an existing health care license such as community health workers) and the revival of an advanced certification designed to acknowledge more senior professional diabetes educators. These categories are integral to a directed career path whereby mentorship is a formal part of the process.
With a clear educational and training path, specific requirements of certification and licensure, and standardized training content, entrance into the profession is theoretically available to all who have the desire, the work ethic, and talent to do so. However, according to Larson, positioning professionalization as a meritocratic process stands in conflict with the exclusivity established through certification and licensure (Larson 1977:50-52). This brings to question the degree to which these processes are meritocratic and democratizing since not all persons who would like to become professionals have equal access to education, mentorship and social networks, or the means to participate in the processes of credentialing and licensing (e.g., tuition, fees, study materials, and time). Indeed, while those with the Level 1: Associate Diabetes Educator (ADE) certification would not qualify to become CDEs, it does extend the reach of AADE over the activities of lay educators and reinforces the boundaries between which work they may or may not do, enacting professional dominance and often marginalizing the activity of those who the less powerful in the field (Freidson 1970a:369; Bowker and Star 1999:298; American Association of Diabetes Educators 2015c).

**Stage 6: Achieving Autonomy**

The ultimate goal of a professional project is to achieve the right to individual entrepreneurial practice of the profession. To this end, AADE is calling on its members

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15 The exception to this is a new “Unique Qualifications” pathway, which stipulates that some ranges of DSME work experiences and expertise may qualify an applicant for the CDE.
to prove the value of diabetes education and to get involved in organizational leadership, both through AADE and also where they work (Burke et al. 2011). The calls for leadership and demonstration of value and pervasive throughout the present era of health care. Slavkin suggests that, “Perhaps as never before, leadership is urgently needed to envision the future, to reallocate resources, to monitor progress using information technology, and to engender both evidence-based as well as outcome-based health care for all Americans” (Slavkin 2010:36). Professionalism among health care leadership is key to “ensuring the commitment of the organization[s] to patients’ rights and well-being,” a serious consideration when often what is best for the patient is at odds with what is best for the organization (Fontanarosa 2014:146).

Among diabetes educators, there is an acute awareness that their job security depends on the recognition of their value in health care and that this is most easily demonstrated in terms of revenue generation in for-profit health care. Lydia, who works in a hospital-affiliated outpatient clinic explains why demonstrating value in these terms is difficult:

Unfortunately, we fight for our existence because it doesn’t make money, even though we have the research that shows that it works. […] Reimbursement’s an issue. But we’re constantly in threat of being closed and that’s happened nationally because we’re not moneymakers. Because we’re not black and white with our money. We’re making lifestyle changes that impact the whole medical system, [but] that doesn’t look good on a budget.

Mandy is the director of the diabetes education program for the hospital where she works and she faces the same pressures:
What we do doesn't necessarily generate revenue. We're lucky to break even with a small profit, potentially, but they're shutting down diabetes programs left and right. Education's one of the first to go, so we're fortunate in that they support what we do and they find value in what we do. They keep us around, but it's very difficult to track the downstream revenue—cost savings—that we provide. You know, that's our goal. It's not necessarily to make money, but to prevent complications and things down the road for these folks.

The majority of diabetes care workers I interviewed mentioned recent closures of diabetes centers across the metro area due to budget cuts over the past few years. They are distressed by this trend because it is reducing the number of CDEs available for patients at a time when the incidence of diabetes diagnoses is rising. AADE provides materials for members to pitch the clinical and economic value of CDEs to practices and health care organizations. For example, the speaking notes of a canned presentation titled “Diabetes Educators: Supporting You, Empowering Your Patients,” AADE includes the following script:

Diabetes educators can help you. When we assume time-consuming patient training, counseling and follow-up duties, it helps you increase your efficiency; as well as meet pay-for-performance and quality improvement goals. We track and monitor your patients’ progress and provide you with status reports. And we can help your high-risk patients delay the onset or escalation of diabetes through prevention techniques and self-management training. [If applicable, let your audience know your direct effect on meeting performance goals required in the Affordable Care Act.] (American Association of Diabetes Educators 2014:8)

In addition to supporting CDEs who wish to partner with medical practices and hospitals, AADE also offers a number of resources to members who wish to engage in more entrepreneurial pursuits such as starting a diabetes education program, making the business case for diabetes education, securing reimbursement, developing business plans, and marketing their services (American Association of Diabetes Educators 2013a,
One of the newer benefits of membership is online access to a reimbursement expert to assist CDEs with billing Medicare and other payors for their services. By providing a resource to members that further empowers them to maximize reimbursement from payors, AADE is equipping CDEs who wish to work independently from a medical practice or hospital to further their autonomy through financial independence.

Strange Bedfellows: Pharmaceuticals and Diabetes Education

When I entered the field, I expected to see a large Pharma presence in diabetes care because medical management is the dominant treatment paradigm. However, I was surprised by the depth of the involvement of Pharma in terms of AADE conference sponsorship, CEU event sponsorship, and support for individual diabetes educators working in the field. It struck me as odd that there would be such a presence given that, one of the often cited benefits of diabetes education is that it has the potential to reduce the need for medications, thereby reducing the cost (and profits) of diabetes care. What could possibly be in it for Pharma?

Everywhere you look at an AADE conference, you see a pharmaceutical company logo. AADE has created an Industry Allies Council which recognizes different levels of financial support from corporations and rewards them with increased visibility to AADE membership (through prominent logo placement, access to AADE membership mailing lists, and co-sponsorship with official AADE functions such as CEU events),

Pharmaceuticals include medical devices for this discussion.
depending on their level of financial contributions to AADE and the AADE Research and Education Foundation (American Association of Diabetes Educators 2013c, ). In exchange, the stated benefit to AADE is to “establish a more stable industry support environment for AADE” (American Association of Diabetes Educators 2015b).

In clinic waiting rooms, I noticed a broad variety of diabetes education pamphlets, all with recognizable Pharma logos on them. In interviews, when I asked DCWs about what sorts of tools they use in the course of doing diabetes education, virtually all of them either specified tools from particular companies such as the popular Low Blood Sugar handout from Novo Nordisk (see Appendix C). Some DCWs expressed frustration when discussing workplace policies that prohibit the use of any educational materials with Pharma logos, especially since some are especially useful. Their frustration is compounded when their employers also fail to allocate budgets for purchasing unbranded versions of the materials from health information publishers. DWCs often find ways around this limitation, such as producing their own materials with the same information and telling patients about online patient support programs. For example patients have free access Novo Nordisk’s Cornerstones4Care17 program, where they can get the Low Blood Sugar handout without receiving it directly from a diabetes educator. When I asked participants about their interactions with pharmaceutical sales reps (reps), the responses were a mixture of appreciation and apprehension.

17 Cornerstones4Care program details can be found at https://www.cornerstones4care.com/ (accessed February 20, 2015).
Frequently, blood glucose meters are given to clinics that treat diabetes free of charge. As a primary tool for diabetes self management, having an actual meter on hand with which to train patients in how to properly measure their blood glucose levels is helpful. There are many meters on the market at a wide range of prices, but many patients who are seeing an educator soon after diagnosis or those who cannot afford the out of pocket cost receive a free meter from the clinic. Meghan (RD CDE) is concerned with the ways that CDEs rely on free blood glucose meters:

Any time there’s something that’s being given for free there’s this sense of, “What are [their] expectations?” […] I’m sure the reps give stuff out free expecting that the people are going to use their meter and I get that. […] Ideally, I would have a stock of every single brand that was out there and [patients] can choose whichever one they wanted and then we would teach from there, but that just doesn’t happen. […] In the real world, this is the way we’re functioning. […] I just have mixed feelings about a lot of the this stuff. I don’t want to feel like I’m indebted to some company ‘cause I use their meter, or something.”

One of the major problems she has with this model is that the meters that are on hand are not necessarily the ones that are best suited to the patient and test strips may not be covered by insurance, a considerable expense at an average of $1.00 per strip.

Meghan feels that her lower income patients who receive a meter at their diabetes education appointment have less freedom to choose the device that is most appropriate for them in comparison to better insured and/or affluent patients who are in a position

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18 In some cases, meters are also shipped to individual educators since they do not require a prescription. Since I am a member of AADE and I spoke with a representative from LifeScan, they have sent me 16 start up kits that include a meter, a small number lancets and test strips, and a carrying case. I have also received a higher end meter kit from iHealth that works through an attachment to an iPhone. I have subsequently donated these meters.
to purchase the meter of their choosing. Susan is also acutely aware of the primary role
of reps as promoting sales of their products, but she has a more collegial relationship
with reps. She states:

We really lean on a pharmaceutical company because they have wonderful materials. I would say nowadays the sales people for pharmaceutical companies—I look at them as developing relationships. Obviously they’d love for their medication to be used the most, I mean let’s not be foolish, but they are there to help the patient, as well. [. . .] These are great, free tools. They are wonderful. [. . .] But I would say the committed sales people who’ve developed relationships are like an educator I can lean on for financial support and guidance, or how about this or how about that? So I don’t really like to call them sales people even though that’s probably what they are.

Susan sees reps as a trusted resource for helping her patients get what they need.

Several participants described the ways that Pharma provides free or low-cost CEU
opportunities for them above and beyond the material support they give for educational
materials, drug samples, patient assistance programs, and other activities.

As I observed at conferences and CEU events and learned from DCWs, a new
question occurred to me: If prescription drug sales depend on filled prescriptions and
the vast majority of CDEs do not have prescribing privileges (it is outside of the legal
scope of their licensure), why would Pharma invest so much money in their
relationships with diabetes educators? With this in mind, I approached at least a half
dozens pharmaceutical sales representatives involved in diabetes care that I encountered
in the field, either at conferences or in clinical settings, to see if any of them would be
willing to talk to me confidentially about their work. The reps I approached directly all
redirected me to a public relations contact. Brian, a Pharma rep who works for Pharmco,
was referred to me by a NP CDE participant who relies on him for discount vouchers and information regarding new drug development.

Brian and I met at a café in the middle of a weekday, just after the lunch rush. On the phone, he told me he required anonymity because participating in the interview would be grounds for dismissal. As the primary earner in his family, he was concerned about the measures I will take to protect his confidentiality, much more than any other interview participant I have encountered. He declined the incentive I offer him for fear that it would create a “conflict of interest.” His sensitivity about financial incentives makes sense in the increasingly restrictive legislative context for pharmaceutical sales. Over the past 20 years, and especially since 2004, several laws have passed that limit the types of incentives and contacts that pharmaceutical reps may have with providers. Brian has been with the company for 10 years and has seen a dramatic shift as a result of the changes. He noted:

> You know, it’s not quid-pro-quo [. . .] at least it’s not something that we engage in at all. Those days where you used to be able to do some type of entertainment stuff are gone. I mean those restrictions on the pharmaceutical industry have changed so drastically it’s—people I think are really surprised if they’d know how limited the amount of stuff we can do in terms of entertaining.

With financial limitations in place, Pharmco’s sales strategy has changed substantially. Brian’s compensation no longer depends on sales within his territory, but instead is

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19 A detailed discussion of the legislative shifts is outside the scope of this dissertation. However, the broad trends have to do with ensuring transparency and limiting the ways that pharmaceutical companies may interact with physicians. The concern is that pricey incentives bias physician prescription choices in such a way that the financial interests of the prescriber and pharmaceutical company are put above the patient’s health interests. For a list of legislation at the state and federal levels, see *Marketing and Direct-to-Consumer Advertising (DCTA) of Pharmaceuticals* (Hanson et al. 2013).
mostly tied to the ways that Pharmco’s customers (prescribers) perceive the company.

Under the new program, Brian’s focus has shifted to “adding value” by “partnering” with physician’s practices through “giving them resources to help their patients, [so] they’re more likely gonna continue to have those patients a) take better care of themselves and b) continue to be their patient and not go to another physician.”

The new service-oriented sales strategy was developed in response to restrictive legislation as well as in response to the increasing role of the insurance industry in pre-determining which drugs will be sold through inclusion or exclusion from formulary lists.

Conventional sales approaches matter less when the decision is not solely up to the prescriber and patient. Even though he is paid less money under this new model, Brian prefers working this way:

For me, it feels better to go into an office and to honestly focus in on the person that you’re calling on, the physician or the nurse, whoever’s treating diabetes. It could be an office staff member, sometimes it’s a medical assistant. They might do a ton of education in that office. In the old model, they don’t write prescriptions, so you didn’t care. You didn’t spend time with them because all you wanted to do was get to the end user whose writing a prescription.

One of the primary ways that Pharmco supports medical practices is by offering diabetes educational materials in print and online through an interactive website that supplements AADE7 curriculum (though they are not explicitly branded or endorsed by AADE). They also have videos available on DVD or for online streaming so that patients can play and re-play parts as needed, learning in their own time. Some companies also offer the services of a CDE to fill in the gaps where there are insufficient numbers of available CDEs. Ella, who works for a competing pharmaceutical company, explains:
You may have even heard from some of my peers that many of the diabetes programs that have been available in communities are actually shutting down more and more and more. As the number of people with diabetes increases, the usual venue for a patient to get information would [be to] come to the hospital where they have a diabetes center and a diabetes program where classes were a part of that. And more and more every year we hear about more and more of those programs closing down.

As a CDE, Ella (RD CDE) travels throughout a region in the metro area that is largely medically underserved. She offers diabetes education classes for patients free of charge to physician practices where they do not have ready access to a diabetes educator. Ella presents the AADE7 curriculum for all patients, but the company requires that in order for her to offer the service, there needs to be at least one patient who is on a drug that the company offers. Patients on those specific injectable drugs are given additional instruction on how to use them properly.

In the present legal environment for pharmaceutical sales and the ways that prescribing decisions are influenced by insurance company formularies, it makes sense for the pharmaceutical industry to find other ways to appeal to prescribers. By providing resources to diabetes educators, including substantial donations to AADE, Pharma increases access to prescribers through a gatekeeper that the law does not restrict in the same ways as physician interactions. The instrumental support they provide through educational materials and, in some cases, offering diabetes education classes, serves the prescribers and not the diabetes educators, a distinction that is well camouflaged in the industry face that is presented through AADE. Educators are right to feel some apprehension about Pharma’s motives since the resources they offer to health care
practices have the potential to undercut their efforts to monopolize diabetes education through professionalization. While diabetes education is underfunded and under-supported within healthcare organizations, Pharma and AADE seem to have a mutually beneficial arrangement. As policies evolve, however, this relationship will undoubtedly shift.

**Conclusion**

Throughout the course of conducting this research, I have talked to countless diabetes care workers who consider themselves to be professionals or professionals-in-training in their fields. In interviews, they cited their education, training, certifications, and work experience as the special qualifications they have achieved that set them apart from others who might deliver a necessarily lesser form of diabetes education, including physicians and lay community health workers. The AADE is urging its membership to demonstrate the value of their special knowledge to health care organizations in order to secure more stable employment in diabetes education for its members and expanded funding for diabetes education centers.

Observed through the framework of the professional project, diabetes education is effectively becoming a profession distinct from nursing and dietetics. AADE has shifted its focus toward politics and mobilizing its membership base in support of the organization and its legislative efforts in order to pursue the final stage of professionalization: professional autonomy. Their success or failure in securing legislation and licensure that supports their autonomy will affect the health care
industry beyond patient care, further complicating their relationships with providers, payors, and Pharma. The elevation of diabetes education within health care would serve both the diabetes educators and also the patients with whom they are interdependent.

By examining the place of diabetes education among other health professions and their relationship with Pharma, I have shown the ways that diabetes educators negotiate to gain the resources with which to do their work, to garner the cooperation of other health care professionals, and the ways they are affected by stakeholders outside of their sector, namely Pharma. In the next chapter, I will present another dimension of negotiated diabetes care: the use of patient data as a primary currency in negotiating diabetes care.
CHAPTER 6

TECHNOLOGY, DATA, AND POWER IN DIABETES CARE

In the negotiated care perspective, the overlaps between social worlds are where exchanges occur and, in the process, the stakeholders negotiate in order to secure the resources they need in order to do their work. By mapping the exchanges of major elements of diabetes health care practice, we are able to see larger patterns of exchange in the health care system as a whole. Based on observations and interviews, I have identified five primary stakeholders in clinical diabetes care: DCWs, Providers, Payors, Pharma, and Patients (Figure 7). As discussed in Chapter 4, DCWs provide DSME, MNT, case management, health information, and other services to patients. In order to gain the resources they need, including access to patients, continuing education units, and access to prescription drugs and lab tests on behalf of their patients, they negotiate with Providers, Payors, and Patients. In exchange, they offer patient data that are used by Pharma to develop and market their products, by Payors to contain health care costs, and by Providers to manage patient care and secure payment from Payors.
In this chapter, I present the best practices in blood glucose self-monitoring (BGSM)\(^1\) and show the ways that patients, providers, and diabetes educators negotiate diabetes care through BGSM practices. The diabetes log book, the data-text produced by and under direct control of patients is a particularly useful site for observing the negotiations and power dynamics inherent in navigating the health care system of patients. I begin with an overview of best practices (based on SOP documents discussed in Chapter 4). Then I draw on interviews with diabetes care workers, primarily CDEs, to

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\(^{1}\) The terms blood glucose self-monitoring (BGSM), testing, and checking are used interchangeably in the literature and among health care providers.
introduce the diabetes log book as a site where patients exercise power in negotiations over their care, situating their data-work in the discourse on patient compliance.\(^2\)

**Best Practices (The Ideal Case)**

According to Hayes and Aspray, “patients as well as providers must participate in treatment to achieve optimal outcomes in diabetes. Both must gather and share vital information” (Hayes and Aspray 2010:34). This reflects a shift in the culture of health care toward patient self-reliance that we see in managed care and shared decision making (SDM) and the availability of increasingly sophisticated and patient-friendly blood glucose monitoring technologies.\(^3\) What began as point-of-care (POC) blood glucose testing in the health care practice setting, a massive improvement over urine glucose testing in terms of accuracy and usefulness for achieving tighter glycemic control for insulin-treated patients, has evolved into an $8.8 billion industry worldwide\(^4\) (Hughes 2009:1219).

As we saw in Chapter 4, BGSM is a central feature of the standards that define good diabetes care in the U.S. This has been enabled by technological innovations that have made blood glucose testing patient-friendly, through the development of meters

\(^2\) For the sake of limiting the scope of the dissertation to the work of diabetes care, I have chosen not to take up the issues around expertise and knowledge that the analysis of the log book invites. This is a limitation to this research that I will remedy before publication.

\(^3\) These personal medical devices are referred to as blood glucose monitors, blood glucose meters, meters, and glucometers interchangeably. I will default to meter for the sake of simplicity.

that are small in size, easy to operate, and relatively accurate. In the process, the expectation has been set that patients will act as technicians in the collection and reporting of blood glucose data to their health care providers, “not only shap[ing] a therapeutic plan, but also [paying] attention to habits and lifestyle and develop[ing] competences in self-monitoring” (Bruni and Rizzi 2013:33). Those who do this data work correctly are “good,” “compliant” patients (Broom and Whittaker 2004; Gingras and Aphramor 2010). What follows is an overview of the ways patient data are collected, transmitted, and used among patients, providers, and diabetes educators (Figure 8).

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5 See Blood Glucose Meters 2014: Will meters be more accurate? And Getting the Most from What You Have by Wahowiak (2014) for a consumer-facing explanation of the state of the technology and issues around accuracy.
The Patient-Technician

Patients collect data by regularly testing their blood glucose levels with a blood glucose meter and recording the value into a log book (Appendix D). If they are working with a diabetes educator and/or dietitian, they may also be measuring their food for accurate portion sizes and recording the nutritional information for the foods they eat into a similar log. The logs for both are created either by manually writing things down (into a log book or a food journal) or using technology, such as smart phone apps and websites where patients can enter the data and/or select from drop-down lists or the use of personal medical devices that record blood glucose data and upload it to software. Patients report on these data by bringing their log books and/or printed reports from software to appointments with providers and diabetes educators. In addition to these data, patients are expected to report on medication use and their perceived state of wellness/illness. Ideally, patients have regular visits with their provider and diabetes educator, they the adopt the behaviors the diabetes care workers have prescribed for them, and they follow up with the practitioners as requested.

The Provider

For newly diagnosed patients, the provider preforms an assessment to gather information about the patient’s medical history, lifestyle, medications, and biometrics. Based on the diagnostic test results, the provider prescribes medication. At this time, the provider will have a trained practitioner in their practice (e.g., a nurse) demonstrate blood glucose testing to the patient, if they have meters on hand. Otherwise, they will
request that the patient return to the office after acquiring a meter or that they go to diabetes education for instruction. For established patients with diabetes, the provider reviews the patient-reported data and orders lab tests to monitor the physiological effects of the medications and/or lifestyle interventions on the patient. Based on the test results, the provider may adjust medication, refer the patient to a diabetes educator, and/or refer the patient to another provider (in the event of complications or other comorbidities).

The provider and patient agree on a treatment plan (which lists details about medications, follow up, and referrals) and, if the patient is referred for other services (such as diabetes education), then they also produce a referral document for the patient, insurance, and the diabetes educator. For diabetes education, the referral document specifies which treatment, usually DSME or MNT (occasionally insulin titration instructions, too) the diabetes educator or dietitian is to provide the patient, including billing and diagnostic codes. In practices where it is possible (e.g., through shared practice or electronic medical records systems in the same health system), the patient’s chart, which contains the lab test results and treatment plan, is made available for the diabetes educator or dietitian. Referee practitioners report to the provider on their work with the patient, data that providers use in adjusting treatment plans going forward.
For new patients, regardless of the duration of the diagnosis, the diabetes educator performs an assessment (similar to the one the provider has already done) that includes additional questions about diet history and lifestyle. For all patients, the educator reviews the treatment plan and lab test results with the patient to assess the way the patient understands the provider’s instructions. The patient reports on their medication use and their state of wellness/illness. The educator provides information to the patient depending on the prescription (i.e., DSME or MNT) and teaches the patient how to collect and report data on glycemic control (blood glucose meter readings recorded in a log) and their lifestyle choices (food, and sometimes exercise, listed in a journal or diary). The educator reports on the progress of the patient in terms of their compliance or (non-compliance) with the treatment plan and DSME/MNT. In this report, the educator may make suggestions to the provider for future treatment plans and request that lab tests be ordered for the patient.

Data Transmission

The transmission of the data from patients to providers and educators is generally verbal and paper-based. Sometimes a patient is asked to make a copy of their log and to fax it to the provider or educator’s office during periods of close monitoring (e.g., during insulin titration or after repeated episodes of hypoglycemia). Providers and

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6 Personal medical devices, automated reporting, and web-based patient-physician access portals are changing this, albeit slowly.
educators have more options available to them now that more health care organizations are adopting the use of electronic medical records (EMR) and digital data submission in order to receive payments from CMS (American Association of Diabetes Educators 2014d; Centers for Medicare & Medicaid Services 2014).

A common feature in EMR software products is a communication platform that allows messaging between providers and educators and from both to patients, in compliance with HIPAA requirements (U.S. Department of Health & Human Services 2003). Since digital communications between health care practitioners and patients depend on so many factors (e.g., computer literacy, Internet access, and the presence of the HIPAA compliant communications platform), most still depend on paper and verbal communications as the default mode unless all involved parties are working on the same system (as in the case of group practices and hospitals that have adopted EMR). A large problem with the health information systems as they are is they contribute a fragmentation of care. This is particularly problematic in the management of chronic illnesses where “the odds of coordinated care are quote low if the various care providers are not part of the same organizational structure” (Hayes and Aspray 2010:67).

**Blood Glucose Self-Monitoring and the Diabetes Log Book**

Blood glucose self-monitoring (BGSM) is a central focus of DSME. A significant portion of classroom and one-on-one time is spent teaching patients how to test their blood sugars using blood glucose meters. Often the meters have been donated by a
pharmaceutical company and it is in the first meeting with the diabetes educator that
the patient receives the meter and training in how to use it. Self-monitoring is crucial for
patients who depend on insulin in order to avoid hypoglycemia, a dangerous drop in
blood sugar. However, the positive relationship between self-monitoring and patient
outcomes for type 2 patients who only take oral (non-insulin) medications is less certain.
(Farmer et al. 2012; Polonsky and Fisher 2013; Shah 2014; Houle et al. 2015).

Nevertheless, by definition in the SOPs that govern diabetes care, a key component of
diabetes self management is monitoring. As Bruni and Rizzi observe, “[t]he glucometer
and the glycaemia logbook are the main instruments involved in patient disease self-
management” (Bruni and Rizzi 2013:33).

When a patient tests their blood glucose, they must follow a protocol to ensure
that a good sample of their blood has been taken, that the equipment is in good
working order, and that their data are recorded. A blood glucose testing kit includes a
meter, lancets, test strips, and a lancet device (Figure 9).

![Figure 9. Blood Glucose Test Kit](image-url)
Generally, the steps to testing are as follows:

1. Wash your hands. (Note: Warm water also improves circulation.)

2. Load the lancet into the lancet device (a spring loaded needle that is set at a predetermined puncture depth).

3. Load a new test strip into the blood glucose meter to turn the meter on. It should indicate on the display that it is ready.

4. Press the tip of lancet device against a fingertip and press the trigger to puncture the skin. Squeeze the fingertip until a round droplet of blood is on the surface of the skin.

5. Without smearing the blood, touch the edge of the test strip to the droplet. Wait for a few seconds.

6. Read the blood glucose level number on the display.

7. Record the number, time of day, and any relevant details about medication and food as context for the number in the log book.

The frequency of the testing depends on the types of medications the patient is on (i.e., if a patient is taking multiple types of insulin, they will need more intensive self-monitoring in order to safely use those medications). However, in practice, as Peter (MD) says, “the intensity of the checking depends on where you are, what your complications are, and what your goals are.” Furthermore, the frequency of testing is also set based on the affordability of testing supplies and the willingness of the patient
to follow the protocol. When asked which patients do not test, Peter describes them this way:

People who are frustrated. People who don't have money to buy test strips. People who don't want to bother testing. And some people, really, if their hemoglobin is 6.0 and they're testing once a week, I can't hassle them too much because you're right on target. But on the other hand, if it's 9, you should be under 7. [If] your glycosylated hemoglobin\(^7\) was 9, and you're not checking your sugars, I'm gonna be pretty concerned about that. Honestly, check at least once a day. [. . .] One a day and it gives enough measurement over a couple of weeks. If you have enough money, you can do three a day for me. The more data I get, it's all helpful information. And what limits you is the patient's willingness to test. And also asking them to buy this stuff. And the strips are expensive.

As a provider who specializes in caring for patients with endocrine disorders, especially insulin-treated patients with diabetes, Peter nominally ascribes to the clinical guidelines for SBGM in diabetes care in referring to A1C test values as target thresholds for glycemic control. However, we see that he compromises his expectations of patient testing depending on the patient's A1C. He observes the expense\(^8\) and patient’s willingness to test as key variables and he adjusts the instructions for testing to increase the likeliness that the patients will follow through, giving him some data from which to make decisions about their medications. Peter typically receives the data in the form of a log book.

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\(^7\) Glycosulated hemoglobin, A1C, HbA1C all refer to the same laboratory test that gives a three month average measure of glycemic levels. It is used in combination with BGSM. People without diabetes have A1C values at or below 6%. The guidelines for a patient with diabetes are to reduce their A1C to keep it below 7%.

\(^8\) On average, test strips cost about $1.00 each. If a patient is testing three times per day, that amounts to a $90 cost per month for test strips if they are uninsured or underinsured.
Typically, a log book is a booklet or sheet of paper (Appendix D) on which people record these data with a pen or pencil. New blood glucose monitoring devices (e.g., meters, continuous glucose meters, and insulin pumps), however, have built in log book capabilities. That is, the device stores the number and time of day (and other data that might be input by the user) until it is uploaded either by plugging the device into a computer via cable or wireless network. The highest-tech meters on the market today are able to store the data in the cloud wirelessly in order to share it with several concerned parties, such as the patient, caregivers, health care practitioners, and the device manufacturer. In these cases, the patient is assumed able and is expected to print out the reports to bring with them to office visits (Appendix E).

Among practitioners, there is near consensus that SBGM is crucial to the safe management of type 1 and type 2 diabetes because it allows for adjustments to insulin and/or food that can prevent dangerous episodes of hypoglycemia (Clarke and Forster 2012:91). When it comes to non-insulin-treated type 2 diabetes, however, it is unclear as to whether there are health benefits to SBGM and there is wide variance in the ways that it is used in practice. Despite the controversy over its efficacy for managing non-insulin treated type 2 diabetes, SBGM is a core component of DSME in part because it supports medical management. Patricia (NP CDE) explains, “If they don’t test the blood sugar, we don’t have data to know what’s going on with their blood sugars. It’s hard for us to adjust their medications or to prescribe medications.” As a nurse practitioner, Patricia has prescribing privileges and acts as the health care provider for many patients
in her outpatient endocrinology clinic. Like Peter (MD), Patricia frames the importance of SBGM as a way for it to aid the provider in patient management. Unlike Peter, Patricia does not discuss strategies to accommodate reasons that patients may not test, suggesting perhaps that testing is less negotiable to her as a CDE.

Cynthia (RD CDE) describes a common difference between the way that providers and non-provider CDEs approach testing:

I’ll say, ‘Did your physician ask you to check your blood sugars?’ They say, ‘No, he just said to come back and have it checked. He’ll check my blood every three months or every six months.’ I will usually say, ‘Well that’s okay, but that doesn’t really give us a very good picture of what’s really going on on a day-to-day basis. And if we want to make sure you don’t end up on more medicine, then I think it’ll probably be a good idea if you took care of that at home and you really monitored that.’

As a CDE, Cynthia believes so firmly that SBGM is crucial to diabetes management that she contradicts the providers’ instructions. By using inclusive language and identifying with her patients (the repeated use of “we”), she suggests to the patient that they can achieve a better outcome if the patient follows her advice. This does not overtly challenge the authority of the provider, but Cynthia is asserting her expertise as a CDE and conspiring/building rapport with her patient in the process.

For professional diabetes educators, interpretation of SMBG data is an activity through which they distinguish themselves from non-professionals and assert their credibility. Recall the way Susan (RD CDE) distinguished professionals from non-professionals in Chapter 5. She said, “If you’re seeing a dietician who’s not looking at a log book or if you’re seeing a dietician who’s not even aware of your medications, then
that’s not a diabetes educator.” Indeed, Susan places strong emphasis on the importance of the log book from the very beginning of her relationship with the patient in the initial assessment:

Well the assessment can be—well the physical assessment, the diabetes assessment could be anything from—everything. I mean it’s insulin, the storage, how are you taking it, is there a leakage, how many times are you checking your blood sugars, where are you recording that.

As discussed in Chapter 5, one of the ways a profession gains authority is through the use of science to guide their activities. Another way to consider the importance of BGSM data, then, is in the ways that our culture privileges “objective” numerical data over subjective qualitative data. Linda (RN CDE) describes the way she uses the data to gain credibility when negotiating insulin use with a patient or provider who does not believe it is necessary:

So the way that you can prove to the patient and/or the physician that they actually need that back in the picture, is for a patient to do two hour post-prandial checks—two hour after-meal checks. And that probably many times will reveal, ‘Oh my gosh, look how high this patient is after meals! It’s because you’ve taken out the pill that was once there that needed to stay, but insulin needed to be added in addition.’

In a way, this use of the patient-collected data supports the reasons that providers Peter (MD) and Patricia (NP) advocate for BGSM: to aid in medical management. The difference, however, is that because medical management is outside of the SOP and licensure for the vast majority of CDEs, they are not using the data to make medication changes, but rather to influence the decisions of those who do have that power. Their
authority in this case is limited by the quality of the data that the patient is willing and able to provide.

The Diabetes Log Book As a Teaching Tool

Diabetes educators use a variety of methods to deliver the AADE7 DSME curriculum. Regardless of the medication a patient is prescribed, their work with the diabetes educator usually begins with BGSM. For example, Janice (RD CDE), who works in an outpatient setting, describes her usual routine for the first visit with a new patient:

“You assess them, go over all their medications, and teach them the meter. So you do all that preliminary stuff and get them going and then they have four classes.” Ideally, a patient who is attending DSME classes will already have a meter before they begin. The educators like for that to be established before they are in the classroom because they do not want to use classroom time to teach the patients how to use a particular meter, given that there are several on the market. As a part of instruction on the use of the meter, patients are shown how to record the data into their log books. Log books already in progress are useful in the classroom. Susan (RD CDE) explains:

So, you know we have the log book which is an education tool right there, because if they focus on the log book then they know that they’re looking at their blood sugars. We can teach them from that. We can teach them on how the blood sugars are affecting their food. Carb counting. It all comes from that log book.

In addition to establishing the expectation of BGSM with the patient from the outset, it is a common approach for educators to draw on the patient’s own data in order to teach them more complex concepts, such as the relationship between the
carbohydrates they eat and their blood glucose readings. Janice (RD CDE) describes her approach:

We ask them to keep food records, we ask them to keep blood sugar records, and then we kind of talk about it with their permission. [. . .] so you try to guide them and say “This is what I see.” Don’t tell them what to do, but “This is what I see. How can you make improvements to improve the balance in your diet or the nutritional value?” Because some people eat pretty calorie dense and very low nutrient dense foods. So you try to direct them in that way.

In this example of a one-on-one strategy for using the log book as an educational tool, Janice’s approach demonstrates the sense that patients have ownership of their data and the process of managing their diabetes. By asking permission before using the data in the education session and presenting her observation in a way that allows the patient to interpret it, she guides the patient to the conclusion that she wants them to take from the observation and keeps the onus on them to make the decision to act.

In some cases, patients work together to interpret the data as a group—peer education. Joan (RN CDE) describes the way this happens in an educational support group she runs for insulin-treated patients:

It’s not really social, but they feel comfortable around other people that they learn are going through the same thing. We do an insulin titration group. So we look at all the log books, we have to have them sign a HIPAA consent. [. . .] So we simply put all the blood sugars up there [on a marker board], and we put the medicines, and then we talk about how they compare to the target ranges, and what do you think we need to do to improve this?

Joan’s group is unusual in this approach. Working in a public clinic that does not charge for diabetes education, Joan has had more freedom to develop ways for her patients to learn complex concepts such as how to adjust their insulin based on BGSM data.
However, she is still subject to the laws that govern patient privacy through HIPAA. Because of institutional constraints around billing and privacy policies, it is uncommon for patients in a diabetes education classroom setting to share their data with other participants in this way, however helpful it might be.

The lessons that diabetes educators are teaching through the log book are how to collect and interpret BGSM data in order to “empower” patients to manage their disease. Audrey (RD CDE) explains:

I think helping empower people to take more control of their diabetes is gonna help their quality of life. That’s probably my main—my main goal is just helping quality of life for the person, whatever that is for them.

Perhaps the most important lesson that patients receive, from the perspective of the diabetes educator, is how to be a good diabetic. This is not the language that the participants used, but elements of goodness and badness can be found throughout when they discuss their successful patients as being controlled or they express frustration with non-compliant patients. The language they use around these ideas reflects current discursive shifts, popularizing the language of empowerment or adherence over compliance.

(Non-) Compliance, (Non-) Adherence, and Patient Empowerment

As the participants have demonstrated, they use “(non-) compliance,” “(non-) adherence,” and “empowerment” when discussing their patients. I was careful when asking questions about the ways that the participants worked with patients because of the debates over language usage in this arena (Lutfey and Wishner 1999; Bissell et al.)
2004; Broom and Whittaker 2004; O’Rourke 2006; Cyrino et al. 2009; Sandman et al. 2012), not using any of these terms until the participant did. I was curious to see if there would be any patterns related to disciplinary training or practice setting relative to the usage of (non-) compliance, (non-) adherence, and empowerment. Both the MD and the NP in the study used compliance language, which might be attributable to their medical training. The rest of the participants used a combination of the terms without any particularly strong pattern. For example, Hector (CDE) does this when describing his difficult-to-manage Veterans Administration patients:

   Our patient population I think is [. . .] a reflection of what happens in society at large. I know that the American Diabetes Association wants to stay away from using that term, ‘non-compliance,’ but I cannot think of any other term, and there are patients that admit, themselves, [that] they’re non-compliant, not adhering to their treatment.

In referring to the ADA, Hector acknowledges that he is breaking with the language shift that his profession endorses and he explains it is because he believes the change has no real meaning. What I found was that the participants usually meant the same thing regardless of which term they used: the degree to which the patient was following their instructions and the provider’s instructions for their care.9

   The controversy over which language is used to describe patient behaviors with respect to provider instructions is rooted in the ideological divide between the traditional patient-provider relationship where the provider instructs the patient and

9 This is why I have chosen to use “compliant” in my analysis, recognizing that it is the underlying concept the participants are re-packaging.
the patient follows their instructions (compliance paradigm) and the more recent shift
toward shared decision making (SDM) and the collaboration of patients with their
providers to agree on a plan which the patient is then expected to follow (adherence
paradigm) (Sandman et al. 2012). Under the compliance paradigm, the concern is the
degree to which a patient follows the instructions of the provider, implying that
determining the course of treatment is the sole purview of the physician. According to
Sandman et al., compliance “describe[s] a situation where the health professional arrive
[sic] at specific medical or health advice by consulting biomedical research for what is
statistically in the best interest of the patient group to which the patient belongs, based
on a professional view of what this ‘best interest’ [is]” (Sandman et al. 2012:115).
According to Lutfey and Wishner, “the very word ‘compliance’ suggests that patient
acquiesce to, yield to, or obey physicians’ instructions; it implies conformity to medical
or medically defined goals” (Lutfey and Wishner 1999:635). In this patient-provider
relationship, the provider exercises power in setting the terms of the treatment and it is
the patient’s responsibility to follow the instructions. When a patient does not comply
with these requirements, compliance language “suggest[s] a moral flavor to the social
consequences of not adhering to a treatment regimen: a ‘noncompliant’ patient is also a
‘bad’ or ‘difficult’ patient” (Lutfey and Wishner 1999).

Adherence shares many characteristics with compliance, but is distinct in its
“attempt to recognize a patient’s right to choose, and to remove the concept of blame”
(Horne 2006:66S). Moving away from the biomedical model, adherence is intended to
recognize patient autonomy and the social context of care. This is an important point because, as Lutfey and Wishner (1999) observe, this perception of the patient affects the care patients with diabetes receive:

In diabetes care, labels of patient ‘compliance’ affect the types of regimens they have, which, in turn, affects their likelihood of incurring long-term complications. Patients who do not manage regimens well and are not able to maintain tight control are more likely to be labeled ‘noncompliant,’ and, as a result, are often advised to manage their blood sugars in ways that will minimize hypoglycemia and its accompanying danger at the expense of maintaining higher average glucose levels. Because patients with these regimens maintain higher average glucose levels, they are more likely to have complications. Insofar as the process of labeling patients as ‘noncompliant’ has social aspects that have not been thoroughly explored, the shift to an ‘adherence’ paradigm can improvise our understanding of patient behavior and thereby further improve glucose control. (Lutfey & Wishner, 1999, P. 637)

Lutfey and Wishner suggest that by changing the language and thereby refocusing care decisions and behaviors on the autonomy of the patient and understanding patient motives for their choices, the underlying biomedical, compliance-based philosophy of care should be reformed, expanding the range of options available for patients to achieve good health outcomes without compromising on the quality of their health care.

The relationship between adherence and SDM depends on the way SDM is defined, since there are many variations in the value placed on the ideals of patient autonomy and the resultant expectations in decision making that are imposed on the patient. According to Sandman et al., “the concept of personal (in this context, patient) autonomy consists of four components: will or preference (henceforth termed preference), decision, action, and the intermediate relation of ‘because’” (Sandman et
al. 2012:118). Accordingly, for a person to be self-determined, their actions need to match their preferences. The ‘because’ factor is important in determining to what degree the preferences truly belong to the patient. The more aligned the activities are with the preference and the more personal the reason for it, the more autonomy the patient has (Sandman et al. 2012). That is, if a patient is following a regimen to please their provider or to avoid conflict, that patient does not exhibit a high degree of autonomy in comparison with someone who does it because they do it in order to live more healthfully. By this logic, a patient who does not adhere to a regimen may very well be exercising autonomy by doing so.

In DSME, there is a strong push away from compliance and toward adherence, especially through the lens of empowerment. In 1991, Funnell et al. published an influential article that helped to make the transition toward DSME as a tool for patient empowerment. In it, they promote the value of the expertise that patients have in their own lives and position patients as partners in their care. They highlight the partnership with patients in their definition of empowerment:

Empowerment is an interactive process of cultivating the power in others through the sharing of knowledge, expertise, and resources. Thus, it is more than just a new approach to patient education. Empowerment represents a conceptual shift in the relationship between patients and educator. The patients are no longer just consumers of our services, but active partners in the provision of their diabetes care. (Funnell et al., 1991, P. 41)

From an empowerment frame, the patient and educator are equals where “patients are seen as experts on their own lives, and the professional is seen as the expert on diabetes who serves as a resource” (Funnell et al. 1991:38). The educator uses their
professional tools to impart the skills that the patient will need in order to manage their
disease through DSME. When discussing patient empowerment, Juanita cites education
as crucial element:

You empower them by educating them, number one. There’s a great prophet
that said, ‘My people perish because of lack of knowledge.’ Ever so true today. If
a person is empowered with that, number one, and as you’re educating, you’re
educating yourself. [. . .] Our first visit, [I tell the patient] you’re the teacher and I
am at your mercy because the more you share with me the more I can help
you.’[. . .]

I give them the respect that they’re due and then I try to learn as much as I can
about them. And then give back to them [on] what they feel would help them,
with some added tools that they can consider. So they’re empowered through
that knowledge and other things that can come around that.

Recall from Chapter 4 that Juanita works in a hybrid community/outpatient hospital-
based clinical setting that does not bill for DSME services and where she has a large
degree of control over how diabetes education is done and at what pace. The way
Juanita talks about the respect she has for the patient and the addition of diabetes tools
toward the goals the patient sets are consistent with the ideal of patient empowerment.

It’s Up to You: Personal Responsibility

In diabetes care, the preference for the term adherence in DSME reflects the
underlying principle of patient-centered care where the patient is expected to take
responsibility for their own care by setting goals and achieving them. When most of the
participants mentioned empowerment, they frequently did so in the sense that DSME
requires for patients to “take ownership” or be “team leaders” in their care. Mandy (RD
CDE) says to her patients: “You as the patient are part of the team. The team doesn’t manage you. You are the leader of that team and you employ us to help you.”

Diabetes educators have a clear sense of where their responsibility for the patient’s care ends and where the patient’s begins. When asked about the responsibilities or duties of the patient, virtually all participants were clear about their role as a the provider of information and their patient’s role as the one who is responsible for following through. Linda (RN CDE) approaches it this way:

It’s all, I would say, up to them. We can give them the tools for what they need to do to manage their diabetes and we can show them that you can lead a healthy life with diabetes. But when it comes down to it, it’s up to them, so it has to come from within them.

Mildred (RN CDE) agrees with Linda. While she asserts to her patient that it is her choice whether to follow the diabetes management regimen, Mildred also provides additional contact information in order to make herself available to assist the patient.

What I tell the patient is, ‘I can give you all the information that you need and I can help you, but ultimately the decision is totally up to you and it’s your body and you can do what you want. But if you want the help, you can call me. Here’s my number. I have an email. You know, it’s totally up to you.’

To manage diabetes is up to the patient, however “successful management” has a specific meaning in the world of diabetes care. Patients who achieve “good control,” keep their blood sugars between the guideline thresholds, make regular progress toward achieving glycemic control, and follow the instructions of their practitioners.

Susan (RD CDE), who refers to this as “ownership,” describes it this way:

Ownership could be, it’s like setting goals. And that because we’re a recognized program as of a couple months ago we’re having patients set goals. And so
ownership is checking their blood sugars. Obviously we’d like for them to check more than once a day, but if that’s what we can get, that’s a starting point. Ownership could be ‘Don’t forget about your appointment.’ Or, ‘If you need to change your appointment, call.’ Don’t do a no-show. Ownership can be anything when it comes to a great—if you’re a person that you’re checking your blood sugars three times a day, great. Ownership could be ‘Fax those numbers to us.’ So it depends.

The specific activities that are expected of the patient are that they will coordinate their health care appointments, that they will do BGSM, and that they will report their data to the educator. Goal setting is so fundamental to diabetes care work that some of the participants include it in their description of diabetes care work. Janice (RD CDE) includes this element among others:

Diabetes care work means providing information and resources to people to [. . .] enable them to participate in their own self-management care and to achieve the goals that they would like to in terms of blood sugar control, reduction of long-term complications, weight management, and really even psychologically improving their self image.

Goal-setting is a key component of the AADE7 curriculum and AADE site certification. The underlying principle is that having patients set goals for themselves and write them down for themselves as a part of their patient record, it will engage them in shared decision making with their diabetes educator. Most frequently, patients are offered a range of goals that directly correspond to AADE7 outcomes and objectives. In theory, this type of patient engagement is supposed to yield higher patient compliance. When asked about what frustrates them in their work, the participants consistently talked about institutional constraints and patient compliance. Patricia describes her experience:
It’s very frustrating—very frustrating to see patients over and over again make the same mistakes or do the same, um, noncompliant behavior. I mean they come in for their appointments, [. . .] but they’re not doing anything that we asked them to do last time, you know, to help themselves get better, but they’ll keep their appointment. Some of them just don’t even show up, then, after a while. [I say to patients,] “You need to do these things in order to help yourself in addition to what we’re giving you ,” and they realize the work that they actually have to do to help themselves [and] they don’t come back.

Imparting ownership is an important part of teaching the skills for patients to advocate for themselves, but limiting the options available to the patient in a way that boils it down to compliant or non-compliant belies the degree of power it is assumed patients can have in negotiating with health care practitioners. In their research on empowerment discourses in dietetics, Gingras and Aphramor reported a question that was posed by the West Midlands branch of the British Dietetic Association in 2005 that captures the essence of the empowerment most of my participants describe: “Can we empower our patients to increase their compliance to treatment?” (Gingras and Aphramor 2010:82).

Cooking the Log Book: Patient Non-Compliance or Agency?

One of the things that demonstrates patients’ difficulty in speaking up and questioning their providers’ decisions regarding their care—one of the issues “empowerment” is supposed to address—is the ways patients work to appear compliant even when they are not. It is so common a practice for patients to turn in falsified log books at provider or educator visits that the practitioners expect to see it.

Peter (MD) describes what he is looking for when he sees a patient’s log book: “A log book that has any number written in the same color ink on the same line is probably
fake. I want a log book covered in blood, with different colors of ink, with tattered pages, and some pencil marks in there, too” (Figure 10). A log book that is too neat and too perfect raises a flag for the provider because the conditions of testing are simply not that neat and orderly.

![Figure 10. Example of an Ideal Log Book](http://www.management-krankenhaus.de/sites/management-krankenhaus.de/files/images/special/3411492_preview.jpg)

Similarly, Susan (RD CDE) includes testing the veracity of the log book data in her description of the assessment:

Well the assessment can be—well the physical assessment, the diabetes assessment could be anything from—everything. Everything imaginable. I mean it’s insulin, the storage, how are you taking it? Is there a leakage? How many times are you checking your blood sugars? Where are you recording that? We’ll check to see that the information in the meter is correct to the log book.

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Patients who enter the data from their meters manually, either on paper with a pen or pencil or by entering the numbers into software, sometimes record numbers that are more favorable than the actual value. This is done to appear compliant, avoid conflict, or to please the practitioner. Susan assumes there will be falsified numbers and has built data verification into her patient care routine. She does this by cross-checking the numbers that are recorded on the log book with those that are stored automatically in the meter. Instead of telling the patient this is what she is doing, Susan (and others) do this under the guise of checking the meter to ensure it is working correctly. Patricia (NP CDE) gives us another example of this:

One of the things is trying to get patients to be honest with me about how they’re doing their medications. I mean if they’re not checking their blood sugars, I kind of know. They don’t bring their readings in, they don’t bring their meter in. Okay, they’re really not checking their blood sugars as much as they say they are. And even patients who bring their meters in, they may forget that they have it or something and, ‘How often do you check your blood sugars?’ ‘Oh, about five times a day?’ ‘I want to check your meter because I want to make sure your meter is working okay. Do you have it with you?’ Sure, they give me their meter—they’re checking two or three times a day. So, I don’t know if it’s the perception that they’re checking more or if they just want to please me. But part of my challenge is to get them to be honest with me so I can help them.

Since she is the provider for her patients, Patricia relies on the data to make prescribing decisions for their medications. Patient data falsification makes it difficult to gauge the effectiveness of a treatment regimen or to detect when changes might be needed. The patient’s non-compliance with BGSM limits Patricia’s ability to do her job, which might cause harm to the patient in the long run. Because of patient BGSM non-compliance,
some practitioners rely primarily on the A1C blood test to verify patient data and to supplement it. Cynthia (RD CDE) explains how it works:

The very sophisticated machine that does this test can give us an average of what your blood sugar has been. So I can calculate what your average blood sugar has been, based on the number that it gives us. So if it says your blood sugars, your A1C was 6.6, which is just into that new [diabetes] diagnosis, your blood sugars have been probably right around 130, which is high enough to be considered diabetes. If you have an A1C of 9, 10, or 11, then we’re talking in the 2s, and even 300s, as an average blood sugar.

Ultimately, the practitioners want for their patients to check their blood sugars regularly, record them accurately, and report them when requested in order to help them make treatment decisions. Simply verifying and supplementing the falsified or missing data will not achieve this end. Audrey (RD CDE) takes a different approach in order to gain greater patient compliance with BGSM:

What I try to do is—you have to establish a relationship with somebody. So you can’t say, “Well, you know, obviously you’re not telling me the truth.” But what I’ll sometimes do, and in this particular case, he hadn’t had any blood sugar records [and] didn’t have any food records. So I say, “You know what? Let’s have you keep a record for two weeks and come back.” Because it may be that maybe he’s at this point not eating very much and what he is telling me is truthful. Or maybe he’s eating more than he realizes, because a lot of times what happens is people just don’t realize, because they think of their meals only as what their eating, and they don’t think about their snacks or other things that they might be eating. Or they want to tell you their best thing. If the MD asked me, I want to tell the best thing that I ate. I’m not going to say that I’m having a Ho-Ho at night or whatever.

The importance of developing rapport and trust with the patient in order to ensure greater compliance with diabetes self-management and to facilitate giving patients appropriate, useful information when they need it came up in several ways in the interviews. As we see in these covert data verification processes, however, trust is not
reciprocated from the DCW to the patient. This dynamic belies the notion that DSME is at all a collaborative process in which patients are truly driving their own care.

Audrey offers a couple explanations for why patients might falsify their data: misunderstanding of when they are supposed to test and wanting to appear compliant. She recognizes that even she would falsify data if she had to report on what she was eating in order to give the appearance of virtue. As with all choices that patients make, they make them within the constraints of their social, political, and economic context where their priorities might be different from those of the practitioner at any given time. That is, patients make choices among a subset of options that are actually available to them, constrained choice, and to judge their actions without understanding their constraints leads to negative moral judgments inherent in the “non-compliant” label (Bird and Rieker 2008). I am unable to discern the actual reasons that patients have for turning in false data, but all of the participants would agree with Hector’s (CDE) assessment: “Why is it this patient is not maintaining an A1C? Because it’s human behavior. You’re dealing with humans.”

For many patients, non-compliance is enacted through the log book. It is the data-text that they alone control. The “good patients” do not engage in these activities, but it is a common enough situation where patients have falsified data that it is a part of the routines around patient visits. Technology can undermine patient agency in this way. The A1C is used to verify the values in the manual log book. For digital log books, the automation of data recording and reporting reduces the opportunities to falsify data
and imposes greater responsibility on the patient to learn how to recognize and manage patterns. In a way, it extends the surveillance of the patient by the powerful institution and its members. Educators respond to this form of non-compliance by redoubling their efforts to educate the patient about the importance of BGSM. Non-adherence can be a way to exercise patient agency (Sandman et al. 2012:116). However, through the lens of adherence, it is presumed to be a lack of understanding and not a rational choice.

**Conclusion**

CDEs use an empowerment discourse to engage in collaborative care as defined by the their health care disciplines. However, their frustration with patient non-compliance, whatever they call it, belies the collaboration they suggest to their patients. As Gingras and Aphramor (2010) observed in their research on dietetics professionals, the empowerment they try to instill in their patients is empowerment to comply, an *empowerment-compliance complex*. Diabetes educators are empowering their patients to comply with the treatment/management regimes imposed by the doctrines of patient centered care, personal responsibility, and the AADE, which mandates BGSM for patients with diabetes. CDEs who are more attuned to what motivates their patients toward non-compliance frame their activities as barriers (e.g., cost, misunderstanding instructions, unwillingness to test, diabetes burnout), but the barriers in this case are *barriers to compliance*. Through DSME, CDEs systematically enact the empowerment-compliance complex in developing *good diabetics*: patients who have internalized the
dominant medical discourse of control and management so that it seems not only rational, but also morally right—what Foucault calls governmentality (1994).

BGSM is a cornerstone of DSME. The processes of data collection, data recording, and data reporting discipline the patient into compliance with the dominant diabetes treatment/management regimes. Therefore, when the log book is used as a teaching tool to “get patients to understand,” or to “convince them” that BGSM is an important, worthwhile activity that they should engage in if they want to be “good” patients who are worthy of the interest of health care professionals, it activates the master texts of health care policy. As Mol ([2006] 2008) sees it, the main problem with individualistic health care that is done in this way is it prioritizes a logic of choice over a logic of care, where “shoulds” and “oughts” not only prescribe behaviors, but also attach a moral value to it. She explains:

‘Choice’ was framed as a normative project: granting patients the possibility of choosing is a good thing that should be put into practice. However, when public health campaigns encourage us to ‘choose a healthy lifestyle’, something different is happening. Suddenly it is assumed that, as it is, the way we live already follows from the choices that we make. Nobody stops you from living in a healthy way, now, do they? (Mol [2006] 2008:67)

Labeling around patient compliance, in whatever language, imposes a morality on the choices patients make under a market-driven health care system where patients are consumers and the products they receive are bounded, well-defined transactions (Mol [2006] 2008:23). In contrast, if DCWs were working from a logic of care, where “care is an interactive, open-ended process that may be shaped and reshaped depending on its results,” the focus would be not on whether the patient was compliant, but rather on
whether the results of the care are better (Mol [2006] 2008:23). Through the logbook text, the activities of the patient are regulated by frontline care workers, an activity that is itself regulated by professional guidelines and standards of care, which exist to *enact* the dominant health care discourse that uses “patient centered care” to uphold the neoliberal doctrine of personal responsibility. Without a logic of care as the underlying philosophy of the health care system, the discursive shift away from compliance and toward empowerment will be little more than a change in the words we use to describe patient behaviors.
CHAPTER 7

NEGOTIATING DIABETES: PROFESSIONAL DIABETES CARE WORK IN THE U.S.

The Diabetes Care Work Study is an institutional ethnography (IE) of the problematic of diabetes care, investigated from the standpoint of frontline diabetes care workers (DCWs), using several data types and beginning with the question, “How is diabetes care done?” This research is based on in-depth interviews with participants in a large Midwestern metro area who work in a professional capacity with patients who have diabetes (primarily diabetes educators). I also performed ethnographic field observations of professional association meetings, continuing education events, and other social events for diabetes care professionals. Finally, I analyzed the texts that coordinate the activities of professional diabetes care in order to gain a better understanding of the factors involved that might support or inhibit effective diabetes management. Most IE research is centered on the interactions and activity that occurs within a single organization or firm in order to understand the connections between that activity and the world in which it exists. By taking the standpoint of people working in the same arena, though not the same organization, this research contributes an example of IE performed on a larger-scale social institution, in the same vein as DeVault’s (1999) research on nutrition professionals.
This research takes up the suggestion that Social Worlds Theory (SWT) should be central to health care research that focuses on practice in the context of policy (Tovey and Adams 2001). Building upon Strauss’ (1978), Figert’s (1996), and Clarke’s (2005) conceptions of SWT, it contributes to the literature by demonstrating the flexibility of this theoretical framework to expand beyond arenas and into the larger context in which those arenas are situated. It also presents an alternative view of the structure of U.S. health care as overlapping social worlds, rather than as a hierarchical structure, which accounts for external factors that affect the negotiations that occur where the worlds overlap and highlights the ways that the actors and their work are not discrete entities within the system.

This research defines and demonstrates the utility of a negotiated care framework for understanding the fluidity of the interactional work and power dynamics in decision making that occur in health care. Through negotiated care, I present the everyday frontline carework that DCWs do, the professionalization of DCW, and the ways that patient blood glucose self monitoring (BGSM) data are used in negotiating their care. Throughout this research, the dat show the ways that the various stakeholders leverage resources, such as money, patient data, medications, and political power in order to achieve their ends and the connections between the hyperlocal experiences of the patient-health care practitioner relationship (individual), the larger area of practice (profession), the health care system (cultural institution), and the society in which they all reside.
This research contributes to the literature on SDM by expanding the scope of inquiry beyond the physician-patient relationship and adds to an emerging literature on SDM for chronic conditions, especially diabetes. Furthermore, it does so from the perspective of frontline care workers who are structurally positioned as an intermediary between physicians and patients, a vantage that provides insights into not only their position, but to their relationship with those who have more and less structural power than themselves. Viewing the processes by which patients and their health care practitioners arrive at therapeutic decisions overtly as negotiations recognizes the fluidity of power in these interactions, a necessary precursor to the collaboration that the contemporary patient-centered care and empowerment health care delivery models (such as the medical home model) require.

By examining professional diabetes care work from the standpoint of those doing the work (primarily diabetes educators), we learn not only what is included in the standards of care for diabetes management, but the ways that those texts coordinate and regulate the actions of the workers. Through the study of the texts that govern their licensure and define their areas of practice, we see the work that participants do that is beyond the scope of their licensure. That is, the invisible social casework that DCWs perform largely without adequate training, recognition, compensation, or institutional support, but that they do anyway in service to their patients. Their out-of-scope work points to larger, structural problems that leave their patients in need of assistance with
food security, medications, mental health care, and social support—things patients need in order for diabetes self-management education to be effective.

In order to understand how diabetes educators access what that they need to do their work (e.g., patients, educational tools, status, credentials) in negotiations with other non-patient stakeholders (e.g., providers, pharmaceutical companies, payors), I presented the state of their profession and the way it is situated in the organization of U.S. health care. By observing the American Association of Diabetes Educators (AADE) through a Professional Project frame, I revealed the political and professional priorities of the emergent profession of the diabetes educator. Because diabetes educators do not yet enjoy professional autonomy, they rely on other stakeholders within the health care industry in order to gain the financial and political power to assert their expertise and exclusive domain over diabetes education. At present, AADE is supporting political activity toward securing independent licensure that would liberate much of the work of Certified Diabetes Educators (CDEs) from medical oversight. If they are successful in elevating the status of diabetes education within healthcare, it is likely that it will become more available to the patients that need it and the workers who wish to enter this field.

Finally, with an understanding of the work of professional diabetes care and its organization in the larger health care system, I turned my attention to the negotiations that occur between the frontline DCWs and their patients. The participants show us the ways that DCWs experience the fluidity of power dynamics with their patients, who
solely produce and report the daily blood glucose data which clinicians use to inform
their recommendations and prescriptions for medications: the diabetes log book.

Through the production and transmission of patient data through this patient-produced
data-text, we see how patients, providers, and diabetes educators negotiate in order to
achieve (or not) goals that are set by the dominant biomedical regime: patient
compliance. Situating it in the compliance/adherence/empowerment health care
discourse, we see the practice of BGSM as an extension of the doctrine of personal
responsibility that belies the notion that patient-centered care is anything other than an
extension of institutional power. This is an important point if we will embrace the ideal
proposed by patient-centeredness through health care reform.

In addition to the contributions this research makes to the knowledge on SDM,
each of these areas of inquiry also makes contributions that could improve diabetes
care, the conditions for frontline care workers, and future research in these areas. By
exposing the invisible social casework involved in diabetes care work and its centrality to
providing good patient care and achieving good patient outcomes, this research
contributes to the literatures on carework and diabetes care practice. The examination
of the professional project of diabetes educators contributes a contemporary example
of professionalization to a long-established, though recently less active, literature on the
professions. It also sheds light on the role of the pharmaceutical industry in health care
that extends beyond the production of medicine and conventional pharmaceutical sales
which, if expanded in future research, will contribute to the literature on the
pharmaceutical industry in clinical practice. Most importantly, however, this study contributes to the literature on patient-centered care, particularly by demonstrating the ways it is limited in the current system. Without attitudinal change and changes to the health care education systems, the doctrine of compliance and its limitations will persist, especially in chronic illnesses such as diabetes.

Looking Ahead

There are limitations\(^1\) to this study, primarily in the narrowness and homogeneity of the sample, time and budgetary constraints, geographic constraints, and the institutional form of the doctoral dissertation. However, the depth of the data on the practices of the DCWs who participated and the commonalities among their experiences they shared, language they used, and the concerns they raised suggest that this study provides a firm foundation for expanding the research by conducting more extensive preliminary literature reviews per topic (breaking with the IE form), interviews, and observations related to the major themes I presented in this research (and those I have set aside for future research). In order to gain other perspectives, the methods used for this study can also be applied to other stakeholder groups such as patients, providers, payors, and the pharmaceutical industry. New research questions include:

- How does “professional care” differ from “care,” more broadly?

\(^1\) These are discussed at length in Chapter 3.
• What is the relationship between trust and compliance and their implications for diabetes care?
• How is non-professional diabetes care done?
• How is DSME experienced by patients and their families?
• How does diabetes factor into patients’ decision making?
• What is the role pharmaceutical industry in diabetes care?
• How do payors influence diabetes care?
• How do public discourses on diabetes (as observed in mass media) relate to health care discourses on diabetes?
• How do providers do diabetes care?
• How do providers view diabetes educators?

Another area for expansion is to replicate the study in the contexts of other health care systems in order to examine the role of payor structures and culture on diabetes care. Most immediately, I am interested in doing this work within the U.S. Veterans Administration. Then, I would like to expand the research into cities in Canada, the U.K., and the E.U. The goal would be to produce a book-length study comparing key aspects of diabetes care across these contexts. Beginning with this dissertation and taking up Mol’s ([2006] 2008) Logic of Care theoretical framework as a starting point, this research will be useful for identifying a new set of best health care system and political conditions for doing diabetes care, something that is sorely needed if we want to minimize the ill effects of the global diabetes epidemic.
A Modest Proposal: Treat Diabetes Care As Preventive Medicine

In 2010, the Patient Protection and Affordable Care Act (ACA) (Affordable Care Act 2010) was signed into law. As of March 7, 2015, this landmark legislation has reduced the number of uninsured Americans by 7% (from 20.2% to 13.2%) since the health insurance exchanges opened in October 2013 (U.S. Department of Health and Human Services 2015). Among its great achievements are expanding dependent health insurance coverage until age 26, setting minimum coverage requirements for essential health benefits (e.g., hospitalization, prescription drugs, chronic disease management, and preventive health services), and eliminating dollar limits on essential health benefits (Mason 2011; Padula and Gielau 2012; American Association of Diabetes Educators 2014b; American Diabetes Association 2014). In addition to these benefits, preventive care services are to be provided at no out-of-pocket cost to the patient (not subject to the deductible) and no insurer can deny or rescind coverage due to the existence of a pre-existing condition. The law includes subsidies to the states to expand Medicaid (at their discretion) so that the poorest are able to access health insurance at no cost and tax credits for those with middle-class incomes to offset the cost of buying insurance through newly established insurance marketplaces. These all sound great on the surface, but the way the law is written creates some uncertainties and problems for people who still find health insurance unaffordable, and this is especially true for people with diabetes.
Benefits specific to diabetes include free diabetes screening as part of preventive services and coverage for MNT for people with diabetes (depending on the state). However, a diagnosis of “pre-diabetes” does not qualify for diabetes prevention education with diabetes educators, even thought it overlaps directly with DSME curriculum and patients would certainly benefit from CDE expertise. In that case, patients may be referred to a community based Diabetes Prevention Program (DPP) if one is accessible, but those services are not a part of the health record nor tied to the patient’s medical care. Coverage for DSME for people who have been diagnosed with diabetes is not assured, according to AADE, but it “is clearly part of the mainstream treatment regimen for diabetes, so we believe it will be covered in virtually all Marketplaces”(2014b). However, when it is covered it is usually for a limited number of sessions and, as discussed previously, the content of the education is pre-determined. When it comes to prescription drug coverage, patients are at the mercy of which drugs and personal medical devices (e.g., insulin pumps and meters) are on the insurance formulary, which means that while they technically have insurance coverage for their medications, the drugs they and their providers prefer for them to use might become prohibitively expensive with a change in health insurance plan.

Given the difficulties experienced by lawmakers in negotiating, passing, and enforcing the ACA (Staff of the Washington Post 2010; Starr 2011; Brill 2015), I expect that health insurance reform (as opposed to health care reform) will be the best we will get in the U.S. for quite some time. In light of this, and based on what I have learned
from frontline diabetes care workers, I propose that there are three ways the ACA could be amended in order to improve diabetes care:

1. Re-categorize diabetes management as preventive care (including the services of endocrinologists, DSME, and diabetes-related lab tests), exempt from out of pocket costs and deductibles. Doing this would ensure that patients with even high deductible insurance coverage will be able to receive the care they need in order to avoid complications and comorbidities.

2. Cap out of pocket costs for diabetes drugs and personal medical devices so that choices for these are made based on the needs and preferences of the patient and their provider, not insurance company formularies.

3. Require coverage of diabetes education services (DSME/T and diabetes prevention) with no out of pocket costs to the patient. Within the frame of the medical home model the ACA promotes, diabetes education is a valuable service for reducing overall patient costs and improving well-being. Treating it as a revenue source puts constraints on diabetes educators and patients that are not conducive to self-management.

**Suggestions for AADE**

At present, AADE’s legislative focus is on state initiatives for licensing CDEs and The Access to Quality Diabetes Education Acts to amend title XVIII (Medicare) of the Social Security Act, which would recognize the authority of licensed CDEs in managing diabetes care for patients (American Association of Diabetes Educators 2015a) While
those acts would assert greater professional autonomy for CDEs and they would likely increase the quality of diabetes education, the changes to the ACA that I propose would also increase the size of their share of the health care market, promote growth in their employment, and allow them more time to focus on patient care instead of coordinating prescription assistance for their patients.

Another way that AADE could work toward addressing their members’ concerns about the dearth of resources available to them and their patients in terms of emotional and social services support would be a change to the DEAP site certification requirements. Given the challenges diabetes educators face in performing invisible social casework, it would be beneficial to include a staff social worker as one of the requirements of site certification. Because of the influence the of CMS on setting reimbursement standards for the health care industry and the requirement of DEAP certification for reimbursement, this change would have far reaching effects. Furthermore, the explicit inclusion of social workers in diabetes care practice is also aligned with the medical home model and recognizes the social-psychological aspects of chronic disease management.

Conclusion

By approaching diabetes as a social problem and engaging in sociological research into diabetes care, I have demonstrated the interconnectedness of all levels of power structures of health care and made clear connections between the values we apply to the social institution of health care, its practice, and implications for patient
Sociological theories and methods are powerful tools in the fight for better diabetes care. However, for changes to the health care system to occur, we need to change the social and political context in which health care policy is made. This requires social change that prioritizes the good of the society over the good of the individual—a position directly opposed to the current system oriented toward profit and steeped in the ideology of personal responsibility. No amount of individual self-care can solve the structural problems that cause and perpetuate diabetes on a macro scale, which means that the conditions (and outcomes) of diabetes care will not improve while we remain on this path. Until that happens, though, it is worthwhile to continue this research and to find ways to make changes at the policy level that can help patients and frontline care workers take better care of persons with diabetes.
APPENDIX A

RECRUITMENT FLYER
Diabetes Care Work Study

Do you work in diabetes care in the [blank] area?

Would you like to help in the effort to improve diabetes care?

Are you at least 18 years old?

We want to hear from you!

Melissa Howell, a doctoral student in the Department of Sociology at Loyola University Chicago, is conducting a dissertation study on diabetes care to gather information about the work that goes into diabetes care and the people who do it.

You will be asked to participate in a confidential one-hour interview at a time and place that is convenient for you. You will receive a $20 Visa gift card for your time.

Thank you for your help!

If you have any questions, please contact the researcher, Melissa Howell, at Loyola University Chicago
diabeteswork@gmail.com or (312) 508-3823
or her faculty advisor, Dr. Anne Figert at afigert@luc.edu or (773) 508-3431.
APPENDIX B

INTERVIEW GUIDE
<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>How old are you?</td>
</tr>
<tr>
<td>What is your job?</td>
</tr>
<tr>
<td>How long have you been working as _____?</td>
</tr>
<tr>
<td>How did you train for your job?</td>
</tr>
<tr>
<td>What’s diabetes?</td>
</tr>
<tr>
<td>What goes into diabetes care?</td>
</tr>
<tr>
<td>Who does diabetes care work?</td>
</tr>
<tr>
<td>What type of work do you do?</td>
</tr>
<tr>
<td>Tell me about last week.</td>
</tr>
<tr>
<td>Tell me about the most recent time you felt very satisfied with your work.</td>
</tr>
<tr>
<td>Tell me about the most recent time you felt frustrated with your work.</td>
</tr>
<tr>
<td>Think of a time when you were thrown an unexpected curve ball with your work. How did you handle it?</td>
</tr>
<tr>
<td>Tell me about a time when you disagreed with a treatment plan. How did you handle it?</td>
</tr>
<tr>
<td>What helps you do your job well?</td>
</tr>
<tr>
<td>What makes it difficult to do your job well?</td>
</tr>
</tbody>
</table>
APPENDIX C

PHARMACEUTICAL INDUSTRY SPONSORED EDUCATIONAL MATERIALS
Low Blood Sugar Handout, Novo Nordisk

Low blood sugar (Hypoglycemia)

Causes
You might get low blood sugar (also called hypoglycemia) if you:
- Take certain medicines and eat too few carbohydrates, or skip or delay a meal
- Take too much insulin or diabetes pills (ask your diabetes care team if this applies to you)
- Are more active than usual

Signs and Symptoms
Here’s what may happen when your blood sugar is low:
- Shaky
- Sweaty
- Dizzy
- Sudden behavior change
- Hungry
- Weak or tired
- Headache
- Nervous or upset

If low blood sugar is not treated, it can become severe and cause you to pass out. If low blood sugar is a problem for you, talk to your doctor or diabetes care team.
Low blood sugar (Hypoglycemia)

What to do if you think you have low blood sugar

Check your blood sugar right away if you have any symptoms of low blood sugar. If you think your blood sugar is low but cannot check it at that time, treat anyway.

Treat by eating or drinking 15 grams of something high in sugar, such as:
- 4 ounces (½ cup) of regular fruit juice (like orange, apple, or grape juice)
- 4 ounces (½ cup) of regular soda pop (not diet)
- 3 or 4 glucose tablets
- 5 to 6 hard candies that you can chew quickly (such as mints)

Wait 15 minutes and then check your blood sugar again. If it is still low, eat or drink something high in sugar again. Once your blood sugar returns to normal, eat a meal or snack. This can help keep low blood sugar from coming back.

For more information, visit Cornerstones4Care.com
APPENDIX D

MANUAL DIABETES BLOOD GLUCOSE LOG BOOKS
If you have high blood glucose, make notes in your log and talk with your health care team about whether you need to change your meal plan, physical activity, or diabetes medicines.

**Having low blood glucose means that your blood glucose level is too low (below 70 mg/dl). Low blood glucose can be dangerous. Symptoms include being:**
- hungry
- light-headed or confused
- nervous and shaky
- sleepy
- sweaty

If you think your blood glucose is too low, check it. If it’s below 70 mg/dl, have 1 of these items right away to raise your blood glucose level:
- 3 or 4 glucose tablets
- 1 serving of glucose gel (the amount equal to 15 grams of carbohydrate)
- ½ cup (4 ounces) of fruit juice
- ½ cup (4 ounces) of a regular (not diet) soft drink
- 8 ounces of milk
- 5 or 6 pieces of hard candy
- 1 tablespoon of sugar or honey

After 15 minutes, check your blood glucose again. If it’s still below 70 mg/dl, have another serving. Repeat these steps until your blood glucose is at least 70 mg/dl.

---

**Toolkit No. 29**

**Blood Glucose Log**

<table>
<thead>
<tr>
<th>Date: From</th>
<th>to</th>
</tr>
</thead>
</table>

| Name: | |
| Phone: | |

| My Doctor | |
| Name: | |
| Phone: | |

| My Diabetes Educator | |
| Name: | |
| Phone: | |

**ADA Targets for Blood Glucose**

<table>
<thead>
<tr>
<th>Before meals: 70 to 130 mg/dl</th>
<th>My Usual Results</th>
<th>My Targets</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 hours after start of a meal: below 180 mg/dl</td>
<td>below</td>
<td>below</td>
</tr>
</tbody>
</table>

**TO MAKE MORE MONTHLY LOGS:** Make one (1) copy of this page and two (2) copies of the next page. Cut the pages in half, placing this page on top. staple in the upper left-hand corner and fold to fit in your pocket or purse.

**Provided By:**

American Diabetes Association  1-800-DIABETES (342-2383)  www.diabetes.org

©2009 by the American Diabetes Association, Inc.  11/09
Use this logbook to help you learn how food, medication, and exercise affect your blood sugar. Then make healthy decisions each day to better manage your diabetes.

Here’s how to work with your logbook:

1. Fill in the date.
2. When testing blood sugar before and after meals, write down the “before-meal” result in the Before column and the “after-meal” result in the After column. “Fasting” refers to your blood sugar reading before breakfast (when you wake up).
3. Jot down how many carbs you’ve eaten and any amount of medication you’ve taken.
4. When your result is high or low, circle it so you can see it at a glance.
5. Use the Comments section to remark on anything important—like diet, exercise, or stress.
6. Test your blood sugar as recommended by your doctor.

Tips: To minimize the pain of testing, change the lancet after every use.*

* Lancets are sharps and for single use only. To reduce the risk of infection.

What are your blood sugar goals?

Start by asking your healthcare professional to set your blood sugar goals and your schedule for checking your blood sugar.

<table>
<thead>
<tr>
<th>Where to check</th>
<th>My goals</th>
</tr>
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<tbody>
<tr>
<td>Fasting (before breakfast)</td>
<td>__________ mg/dL</td>
</tr>
<tr>
<td>Before Meal (lunch / dinner)</td>
<td>__________ mg/dL</td>
</tr>
<tr>
<td>After Meal (any meal)</td>
<td>__________ mg/dL</td>
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<table>
<thead>
<tr>
<th>Day</th>
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<th></th>
<th></th>
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<th></th>
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<th>Bedtime</th>
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<tr>
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</table>

Circle the result each time you're above or below your target. Add comments on diet, exercise, stress, etc.
APPENDIX E

DIGITAL DIABETES BLOOD GLUCOSE LOG BOOKS & REPORTS

Two Week Glucose Summary with Logbook

<table>
<thead>
<tr>
<th>Glucose Statistics</th>
<th>Breakfast</th>
<th>Lunch</th>
<th>Dinner</th>
<th>Bed &amp; Sleep</th>
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<tbody>
<tr>
<td></td>
<td>5:01 AM-7:00 AM-10:00 AM</td>
<td>10:01 AM-12:00 PM-3:00 PM</td>
<td>3:01 PM-6:00 PM-9:00 PM</td>
<td>9:01 PM-11:30 PM-5:00 AM</td>
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<tr>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
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<tr>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
</tr>
<tr>
<td>Highest</td>
<td>Low</td>
<td>Within</td>
<td>High</td>
<td>Low</td>
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<tr>
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<td>Low</td>
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<td>Within</td>
<td>High</td>
<td>Low</td>
</tr>
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<td>Within %</td>
<td>Low</td>
<td>Within</td>
<td>High</td>
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<table>
<thead>
<tr>
<th>Logbook</th>
<th>Breakfast</th>
<th>Lunch</th>
<th>Dinner</th>
<th>Bed &amp; Sleep</th>
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<td>5:01 AM-7:00 AM-10:00 AM</td>
<td>10:01 AM-12:00 PM-3:00 PM</td>
<td>3:01 PM-6:00 PM-9:00 PM</td>
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<td>7/17/2009 Friday</td>
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Bold italic indicates blood glucose values outside of target range (71 - 180 mg/dL)
Sensor Daily Overlay for Brian Moses
Dec 1 – Dec 7, 2013
(7 days)

HbA1c: No Data
Pump: Minimed 530G - 751
Sensor: In use

Sensor Data (mg/dL)

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<thead>
<tr>
<th>Date</th>
<th>12/1/13</th>
<th>12/2/13</th>
<th>12/3/13</th>
<th>12/4/13</th>
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<th>12/6/13</th>
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<td>158</td>
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<td>22.2</td>
<td>37.4</td>
<td>16.4</td>
<td>34.7</td>
<td>9.7</td>
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Excursion Summary

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<td>5</td>
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<td>A1C Above Limit</td>
<td>23.1</td>
<td>27.4</td>
<td>65.9</td>
<td>23.8</td>
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<td>0.3</td>
<td>0.0</td>
<td>0.2</td>
<td>0.3</td>
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Duration Distribution (hh:mm)

Above 140
- 16:45: 70%
- 7:20: 32%
- 13:25: 63%
- 12:35: 54%
- 15:05: 64%
- 23:20: 96%
- 9:25: 62%
- 11:26: 55%
- 59:25: 36%

Below 70
- 0:00: 0%
- 0:00: 0%
- 1:15: 0%
- 1:25: 0%
- 0:40: 3%
- 0:00: 0%
- 0:45: 3%
- 4:55: 3%

Within (70-140)
- 10:10: 88%
- 10:10: 88%
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VITA

Dr. Melissa M. Gesbeck received her doctorate from the Department of Sociology at Loyola University Chicago. As a medical sociologist, she is most concerned with issues of wellness and illness in our culture and the ways that we approach them through caregiving, the health care system, and public policy. At the heart of her work is a desire to promote well-being in patients, communities, and health care workers.

While at Loyola, Dr. Gesbeck conducted several research projects, including a survey study of perceived access to health care services for women (2009 MA Thesis), a photo-elicitation interview study of the ways families make food choices (2011), and an institutional ethnography of professional diabetes care work (2015 PhD Dissertation). She has presented her work at local, regional, and national conferences and has an article under review for publication at the time of this writing.

Before attending Loyola University Chicago, Dr. Gesbeck attended the University of Illinois at Chicago where she earned a Bachelor of Arts in Sociology and Gender and Women’s Studies, cum laude and with Departmental Distinction in 2007.