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The Violence of Abstraction: Learning to Live With Type-2 Diabetes in Everyday Life

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The Violence of Abstraction: Learning to Live With Type-2 Diabetes in Everyday Life
by
Jenny Epstein

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of Washington University in
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# Table of Contents

List of Figures ........................................................................................................ vi

Acknowledgements................................................................................................ vii

Chapter 1: Introduction .......................................................................................... 1

1.1 How this project began ...................................................................................... 4
1.2 Scope of the project .......................................................................................... 8
1.3 Foucault, Lefebvre and the anthropology of diabetes ........................................ 12
1.4 The violence of abstraction ............................................................................. 21
1.5 A closer look at Henri Lefebvre ....................................................................... 23
1.6 Overview of chapter ....................................................................................... 24

Chapter 2: Methods ............................................................................................... 27

2.1 Historical analysis ............................................................................................ 27
2.2 Ethnographic data collection ........................................................................... 29
2.3 Analytic auto-ethnography ............................................................................ 30
2.4 Life-history interview tool ............................................................................. 32
2.5 Recruitment sites and population interviewed ................................................ 38
2.6 Participation in and observation of diabetes education programs ................... 45
2.7 Conferences attended .................................................................................... 46
2.8 Participant observation as a HealthCare Navigator .......................................... 48
2.9 Interviews with health care providers ............................................................. 48
2.10 Media analysis .............................................................................................. 48

Chapter 3: The Re-settlement of Tacoma ............................................................... 50

3.1 “Tacoma, City of Destiny!” Connecting the old and new ............................... 52
3.2 The production of uniform social space .......................................................... 57
3.3 The platting of a railroad town ....................................................................... 60
3.4 Organized labor and the downtown core ....................................................... 65
3.5 Manufacturing moves out of the downtown core .......................................... 67
3.6 Designation as a superfund site ................................................. 71
3.7 Loss of a city core ....................................................................... 73
3.8 The rising local economic importance of healthcare ..................... 74
3.9 Tacoma’s demographics and neighborhoods today ....................... 80
3.10 The formation of diabetes corridors .......................................... 82
Chapter 4: Epidemiology and history of type-2 diabetes ..................... 85
4.1 Type-2 diabetes: a transmutable disease ..................................... 86
Chapter 5: Emergence of a Scientific Body ....................................... 93
5.1 Claude Bernard and the measurement of bodies ............................ 96
5.2 Creating a scientific subjectivity ............................................... 98
5.3 Insulin, self-discipline and the diabetic subject ............................. 100
Chapter 6: Diabetes Education Programs ........................................ 112
6.1 Bodies in everyday life .............................................................. 113
6.2 Diabetes self-care skills ............................................................ 117
6.3 American Pharmacy Association Diabetes Management program .... 119
6.4 Journey for Control: training for medical professionals ............... 134
6.5 Journey for Control: observing group sessions .......................... 138
6.6 Journey for Control: implications ............................................. 142
6.7 Diabetes Expo, Seattle Expo ...................................................... 143
6.8 Concluding remarks ................................................................. 149
Chapter 7: General Description of Interviews .................................... 152
7.1 Work and patterns of social connection ..................................... 157
7.2 The course of diabetes ............................................................. 161
7.3 Race/ethnicity/geography ....................................................... 163
7.4 Marriage and gender ............................................................... 164
7.5 The safety net of SSDI ............................................................ 166
7.6 Complimentary Alternative Medicine (CAM) and digital data trackers ...... 168
7.7 Patterns of control ................................................................... 174
Appendix 1 .......................................................................................................................... 319
Appendix 2 .......................................................................................................................... 320
Appendix 3 .......................................................................................................................... 321
Appendix 4 .......................................................................................................................... 322
Appendix 5 .......................................................................................................................... 323
List of Figures

Figure 3.1: Tacoma! Gateway to Health! .................................................................53
Figure 3.2: “Looking up 11th Street” Downtown Tacoma, 1907...............................64
Figure 3.3: Wheeler-Osgood plant, circa 1927.........................................................68
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Washington University in St. Louis

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viii
Chapter 1: Introduction

Urban, industrialized space usually evokes images of a built environment that is intensely human-made, of people living in close proximity and yet also isolated and anonymous. One doesn’t immediately think of how the space and routines of daily urban life and human biologies are closely intertwined or how urban life shapes the ways people take care of themselves and each other. Yet these were the unexpected and profound connections I encountered among residents of Tacoma, WA, living with type-2 diabetes. Closely interwoven into the routines of daily life were loss and disenfranchisement, abstraction and alienation that brought into sharp relief how little value was placed on caring for one’s health. Under the guise of changing simple, daily routines were intense struggles to break the powerful hold of what was familiar and known, and particularly, to find new meanings that made it worth the effort. How social spaces are conceived, particularly the space of human bodies in urban settings is the underlying dimension that links past and present, the local and universal to the ongoing narratives of progress and development in this project.

Rick’s story of diabetes is one of struggle to regain a sense of place in the world and to find new reasons to care for his health. “I’m blue-collar, I was busting my ass all my life. It’s hard mentally, how to get back in.” Two years before I met Rick, he had lost his sawmill job of 30 years when X Corporation declared bankruptcy. “We all lost our jobs, we were all laid off. They went broke; they said they had no money. Everyone lost their pensions, retirement. They took it all away. There was no recourse. I mean they just packed up corporate headquarters in
Portland and moved everything out.” I first talked to Rick at a volunteer clinic that serves people with limited incomes and no medical insurance. Losing the work that had held his life together for decades not only changed the routines of Rick’s life radically; it had also disrupted his ability to manage his diabetes. Before he was diagnosed with diabetes and changed his daily routines, Rick weighed almost 350 lbs. Now, he is trying to regain control without the stability and purpose of his old life.

Rick established a strong sense of purpose and self early in his life: “Yea, I graduated high-school, I found a decent job, I got married when I was young…I had three great kids. You know, I was always the provider. It, it wasn’t like that when I was growin’ up… I swore I’d never make my kids go through that… I’d always tried to be there for them. That part of my life [work and family] was set, almost in stone. I didn’t worry about things going wrong.” After losing his job at age 57, Rick has found himself in a place where he must re-think who he is and what he should be doing to give his life purpose. As we talk, it becomes clear that his inability to control diabetes is tightly bound up with the loss of his working life, and the ways work defined his place in life. Since losing his job, time and care for his body has come to mean something completely different than when he was working. “There’s something to be said for being scheduled. I’d be up to 3 am with work, 8,9,10, 12 hour shifts, but you’d have breaks, a break here, lunch there. It was just easier. Everything was set up, everything just fell in order. Now it doesn’t feel that way. I was motivated. Now it’s ‘Oh, I’ll get to it” and that’s not a good way to be. It’s just a really hard thing to be, to be ... mentally up with it, even though I know this thing will kill me if I don’t take care of it. It’s just really super-hard to get a handle on it.”
Like many of the people discussed in this project, Rick’s story of living with Type-2 diabetes (T2DM) is closely connected with work, of losing or finding work, or the physical inability to work at all, due to complications of diabetes. This story also mirrors the past 50 years of Tacoma and its diminishing history as a blue-collar manufacturing city. Not only did Rick’s job disappear, so did the industrial area surrounding the mill, “It’s no longer there,” Rick told me. “The company sold everything. Now they sell cars on it and stuff.” The dislocation Rick feels and his inability to manage diabetes was a shared story told to me by many of the people I interviewed and a key theme explored in this project. It is also an increasingly common situation faced by many Americans as the incidence of T2DM increases dramatically. It is a story that connects human biology to larger social processes of modernization, globalization and dislocation and is the unknowing inscription onto our bodies of the conditions of everyday life—conditions that are detrimental to us and yet form the very fabric of how we live and who we are.

Understanding how social and economic changes that affect people’s desire and ability to manage diabetes is a critical public health issue. The Centers for Disease Control’s (CDC) “Diabetes Report Card 2014,” (CDC 2015a) estimates that one in three (37%) adult Americans (86 million people) had pre-diabetes in 2012. Although rates of new cases of T2DM dropped in 2014 to 1.4 million from 1.7 in 2008, the incidence of diabetes remains dangerously high—so high, the CDC estimates one in three adult Americans could be living with full-blown T2DM by 2050 (CDC 2015a). In addition to the increasing incidence of diabetes, the complications resulting from adequately controlled blood sugars: stroke, heart attacks, end-stage renal disease, blindness and neuropathy, become an additional burden many American must contend with. In
short, as geneticist James Neel (Neel et al. 1998) put it, diabetes is the physical expression of pushing the body’s ability to regulate itself beyond the breaking point. While it is beyond the scope of this dissertation to answer the question of why this epidemic is occurring, it is possible to try to understand how this condition, which is such a part of the routines of everyday life, also challenges and changes how we feel about and take care of ourselves. This dissertation is about the struggle to de-alienate care of ourselves from our own internal histories, even as we use increasingly abstracted tools to manage our bodies and health.

The loss of connection Rick felt was only amplified through the self-care practices he knew he needed to preform. Rick felt lucky to have found early in life a clear life-path and a sense of “belonging to something bigger than myself.” Now, instead of feeling part of a larger world, Rick must turn inwardly and learn to “manage” his own body. Taking control of diabetes is not the connection Rick is looking for and in many ways it isolates him further. As I discuss further in chapter seven, Rick’s sense of self has changed dramatically since losing his job and he does see himself in the measuring and monitoring diabetes requires. For many people interviewed for this project, the measurement and monitoring necessary to manage diabetes exacerbates an already existing sense of disconnection people like Rick already feel towards their own bodies and health. This introduction serves to situate this “violence of abstraction” (Sayer 1987) within ongoing discussions in medical anthropology regarding self-care and disciplinary power.

1.1 How this project began
The impetus of this project began many years ago while working as a pharmacist in an ambulatory care clinic. Diabetes treatment seemed like a revolving door, as I handed out medications to deal with a condition that appeared to be far more complex than the simple directives we handed out: medication compliance, eat less, exercise more. The inability of some people to change how they lived in the face of losing a toe, foot, eyesight or kidneys was too contradictory and the conditions of daily life of the people described were too complex to be easily remedied by simple by-the-book instructions. Some missing piece needed to be identified that I couldn’t even describe. More than this, the language of diabetes diagnosis and treatment seemed to create a barrier rather than a useful tool for many people.

This project is an attempt to bring these two phenomena – (1) the medical abstraction of disease and (2) everyday lived experience – together using anthropological techniques and perspectives. I follow the argument set forth by Lock and Nguyen (2010), which outlined the centrality of the body to understand the production of health and illness. The authors state that leaving the material body aside, leaves in place an unexamined nature-culture dichotomy (57). Lock, in particular has defined a term “local biologies,” which “refers to the way in which biological and social processes are inseparably entangled over time, resulting in human biological difference – difference that may or may not be subjectively discernible by individuals” (90). This relationship is “inextricably situated in time and space (2010: 91)” exemplified by Lock’s ethnographic work on menopause (1993) which showed how the symptoms of menopause differed greatly between women in Japan and the U.S. Lock and Nguyen (2010) argue that trying to speculate whether this difference is purely biological or cultural is pointless.
and that cultural and biological forces form a dynamic relationship that changes over time. This interconnectedness of the material body and social constructions, which include time and space has also been the focus of the work of sociologist and philosopher Henri Lefebvre (1901-1991). However, in contrast to Lock’s anthropological work that examines the pluralities of medical practices, Lefebvre focuses on the spatial nature of all social constructions and how these are expressed in everyday life. One of Lefebvre’s primary concerns is the relentless homogenization of social space (including the body) as a distinguishing characteristic of modernity, one that mitigates the importance of singularity, difference and complexity. Lefebvre’s conception of social space, in which conceptions of the body play a central role, links the material, spatial and political forces that constitute everyday life and shape relationships between body and self that Lock and many other anthropologists discuss (Adelson 2000; Biehl 2007; Lock and Farquhar 2007; Martin 1987; Ong 1988). Lefebvre’s work provides a theoretical tool that explicitly connects the relationship between embodied experience and biological abstraction as political constructions. The aim of this study, however, is not to create dichotomies between, for example, an individual’s need or use of diabetic medications and big Pharma, but to understand how diabetes is conceptualized as a disease state by the people who live with it, to understand the ways medical conceptions and treatment are adopted in terms of individual local experience and history and how these interconnected to larger social process that make so much of our everyday life uniform, exchangeable and therefore commodifiable.

Two main theoretical perspectives guide this inquiry and the methods employed: 1) viewing time and space as socially produced and reflecting underlying social relations,
particularly the relationship of body to self and daily practices of self-care; and 2) viewing spatiotemporal forms, such as abstraction and embodied experience, and linear and cyclical temporalities, as existing in continual relation to each other (rather than dualistic), and forming dominant or subordinate social spaces in everyday life. In this project these forms are not viewed as discrete variables but are integrated within all variables (Aglietta 1979). These themes are drawn from the social science literature in the last decade or so, examining the concept of the everyday (Gardiner 2000, 2004; McCormack 2012; Roberts 2006; Ronneberger 2008; Ross 1996; Stanek 2008) that draws heavily from the work of Lefebvre. These social scientists from a broad range of fields approach the everyday as a political and transformative praxis, an approach that challenges the segregation of politics from culture and “the everyday’s historical ties to questions of praxis, cultural form and social agency” (Roberts 2006:14). In this work, the everyday is conceived as a network of inter-related forces, economic, social, political, technological, and cultural (Stanek 2008); but also the ways in which everyday practice enables the possibility for creation and social transformation. This framework provides a way of shifting anthropological analysis to focus on the structural issues that shape both biomedical and individual practices. The structural issue most relevant to this dissertation is the increasing dominance of abstraction in everyday life, which Lefebvre attributed to changing patterns of capital accumulation including urbanization and the increasing mediation of social relations by technology (Ross 1996).

Left out of this largely theoretical work, however, are examinations of actual people, their lives, and how conditions of everyday life, like T2DM, are dealt with. Ethnographic engagement
with this theoretical framework provides a way of understanding both biological constructions of disease and lived experience as interconnected products of how we live. Diabetes is conceived in this project as not just physiologic dysregulation and the inability to maintain homeostasis, but also, as the increasing global incidence of diabetes reflects, of bodies pushed beyond their physiologic limits and how this growing social problem is addressed in ways that detach it from lived experience and the conditions of everyday life. Drawing on the work of Lefebvre, and amplified with ethnographic and anthropological approaches, I use the diabetes life histories of people living with diabetes as a way of connecting these two distinct but always related types of social space - the conceived and lived - in order to understand diabetes not only as a medical condition but how it relates to the ways people live, their daily routines, thoughts and behaviors. Including the body as an intrinsic part of social practice clarifies social relations embedded in the condition and allows a better understanding of the different forces at play in creating sustainable and healthy self-care practices. In turn, this sheds light on the greater integration of scientific abstraction into practices of self-care and how this rearranges social relations between body and self and how we know and order society and ourselves (McCormack 2012).

1.2 Scope of the project

In many ways, the present project is a traditional medical anthropology study. Much medical anthropological literature has focused on the ways macro-level forces such as structural violence, bureaucratic medicine and political economic forces play out in the lives of individuals facing illness (Brotherton 2012; Farmer et. al. 2006; Garcia 2010; Livingston 2012; Montoya 2011; Petryna 2002; Whitmarsh 2009). In particular, Mendenhall (2015) discusses the
connections between T2DM and structural violence endemic in the life-stories among Mexican immigrant women living in the United States. As will be discussed in detail below, her work examines diabetes and depression as a “syndemic” (Singer and Clair 2003) interaction. In contrast to Mendenhall’s work, however, the life-stories I collected are more specific to the ways people living with diabetes make sense of the condition and how they construct (or not) practices of self-care over time. And unlike other recent medical anthropological inquiries, instead of structural violence, I focus on the macro-level forces that produce “social space” (Lefebvre 1992), which shapes both conceptions of the body, relations of body to self and the daily routines of people living with T2DM in Tacoma, WA. In this regard, the current project complements, yet extends, existing medical anthropological engagements with chronic illness and with diabetes in particular.

Specifically, I discuss how objectification of one’s body through scientific abstraction, necessary to control diabetes, can further alienate already tenuous relationships between body and self. Learning to control diabetes on a sustained level means creating individual meanings and purpose that challenge, but are never separate from, the macro-level abstractions that increasingly constitute everyday life. To understand the nature of these macro-level forces and how they shape diabetes self-care practices, I bring together two stories of spatial rearrangements in the mid-to late 19th century that at first glance would appear to be unrelated. These two stories help explain how older forms of progress and development are expressed in new ways in the context of diabetes care in contemporary United States. I use Tacoma, WA as an exemplar of
how the discourse of progress and development has played out in the United States and how this history shapes the lives (and local biology) of type-2 diabetes self care practices today.

The first story, discussed in more detail in chapter three, is the re-settlement (Harris 1997) of Tacoma beginning in the 1870s, by the North Pacific Railway, which platted out the streets of Tacoma as a speculative real-estate venture. The city design followed a grid-pattern used by railways throughout the West whose uniformity made the value of lots obvious to speculators (Hudson 1982). Thousands of mobile, skilled and unskilled workers were attracted to the region and took possession of “unused” land and resources as the landscape and waterways were straightened, leveled and channeled to facilitate further commerce (Chasan 1981). For almost the next 100 years Tacoma was a highly industrialized city. Machine power, mass production and the dream of upward mobility through one’s labor as an autonomous worker were all tightly intertwined with the intense spatial transformations that made industrialization possible. As discussed in chapter three, the intense re-arrangements of waterways created the Port of Tacoma, one of the top ten container ports in the United States. These spatial rearrangements of land and water therefore also enable the global flow of cheap, high-caloric, commodity food, which has greatly contributed to the global explosion of T2DM - the coca-colonization and McDonaldization of globalization (Zimmet 2000).

The second story concerns Claude Bernard’s pioneering physiology on diabetes in the mid-19th century. The slow and difficult process to understand diabetes as a relationship between a particular set of physical symptoms and high sugar levels in the blood was not only the product of a new system of thinking but also due to the increasing incidence of the disease. Although
symptoms of diabetes had been identified for thousands of years, it was only in the 18th century that it became common enough for physicians to see a few cases in a lifetime (Feudtner 1996). After mid-19th century, Galenic perceptions of the body as fluid and in constant communication with the surrounding world were marginalized as disease was perceived as organ pathology emanating from within the body and separate from the external world (Rosenberg 1977). As bodies and disease were increasingly abstracted, the importance of subjective experience, so important in Galenic practice also disappeared. Figlio (1977) explains: “Instead of self as extended into a unique and inviolable corporal body, the self now only loosely possessed a body that could be serviced by technique, separate from the self” (277). This shift in the mid-19th century in the conception of bodies has been the focus of scholarship by Duden (1991) and Rosenberg (1977) and also the work of Figlio (1977), Jewson (2009[1976]) and Foucault (1973), who describe how constructions of disease and the body are not purely cognitive but include the history of medical institutions, medical technologies and clinician-patient relationships. Nature could be ordered by methods that unified (at some level) all forms of social space. Like the uniform grids, leveling and straightening that made industrialization possible in Tacoma, the new science of physiology enabled biological phenomenon to be isolated and measured, ushering in an abstract reality of human bodies. Bodies became universally recognizable and knowable but also separate from the social reality of daily life.

These two processes of spatial transformation and abstraction, one of landscape and the other of human bodies continue to shape everyday practices in the 21st century. The city grids that helped to create the urban, industrial space of Tacoma, continue to shape everyday life
through an increasingly dispersed city landscape highly dependent on automobiles. Likewise, the abstraction of human bodies enables blood glucose monitoring a necessary tool to escape the debilitating effects of T2DM. It is here that the work of Lefebvre provides a particularly apt way of connecting these two histories of spatial transformation and to understand the simultaneous “spaces” (abstract, material and lived) that people inhabit. While political economic perspectives in medical anthropology, (Baer et al. 2012; Farmer 2004; Rylko-Bauer et al. 2009; Scheper-Hughes and Bourgois 2004), are useful in constructing a critical perspective, they can also leave the historical construction of categories of knowledge largely unexamined (Coronil 1996; Valverde 2003). In this project, scientific abstractions of the body and the construction of uniform subjects are viewed as the product and producer of sociopolitical structural forces. This critical perspective includes not only the bracketing of disease from social context and individual focus in biomedical practice, but also an examination of the abstraction inherent in everyday life that creates universal bodies and static subjectivities.

1.3 Foucault, Lefebvre and the anthropology of diabetes

I will next review some of the main approaches by which diabetes has been studied in anthropological literature. This will help clarify what Lefebvre’s work brings to the questions anthropologists have raised regarding bodies, subjectivities and living with diabetes. At the end of this Introduction I discuss Lefebvre’s work in more detail and how it is useful in addressing questions and concerns raised by medical anthropologists.

Because Foucault’s understanding of the body forms a theoretical frame for much medical anthropological literature, I begin here with a brief examination of how Lefebvre’s
conceptions of the body differ from Foucault’s. At the same time, Foucault’s formulation to think about care of the self as “an attitude, a mode of behavior; [how] it became instilled in ways of living; [how] it evolved into procedures, practices and formulas people reflected on, developed, perfected, and taught” (Foucault 1986:45), has profoundly shaped my own thinking and forms a foundation of this project. Considering how the works of Foucault and Lefebvre both converge and diverge provides a starting place for examining medical anthropology texts on diabetes.

Both Foucault and Lefebvre recognized that configurations of space also maintain systems of economic and political power that reduce multiplicity through uniformity and order (Stanek 2008). Spatial abstraction separates, but at the same time it systematizes (Lefebvre 1992), a concept Lefebvre shares with Foucault who described how uniformity of spatial arrangements was essential for disciplinary power and the creation of docile bodies: “Each individual has his own place; and each place its individual” (Foucault 1977:143). As described in chapter five, the emphasis on individual responsibility in diabetes education programs invoke this type of power. In many ways, the relationships Foucault and Lefebvre identify between bodies, space and power compliment each other. However, Lefebvre’s greater emphasis on the development of urban space and the relationship between creativity and abstraction in everyday life made his work more suited to understanding the data I collected on diabetes as a disease state and the ways people lived with the condition.

Foucault (1973,1977) focused on the production of bureaucratic disciplinary power in newly emerging institutions such as hospitals and prisons. The spatial arrangements of these
institutions also enabled bodies to be isolated and disciplined. Bodies were acted upon, forming an “empty signifier” that could be continually reconstructed through external discourses of power (Gardiner 2000). Lois McNay (1991) points out that, in theory, Foucault describes power as never being a totalizing force, but his historical analysis depict power relations as unidirectional, “monolithic force[s] with an inexorable and repressive grip on its subjects” (134). In addition, bodies “give no material resistance to the operations of power” (134). Recognizing that he had perhaps over-emphasized this totalizing aspect of subject formation (Foucault in Rabinow 1994:225), Foucault began focusing on “technologies of the self,” defined as that “which permit individuals to effect by their own means … a certain number of operations on their own bodies…so as to transform themselves in order to attain a state of happiness, purity, wisdom perfection or immortality” (Foucault in Rabinow 1994:225). In technologies of the self, bodies are again acted upon, this time by the individual. “I am more interested in the interaction between oneself and others, and the technologies of individual domination, in the mode of action that an individual exercises upon himself by means of the technologies of the self” writes Foucault (Foucault in Rabinow 1994:225). However, as Lupton (1997) writes, echoing McNay, “Foucault’s concept of resistance was never really explained in detail” (102) and articles that examine technologies of the self through ethnography (Borovoy 2016; Brodwin 2015; Ecks 2004) focus mainly on the ways individuals adopt disciplinary behaviors at the level of everyday life. While Foucault clearly saw the potential of resistance “to refuse what we are” through “new forms of subjectivity,” (Foucault in Dreyfus and Rabinow 1982:216), the ways that resistance might be generated remained underdeveloped before Foucault’s death (Lupton 1997).
In contrast to Foucault’s view of the body being acted upon, Lefebvre saw possibilities for creative transformation through dominating forces of bodily abstraction, a process that helps to explain how some people living with T2DM created sustaining practices of self-care. He saw the body as a “conflictual unity,” (Roberts 2004) that simultaneously contained different spatial (and temporal) forms. The body was a site of multiple cultural forms, and a focal point of resistance because it can never be completely understood or contained, rather than a body that is acted upon by totalizing social relations. Rather than holding care of the self and disciplinary power as separate processes, I have tried to show how they are intrinsically related, how the ways people make sense of diabetes and create life-sustaining practices are always in relation to the disciplinary power of scientific abstraction.

Given Lefebvre’s alternate understanding of bodies as a site of both discipline and creative resistance, his work offers anthropologists interested in issues of health, disease, and bodily management a complementary framework to rethink Foucault’s important conceptions regarding the body, in particular technologies of the self (Brodwin 2015). Lefebvre’s more explicit examinations of the body as a type of social space and as a “conflictual unity” helps to explain how technologies of the self and disciplinary power might interact, as I discuss in the work of Guell (2012) and Mol (2008) below. First, however, I want to contextualize their works within the broader category of ethnographic work on diabetes.

Medical anthropological ethnographies on diabetes have tended to focus on the distinctions between lived experience and biomedical discourse as explanatory models (Hunt et. al. 1998; Mendenhall et. al. 2010; Joe 1994; Poss and Jezewski 2002; Smith-Morris 2006) or on
issues of compliance (Borovoy and Hine 2008; Broom and Whittaker 2003; Ferzacca 2000; Hunt and Arar 2001; Schoenberg et al. 2005). These studies show the priority patients give to social obligations and personal habits over the risk-reduction behaviors prescribed by medical practitioners, a pattern identified by Trostle (1988) in his critique of compliance. Drawing on Kleinman’s (1988) conception, explanatory models are schemas that provide cognitive frameworks to interpret illness, provide courses of action, and answer such questions as the cause of illness, timing, symptoms, treatment possibilities and their efficacy.

One important limit of the explanatory model approach is that they do not incorporate time as an integral part of analysis and therefore categories of knowledge, like “disease” or “the body” are not examined historically, an exclusion that conveys neutrality and as many feminist writers on science have discussed, hides bias (Harding 1991, 1995). In addition, explanatory models leave out how patients’ self-care practices change over time. In the explanatory model view, patient and provider concepts remain a contrast of conceptions of disease and illness rather than evolving as part of a dynamic process. While work on diabetes in Native American communities does stress the importance of collective history (Adelson 2000; Ferreira and Lang 2005; Garro 1995; 2000; Rock 2003; Smith-Morris 2006; Sunday et al. 2001), left unexplored is how these collective experiences of diabetes actually shape (or not) individual self-care practices over time.

Hunt and Arar (2001), provide one of the few studies that discuss how diabetic self-care practices do change over time. They found that diabetes self-care can be viewed as a continuing series of micro-decisions that balance demands of medical management with social obligations. I
build on this work, focusing on the central role the body plays in integrating medical abstractions into the obligations and routines of everyday life. I also use histories of both diabetes and diabetes life-stories to understand how both macro and micro levels are continually produced each in relation to the other.

Three recent works in diabetes move the focus away from explanatory models to examine the relationship of self and diabetic self care practices (Guell 2012), the dichotomy of care and choice (Mol, 2008), and the relationship between structural violence and diabetes (Mendenhall 2015). I consider each of these in turn.

In her work on Turkish immigrant women living with diabetes in Germany, Guell (2012) argues that “doing diabetes” is about managing one’s body and not about “being diabetic.” Guell is interested in how a people learn to care for their diabetic body and in the use of technology, such as glucose monitors that make diabetic bodies visible. The self is kept separate from this bodily management, however, but shapes the way participants exist “at the margins,” as immigrant women living in Berlin. Guell sees both body and self as mutable and flexible, but also distinct from the other. Left out of her analysis are technologies of (disciplinary) power, which create bodies that can be bracketed off from an individual’s lived experience (Foucault 1973). Self in Guell’s study had to do with the “creative tools of the weak” (de Certeau 1984) used to manage diabetes by the women she studied, The tactics the women engaged in to manage their bodies recalibrated standard medical strategies for managing diabetes. (Guell 2012) rather than diabetes changing who they were.
However, while Guell observed the strategies and tactics these women employed with little help from the medical establishment, she does not engage more deeply into why this self-care happened in the first place or differences between women who managed diabetes well and those who did not. In contrast, in this dissertation by collecting diabetes life histories, a different picture emerged. While some people are able to care for their “diabetic body,” as distinct from self, this was not the case for a great many people. Instead, self-measuring and monitoring heightened an already disconnected relationship between body and self and forced people to be consciously aware of the “unseen routines” (Harrison 2000) of their daily life. Instead of being able to use one’s body as a means of escape from the minuitia of demands, fears, and stresses of daily life, through emotional eating for example, a diabetic body had to cared for in ways that uncomfortably heightened awareness. Importantly, Guell identifies the “self” of the women she studied as being a social rather than individual entity (519). This is a key cultural distinction between the women she studied and the Tacoma residents of this study and a subject that I discuss in detail throughout this project, particularly in chapters nine and ten.

In her book *The Logic of Care* (2008) Annemarie Mol presents a look into clinic-based diabetes treatment in Denmark that would, I think, be recognizable to any clinician in the United States, defining a dichotomy between “the logic of choice” and “logic of care.” Mol defines the logic of choice as rational decision-making based on facts and as representing a false sense of freedom. The logic of care, which is the focus of the majority of the book, is defined as practice, the ambiguities and constant experimentation of living with diabetes. Mol is particularly interested in *not* dividing her analysis into simplified oppositions and includes both clinical
practitioners and patients as involved in the logic of care. Mol states that the logic of care is concerned with practice and the unpredictable, ongoing processes of practical activities that include risk, mental and emotional effort and opportunities. The logic of choice on the other hand, is used to create the illusion of freedom, with making private decisions as a consumer. This logic is also linear and detached from practice.

However, in the current project I argue that abstraction and lived experience, which can be equated to choice and care, do not exist as a dichotomy and cannot be separated in actual practice. Cultural practices, such as care and choice, are not opposed but are inter-related, transformed and restructured through everyday practice. The work of Lefebvre is therefore useful in understanding the body as a site of multiple forms of spatial constructions more clearly identifies both the barriers and pathways people find to deal with T2DM. The goal of this current project, therefore, is to broaden the boundaries Mol sets and to reconfigure the dichotomy she creates between care and logic.

For many people, mechanical and repetitious acts of blood glucose (BG) measuring and monitoring only increase an already existing sense of dissociation between body and self. Measurement and monitoring makes diabetes visible as Guell (2012) points out, but at least for many of the people in this study, it also created a greater barrier towards caring for their diabetic body. It was only through the greater deterioration of their body that new ways of connecting body and self became a necessity. However, I determine diabetes self-care practice as holding possibilities of both alienation and transformation. Following Lefebvre’s definition of the everyday as a site not only of abstraction and alienation but also resistance and transformation,
diabetes self-care practices allow other ways of being to come into play that allow us to “reject what we are” (Foucault in Dreyfus and Rabinow 1982:216) and (re-) connect “the practice of creativity” (Foucault in Dreyfus and Rabinow 1982:237) with self-care.

Emily Mendenhall (2015) connects structural violence with the health and well being of Mexican immigrant women living with diabetes in the United States. She discusses three forms of interconnecting structural violence to understand how the women she interviewed understood diabetes, using their life-stories to situate these understandings. Mendenhall discusses the well-established connections between T2DM and poverty, poor nutrition and urban development that are exponentially affecting disadvantaged populations throughout the world. She strongly views diabetes as a social condition, using the framework of “syndemics” (Singer and Clair 2003) to connect biological disease and social context. Life stories form an important part of the work, used to explain not just the frequency with which depression and diabetes occur together but also how social suffering is expressed biologically. Mendenhall’s approach significantly broadens and politicizes understandings of diabetes.

The connection Mendenhall makes between structural violence and diabetes is important to this dissertation as well. However, I wish to focus on a much less overt form of violence. Instead of understanding how social violence in the form of poverty, discrimination and upheaval are causative factors and broaden definitions of disease, I focus on abstracted conceptions of the body as a key barrier to developing sustained practices of self-care. While many of the people I talked to had extremely stressful lives due to unemployment, injury, poor health and past trauma, I wish to focus on a much less noticed and subtler form of violence; one that holds out the
promise of better health but can also accentuate the alienation between body and self many people already struggle with.

1.4 The violence of abstraction

The concept of “the violence of abstraction” comes from the work of Derek Sayer (1987) who discusses the essential role of abstraction in modernity to uproot and make interchangeable all aspects of everyday life. As I discuss in the section below on the work of Lefebvre, uniformity and fragmentation of social space, particularly human bodies, represents an internal colonization of everyday life, making it both globally connected and impersonal at the same time. Biological conceptions of the body give rise to uniform and interchangeable practices of self-care (described in chapter five) that have no direct connection to the lived experience of the individual performing them. How people learn to give meaning to practices of self-care (or not) forms the ethnographic core of this dissertation in chapters seven through ten. Unlike Guell, I see body and self as always connected and under constant, intertwined construction. Bodily practices that manage “the diabetic body” are at the same time reflections of selfhood also internalized within the body.

Like Mendenhall, I use life histories to get at how people think about diabetes, but the focus of my interviews differed. Instead of a general life-history, I am interested in how people explain their own diabetes self-care history. I wanted them to tell me, through their own understanding, reasoning and life events, the individual ways they valued their bodies (or not) and the practices connected to these values. Most importantly, I wanted to see patterns over time, to understand how people changed (or not) and the barriers or pathways that contributed to
change. Sustained care of one’s body necessitates self-transformation and the two cannot be pulled apart. This is both the biggest barrier and benefit to managing diabetes. While informed by a number of theoretical perspectives, medical anthropological literature on diabetes has focused largely on explanatory models of disease or examinations of power and the body taken from Foucault. In much of this literature a dichotomy is created between biomedical practice and patients’ perspectives of diabetes. My interests, however, require a different sort of theoretical armature, one I believe the work of Henri Lefebvre is equipped to supply. I focus on the ways scientific abstraction, as a form of structural violence, alienates body from self, a pattern of dislocation and disconnection that Lefebvre extends from the body to the global economy (Kirsch 1995). In the next section of the Introduction I discuss the work of Lefebvre as it pertains to this dissertation and then end with an overview of the dissertation chapters.

Rick’s story at the beginning of this Introduction shows the difficulty of preforming self-care practices that are intended to preserve bodily health but are also disconnected from one’s own history and place in the world. Rick’s body disappears into medical facts and mechanical acts, as he struggles with self-care practices that do not re-connect him to the larger world.

Anthropological work on diabetes discussed above, has focused largely on dichotomies either between patient and biomedicine through explanatory models or as the logic of care and choice. Other work has engaged in questions of disease definition to include structural violence, or the ways T2DM self-care provides a site of creative resistance to social marginality. The work presented here adds to these discussions by examining the ways scientific abstraction is increasingly a part of everyday life and the self-care practices necessary to control diabetes. As
will be discussed in much greater detail throughout this dissertation, emphasis is placed on making changes through mechanical and uniform acts that are held apart from an individual’s own history and expectations of the future. Understanding the social context of these different forms of social space and how people living with diabetes learn (or not) to make sense of them can be addressed through an engagement with Henri Lefebvre’s perspectives on spatial forms (especially the body) and subjectivity formation in everyday life. I turn now to an introduction to his theories and have also included a more detailed summary of his terms in the glossary.

1.5 A closer look at Henri Lefebvre

Lefebvre was born in 1901 and grew up in Navarrenx, France. A deeply religious youth, he was also interested in philosophy and began his university studies focusing on Catholic philosophers. Moving to Paris and studying at the Sorbonne in the early 1920s, however, he became interested in Surrealism and also the existentialism of Heidegger (Gardiner 2000). Those influences, along with early Sartre, Nietzsche and French phenomenology, particularly the work of Merleau-Ponty, helped with Lefebvre’s expulsion from the French Communist Party in 1958 but also influenced his much deeper interest in dialectical materialism.

Lefebvre published over 60 books over the course of his life. Rhythmanalysis (2004) was his last book, published posthumously. In it, he introduces a method to think about the social production of time, a perspective he applied much more thoroughly in his work The Production of Space (English translation) in 1992. Rhythm can be analyzed as multiple repetitive patterns that constitute the ways time is comprehended and produced in everyday life. This understanding of time reflects Lefebvre’s similar method of understanding space as composed of various forms
and produced through the actions of people. Throughout Lefebvre’s long writing career the concepts of space, time and everyday life were used as critical tools to problematize taken-for-granted elements of the world (Gardiner 2004), a focus shared by Foucault, the Frankfort School and other critical post-war thinkers. Lefebvre conceptualized “the everyday” as an analytical framework, a way of conceptualizing what is largely taken for granted, and yet exists as a common ground through which all human activities take place. Lefebvre was concerned with the social relations of urban, post-WWII Western Europe that were increasingly mediated by the flood of newly available commodities, cars, refrigerators, stoves, vacuum cleaners manufactured in expanding urban industrial centers. The concepts of space, time and everyday life became increasing interconnected in Lefebvre’s work over his long career, so that how he envisioned everyday life is not separate from how he defined social space. Especially important to Lefebvre’s conceptions of everyday life is urban space and the two are inextricably connected. Practices of everyday life produce spatial forms and arrangements: urban, rural, institutional, private, public, etc., which in turn shape everyday life and subjective experience. The everyday is thus composed of multiple rhythms, temporalities and spatial constructs that encompass not only the most abstracting and alienating aspects of everyday life, but also the possibility for change and innovation.

1.6 Overview of chapters

The dissertation is organized by the following chapters: Chapter two discusses the methods employed in this project. I describe analytic auto-ethnography (Anderson 2006) as a way to situate my role as a resident of Tacoma and medical clinician in this project. I describe
my design of the diabetes life-history tool used and the importance of life histories as a narrative window into how people make decisions and live with T2DM and also the importance of constructing a “spatial history” of both Tacoma and T2DM. Also, I describe the locations where I recruited study interviewees and the Tacoma residents I recruited.

Chapter three focuses on the re-settlement history (Harris 1997) of Tacoma, particularly on the platting of Tacoma as a railroad town, urbanization and manufacturing from the 1880s through the 1970s. Next I discuss how this early history continues to shape everyday life in Tacoma through the loss of manufacturing, the Port of Tacoma and the health care industry as the two largest non-military employers in the area, the epidemiology of T2DM in Tacoma and the formation of “diabetes corridors” (Drewnowski et al. 2014).

Chapter four discusses the history of diabetes as a disease state. I connect the work of Claude Bernard, who in the mid-19th century discovered the continuous presence of glucose in mammalian blood. Through isolation and measurement of glucose, Bernard’s work on diabetes helped usher in the new science of physiology and the increasing detachment of disease from the life of the person experiencing it. I discuss Daston and Galison’s (2007) historical work on the formation of a new scientific subjectivity that corresponded with this new science and how this subjectivity integrated into everyday self-care practices of people living with T2DM. I also give a brief description of the pathophysiology of diabetes and the global epidemiology of T2DM.

Chapter five gives an overview of different types of diabetes education programs I participated in, along with a discussion of the increasing importance of health literacy and numeracy programs as a Federal public health mandate. People living with diabetes are
increasingly held responsible for their own care and diabetes education programs teach people to learn medical facts, make rational decisions and become informed patient/consumers.

Chapters six through eleven shifts the focus of the dissertation to the sixty diabetes life-history interviews I conducted with Tacoma residents. I begin with a demographic description and an overview of the interview data. I explain the three main patterns of diabetes management I found through data analysis and how they relate to each person’s ability to integrate blood glucose measurement and monitoring into daily routines. I devote one chapter to each pattern. In the last two chapters of this section (ten and eleven), I discuss the importance of social and historical connection and self-transformation in terms of spirituality and the structure of the volunteer clinic where I recruited many of the people I talked to.

Chapter twelve is the Conclusion, where I describe how the stories presented here and the role of medical abstraction sits in dialog with anthropological concerns of biocitizenship. I also discuss the ethnographic contributions this work makes to the field of medical anthropology.
Chapter 2: Methodology

In this project, T2DM is viewed as both product and producer of social relations. It reflects the multiple forms bodies can take and how these different forms connect to larger political and economic forces (Biehl 2007; Brotherton 2012; Crane 2013; Jain 2013; Kaufman 2006; Livingston 2012; Lock and Nguyen (2010); Montoya 2011; Whitmarsh 2009). In addition to drawing on this rich literature within medical anthropology, I use the work of Henri Lefebvre to understand T2DM as a social process in which spatiotemporal structures provide more than a neutral backdrop or a static stage within which events take place. I will examine 1) how spatial forms, particularly scientifically abstracted bodies, shape the self-care practices of people living with diabetes; and 2) how these forms interconnect in the “social space” of everyday life (Lefebvre 1992). A brief note on IRB approval: Washington University’s IRB designated this study as exempt and therefore I did not access medical records to validate medical information told to me by interviewees. However, after collecting the first few life-stories, validating medical information through medical charts seemed unnecessary, as I was interested in how people described their lives and thinking rather than numerical assessment. In addition, the diabetes life-events people described corresponded to the blood sugar and A1c numbers related to me during interviews. In other words, if someone described events that indicated they were having difficulty coming to terms with diabetes, lab values were correspondingly high. Consent was obtained through written and verbal explanations of the study and no one objected to having their interview recorded.

2.1 Historical analysis
Methodologically, I use two main approaches to reach my objectives. First, I examine two processes of spatial rearrangements that emerged in the mid-19th century, the abstraction of bodies through physiologic science on one hand and the transformations of landscape that turned Tacoma into an urban, manufacturing center. I connect these two historical processes, which at first seem unrelated, and show how they shape everyday life of residents of Tacoma, WA living with T2DM today. Secondly, as the incidence of diabetes dramatically increases around the world, routines of daily life become reconfigured around new technologies of self-care. I use diabetes life histories of Tacoma residents to connect the exterior space of industrial Tacoma with the interior biological space of diabetes management. These life histories are used to understand how participants write their own biographies of living with diabetes (Wengraf et al. 2002), as they must learn to objectify their bodies in new ways. First, I will discuss the historical analysis used.

The historical examinations used in this project follow three interconnected processes: 1) A history of the “resettlement” (Harris 1997) of Tacoma in the mid-19th century, focusing on the massive rearrangements of landscape that turned Tacoma into an industrial center and port; 2) a social history of T2DM, focusing on diabetes as a dynamic condition; and 3) diabetes life-histories of the Tacoma residents I interviewed. These historical examinations are used to understand the spatiotemporal processes that find expression today in T2DM practices of self-care. Analysis of these historical processes demonstrates the dynamic nature of the social construction of disease and it reflects both material and conceptual social conditions. Life histories provide a narrative window into how diabetes is experienced rather than observed by
the researcher (Kramp 2004). The subject is narrator of his or her own decision and meaning-making *over time*. Using life-histories focused on living with diabetes as a process, not as a snapshot in time or as an object of observation, which has been the methodology of some previous anthropological work (Borovoy and Hine 2008; Ferzacca 2000; Garro 2000; Mendenhall et al. 2010). These three histories, of Tacoma, diabetes and lived experience connect micro and macro social levels for analysis and reflect a distinctly American perspective of diabetes. On a micro-level, Tacoma’s manufacturing history lives on in ideals of individual initiative and hard work to attain social autonomy, even as on a macro-level, manufacturing and related employment no longer provide a means to reach this goal.

2.2 **Ethnographic data collection**

The following is a list the primary sources of ethnographic data collection for this project:

1. Analytical auto-ethnography

2. Fifty-eight diabetes life-story interviews conducted in Tacoma, WA between May 2013 and June 2014.

3. Participation in diabetes education programs for medical professionals and observation of diabetes education programs.

4. Attendance at medical conferences related to diabetes.

5. Training and volunteer participation as a Health Care navigator for the Affordable Care Act at a social service organization in Tacoma between Nov. 2013 and July 2014.
6. Formal and informal interviews with health care providers and participation in social/medical service organizations in the Tacoma/Puget Sound area including Project Homeless Connect and the Washington Health Foundation.

7. Media analysis.

2.3 Analytical auto-ethnography

The questions and argument of this project surrounding conceptions of the body as social space and how people learn care of the self over time were first raised by my experiences from years of handing out prescriptions as a pharmacist and playing my own particular role in the T2DM epidemic. The term “analytical auto-ethnography” refers to an ethnographic methodology with which the researcher self-identifies as a member of the community she is investigating. It also engages in a reflexive analysis of the community, and uses dialog with informants to clarify beyond one’s own understanding how local understandings connect to broader theoretical and social phenomena (Anderson 2006). This role as researcher fits with the choice of topic and research site as it reflects my “native” perspective as someone familiar with diabetes in medical practice (as a pharmacist) and as a resident of Tacoma.

Barbara Tedlock (1991) examines the belief that “going native” or being a native ethnographer poses a danger to scientific objectivity. Tedlock states, “The implication is that a subject’s way of knowing is incompatible with the scientist’s way of knowing and that the domain of objectivity is the sole property of the outsider” (1991:71). In contrast as discussed above, the impetus for this project was my own participation in treatment and experiences dealing with T2DM. Instead, Anderson (2006) describes the role of the auto-ethnographer as “a
more analytic and self-conscious participant in the conversation that is the typical group member. Understandings, both as member and a researcher, emerge not from detached discovery but from engaged dialogue” (382). One of the goals of this research was to provide a reflexive space so that both interviewee and interviewer were, to some degree, participants working to co-produce knowledge and understand a process they were familiar with in different ways. Analytical auto-ethnography therefore corresponds with the methodology of the life history interviews as it creates a space for self-reflection, discussed below.

Zaman (2008) describes being a “native” (Bangladeshi MD/anthropologist and doing research in a Bangladesh hospital) as referring to his own understanding, knowledge, and experience as a doctor and as an “opportunist researcher,” as taking advantage of an environment he knows well. Zaman’s explanation of his roles as physician and anthropologist resonated with my own experiences, in that I understood the basics of clinical practice from working in an ambulatory care clinic. At the same time, as Zaman also points out, my familiarity with clinical practice perhaps made me take for granted what I should have examined. Re-listening to a few of the interviews I did, I can hear myself coming through, acting as a pharmacist in questions and comments I made. Familiarity with treatment course, possible medication side effects, drug names, doses, etc. became part of the interview as I filled in information or asked questions to clarify medical treatment. Instead of being an outsider, I was part of the T2DM world being discussed. However, these interviews were far too personal, wandering in their direction, and time-consuming to be anything similar to a medical experience. As I listen to the life history interviews, I realize the shift in questioning and tone of the interview is validation of shifting
between pharmacist and anthropologist and different forms of knowledge I was trying to understand. As will be discussed below, using life histories of diabetes helped to shift these boundaries (Wengraf et al. 2002). These two different ways of thinking and interviewing, one linear and professional, the other historical and contemplative, lies at the heart of this project. These distinct but always connected forms are not (only) the result of methodological choices. It represents the deep-seated structural constructions that shape everyday life of abstracted space and lived experience.

2.4 Life-history interview tool

In Tacoma, Washington, as everywhere, T2DM arises from conditions of everyday life. For the Tacoma residents I interviewed, these conditions are marked by long hours of work, cheap and/or high caloric food, stress, and little inclination and/or time for self-reflection and self-care. Personal histories of living with T2DM provided a methodology to demonstrate how lived experience is held in tension with the new perspectives of bodily abstraction as people learn (or not) to manage diabetes. Diabetes life histories provided a way to understand the construction of self-care practices as an integration of lived experience and scientific abstraction. Most importantly, at a micro level, life history interviews reveal the centrality of the body, and the difficulty people have in objectifying their own body through self-monitoring and measurement necessary to come to terms with diabetes and makes ordinary actions of daily routine a site of reflexive reason but also holds the possibility of further alienation.

Life histories allow the examination of individuals as socially embedded actors, and have the ability to break down complex, multi-factorial situations into more easily identifiable “maps”
(Davis 2006). Complex situations, such as how decisions regarding diabetes self-care occur over
time, can be identified or made clearer when examined as outcomes from an ordered sequence of
events. The goal of the interview process is to identify threshold effects that change how people
use (or not) diabetic medications and/or blood glucose monitoring in everyday practices.
Through an interviewee’s life history narrative, threshold effects and trajectory patterns can be
collaboratively (by both interviewer and interviewee) identified to piece together significant and
complex relationships leading to both constructive or destructive self-care practices. The aim is
to identify episodes of crises/change, the way people coped, formal and informal forms of social
support and, ultimately, long-term trajectories. Interviews were conducted until patterns of the
three main trajectories; medical events, life events and experience were repeated in sufficient
numbers for analysis.

I designed an original tool for collecting life-history data using two published life-history
methodologies (Davis 2006; Griffiths et.al 2007). The first part of the interview drawn from the
work of Davis (2006) consists of a vertical axis representing well-being, the horizontal axis
representing time and trajectory patterns (appendix 1). Three timelines of living with diabetes are
constructed to form an interconnected whole. To avoid over-generalizations and uncover all life
events contributing to self-care decisions, the first two timelines work out concrete details of an
individual’s medical and social history.

1. Medical history (as understood by the individual, not through access to participant’s
medical chart): medical diagnoses, blood glucose, weight, other medical conditions, and
medications. Included is how many times a day blood sugars were being checked, how
recorded, and when/where they were read. I did not ask people what their current A1c was until the end of the timeline, if they had not already volunteered the information. By that time people understood the purpose of the interview was not to create a medical evaluation, but to understand their own processes of thinking.


3. Experience history: the feelings, desires, thoughts, and meanings experienced along with learned understandings, coping skills and knowledge acquired during the previous two timelines for the events recorded in the above two timelines.

The final step of the interview consists of completing a “care diagram,” drawn from the work of Griffiths et al. (2007), consisting of six quality of life domains selected by the WHO as relevant worldwide for the promotion of good health. This diagram helps to triangulate and summarize relationships identified in the life-history interview, to identify areas important to an individual’s well-being, and to explain how these areas of well-being influence (or not) diabetes management. This information also summarizes how individuals invoke responsibility for diabetes and how this responsibility shapes how they see their future. Most importantly, this last section of the interview allows participants to explain their own processes of reasoning and experiences and space for critical contemplation (Sandelowski 1991).

The care-map tool: This instrument consists of six domains (appendix 2). The “map” was adapted from Griffiths’ et al. (2007) design of a “life map” that uses six domains of health determined by the WHO: economics, environment, physical health, social support, spiritual
support, and psychological support. Completing this portion of the interview involves three parts: 1) listing criteria for each domain that a person feels is important to their diabetes self-care practices; 2) ranking the importance of each domain in their life and their future management of diabetes; and 3) ranking the importance of each domain to blood sugar control. Each domain had a list of characteristics (appendix 3) printed on slips of paper that participants were instructed to read. They were informed that these were suggestions only. We discussed what from the list was important or not to each person, and other topics important that were not listed. Both sections of the interview were crucial to the other. Without the timelines, people would not have been able to reflect on what had happened to them and how their lives had changed over time. Without the discussion of domains, many crucial insights of how people felt and what they had learned would have been lost, along with important patterns that contextualized people’s lives in relation to gender, race, ethnicity, and class.

Each interview began with a description of how the interview was going to begin and end. I explained that we would be creating a timeline, beginning with when people first realized they had T2DM. Sometimes this corresponded to when people were diagnosed at a clinic or had lab work done, other times it did not. I explained that we would begin with medical events first, such as drugs prescribed or hospitalizations, and their social situation at these events, such as employment, access to insurance, or living situations. Lastly, we would discuss what people had learned through their experiences. These timelines quickly became intertwined, and people would begin to discuss related topics important to them. A frequent question was, “Is this really what you want to hear about?” when they felt that they were getting off topic. Starting with
medical events first and slowly establishing a larger chronology uncovered other forgotten events and revealed a great amount of contextual and historical data. The life-story process allows for the examination of multiple causations of events in their telling, both obvious and indirect, which would have been lost in a variable-based approach (Davis 2006).

Unlike the collective, institutionally based narratives of self-care I collected through T2DM education programs (discussed in chapter six), actual experiences of living with T2DM are far less organized. Life stories are not collected systematically and tabulated in the same manner as quantitative data, instead they were examined as individual experiences that disrupt the increasing shift toward quantification and integrated data-collection in medical practice and for compliance monitoring. Life histories become a way of getting at what has been excluded, included, valued, and put aside over the course of a participant’s experience with diabetes. At the same time, life histories challenge collective narratives, in this case linear, abstracted medical models of T2DM, as the locus of responsibility for self-care practices and how conditions like diabetes become a site for self-transformation.

As a methodology, one of the benefits of a T2DM life history for participants is reflecting on past practical activities, and how people view the future in terms of past beliefs and behaviors (Wengraf et al. 2002). As a methodology, it allows interviewees to explain their own processes of making connections between one’s daily activities, eating, moving, and sleeping, and how care of the self is conceived, as T2DM itself moves everyday life beyond ordinary routines and what is taken for granted. The unstructured nature of the interviews allowed people to explain events that explained the course of diabetes from their own perspective, but more importantly, it
supplied an understanding of the contradictions, conflicts and emotions that could not be easily verbalized. For example, some people expressed a desire for their physicians to demand strict accountability for making diet and exercise changes while at the same time stating that they never followed physician instructions. In addition, the social isolation and sense of social exclusion brought on by unemployment and/or the effects of T2DM, particularly among some of the men, was not something easily verbalized, but came through as they talked about the importance of work, belonging to community organizations, and values derived from these activities.

Lastly, as a methodology that enables reflexive thinking, life histories were used to examine the potential of T2DM to motivate quite dramatic and positive changes in people’s lives. This potential of life story interviews elucidates what Reeve et al. (2010) termed “creative capacity,” equating it with an individual’s ability to maintain continuity of self, despite terminal illness. Importantly, he discussed how creative capacity could be enhanced, decreased, or exhausted by life events. Carel (2007) also showed how creativity and adaptability are two possible responses to illness and how chronic conditions hold the potential for personal growth and transformation. In this project, life histories are used to understand creative transformation in the context of living with T2DM. However, instead of viewing this capacity as a concept of individual agency as the articles by Carel and Reeve et al. propose, diabetes is viewed relationally, always held in tension with social context, and especially how it is constructed (especially spatially) as a disease state. Life stories show the various ways both linear and historical temporalities are used to attain or attempt to attain social autonomy. Mastery of self-
care skills is just one part of this process, which includes spirituality, facing both the past and the future and the physicality of self-worth.

2.5 Recruitment sites and population

T2DM is a condition strongly correlated throughout the world with lower incomes (Cowie and Rust 2010; Drewnowski et al. 2014; King and Rewers 1993; Lipska et al. 2014; Zimmet 2000). Understanding T2DM as a condition of marginality means also understanding the self-care practices of people living at the margins (Ecks and Sax 2005) without health insurance due to lack of employment (many times due to the effects of T2DM) or poor job benefits. The population recruited here makes visible the reliance placed on individual autonomy and the precariousness that results when fragile social foundations are disrupted. Unemployment is a factor that contributes to the development of T2DM and places a further strain on dealing with the condition. Tacoma’s long history as a blue-collar city, and the structure of life story, gives voice to the conflict many people experience trying to reconcile different values and practices between work, unemployment, and taking care of one’s self to maintain social autonomy.

Two clinic sites were used for recruitment. While both clinics had the goal of providing medical care to underserved populations, they were quite different in their size, structure, and operation. Because of this difference and the part it played in recruiting, the two clinics are explained in detail next, to situate them in Tacoma and as an example of how a sense of belonging/involvement in the provision of medical care also influences one’s self-care.
VolunteerCare (a pseudonym) was an all-volunteer clinic that came together Wednesday evenings in an unused facility building on a university campus in Tacoma. Jane, a registered nurse (RN), began organizing the clinic in 2008. In one of our first conversations, she told me that the clinic handed out no medications and therefore “didn’t really need a pharmacist,” but she was welcoming and willing to show me how the clinic worked. Holding judgment and giving the benefit of the doubt was a part of Jane’s character I watched her display over the next seven months (between March 2013 and January 2014) as she managed the volunteers, patients, and innumerable problems and as I recruited interviewees. Jane’s character and life experiences played no small part in the success of the clinic, and certainly influenced why people agreed to talk to me when I told them about this project.

Jane’s involvement in the tightly woven volunteer network and the completion of a needs assessment of working-poor in Tacoma became the impetus for VolunteerCare. It first took shape when the director of the local food bank where Jane and her husband volunteered handed her an article from a needs assessment done of people using local food banks in Milwaukee. Overwhelmingly, these clients were working poor who made too much to qualify for Medicaid or food stamps. They also had high rates of untreated T2DM and used the ER more often. Through connections with the University of Washington School of Nursing in Tacoma, Jane helped organize a similar needs assessment in Tacoma, with similar results.

It is important to acknowledge the atmosphere and intention of the VolunteerCare clinic, because both played an important role, as mentioned, in the willingness of people to talk to me
about their lives. Clients and volunteers explained to me how the relationships they formed through the clinic helped them through difficult periods. Interviewees told me the personal obligation they felt to the volunteer staff and their non-judgmental attitude helped them to attempt changes they knew they needed to make. Volunteers helped each other through difficult personal times and the clinic was a source of social capital to network job interviews, provide social introductions, and to learn what was going on in the South Sound. My understanding of the Pierce County Health Department volunteer organizations and the social services of Pierce County would have been greatly diminished without my involvement at VolunteerCare. Despite its success, however, it was never Jane’s intention to create a permanent medical service. After operating for four and a half years, VolunteerCare closed its doors in January 2014 when the Affordable Care Act began operation. Jane’s intention from the beginning was to fill a gap until the implementation of the ACA, never to provide a permanent service.

While the clinic operated without any high-tech equipment, in fact very little equipment at all, it required much time, ability, and optimism to cobble together the support needed to operate successfully on a shoestring budget. VolunteerCare strictly followed a medical protocol, actually designed by the Indian Health Service, for only the three conditions: diabetes, hypertension, and hypercholesterolemia. However, even this limited scope was unusual for a volunteer clinic. Jane explained to me that volunteer medical clinics usually only see acute conditions. Storing medical charts, providing follow-up and a 24/7 answering service were obligations other volunteer medical organizations in Tacoma (and elsewhere) were not willing or capable of providing. VolunteerCare Jane had a no-time-limit policy for appointments. In fact,
the medical director had quit a job because the medical corporation she worked for implemented a seven-minute time limit on all walk-in appointments. VolunteerCare operated on the dictates of an experienced volunteer staff, direct patient feedback, and the strong personality of its clinic manager, creating a unique environment.

In interviews with Jane and the volunteer staff, we discussed the different barriers and solutions that occurred over the four and a half years of VolunteerCare’s existence. Looking back, they all agreed that being able to have direct input to solve problems, their similar ethics of what medical practice should be and the social support they received from patients and other volunteers played a large part in the clinic’s success. Running the clinic successfully took a dedicated, experienced group of people, judging from the numerous barriers and community partnerships Jane and the other volunteers negotiated. Jane attributed the success of finding support to the good PR that donating provided to the large hospital and retail chains she partnered with, and also to the fact that the small clinic posed no threat to the local medical structure and kept people from seeking help at local ERs for their uncontrolled chronic conditions.

2. Community Health Clinic (CHC)

The second clinic recruiting site, CHC (a pseudonym), also came into existence through community activism, but has slowly gained in size and scope of care over the past few decades, losing much of the accessibility found at VolunteerCare. CHC began in 1969 as a volunteer medical organization in the medically underserved communities of Hilltop and Eastside neighborhoods in Tacoma. By June 2013, it had expanded to five clinics with in-
house pharmacies, dental care, laboratories, and pediatric clinics. CHC has continued to expand into a more conventional and bureaucratic medical practice, and in January 2014, opened a new 54,000 square foot, three-story clinic in the Hilltop neighborhood. The clinic was a rare new business development in the Hilltop, and was funded through a complicated mix of private donations, foundations and grants from city, state and federal governments, tax credits, and investment funds (CHC website 2015).

Missing in my dealings at the clinic was the intimacy and direct input of VolunteerCare. The difference also came through in the absence of belonging to CHC the way interviewees did with VolunteerCare. Part of the difference was size and the separate locations of five clinics. It also reflected the separation between the clinic operations, the clinic health board, state and federal funding sources and the necessity of paying attention to an economic bottom-line (however, without the support of CHC, VolunteerCare would not have been able to exist).

Because of a two- to three-month wait period for new, chronic care appointments, in an effort to accommodate more visits per day and streamline clinic flow, CHC had recently implemented a policy that permitted patients to discuss only one issue per clinic visit. This angered both patients and physicians, as I found out through interviews. One person even cried as she described losing her much-liked physician after he left CHC because of his irritation with the policy. These differences reflected human interactions in the two settings, and certainly affected how people perceived my project, since it was much easier to recruit people at VolunteerCare.

VolunteerCare had been operating for almost four years when I started coming to the clinic, so its atmosphere, ways of operating, and volunteer interactions were firmly established.
My project there was treated as a part of this more personal way of providing medical care and contributed to the less-intrusive quality of my project. At CHC, this direct personal relationship was absent. In fact, when I first described the goals of my project to the CHC medical director, his interest came as a way of showing concern for patients at CHC and of how seriously T2DM was taken there.

I used a similar system to recruit interviewees in each clinic setting. An RN or medical assistant (MA) identified people to me as having T2DM as they checked in, and I discussed participating in my project as they waited for their appointment. In total, I interviewed 60 people, 34 from VolunteerCare and 26 from CHC. Because of its smaller size and patient population, I talked to every person identified as having T2DM at VolunteerCare. The CHC clinic where I did most of my recruiting was busy, and medical staffing was in flux, which made my involvement there more complex to negotiate. I inquired more people at CHC to get 26 interviews than I did to get interviews with the 34 people at VolunteerCare. Since CHC saw far more people than VolunteerCare, I also had the opportunity to talk to many more potential interviewees. But the goal of the project seemed to intrude into protected personal space more frequently at CHC; I have twice as many declines from CHC as VolunteerCare, and this fits with the more intimate and informal atmosphere of VolunteerCare. Selection for interviews was therefore biased due to convenience sampling and location sites. Nevertheless, the number and range of participants gives a good picture of how people learn to deal with diabetes over time.

Financially, patients at CHC were better off. Many people ended up being referred to VolunteerCare after an ER visit, a last resort when symptoms from T2DM became
uncontrollable due to not being able to afford any medical care or medication. Medical visits to CHC were $30, an expense many VolunteerCare patients couldn’t afford. This financial difference perhaps contributed to the greater willingness to be interviewed at VolunteerCare; I offered a $30 gift card that for many interviewees meant a big difference in their monthly budgets. I became very familiar with buying gift cards at Wal-Mart and Grocery Outlet; gift card choice was for practical spending. Most interviews took place in libraries convenient for the interviewee. Small study rooms allowed for private conversations, but when these were not available or if transportation was an issue, we went to nearby coffee shops or people’s homes.

Interviews took at least an hour; the longest was a little over three hours and the average about half that length. People were told they needed to be at least 25 years old and to have had T2DM for five years, so that they would have had experience dealing with diabetes, making decisions and forming opinions regarding self-care practices.

The reasons people why people did agree to be interviewed varied, but had little to do with how well, or not, their T2DM was controlled. People had to trust me enough and be interested in telling me their stories (or need the money) to agree to the interview. Largely, it seemed related to a desire or willingness to talk and reflect. For some people, the potential for this type of personal exposure seemed too much. A couple of VolunteerCare people repeatedly cancelled appointments after scheduling them, as one person told me, “It’s something I want to do but I just can’t now.” Two women, who did eventually agree to an interview after cancelling twice, told me they had come to a more positive place dealing with diabetes and were now able to talk about themselves. One told me she was no longer giving “credence to blackness and pain”
and the other had just lost an uncle to T2DM complications and talking to me was a step towards taking more control in her life.

Because T2DM management stretches out over decades, by using life history interviews, I was able to talk to people who had for years, sometimes decades, done little to manage their condition. Many times after the interview ended, people began discussing what they had just talked about (most of the feedback I received about the interviews happened after I turned off the recorder). This musing was an important validation to me, because reflecting on what had been learned through experience was my intent for using life history interviews in the first place. One person told me, “I thought this was going to be a bunch of BS to be honest, but it’s given me something to think about.” The man who said this agreed to the interview because he needed the money, but the interview also allowed him to explain what motivated him to live the way he did and to make the choices he did. Putting together events and meaning in narrative form was an opportunity for a different way of understanding diabetes.

2.6 Participation in and observation of diabetes education programs

In chapter five I describe in detail the certificate diabetes-training program for pharmacists I attended along with the diabetes-training program sponsored by Merck for health care professionals, Journey for Control.™ As I describe in the chapter, these programs demonstrate the shift of medical abstraction into the domain of daily routines from institutional settings. Chronic disease management requires an informed patient-consumer, the need for which has created a new service niche for pharmacists. The programs presented are not selected to provide an in-depth look into the increasingly emphasis on medical treatment as a consumer
service, but to give an idea of the scope of diabetes education programs, namely the focus on teaching quantitative skills, medical facts and rational decision-making. These lessons formed a common core that people I interviewed drew upon to manage diabetes. People are taught to understand and manage diabetes by learning objectify their bodies through these standardized and uniform programs and while there is room for individual adjustments the goal of the programs is to teach a new way of understanding one’s body through blood glucose measuring and monitoring skills.

2.7 Conferences attended

I attended the following conferences some of which are also mentioned in more detail as they relate to specific topics.

1. *World Congress Insulin Resistance Diabetes and Cardiovascular Disease*, November 7-9 2013, Universal City, CA. and

2. *Insulin Resistance & Chronic Disease Prevention Symposium* April 18, 2013 Squaxin Island Museum, WA. These two conferences on insulin resistance helped to understand the focus of current medical treatment for diabetes. Insulin resistance points to a new direction in how diabetes is defined and treated. More generally, it moves bodies away from being conceived as self-contained systems that work to maintain homeostasis and towards the thinking of physiological processes as always being in communication with environment and flexible to the demands and adaptability that requires. However, as Margaret Lock (2015) notes, this perspective does not necessarily mean that the social factors contributing to the global increase in diabetes are also considered as a serious
focus in medical research. The two conferences I attended offered two almost opposing views of the etiology and treatment of diabetes. At the World Congress, discussion rarely moved beyond the cellular level, while the Squaxin Island conference focused on the social determinants that contributed to insulin and diabetes. The two conferences put into perspective how conceptions of diabetes could influence how people take responsibility for self-care, and helped to clarify how medical abstraction dissociated disease from both collective history and lived experience. While slightly outside of the scope of this dissertation these conferences helped to understand the divides in medical practice surrounding diabetes and treatment.

3. *Functional Medicine for the Underserved*, Santa Clara University, CA 2013. Organized by Integrative Medicine for the Underserved (IM4US), a volunteer organization composed of all types of medical providers, not only allopathic providers. They seek to provide what they call a “relational approach” to treating chronic disease in underserved communities, “where doctors take the time necessary to understand the patient’s unique situation before reaching for the prescription pad” (IAM4US.org).

4. *Strengthening Research in Integrative Healthcare Around the World* presented by Integrative Medicine and Health Portland, OR May 2013. This is a much larger and heavily endowed conference that also examines alternative medical approaches that challenge positivist medical approaches. Both conferences were helpful in understanding how medical practitioners and researchers are asking questions that address commonly encountered treatment issues using tools that also broaden the scope of medical care.
2.8 Participant observation as a HealthCare Navigator

In November 2013, I attended training to become a Washington State HealthCare navigator. I volunteered at a community outreach center located in one of the neighborhoods where a number the Tacoma residents I interviewed lived. This experience gave me another perspective into the realities people I interviewed dealt with and the safety-net services available. I discuss this experience in chapter ten.

2.9 Interviews with health care providers

While these activities are not explicitly part of this dissertation, they contributed greatly to understanding the safety-net services available for people struggling to manage medical issues with limited resources. It also gave me insight into the implementation of community health workers (CHW) through ACA guidelines, in clinical settings to supply needed social support to manage chronic conditions. For example, I attended a meeting of the Pierce County Medical Society, where the implementation of a CDC-funded community project in Tacoma was discussed. CHWs were seen as a way of allowing physicians to focus on the “medical issues they were trained to handle” and CHWs as a bridge between physicians and patients. I worked throughout the data-collection of this project and talked to medical clinicians regarding their ideas of the scope of care they felt responsible for and the constraints or opportunities they experienced in implementing these.

2.10 Media analysis

This was conducted almost exclusively through the Internet, focusing on:
1. Pharmacy journals related to shifts in professional practice that I discuss briefly in chapter five.

2. Medical journals to understand developments in diabetes epidemiology, pathophysiology and treatment.

3. Diabetes chat-rooms and on-line support groups devoted to diabetes management from the perspective of people living with diabetes; Pharmaceutical industry publications and health care industry business journals were consulted to understand how support services to manage T2DM are increasingly viewed as a deep revenue source. The global industry surrounding diabetes self-care is estimated to have generated from $35 to $58 billion in sales in 2013 (Betz 2012). As discussed in chapter five, support services not only generate profit but create an informed patient-consumer.

In summary, these methods serve to understand the social construction of diabetes beginning with new conceptions of the body with the development of modern physiology in the mid-19th century. The methods employed demonstrate the ways spatiotemporal structures are continuously produced through political, economic and cultural forces and link spatial rearrangements of external landscapes to internal spatial arrangements of human bodies. The methods used help to understand this link between these forms of space as a shared historical process, rather than two distinct and unrelated stores. They also help to understand the broader social context of residents in Tacoma to understand the increasing presence of abstracted space in everyday life as they deal with the increasing epidemic of diabetes.
Chapter 3: The Re-settlement of Tacoma

Understanding the lived experience of diabetes among the residents of Tacoma requires an understanding of the relentless dismantling and transformation of all manner of spatial arrangements that continue to shape everyday life.

While people have lived on the land Tacoma occupies for tens of thousands of years, Tacoma’s “history” in this project begins with its abrupt appearance as an urban space in 1873. The regularly platted streets of Tacoma that ignore the steep cliffs rising up from Commencement Bay or the straightening of the Puyallup River are more than just the containers of or backdrops for how people live in Tacoma. The platting, mapping, and transformation of land into an urban social space connected Tacoma to other rearrangements in the mid-century, not only to the building of similarly designed railway towns across the West (Hudson 1982), but also to new ways of understanding human bodies in medical science. In these processes, as space (including bodies) became more abstract, the social connections binding bodies to land and bodies to self became less fixed, more impersonal, and detached from history (Cooter 2013; Figlio 1977; Jewson 1976; Rosenberg 1977). Spatial uniformity brought the ability to control, manage, buy, and sell, unencumbered (or lessened) by attachments to tradition, local history, or lived experience (Harootunian 2000; Lefebvre 1992; Ross 1996). It also introduced mechanical repetition and linear temporality that Lefebvre and many other thinkers (e.g. Crary 2013; Osborne 1995; Aglietta 1979) have identified as profoundly shaping everyday life since the mid to late 19th century. Tacoma’s landscape created the need for skilled and unskilled labor and the autonomous worker, who in turn is dependent on work to maintain her autonomy (Harris 1997).
The re-arrangements of land and exploitations of resources that define Tacoma’s history continue today in the high-stakes modernization of the Port of Tacoma as it competes in the global market of container shipping. The technological innovations that reduce barriers to the global movement of commodities through the Port of Tacoma also result in the production of social space at the level of lived experience (Ross 1996). As such, the speculative business history of Tacoma is more than a neutral backdrop to the diabetes life-stories of the people I interviewed. The technological and spatial transformations that began as a speculative railroad real estate venture and continue to guide our relationships between body, place, and self.

In this chapter, along with descriptive sections of Tacoma to understand its particular history, I describe the remarkably quick transformation of Tacoma’s forests into uniformly platted streets, with electricity, steam power, banking and transportation for goods that created the necessary material conditions to connect the South Sound with a much larger geopolitical framework of capitalist exchange (Clayton 2000). I discuss the underlying temporal logic that defined Tacoma’s re-settlement as it also plays a pivotal role in the rational decision-making (and attenuation of lived experience) of diabetes education programs discussed in chapter five. Lastly, I discuss the rise of the health care industry, as a major employer in the South Sound, a new industrial “space,” as the extractive industry and manufacturing of the past is no longer viable in the region.

This chapter also introduces two key themes that are established with the re-settlement of Tacoma and remain relevant in the lives of the people I interviewed. Perhaps the most important is work and the procurement of social autonomy through earning a wage. Tacoma was never an
agricultural center, and although rich farmland surrounds the area, industry (including food processing) has determined the type of work and workers. The second theme is the twin processes of “de-territorialization” and uniformity that make possible the commodification of everyday life (Harootunian 2000). The uprooting of all fixed entities, and the uniformity of design and practice, mark the appearance and expansion of industrial capitalism in Tacoma’s resettlement. These processes continue, turning inwards with the management and treatment of uniform and interchangeable bodies to control diabetes.

3.1 “Tacoma, City of Destiny!” Connecting the old and new

Shortly after the implementation of the Affordable Care Act (ACA) in 2014, retro-looking billboards with the message “Tacoma, Gateway to Health!” began appearing around Tacoma. The style and optimistic message were seemed to replicate Tacoma’s late-19th century boosterism, when slogans such as “Tacoma: Gateway to the Pacific Northwest!” and “Tacoma: City of Destiny!” were used to promote settlement and investment. The new billboards appeared to freeze time and link the passage of the ACA with the long-gone industrial boom of Tacoma’s early (re)settlement. The paradigm of progress and development from old Tacoma was resurrected, but instead of exploiting external resources, the new slogan was aimed internally, professing the same values of progress and development taken from an old city promotional campaign. It seemed to promote the discovery of a new frontier of natural resources there for the taking; one only needs to exert will and work hard to attain good health. However, instead of promotion by the Northern Pacific Railroad (NPRR) or the Tacoma Land Company, these
messages were sponsored by MultiCare, the largest healthcare provider in Pierce County; the Pierce County Health Department; and CHIP, a federally funded health promotion program.

Figure 3.1: Tacoma! Gateway to Health!

But why promote “health” as if it were some new product? What was the odd tension created between Tacoma’s faded industrial past and the new, Federally funded “insurance market-place” of the ACA? The two stories at first seemed to have nothing to do with each other. Reflecting further, however, there are similarities between the two. Both reflected ideals of progress and development: one, the internal space of biological abstraction and medical technology; the other, the external, industrialized space of Tacoma’s past. Control, mastery of environment, and perfectibility has shifted from the external environment to the body (Dinerstein 2006). The billboard seemed to connect these two disparate stories through the always-forward-looking paradigms of mastery of environment through technology, so that the world we imagine internally corresponds to the world we face outwardly. Tacoma’s industrial transformation,
created by massive rearrangements of land and water to “improve” nature (Cronon 1991), moved inward to manage and improve the bodies of its citizens. However, as Rick’s story at the beginning of this dissertation describes, this inward movement requires a much different type of work.

Throughout its history, Tacoma has been known as a blue-collar city, still defined by the manufacturing jobs that dominated the economy until the 1970s. Working hard has been part of the ethos of Tacoma’s history (Chasan 1981; Morgan 1979), and is still relevant today as evidenced by the interviews of Tacoma residents living with diabetes that follow in later chapters. I was frequently told, “I’ve worked hard all my life,” or, “I’m not afraid of hard work,” as an apology for being idle due to complications from diabetes. The emphasis on hard work connects the creation of Tacoma as an industrial center (Boyce 2002; Chasan 1981) to accounts of Tacoma’s Euro-American settlers (Gallacci 2001; Morgan 1979), through labor battles in first half of the 20th century (Baldasty 1999; Markholt and Fitzpatrick 1993; McKean 1941; Rajala 1989;), and finally, to the interviews of Tacoma residents living with diabetes in the 21st century. In this chapter, I explore how the mobile, autonomous worker of Tacoma’s “resettlement” in the late 19th century connects to the consumer/patient of the 21st century, shifting the spatial landscapes that have shaped Tacoma. This American re-settlement history of a largely immigrant population detached from the circumstances of previous lives (Harris 1997:253) connects to present-day acceptance of diabetes self-care as a largely individual responsibility. The social networking and support Guell (2012) describes among diabetic Turkish immigrant women in Germany is not a dominant cultural behavior among Tacoma residents.
When I first moved to Tacoma in 1990, prior to entering graduate school, it was an odd mixture of both fading Victorian excess and remnants of industrialization, set within a beautiful natural landscape. From the interstate that cut through Tacoma, I could look out over an area called the “tideflats”- thousands of acres of flat, treeless land filled with oil refineries, pulp mills, huge cargo cranes, and emissions from industrial chimneys. To the east, Mt. Rainier majestically loomed over this industrial subdivision, and to the west, I could see the water of the Sound. There was nothing about the area that suggested a tide, sea-life, or marshes – it was solidly concrete and industrial; the term “tideflats” seemed a complete misnomer.

Downtown Tacoma in 1990 was mostly deserted. It consisted of many Victorian-era brick buildings that had been left to survive on their own, and unused parking garages. Pockets of business, mostly antique stores, existed in the ground floors of the brick buildings. A Woolworth’s with worn wooden floors and an out-of-business Kress Department store sat a few blocks away from an imposing, but empty granite block of a building with marble columns. Its facade read, “Bank of California, 1886,” and it seemed to be built for a completely different city.

Continuing north of downtown and along the south shoreline of Commencement Bay were the remains of old wooden piers, one after the other for almost two miles, their blackened, massive timbers stretching hundreds of feet out into the water. But the only evidence of industry along the shoreline were a single grain elevator and the bankrupt ASARCO plant, shut down and declared a Superfund site a few years before I moved to Tacoma. Throughout the 1990s, there was a steady transformation of downtown and its main thoroughfare Pacific Avenue, where most of the deserted brick buildings stood. The University of Washington opened a branch in Tacoma.
and restored many of the abandoned buildings as part of the campus. By the early 2000s, the Washington History Museum, the Tacoma Art Museum, the Chihuly Glass Bridge and Museum, and other public arts ventures had all opened in the once abandoned city core.

By 2011, when I returned to the city to conduct my dissertation research, Tacoma was very much back in a bust, this time the Great Recession. Real estate speculators, betting on Tacoma finally becoming a second Seattle, had bought and forfeited on property throughout the city, including the original Northern Pacific Railway building, a brick Victorian with a commanding view of Mt. Rainier and Commencement Bay. Purchased from the city by a group of speculators, the railway building stood empty, half gutted in its transformation into high-end condominiums. But booms and busts have defined Tacoma since its conception as a speculative real estate venture by the Northern Pacific Railway in the 1873. The cyclical rise and fall of prices of Tacoma’s past, of over-production and over-speculation of lumber, ships, ore, paper, and wheat formed unpredictable but repeating patterns of development that still shape Tacoma today, in the juxtapositions of long-gone industry, decaying Gilded Age speculation, and natural beauty that surround Tacoma.

Today, the forests that originally covered Tacoma and provided the source of its early wealth have disappeared along with lumber processing and manufacturing. The one resource that has survived is Commencement Bay and with it, the Port of Tacoma. Because of its protected deep-water bay and ability to accommodate the ever-increasing size of container ships, The Port of Tacoma is among the top ten container ports in the United States. With speed and efficiency, containers can be unloaded from and loaded onto trains or trucks, and within hours moving on
rails or interstates to national markets. The Port Industrial area is not only Tacoma’s largest employer, it is also the second most transformed landscape (after Seattle) in Washington State. The Port is the product of the fragmenting of Tacoma’s old manufacturing core into more isolated and contained areas that are now connected by cars and individual drivers rather than the ferries, trains, and street cars that once moved and connected people. Instead of a central core, Tacoma is now made up of distinct and loosely connected commercial and residential areas that do not create an active or unifying center – it lacks a space that brings people together for collective, public social engagements. Unlike Seattle or Portland, Tacoma is still looking for its own unifying character. This more fragmented and indistinct city forms the social context for the people I interviewed in this project.

3.2 The production of uniform social space

The creation of Tacoma as a manufacturing center is also the story of a completely new way of relating to and using land. Geographer Cole Harris (1997) uses the term “resettlement” in his history of British Colombia to call attention to the dispossession and displacement of millions of inhabitants during the 19th century by new immigrants and capital. The term “resettlement” defines a process: “The creation of an immigrant society in a reconfigured geographical space as a culminating colonial process” (253). Early migrants to Puget Sound, a few hundred miles south of British Columbia, were drawn to the south Puget Sound area for much of the same reasons. Early promoters described the settling of the Puget Sound region as making something out of “nothing,” as this 1869 speech to promote immigration to the South Sound states: “While the Indian makes no fixed habitation, really occupies no land, and surely reduces none to possession.
Our race, following their destiny in Obedience to God’s great law that the earth shall be made to contribute to the benefit of His creatures, appropriate it to a useful purpose. Upon this principle earth has been reclaimed to civilization. Christianity and human progress have advanced” (Evans 1869). William Cronon (1991) and David Nye (2003) have called the 19th century transformations of landscape in much of the West “second nature” or “second creation.” These “spatial rearrangements” created commercial value along with legal possession and the right to exploit land and resources. The creation of commercial wealth therefore required the creation of a particular type of landscape and involved surveying, mapping, and division of land, reconfigured into rectangular plats that could be developed, bought, and sold.

The dispossession of Tacoma’s Native population was as much a product of changes in the region’s original landscape as to the influx of new immigrants and destruction of resources (Clayton 2000; Harris 1997; Thrush 2007). Tacoma’s re-settlement also followed a temporal form of a single, linear scale of development. Change was viewed as always being “from simple to complex,” so that the “present” of White settlers would be the “future” of Native populations (Osborne 1995). This linear temporality and scale of development followed the injunction that humans “subdue and have dominion over the earth,” making the exploitation of resources and profit through logging, manufacturing, and shipping justifiable by an ethos of God-given right and human betterment.

Tacoma’s appearance as urban space was not a slow, steady, rational process that transpired over the course of the 19th century. Instead, with the arrival of the railroad in 1873, Tacoma seems to have materialized almost fully formed from the lush, old-growth forests that
once completely covered the South Sound. The furious dramatic rush to create a modern city exemplified the temporal qualities most admired by many early writers describing Tacoma. Early writers seemed almost giddy with the possibilities of this speculative future, even though they didn’t seem to really understand how such rapid development was possible, making it all the more magical. Tacoma’s sudden emergence seemed to mark the beginning of a new era of existence, not only because of its speed of development, but also from its lack of a past, unlike the slowness of time in the “established” eastern United States, to hinder its forward momentum: “Were an easterner, accustomed to eastern slowness of development…to behold the Tacoma of today, he might easily conceive himself face-to-face with the magic of Aladdin’s lamp. I saw Tacoma in 1887, and again in 1889 and 1890 and the growth of the city in this short time was such that in both cases I hardly recognized the place. It seemed as if some fairy had visited the town and changed every black stump into a four-story brick building by touching it with her wand” (Hestwood 1893). Tacoma’s materialization had the spontaneity of an event made possible because of its lack of connection to the past. Tacoma’s emergence was testament to the effortless abilities of technology to improve human social conditions, and validated the agency attributed to technology rather than human behaviors (forming a blueprint for the current IT industry further north in Seattle and Redmond).

Even in an age of wild speculation and boom-and-bust business cycles, Tacoma stood out in its first decade. In an 1889 tour of the Pacific Coast, Rudyard Kipling described Tacoma as “literally staggering under a boom of the boomiest….I do not quite remember what her natural resources were supposed to be, though every second man shrieked a selection in my ear. They
included coal, and iron, carrots, potatoes, lumber, shipping and a crop of thin newspapers all
telling Portland that her days were numbered” (Kipling in Morgan 1979:43). Tacoma’s
population jumped from 6,000 in 1885 to 36,000 in 1890, then to 52,000 in 1893. In 1893, fewer
than half of the residents had been in town more than three years (Morgan 1979). The “true”
purpose of Puget Sound’s resources, especially lumber, could be fulfilled through their
transformation into commerce.

Fantastic projections of limitless resources and development were especially common in
accounts of the limitlessness of the region’s forests. Both the size of trees in Tacoma’s forests
and the belief that the supply would go on forever is evident in the wastefulness of early logging:
“The only trees cut were those which would produce at least three logs 24 feet in length and with
a minimum diameter of thirty inches. The trees were cut not less than 12 to 20 feet from the
ground in order that cutting through the thick and enlarged base might be avoided. After the trees
are felled the tops of which were considered too slender were cut off and 40 or 50 feet more of
the trees were wasted” (Buchanan 1936:41). The quick transformation from forest to urban space
is documented in photographs of rutted dirt, stump-lined streets changed to graded, paved, and
streetlight-lined thoroughfares in a few short years. De-forestation was progress, but this
transformation took a particular configuration. The spatial design of Tacoma followed a well-
used recipe of land speculation and platting and selling town lots around the new railway stations
(Hudson 1982). This repeating business process reflects the connections of linear temporality
discussed above with a particular uniform and reproducible cityscape discussed next.

3.3  The platting of a railroad town
Tacoma was platted out by railroad engineers who created similar cityscapes from the Midwest to the Pacific coast; the regularities of city design were the distinguishing feature more than any unique characteristic that separated one place from another (Hudson 1982). The subsequent dredging, sluicing, straightening, and flattening of Tacoma’s steep cliffs and tideflat area created a shared a dynamic of progress and development with towns and cities across the West undergoing similar transformations. The ability to transform space into something with commercial value as if by magic was firmly linked to the standardized city plats designed by the railroad’s engineers. In Tacoma, the wealth potential from a deep-water bay with dense forest growing up to the water’s edge was recognized early on. However, without transport there would be little profit. New rail lines, wagon routes, and shipping ports were built to connect the fish, timber, ore, and wheat of the North West territories with markets in Japan and San Francisco. The twin processes of clear-cutting forests for timber and the platting of city streets governed a transformation of landscape that happened almost concurrently along the entire coast of Washington Territory in the mid-to-late 19th century.

In 1873, Northern Pacific Railroad (NPRR) built the first rail terminus in the Puget Sound region at “Tacoma.” However, before announcing their decision to build at their chosen site, the NPRR created the Tacoma Land Company, a subsidiary led by directors of the railroad, which purchased 16,000 acres surrounding the planned site, including three miles of adjacent shoreline. This business venture was developed by the Illinois Central railroad: buying “undeveloped” land, platting the streets and lots to be sold as a new city according to uniform designs, all owned and controlled by the railroad company (Hudson 1982). Tacoma almost
escaped this conventional town platting when the Tacoma Land Company briefly considered a city designed by Frederick Olmsted (of Central Park fame). It is unclear how Olmsted became connected with the project, but a past professional association with Charles Wright, the wealthy Eastern banker, railroad tycoon, and president of the Tacoma Land Company, is thought to be the reason (Johnston 1975). Olmsted designed what now sounds like an ideal urban space using the steep hills rising up from the bay to create a terraced city; long contoured streets avoided steep grades and provided unobstructed views of the Sound from any location:

The new plan is, as far as we know, unlike that of any other city in the world...The most peculiar features of the new plan are the varying sizes and shapes of the blocks, and the absence of straight lines and right angles. Every block and every street and avenue is curved...The curvature of the blocks does away with corner lots and their great length with much of the misery of street crossings...The first [of three ‘grand avenues’] is intended for business of the town and for country trade and driving; the second takes past the principal parks and the third will be magnificent for residences...as it will be high and slightly with nothing between it and the water (Johnston 1975:101).

Unfortunately, the commercial value of uniform grids with corner lots, rectangular streets, and blocks ultimately won out. The grid design was instantly understandable in its interchangeability with other Western cityscapes. The right angles and parallel streets translated into easily recognized commercial value and the selling of lots to investors. Speculators wanted corner lots on the widest streets for the most commercial traffic; looking at Tacoma’s approved plat they could tell where the principal intersections and most valuable business real estate would lie. The first city platting, which made it obvious to speculators what streets would be of high commercial value, also made class distinctions between residents legally binding through property ownership (Harris 1997). The platting of Tacoma’s streets was necessary not only to
generate commercial wealth and signify progress, but also legitimized distinctions between social groups and classes through spatial arrangements.

In April 1874, the sale of lots began. From the same 1889 tour of the Pacific Coast, Rudyard Kipling captures the desire for corner lots and the effect of the grid design on the steep hills of Tacoma: “We struck the place at twilight. The crude boarded up pavements of the main streets rumbled under the heels of hundreds of furious men all actively engaged in hunting drinks and eligible corner-lots. They sought the drinks first…Beyond this street [probably Pacific Ave, the main thoroughfare] rose many hills, and the town was thrown like a broken set of dominos over all” (Morgan 1979:270). Perhaps in more prosperous times Olmsted’s plan might have been approved, or promoted as another distinguishing feature of Tacoma’s uniqueness and destiny. But, the bank supporting the NPRR had suddenly failed at the end of 1873, and quick money was needed. It was not the time for an unconventional business approach.
Even before Tacoma’s streets were measured out, the NPRR recognized the commercial potential of the shoreline and tideflats. The NPRR claimed three miles of shoreline stretching south from the proposed railroad terminus from federal land grants, and it was along this stretch of shoreline that Tacoma’s early manufacturing began. By 1890, in photos and written descriptions, this shoreline was a mass of smoke stacks, grain elevators, and docks next to railroad tracks and waiting trains. By 1899, the shoreline had undergone significant changes with dredging and filling to create the first man-made waterway lined by warehouses, rails, and ships.
Twenty-five lumber mills operated along the shoreline, and at its end lay the ASARCO copper smelter with one of the tallest smokestacks in the world, spewing a lemon-colored trail of smoke into the air.

### 3.4 Organized labor and the downtown core

As many scholars have noted in recent work on the history and geography of the Pacific Northwest, the “colonization work” of the 19th century was uneven in its rates and intensity and excluded many people benefitting from their participation in the generation of profit. Raibmon (2005), Harmon (2000), and Oliver (2010) in particular discuss how scientific exploration, capitalism, and imperialism worked together in unique ways in the region, so that the history and present-day existence is not simply a local reflection of global phenomena. As discussed in the introduction and following in interview chapters, the ideals of uniformity and mechanical reproduction are never complete. The massive rearrangements of landscape designed to facilitate the connection of forests to markets also created a community of skilled, unskilled, and mobile workers, and the rise of union militancy. The power of collective bargaining played an equally important part of Tacoma’s history, as did the uniform platting of city streets and future-oriented temporality. Tacoma’s early prosperity brought a demand for skilled labor in the form of plumbers, plasterers, tailors, musicians, barbers, cooks, bricklayers, stonecutters, etc. (Morgan 1979; Rajala 1989). Labor was as much of an outcome the rearrangements of landscape as the commerce it generated. The IWW also had a strong presence in Tacoma, which became a winter base for itinerant loggers and workingmen by 1910. An article in the 1919 Spokane Review described the logging work-force of single, itinerant men who were mostly foreign-born, as
possessing questionable characters and politics and a threat to respectable members of Spokane’s community, even as Tacoma-based Weyerhaeuser Lumber Company recruited thousands of men, mostly immigrants, to log the 1,500,000 timber acres it owned in the Northwest.

In February 1919, a general strike was called in Seattle and shut down the region for a few days, an act that captures the militancy and extent of labor in Puget Sound. That same year, in Tacoma, over 6,000 union men and women took part in the 1919 Labor Day parade in downtown on Pacific Avenue. A photo of the event shows the broad street lined with small and large businesses, movie theaters, restaurants and bars. Pedestrians stand three to five deep down the mile-long corridor watching the parade (Digital Collections 1919). In the same downtown area, a 1934 maritime strike shut down the entire west coast as the longshoreman and lumber handlers unions walked off their jobs. A year later, lumber workers walked out of the forests and mills. Photos taken in Tacoma’s downtown show thousands of strikers and hundreds of armed National Guard soldiers with fixed bayonets, drawn up in opposing lines after mill owners called the National Guard to keep workers away from the mills and scab laborers (Rahe 2012). The photo was also taken downtown on Pacific Avenue, and shows not only the tension and violence of the strikes, but the proximity between manufacturing and commercial businesses, and also the centrality and public nature of Tacoma’s downtown core.

A 1941 business review of Tacoma’s economic prospects discusses the degree of unionization in Tacoma: “The fact that Labor is so strongly unionized and receives such high wages acts as a deterrent to influx of new industries, and by increasing costs of production, makes competition with other areas still more difficult” (McKean 1941:318). The close
relationship between labor and industrialization in Tacoma is also mirrored in the beginning and dissolution of the *Labor Advocate*, first published in Tacoma in 1909. Once considered “one of the best labor papers in the country” (Baldasty 1999), it struggled financially by the early 1970s and folded in 1977, as the old industrial core of Tacoma disappeared. Little of the mass support for labor from past decades is evident in Tacoma today. Although there is a strong sense of Tacoma’s being “working class,” the industry and centralized urban space that sustained collective action no longer exists. Rick’s story, presented earlier and discussed later in the interview chapters, illustrates the lack of collective recourse when one of the last big lumber mills, Louisiana Pacific, ceased operation in Tacoma, claimed bankruptcy, and closed.

3.5 Manufacturing moves out of the downtown core

A shift was underway through the first part of the 20th century from employment in logging, canneries, and fishing towards lumber manufacturing especial pulp, plywood, and other wood and chemical processing, and along with it, movement east to an area known as the tideflats. The lumber mills that lined the Commencement Bay shoreline and were controlled by the NPRR were closing by the end of WWII. The Harvard Business Review in 1948 noted the decline as a warning to business investment: “The forests, the fisheries, and the soils of the region already give indication that the cream-skimming stage is past” (Chasan 1981:87). The story of the Osgood-Wheeler Company illustrates the move away from raw lumber in the early years of the 20th century and the decline of the wood products industry by mid-century. In 1918, Osgood-Wheeler started the first plywood manufacturing plant in the United States on the newly dredged City Waterway. By 1927, the plant covered 14 acres and employed 1,500 workers.
By 1951, the supply of Douglas fir needed for plywood was no longer available in Washington State, and the plant was considered too antiquated to upgrade. The company dismantled, sold what it could and left the rest for demolition. As will be discussed further, in 1983, the EPA declared the site of the old factory (and all along the south shoreline to the ASARCO plant) part of the Tacoma Industrial NPL Superfund site. Industry was moving east into the tideflats, away from the polluted and outdated downtown core.
The tideflats is a delta formed from the confluence of four rivers that begin 60 miles to the east near Mt. Rainier. It is also Tacoma’s most transformed landscape, and the second most altered landscape in Washington (after Seattle) (Chasan 1981; Thrush 2006). Despite the “natural advantage” of the deep-water harbor mentioned so frequently in promotional material of Tacoma’s Port, getting cargo on and off the Sound was not easily accomplished before man-made waterways were built. The steep cliffs surrounding Commencement Bay severely limited shoreline access, which the NPRR controlled completely anyway. The only other access was through the river delta or tideflats, further north and east, where the four rivers and several smaller waterways emptied into the Bay. In 1880, however, this area was an almost impenetrable mass of trees, towering log-jams, moss, ferns, and streams (Morgan 1979).

The completion of the City Waterway in 1918 and the Thea Foss waterway in 1921 marked not only the eastward expansion of industry into the tideflats, but also a big break between private and public funded development. Despite the NPRR objections, the Army Corps of Engineers completed dredging the waterways in 1921. The area became the publically owned Port of Tacoma and the tideflats declared an “Industrial Development District.” Before WWII, the original marsh was mostly undrained; by 1958, all four rivers flowing into the delta were diked, channelized, and straightened, and by 1960 this area became an almost residence-free industrial zone, removed from the day-to-day workings of the rest of the city. Throughout the 1960s and 1970s, the Port took its present form of five man-made waterways of straight, deep channels, lined up in parallel like giant piers across the former marsh. The largest is the Hylebos Waterway, a three-mile-long, 200-foot-wide channel. The best way to understand the enormity
of the tideflats’ transformation is by viewing topography maps from 1888 to 1980 (appendix 4). The Port itself extends far beyond the original marshland into Commencement Bay and was made from dredging of hundreds of thousands of tons of fill from the mud marshes that made up the tideflats.

After WWII, the recognition by the public Port’s board of directors of the need for greater uniformity and efficiency to connect to outside markets would enable to Port to remain viable. Along with the final dredging of the tideflats and straightening of the rivers, the completion of I-5 north-to-south and I-90 west-to-east were the big projects of landscape transformation in the post-war period. To become one of the top-ten container ports in the United States meant an even greater effort of land and water rearrangement than earlier transformations. A completely new type of industrial space came into being that emphasized speed loading and unloading cargo and room for larger container ships along with its separation from commercial and residential areas, as this Seattle Times article explains: “Tacoma’s port is separated from the urban core and faces no pushback from waterfront gentrification, for now. One trucker told me it’s a much faster and easier port to serve than congested Seattle.” The article goes on to explain how Tacoma embraces its industrial identity and that this translates into strong backing for the seaport (Talton 2012). These transformations of land and water to accommodate trade also shaped the way cargo was manufactured for shipping, the type of boats built, the technology to load and unload the cargo, and the attendant types of work people performed. With the development of the Port for container shipping and the opening of I-5 in 1969, Tacoma became a dispersed city. Instead of the centralized space of the original industrial area next to the
downtown commercial district, two new areas came into prominence in the 1970s, the Industrialized Development District and the big-box stores surrounding Tacoma Mall, both creating dependence on the automobile for people to work and shop. As discussed next, by the 1980s, Tacoma had become a much less centralized and communal city, a social space that both intensifies the locus of responsibility for social autonomy and self-care to the individual and shapes daily life now.

3.6 Designation as a superfund site

The industries along the waterways close to Tacoma’s downtown, and the old shoreline once controlled by the NPRR, slowly moved or went out of business in the 1960s and 70s. The area was polluted and deserted by the early 1980s. In 1981, toxic levels of contaminants were “discovered” in 258 acres, and much of the old industrial core was identified as a National Priority List (NPL) Superfund site in 1983. The NPL designation meant that the area was not just a polluted Superfund site, but was among the most toxic places in the United States, not surprising given the amount and types of industry that existed in the area for so many decades. Unlike many Superfund sites, where one company or one or two types of contamination are identified, the Commencement Bay site had over 480 potential sources as possible polluters, and a vast array of pollutants. The ASARCO copper smelter, just one site identified on Commencement Bay, had pumped over 15 million tons of arsenic, copper, PCBs, and lead into the soil and water from 1890 to 1985. The American Plating Company also declared bankruptcy in 1986, three years after the area was found contaminated. The factory’s wooden beams and siding contained high levels of cadmium, chromium, copper, lead, nickel, and silver and were
removed along with 1,000 tons of soil, 18,000 gallons of effluent, and 1.75 tons of trash to toxic waste sites (Tacoma News Tribune 2015).

It has taken 30 years to transform not just this site, but also the entire industrial area, to something habitable once again. What has changed dramatically, in part, is the value placed on water and land as amenities for recreational activities and their beauty, as the above-mentioned article goes on to explain: “While the transformation of the American Plating site has taken decades of on-again off-again effort, the persistence of those pressing forward with the project is now paying off as it has for the rebirth of much of the waterway into a yacht-lined neighborhood populated with museums, condominiums, and restaurants, linked by a waterfront esplanade” (Tacoma News Tribune 2015). New bike lanes and pedestrian walkways from downtown along the shoreline give little hint of the intense industrial activity that sustained Tacoma’s economy for so many decades. Luxury condominiums overlooking Commencement Bay now drive the value of area: “The Thea Foss Waterway is quickly becoming a popular place to live, work and play. Mountain views, marina access, walking distance to downtown Tacoma and nearby services make Foss Waterway an attractive master planned community. Development sites are available along …just 35 miles south of Seattle. The Foss Water way Development Authority …can be advocates for developers through our established relationships with regulatory agencies” (Tacoma Waterfront Asso. 2015). The ASARCO site was situated on a quite scenic promontory, with dramatic views of both the Sound and Mt. Rainier, again calling attention to the odd partnership of heavy-duty industrialization and scenic beauty that have always marked Tacoma. The huge smoke stack was dynamited on a Sunday in 1995, with thousands of
spectators watching, as an unofficial end to Tacoma’s industrial past. Now, twenty years later, a
gated condominium community has been built, advertising a new type of urban living,
combining natural beauty and convenience (however, residents are warned not to grow vegetable
gardens directly into the soil). This new residential space represents discontinuity with the past;
it is also the site of new daily routines, relationships between work and leisure, and public and
private space for socialization.

3.7 Loss of a city core

The three decades from the mid-60s to the mid-90s mark a huge break in Tacoma, a shift
in how its urban space was defined. The city was spreading out, and people were mobile and
connected in new ways, and yet at the same time more isolated. Without much fanfare, the great
industrial destiny of Tacoma became the polluted muck being dredged from the old waterways.
A door was closed on industrialization, and a new process of demolition and reconstruction
began. The no-longer-profitable and dilapidated docks and warehouses were torn down, the
small businesses that lined downtown were replaced by parking garages, and the working-class
neighborhood close to the old waterways and downtown were leveled for I-5.

The process of reclaiming and transforming the industrial center now seems to be turning
into a continuous search to find a new “value” for Tacoma, a new process of transforming it into
something of value. The break with manufacturing has also been a break from the dominance of
organized labor and the often-violent confrontations between union workers and industrialists.
Along with the inward turning of industry to health-care, Tacoma residents have also become
more socially fragmented and less collectively political. A new subjectivity is forming, quite
different from the wild speculation of Tacoma’s early days or the skilled and semi-skilled industrial worker of the 20th century, but Tacoma has been left behind from the high-tech affluence of Microsoft and Amazon in Seattle, just “up” I-5.

The abruptness of Tacoma’s early re-settlement years made the connections between rearrangements of space and social relations obvious to even a casual observer. Today, Tacoma is going through a slower transformation that creates new habits of daily routine, leisure and work, relationships between body and self, and self and others that will shape how bodies and health are defined. In the present, however, diabetes is forcing (many times very unwelcome) conscious awareness of daily routines, how one uses and thinks about one’s body in daily life and the sometimes detrimental effects these create. Daily routine and what health means must be reconsidered within the changing configurations of social space. In a similar way that rehabilitation of Tacoma’s old industrial core creates (or attempts to create) new productive value for land, new forms of industry emerge replacing the social spaces that centered on manufacturing. T2DM, as a product of everyday life, also becomes a site of new productive value in this emerging health care industry. As will be discussed in greater detail in coming chapters, as both a medical abstraction and a source of productive economy in the health industry, it is also becomes detached from the lived space of everyday life.

In the next sections, I describe Tacoma in 2013-2014 and the rising importance of the health care industry as a driver of the local economy, and the rising incidence of T2DM and its greater prevalence among residents of lower socioeconomic communities of Tacoma.

3.8 The rising local economic importance of healthcare

74
The “Tacoma: Gateway to Health” billboard connected the boosterism of old Tacoma with recent, more inward-turning processes of the new Tacoma in new forms. The language of forward-looking progress is unmistakable in an executive summary of the “Economic Contribution of Healthcare Industry to the City of Tacoma”: “The healthcare industry in Tacoma was selected for its job generating capacity, directly tied to the explosive growth in demand for healthcare services…This healthcare industry cluster has propelled the Tacoma economy forward by attracting substantial human and financial resources to the City…” (2012) Terms like “the healthcare industry,” “the healthcare economic sector,” and “the healthcare business cluster,” are repeated in many of the economic development plans for Tacoma posted online. In a 2008 “Downtown Tacoma Economic Development Strategy” prepared by AngelouEconomics, healthcare is an important resource for future business development: “Health Care Services will be a high growth sector, as the aging U.S. population becomes the next dominant demographic story over the next 20 years. By 2010, nearly 15% of the population will be seniors 65+, the period in one’s life where nearly half of healthcare expenditures occur…With this massive demographic shift, an estimated 4.3 million additional jobs will be created in the health care sector by 2014, with residential and elderly care receiving the highest rates of growth” (City Of Tacoma.org 2008).

The two biggest employment sectors in Pierce County and Tacoma (after the military at Joint Base Lewis-McCord) are the Port and healthcare (Anderstone 2014; City of Tacoma.org 2014). 30,000 jobs, both public and private, are connected with the Port of Tacoma, relating to warehousing, storage, truck transportation, and port freight activities (Port of Tacoma.com
However, healthcare is the largest private employer in Pierce County, employing over 30,000 people in 2,500 businesses: hospitals, clinics, long-term care, pharmacies, and home health (City of Tacoma.org 2014; Vieming 2015). In Tacoma, healthcare and social assistance employs 16% of the city’s work force (Data USA 2015). The two largest hospital-based systems, Franciscan Health System (owned by a Catholic Health Initiatives, a nationwide network of hospital systems) and MultiCare Health System, together employ over 12,000 people in Pierce County, but that number is mostly centered in Tacoma (City Data.com 2014; City of Tacoma.org 2014).

Along with being the largest private County employers, MultiCare and Franciscan control 88% of the inpatient healthcare market in Pierce County, so that along with controlling most healthcare options in Pierce County they also control a large segment of local employment (Washington Can! 2011; Washington Can! 2014). MultiCare recently bought hospitals in neighboring counties to the north and east of Tacoma, and Franciscan has expanded by buying two more hospitals within Tacoma. This pattern of healthcare sustaining economic development is not unique to Tacoma, however. A New York Times article from 2015 describes how the healthcare industry is supplying jobs in rural communities across the United States as traditional employment disappears: “This isolated rural community has lost a lot of the energy of its heyday, when shoppers roamed downtown sidewalks, freight trains rumbled past the Big Blue River, and streets clogged at quitting time as factory workers spilled out their plants. But it has yet to lost its economic pulse, thanks in large measure to the Beatrice Community hospital and Health Center… The hospital has become an economic anchor of the town” (Searcey 2015).
Throughout the Great Recession, which hit Pierce County particularly hard (it had the largest foreclosure rate of any county in Washington state), the two healthcare systems managed to post operating profit margins of over 7% from 2006-2010. A December 21, 2010 an Olympia newspaper published an article surveying salaries of non-profit hospital CEOs in the Puget Sound area that found that most received compensation of over $2 million during this period. MultiCare CEO Diane Cecchettini, however, received a $4 million payout of deferred executive benefits in 2008, which the article questions in terms of the non-profit status and the unreimbursed community needs and benefits it should be providing to warrant their tax designation (The Olympian 2010).

The discrepancy between large profits and not-for-profit companies is one focus of the largest healthcare union in Washington State, the SEIU1199NW, which represents 26,000 healthcare workers across Washington State, including low-paying health support jobs at MultiCare and Franciscan. A union publication (Washington Can! 2011) focuses on the profits generated by the local healthcare industry, the increasing consolidation of the healthcare marketplace in the State and the fact that many healthcare support employees and union members are unable to pay hospital bills after getting medical care from their own employers. The stories discussed in the union publications are similar to the stories I heard in interviews. A vicious cycle emerges of ignoring medical problems due to lack of money, visiting the ER when symptoms are life threatening, and being unable to pay the bills or get control of one’s life after the medical crises. In addition, the high cost of most medical tests, especially imaging, and the lack of continuity between ER treatment and primary care, take the whole process to extreme
levels of stress for the people involved. What becomes apparent is that for many of the workers in the new Tacoma industry, progress, development, and modernization comes with an old-fashioned economic marginalization.

As of Nov. May 2014, with the passage of the ACA, 111,457 people, 14% of Pierce County’s population, are now enrolled in Washington Apple Health, the name for Washington State’s expanded Medicaid. Another 126,876 people get health insurance through Medicare, so that 30% of Pierce County’s population relies on some form of government assistance to access medical care (GOA Report 2014). How this huge patient influx will play out on operating profit margins for the big health care systems in Pierce County over the next few years remains to be seen. However, a 2011 “Pierce County Strategic Industry Clusters” report states that healthcare related employment is expected to grow almost 3% by 2018, the highest of any business cluster in Pierce County (Strategic Industry Clusters for Workforce Development 2011).

Understanding the lived experience of diabetes among the residents of Tacoma requires an understanding of the relentless dismantling and transformation of all manner of spatial arrangements that continue to shape everyday life. How a disease state like T2DM is addressed reflects the spatiality and temporality of bodies and other modes of socially constructed space. The history of Tacoma’s industrialized past and the rise of healthcare as a service industry signal a shift in the narrative of progress, development, and modernization. While not as visible as deforestation, this inward shift is perhaps more intense in its management and rearrangement of modern subjectivities. The uniform platting of Tacoma’s city streets bears a resemblance to the even more uniform and abstracted nature of biological bodies as the incidence of chronic
conditions like T2DM increases exponentially around the globe. The two stories of development share an intricate relationship and are expressed in the bodily practices and internalized definitions of selfhood of the people I interviewed for this project. Viewing bodies as social space gets them and diabetes out of the narrow paradigm of medical clinics and issues of compliance and care and into the broader context of everyday life of which they are both product and producer.

As will be discussed in the next chapter, the development of modern physiology at roughly the same period as the uniform platting of Western railroad towns follows a similar pattern of integration of abstract, conceived spaces with the lived and perceived realms of everyday life. In post-industrialist economies, the increasing importance of biotechnologies and the proliferation of various kinds of biologically based citizenship reflect the dominant ethos of abstract rationalism in daily life (Gardiner 2000) that has been well documented by medical anthropologists. In the next chapter, I discuss the history of T2DM, paying attention to how definitions of diabetes and ways of understanding human bodies reflect broader arrangements of social space, namely this increasing abstraction. This orientation, following Lefebvre, connects the human body to the global economy and back, as products and producers of similar social processes. Two global forces are emerging, not in opposition to each other but each as the product and producer of the other: the global health industry that includes conglomerates like actuary giant PriceWaterhouseCooper (PwC), Big Pharma and CVS Health, a pharmacy-prescription processing giant on one hand, and on the other, populations around the world developing T2DM at astonishing rates. The increasing commercial value of the healthcare
industry in Tacoma and the local dominance of a few growing hospital systems play out on both a global and local scale, as do the stories I collected of people living with T2DM.

### 3.9 Tacoma’s demographics and neighborhoods today

Tacoma (population 200,000) is the third largest city in Washington State, and has more non-white residents (32%) than the surrounding Pierce County (24%) and the state (21%), along with a lower median income ($49,000) than the County and State ($59,000). Today, the city of Tacoma is divided largely along the same early class lines that formed in the late 19th and early in the 20th centuries. One economic dividing line is 6th Avenue (Fitzpatrick 1993), which runs east-west about 8 miles, separating Tacoma into two almost separate cities. The North End is largely Caucasian and white-collar: industrial managers, attorneys, engineers, medical professionals, and professors from the University of Puget Sound, which is located in this neighborhood. Tacoma retains some of its old splendor in this heavily tree-lined area. The many Victorian homes and new mansions have views of the Sound and Mt. Rainier that are quite spectacular; Tacoma’s reputation for being “Grit City” does not apply consistently.

To the south of 6th Avenue are the people who work at blue-collar jobs in the Port of Tacoma and the huge Joint Base Lewis McCord (Anderstone 2014; Tacoma City-Data.com 2014). This is the neighborhood where most of the people I interviewed lived, and also where the majority of Tacomans reside: truckers, laborers, service sector and retail workers, rank and file military, and healthcare support personnel (Anderstone 2014; Tacoma City-Data.com 2015). In the south and Eastside of Tacoma, poverty and unemployment rates are the highest in the city. On average, the people in these neighborhoods live on less than half the income ($15,000 and
$17,000 per capita) of those in the North End of Tacoma ($41,233 per capita) (Tacoma City-Data.com 2015). Unsurprisingly, the South and East of Tacoma also have the highest concentrations of non-white residents, and the highest rates of less than high school education (City-Data.com 2014). On the Eastside of Tacoma, less than half the population is white (48%), and a high percentage of the population was born outside of the United States; Vietnamese, Cambodian, and Hispanic communities that have grown since the late 1970s. Towards Fort Lewis, a major Korean business district stretches for miles along South Tacoma Way, a major thoroughfare from Tacoma to the Fort Lewis/McCord Base.

The houses in the south Tacoma neighborhoods I visited for interviews are small (many around 800-1,000 sq. feet), wooden, and built before WWII for working-class families that still live there. Discount grocery chains such as WinCo and Grocery Outlet are located here. South Tacoma Way is a main artery and has a well-worn appearance. Discount appliance and grocery stores, biker bars, new and used car lots, family-style restaurants known for their huge portions, payday loan stores, and tattoo parlors line the street, until much further south where the Korean businesses begin. The Eastside, or Salishan, was built-up during WWII as housing for civilian military workers. Asian grocery stores, nail salons, a variety of smaller retail businesses, and Mexican and Vietnamese restaurants are now the dominant businesses. The Puyallup Tribe also has its main administrative offices, cemetery, and medical clinic, and has built a large casino right along I-5 on the Eastside.

The majority of Tacoma, like most of western Washington State, votes for the Democratic Party; in 2012 Obama beat Romney here by a 67% to 30% margin. Tacoma is not as
strongly Democratic as Seattle (where Obama won by an 83% to 14% margin), and occasionally Republicans do manage to get elected in County elections. However, results from the 2012 General Election show another division. Same-sex marriage and the state regulation of marijuana, issues also on the same ballot, passed by roughly 2:1 and 3:1 margins respectively in North End precincts; in east and south Tacoma, these two issues came to a close tie or lost, indicating that the east and south are more socially conservative (Anderstone 2014).

3.10 Formation of diabetic corridors

These geographic divisions play out in rates of chronic disease throughout Pierce County. The correlation between higher rates of T2DM, lower SES, and impoverished neighborhoods are well documented (Drewnowski et al. 2014; Hipp and Chalise 2015) and Pierce County and Tacoma, with lower per capita income and education levels, and greater numbers of people living below the federal poverty level (FPL) than the state, bear this out. Pierce County has the highest rates of diabetes, heart disease, and stroke in the state, and Tacoma has higher rates than Pierce County. 34% of residents in the county are listed as obese, compared to the state’s 25% (a total of 64% if overweight is included) (Tacoma-Pierce County Health Dept. 2014). In two Washington State Department of Health (WSDH) reports from 2009 and 2014, higher rates of obesity correlate with lower levels of income and education (WSDH 2009; WSDH 2014) and in Tacoma, households with income less than $20,000 per year, the obesity rate was 40%. However, no data were available based on income or neighborhood.

The prevalence of T2DM shows the same correlation as obesity/overweight: T2DM rates are 9.5% in Tacoma, while the state is 7.2% and Pierce County is 8.2% (Tacoma-Pierce County Health Dept. 2014).
Health Dept. 2014). These rates are significantly higher than in King and Thurston Counties to the north and south respectively (WSDH 2015). For Pierce County and Tacoma, data correlating prevalence rates of T2DM with neighborhood census-track data is not available, so it is not possible to correlate specific neighborhood income levels, education or employment data with diabetes prevalence rates. However, in King County, census track data and estimated diabetes rates have been compared in a statistical analysis in one study (Drewnowski et al. 2014). In this CDC-sponsored study that used data collected in 2005-6, college degree had the strongest negative association with T2DM. Also, for each 50% increase in median home value, diabetes prevalence was 1.2 percentage points lower. Although the prevalence of diabetes was only 6% in King county (at the time), the authors found a much higher prevalence of 15% in what they called a “diabetes corridor” in south and southeast King County. This higher prevalence correlated with lower home property values.

The neighborhoods in south and southeast King County have much in common with south and east Tacoma: both have a large number of residents who are not native English speakers and were born abroad, a higher percent of people living below FPL, and fewer people with college degrees than the rest of the city or county. The startling difference in T2DM prevalence based on neighborhoods in King County, which has consistently much lower rates of obesity and chronic disease and higher SES than Pierce County, is cause for concern as to how much T2DM might vary within neighborhoods in Tacoma. As mentioned, data from the United States as a whole shows strong correlations between obesity, diabetes, education levels, and poverty levels (CDC 2015a; Hipp and Chalise 2015). Micro-trends within counties or cities that
do not have the Public Health funds or personnel to run the type of analysis done in the CDC study raises concern as to prevalence rates of T2DM in the Tacoma neighborhoods where almost all interviewees in my study lived.
Chapter 4: Epidemiology and History of Type-2 Diabetes

In this chapter, I discuss the physiological history of diabetes to give a general understanding of how it is defined in biological terms. The spatiotemporal changes discussed in the previous chapter on Tacoma re-settlement correlate with the way both bodies and diabetes also redefined spatial constructs in the same decades. The dissociation of spatial constructs from what was local and singular into uniform, rectangular street plats, easily recognizable and understood by outside speculators, also made land profitable and manageable. These rearrangements in social space give rise to a particular type of discipline and control that has characterized diabetes treatment for the last century. As the scale and level of biological abstraction increased, the notion of a unique and inviolable self/corporal body, so critical to medicine before the mid-19th century, became more and more attenuated. I begin this discussion with a brief description of the increasing incidence of the global diabetes epidemic. The as-yet not clearly understood effects of development and modernization (such as the re-settlement of Tacoma) in the last century particularly correlate with its increasing global presence.

The global prevalence of type-2 diabetes is a distinctly modern condition. Until the early decades of the 20th century, little mention is made of diabetes, or that it posed any major public health concern, in primary medical literature. Since the late 1950s, this has changed dramatically, as the incidence of diabetes has risen quite sharply. For example, in the United States in 1958, 1.58 million people were diagnosed with diabetes; by 2013 that number had risen to 22.30 million. Most startling is the dramatic increase between 1991 and 2013, when the prevalence of diabetes increased from 6 million to 22 million (CDC 2016). These numbers from the CDC do
not separate type 1 from type 2, but 95% of all diabetes cases in the United States are type-2. Also important to keep in mind is that almost half of all adults with diabetes are between 40 and 59 years old, so that as the age of the U.S. population increases, the number of people with T2DM will rise proportionally. However, even with those considerations, the increased prevalence since the early 1990s is remarkable. In addition, some 316 million people under the age of 50 are estimated to have Impaired Glucose Tolerance (IGT), a condition that can progress to T2DM if left unaddressed. If the same trends continue, 1 in 3 adults in the United States could have diabetes by 2050 (CDC 2015a). However, recent statistics from 2014 show a decline in the number of new cases of diabetes, down to 1.4 million new cases in 2014 from 1.7 million in 2008 (CDC 2015b). Unfortunately, 1.4 million new cases is still double the incidence of diabetes before the early 1990s (Tavernise 2015). Globally, the same dramatic numbers exist: in 2007, 246 million adults were diagnosed; by 2013 that number had risen to 382 million adults, and is expected to increase to 592 million by 2035 (International Diabetes Federation, 2015).

4.1 T2DM: a transmutable disease

From a physiological perspective, T2DM is a dysfunction of metabolic feedback systems that maintain blood glucose homeostasis. Over the last century, through a combination of the rising incidence of diabetes and knowledge gained through lived experience, pharmaceutical development and use, and scientific research, diabetes is now understood as a complex system that includes constant engagement between bodies and environment, extending even to past generations (epigenetics). Current thought on type-2 diabetes focuses on two main mechanisms: 1) Reduced sensitivity to insulin in liver, muscle and adipose tissue; most cells cannot absorb
glucose directly from the blood, and insulin is required to enable the transport of glucose from blood into cells where it can be used as fuel. In T2DM, cells become insensitive to the presence of insulin in blood and it takes greater and greater amounts of insulin to transport glucose into cells. This is “insulin resistance.” In addition, in people with diabetes, the liver becomes insensitive to the suppressive effects of insulin and keeps synthesizing glucose even though high levels are already present in the blood. Insulin resistance affects multiple organ systems including the brain, gastrointestinal system, muscles, adipose tissue and kidney, all of which contribute a particular part to maintaining glucose homeostasis. 2) The progressive decline in beta-cell production of insulin and dysregulation of insulin release from the pancreas in response to high levels of glucose in blood; unlike type-1 diabetes, when no insulin is produced in the pancreas, type-2 is a condition of delayed and then over-compensation of insulin release in response to food, at least at the onset of the condition. Over years, pancreatic beta-cells can stop making enough or any insulin due to the increasing demands from insulin resistance. Oral medications that make cells more sensitive to insulin or suppress the production of glucose by the liver therefore have no benefit in type-1, but work in type-2. However, as beta-cells become less able to keep up with the demands for insulin and produce less and less of it, type-2 diabetes resembles type-1, and injecting insulin is the sole pharmacological means of keeping blood sugar levels down.

Maintenance of glucose homeostasis is not easily reached by simply injecting boluses of insulin, although as discussed below, this was the approach treatment took in the first decades after insulin was first synthesized (and before diabetes was classified as two distinct
physiological processes). The increase of the incidence of diabetes and failure of treatments to adequately control complications have forced recognition of the complicated and systemic nature of glucose regulation. In this chapter, I discuss the ways understanding diabetes has evolved over the past 2,000 years and how these evolutions reflect not only changing conceptions of what diabetes is, but also how bodies are conceived and how historical analysis of these changes are conducted. Understanding diabetes as a social construct allows us to step out of the naturalness of biological perspectives and a linear temporal structure that make “diabetes” a unexamined variable in much anthropological literature on diabetes (c.f. Borovoy and Hine 2008; Ferzacca 2000; Garro 2000; Hunt and Arar 2001; Mol 2008). The rising incidence of T2DM worldwide makes the management of bodies and medical treatment an increasingly common aspect of everyday life. The construction of what diabetes is becomes a way of understanding the shifting conceptions of bodies and disease as rooted in the social production of space.

Diabetes represents what medical historian Chris Feudtner (1996) describes as a “transmutable disease,” one whose natural course and definition is altered over time through medical intervention. I discuss the impact of Claude Bernard’s discoveries in the mid-19th century in greater detail later, but in summary, Bernard found that glucose was maintained at fairly constant levels in mammalian blood and that higher levels of glucose correlated to symptoms of diabetes. However, for hundreds of years the nature of diabetes was little understood. In 1674, the physician Willis wrote about diabetes, “It seems a most hard thing in this disease to draw propositions for curing, for that its cause lies so deeply hid, and hath its origin so deep and remote” (Symonds 1960). In 1895, even the discovery of insulin secreting
islet cells in the pancreas did not completely reveal the “seat of the disease” (Osler 1895). In 1955, decades after the isolation and manufacture of insulin and the shift towards an organ specific cause (“pancreatic dysfunction”) of diabetes, a well known dialectologist wrote of the difficulties of trying to categorize the myriad of symptoms and outcomes diabetes presented: “Since then this problem [the waxing and waning of hyperglycemia during infection] has interested me and has stimulated thoughts that perhaps there are some forms of diabetes which are not permanent throughout life but which remit or disappear under influences as yet unrecognized. The relationship of obesity to the development of frank clinical diabetes presents a similar problem” (Downie 1955:864).

Instead of a single homogenous pathological entity, diabetes has become two distinct diseases, identified in large part by their different responses to new pharmacological treatment in the 1960s (Greene 2007; Sinding 2004). After decades of using insulin and slowly noting a correlation between body type, resistance to insulin effects, and the discovery of antibodies to pancreatic islet cells, a distinction was made between type-1 diabetes as an auto-immune disorder and type 2 diabetes. Jeremy Greene, in his book Prescribing by Numbers (2007), shows how the development of a new, oral medication, tolbutamide, also helped define T2DM as a disease separate from Type-1. Tolbutamide has no effect in the diabetes of young children (or type 1, who do not produce any insulin at all) and Upjohn, the original developer and manufacturer of tolbutamide (Orinase) wanted to make sure that physicians did not prescribe it where it would have no beneficial effects. Distinguishing between diabetes that was “Orinase responsive” and diabetes that required insulin became a major marketing campaign through the
1960s and 1970s. In addition, with the development of new chemical strips that could be used to easily detect glucose in the urine, finding the “hidden diabetic” became another marketing push to diagnose diabetes in older adults before it became frankly symptomatic.

Some authors (Dumit 2012; Pollock 2011) critical of pharmaceutical companies and the over-marketing and use of pharmaceuticals have used Greene’s discussion of T2DM to question the “realness” of many asymptomatic, chronic conditions that were newly defined in the 1970s. By focusing on the marketing of drugs, they create a rather black and white world, but rather than trying to understand whether these new diseases are “real” or the result of pharmaceutical marketing, it is important to not lose sight of the ways technology redesigns physical bodies, ways disease states are understood, and surrounding cultural practices. As will be discussed later, innovations like the synthesis of insulin are not linearly progressive or predictable in their effects over time. Pharmaceutical developments, such as insulin and oral diabetes medication, have changed not only the natural course of diabetes but also how it is understood as a disease.

In the last decade of the 20th century, the cause of insulin resistance was proposed as the constant but dysfunctional communication between bodies and environment by geneticist James Neel: “It now seems preferable to conceptualize these diseases [T2DM, hypertension and obesity] as resulting from previously adaptive multifactorial genotypes, the integrated functioning of whose many-faceted genetic component is seriously disturbed by the complexly altered environment. It is our thesis that the three disease entities …all in very large measure reflect genetically complex homeostatic systems now pushed to and beyond their limits” (Neel et al. 1998:13). Neel had also proposed the “thrifty gene” hypothesis in the 1960s, to try and
explain the higher prevalence of T2DM in Native American communities. More recently, and continuing the work of Neel, there has been a shift towards explaining T2DM in terms of epigenetics, as a molecular process involving genes and biochemical processes continually modified by the environment. At the 11th annual World Congress Insulin Resistance Diabetes and Cardiovascular Disease in Los Angeles, T2DM was described as an entire body-system imbalance: “In recent years, there has evolved significant awareness of the contribution of multiple systems to energy metabolism, obesity, diabetes, and cardiovascular disease; notably incretins, gut hormones, and the brain. Of particular interest is the complicated interrelationship of nutrients, the gut, fat cell, insulin, leptin, and their respective resistance states, along with circadian rhythm, sleep disturbances, and the neuroendocrine system.”

For a disease state like “diabetes,” which has been mentioned in medical writings for thousands of years, medical historian Roger Cooter (2013) warns that the easy conclusion that signs and symptoms that exist today as “diabetes” do not make it the same disease written about 2,000 years ago. What T2DM is today reflects modern conceptions of human bodies and pathology, not a clear linear history of discovery. Cooter defines this type of history as “the biography of disease” because it looks back over time to trace a linear progress of disease discovery or treatment. Cooter writes: “The illusion is that a history of a disease is being created, whereas in fact, the present understanding of the disease is being confirmed. It is our biological understanding of the disease that is running the show, not the pursuit of any historical understanding” (165). Likewise, historian Barbara Duden (1991) states the goal of historical analysis is “the reality generating experience of the body that is unique and specific to a given
historical period” (31). With this goal in mind, the discovery of constant levels of glucose in mammalian blood in the 19th century are viewed here as ushering in more than a new way of understanding disease pathology. Instead, it is important to think about how disease state definitions reflect the temporal and spatial contexts they exist within, and not as neutral background. Particularly, I wish to call attention to the ways the new science of physiology made the internal space of bodies complementary to the uniformity and exchangeability of external space of Tacoma’s re-settlement, discussed in the previous chapter. Being studied as an abstract, scientific entity allows bodies to be dissociated from the perceived and lived realms of everyday life (Lefebvre 1992) and bodily experience to be imagined as universal (Duden 1991).

The spatial rearrangements that characterized the re-settlement of Tacoma and made city street designs uniformly recognizable are reflected in the ways bodies are reconfigured as biological bodies that allow them to be also uniformly recognizable. Most importantly, it reflects the increasing dominance of what Lefebvre (1992) defined as the abstract, conceived spaces of modern capitalism over the perceived and lived realms of everyday life (Kirsch 1995). If, as Biehl and Locke (2010:318) suggest, “In the merciless interface of capitalist and scientific discourses, we are all a new kind of proletariat,” it is important to understand how biological abstractions of disease are both a product of and produced in the same social dynamic that re-settled Tacoma, and it is also a reminder that the routine actions of how we eat, sleep, exercise, and relate to one another and ourselves can be a source of physiological dysregulation, as the epidemiology of T2DM bears out.
Chapter 5: Emergence of a Scientific Body

To disrupt the “naturalness” of how the bodies and diabetes are viewed today, the following quote from Aretaeus of Cappadocia (Gale 2014) in 200 AD is used to illustrate a humoral perspective, which dominated medicine until the scientific revolution of the 19th century. Disease was understood as a disruptive transformation in a normally fluid body:

Diabetes is a wonderful affection, not very frequent among men...Being a melting down of the flesh and limbs into urine. Its cause is of a cold and humid nature as in dropsy. The nature of the disease is chronic and it takes a long period to form; but the patient is short lived if the constitution of the disease is established; for the melting is rapid, the death is speedy. Moreover, life is disgusting and painful; thirst is unquenchable; excessive drinking is disproportionate to the large quantity of urine; and one cannot stop them either from drinking or making water.

The author also points out the extreme rarity of diabetes (writing during roughly the same period, Galen stated he had only seen two people with the condition) and its extremely painful end. Aretaeus understood diabetes as a condition that took “a long period to form” and coalesce into a definitive expression. One gets a sense of the humoral nature of bodies; their fluid and transformative capacities and most importantly, symptoms experienced by the patient that determined the essence of the disease, in this case its “cold and humid nature.” Diseases had a particular nature, of experientially related symptoms, rather than internal and hidden cause (Jewson 2009 [1976]). However, the “nature” of diabetes could not be easily identified. Remedies focused on treating the thirst of the stomach, the continuous need for fluids and yet the inability of the body to retain them. A diabetic patient’s medical history included exposures to extreme heat, cold, and physical exertions (Hodgkin 1854). Disease (and diabetes) was firmly rooted in the state of the person and the qualitative alterations of vital properties (Duden 1991).
In his work, *Birth of the Clinic* (1973), philosopher Michel Foucault connects the developing institutional spaces of hospitals in eighteenth century France with new ways of seeing the body, which he defines as the “medical gaze.” The two developments are interconnected and signal a radical break with past practices of “seeing” the body. One of Foucault’s important points is that bodies do not follow a linear, step-by-step progression in how they are understood, but are rooted in systems of thinking specific to a particular time and space. Although Foucault does not stress spatial development in the same manner as Lefebvre, he still views the construction of all social spaces (including bodies) as interconnected through their particular and shared qualities to produce power. Foucault locates the rise of institutions like hospitals and the development of a medical gaze with a new type of disciplinary power of the state.

Along similar lines of reasoning, medical historians David Armstrong (1983), Roger Cooter (2013), N.D. Jewson (2009[1976]), Charles Rosenberg (1977) have investigated the significant transformations of how bodies were conceived throughout the 19th century. As one historian, Charles Rosenberg (1977) put it: “Medical therapeutics changed remarkably little in the two millennia preceding 1800; by the end of the century, traditional therapeutics had altered fundamentally” (1977:485). He goes on to describe the system of humors prior to both the body and symptoms of disease becoming isolated and measurable: “The key to understanding therapeutics at the beginning of the nineteenth century lies in seeing it as part of a system of belief and behavior participated in by physician and laymen alike. The body was seen, metaphorically, as a system of dynamic interactions with its environment. Health or disease
resulted from a cumulative interaction between constitutional endowment and environmental circumstance. One could not well live without food and air and water; one had to live in a particular climate, subject one’s body to a particular style of life and work. Each of these factors implied a necessary and continuing physiological adjustment. The body was always in a state of becoming - and thus always in jeopardy” (5).

By the end of the 19th century, however, physicians could rely on a physiologic process to explain the “why” of diabetes: “Medical theory changed from that of an integrated conception of the whole person to that of a network of bonds between microscopical particles” (Jewson 2009[1976]:622). Duden (1991), drawing on the work of Karl Figlio (1977), writes, “a new body perception became commonplace, which involved a degradation of the notion of a self extended into a unique and inviolable corporeal volume, to one in which the self only loosely possessed a body…This gaze turned the body and the person who possessed it, into a new kind of discrete object. And made possible the creation of a private body, but this body could still be read only through the grid of the ‘anatomical atlas.’ The reality of this body was the product of these descriptions and not vice versa, for what took hold was the belief that these clinical descriptions truly grasped and reproduced ‘reality’” (4). The measurement of isolated, chemical entities in mammalian blood became the grid on which the corporality of human bodies was understood. Gone was the permeable body of the Middle Ages, in constant internal flux and subject to miasmas of disease.
5.1 Claude Bernard and the measurement of bodies

A “watershed moment” defining this transformation was the work of the great 19th century French physiologist Claude Bernard, whose experiments over the decades 1840-1860 related to the presence and measurement of glucose in human blood. Beginning in 1845, Bernard became interested in the clinical problems of diabetes through his work in La Charite Hospital in Paris, a highly populated urban center where the prevalence of diabetes was high enough for Bernard to observe patients and begin to formulate his own ideas. Observational anatomy lost ground to the study of experimental physiology, incorporating the theories and techniques of physics, to understand the cause of disease (Jewson 2009[1976]). The body, as Bernard defined it, was governed by the same natural forces as inanimate matter, and could be understood by gathering observable, empirical, and most importantly, measurable evidence to explain bodily symptoms. The function of physiological processes was to control or regulate the internal environment following laws of chemistry and physics (Cziko 2000). Bernard’s investigations answered a series of complex questions: Is there sugar in the blood of an animal without a food supply of carbohydrates? And if blood sugar was present, how did it get there? Did the body manufacture its own glucose? Bernard’s work linked three important concepts that characterize modern constructions of diabetes: 1) that glucose was always present in blood and regulated by homeostatic systems, 2) that high levels of blood glucose could cause symptoms of diabetes, and 3) that lowering these levels would control the symptoms of diabetes (Gross 1998).

Up until Bernard’s work, the presence of sugar in blood was considered to be pathological or accidental, as the result of eating particular foods, for example, and Bernard
strongly shared this view. Bernard describes his discovery this way: “The theory, which then prevailed and which was naturally my starting point, assumed that the sugar present in animals came exclusively from foods, and that it was destroyed in animal organisms by the phenomenon of combustion. But I was immediately led to see that the theory about the origin of sugar in animals, which served me as a starting point, was false” (Grmek 1968:143). Bernard’s work on this subject began in 1843 and continued through September of 1848 when he realized sugar was actually produced continuously, irrespective of diet, a discovery that was “absolutely incomprehensible” when he first made his measurements (150). Bernard did not figure out the specific physiological processes of how bodies regulated glucose levels, but his work ushered in a methodology and conception of bodies that became the scientific “fact” and excluded any default to humoral causations to explain diabetes and introduced a new sense of corporality based on modern rules of physiology.

Bernard’s notebooks, laboratory journals, and other scientific manuscripts have been archived and are available for researchers to understand Bernard’s day-to-day reflections, confusions, and most importantly, how he put together scientific rationalizations of his experiments. One historian, Grmek (1968), who examined Bernard’s work in the 1960s, remarked on the difference between the actual process of understanding glycemic control in animal bodies that occupied Bernard for years and how he described this same process in scientific writings: “On the one side, his original manuscripts suggest a very complicated gradual development of his discoveries, while on the other side, his published works show a tendency toward a secondary rationalization, that is, a very strong post hoc simplification of facts” (Grmek
Grmek writes that the *unexpected* result of one experiment changed the whole direction of Bernard’s investigations. This smoothing out, however, helps to obscure the significance of material practices. This process of mitigating uncertainty, confusion, and back-and-forth thinking that explain the actual processes of how scientific facts were arrived at through practice (and over time) reflect a smoothing out and creation of a series of rational decision-making steps that could be endlessly reproduced.

### 5.2 Creating a scientific subjectivity

New theories and experiments also extended to new moral and ethical standards of the scientists involved in this new science. Daston and Galison, in their book *Objectivity* (2007), describe how subjectivity, came to be, as something to be distrusted and controlled. Objectivity was an act of willful self-restraint to suppress interpretation and instinct and became the ideal of scientific practice. “Let nature speak for itself” was the mantra of scientific Objectivity. Daston and Galison (2007) describe the type of subjectivity required: “To embrace mechanical objectivity was to turn the will inward upon itself, a sacrifice vaunted as the annihilation of the self by the self, the supreme act of will” (231). The scientist tried to eliminate knowing through experience as much as possible, to be replaced with mechanical repetition through diligence and self-restraint (121). What is most intriguing about the authors’ depiction of 19th century scientific objectivity is its moral tone. Objectivity was mechanically virtuous because of its indefatigability and self-command to control impulses and wandering attention. “Self-discipline, self-restraint, self-abnegation, self-annihilation and a multitude of other techniques of self-imposed selflessness” (203) were used to replicate what “the machine effortlessly accomplished,”
producing objects, images, or experimental results “uncontaminated by interpretation” (139) and, most importantly, uniform in their reproducibility. A strong scientific will was needed to maintain the divisions and the tensions between impartial observer and yet active investigator. Most importantly, the transformation to a scientific subjectivity constructed a monolithic self, defined by an indomitable will.

The scientific objectivity coalescing in the mid-19th century also reflects the state of crises and upheaval of how scientists understood their specific disciplines and science as a whole. New scientific innovations gave a “point of causing vertigo for its practitioners” (Daston and Galison 2007:212) with ever more exact instruments to measure and precise ways of observing the world. Bernard declared that science could only provide provisional theories; knowledge was obtained and continually overthrown by empirically derived natural laws. What was fact a decade previously became outdated and useless as new ways of seeing and measuring changed reality. A distinct division could be drawn between the external world of objectivity, which constantly changed, and the subjective world that required self-denial and stasis. Constant change could no longer be rooted in the fluidity and morphologically indistinct flows of humoral bodies, but on isolation and measurement of bodily processes. As bodies became more dissociated from lived experience and yet a source of constant change, subjectivity became uniform and static through the exertion of will.

Echoing the Figlio quote above, the increasing domination of abstracted space immobilized subjectivity through the identity of scientist as objective observer. What is held static and what is allowed movement reflects a broader shift in the way responsibility for disease
and locus of control was invoked. As will be discussed next, it can also apply to how diabetes is defined and the type of identity created that surrounds being diabetic from a medical perspective. The doctrine of science as endless work, fueled by an unflagging will, is the organizing principal of practices of diabetes self-care, reproduced in the dietary regimens of Allen and Joslin, and in a much modified and user-friendly form, in the diabetes education programs presented in chapter five. In diabetes education programs, self-regulation and the responsibility to learn medical facts, and to apply these facts to one’s body, omits the need to understand oneself in new ways, discounts the transformation of self, and allows rational decision making to be detached from lived experience. As Jonathan Crary (1990) notes, representational convention connects to larger social processes that uproot, make mobile, and clear away that which impedes circulation, connecting scientific bodies to the re-settlement of Tacoma through the production of uniform and exchangeable forms of social space. As discussed next, diabetic subjectivity in medical discourse has many character similarities to the stories of entrepreneurial success of Tacoma’s re-settlement.

5.3 **Insulin, self-discipline and the diabetic subject**

Just as scientific moral responsibility depended on recording and synthesizing one’s observations, the ultimate self-care responsibility in any T2DM program is measuring, recording, and making sense of one’s blood glucose levels. Through all of the different conceptions of the body and transmutations of diabetes, a particular type of discipline and control has emerged. Mechanical practices combined with highly moral goals were used to keep children with diabetes alive (type 1 diabetes, although there was no differentiation at the time) and have defined
diabetes treatment ever since. The epitome of bodily control in diabetic treatment was the development of starvation diets by Frederik Allen at the Harvard School of Public Health around 1909. A 1915 book, Starvation Treatment of Diabetes, listed hundreds of pages of case studies with graphs of calories and grams of fat, protein, and carbohydrate in rigidly fixed proportions and times. Patients were expected to adhere to these practices at home and to measure glucose in their urine and have their blood glucose levels measured. The dichotomy between lived experience and the value placed on mechanical objectivity reached its most extreme by the early decades of the 20th century, right before the synthesis of insulin, but has remained a central component of diabetes treatment and education programs to the present.

The synthesis of insulin in 1922 was “a thunderbolt,” celebrated at the time as a medical miracle that held the promise of providing physicians with a drug of unprecedented power and efficacy, and perhaps even a cure for the disease (Feudtner 2003). The work of Banting, Best and Macleod to synthesize insulin, follows on Bernard’s work of isolation and measurement to provide uniform and predictable treatments for medical conditions. Administration of insulin also fit with conceptions of single organ pathology - by replacing the missing “part,” diabetes would disappear. In June 1922, at the Shattuck Lecture in Boston, Joslin announced that insulin was “the advent of the promised land” for diabetics and that it would lead to the disappearance of all diabetic complications (that were common, so far), such as infections, gangrene, and coma. However, to achieve these goals, patients still had to adhere to recommended regimens. An integral part of these treatments, advocated most famously by Eliot Joslin, equated control of diabetes to patient courage, strong will, and discipline, leaving the body as the battle site between
Physician and disease. Physicians based judgments of a patient’s moral character on success or failure of treatment. In a 1924 Diabetic Manual for the Patient, Joslin wrote, “Therefore, face the facts, accept your situation, study the disease and become master of your fate. By so doing you are sure to help those less fortunate and may defer or even prevent the onset of diabetes in other members of your own family” (Joslin 1924). All manifestations of diabetes could be eliminated, except of course, the constant daily discipline and monitoring required of the patient. In the first decades of insulin treatment, patients took on the static subjectivity of the new scientific approach, but were not expected to take independent responsibility for treatment decisions. As a result, how people actually lived with diabetes became ever more separated from how biomedicine conceptualized (and treated) diabetes.

In the decades following the synthesis of insulin in 1922, it became apparent that finding an organ-based cause for diabetes did not provide a hoped-for cure. Because diabetics had not lived long after contracting severe symptoms of high blood sugar, the long-term sequela of retinopathy, kidney failure, and neuropathy was unknown. From the 1930s onwards, people who had managed to survive starvation diets and benefited from insulin were now experiencing these unexpected effects of continuous high blood glucose levels. A patient of Joslin’s wrote to the doctor in 1960, explaining his conflicting thoughts on his progressing blindness, “I know the personal hell I have gone through trying to rationalize my coming blindness. Yet, I hasten to add, I have been grateful for every day of life I have had since first becoming diabetic” (Feudtner 1996:161). In 1946, even as clinical experience of insulin treatment was proving how difficult diabetes was to manage, Joslin admonishes readers of his diabetic manual, “That adherence to
treatment with diet, insulin and exercise finds ample justification in the good health, comfort, and longevity of those who obey the rules as contrasted with the poor health, suffering and shortened lives of those who are careless” (Feudtner 2003:44).

Narratives in medical discourse increasingly stress the importance of physician expertise and the moral obligation of patients to follow physician directives (Feutner (2003; Tattersall 2009), even as the early promise of insulin disappeared. During this period (1930-1950s), popular discourse on diabetes still focused on the moral responsibility of the patient. An article from *A Boys Life* in Jan. 20, 1930:39 sums up this attitude: “When diabetes attacks, it has come to stay. It rarely gives up. A diabetic has two choices, either to put up a cheerful, continuous fight or weakly surrender. Halfway defense spells defeat. But a courageous unyielding fight is almost sure to win. One great danger is that with the aid of insulin and correct diet, the diabetic feels so much better that he is lulled into a false sense of security. He takes liberties with his diet or neglects to take insulin as directed. Then, with crushing swiftness, diabetes may claim another victim.” Similarly, in Sept. 7, 1953:108, *Life* magazine ran an article called “The Man Who Beat Diabetes” about tennis star Bill Talbert: “Because of insulin, and because of all else doctors have learned about this mysterious aliment, it no longer needs to be dreaded. Even so, through ignorance, bad advice and fear, despair still afflicts parents of diabetics and diabetics themselves.” Insulin treatment soon led to new questions about the meaning of therapeutic control, who had authority to define what form this control should take, and the realization that new technology (such as improved forms of insulin) could lead not to control but to unexpected “transmutations” of diabetes.
“Diabetes” is not a static condition. Despite the best intentions of science to predict and control the story of diabetes, unexpected transmutations of bodies and disease occur over time as both interact with changing environmental forces and new technologies. Unlike the narratives of physician control discussed above, where patients were expected to adhere to a physician’s orders, as discussed in the next chapters, responsibility has shifted. In patient-centered care, both medical practitioners and patients are partners in decision-making and responsibility as boundaries shift with the advent of new technologies for treatment and monitoring. Underlying these shifting responsibilities is the abstracted body and disciplined subjectivity developed one hundred years previously. Diabetes self-care in education programs, discussed in the next chapter, relocates the domain of scientists and the split between seer and seen, to people living with diabetes.

Without situating what “disease” means historically, and how specific disease states evolve in relationship to social conditions and technology, “diabetes” becomes a static condition, or a “biography” of a disease, “an engagement with the medical present, not the past” as Cooter states (2013:165). As the use of insulin over time shows, both patients and clinicians have learned that “diabetes” was far more complicated to live with than simply giving shots of insulin. For example, the timing of insulin release in relation to ingesting food, its effects beyond glucose regulation, and how these effects change over time have all contributed to what Feudtner (1996) called the transmutation of diabetes. A modern condition like T2DM raises underlying issues, such as the way powerful pharmaceuticals like insulin have altered our understandings of not just human bodies but how we live in the world. Separating symptoms from risk, as though these stay
inert over time, ignores how bodies change over time in relation to technology. Rather than questioning the “truth” of a disease, perhaps the questions to ask are “What forms do these intertwined entities take? Who and what social institutions have the social authority to define them? More specifically, who has the social control to define and control what held in stasis and what is allowed transformation and movement over time? Who has the authority to learn from experiential practice and define medical knowledge?”

As mentioned above, the division and tension Daston and Galison identified in the 19th century has broadened beyond the social domain of scientists to the control and discipline advocated by physicians like Joslin and Allen, and continues today in T2DM education programs, discussed next. The scientific observer’s need for a controlled and static subjectivity in relation to the constantly changing nature of scientific knowledge has become, 150 years later, the same subjectivity advocated in education programs for someone living with T2DM. The pace of innovation and scientific change noted by 19th century scientists becomes a self-care responsibility for people living with T2DM, along with the training and imperative to monitor one’s blood glucose levels as a moral act of self-care. In less extreme forms, the diets Allen designed keep diabetic children alive have morphed over the decades into T2DM education programs. The need to measure, calculate, and schedule food and eating becomes a learned skill that also facilitates “the shift to include patients as part of the cycle of care” and becomes a “value-added” service that turns self-care into a commodity that can be provided world-wide: “Pharmaceutical companies must spend as much time connecting with their patients as they traditionally have with healthcare providers, with thoughtful dialogues and full transparency”
from an article in *PharmaVoice*, “the forum that allows business leaders to engage in a candid
dialog on the challenges and trends impacting the industry” (PharmaVoice.com 2014) entitled
“Stepping Up Brand relevance in the New Age of Healthcare.” The article goes on to say,
“Consumers will have to sharpen their knowledge to address their newfound role, and they are
hungry for information” (Brooke 2014). Or, as Pascale Witz, director of Sanofi Patient Solutions
(one of the largest insulin manufacturers) put it in an article in *PharmExec*, another Pharma
industry publication, “We identified a subtle but unmistakable shift from providers to the patient
as the ultimate customer in diabetes care…a development process focused on the patient directs
us to create not just a great drug, but a well-designed solution – a solution that allows the patient
to act on his own to comply with therapy” (Looney 2015).

Both the platting of Tacoma and biological standardization beginning in the mid-19th
century defined social “space” in new ways that connect to larger processes of abstraction in
both modern capitalist and state-controlled social systems. This emergence of abstract space is
reflected in processes of modernization, progress, and development that seek to improve nature
and even ameliorate social suffering by refiguring and continually modifying both landscapes
and bodies that fit together in an ongoing cumulative process. Most importantly, in this shift
towards global pharmaceuticalization, is how experimentation, learning through experience, and
responsibility are constructed through patient education programs and “value-added” services
facilitated through international business conglomerates like actuary giant
PriceWaterhouseCooper, retail pharmacy giant CVS Health, or the largest insurance provider in
the United States, United Health Group, as they position themselves as service providers in the health industry.

The inextricable intertwining of science, technology, and marketing is captured in an article entitled “The Making of a New Disease,” PharmExec.com in 2004, which describes insulin resistance as an emerging market opportunity:

Science is beginning to understand the role of insulin resistance. Now its industry’s turn to draw the blueprints for the biggest market yet...Like any new disease, this one offers significant challenges to pharma. But for companies that meet them – especially the challenge of finding an appropriate role for medication in treating a disease with a large lifestyle component – [insulin resistance] will be a force reshaping products, companies and markets for decades to come. (Breistein 2004).

The importance of branding disease connects to the increasing role pharmaceuticals play in managing daily life and the strange new world the global diabetes epidemic creates as it becomes a business opportunity. The necessity of learning not only scientific physiology of disease states and mechanism of action of drugs also reflects the increasing role technology plays in managing daily life and the type of subjectivity this entails.

For many of the people I interviewed (and will be discussed later in much greater detail), diagnosis of diabetes offered an explanation and clarity to the symptoms they were experiencing, but at the same time, diagnosis and treatment led to an expected conformity to an ethics of self care and identity as a diabetic that they were not willing or were unable to adopt. For many of them, their diagnosis and treatment were a necessity that further isolated them from the social support they desired. This is the dilemma of biomedical treatment: the power to control the
symptoms of diabetes is tightly wedded to scientifically abstracted models of diabetes that strip away the social world of the person, situating people not through but in opposition to the social worlds they belong. For many people, health disparities are a part the social worlds they live in, as the epidemiology of T2DM shows in its clustering in lower socioeconomic countries and neighborhoods. The autonomy of treatment increasingly conferred on people living with T2DM further isolated and added additional stress to lost jobs, lack of money, and an incomprehensible future. The tension that emerged through interviews I conducted reflects not only the tremendous disruption of social lives caused by diabetes, but also something deeper and subtler in the way a diabetic subjectivity and bodily experience are imagined to be universal (Duden 1991) and disconnected to one’s knowledge of self gained through lived experience.

Foucault in particular discussed how narrowing norms of behavior in practices of self-care (ethics) are reflective of the increasing control that is required in modern life. We find relief in diagnosis but at the same time this requires conformity to particular ethics that may strip away or require a new sense of self. Patrick Hutton (1988), in a discussion of Foucault’s work on technologies of the self, states that, “We are beings that create forms which ironically imprison our creativity” (137). Biological understandings of T2DM create a universal aggregate, neatly bounding an otherwise amorphous condition of modern life, where it is held constant and external from lived experience. The objectivity of the mid-19th century, described by scholars such as Daston and Galison, as a new phenomenon that defined the elite domain of professional scientists, has slowly made its way into everyday self-care practices. The subjectivity described here thus creates a discontinuity from the history of one’s lived experience, changing the routines
of daily life so that self-care is held as distinct from one’s lived experience. As will be discussed in much greater detail in coming chapters, this gap between self-care practices and a person’s lived, everyday existence is a barrier many people interviewed could not reconcile.

However, before leaving this scenario as too completely dominated by a fixed subjectivity and changing scientific body, another type of responsibility, created from knowledge gained through lived experience, persists simultaneously. Even as bodies and subjectivity become more fixed within an abstracted biological space, they change in unpredictable ways. Sometimes from unexpected adverse effects of medications that only become evident over time, sometimes from the unknown nature of T2DM, and sometimes through new, creative practices of management learned from experience. Although responsibility for controlling T2DM is increasingly invoked through rational thinking and adherence to medical technology, the movement needed for self-transformation and to create sustaining practices of self-care still persists and forms a mechanism for change rather than repetition. While scientific abstraction attempts to fix bodies as objects, they are of course not the same thing. Production of objects can be completed and repeated, but bodies and subjectivity are always in the process of becoming over time (Kirsch 1995). This tension between conceived and lived social space is what Lefebvre identifies as the characteristic of modern, everyday life, and plays out with greater intensification in the lives of people living with T2DM.

Jonathan Crary (1990) notes that both Kuhn (1979) and Hacking (1983) also view changes in the mid-19th century as the period when measurement takes on a primary role in physical sciences. The implication of these changes plays out today in the medicalization of self-
care. The smoothing out of the complexity of practice and subjectivity into something that can be reduced to a series of linear steps and managed through rational decision-making requires quantification and abstracted social space that plays not only an increasing role in everyday self-care practices (Gardiner 2004; Simonsen 2005) but also in the ability to identify large numbers of people with hidden signs of disease (Armstrong 1995), such as screening large numbers of people for diabetes based on a single finger stick or to assess diabetes risk based on numerical data from thousands of anonymous individuals. The complicated intersections of business, marketing, and clinical practice that use this data and on which treatment decisions are based can be briefly outlined from a report published by the American Association of Clinical Endocrinologists (AACE), sponsored by GlaxoSmithKline in 2005, titled “The State of Diabetes in America” (Peck 2005). The report was a compilation of data from businesses that sell medical data: Surveillance Data, Inc., Harris Interactive and HEDIS Quality Comparisons. The report found that two out of three people in the United States who have been diagnosed with diabetes did not meet AACE guidelines of an A1C of 6.5%, and 61% did not know what an A1C level was, even though 84% of the people surveyed felt they were doing a good job controlling their blood sugars. Comments from the Chair of the report, Jamie Davidson, M.D., point to the new partnership of clinicians and patients discussed in the next chapter: “The medical community needs to intervene earlier and more aggressively to control blood sugar because of the link between high A1C levels and diabetes-related complications. We also need to encourage people with type 2 diabetes to take control of their own health by educating them about the central role they themselves play in the long-term management of their diabetes” (AACE 2005). While the
use of quantified data is presented as a powerful tool to promote health, it is also used to reduce self-care practices to a rational and uniform experience. Left out, as discussed in the coming chapters, is the importance of learning how to create meaning and reattach data to one’s own history.

In summary, in this chapter I have shown how bodies, beginning with the development of a new science, physiology, in the 19\textsuperscript{th} century also came with a new type of scientific subjectivity. This subjectivity required strong will and control to create a sense of dissociation from one’s surroundings and the observed phenomena being studied. Daston and Galison (2007) discuss the development of this practice that created a sense of distance between subject and object as a scientific domain in the 19\textsuperscript{th} century. Integral to creating a separation between subject and object was the containment of all phenomena through their fragmentation and the subsequent isolation and measurement of their parts. Bodies became knowable as discussed in this chapter through their uniformity and universalizability rather than through their connection to the unique individual that also existed in that body. Understanding this historical process, which redefined bodies as abstracted space, makes the difficulty many people have in managing diabetes clearer. The type of objectification necessary to manage diabetes requires a further disconnection of body and self that I will discuss in the following chapters. In the next chapter, I describe how patient-centered T2DM education programs disseminate the type of diabetic body and subjectivity, a configuration of informed patient/consumer, advocated by the AACE. Once the province of 19\textsuperscript{th} century scientists, objective observation and willful self-control are phenomena that have slowly made their way into everyday practices of self-care.
Chapter 6: Diabetes Education Programs

As the center in “patient-centered care,” people living with diabetes must also create a new biography of self (Webster 2007) as the demands from the global diabetes epidemic create rearrangements of social space in everyday life. In this chapter, I examine the ways responsibility for diabetes management is invoked through diabetes education programs. In the previous chapters, I have discussed how historical spatiotemporal shifts reflect shifts in social relations (Ross 1996), specifically in the ways Tacoma’s resettlement (Harris 1997) and massive rearrangements of landscape intertwined with the temporal structure of progress and development that was linear and always forward-looking. This rise of urban, abstracted space in the 19th century is paralleled in the new science of physiology. Claude Bernard’s discovery that glucose could be measured in blood and that high glucose levels contributed to the development of diabetes reflected both the rising incidence of diabetes in urban centers, such as Paris in the 19th century, and how the unfolding of disease (and diabetes in particular) made it separable from the lived experience of the individual. Jonathan Crary (1990) describes this type of 19th century development as a “process by which capitalism uproots and makes mobile that which is grounded, clears away or obliterates that which impedes circulation, and makes exchangeable what is singular” (10), all a necessity for new flows of production, information, and commodities.

In this chapter, I describe the ways these same macro-level processes of dissociation are produced on a smaller scale through diabetes education classes regarding T2DM management. These rearrangements of spatiotemporal structures that characterized progress and development
150 years ago move inward with increasing significance, as diabetes becomes an endemic condition on a global scale. For people living with T2DM, the skills of a detached rational observer, once the domain of 19th century scientists described by Daston and Galison (2007) in chapter four, are now taught as highly specific skills to manage daily life. In upcoming chapters, I describe how the abstract rationalism taught in diabetes education programs is integrated into the lives of people living with T2DM in Tacoma, Washington.

Important to keep in mind is how losing its manufacturing and retail core has made Tacoma a city without a center, reconfiguring the social relationships of the people living there. As a lumber-manufacturing center, work and workers in Tacoma revolved around a largely pedestrian, downtown core that brought people together for entertainment, shopping, business, and the labor demonstrations that reflected Tacoma’s strongly unionized population. The independent, mobile worker that has always been the majority of Tacoma’s population has become, in the last half of the 20th century, more socially isolated as a result. The implications of this will be discussed in the diabetes life-stories in the following chapters.

6.1 Bodies in everyday life

The ability to attach biological meaning to numbers and to comprehend time as a method to keep track of self-measurements are important management skills taught in T2DM education programs. Measuring and calculating insulin dosing, the ability to interpret food labels, calculating carbohydrate content, measuring food and calorie content, and understanding how the length and level of exercise affect blood glucose levels are all part of the constant attentiveness advocated for good T2DM management. Scientific rigor and technology, rather than history, are
valued, and controlling diabetes becomes disconnected from personal meaning. Modern medical
treatment, which depends on an interchangeable, abstracted body, diminishes the experience of
what is local and singular (Crary 1990). The importance of an individual’s *personal time*
(personal history, lived experience) is minimized and simplified, as daily practices are
configured around a spatiotemporal structure that excludes responsibility of learning from or
making sense of one’s own past life experiences.

In her study of clinical management of T2DM, Annemarie Mol (2008) discusses the
different temporal structures inherent in chronic disease management. She defines this split as
the difference between “the logic of choice,” and the “logic of care.” In Mol’s model, choice is
instantaneous decision-making and temporal linearity, so that the logic of the customer,
“deciding what might be the best treatment, product, goal or way of life” (86) predominates. Most importantly in her model, the logic of choice is disconnected from bodies and practice. The logic of care, on the other hand is connected to practice, to bodies and to learning new skills over time. Mol is attentive to how the lived aspect of T2DM can be reduced to a series of skills and rational decision-making in clinical practice, but she places the logics of care and choice as a dichotomy *within* a biological construction of T2DM and largely within the clinical domain. Instead of rooting choice *and* care as historical processes that result from biological abstractions of the body, Mol defines the logic of choice as detachable from the logic of care.

As discussed in the Introduction, I wish to rearrange the boundaries of Mol’s analysis and situate both logics within the body and reconnect them to larger historical processes. Instead of creating a dichotomy largely within the medical domain, I show how rational abstraction and
lived experiences are held in tension, each shaping the other as people learn (or try to learn) how
to manage diabetes. In the following discussion of diabetes education programs, I explain the
various forms education programs can take, and also how people are taught to think about
controlling diabetes by medically abstracting their bodies and disciplined routines. However,
while medically abstracted bodies and linear temporality predominate in these education
programs, they do not form a totality in everyday life. Diabetes education programs are
examined in this chapter to understand how people are taught to think about their own bodies, as
they also become a site of convergence of larger social forces, such as increasing isolation and
scientific abstraction mentioned above.

Lefebvre’s model of everyday life and social space provides a method to understand how
individual bodies exist within different and sometimes conflicting modalities of space and time
that constitute everyday life. To Lefebvre, the body is the focal point of social space, and it is
through the constant interplay of concrete materiality and thought concept, feeling, and
experience that the everyday life is produced (Schmid 2008). Lefebvre dissolves the division
Mol creates by understanding the body as a mediator of the relationship between the logics she
identifies. Further, it is by transcending the conflict of this relationship that an active and
transformative subjectivity develops (Simonsen 2005).

In health care services such as diabetes education programs, people learn to control
diabetes by conceptualizing their own bodies through the lens of scientific abstraction. I wish to
emphasize the necessity of this step to understand diabetes. As was discussed in the history of
diabetes chapter, measurement is how we understand diabetes, and as discussed in later life-
history chapters, measurement is essential to understanding embodied experience. However, it also introduces an abstracted bodily form into daily routines that separates self-care practices from lived experience (How people re-connect creativity and self-care is the subject of later chapters).

Living with T2DM introduces not only new forms of spatiotemporal structures into daily life, but also new rules of functioning consisting of biological facts, external scales of measurement, and numerical goals. Managing diabetes means an objectification of one’s body by learning and applying these biological rules of functioning: learning medical definitions of T2DM, how one’s body works in biological terms and the way pharmaceuticals work to regulate those processes. Education programs emphasize self-discipline, decision-making based on scientific facts, and the necessity of measuring and monitoring, all practices that create a scientific detachment developed in the 19th century (both bodily conceptions and subjectivity), but applied today to one’s own body and daily routines. Not only are bodies made equal and exchangeable, controlling diabetes means having the skills to convert daily routines into quantitative data such as schedules and measurement. In turn, these skills, which are taught in diabetes education programs discussed in this chapter, create new relationships between body and self that are detached from a person’s lived experience.

As discussed by Daston and Galison (2007), practices of objective observation were an important part of Claude Bernard’s experimental techniques in the new science of physiology: “To embrace mechanical objectivity was to turn the will inward upon itself, a sacrifice vaunted as the annihilation of the self by the self, the supreme act of will” (231). Daston and Galison
emphasize the effort that scientific objectivity required of the scientist to act as both active experimenter and passive observer, of “endless work and unflagging will” (230). One hundred and fifty years later, the need to learn and apply this “supreme act of will” is now part of the skills and daily practices of people living with T2DM. Instead of a scientist needing to split in two, to become both seer and seen, T2DM education programs teach the patient the measuring, monitoring and understanding BG levels that require the same type of objective observation. The three education programs discussed in this chapter purvey a particular type of relationship between body and self as much as they explain these self-care skills.

6.2 Diabetes self-care skills

The diabetes education programs presented in this chapter give an overview of the type of information and skills taught by medical professionals to each other and to people living with diabetes. The examples included here are not meant to provide a comprehensive overview of all training programs, but to introduce their tone and structure. The three programs discussed here illustrate different contexts of education programs as they are used to facilitate new relationships between clinicians and people living with T2DM, and new commercial spaces for chronic disease management.

Before discussing the programs, it is important to mention an underlying proficiency upon which all these programs depend. Numeracy training is one part of a broader medical educational approach of the Federal Health and Human Services (HHS) titled “Health Literacy,” adopted as a key component of the Federal government’s Healthy People 2010 national health objective, and defined as “the degree to which individuals have the capacity to obtain, process
and understand basic health information and services needed to make appropriate health
decisions” (HHS 2000). The lack of ability to use numbers is a barrier to “optimal care and
patients’ execution of successful self-management” (White et al. 2010), and has been identified
as an important, but understudied barrier that contributes to health disparities in medical
underserved populations (Osborn et al. 2009, Rudd 2003, Shaw et al. 2008). Addressing this
barrier was the goal of one such program at the clinic where I recruited interviewees: “To teach
patients the math skills they need to successfully manage diabetes, focusing on skills such as
understanding blood glucose values, monitoring dietary intake, taking oral medications correctly,
and adjusting insulin doses based on blood glucose values and carbohydrate intake” (email
communication 2012).

Numeracy is a necessary skill to manage T2DM, but also helps create a particular way of
relating between body and self as will be discussed in the following examples. Health literacy
and numeracy are skills that are emphasized over making sense of diabetes through lived
experience, and lie at the heart of the education programs discussed next. Through skills such as
numeracy, an equivalence of meaning and subjectivity is created through uniform self-care
practices. Increasingly, through numeracy and the programs to be discussed next, a linear
temporal structure plays out—a dehistorization, so that the past is situated in the present
(Harootunian 2000; Osborne 1995). Daily routines, in the form of mechanical repetition, play an
increasingly dominant and antagonistic role in everyday existence, experience, and self-care
practices, as Lefebvre discusses. Mastery of new skills is both a necessary step in controlling
diabetes and a new biography of self learned in the following diabetes education programs.
The first is a diabetes-training program for pharmacists in which I participated, sponsored by the American Pharmacists Association (APhA). Certificate training programs for pharmacists to help patients manage T2DM have become widely available since 2000, as both become partners in newly reconfigured patient/consumer relationships. The second diabetes education program discussed is sponsored by Merck pharmaceutical company and is called “Journey for Control.” This program is designed for both medical professionals and people living with diabetes. I participated in the training for medical professionals and also observed program sessions with patients in clinical practice. The program emphasizes teaching medical facts surrounding diabetes and rational decision-making skills based on those facts. Finally, I describe a Diabetes Expo sponsored by the American Diabetes Association (ADA), held in Seattle and Portland. These one-day conventions are a merging of commercial interests and non-profit disease advocacy organizations that together create a marketable representation of what it means to live with diabetes. The Expo is one example of the rearrangements of social relations in everyday life as the uniformity and facticity of diabetes is used to sell products and methods for its management. Taken together, these three trainings show how scientific abstraction becomes integrated into practices of self-care and part of the daily routines of people living with T2DM.

6.3 American Pharmacy Association Diabetes Management Program

4/10/2014. Pharmaceuticals are traditionally dispensed as the final act of a medical appointment. Pharmacists have traditionally acted as the professional, but neutral, conduits between patient and physician. This role is changing as the complexity of managing daily drug regimens, commonly consisting of 12-15 medications, increases. In the United States, certificate-
training programs, which enable pharmacists to provide specialized medication management services along with traditional dispensing duties, are becoming a requirement for professional practice. New areas of professional training include: chronic disease management, immunizations, anticoagulation services, and medication therapy management. Since the 1970s, pharmacists, professional organizations, and academic programs have identified the provision of reimbursable services as the way to re-professionalize in a rapidly changing medical environment. As professionals looking to establish a new niche for themselves, pharmacists have adopted the role of easily accessible medical service providers, offering a specialized but necessary addition to medical treatment. “Pharmaceutical care” is a key term used to describe this specialized knowledge provided to improve treatment outcomes for both patients and other health care professionals. As management and treatment of chronic diseases (like T2DM) are increasingly a fixture of American life, these shifts in professional activities and responsibilities signal broader rearrangements in daily life.

João Biehl and Peter Locke (2010) used the term “pharmaceutical abandonment” to call attention to the increasing use and failure of pharmaceuticals to solve problems that have complex social origins. However, addressing pharmaceutical treatment failure is also the intense focus of the pharmaceutical industry, the medical marketplace of the Affordable Care Act (ACA), and a justification of expanded roles for pharmacists. The integration of ancillary services into ambulatory care practices has become a benchmark for reimbursement in the ACA and federal programs like Medicare part D. Instead of abandonment, new areas for reimbursable services have emerged that strengthen the role of pharmaceutical management of everyday life.
The reluctance to intensify therapy when treatment goals are unmet has been defined as “treatment inertia,” targeting medical providers as equal participants in not meeting quantified treatment goals. Along with compliance measures for patients, prescribers are then also held accountable for not meeting treatment goals.

Effective self-management of chronic diseases places increasing emphasis on “increased patient participation in care and collaborative goal-setting and planning of treatment” (Wagner et al. 2005) through medically informed patients and new responsibilities. The relabeling of federally funded ambulatory care clinics to “Patient Centered Medical Homes” (PCMH) and the increasing use of the term “medical home” in professional medical journals describes the integration of both medical professions and patients into a new relationship to improve treatment outcomes. An article in the New York Times from August 2010 describes this new relationship between pharmacists and people living with diabetes: “Eloise Gelinas depends on her personal health coach. At Barney’s Pharmacy, her local drugstore in Augusta, Ga., the pharmacist outlines all her medications, teaching her what times of day to take drugs that will help control her diabetes. Ms. Gelinas, a retired nurse, also attends classes at the store once a month on how to manage her disease with drugs, diet and exercise. Since she started working with the Barney’s pharmacists, she boasts that her blood sugar, bad cholesterol and blood pressure have all decreased. ‘It’s my home away from home,’ she says” (NYT 2010). “Home” reflects both the amelioration of isolation experienced by many people after a diagnosis of T2DM, but also a shift in the domain of illness in everyday life. Instead of the experience of illness as a break from
daily routine, a distinctly different quality of time, a “home away from home” implies a newly integrated space for illness with no interruptive break.

The following discussion of one certificate training program I attended shows how pharmacists learn to use their clinical expertise managing drugs as a service to people living with diabetes. In particular, it is used to illustrate what Jamie (2014) has described as “bodywork” unique to professional pharmacy practice. The body is essential to pharmacy practice as the site to which all medications are administered and pharmacological action occurs. This type of bodywork is also implicated in the standardization of bodies as pharmaceutical use, as a mass-produced commodity, increasingly manages many aspects of daily life. Jamie draws on the work of Kerr (2013) and Måseide (2011) who include “absent bodies” or bodies only made visible through technology in her discussion of pharmacists’ bodywork. This is an important point because it recognizes the existence of multiple bodies in everyday life including increasingly abstracted bodies made visible through pharmaceutical use and technical devices (Kerr 2013).

The education program discussed next show how abstracted bodies are located as the locus of responsibility for control of diabetes.

In May 2014 I attended a disease management certificate training developed by the American Pharmacists’ Association (APhA) titled “The Pharmacist and Patient Centered Diabetes Care.” This one-day program took place in the Bay Area of California, and is offered nationally through many state pharmacy associations and pharmacy schools. Based just on the number of times a year it is offered, it is a popular program, offering a disease management certification from the largest pharmacy organization in the United States. The morning session
was mixture of didactic teaching and group discussion: going over case studies and then
discussing the reasoning and logic of our decision-making. In the afternoon, we practiced taking
blood pressure, performing blood glucose finger sticks and foot exams, and giving insulin
injections. In many ways, the structure of the APhA program and patient training offered through
“Journey for Control” (discussed later) had much in common, as both programs required
practicing how to apply the same types of facts and rational decision-making to diabetes cases.
The information for pharmacists was more technical, but there was no difference in the overall
content. Both pharmacists and patients have a shared responsibility to stay updated on the most
current medical information.

A PowerPoint slide at the beginning of the day laid out our learning goals, with the
heading: “Informed, Activated Patient.” In bullet points, it identified the types of thinking we, as
pharmacists, were to help facilitate in our patients:

- Has sufficient information to become a wise decision-maker about his/her illness
- Understands the importance of his/her role in managing the illness and acts on
  this understanding
- May function independently or with caregiver assistance

Our instructor explained that since she worked in a retail pharmacy, one not connected to
a medical clinic, she did not work with other clinicians to make medication adjustments. Her role
was to help patients use insulin safely. “Do I do dosage adjustments in my practice? No. Most of
the time, why we’re teaching you this is to understand what patients might be doing and to help
them with their correction dose.” Our responsibility as pharmacists was to collect and analyze
current treatment guidelines and convey these facts and help organize them for patient. In the long run, however, it was up to the patient to use the information and make decisions to get glucose patterns within desired ranges.

In the first case study, we discussed a 54-year-old woman’s medications and blood glucose levels in the morning, afternoon, and evening. Her blood glucose levels were above and close to targeted levels throughout the day, and her A1C, a three-month average of blood glucose, was higher than the treatment goals we had reviewed earlier. We discussed treatment changes in small groups and then shared our strategies for getting her A1C down. Should we add drugs or could her present regimen be increased? How aggressive did we want to be? Make big changes all at once, or smaller drug adjustments? What were the benefits and risks of each drug and did this fit with the lab values of this patient? In my group, we began by volunteering what we each thought was the most important number that needed to be adjusted. It was a familiar process, one that everyone had been through countless times in pharmacy school, at work, and in other training programs. The numbers in front of us represented a puzzle, independent of the person they belonged to, that needed to fit together.

After we re-joined as a big group and discussed our decision-making, our instructor told us, “What you have done is ‘pattern-managed’ this patient. You have looked at what her blood glucose is, and have made decisions on how to change her therapy. Which is really what I try and talk to patients about. We’re not, ever deciding based on one number. A lot of people tell me, ‘Oh, I don’t check my glucose. My doctor does that at the appointment. They’re not even talking about the A1C; they’re talking about that one check. That is one number they’re talking about.
We tell people we need to look at all of the numbers over the day to get an idea of what’s going on.” Later, after examining another case study, this time adjusting an insulin dose, our instructor told us, “Pattern management allows us to determine where to go. Our goal is to find where to add medications, increase dosage, using the numbers. And to look at other variables such as meals and activity. Look at those post meal [glucose] levels! Which piece of the puzzle is affecting it [A1C] more?” There isn’t necessarily a right answer to any of the case studies presented, as there was always more than one possible treatment plan, but our decisions had to follow a logic of using facts correctly and paying attention to the details numbers told us. “How many times a day are you going to tell them [patients] to test [BG levels]? Just once? Twice a day? Four? I see all sorts of different numbers! This may be our biggest point of debate. Well, as those of you who work retail know, some of that answer is going to be dependent on the insurance payer… We want to know, which one of these components is making her A1C go up? Her fasting or her post-prandial levels? And that’s important because patients, if they’re checking their blood sugar levels, are most likely to be checking their fasting [BG levels]. The trick is gonna be educating her as to what the number is, and what exactly she’s supposed to do so she certainly doesn’t over-treat. It [testing] becomes an education piece, ‘You ate a bowl of ice cream’ versus ‘You ate a nice salad,’ what’s the difference [in BG numbers], what happened?”

We must translate skills and drug knowledge into a reimbursable professional service. “So, here are reasons to test: increase patient’s awareness, helping them to get to target, helping them recognize between hypoglycemia and not, and then also cost. Helping patient motivation
and [teaching] how will those results be used?” We learn how to train people to interpret what they do every day in terms of numbers, and how to match daily activities to drug effects. Most importantly, we give sole responsibility to mastering facts and skills as a way to manage the symptoms of diabetes. Focusing inward and mastery of one’s body through biological facts and uniform practices connect numbers to an individual’s ability (and responsibility) to maintain social autonomy.

Even though it has been the experience of every pharmacist in the room that bodies behave in unpredictable ways, that drugs are not uniformly predictable over time, or that people cannot repetitiously do the same thing every single day, we use an ideal model of uniform bodies, drug effects over time, and perfect compliance to learn what we know. The logic of numbers, their patterns and story, take precedence over the history of the person to whom they are being prescribed, even as treatment is centered on the patient. For both pharmacists and patients, pattern identification based on numbers becomes tied to expert, evidence-based guidelines and treatment algorithms developed so that decision-making is also uniform. Different governing bodies, such as the American Diabetes Association, advise treatment strategies that are more or less aggressive than other expert groups, but these associations of experts are given responsibility to organize and analyze facts for us.

The mitigation of lived experience in the case study examples we discussed was repeated through guidelines. Decades of both personal and clinical experience that went into making expert guidelines disappeared as the actual experience of T2DM was squeezed down and simplified into a planned route. Unspoken throughout the training was how guidelines from a
few years ago are discarded without discussing much of the process that went into how a new recommendation was created. For example, our instructor told one group: “What do the guidelines tell us? If you were initiating the pre-mix, well, I don’t see insulin pre-mix used that way. If you were initiating insulin you’d start with the basal [insulin].” Why is pre-mix insulin no longer used “that way”? Probably many of the pharmacists attending could give clinical reasons why pre-mix insulin is losing favor as a treatment option, but the role of guidelines is to take on that responsibility and simplify a complex process.

Continuing education programs are attended to learn about new facts, not to understand the history behind them. “So, one unit of insulin will bring down the glucose by 50 points. In general this rule holds. But that generalization is not a good place to start.” The general rule of one unit of insulin to one kilo of body weight, once widely used, is now no longer a recommendation. A more accurate rule, the current rule, is to calculate a new dose based on the total daily insulin of each patient. “In this patient then, for them, one unit of insulin will bring their glucose down by 36 points. That’s quite a bit different than 50 points.” Facts are updated in an agentless way, so that only the logic of the new decision is emphasized. Guidelines and algorithms serve the same purpose as identifying patterns through BG levels: both provide a method of understanding that eliminates individual experience and social embeddedness. The greater importance for both pharmacists and patients is to keep current of new facts, technology, and rules for decision-making; the social process of how these facts came to be is not necessary information.
Memorization of drug half-life, dosages, and pharmacology served “to optimize medications and help coordinate what needs to be done first.” Meals and post-prandial glucose levels were treated in the same manner as drug adjustment, with the goal to find out why food patterns were chosen by the patient, “So, what do you think is going on with Erica in this case? What are her numbers doing after she eats? There are some things we can open her eyes to. The trick is, what is Erica’s pancreas doing two hours after she eats? Can her pancreas keep up with those excursions in blood sugars? The closer we get to goal, a lot of times it’s those post-prandials we have to pay attention to. Often the fasting [glucose level] is OK, but those post-prandials are starting to show a decline and it shows the patient is having a harder time keeping up. OK, does that make sense? Well, she has some work to do.” Food and eating were given the same mechanistic, quantifiable effects as medications, so that eating could be analyzed in the same way. The unexpected twists and turns of drug effects, how bodies change over time in their response to drug therapies, and the complicated attachments between food and people are far outside of what we were to consider. We were always in the present, facing a future built predictably in sequence.

Even though it is incomplete, understanding just the facts of T2DM as presented, through adjusting dosages or selecting medications for a particular patient, provides a stable sequence to account for unpredictable and unexplained realities:

So we’re going to talk about what we’re going to recommend for John. There are many options out there and so we’re kinda looking at what change are we recommending and what are our rationales for that. What you have to think about is what are the therapies available to us, how so
they work, what is their effectiveness and what is their side-effects. So, let’s just start one by one [by drug class].

As we went through each group of diabetes medications available for treatment, we made decisions based on the decrease a BG level required to meet goals, kidney function, age possible adverse effects, and what a patient’s insurance company would pay or the patient could afford. Putting together all the factors needed to make sense of BG levels can be difficult. Quantification and a step-by-step approach is not always an easy process to understand or to accomplish. But what we, as pharmacists, are training people to do is to connect details of daily routines to external scales of measurement and interpretation. Most importantly, connecting numbers to daily routines disconnects them from lived experience. As pharmacists, we teach a two-step process: to connect and make sense of daily routines through numbers, which in turn abstract these routines away from one’s lived experience.

The pharmacist-training program (and patient-oriented Journey for Control sessions discussed later) emphasizes standardizing definitions of terms, understanding the expectations of treatment, and the scope of T2DM management. Pharmacists are taught to explain blood glucose, blood pressure, and cholesterol ranges along with schedules for dental, eye, and foot exams, nutrition appointments, vaccines, blood chemistry labs and depression screening. Both pharmacists and patients become partners in learning the importance of and keeping track of this scheduled maintenance. These tasks never completely negate the person living with T2DM, but they do impose an equivalency and interchangeability with anyone living with T2DM. For pharmacists as health care providers, we are taught to pay attention to and help maintain these
schedules as a part of our assessment of pharmaceutical treatment. These uniform, non-drug schedules related to T2DM self-care become a part of the mechanistic and uniform temporality of pharmaceutical treatment. Our instructors explain that our roles as pharmacists are, “educating the patient on diabetes care. That means doing more than just explaining how to start metformin. It means helping someone use a blood glucose meter for the first time, [to teach] how to get data back, [to teach] how to set goals.” Self-care practices take up where drugs leave off, with the same mechanical repetition.

As we work to form partnerships, we are taught to set “a negotiated self-management plan, including specific, measurable actions the patient chooses to take to improve his/her health.” The APhA program ends in a similar manner by setting a goal for pharmacists using the same, step-wise approach: “My challenge for you, is what will you be doing different when you go back to work? I want you to write down the one thing you’ll be doing differently. Make a decision to do one thing differently and once you get confident add a second thing and then a third. And before you know it, you’ll have a nice little diabetes program going.” Decision-making is always stressed as forward-looking, for benefits in the future. For both pharmacists and patients, incremental, rational changes can save one’s career and life. In much the same way that the past and traditional thinking were rejected as a hindrance to development of early Tacoma, new pharmaceuticals and new medical “facts” erase the past and create forward movement. The future is produced by looking to the next technological development or medical fact to solve existing issues related to diabetes, rather than a reflexive examination of one’s past, the priority or value given to self-care in everyday life and health, or expectations of the future.
Left out of the pharmacist-training program is to fully appreciate the difference this quantifiable, measured, and scheduled management presents for most people, and what they have to give up or acknowledge about themselves to implement the monitoring recommended as self-care practices. As will be discussed in the diabetes life-story interviews, the everyday circumstances that make body and self both product and producer are a dynamic that continually challenges abstracted space as the locus for all responsibility to manage diabetes.

6.3 *Journey for Control: Background*

The next program to be discussed, *Journey for Control*, (JfC) connects medical abstraction to the practices of daily life, using numeracy skills and clinician-patient partnership formation discussed above, in a group discussion format. People living with T2DM learn how to make rational self-care decisions and to follow a uniform journey through Conversation Maps®. Pharmaceutical companies, like Merck, cannot provide direct treatment advice to the public, but they can sponsor disease management information through proprietary educational programs and provide information about disease states in a public health format called “disease branding.” This advertising strategy is described as raising “customer awareness” with the goal of creating a “new understanding of diseases that have been around for many years, awareness of little-known conditions [and] a more positive perception” of a particular disease state (Parry 2007). This “value-added” health service offered by a pharmaceutical company is a way to address the abandonment many people experience when they are given a diagnosis of diabetes but little information about how to manage it afterwards.
Through ancillary medical services, pharmaceutical companies also develop subtle relationships between the nature of a particular disease and pharmaceutical management. The building of a branded disease is discussed in a Pharma publication using the example of GERD: “The term heartburn was coined decades ago by antacid brands, and suggests that the mechanism of action in the treatment of indigestion is acid neutralization, which is exactly what antacids do. However, researchers discovered in the 1980s that chronic heartburn could be further described as a malfunction of the esophageal sphincter...Glaxo and its drug Zantac worked to rebrand chronic heartburn as a more insidious medical concern” (Parry 2007). Jeremy Greene discusses a similar process in the 1960s with the marketing of new oral diabetes medications (chapter four).

The biological emphasis in JfC conceptualizes diabetes in a particular way that appears factual and neutral. It also creates a simplified conception of diabetes by excluding many complex non-biological issues of self and self-transformation that many people confront when they actually have to start managing diabetes. However, simplification in this case does not imply ease, as learning the facts of diabetes is no easy task. As will be discussed in later chapters, the emphasis on rational decision-making and on explaining diabetes as a biological condition leaves people with little understanding of why they cannot make the changes they know they need to make to avoid the serious consequences of chronic high blood sugars.

Early on in the program, diabetes as a medical condition, i.e. a biological one, is introduced early on in the program and differentiated from the feelings and emotions people have surrounding diabetes. Printed material for patients reads: “When it comes to managing your diabetes, you’re in the driver’s seat. Your health care team and support network will be there to
help you, but managing your blood glucose levels and your diabetes is up to you. You will have a lot of choices to make as you go through each day. The more you know, the more able you will be to make wise choices. Since each one of you comes to this session with your own experience and understanding of diabetes, how would you describe diabetes in your own words?” However, in the instructor’s manual given to help facilitate patients to learn the material, the following appears:

Facilitator Tip for this section: Many participants will begin to describe how they feel about diabetes, or how they are feeling in general in response to this question, as opposed to actually describing what diabetes is. This is okay and a very natural response. However, the next few questions are intended to help people better understand what diabetes is.” (Journey for Control teaching manual: 6) [italics added]

“What diabetes is” is operationalized as: 1) a biological condition and 2) which exists independently from the lived experience of diabetes. Through the group sessions of the program, participants begin the process of dissociating diabetes as a medical entity from the context of their own experience. Emotions, reflexivity, and value systems regarding one’s health are treated as distinct and unessential from a biological understanding of diabetes. In fact, as described below, they can be viewed as a barrier to stability and sustained control of diabetes, whereas these can be achieved through rational abstraction. In this training, one’s own body has no individual past and can be understood in exactly the same (disembodied) way as everyone else’s.

6.4  Journey for Control: Training program for medical professionals
Journey for Control (JfC) is a T2DM education program sponsored by Merck but designed by a medical education company with a global focus. Healthy Interactions LLC (HI) designs programs and trains both health care practitioners and patients for a large variety of health care concerns. “Millions of people in more than 120 countries guided by more than 60,000 healthcare professionals” have been trained through the program, according to the company (Healthy Interactions 2015:2). In literature written about the program, JfC is described as a product of the “diabetes industry,” a partnership of “healthcare experts including Healthy Interactions, the American Diabetes Association and Merck, Inc.” (Grenci 2010). I first heard about the program through two pharmacists who managed pharmacy-based disease management programs at federally funded ambulatory-care clinics. They were interested in JfC because of its group learning structure, much different from the one-on-one programs already in place at their clinics.

Merck’s website states, “Only licensed health care professionals are eligible to attend Conversation Map training sessions, receive Conversation Map educational tools, and conduct participant sessions using the tools” (Journey for Control Educator 2013). Training is offered throughout the United States, and I attended a program in California’s Bay Area in July 2013; it took place in a large hotel meeting room and was attended by about 30 other medical professionals. When we were asked to state our professions and where we worked, I learned that I was the only pharmacist in attendance. Most of the participants were nurses or nutritionists, almost all female. Most interesting, many of the people I talked to worked for for-profit health service companies that contracted with bigger clinic systems in the Bay Area to provide patient
education. An important selling point of the program is that it is recognized as a reimbursable program for Medicare patients so that health systems can contract out educational services and be reimbursed. All instructors were given the five maps, a large teaching binder with materials needed to conduct classes, and password access to the website HI maintains for instructors, patients, and medical providers.

First, we were taught the general structure of the program, which was divided into four two-hour sessions with groups of 6-8 people that met once weekly. Each training session had its own colorful, cartoon-style “map,” about the size of a small table, that a group sat around. The map served as the “journey” or outline of the topics discussed at each meeting. The sessions were not rigidly organized, and depending on each setting could be arranged to emphasize topics participants, facilitators, or clinic/hospital administrators felt were important. The four sessions consisted of a general overview of diabetes titled “On the road to better managing your diabetes,” “Diabetes and healthy eating,” “Monitoring your blood glucose,” and “Continuing your journey with diabetes,” which was devoted to understanding medications. An optional fifth session covered gestational diabetes.

Emphasized at my training was explaining diabetes in terms of physiologic mechanisms. Although the terms “Socratic, not didactic,” “learner driven,” and “self-empowering” were used to describe the teaching method, this actually meant teaching participants the “medical gaze.” As our training instructor told us, “The information presented is not dumbed down – the purpose is to educate.” Certainly, the complexity of understanding the biology of T2DM was not dismissed - just the opposite happened. The “journey” of the program is the work required by participants
to understand T2DM as a physiologic process, and to develop “analytical skills using this knowledge throughout their lifelong journey with diabetes” (JfC teaching binder). In both the live training and the teaching binder, emphasis was placed on using this knowledge to set goals that were mutually determined with participants. However, like the partnership between pharmacists and patients mentioned in the APhA program, goals are determined within the constructs of medical expertness and T2DM as a biologically constructed condition. Ultimately, our goal as group facilitators was to develop participants’ rational decision skills to “make successful transitions.”

The complexity and length of time needed to learn how to apply biological facts to deal with it were not dismissed in the training for both clinicians and patients. In the “guiding principles behind the design and intended use” of the program was a startling statement coming from a pharmaceutical-company sponsored program: “As a society, we often want simple solutions to complex problems.” An adjacent photo of a middle-aged African American man holding a golf club and ball states: “It took me years to wrap my brain around the fact that I had a chronic condition that needed to be actively managed by me.” Active management in the training meant becoming an informed consumer/patient, an active participant in the medical home and mastery of self-management skills. Making “good decisions” was the ability to integrate these facts into daily routines. Most importantly, we were taught in the training, was that a biological emphasis and successful decision-making prevented “diabetes burnout,” defined by our instructor as “the emotional side of diabetes and the nosedive of the group.” This rationale is what drives the crucial dissociation made in the sessions between lived experiences and
medical fact. The ability to make good decisions relies on this separation, and not separating the two leads to frustration, resignation, and uncontrolled diabetes.

While the structure of the program rests on scientific neutrality and facts, these are kept separate from placement within the jurisdiction of a clinical domain: “The Map tools methodology promotes critical thinking and the responsibility of patients for their own learning and action. Patients will tolerate what healthcare professionals have to say (they will listen, be nice, ask for answers, etc.), but they will ultimately act on their own conclusions” (JfC teaching binder). This phrase “patients will act on their own conclusions” was also repeated in the live training. Self-management skills are gently shifted away from the domain of the clinic: “Within the safe environment of their peer group patients are not told how to think or what to do, but are instead encouraged to think for themselves and discover what is meaningful to them about diabetes” (JfC teaching binder). The empowerment offered by the program is provided through learning a biological rationale for diabetes. The advocacy for shifting medical knowledge out of the domain of medical professionals lends the program a degree of patient-advocacy legitimacy and a patient/consumer who understands their condition from the same clinical dissociation as their medical partners. Both groups view diabetes from the perspective of what Lefebvre defines as abstracted social space, separate from lived experience. Neutral language was also encouraged, such as avoiding the word “normal” to describe ranges of blood glucose control and instead to frame questions as “What is your target blood glucose?” The skill we, as medical professionals, were expected to teach/share with participants, was to detach diabetes from the particularities of one’s daily routines and then re-apply these as rules/ethics into everyday
practices. Diabetic rules of functioning must first be abstracted away from the activities, social relations, and values that make up an individual’s daily routine before they can be integrated into those routines.

6.5 Journey for Control: Observing group sessions

Returning to Tacoma, I wanted to see how the program was actually used. After calling several clinics in Tacoma, I found that some ambulatory care clinics within the three biggest clinics (Franciscan Health System, MultiCare, and Group Health) had stopped conducting group education classes, and currently used one-on-one training. One diabetes educator I talked to at MultiCare stated that the shift to an individual education program had more to do with maximizing insurance reimbursement strategies (some insurances did not pay for group education programs) than any issue with the program itself, which she liked. Unexpectedly, it was the group participation and self-directed learning designed into the program that some facilitators did not like. “Once you put the maps down [on a table], you lose control,” a certified diabetes educator (CDE) told me. Her main concern was missing “big agenda topics” that needed to be met to meet clinic education goals. She stressed to me that the program let people talk about what they wanted to and groups could “get stuck on one topic,” spending too much time on one topic when there were three to four more topics that needed to be covered for Quality Assurance and program monitoring. Interestingly, the CDEs that I talked to could not really answer my questions as to how well the program (or any diabetes program) helped or did not help individuals change their mind-set as to how to deal with T2DM. At Group Health, for
example, quantitative results from participants in diabetes education programs were tracked through larger data sets of lab values.

In many ways, the promotional literature of JfC, directed to people living with T2DM, identifies a real need: “When it comes to diabetes, knowledge really is power. The more you know about diabetes, the better you’ll be able to manage it.” The type of knowledge is to understand one’s own body as quantifiable and what numbers mean to make decisions. The JfC program walks a fine line. It distances learning from the rigid structure of a clinic visit, and still fits it within a medical perspective of diabetes. It “empowers” patients by shifting control to an educated patient. However, while patients are taught to learn, share, and utilize biological knowledge of T2DM, they are not taught how to reconcile this knowledge with their past lives, a focus of future chapters. Repeatedly stressed in the four sessions I watched (all at one Franciscan Health System clinic at the main hospital complex in Tacoma) were definitions and normal ranges of blood glucose, A1C, cholesterol, and blood pressure.

In the first lesson, the following main topics were read aloud from a printed card: 1. What diabetes is and some of the most common myths about diabetes. 2) What blood glucose and insulin are. 3) Monitoring your blood glucose and using the results. 4) Managing diabetes with healthy eating, physical activity and taking medicine. 5) The importance of having a plan and engaging a support network and healthcare team. The instructors made sure that everyone knew what target blood glucose ranges, blood pressures, cholesterol, and post-prandial glucose levels were by asking participants to define these terms throughout the class and help each other out when someone stumbled over a definition or range. When one participant said he was surprised
at the amount of biological terms and facts he was expected to understand after one class, the instructor told him, “No, this isn’t a soft-ball approach.”

The emphasis on maintaining a “correct” medical explanation of T2DM was reinforced throughout each session as we moved around the different stations on the map in front of us. Participants read question and answer sections to each other from cards, and attempted to answer. Cards asked us to explain how activities such as “eating more carbs,” exercising more than usual, stress at work, or drinking alcohol might cause blood sugars to go up or down. Other question and answer session asked us to identify the roles of different organs that regulate blood glucose and to identify as “facts or myth” different statements about diabetes. In each session were the gentle but insistent reminders that understanding these facts could save one’s life. Instructions from one section of the map read: “In addition to knowing what diabetes is, you will be able to make smarter decisions if you have the correct information. Focus on the fork in the road in the upper left of the map. Myths can lead you down the wrong road when it comes to managing your diabetes while the facts can serve as a road map for better managing your diabetes.” When we discussed the complications of T2DM at another stop along the map, all the groups I observed became quieter, and no one interrupted with questions or stories. The tension lightened as explanations of how controlling numbers also reduced risk for these complications.

The two facilitators I watched did not allow much discussion among participants as to how they felt about diabetes, or even their reasons for attending the class. Both had been conducting diabetes education classes for decades and had smooth control that promoted discussion on the topics they wanted to discuss. But, interest and energy to keep participating
remained until the very end of each two-hour session I attended, sometimes far beyond my own interest. Unlike the APhA diabetes training, where pharmacists accepted the universal ideal of scientific conceptions of diabetes, in the JfC groups personal experiences made their way into the sessions through quick jokes and brief comments surrounding fears, uncertainty, inertia, or bad experiences. Although the instructors were practiced at keeping each session moving along the map in front of us and focused on diabetes as a disease, comments about personal experiences taking a particular drug, or blood sugar readings that were way too high or low, were quickly exchanged between people who had just been diagnosed and those who been living with T2DM for a long time. This actual experience reassured those who were recently diagnosed about what the future held and that life went on despite scary episodes of low and high blood glucose, or even visits to the ER, and that it was possible to go on vacations and continue with activities they enjoyed before being diagnosed. This slice of lived experience, the quick stories and humor interspersed throughout the sessions, kept people participating (along with the teaching experience of the instructors). However, while they validated the legitimacy of medical fact, they never structured the sessions, nor were they allowed to directly challenge the locus of diabetes as a separate and abstract verity. Most importantly, inertia and uncertainty regarding the future (discussed in later chapters) were treated only as barriers to managing diabetes that could be circumvented by focusing on medical facts and making good decisions.

For the participants in the sessions, control of diabetes was taught as a uniform process. They needed to examine all of their daily routines and re-assess them in terms of learning the biological rules that defined diabetes. Their routines would no longer be just eating breakfast or
taking the dog for a walk, but activities that they would pay attention to as they raised or lowered their blood sugars, blood pressures, weight, etc.

6.6  Journey for Control: Implications

The use of a “diabetes map” connects very different people, lives, and stages of diabetes to a uniform way of thinking and practicing self-care. This uniformity of care is a selling point. Promotional material for JfC states it targets “the 95% of the global population that does not already receive optimal [diabetes] care,” meaning that 95% of the world’s population diagnosed with diabetes is not receiving in-depth diabetes education classes. Healthy Interactions promotes JfC as a standardized methodology no matter where in the world it is used: “Facilitators are trained in the same way be they in Los Angeles, Hong Kong, Barcelona or Karachi…the standardized methodology is the same and the patient experience is consistent worldwide. Therefore, the participant experience is standardized, and each patient experiences the same level of engagement, though perhaps in a different language” (Healthy Interactions 2015). Of course, this level of uniformity is not possible. The sessions I attended were modified in various ways by the facilitators to meet clinic education goals, and each had their own teaching style. But the program was successful its intent to facilitate decision-making as a skill within a uniform biological lens. It introduced new concepts of pathology, target numbers, and schedules to which people needed to pay attention: foot and eye exams, and blood pressure, cholesterol, and kidney function monitoring.

The necessity of this abstraction to control diabetes is not without cost, however, as will be discussed in the coming chapters. Through programs like JfC, controlling diabetes and care of
the self are conflated. As medical abstraction enters into the home, or is conflated with the home, the relationship between body and self also changes. As responsibility for self-care shifts towards medical treatment and the use of pharmaceuticals, the important ways that losing weight or changing everyday routines also changes how we think of ourselves, the ways the quality of the relationship between body and self, changes is not given validation. “Journey for Control” implies movement and transformation. Each “map” for individual sessions uses travel and change to foster the expectation and feeling of movement. Bodies are transformed, but the self, one’s own history, is held distinct and in stasis. As will be discussed in the interview chapters, the separation and stasis of self that abstraction requires to manage diabetes is the stumbling point for many people I interviewed. The implied movement in the journey to control diabetes is therefore separate from body/self transformations. Movement through time is composed of uniform acts, one following the other, “all geared towards an unreflective activity of self-preservation” (Agnes Heller 1984 in Gardiner 2000: 137).

The next education program I attended was the Diabetes Expo in Seattle (and Portland), a one-day diabetes event, which brought together commercial, academic, and clinical interests. Events like the Expo are both a product of the growing diabetes epidemic and designed to promote products for the patient/consumer living with diabetes.

6.7 Diabetes Expo, Seattle Convention Center

4/13/2013. A nurse I talked to once referred to the overwhelming number of products available to “help” people with T2DM and the profits they generated as the “diabetes industrial complex,” and entering the Diabetes Expo in the huge main hall of the Seattle Convention Center
seemed like entering the heart of it. The Expo was a plethora of gadgets, services, facts, and especially optimism related to all things diabetes. About 70 vendors of all types and sizes lined the isles: WalMart, Rite-Aid, glucometer companies, insulin devices, insulin pumps, many pharmaceutical companies, food products designed just for diabetics, diabetic shoes, eye care, acupuncture, anti-oxidants, dental health products, exercise equipment, “kidney health,” and even home remodeling services. By noon, hundreds of people were talking and walking through the rows of booths. The atmosphere was very much like an upbeat infomercial rather than clinical “disease management.” No aspect or perspective of living with diabetes was left unpackaged or not-for-sale. The message upon entering the hall was clear: there is no possible way you cannot be healthy with all these products available for you!

By far, the busiest space in the Convention Center was the large Bartell’s Drug area. About 40 pharmacists and pharmacy students from the University of Washington School of Pharmacy were available to check glycosylated hemoglobin (A1C) levels (a blood test that measures a three-month blood glucose average), blood glucose levels, weight, cholesterol, and blood pressures. About 50 people waited in line to enter the area, and perhaps another 30 people were already going from station to station for each test. Admission to the Expo was free, and the people waiting patiently in line would get free lab work, along with free glucose meter strips. Despite the snail-pace, no one left the line; the free lab work seemed to be the big draw of the Expo. A 50-ish looking woman waiting told me she and her sister made the trip downtown by bus together: both had T2DM and had been financially unable to buy glucose meter strips for a while. They had seen the advertisements for the Expo and the chance for free testing and strips,
which they both needed. She and her sister used the free blood pressure checking machines at their local Walgreens to monitor that, but blood sugar testing was less easy to access, so they paid close attention to free public events. She had a big bag from the Expo filled already, and was hoping she could get her eyes examined there as well.

In the larger demonstration areas, there were chairs set out for an audience and back-to-back lectures on what made a particular food healthy, what types of foods were not going to shoot blood glucose levels up, how to exercise, and what needed to be done to “keep numbers low.” As I walked around, the consistent message encouraged us to be open to a “new start.” Posters of smiling people offered messages encouraging us to embrace a positive, forward-looking attitude, to learn new skills and cultivate an attitude of self-help; “just start” by making small changes. But this message comes with a caveat: “Starting” is dependent on individual choice and strength of will. “The tools are all here! It just takes your decision and effort for the doing.” Not everyone was buying into the optimism on display. I overheard a brief conversation between a 60-ish male attendee and a much younger female nutritionist: “What I want to know,” he said, “is how do I get rid of diabetes?” The man laughed, but it’s not really a joke. “Well, I wish I could change your genetic make-up!” she answered back. A poster at the booth stated, “Diabetes runs in families. Know your risk so you can prevent it. Take the test.” Diabetes is a state one’s body enters into silently and unknowingly, a physiological misstep that must be accepted and corrected through a new start of daily routines.

Since this was Seattle, no convention on a health issue would be complete without alternative medicine booths. Acupuncture, Naturopathy, Homeopathy and Reiki were some of
the therapies offered. Bastyr University, a naturopathic college in Seattle, had a big booth also. However, despite these alternative methods of treatment, what diabetes “is” was retained as a biomedical reality. In a conversation with a reflexology practitioner, she told me that she relies on blood glucose and A1C measurements to determine if she can realistically help people manage their diabetes. If the A1C was close to 9%, she felt that biomedicine and pharmaceutical treatment was a better option, “They’re too hard to manage” she tells me, meaning getting higher blood sugars down without drugs is difficult. As in the Journey for Control question asking participants to describe what diabetes is, the desired answer was in physiological terms. At the Abbott “Myths and Facts” booth, a “frequently asked questions” card read: “If I lose weight will my diabetes go away?” I asked the woman at the booth what the answer was and she tells me: “Because of damage to pancreatic beta-cells, by the time most people are diagnosed and the degree of insulin resistance over time, diabetes is for life.” Diabetes is a process of unnoticed biological changes at first. It will “progress,” as an unstoppable process, as attendees to the Expo were continually reminded, and can only be slowed or stalled through conscious effort; diabetes begins long before we are aware of it. In a few years, however, will this “fact” be thought of as myth? As both testing and the diabetes epidemic become more common, how will this fact change along with what “diabetes” becomes? This aspect of what diabetes “is,” is put aside in the same way that changing facts surrounding diabetes are put aside in the APhA training program for pharmacists. Viewing diabetes as an ongoing practice in which it is both product and producer, however, challenges its locus as a stable and abstract verity.
Uniform biological facts connect to uniform and impersonal self-care practices, and through these ideal behaviors, to a predictable future. The great variability in the course of diabetes between people (discussed in later chapters) was replaced with a uniform disease state and equal opportunity management: “Join the movement to Stop Diabetes and learn how to live healthy, be active and change the future of diabetes.” How does a person gain autonomy in the face of genetic predisposition? How is it possible to “Stop diabetes?” The optimism of self-management is hard to resist with upbeat talks like, “Eat better, Move more, Feel Great!” At an exercise lecture, the speaker told listeners, “From a scientific point of view or if I was talking to MDs in the audience, we would talk about all the complex processes that make up diabetes. But what I can say to you is much more simple. Walking can delay diabetes…” The “25 minute walk” was printed on many posters and pamphlets throughout the convention center as the amount of walking and time needed everyday to prevent those “at risk” from developing T2DM. While the causes of diabetes are difficult and obscure, with simple, daily actions, symptoms can be prevented. Pharmaceuticals of many types and from all the major companies were there to step in and offer help also, ready to take the place of these routine daily practices. At the “Actos for Prevention” booth, I overheard an exchange between two slightly over-weight, middle-aged men, a sales rep and an attendee: “I’m sure you would rather be walking 25 minutes than taking a pill,” and they both started laughing. Because diabetes is a uniform and discrete entity, both walking and pill taking are exchangeable behaviors that educated patient/consumers can choose between. The uniformity of diabetes on a global scale allows choices and attitudes towards its management to be interchangeable as well. The payoff promised through uniform self-treatment
is the avoidance of serious complications. Diabetes treatment becomes an imposition of consumer choice in daily life that has previously never existed before. While patient/consumers are expected to be active and autonomous participants to manage diabetes, the partnership is defined within the parameters of scientific abstraction and linear temporality.

Everyone manning the booths was glad to talk, and intense conversations about food products, injection devices, glucose monitoring, and glycemic indexes went on as I walked down the isles. I was struck at the contrast of this openness and encouragement for conversation, compared to the “efficiency” and rush of a clinic or pharmacy. Even Rite-Aid, the third-largest pharmacy chain in the United States, showed a different personality at the Expo: “Wellness by Rite-Aid, your complete guide to our wellness store experience. Introducing Wellness by Rite-Aid. When it comes to maintaining and improving your health it helps to have somewhere to turn. That’s why we’ve transformed your Rite-Aid into a destination of wellness. It’s the same pharmacists you trust. And the same great services. Just a lot more of them.” The upbeat services offered struck a receptive chord in the attendees, and it seemed that at least for the duration of the Expo, what was being sold had many buyers.

I told a young Latino man standing in the Bartell’s line with his daughter about my own study. He was impatient with its emphasis on self-reflection: “You just have to face it, accept it and move on. I’ve got too much at stake because of my daughter.” But he also said that he was newly diagnosed and had many family members with diabetes, and perhaps that is where his impatience came from. He told me that an uncle was moving up from Mexico because he wasn’t taking good care of himself: “He needs the family’s support.”
6.8 Concluding remarks

The Affordable Care Act (ACA) went into effect seven months after the Expo was held. Washington State currently provides expanded Medicaid, so many of the people standing in line waiting to get lab results may no longer have the same impetus to make a trip to downtown Seattle for free testing. However, the plethora of services and products at the Expo reflects just a small part of the global arena of self-care services. The commercial opportunity of the diabetes industry is estimated to be in the hundreds of billions of dollars worldwide, much of it through the provision of new technologically-based services that fit within the ever-forward-looking discourse of progress and development (Accenture.com 2015; Alazraki 2011; Price Waterhouse Cooper (pcw.com) 2015; researchpartnership.com 2014;). The wide array of services provided at the Diabetes Expo fills the gap between clinic and home as these two spaces merge and create new commercial markets. Both clinicians and patients, as partners in this emerging commercial space, share in similar decision-making using the same medical facts. To be successfully applied, whether one is a patient or a pharmacist, decision-making must be practiced, starting with small goals and always updated with new facts and new technology. New scientific information about T2DM is continually produced as new drugs and human physiology dynamically transform one another. In turn, these changing scientific conceptions of T2DM result in new types and schedules of medical monitoring. For both medical clinicians and patients, actively pursuing and learning new facts is a shared responsibility to manage a physiologic body. The patient education techniques taught fit with broader American discourses (and Tacoma’s resettlement) of mastering nature, and progress and development (Kwinter 1996), but are incomplete in daily life.
Lived experience and how a person views their own history changes over time, sometimes conflicting and sometimes motivating change.

The remarks of the young man quoted above illustrate the fluidity of responsibility and how it takes shape for oneself and others over time. Different temporal perspectives, including the ahistorical structure of biomedical abstraction, were pulled together in his short conversation: his past experiences watching relatives deal (or not) with T2DM, thinking of the future and his relationship to his daughter and the implied decision to be different, his present mastery of self-monitoring skills based on bodily objectification and linear time, and the support an older relative needs to (hopefully) learn new skills. The questions I will be examining further through interviews of people living with T2DM explore the view that control of diabetes is different from care of the self. The former views problem solving as constituted through an abstracted body that allows decision making to seem independent of lived experience; the latter is a different process that emerges in relation to control but enables a real transformation of self. This proposition seems unconfirmed by the diabetes education programs presented here. Certainly, these programs help people learn positive skills that improve their lives. On the other hand, care of the self is transformation of the self, a de-alienation of creativity and daily routine that is unique to each individual.

In the next chapter, I turn to the ways spatial forms, particularly scientifically abstracted bodies, shape the self-care practices of people living with diabetes. These life histories are used to understand how participants write their own biographies of living with diabetes, as they must learn to objectify their bodies in new ways. Measurement and monitoring are necessary practices
to make diabetes visible as Guell (2012) states, and to control the symptoms of high blood glucose levels. From a biomedical perspective, which is what this dissertation focuses on, diabetes is understood through measurement. And, as illustrated by the comments of the reflexology practitioner at the Diabetes Expo, understanding blood glucose also shapes American alternative medicine practices. How people come to terms with this crucial step of self-abstraction is the connecting thread of the following chapters. As discussed in the Methods chapter, I have used diabetes life-story narratives as my main source of ethnographic data to get at a specific aspect of self-care practices, how people integrate measurement and monitoring into daily routines *over time*. Through these narratives, a person’s reasoning, in context with life events deepens anthropological understandings of the lived experience of diabetes and furthers the scope of ethnographic data collection.
Chapter 7: General Description of Interviews

In the next three chapters, I examine the lived experience of T2DM through life story interviews. These stories are distinct but never separate from the skills, decision-making, and linear temporality taught in the health services I discussed in the previous chapters. I use life histories of T2DM to illustrate how these dominant social forms are integrated (or not) into an individual’s daily life-practices. The necessity of measuring BG levels to control the symptoms of diabetes reflects the slow integration of scientific abstraction and subjectivity into the web of everyday self-care practices of people living with T2DM. Key to understanding the lived experience of diabetes is its connection to 19th century spatial rearrangements that enabled global processes of progress and development, as they uprooted and made mobile all “things,” clearing away obstacles to uniformity and exchangeability (Aglietta 1979; Crary 1990; Roberts 2006) and continue to shape everyday life. In this project, 19th century spatial transformations and the experiences of people living with T2DM are not held as unrelated events with two separate histories. Instead, I have tried to hold these transformations as different aspects in a shared global process, the inward movement progress and development. I have used the life stories of Tacoma residents living with T2DM to connect the exterior space of industrial Tacoma and the interior biological space of T2DM. Rick, whose story appeared earlier, is representative of the rapidly disappearing manufacturing and working class that once dominated Tacoma. No longer employed by Louisiana Pacific, Rick is now part of a chronic disease consumer class that supports the healthcare industry in Tacoma.

Throughout the next three chapters, I describe the ways measurement and embodied
experiences are integrated into daily practices, as people learn to make sense of T2DM. As both product and producer of everyday life, T2DM is a convergence of social forces expressed through human bodies. Following the work of Lefebvre, understanding how bodies are theorized provides a means of identifying the spatial and temporal structures that constitute everyday life. Bodies, in particular, exist as a form of social space, composed of constantly reciprocating elements and are prone to constant changes and realignments (Lefebvre 1992). The integration of measurement and monitoring to control diabetes is one such realignment. For many of the people I talked to, however, the degree of measurement and monitoring and subsequent self-discipline required to control diabetes was a struggle. The reality of this struggle is seen in the epidemiological data that has been collected over the past two to three decades. Complications from T2DM remain one of the highest health care expenditures in the United States with roughly $72 billion spent on hospital inpatient care of T2DM in 2012 (American Diabetes Asso. (ADA) 2013). The high rate of complications due to T2DM are expensive, and as evidenced from a number of the interviews I collected, traumatic for the people living with them.

However, the estrangement between body and self that many people experience as they begin to make sense of T2DM is not a permanent state of being. The self-objectification of one’s body produced through measurement and monitoring shifts over time, from employing practices that control diabetes to creating practices of self-care. I describe the variety of ways this can occur and the long time it takes for many people to comprehend this shift. The bigger issue that emerges from the stories told in this chapter is that real control of diabetes, created by practices that are sustained over decades, are at odds with the needs of the global health services industry
described in the previous chapters. In addition, uniform, mechanistic practices that are external to personal history and meaning (and therefore to transformation of self) in the long term do not control diabetes. As people learn to make sense of T2DM through their own histories and self-understanding, the human body also becomes a site of resistance. As discussed in the third chapter of interviews, people use rational decision-making, measurement, and monitoring but move beyond these self-objectifying practices through contemplation and self-analysis. Self-care emerges as people create meaning and place their own value on health.

In total I interviewed 58 people: 37 women and 21 men from two primary care clinics, one a volunteer clinic and the other a federally funded Community Health Clinic (CHC). Although it was easier to recruit people from the volunteer clinic, as I discussed in the methods section, the total number of interviews reflects a fairly even split of people between the two clinics. I have discussed recruitment in the methods section, and addressed bias in selecting the people I did interview. Ages of interviewees ranged from 34 to 72 years, with half of people between 50-60 years old. Although I wanted to only interview people who had been living with T2DM for at least five years, I did end up interviewing two people who had been aware of diabetes for a shorter time period. The youngest ages of diagnosis with diabetes were 27 and 30 (one woman also had gestational diabetes). The average age of diagnosis was 49 years, and the average time living with diabetes was 8.74 years.

Of the 58 interviewees, 42 were Anglo-American, ten were African-American, four were Latino, one was Samoan-American, and one was Micronesian. This population breakdown reflects the population of the clinics I recruited from, and not necessarily the population of
Tacoma. East Tacoma has growing Cambodian, Vietnamese, and Ukrainian communities, but the people I interviewed (except for the woman from Micronesia), had all been born in or living in the United States for decades. South Tacoma and Lakewood, areas with large working class neighborhoods and close to the clinics I recruited from, made up the majority of addresses of the people I interviewed. Except for two people, everyone considered the United States home. For one man from Mexico, the cartel violence in his home-village prevented him from retiring there, and the woman from Micronesia planned on returning home “eventually.” Except for three additional people-- one woman returning to live in California and two men who had recently moved to Tacoma—the interviewees considered the Pacific Northwest a permanent home.

Although almost everyone I interviewed considered the Northwest their home; proportionately, more African American interviewees were first-generation residents of the area. Only two of the African-American and none of the Latino interviewees had been born in Washington State; all had moved to Tacoma due to military or civilian jobs or to join family members already living there. African-American interviewees came from the South (Mississippi and Alabama) and East/Midwest (Illinois, Maryland, and Missouri). Only two African-American women grew up in Tacoma. Of the Anglo-American interviewees, all except for five had spent the majority of their lives on the West coast: California, Oregon and Washington state. Three had moved quite a bit either because they were in the military or grew up in military families (Joint Base Lewis-McCord borders Tacoma to the south).

Tacoma was home, but it seemed to provide a neutral backdrop to work and family rather than playing a significant role in how people described themselves or their lives. There was little
mention of Tacoma’s history or of being involved in local politics or civic organizations. People who grew up outside of the West, however, talked about the importance of place and how that shaped upbringing and views of T2DM. More than belonging to a place, work in logging, lumber processing, or being connected to the military described a characteristic of connecting one to the area in a distinct way. Regional belonging did not seem to be a significant factor in how people viewed themselves or T2DM.

While I did not ask people directly about income, money was a major source of stress or concern for everyone with whom I talked. People who had a steady source of income at the time of the interview also told me about periods of extreme poverty, some experiencing homelessness. Likewise, people who were presently in unstable living conditions had also experienced many years of employment and financial stability. Work and diabetes had intertwining roles in how people both ignored their health and paid attention to it in order to keep working. Not having medical insurance was the primary qualification for care at the volunteer clinic and lack of money was a much bigger source of stress for people recruited from that clinic. In contrast, the CHC clinic operated on a sliding scale, and people with no insurance could be seen for $30 per visit. However, lab tests and medication costs quickly added up, forcing people to closely strategize how they would manage to pay for medical care.

A vicious cycle emerged when medical care was deferred or diabetes was ignored due to financial stress: symptoms and/or numbers would worsen, requiring more medication and medical visits precisely at a time they could not be paid for. As In the next chapter, I discuss in greater detail people ignoring T2DM because of its interference with work commitments due to
the amount of self-monitoring and discipline it required turning into a double bind. When symptoms became too uncomfortable or serious to ignore, the amount of self-discipline, monitoring, and measuring needed to manage blood sugar levels became even more time-consuming and restrictive.

Categorization of income did not correspond to social stability. For example, a few people with limited income but with access to social capital were able to live quite comfortably by moving in with and taking care of family members. Others with more substantial income were financially stretched as they tried to maintain mortgage payments and/or car payments for items purchased during a financially better past. Three people I interviewed were homeless. One of them did the interview for gas money to return to her camping spot, another to help pay for expenses to drive back to California, and the third was living in emergency housing. In the methodology section, I described recruitment for this project and the possible bias that the $30 gift card posed. The type of gift cards I gave to people reflected the practical and strategic spending they also described in interviews. Wal-Mart was by far the most popular card, followed by Target and Grocery Outlet - a local discount chain - and finally Walgreens, for prescriptions. In other words, the $30 extra went for practical purchases.

7.1 Work and patterns of social connection

Most striking in all of the interviews was the close connection between personal autonomy, continuity of daily life, and the ability to work. Being able to prioritize self-care over work for the first time was a life-changing transformation for many people as they began to care for themselves, although for many, this re-prioritizing happened after losing work. Work
structured the lives of everyone I interviewed, even if they didn’t work but rather depended on spousal support. The need to work became a catch-22, as work also facilitated the marginalization of self-care or destructive self-care practices to alleviate boredom or loneliness when not working.

The work in which people engaged reflects Tacoma’s “resettlement” (Harris 1997) in the 19th century. Farming and attachment to land was never a large part of Tacoma’s history as a new industrial and shipping center. Controlling land in Tacoma meant exploiting resources and transforming landscapes for manufacturing. The need for skilled labor for manufacturing created the worker of the Northwest and Tacoma: a hard-working, upwardly mobile individual. This type of worker in the mid-19th century was certainly gendered, and men derived greater income and therefore greater autonomy and social stability. But as many stories from the single women I interviewed show, one’s ability to work to maintain personal autonomy cut across gender in 21st century Tacoma. I discuss gender in more detail below and in the interviews, but in general women were much more financially dependent on men: married women reported being supported by their husbands while no men reported being supported by their wives. Many single women who were responsible for themselves financially at the time of the interview had been married in the past and had been financially dependent on their husbands.

There was little economic buffer for most of the people I interviewed; having enough money to cover expenses was an overriding daily concern. Not having work, the need to work, and looking for work were all sources of incredible frustration and stress. The older, single, unemployed or under-employed adults told me that age was a factor in their lack of ability to
find work. There were many ways work took precedence over or interfered with sustaining self-care practices: working two part-time jobs, studying and working at the same time, or getting by on one job that did not provide medical insurance. Some people could not find work that they were trained to do and took a job they felt demeaned them to get by. Commuting long distances to keep working added sedentary hours to each workday. For two younger women with dependent children, childcare and work made learning to count carbs a task for which one woman just did not have any patience: “It’s tedious. It’s so time consuming it annoys me. I just want to eat.”

The types of work people mentioned varied, but for the most part, women worked in service sector jobs ranging from Starbucks barista, cashier, librarian, office manager, child and adult caregiver, apartment manager, medical transcriptionist, and book-keeper. One woman had been the head of environmental services at the largest hospital in Tacoma and had more job responsibility than any of the other women interviewed. She lost her job due to a combination of economics and health; the hospital hired a contracting service to manage housekeeping and her symptoms from diabetes had become disabling. She narrowly escaped homelessness by qualifying for SSDI, which I discuss below.

Men generally worked at jobs outside of the service sector: construction/carpentry, metal salvage, IT maintenance, general contracting, manufacturing and apartment maintenance. Two men had owned their own photography business. More men than women had owned a small business, and more women than men had depended on their partner’s income while working at home. I did not specifically ask about education, but only one person interviewed mentioned
wanting to attend graduate school. Because I did not specifically ask about education, it is difficult to give exact numbers regarding high school completion. Thirteen people did mention trying to complete Bachelor degrees while working and the difficulty posed by working and studying. Two men were starting job retraining as part of receiving Washington State workman’s compensation.

Both men and women expressed frustration at the difficulty of not fulfilling one’s ambitions, especially at not being hired for work they felt they were qualified to perform. Older interviewees frequently mentioned age discrimination. In three interviews (two women and one man), all with younger people (34-42 years old), there was a connection made between the self-discipline needed to control diabetes and life ambitions to finish school or find work that was challenging and satisfying. One woman, 42 years old and diagnosed at the youngest age and with two children (one just starting college), expressed regret at not controlling diabetes symptoms because she realized her present physical conditions severely limited her life physically and limited any ambitions of completing her education and working full-time.

Patterns did emerge that correlated control of T2DM to gender, as I also discuss below. Work provided men with greater sense of identity more frequently than for women. The loss of work was a barrier to developing practices of self-care, as described in Rick’s story. Women struggled to maintain financial and social stability after losing jobs, but the loss of work did not seem to have the same impact on their sense of self. However, single women had a much harder time dealing with T2DM and coming to terms with the self-discipline required to manage it than men, as I discuss below. Controlling T2DM is a much heavier burden for women.
Throughout all of the interviews, the greatest variable was how symptoms of T2DM presented. Some people felt no symptoms for years despite having very high blood glucose levels. Other people ended up in an ER with severe symptoms, such as coma, with the same glucose levels. The course of diabetes over time also varied considerably. One person was able to control her blood sugar levels for decades with diet alone, but other people ended up on insulin quite quickly. These wide variations reflect the many unknowns of the physiologic processes of diabetes, not just the ways individuals managed (or did not manage) symptoms and blood sugar levels. I include the interview of one woman who ended up on insulin quite quickly after being diagnosed and after oral medications did nothing to lower her blood sugar levels. It is possible that she had diabetes for many years without realizing it, but it is also possible that her pancreas stopped producing insulin quite rapidly.

7.2 The course of diabetes

The wide variations in symptoms, the course of diabetes, and the need for insulin or the ability to stay off insulin played a big role in how people thought about and dealt with diabetes and how they saw their future. For some people, losing enough weight to get off of insulin, as I describe, was a realistic goal. For other people, insulin was a daily necessity. One woman who had a very difficult time managing blood sugar levels even on insulin was very frustrated with how much more difficult dealing with diabetes was for her compared to her brother and mother: “They just pop a pill everyday!” Not only did she hate injecting herself, insulin was too expensive on her limited budget. This variability seemed to increase the sense of diabetes as not
really knowable or completely controllable. How medication, exercise, and diet affected one’s own body was something that could only be learned through practice, over time.

These variations in the course of diabetes also affected family dynamics. Laura, whose story appears in the next chapter, describes the frustration other family members have with her eating junk food, smoking, and skipping medications. Laura told me about her older sister who also had T2DM and had lost over 100 pounds over the past three years, a feat she described as being impossible for her to achieve. In another interview, Luis describes how diabetes has ravaged his family: both parents and a brother have died from complications, and two sisters are facing severe disabilities, including one sister on dialysis. Luis and other people I talked to who watched as family members died or faced severe complications had difficulty in understanding why their practices of self-care were so different from people they were so close to. Luis felt an older sister, who was Pentecostal Christian, placed far too much trust in God to take care of her and not enough in her own abilities to manage her body. While Luis was not able to articulate why he was different from other family members, he also described big changes in his past, such as quitting smoking and binge-drinking that point to a life-long ability to assess and implement change.

Through the variety of experiences from interview data, I try to show the sometimes long and complicated processes people must go through to come to terms with taking care of themselves in sustainable ways. The simplified process taught in diabetes education programs - that self-care consists of making rational decisions based on understanding medical facts - hides a much more complicated reality faced by many people interviewed. Although everyone I
interviewed, except for one person (discussed later), understood the need to lower BG levels, the priority this played in daily life varied greatly. Many of the people with poorly controlled diabetes expressed the wish that their body would somehow correct itself, reversing in the same unknown way the process that had caused diabetes. For them, managing diabetes meant managing daily life, and that was not always possible.

7.3 Race/ethnicity/geography

Compared to work and money, race and ethnicity played less obvious roles in how people constructed self-care practices. No overt patterns emerged correlating race/ethnicity to control of diabetes due to the small sample size; however, there were differences in the life events people experienced, such as the geographic origins of people interviewed. Older, African American interviewees mentioned that seeing a doctor on a routine basis was just not something anyone did in the Southern communities in which they grew up. African American interviewees who grew up in the rural South also mentioned older family members discussing how much diet had changed to more processed food, such as being able to buy processed sugar instead of eating raw sugar cane, in their lifetime. These comments were made in passing, to explain to me how different living with diabetes is now from in the past. They also reflect greater personal breaks with the past, compared with Anglo American interviewees, and a different understanding of diabetes arising from lived experience. Diabetes reflects their awareness of how life has changed over the past few generations; more than a biological condition, diabetes also has a social history. As we will see in the interviews, these perceptions of diabetes and lived experiences are tightly integrated into how people deal with their condition. Race, along with gender and marital
or relationship status, all played integral roles in how people were or were not able to control diabetes.

### 7.4 Marriage and gender

Thirty-one people interviewed were single and 27 were married. Ten of the 27 married interviewees were men (21 men in total were interviewed) and 19 of the 31 single interviewees were women (37 women in total were interviewed). Roughly half of both men and women were married. Of the single interviewees, some mentioned partners, but they did not live together full-time. The following table shows the distribution of married and single interviewees into the three categories of control I used: 1) people who are just beginning to deal with T2DM; 2) people who cycled back and forth controlling T2DM; 3) people who sustained control of diabetes (I discuss these categories in greater detail below). Within the first category were people who had put off dealing with T2DM for at least the past five years (five years was the minimum time an individual needed to have had diabetes to qualify for an interview). There are a greater number of women and unmarried individuals in this category, reflecting their struggle to come to terms with diabetes. The life-story interviews show the variety of ways individuals learn (or not) to take responsibility for self-care. Being single and female is a heavier burden in the process of taking responsibility for self-care and dealing with T2DM. As I will discuss further in the three groups of control, race also is a factor in people’s ability to control diabetes.
I assumed gender would reveal some distinct patterns in the quality of self-care between men and women. However, issues related to gender were not obvious in interviews in the way work and money were discussed. From the numbers above, gender and marriage played a significant role in which category of diabetes control people were placed. More striking than gender alone is the difference between single and married interviewees. In the tables, men are overly represented in the “controlled” group, particularly married men, and women are overly represented in the single “Just Beginning” category. The numbers in this study are too small and the categorizing too inexact to come to a conclusive analysis, but men appear to have an advantage in controlling diabetes that I think reflects a greater control in all aspects of life in general. Five women mentioned being in past abusive relationships or being abused as a child; none of the men talked about abuse. Both men and women discussed family dynamics that affected caregiving, such as struggling to overcome discord with their parents, siblings, and children. However, the overall dynamics that distinguished men and women seemed to be the more dependent roles women played, as wives (financially), past histories of abuse, and caregiving to others (not themselves).
Both men and women who had children talked about caregiving responsibility, however, women who were divorced or single with children had both financial and day-to-day caregiving responsibilities. Like work, which could both motivate self-care and become a barrier, caregiving also had this dual effect. Men talked about the responsibility for caregiving as providing financial support, as reflected in Rick’s story, but men also described being the primary caregiver of an infirm parent. Because of the age of the people interviewed, most had grown children and many mentioned grandchildren. For the majority of men and women with children, responsibilities to support and care for children played dual (and sometimes conflicting) roles: the need to be fit for work to financially support them, and also as a motivator to remain healthy to care for them.

7.5 The safety net of SSDI

The financial security that Supplemental Security Disability Insurance (SSDI) payments provided interviewees cannot be overstated. SSDI has been the subject of recent investigative news programs as an abused form of “welfare” payments. *60 Minutes* ran a show in 2013 called “Disability USA” (*60 Minutes* 10/14/13) and *This American Life* on NPR also ran a program titled “Trends With Benefits” (*This American Life* 3/22/13) the same year. NPR reported on disability payments in Hale County, Alabama, where one in four people receive disability. The people awarded benefits are lacking education and job skills. The one general practitioner in Hale County asks people “What grade did you finish?” as part of his determination of SSDI eligibility. However, the program also questioned how benefits for SSDI are awarded and why enrollment has increased dramatically in the past decade. The report tries to uncover the
difficulty of determining what disability really means, but also implies that people are actively choosing to be disabled over working.

However, statistics from the 2010 census show that nearly 20 percent of the U.S. population reported having a disability (census.gov 2012). I mention this controversy, because SSDI for a number of people interviewed was the difference between literally ending up on the streets and having a stable, if financially limited, life. The NPR reporter dismissed how debilitating the symptoms of diabetes can be, stating that: “My editor has a herniated disc and works harder than anyone I know. There must be millions of people with asthma and diabetes who go to work everyday” (NPR 3/22/13). For the interviewees with limited social capital, rather than abusing SSDI, it provided a last-ditch safety net.

Unemployment, deindustrialization, and the rising incidence of T2DM all converge into SSDI statistics. These factors also provide an American context for what Foucault described as “technologies of the self” as “an attitude, a mode of behavior; it became instilled in ways of living; it evolved into procedures, practices and formulas people reflected on, developed, perfected, and taught” (Foucault 1986:45). Foucault identifies the historical ethos of self-care that SSDI statistics alone can’t explain. In the interviews I conducted, SSDI benefits were the result of an ethos of care of the self that was devoted to work. Diabetes is as much a product of the American ethos of maintaining individual autonomy through work, as the complications from it were a threat to maintaining a safe, stable, and livable life.

Controlling T2DM meant taking responsibility for the future and maintaining one’s ability to work. One woman told me of her irritation at being labeled irresponsible when she
could not afford medication: “They [medical clinicians] need to lose their $100,000 a year job and see what they’d do. They need to see this. And they won’t.” Another woman, who had been rather matter-of-fact relating a ten-year history of little to no medical care, quite unexpectedly broke into tears when she described getting medical treatment through the volunteer clinic. For almost eight years she had an office managerial job with no medical insurance. Two years before the interview, she was fired after a dispute with her boss. The emotion she unexpectedly expressed reflected the stress and frustration many felt as they saw their health and ability to work rapidly decline.

The very existence of the volunteer clinic provided a validation of the need not just for medical care, but also for social stability that afforded access to treatment and medication. The clinic was a public statement - an acknowledgement of how easy it was to become disabled and to lose autonomy. Not having the means to be responsible for one’s self care was a source of stress and frustration for many people, augmenting a sense of isolation and separation from past working lives.

Facing the future was an almost unbearable stress for many people. In a separate chapter I describe how trusting in God to provide for the future was a marker of belief for a number of interviewees that created much needed stability in the face of so much uncertainty.

7.6 Complimentary Alternative Medicine (CAM) and digital data trackers

Seattle and its suburbs to the north are home to Microsoft and a thriving IT industry. Tacoma, 30 miles to the south, is much different landscape. The lack of IT start-ups or Google and Amazon employees (at least this was the case in 2013-2014) and the absence of any financial
industry, destination downtown shopping, or world-class health research industry make Tacoma somewhat unremarkable in comparison to Seattle (a city competition that Tacoma conceded decades ago). Seattle is also home to Bastyr University, a nationally known naturopathic college, numerous CAM clinics, natural food stores and organic, locally sourced food. While CAM and sources for organic food exist in Tacoma, like everything else in comparison to Seattle, it is on a much smaller scale. However, I was still surprised to find in discussions of self-care an almost complete absence of the use of digital technology beyond the need to check BG levels, and an equal lack of use of CAM to treat diabetes.

People frequently described using the Internet to get information about diabetes. This was considered a responsibility for self-care, but the use of digital devices, or “self-hacking,” was absent from all but one of the interviews. The one man who digitally tracked his BG was on one oral diabetic medication and had consistently low BG levels. He also liked gadgets; he was a photographer and described tracking his numbers as a type of competition. Being “in control” was important to many people interviewed, but using digital technology to obtain or maintain control was not mentioned. In fact, technological management of one’s body was not mentioned as a marker of medical progress or a signifier of control. The one interview describing use of gastric bypass surgery to lose weight along with an insulin pump (in the next chapter) demonstrated a way to escape self-monitoring rather than to engage with it more. This person also had medical insurance and income to afford this treatment before losing his job.

Certainly, some of this had to do with economics and also with the type of social and cultural capital familiar to the people I interviewed. The ethos of “self-hacking” and belief that
self-mastery and self-improvement could be obtained through data collection did not form a substantial part of self-care practices in any of the interviews. This lack of interest in the power of numbers and data collection contrasted with the Quantified Self meetings I attended in Seattle. There, data collection was used to improve the performance of all types of daily tasks (or give the illusion of improvement) and to make oneself more competitive and successful. That type of ambition was absent from all of the life stories I collected.

Self-management and self-improvement were tremendously important, but people interviewed did not seem to buy into the belief that technology itself enabled self-mastery. The one exception was technology in the form of pharmaceuticals, which played a large role in how T2DM was controlled (or not). Pharmaceuticals filled in to accomplish what could not be achieved through self-care practices and discipline, or because of the severity of diabetes. Medication choices, the need to use insulin, and the desire to get off medications all played significant roles in how people disciplined themselves and how they envisioned their futures. When I asked people if they wanted to get off medications, only a few stated this was not a goal. However, the reasons people gave and the methods employed to discontinue medications varied greatly.

Three women with T2DM that required insulin saw it as a necessity, something their bodies needed to function. Oral medications did not lower their BG levels. One of these women had Polycystic Ovarian Syndrome, which made her highly insulin resistant and required high doses of insulin. For many people, taking diabetic medications was a constant reminder that something was wrong and that they needed to make changes in their life. Not taking medications
meant that they, their lives, and their bodies were “normal.” Diabetes was something they would deal with in the future. For others with a greater ability to control symptoms, medication use was seen as a temporary state. As one man told me, “I hate taking pills. I have to do this, that’s the worse thing about diabetes. I hate the idea I need to take medication. You know, it sounds to me, in my mind there’s a dependency there, um, when it’s like ‘No, I can fix this.’” The man who told me this said he eventually stopped taking medications for about a year, “And that’s how it was, that’s why I did it [stopped taking medication]. And I didn’t see a big change in my numbers, so why should I take medication?” He was back on diabetes medication when I met him at the volunteer clinic, after his numbers started to creep back up. For this man and many people I interviewed, medications were discussed as a temporary fix, a necessity as they worked to lose weight and get BG levels lower through daily practices. This goal seemed more realistic for some compared to others, but I had no way of really making an assessment. Their motivation to get off medication was certainly genuine and served as a goal for self-discipline.

Medication use, then, fit within larger strategies of self-care. Rather than an acceptance or rejection of medical advice, people spent much time in assessing the need for medication, what medication use meant about their bodies and daily activities, past experiences dealing with diabetes and how they determined the course of their condition. Medication use, like medical advice, was just one part of an individual’s practice that was continually evaluated over time. In the next section of this chapter I describe three general patterns of practice and understanding of T2DM identified from the interviews, and describe how these correlate to degrees of control.
7.7 Patterns of control

I have identified three junctures of dealing with T2DM that emerged from analysis of the interviews and were not decided on before-hand. They are not necessarily progressive states, but form distinct patterns of practice. It is the intensity (or lack of) of their presence that structures how well people controlled diabetes. This approach loosely follows the work of Adele Clarke in _Situational Analysis_ (2005), to identify patterns and to examine situations as a whole, rather than looking for isolable variables or cause and effect linearities. The three most important patterns of practice are:

1) making sense of symptoms through blood glucose measurement;
2) self-monitoring and discipline; and
3) contemplation and care of the self.

These patterns of practice correspond (loosely) to three general categories of diabetes control:

1) people who are just beginning to deal with T2DM;
2) people who have cycled back and forth controlling T2DM many times due to loss of employment, such as Rick (Introduction) who lost his job after and;
3) people who are stable in controlling diabetes.

As discussed in the methodology section, I grouped people by their self-reported BG levels and A1c, symptoms, number of years living with diabetes, and length of time controlling diabetes.

Making sense of one’s body through measurement: The first pattern to be discussed is learning to connect BG measurement with the physical symptoms of diabetes: the shakiness and cold-sweats of too low of a blood glucose level or the nausea, fatigue, thirst, and irritability that
come from too high levels. While people may understand what BG levels represent, paying attention to these levels, how food affects them, and how one feels when BG levels are high or low takes time to learn. For example, one woman told me it took years for her to really understand what the peaks and troughs of her insulin doses meant and how those levels determined what her blood sugar levels were doing. Making the connection between measurements and experience only comes about through effort and trial and error by each individual to stick themselves and measure levels using glucose monitors.

One reason it can be difficult to understand the relationship medication use, activities, and BG levels is that the three are in constant adjustment with the others. The effect of each dose of diabetes medication can be altered, sometimes quite dramatically, within a short period of time by daily activities like exercise or calorie intake. As will be discussed in the interviews, the liability of BG levels increases as T2DM is less controlled, a pattern that people noted and used to understand how their condition was improving or worsening. With insulin in particular, being able to predict the degree BG levels will drop comes with experience. In Laura’s story in the first chapter, she is beginning to take an interest in the connection between the numbers and her body, 20 years after she was first diagnosed with T2DM. Laura’s curiosity to measure her BG levels before and after Easter dinner is an example of the connection between numbers and bodies that people must make to understand what they cannot see (high BG levels) and sometimes do not feel. Laura was not aware of a connection between high BG levels and her mood, but for many people I talked to, being easily irritated, impatient, and constantly fatigued meant high BG levels. As Margie describes in the third interview chapter, these symptoms were unexplainable,
overwhelming, and made her question the kind of person she thought she was. She had become someone constantly tired and unable to work the way she was accustomed to.

Like many people, Margie did not realize these feelings were not “who she was” but were the result of high BG levels. Once her numbers and BG levels dropped, she began to realize that feeling tired was connected to elevated BG levels and not a permanent state of being. It is not always obvious, especially when first learning about diabetes, what symptoms are due to what numbers. Numbers become a necessity to warn when BG levels really are high even though they don’t “feel” high. For someone with uncontrolled diabetes, BG levels may have been consistently high for years, and dropping to a “normal” range feels very uncomfortable; only by checking with a finger stick can someone tell what their symptoms really mean.

People claim to distinguish between highs and lows without actually checking with their monitors. However, this isn’t always accurate. A common issue is that people do not always feel high blood sugar levels. Because strips are expensive, most of the people interviewed had gone for long periods of not checking their BG levels. One woman told me she was “really surprised” after her first visit to VolunteerCare: “I thought I was controlling it better.” She found out her A1C had slowly crept up to 11, meaning that her average BG was around 300mg/dl every day instead of the 150mg/dl range she thought she maintained. Another woman told me that the slow, upward creeping of her blood sugar levels was like “being a frog in slowly boiling water.”

In the next few paragraphs, I discuss the second juncture of T2DM self-care practices: self-monitoring and discipline. In the same way that it is necessary for people to use measurement to explain their own body, self-discipline is also necessary to control symptom of
T2DM. Disciplinary power, described by Foucault in *The Birth of the Clinic* (1973) and *Discipline and Punish* (1977), is an inherent part of treatment and embodied experience of T2DM. Bernard’s correlation between BG levels and diabetes ushered in a way of conceiving bodies that made them manageable through measurement and disciplinary practices. Through their own histories, people described why and how self-care practices changed (or not) over time. These were stories were distinct but always connected to abstracted definitions of diabetes discussed in chapter five on education programs. Disciplinary power is inseparable from the particular knowledge and representations of bodies through which T2DM self-care practices are constructed.

Self-discipline: mastering habit and repetition: This second identified pattern of practice focuses on the discipline to restructure everyday activities to manage T2DM. For many people interviewed, practices that exacerbate T2DM were often the ones turned to for comfort, as a way to alleviate isolation, stress, boredom, or all three. Eating, especially junk food, to relieve stress was a common coping strategy. Unfortunately, as T2DM progresses, bodies are less able to regulate themselves and require greater self-discipline. T2DM is characterized (biomedically) as the body’s progressive loss of ability to maintain BG homeostasis. In turn, this means greater conscious effort and tighter control of eating, sleeping, and exercise from the very people less able to manage it in the first place. Everyday practices therefore become less spontaneous as the severity of T2DM increases.

Self-discipline is motivated by a wide variety of factors, ranging from the onset of severe symptoms, seeing the consequences of uncontrolled diabetes in family members, finding stability
in regimented self-care practices and from events outside of an individual’s control. These different scenarios form a significant part of the interviews I conducted and the following chapters. Sometimes discipline was imposed externally (though not always permanently) in a way that an individual may or may not have had any control in creating. Sometimes discipline developed over time through a variety of converging factors, such as finally finding the time to cook at home, work less (or not at all), or as one person told me, “stuck with living with the realities of all this [diabetes].” However, for some people in the stable control group, self-discipline did not really register as a struggle at all.

Contemplation, regaining control and improvisation: For people in this third group, the type of self-mastery that emerged from interviews was different from tightly managed schedules and repetitious skills. Instead, what emerged was a self-aware value of one’s health. Diabetes did not go away, but managing it became part of a complex and evolving self-identity. Positive values about life, many times learned through the loss of physical function, motivated people to preserve what remained or regain what they had lost, so they could see grandchildren grow up or live with less physical discomfort. Over time, the choices and value judgments people made changed. Having or losing work played a large role in how these changes transpired. The loss of work was double-edged. On one hand, its priority over concerns for personal health diminished. People had the time and flexibility in their days to really consider their health. While this was not always a welcomed situation, the ability to make meaning from past experiences also required space for contemplation, something most people had pushed aside as unimportant compared to the daily responsibilities of work. Having time for contemplation was also an unwelcome
reminder for some that they were no longer working or were no longer capable of working.

Unlike T2DM programs that encouraged instructors to not dwell on participants’ past experiences, the life-story interviews showed how important integration with one’s past was to control T2DM. The process of re-constructing a sense of self through one’s own history is a different process and identity from the linearity of T2DM education programs and the simplified biologically based identity of “being a diabetic.” Instead, people created what I perceive as real control of diabetes by making diabetes singular and grounded in their own lived experience. However, this construction is not in static opposition to the self-monitoring and discipline of biological abstraction.

Contemplation and analysis of one’s past and future in terms of self-care practices is a skill that some people developed throughout their life. One man told me, “I guess I’ve always been just real analytical about that kind of stuff [making sense of his health and future]. If I’m going to do something I’m going to know it, you know, what happens. All my life I’ve tried to look for a cause and effect sort of thing.” He applied this same focus to dealing with T2DM. Putting together the control of T2DM as a way to secure the future was a continuous process, even for people who had controlled diabetes for years. Having time for contemplation and analysis and viewing this time as something positive, was a key pattern to gaining control. For many, T2DM remained part of an over-whelming series of events, such as the loss of the physical ability to work or the inability to make changes in daily behaviors to control BG levels. T2DM remained an obstacle to recreating a past instead of a way to regain control for the future.
However, along with the ability to create a space for contemplation, a whole host of forces came into play to give motivation to take T2DM as not only a serious condition, but also one that could be managed. Being diagnosed with T2DM had to produce new practices that would secure the future. For many, the self-care practices needed to control blood glucose numbers played little practical role in daily life. Or, as will be discussed in more detail in the next two chapters, these practices created a greater obstacle in day-to-day lives. As a result, making changes in self-care practices was put off. Only when the physical symptoms became so painful and debilitating were sustainable and healthier practices perceived as beneficial. The life-stories collected here describe creating space for contemplation through the conditions of everyday life.

7.8 Concluding remarks

Facts and expert advice are not the deciding factors in how sustaining changes in self-care behaviors occur. Rather, the skill of reflexive thinking allows transformations to occur. The ability to craft the space needed for contemplation was a crucial step, but not one shared by the majority of people interviewed. Because of this skill, however, being forced to deal with T2DM brought about the paradoxical insight into caring for one’s body and self. As mentioned previously, spirituality also played a significant role in creating stability for contemplation. Contemplation allowed individuals to integrate their past with the future in the present, a process much different than the ever-present linearity of T2DM education programs. The struggle that many people experienced as they attempted new practices of caring for themselves is a critique of the simplified processes of rational decision making and skill learning presented in T2DM
classes. The factors that converge to create practice are unpredictable. The presence or absence of types of practice reflects the type of relationship each person created between self and body, both embedded within a broader social context and the un-predictableness of life.
Chapter 8: Just Beginning

In the T2DM literature and education programs discussed in chapter five, controlling diabetes through self-monitoring and skills learned through medical facts are advocated as empowerment. New, daily routines to manage diabetes form a linear temporality that separates one’s body and diabetes from one’s past. Scheduled cycles of medication, diet, and activity focus on controlling diabetes and bodies external to one’s lived experience. However, for people presented in this chapter, who are just beginning to come to terms with diabetes, self-mastery through habit and repetition did not provide much in the way of support or motivation to learn how to control diabetes. Instead of self-mastery, what emerged from interviews was an exacerbation of estrangements between body and self that many people already experienced in daily life. The struggles of the people in this group illustrate how difficult self-transformation and the creation of new daily habits really are after a lifetime spent ignoring one’s bodily health. Bodies had been used for work at the expense of one’s health or as a way to escape feelings of isolation and boredom through, commonly, enjoyment of eating or junk food. Instead of being able to move beyond repetition and self-monitoring and create meaningful and sustainable self-care practices, people in this chapter struggled to come to terms with the increased self-objectification that control of T2DM requires.

For all of the people grouped in this first section, changes in daily practices were triggered by physical symptoms, sometimes quite traumatic: stroke, impotence, painful neuropathy, and declining vision. These physical symptoms had forced reflexive examinations of daily routines and the recognition that changes had to be made in ways that had never been
attempted before. This meant greater conscious effort and tighter control of eating, sleeping, and exercise, all daily activities that instead of helping to connect body and self had the effect of creating more distance. The stories told here therefore reflect the ways practices of T2DM self-care cannot be separated from practices of everyday life, particularly the important role work plays in shaping connections between body and self and the ability to maintain continuity and social autonomy. For the people in this first chapter, facing the future means coming to terms with the cost of intense desire to be “normal,” to not have to think about and perform daily practices of self-care that made their bodies an object of concern. The interviews presented next are of people trying to maintain control of their lives for as long as they can, in ways that end up being self-destructive.

Most important in this first chapter is the way uniform, scientific constructions of human bodies connect to particular types of self-care practices: the regimented scheduling of food and medication and the self-monitoring needed to keep track of BG levels that people find so onerous. The biggest struggle was to learn the necessary step of making sense of physical symptoms through self-measurement of BG levels. The ability to improvise daily activities and yet maintain bodily homeostasis without conscious effort is replaced by uniform self-care practices that require intense effort to learn. “It’s tedious,” one woman told me about carb counting and exchange, “It’s so time consuming, it annoys me. I just want to eat.” The spatiality of bodies as abstracted, uniform, and homogeneous inherently involves forms of practice that are mechanistic, repetitive, and uniform in experience to all people living with T2DM. In this way,
the emergence of scientifically abstract bodies in the mid-19th century becomes the site of equally abstract self-care practices in the 21st century.

However, as Lefebvre (1992) describes, abstract space is not just a product of medical science but an all-encompassing social space and part of larger economic, social, cultural, and technological developments. The skilled, hard-working, and upwardly mobile individuals once needed for manufacturing in the Pacific Northwest become reconfigured as new demands to maintain individual autonomy emerge. Work remains all-important to maintain individual autonomy, but new responsibilities for self-care also emerge that conflict with or were never important to practices in the past. To maintain one’s ability to work, the lived practices of daily life, eating, sleeping, and activities, become abstract themselves. Accepting these new and abstracted practices is the challenge for people in this first chapter.

I begin with a longer, more detailed diabetes life-story to highlight common themes found in interviews within this group. As I discussed previously in the description of the three main patterns of control, making sense of bodily symptoms through measurement was a first and difficult step in controlling diabetes. This is the dominant pattern of this group of interviews, as the people here begin to confront the growing disabilities they experience from not managing diabetes for so long. In this group, the physical symptoms of diabetes are promoting struggles to gain control of diabetes due to serious concerns for the materiality of their bodies. These struggles are not new and have remained unresolved, sometimes for decades, as people attempt to discipline themselves and retain their ability to work and function independently. They recognize that their social autonomy is slipping away due to diabetes symptoms, but cannot
figure out how they each, as an autonomous person, must change to stop this process. In the first story, Laura *has* lost her social independence, but hopes to regain some autonomy with the finalization of her SSDI paperwork.

### 8.1 Disconnecting body from self: Laura’s story

I talked to Laura, age 58 and Anglo-American, in May of 2013. We spoke at her daughter’s house in South Tacoma. Laura had moved in with her daughter a year previously, following an accident in 2010 that contributed to her quitting her job of 28 years as a para-transit driver for Pierce County and ultimately caused her to lose her home due to financial troubles. After struggling to keep her house and maintain her health without a job, her daughter stepped in, offering Laura a place to live. Laura, her daughter, her son-in-law, and their three yappy little Pomeranians lived in a small, wood-frame home, no more than 900 sq. ft. and typical of the South Tacoma neighborhood that has housed Tacoma’s blue-collar and lower-ranked military families. The house was under the flight path of the huge military transport carriers on their way to and from Iraq and Afghanistan, each plane shaking the house and stopping our conversation as it passed overhead. Laura was friendly, welcoming me into her home and quite ready to talk.

Laura asked me to come to her home for the interview instead of meeting at a library because her truck wasn’t running and she was waiting for her son to help with repairs. Her son-in-law worked nights as a warehouse foreman and slept upstairs while we talked. Laura’s daughter was gone, working at Ross (a discount clothing chain) that had recently cut back all employee hours to 20 hours per week. “The higher ups,” as Laura put it, had made the cuts to get out of paying for mandatory employee medical insurance under the coming ACA. Laura was
home a lot at the time, as her health and finances did not allow her to get out much. She watched her granddaughter, ran errands, and sometimes went to the casino. At the time of the interview, she was very dependent financially on her daughter and son-in-law, something she looked forward to changing when her application for disability (SSDI) finally went through.

Her financial and health problems were long-standing and aggravated by a deep ambivalence towards her health that came out slowly as we talked. She had gestational diabetes during her third pregnancy in 1986, and was told she had “borderline diabetes” in 1998. During this eight-year period, Laura gained over 200 pounds, going from about 115 pounds in 1987 to 321 pounds in 1995. At the time of our interview, Laura depended almost exclusively on insulin to control her BG levels, although she was also still on oral medications. She could no longer use physical activity to control BG levels, to relieve stress, or as a social activity. Severe neuropathy and hip pain made walking, even for just a block uphill in downtown Tacoma for a recent errand, an overwhelming effort. Diet, weight loss, and insulin were the options Laura said were left to her for controlling diabetes. “Gradually, with the diabetes everything has declined in me. I’ve seen people in their 80s and 90s who are more active than me.” However, these severe physical limitations, along with the support from her daughter, seemed to have finally triggered Laura to make serious changes.

Laura had health insurance through her para-transit job for many years. However, even with insurance, Laura was only able to afford medication co-pays by working overtime, so she could still have a financial cushion. Medication co-pays came to $216 per month, plus what she paid for the medical insurance itself. Paying for medications was always a struggle, especially
when Laura was put on insulin, which was far more expensive than her oral diabetes medications. Many times she would just go without medications. But Laura also told me of a long history of cycles of taking and not taking meds that couldn’t wholly be explained by financial problems. Her first big health scare was a stroke in 2002. At the time, her BG was over 500mg/dl. A few years later, at a DOT physical her BG was over 700mg/dl. I did not ask Laura how she was able to keep her job with this medical history, but it contributed to her quitting in 2012. These measurements, which Laura related to me as asides to other issues, point to a long history of bracketing off diabetes control from work and everyday life. Laura could relate these numbers to me, and knew their significance. She also told me that her 2002 stroke was one of the scariest things she had ever experienced and she knew it was caused in large part by diabetes. And yet, as she explained, she still could not connect these measurements to her own life and body.

In 2009, para-transit service was cut when Pierce County residents vetoed a tax increase for public transportation. Laura could no longer work the overtime hours she needed to afford her medication co-pays, and decided to also cut back, eliminating her insulin since it had the highest high co-pay. This wasn’t a good choice – in November 2010, Laura blacked out while driving with one passenger aboard. Her BG level at the time of the accident was 400mg/dl. Luckily, no one was hurt, even though her bus veered across traffic lanes on a busy two-lane highway. “I didn’t even wake up until I hit one of those big, metal guard rails there. The accident happened on a Friday and Monday I went into work and they told me to get with Dr. B. [her long-time primary care physician (PCP)] and get my medications straightened out. But I just told
them, ‘I got to quit.’ I mean, I don’t have it [T2DM] under control; I’m not faithful on all my medications and I just kept thanking God that there was nothing serious, that I didn’t hit another car head-on and that my passenger was seat-belted in and nothing happened.” Laura’s struggle with high BG levels, however, did not end with that accident.

She had fallen twice in the past six months, cracking ribs and her tailbone. She had been trying to adjust her insulin dose on her own, but would forget to eat after taking a dose, or would eat a candy bar that would send her BG too high, after which she would take too much insulin to adjust for the high BG levels and therefore cause a crash. Laura’s lack of skill dosing insulin was not due to a lack of medical advice. The same PCP who diagnosed her with borderline T2DM when she hit 300 pounds in 1998 remained her physician until her accident in 2010 when she quit her transit job. She told me this physician would get so frustrated with her that she would cry sometimes after visits. Laura spoke about “Dr. B.” in the present tense throughout our conversation, and for a while I thought he was still her current physician. Although Laura did not seem to be able to keep her BG levels where this doctor wanted them, it was not because Laura wasn’t listening to or understanding his advice.

Laura also compared the approaches of VolunteerCare with those of Dr. B.: “At VolunteerCare, just maybe the way they talk to me. Dr. B., I mean he was nice too, but it was like [imitating a deeper voice] ‘the harsher I talk to you, maybe the more you’ll realize what you need to do.’ He’d say ‘I know you can do it once you set your mind to it. Once you get serious, I’ll help you.’ You know these guys [at VolunteerCare] have told me ‘lose the weight, quit the smoking’ but they do it in a way that’s not really hurtful to me like Dr. B. would do. I don’t
know, the way they [VolunteerCare] would talk to me and explain things to me as an equal, like I wasn’t the peon underneath them. I mean, when I walked into VolunteerCare, it was like somebody cared for the first time. I mean all of them were really nice.” Laura’s other frustration with Dr. B. was his seeming blindness to her economic situation. Economics and health issues became a vicious cycle; as her health issues worsened, Dr. B. would add medications and increase doses that had a big impact on her monthly budget. At VolunteerCare, Laura’s situation was treated differently. The cost of everything prescribed was tightly considered and discussed in a way Laura did not feel was demeaning.

Many different threads have come together for Laura recently as she enters her 60s: time to reflect on her past and how this connects to her present state of health is the most obvious, but also her grown children’s concern for her health, the recent birth of a another granddaughter, and the concern shown at VolunteerCare. “I think I’m more on top of it. I was in denial. I think why I’m more on top of it now is because of all the disabilities I’ve gotten since the diabetes. And my health, especially when I get sick, colds just linger. I’m kind of understanding where Dr. B. was coming from now, because of all the disabilities. I have neuropathy in my feet, my eyesight has diminished greatly, um, I notice I get sick more easily. Just knowing all the issues I know now, if I had known this 20 years ago when I first found out about diabetes, I think I would have worked more as far as being healthy and fit especially with my weight.” When Laura says “if I had known this 20 years ago,” she means she now understands the pain and limitations of T2DM. She does not mean that she did not understand diabetes. Laura knew “the facts” of T2DM through Dr. B., and she told me she also saw the long-term consequences of T2DM as a para-
transit driver, taking people to dialysis, helping them into her bus as they lost their sense of balance due to neuropathy or because they were losing their eyesight. Yet, she told herself, “Well, that’s not me cause I take care of myself. They out-weigh me by a hundred pounds (laughs ruefully). Well, now I know. I should have been taking my own advice back then.” Slowly, 20 years later, Laura is taking her own advice. However, listening to Laura, it becomes obvious that living with her daughter has played a huge part in how her everyday life is changing.

“So, I’m really starting to see how food affects my sugar levels. I don’t know why it’s taken me so long to comprehend that.” Laura told me with obvious pride that her dinner at Easter only raised her BG levels from 100mg/dl to 132mg/dl a few hours later. When I told her “that’s great!” she said “Yea, that’s what I said too, ‘Wow,’ and that’s without taking any insulin before the meal!” Laura has no problem understanding numbers, weights, calories, and portion size. She has obviously been spending time examining food labels, because she could tell me the calories, carbs, and fat content of various foods that she had been trying or giving up. When I complimented Laura on her knowledge, she started laughing and said, “Well, I have to if I’m going to live with her. Oh God, I’m sorry, I love her, she does help me, but like if she makes something that’s high in carbs, she has one of these little ladle spoons that’s about ½ cup and that’s what she gives me.” The “she” Laura referred to is her daughter, who seems to be extremely concerned about her mom’s health and is also her live-in disciplinarian.

Laura at times seemed as ambivalent about her daughter’s concern as she is about her health. Laura admitted that she doesn’t have the discipline to keep herself healthy, and yet she
also resents having no choice in her diet. Still, lack of money and the well-meaning surveillance was frustrating to Laura. “It was just so hard to get caught back up with everything. I’m glad my daughter gave me a place to stay [in 2011] and I was trying to keep up with my medications, but I just didn’t [pause]. Until she [her daughter] found out. I wish she wouldn’t be so snoopy. In a way I kinda appreciate it (smiling) but there’s times when it’s like ‘Just let me live.’” Laura also dislikes the constraint on her schedule imposed by taking insulin, the need to eat regularly so her insulin dose and food intake correspond, along with the crashes and highs that result when she doesn’t pay attention to this. She told me the need to take special care of herself is embarrassing. As much as she resents the “snoopiness” of her daughter or the “babysitting” of her best friend, she also seemed amazed and deeply touched at this desire on the part of her family and friends to keep her alive.

After listening to Laura for awhile, I saw that while she resents being disciplined in such a high-handed way, it was also frustrating for me just listening to her describe a lack of connection between actions and consequences. For example, despite connecting BG levels and the long-term effects of T2DM, Laura did not seem to make the same connection to her low thyroid levels with how she feels. She told me that the result of thyroid labs had been significantly low until quite recently. Laura’s son had given her five dollars so she could get a thyroid prescription filled, but she hadn’t done it yet. When I told her that low thyroid levels could affect her mood, weight gain, and joint pain, I could feel her skepticism when she said, “Yea, a few months ago, my counselor at Greater Lakes (Pierce County’s publically funded mental health services) told me the same thing.” Laura also told me she had been hypothyroid
since 2004, so I don’t think the Greater Lakes counselor was the first to explain symptoms of low thyroid.

In Laura’s story, the connection between measurement and what she experiences with her body is just now being made, 20 years after she was first diagnosed with T2DM. While Laura has understood what BG levels represented for decades, paying attention to these levels, how food affects them, and how she feels when her BG levels are high or low are only now becoming real to Laura. Her curiosity of measuring her BG levels before and after Easter dinner is an example of this connection. When I asked her, Laura was not aware of a connection between high BG levels and her mood. Many people with whom I talked had learned that being easily irritated, impatient, and constantly fatigued meant their BG levels were high. As will be discussed in the next chapter, many people do not realize that these feelings are due to high BG levels until they drop closer to therapeutic levels and learn to make connections between embodied experience and measurement.

It has only been quite recently, in the past year and especially in the past few months that Laura seems to be a more active participant in her own care. A few weeks previously, Laura’s truck broke down and her son-in-law towed it home. Inside the truck, he found empty pop cans and candy wrappers before Laura could employ her usual strategy of hiding them. Laura’s daughter had regularly thrown out stashes of candy from Laura’s room, and the truck stash seemed to be the final straw. “She had a handful of [candy] wrappers in her hand and yelled at me, ‘Really, Mom, really’? Have at it, have at it!’ and threw them on my [bedroom] floor. She was mad.” Laura stated that since that incident, she has reformed, “I don’t want to get caught
anymore. I do feel better, I don’t know if it’s just cause I don’t feel the guilt, I mean I’m glad that they [her daughter and son-in-law] have hidden certain things. They hide the oil when they’re gone for the day. She [her daughter] bakes *everything* and I *love* fried foods.”

When I asked Laura if changing her food choices also changes her as a person, she says, “I don’t think so. Now I’ll bring healthy snacks with me instead of buying Sno-balls and a Dr. Pepper” (her favorite junk food combo). Laura doesn’t see food choice as a reflection of greater concern for her body. The connection between placing a moral or ethical value on her body and how self-care may fit into that connection is not something that makes sense to Laura. She is just beginning to make the connection between numbers, measuring, and feeling better, although she isn’t sure if it’s just because she doesn’t feel guilty. Laura was at the very beginning process of even putting a meaningful value to her own self-care. “Now I know what it’s like having to make decisions about paying for the house or utilities or medications. What do you do? What do you give up just to keep your medications? I guess I’d rather have my other material things than my health at the time.” What became obvious from talking to Laura is that it is not a lack of understanding the facts of diabetes or blood sugars that bothers her. What bothers her is how these self-care practices create a new and much different way of thinking about and dealing with her body. Laura still sees food choices as a mechanistic switch, and even though she recognizes the damage done to her body from diabetes, she is still coming to terms to create a unique meaning making food choices has to her own life. Her daughter’s concern and the concern she has experienced at VolunteerCare are essential, but external, sources of self-discipline needed for
her own self-care. Laura is at the very first steps of self re-creation and attaching her own meaning to universalistic self-care practices.

With the birth of a new granddaughter, however, Laura seemed to be finding a renewed faith in God and living. Although Laura said she no longer goes to church, she was raised Catholic and still prays everyday. “But you know that saying, ‘One door closes and another opens?’ To me it [her second granddaughter’s birth] kind of renewed my faith in God, because before I’d ask God ‘Why? Why did you take Natalie (her first grand-daughter who died of cancer)? Why did you let me get sick? How could you do that?’ But with Ashley [her second granddaughter] ‘You gave me something back. You gave me another reason to live.’ Letting go of the past. This is hard. I didn’t think I had a purpose in living.” In addition to finding a renewed faith and purpose through God, living with her daughter the past year has given Laura the structure and motivation to be more consistent with taking medications and eating differently. Laura has a great sense of humor and during the interview was not a sad or self-pitying person, but she also displayed a hard-won sense of a future and purpose that had taken a great deal of critical self-examination of her past attitudes.

While work brought a tenuous hold on personal autonomy for Laura, it also brought a simultaneous bracketing off of concern for her body and health. When Laura still was able to get overtime hours, she worked six days a week to earn the extra money needed to pay for medications to control her diabetes. Laura repeatedly mentioned the high cost of medications and the choices she had to make between food, housing, and medications. Underlying these hard choices was Laura’s lack of ability to integrate diabetes self-care practices into her daily life.
Throughout our conversation, Laura related little to suggest that she placed much value on the health of her body. Loss of autonomy from the complications of diabetes had taught Laura the importance of her body, but this consideration was not part of daily routines in the past. The neutrality of T2DM facts, their very design to be uniform and universal, gave Laura little to use to create meaning or value when she visited Dr. B. for diabetes care. In fact, the discipline of medical self-management further accentuated the lack of meaning Laura already struggled with. T2DM self-care required Laura to not only be hyper-aware of schedules and self-discipline, but to be even *more* detached from her body as she learned to measure and monitor herself. It was through the social support of her family and friends, and facing her mortality, that Laura was able to begin to make needed changes.

For decades, the self-care practice of measuring and monitoring crucial to controlling diabetes required a greater ability for self-objectification than Laura could manage. In the past, when she was working and had her own home, Laura would isolate herself from her family. “There were days when I’d tell them [her grown children], ‘don’t bother me, I just want to be by myself, in my own little world.’” Certainly, the effects of high glucose levels on mood and energy (as will be discussed in many of the interviews) created a vicious circle. Mostly though, the quantification and hyper-awareness of daily activities that T2DM self-care practices require did not provide Laura with a meaningful process to connect body and self. What Dr. B. perceived as a lack of seriousness on Laura’s part regarding diabetes was perhaps the accentuated sense of isolation and objectification that diabetes self-care practices created for her. Like many people in this first group of interviewees, Laura’s everyday routines placed little
concern or value on her body’s health, let alone daily practices that would promote good health. Even though Laura told herself that she took care of herself and was different from her passengers with severe diabetic complications, she has come to recognize that she really wasn’t doing that. Slowly, Laura has begun to assign value to her health, but only as her bodily health has declined and with the external support of her daughter has she been able to integrate self-measurement and monitoring into her daily life in ways that were not possible before.

As mentioned in the previous chapter, there are a greater number of women in the “just beginning” category. None of the men mentioned being in past abusive relationships, but a number of women, including Laura, did. Towards the end of our conversation, Laura told me that she had been in an abusive marriage when her first two children were born. Her ex-husband took their children to his native country without telling her, and it was only with the intervention of one helpful in-law that she was able to get them back. “Really, it just set me for a loop; in my heart I thought I’d never see them again.” This story had little to do with diabetes as a disease state, but Laura told it as an important past event that had made her who she was. It illustrates the thinner margin of control many women I interviewed experienced in their lives and points to how self-monitoring and objectification can challenge those already struggling to give value and meaning to self-care practices even further. In the third interview chapter, control of diabetes and the ability to create personal meaning of self-care practices are closely connected.

Work takes priority in Laura’s life as the means for social autonomy, but creates a practice of self-care that marginalizes bodily health and does not allow much time or motivation for contemplation or reflexive thinking. Foucault (1982) describes this lack of priority as ethics,
“which determines how the individual is supposed to constitute himself as a moral subject of his own actions” (238). Connecting measurement to embodied experience is still something of an intrusion in Laura’s life and caring for her body through measurement and monitoring are practices that she is not completely comfortable with. The discipline of eating certain foods at certain times still bothers her, but Laura also recognizes that she no longer has a choice, she can no longer ignore herself in the way she has in the past. Diet and eating are now programmed practices and can no longer be unconsciously preformed due to the severity of her diabetes. However, Laura sees her change in food choices mechanically, with no association to herself as a person; instead of buying her favorite snack, Sno-balls and Dr. Pepper, she now makes sure she carries celery sticks and peanut butter as a snack.

The external discipline imposed by Laura’s daughter and son-in-law, the concern and love that motivate their actions, and Laura’s growing realization of how bad T2DM can make her feel still seem detached from any meaning Laura herself assigns to newly adopted diabetes self-care practices. In the following shorter stories, I relate other life stories that describe similar struggles of self-transformation that are just beginning. In the next two cases, I describe how ethics can be imposed through external social structures, but also how junk food and eating disrupt the construction of sustainable practices that keep diabetes controlled.

8.2 The power of food: Cedric’s story

Cedric is a 42 year old African American male who was diagnosed with T2DM 14 years prior to his interview (in 2000). For a few months after his diagnosis, Cedric took medications and made a few changes to his diet. Within a month or so he felt much better; the fatigue, thirst,
and just “feeling really bad” that led up to a medical visit, disappeared. He explained that after he was first diagnosed, his attitude towards diabetes was, “I ignored it. I thought I was invincible, it [complications] won’t happen to me. I can handle it. I can just stop it at any time. Just put down sodas, do a few push-ups, it won’t bother me. When I’m ready, I’ll be fine.”

After taking medications for about two years, Cedric moved to a new city and “lived life as though I was no longer a diabetic. I mean, I just stopped all my medications. I stopped everything. I didn’t take care of myself at all.” When I asked Cedric what was going through his mind then, he said “Since I felt fine I didn’t see the sense in me trying to monitor anything. I just wanted to be normal, whatever that is, no hang-ups, no diseases.” Cedric repeatedly mentioned “feeling absolutely normal,” and “not thinking about T2DM at all” during the years he stopped medications. Cedric did not have medical insurance after his move, which also helped him ignore diabetes treatment. This period of ignoring diabetes came to an abrupt end, however, when Cedric was incarcerated in a “boot camp” for 5 months due to parole violations. Unlike many people in this group, Cedric had no choice about diet and exercise. His A1C dropped within a non-diabetic range, 5.5%, and he lost 50 pounds from enforced daily exercising and a 2,000-calorie per day diet.

No junk food was allowed in prison. But Cedric described forcing himself to eat junk food after he was released: “Your body feels the difference immediately [junk food after the boot camp diet]. Automatically. I mean it was just so powerful. When I got out, all I could think of is ‘I want Burger King. I. Want. Burger King.’ I went to Burger King, I took one bite and I got so sick. Like, ‘This is not real food.’ Oh my goodness, it was terrible. But [pause] I just kept on
doing it until I got back to that old way of feeling. Looking to food for comfort, that habit of thinking, everything starts from there. When you’re in a negative place you want something to comfort you and I took comfort in food [pause] and that was the enemy. I mean especially bad foods.” It didn’t help at all that the work-release program Cedric was assigned to was a job at McDonalds.

In 2012, Cedric moved to California and was able to get medical insurance with a new job. With the insurance, he was able to start checking his sugars and found they were consistently about 300mg/dl, quite high. Much like Laura, Cedric is now facing a number of serious consequences from having ignored his body for so long: impotence, painful neuropathy, and vision problems. Again like Laura, these physical symptoms are prompting Cedric to live differently. “This time I have to take it seriously. I mean I have to. I’m not 30 anymore, I’m 42. Age and diabetes just crept up on me. Blam, ‘You’re old and diabetic.’ So sluggish. I’ve heard these stories for so long, that if you let diabetes go unchecked for any amount of time, it’s going to catch up with you. It’s just going to come back and catch up with you. And I’m starting to feel that now.” Most upsetting to Cedric is the impotence and neuropathy he has been experiencing since 2013. The neuropathy, in particular, “Just came out of nowhere, just one night. I had dropped a ton of weight. I was working as a meter-reader, you know, walking around all day. I lost sooo much weight. But then, one night, I laid down and bang, bang, bang, bang, bang, ‘What the heck is this?’” The pain from the neuropathy has subsided, but “numbness, no feeling no sensation,” remains.
At the time of our interview, Cedric’s A1C remained high, at 10.8%, which means his blood sugar levels have stayed consistently around 300mg/dl for the past few years. Now, however, Cedric says his outlook is much different, “Now, I can deal with it. No more running, no false sense of bravado. I absolutely have to deal with it if I want to live in a normal way.” Because of his symptoms, Cedric now views taking medications and eating and exercising as the only way to be “normal,” instead of it causing him to be “different.” He calls his past attitudes “Bullcrap. Just bullcrap (laughs). Diabetes is saying [to his past attitude] ‘I’ve got a little something for you.’ And I just refuse to live like that.” Now, after so many years of trying to ignore his body, Cedric is making it his main concern, “Cause I’m realizing, if I’m not well I’m not going to be able to perform, or do anything. So, the first thing is get my body, my self in order, at least functioning how it should and everything else will follow suit.” Cedric’s choice of words “my body my self” describe how his thinking has changed. Now, instead of being something to ignore, or the thing that makes Cedric different, taking care of his body is what will keep him “normal.”

Cedric sees medications as a temporary necessity and mentioned his sister, Drew Carey, and the actor who played Neumann on “Seinfeld” as people who have dropped weight and are no longer on diabetic medications. “Right now, medications are a stepping-stone, which will get my blood sugars under control, which will free me up. As long as I have clear mind, my body will react in the way I want it to. The foods I was eating that got me to this point, they just have to go.” He recognizes however, that “things are a lot easier when you don’t have a choice.” Cedric says he has a lot of support from his mother and sisters, who also have diabetes, but their support
“is no good if you’re not using it.” For Cedric, integrating his past self-care practices into the present means recognizing his past mistakes, particularly the enjoyment he took from eating junk food. Perhaps recognizing the changes ahead of him, Cedric went on to say, “All the good intentions of the world don’t mean a thing unless you put them to good use. And if I don’t, my feet [neuropathy] will remind me.” Like Laura, Cedric is learning to place value on paying attention to and taking care of his body as he faces increasing disability from diabetes. He has barely learned to pay attention to numbers, measurement and how he will use those to understand embodied experience, but he now feels this is a necessary step to prevent further disability and return to a “normal” life. Paying attention to his body’s health is a new type of concern, learned over many years and made expedient as he faces a future without physical health.

8.3 The power of food: Susan’s story

Like Cedric, Susan struggled with using food as comfort and “living to eat,” as Cedric put it. Susan, a 40-year-old Anglo-American woman, worked at a non-profit as a home health aid. Her boyfriend went to bed he went to bed very early for work and evenings were the hardest time of day, “I’m just looking at the walls because I’m bored,” she said. Susan then ran through a list of all the activities she thought of and discarded and reasons why each one didn’t work: internet, walking her dogs, doing puzzles, going to bed early. Nothing seemed to give her the satisfaction of food. “Nothing sucks me in. It’s not an addictive thing to me [internet], where food is. I don’t drink, I don’t smoke. That’s my vice [food].” Susan uses food and her body to provide an embodied escape from stress, isolation, and boredom. Diabetes self-care practices
only magnified her desire to disengage from routine and did not provide the embodied escape that food gave her.

Susan seems to live in two completely distinct worlds that both require practices that are neither sustainable nor satisfactory to her. In one she finds self-discipline intolerable and the other gives momentary relief but just adds to her stress. “They [her medical providers] keep telling me that if I lose the weight, and control it [T2DM], then I can lose the medication. I know how to do all this. I know how to eat right and exercise and lose weight. I know what my body needs, it’s just to do it.” What seems to do her in is the effort and planning that “eating right” takes. “It’s like, ‘we’re done.’” Unlike the comforting void of food, Susan’s “healthy routine,” as she defines it, seems to overwhelm her. She gets “tired of eating the same things,” of planning meals and the conscious effort diabetes requires of her, and she gives up. “When it gets busy and crazy, I forget all that and just step off and don’t do it.” Susan stated that she doesn’t check her BG levels too often because she “knows her body,” but then stated she knows this isn’t always an accurate way to know her BG levels. Checking BG levels is part of her “healthy routine” and irritates her in the same way planning and scheduling do.

The cycle of trying to do too much and then experiencing overwhelming stress seems to be a repeating pattern. Measuring and monitoring have the opposite effect she feels from food. As part of these cycles, Susan has also been on many diets in the past. After being diagnosed, she lost 60 pounds over 2 years, then gained it back. She lost 30-40 pounds in another attempt, and almost got off insulin. Her last “healthy routine” ended when she was working full-time, going to school, and taking care of her great aunt. There was too much to do every day, she said, and she
began eating again. While Susan can list many reasons she cannot maintain her diabetic routine, she also gets very upset when her blood sugar levels increase. Recently, her MD added short-acting insulin, and she now injects four shots of insulin a day: one before each meal, along with the long-acting insulin she had been using. This adds more expense and even greater scheduling. Susan told me, “I remember calling my boyfriend and crying. ‘OK, I’m not taking care of myself the way I need to’ (at this point her voice shakes and she sighs). It’s like it’s fresh for me again [starting on insulin]. I keep raising my insulin dose because my blood sugars are out of control.” When I asked if her doctors made her feel bad about this increase, she said emphatically, “No, my doctor is great. He has been through Weight Watchers too, so he knows. Oh yea, I cry with him…” But, at least for the present, Susan, like Cedric, uses food and her body as a way to create a void; self-mastery of the everyday is achieved through numbing rather than an intensification of affective awareness. Diabetes self-care practices never became a part of Susan’s routine because she could not sustain the self-objectification that diabetes self-care practices require. Abstract rationalism provides self-awareness, but without the comforting void that food provides, and without any personal meaning Susan can attach to it. Instead of the sense of timelessness she finds from food, diabetes self-care practices break down time into uniform and planned segments that make her more aware of boredom. Unlike Cedric, Susan has attempted to integrate measurement into daily activities. However, she has not been scared into replacing her attachment to food with detached measurement.
8.4 Giving responsibility to technology: Jerry’s story

The role medications play in controlling T2DM is highly individual. Their use, or lack of use, explains who someone is and how they want to live. When pharmaceutical use is measured as an index of medical compliance, this important factor of lived experience is ignored. It shifts responsibility for successful diabetes control to the use of pharmaceuticals and away from how people develop an ethics of self-care. Pharmaceuticals can be thought of as stepping-stones to managing diabetes as Cedric described or, as in the next story, as a way to avoid thinking about one’s body or diabetes. The story of Jerry, a former Washington State highway patrolman and police detective, illustrates how medications can be heavily relied upon to achieve the same state of “normalcy” Cedric was trying to achieve by not taking them. Instead of just “pretending” he didn’t have T2DM, Jerry used an insulin pump and lap-band surgery to avoid thinking about diabetes or his body. Jerry’s story shows how technology can be used to replace active awareness, measurement, and scheduling that diabetes self-care requires.

Jerry had worked as a highway patrolman and detective for over 30 years. Compared to many people I interviewed, Jerry’s financial situation was fairly secure. However, tax cuts in Washington State had forced an early retirement before he turned 65. Even though he had two retirement pensions, and he and his wife rented out the basement apartment of his large house, his income did not come close to paying his mortgage (in Tacoma’s North End), payment on a new truck, and the high cost of pump supplies and the analog insulin necessary. His retirement pensions included no medical insurance, and at 61 years old, he was still too young for Medicare. On the day we met to talk, Jerry had just taken and passed a driving exam so that he could
qualify as an instructor at a police driving school. He really needed more money and was greatly relieved that he had passed the exam and that his life was getting back on track.

I met Jerry at the VolunteerCare clinic when he showed up looking for a physician to write a prescription for insulin and pump supplies. He had applied for and received patient assistance for the pump itself, but needed a doctor’s prescription for the insulin. The medical director at VolunteerCare, however, did not feel comfortable writing the prescription, much to Jerry’s irritation. Treatment with an insulin pump fell outside of the limited scope of treatment and medication formulary the clinic followed. Jerry, however, said he thought the pump was great. While people with type-1 diabetes routinely use insulin pumps, they have only recently been prescribed for controlling T2DM. Instead of having to inject a separate shot of insulin, Jerry’s pump delivered a programmed amount of insulin 24 hours a day. He did not have to think about insulin or T2DM at all. However, he had stopped using the pump due to the high cost of supplies, and either relied on self-administered shots or went without insulin. For a while, he had even reused pump supplies to the point he had developed skin infections at the pump insertion site.

Jerry was first told he had high BG levels in the late 1980s, and was then diagnosed with T2DM in 1991. He began using insulin in 1992 or 1993, and then the pump in 2008, five years prior to our interview (in 2013). Using the pump was not his physician’s idea, and he only reluctantly agreed to prescribe the pump, a result of direct-to-consumer medical advertising. “At the time, it wasn’t what they did for T2DM. I just happened, or I got called or I heard about it or something and I kind of checked into it. And Metronics [the pump company] took the ball and
ran with it and got my doctor to buy off on it, and I got it.” Shortly after getting the pump and considering his physician’s continued discomfort with it, Jerry found a new doctor who agreed with Jerry’s mindset towards treatment. When I asked Jerry what interested him so much about the pump in the first place, he said, “To me, it was the greatest thing since sliced bread. It just made things simpler for me. The company would send me my stuff and then bill my insurance. It was just real simple for me. I only had to deal with one type of insulin and inject myself once a week instead of four times a day.” Now with no money to pay for the pump supplies, Jerry had to check his BG levels and adjust his insulin dose once again.

Still, the pump didn’t control Jerry’s BG levels all that well. He and his wife ate out almost every dinner, and while his BG levels in the morning could be as low as 100mg/dl, “I still had to watch it [what he ate].” Jerry also told me that he got shaky when his BG level went below 120mg/dl, an indication that his body had become accustomed to high glucose levels. “I’ve never been a very good manager of my insulin and the pump did it for me. The pump spoiled me.” When I asked Jerry if he had any interest in getting off of the pump, he told me, “Well, you know, about five years ago I had my stomach banded and I lost about 100 lbs. and I thought my blood sugar would go down but it didn’t. But I really need to lose another 100lbs.” Jerry said he weighed 300lbs at the interview and about 420lbs before the lap band. “Maybe if I lose the next 100, maybe there would be a drop” [in BG levels].

Jerry had pursued using technology far more than any other person I interviewed (in large part because he had the financial means to do so). However, as I talked to him, Jerry seemed more and more stuck and disillusioned with the work it still required. To lose 100 more pounds
meant tightening up the lap band, and that meant again going uncomfortably hungry or getting sick from eating more than a small-size stomach could tolerate, like he did when he first had the band placed. Even so, Jerry told me, “When I get ready, I think that’s gonna have to be the solution.” Diet didn’t seem to be a consideration for him. He stated that walking was not possible because of neuropathy, and he said he moved so slowly he couldn’t work up a sweat. Like Laura and Cedric, he mentioned feeling the long-term effects of poor T2DM control and even though he “relished the idea” of not being on medication for diabetes, that was the desire of not wanting to deal with T2DM at all.

Both the insulin pump and the lap-band placement took place in 2008. To Jerry, both approaches seemed like an effortless way to gain control of his weight and T2DM. Unfortunately, that wasn’t completely the case (Jerry did say his morning BG checks dropped significantly after getting the pump). Jerry wanted a treatment that would mimic his self-regulating, pre-T2DM body and life, one that required little mindfulness on his part. Both Cedric and Jerry wanted to forget T2DM completely or, at least have effortless control. As one person told me “I just want a pill to make it go away.” As all these stories keep repeating, it was obvious that people in this first group had little conscious connection to their bodies. They used them in ways to maintain social autonomy and to function in everyday life that did not value bodily care or health. Jerry was very compliant with his insulin pump and treatment when he had the money to pay for supplies, but the value this had for Jerry was not so much his health as the ability it gave him to keep it out of his awareness. The people presented so far struggle to control diabetes
because they are unable to move beyond the objectification of their body that abstract rationalism and diabetic self-care practice provides.

8.5 Re-defining self-care: Marie’s story

Physical symptoms are a strong motivator in the stories above, but to Marie, a 54-year-old Anglo-American woman, the reasons are less straightforward. For the past decade until she was laid off, Marie worked from home as a medical transcriptionist, and had gained 135 pounds over the past decade. Shortly after her diagnosis, she had done her own research and requested to be prescribed metformin, a new approach at the time to reduce insulin resistance. Despite this promising start, requesting medication was the extent of Marie’s efforts to manage diabetes; “I think my MD realized I was a lost cause.”

Marie lost her job as a medical transcriptionist after 25 years in 2010. MultiCare Health Systems began contracting out transcription services instead of having an in-house service, and Marie found this new system even more stressful than the old system she was at least familiar with. Losing her job, however, turned into a blessing for Marie: “I was so happy not to have go through that anymore.” She now lives with her sister and brother-in-law in their condominium to share expenses, which she enjoys. Marie had worked evenings and graveyard shifts, so her work schedule never matched a “normal” day, and she “couldn’t be bothered” to figure out when to check BG levels. Plus, she used food, especially junk food, to stay awake. Marie’s primary concern was working. “To me, just keeping working was the deal. All I wanted was to sleep and feel halfway decent to get up and keep working. Just keeping my sanity was my concern. I couldn’t be bothered with diabetes.”
Marie was one of the few people to connect growing up poor with a disregard for one’s health or a feeling that daily care for one’s health was a luxury, not a necessity. “I grew up in a poorer area [Salishan] and people just lived that way [with physical complications and poor health]. Now I see 103-year-old women at my condominium making turkey dinners for Thanksgiving. Or, there’s this 89-year-old lady complaining about her knee and I’m thinking ‘Well, you’re 89 years old,’ but she has such expectations for herself. I never saw that as a kid.”

Later, Marie went on to say, “When I was younger it was taking care of the kids [her siblings] and stuff and then I started working and working overtime. I’ve never had time to just think about the way I feel. And you know that is really cool [having time to think]. I’ll sit there and think ‘Why do you feel irritated, what was it?’ and then it’ll come to me, ‘Oh, that’s what happened.’ I was just like a little savage girl before running through life.”

Now Marie finds herself in an entirely new place. “I never wanted to do that [take care of herself]. Now I’m stuck with living and the realities of all this stuff. So, now, okay. I don’t know.” In the past few years Marie taught herself how to cook and stated that she “loves food.” But unlike Cedric or Susan, food is a way to take enjoyment in doing something rather than a way of deadening herself. She talked about finding healthy recipes and losing 40 pounds by cutting portions. Marie stated that she is now realizing “I’m here and I have to play. I’m an unwilling participant. [pause] And I have it good, I’m very thankful for what I have. I mean, it doesn’t seem like it, but I am… You’ve got me crying.”

Spirituality is not a big part of Marie’s life but she wonders a great deal at her change in attitude about taking care of herself. She wonders at what her responsibility is “especially when
your life gets a little bit better and you’re wrestling with everything. You know, you should do what you’re supposed to do.” When I asked her what that was, she told me, “Well, uh, to show appreciation. Not taking care of our selves… [it] doesn’t reflect that [showing appreciation]. But I don’t know beyond that. You know, ‘Leave me alone’ that’s the way I used to be.” Marie attributes a great deal of her feeling “so much better” to God, but she stated that she still can’t comprehend her feelings fully.

Marie could not pinpoint why she had changed her mind about the importance of her own health, but it was not promoted by physical decline or fear of what the future might bring. Marie said she feels like she is slowly joining the human race and is tired of the “doped state” high blood sugars. Marie described the long process of making the connection between blood glucose measurement and how she was feeling: “I’d say to my doctor ‘My vision is blurry” or ‘My feet are really scaly’ and he’d say ‘Well, what’s you blood sugar?’ and I’d say ‘I don’t know’ cause I never checked them. I was in a stupor or something. I knew there was a connection but I never made the connection.” Measuring blood sugars did not bother Marie the way it did those in the previous interviews, so much as it was just completely irrelevant to her life or priorities.

“Ignorance was bliss,” Marie tells me as to why she never checked her blood sugars. Without work to cause stress and consume time, living with her sister and brother-in-law, and perhaps just growing older, Marie said she is now trying to figure things out, break them down and not just ignore them if they bother her. Marie’s A1C is close to 10%, so it is highly likely she will be on insulin. “I would prefer not, but if I need to be on insulin then I’ll do that.” Marie’s concern for her health and body comes from a profound shift toward appreciating being alive that she
cannot really explain. It perhaps comes from a multitude of factors, but points to how transformation of the self is never fully knowable.

8.6 Diabetes isn’t real life: Ima’s story

Ima, a recently diagnosed woman from Micronesia, will be the last person discussed in this chapter. I first met Ima at the CHC clinic after her T2DM visit there. She had been told that her A1C was below 6%, even though she had not been taking any medications recently. She had recently come back from spending the last few months “back home” in Micronesia, and her physician attributed the drop in her BG levels to her being so much more active. “No car, no restaurants. You have to go up the mountain to get wood, fishing, hunting for food. Fresh food, not food you buy in a store.” Ima described picking and eating fresh coconuts and bananas growing in the yard of her family’s Micronesian home. She said her doctor wanted her to re-start metformin because he told her, “’When you stay here your diabetes will come back.’”

Although many members of Ima’s family have T2DM (they now live in Oregon), she does not seem to be very concerned about it. It’s her children who won’t let her eat ice cream and her husband who gets angry at her: “You don’t care about yourself” or “You stop” when she starts to have a third portion of something at dinner. Ima doesn’t check her BG levels. She doesn’t like poking herself and the numbers seem more of an unnecessary imposition than anything helpful to her. When she eats something “bad for my diabetes, then I don’t check.” While money is tight for her family, she does have medical insurance through her husband’s job, and money for medication or clinic visits does not seem to be a significant issue.
Ima told me, “I only care if my diabetes is very bad and I cannot see.” Despite how this sentence reads, when Ima said it, she did not mean she didn’t care about herself. She meant that diabetes is still not a concern for her; it isn’t real to her. In fact, she told me “I teach my kids to respect yourself, to love themselves as they love someone else.” Appreciation for “everything we go through” is Ima’s philosophy of life. When I said that’s not always easy to do, Ima told me, “Us, from our country, we have support. Even if we’re far away, we support each other.” When I asked Ima if she felt Americans don’t have that support, she said, “Some. Some just think by themselves. That’s why they suffer, because they don’t want to share. In our country we really share, we really love each other. Even if we don’t ask [when we need help, family members will say] ’OK, here’s the money.’ We really help each other. That’s why we don’t feel bad, we don’t feel lost. Even though we come from a poor country, we believe we are strong because we love, we share, we care, and it makes people healthy.”

Ima misses Micronesia and the community support of her family home, but she is committed to staying in the United States until her children finish school. The education they receive here, she says, is better than what they could get back home. The stress of paying utility bills, rent, and store-bought food is worth it to her for her children. Ima told me her CHC doctor also told her, “If I were you, I’d go back [to Micronesia].’ I don’t know, I want them [her kids] to finish school.” Ima’s lack of urgency is similar to Cedric’s, who thought if he just did a few extra push-ups, he could control diabetes whenever he was ready. Diabetes is not real to Ima, and even though she has a profound respect for life and caring for oneself and others, she has not seen any reason (yet) to connect that to concern about diabetes. Ima is not unlike Marie, who
understood the connection between how she felt and her blood sugar levels but did not really get that connection until many years later. From Ima’s story, it becomes clear diabetes is not only about respecting one’s health and caring about life, but also understanding numbers and blood glucose measurement as something real. Like all of the people discussed before her, Ima did not take diabetes seriously soon after being diagnosed. Numbers and measurement had no connection with what she felt was important: family, caring for community, and getting a good education for her children. Ima has no interest in checking blood sugar levels now, but numbers are the reality of how diabetes presents as a disease and slowly changes how people perceive and take care of their bodies and selves.

8.7 Concluding remarks

Isolation and the lack of value of one’s bodily health dominate these stories. Health, or concern for one’s body, has little value, or conversely is treated as a luxury few can afford until the symptoms of diabetes can’t be ignored. Being able to work, get by, and do this day after day with as little fuss as possible, with as little concern for oneself, unites these stories. Work is valued over health, and food numbs the social isolation this focus brings. The discipline required to bring BG levels down disrupts the continuity of people’s lives; many people for the first time were forced to comprehend their own mortality, past behaviors, and future health. It was no longer something to be deferred for the future or a luxury that just didn’t fit with “living to work.” The reality of the importance of bodily health is revealed through increasing disabilities and living with the fear of future complications from diabetes.
Individual discipline needed to control the symptoms of T2DM requires an intensification of the very state of being that people have numbed themselves to avoid. The only way out of the severe disabilities caused by T2DM is through greater social isolation that self-objectification and monitoring creates. Learning these new skills creates new conflicts and contradictions to the routinized and familiar daily practices that make up everyday life in Tacoma. Linear temporality of T2DM education programs and the common focus on work negate both the past and the important responsibility of learning from one’s own experience. Care for oneself goes against the autonomy achieved through work because it requires contemplation and consideration of the value (non-economic) of one’s health and well-being.

Over time, people in this chapter (except for Ima) are reassessing what is necessary in the present with what they have held important or what worked in the past to get them through everyday life. Diabetes is now challenging in unexpected ways things that were once taken for granted, self-evident, or considered inevitable. However, the framework of abstract rationalism that every person here must use to understand diabetes does not make this challenge easy to understand or implement in daily life. The mastery of facts, calorie counting, and diet control are abstract practices that must be integrated with a much deeper, internal realignment of self and body to control diabetes. All of the people presented in this chapter (with the exception of Ima) are just beginning to see what diabetes really means in their life.
Chapter 9: Still Learning/Flux

In this chapter, I examine the ways life experiences disrupt or motivate an individual’s ability to control diabetes. T2DM is a condition that waxes and wanes along with the changing circumstances of each person’s life and how these conditions play into controlling diabetes. I describe the ways diabetes self-care practices, once established, can change over time. In these stories, the necessity of measurement and monitoring is accepted as such, but for various reasons, it has not been sustainable for long periods of time (I discuss long-term control in the next chapter). While medical abstraction is the primary tool people use to make sense of embodied experiences, this form of social space (conceived) is still incomplete in its ability to dominate experienced space (lived) or to sustain self-transformation.

I begin with one longer life story that exemplifies a shared pattern of losing and gaining control of T2DM over time, and then shorter variations of this pattern. The first story, that of Steve, shows how the abstracted space of medical management was repeatedly adopted and then dropped as he related how he is finally coming to terms with both living with T2DM and finding new direction in his life. The next three stories show the variety of ways that gaining and losing control happen, such as losing work and losing a sense of purpose in life, or slowly gaining control of T2DM over time. The following stories show how different forms of social space, scientific abstraction, and lived experience are taken up or put aside in relation to the demands of everyday life. Within each person’s life-story, these forms of social space are held as mutually constitutive, each reflecting distinct but interconnected temporal structures and practices. In this
chapter, I discuss how these forms are integrated in everyday life, as people use their abilities and inabilities to control diabetes as a way of understanding themselves.

9.1 Bouncing between extremes: Steve’s story

Steve, a 45-year-old, Anglo-American man, was diagnosed with T2DM in 2004, nine years before we met. He lived with his girlfriend and her parents in their home on Fox Island, one of the small, bucolic island communities that dot the Puget Sound. Steve’s daily life seemed at first to be equally bucolic. Over the past three years, he had spent the majority of his time acting as the caregiver to his girlfriend’s parents, who had multiple health concerns. Instead of hiring a full-time aid, Steve stepped in three years ago when his job as a service representative at Costco became intolerable. Steve seemed like he was a member of his girlfriend’s family, and life was quiet and comfortable, “Perhaps too relaxing,” as Steve put it. He was casting about to find a new direction for work that would incorporate his interest in photography and give him a challenge to complete. Although Steve’s life was comfortable, he had no health insurance and did not have the financial means to pay for medical care out of pocket. Since his diagnosis in 2004, Steve had vacillated between what he called “good and bad cycles” of control, the good cycles lasting for months at a time. When I talked to him in May of 2013, Steve had been on a “good cycle” for about six months, losing weight and monitoring his blood sugar levels closely.

Steve had grown up and spent his adult life in the Pacific Northwest, moving between southern Alaska and western Washington. He worked in camera stores and as a photographer most of his adult life, at one point owning a photography store in Juneau. He moved to Seattle to study graphic arts in 2008, but dropped out after a year, partly due to mounting school debt and
also because he felt that none of his plans would work out. Steve felt that relationships with people were a critical part to learning about oneself, “Because really that’s the only way to grow, I think, to become something else, to learn, is to learn from other people.” Understanding what he wanted to get out of life was a theme Steve returned to often as it intertwined with cycles of dealing or not dealing with diabetes. As we talked, Steve explained how these cycles were similar to other cycles throughout his life, such as those regarding college and jobs.

Steve had his blood sugar tested at a health fair in the mall where he was working in 2004. His BG was around 400mg/dl (very high) and his A1C was 10 when he went for his first T2DM appointment. This meant that his blood sugar levels had been consistently around 300mg/dl for at least the past three months. Steve felt that T2DM was “extremely freaky, kind of end-game stuff” when he was diagnosed; he went to T2DM education classes and for about three months ate hardly any carbohydrates at all. “They say its progressive and it doesn’t go away, but I was young enough that if I do the right stuff I can keep it at bay and prevent the bad stuff from occurring hopefully for as long as possible. So, that’s what got me going on diet and exercise and all that stuff. And it worked great, but it worked so well I kind of fell off, ‘Well I’m doing so well’ then I’d have a piece of pizza, or lasagna.” He quickly gained back the 15-20 pounds he had just lost and established a repeating pattern. “What I’ve found over the last, what is it now? Nine years since I found out, I’ve gone through cycles of being really good and then ‘Oh, I can have a hot dog with a really big bun (laughs), stuff like that.”

When I mentioned that the way he described eating sounded like someone trying to quit smoking he said, “It is like that, or anything that you like to do. When it comes to food, for me,
it’s like ‘Oh, I haven’t had pizza for six months, I should be able to have a few pieces of that…’ So, it’s been back and forth.” In Steve’s “good cycles” he eliminated almost all carbs and counted the calories of everything he ate, and although his BG levels went down, he was not able to sustain the intensity. Over the previous summer, Steve had been eating a lot of “stuff [he] knew [he] shouldn’t” and not checking his BG levels, partly because of the expense of the strips. He had once again gained 15-20 pounds and when he did start checking, his BG levels were “all over 200 no matter what, so I was, I started changing my diet back to where it was, where it should be and not allowing myself to cheat, ‘Oh, I’ll just have this candy bar to tide me over the afternoon. It’s a nut roll bar so it’s mainly protein,’ right? (laughs). So, I got strict on myself and not allowing myself any carbs.” Steve fell back on his established pattern of strict discipline once again, but this time he noticed a new a pattern in his BG levels.

Due to intense checking of his BG levels, Steve made a connection between the brittleness of these levels and the control of diabetes. Throughout late November to January, he had become aware of his body’s inability to handle any carbs. “What I noticed was that eating just a little bit [of carbs] would make it [his BG levels] go up.” So, not only were his blood sugars high, all over 200mg/dl, but instead of rising slowly after eating carbohydrates, his levels would shoot up quickly. Steve’s father also had T2DM, and Steve described him as being extremely disciplined about exercising and eating. From watching his father eat and check his BG levels, Steve knew he should be able to eat the same amount without having his BG rise so sharply. After noticing this trend, Steve became more determined to eliminate all carbs from his diet, at least until he felt more in control and further into a good cycle once again. “So now that
I’ve got it down, it seems to trend, you know, so once you get it down, I’m able to eat a little bit more, I can have a sandwich with a good portion of bread and it’s [his BG levels] still OK with that. But (pause) it took a while to get myself down so that wouldn’t happen. Now it seems to be trending good, even when I have a little bit of something that I’m not supposed to, so...” Still, his BG levels were sometimes high in the morning for reasons Steve could not piece together, and that concerned him because it spoke to his body’s declining ability to bounce back from a bad cycle.

Steve had a great deal of time to think during the past three years living on Fox Island, a beautiful place with views across Puget Sound, access to walking trails, and a quiet environment that he preferred. He saw this situation as both a blessing and a curse. “Oh it’s great, I couldn’t ask for anything more, it’s a pretty ideal situation, it’s no stress (laughs).” He took his camera with him on his daily walks; “There’s a lot of cool stuff to see, blue herons, Mt Rainier.” But he also felt unchallenged: “I’m just coasting and it’s frightening because I have no problem with that. It’s scary to me because I feel like I need to have more inspiration. When I get ideas about something I get into roadblocks mentally about executing them.” Like many of the people interviewed, Steve talked a lot about work. Photography is what Steve enjoyed most, “But finding a [commercial] niche…that’s the big problem there. After working retail for so many years, I just got really fizzled out. I never really stuck with college and followed through with it for a goal. For whatever reason I just get side-tracked…life I guess. It would be nice to find something to get excited about.”
Steve compared his last three years of not working to his father and grandfather. “I found out how lazy I am. I mean, I grew up with the idea that you always work hard. My dad worked for the state for 30 years, my grandfather owned his own business and always had a number of things going on, worked hard and it was always the ‘work hard’ ethic punched in. You know, I always had a job from when I was 16 on, full-time, (pause) so the idea of not working, or doing what I’m doing now, is pretty ‘What are you doing? (laughs)’” Taking the time to think at the expense of work is not something Steve or many of the people interviewed had the desire or luxury of doing. However, during the past three years, living on Fox Island had given Steve plenty of time for contemplation, “It’s rare, it’s kinda rare. You know, you don’t find yourself typically in a situation like this. I mean I’ve always had a job of some kind; I’ve never had a lapse like this. But I think mentally, I was like ‘Well, this sounds good.’ I think I was ready to relax a bit, maybe ponder where I am and what I want to do. It’s funny what I’ve learned over the past three years is that I used to blame things on other factors, you know, like ‘Well, I’m always working, I don’t have enough energy to do anything else, when I get off of work I don’t have time to be focusing on whatever career idea I had or creative idea.’ But what I found is that now even though I don’t have stresses like these past three years, I can blame it squarely on myself for not taking the initiative. So, I’ve learned that about myself. Over the past three years I’ve become a philosopher (laughs) sitting and pondering things, as opposed to being driven.” Having time to think has allowed Steve to make a connection between his cycles of self-care and living in a “fog” that caused him to be 60 pounds overweight for decades. “Mentally, I think it [losing weight and being in control] will clear up some of the fog going on with decisiveness, to
be more goal-oriented, and…just trying things. Right now I’m not trying things just cause it’s easier not to. I’ve upped my level thus far, but I need to up it another level, that’s why I can stand to lose 60 pounds or so and that’s a huge amount when you think about it. But I’ve been heavy for so long, I don’t even notice it; I look at it as normal when it’s not. I accepted it many years ago so now it’s a matter of bumping up my energy level more. I truly think in my head, if I can lose that weight then I can get off medications or at the very least, reduce the dose. So…that’s my goal. I can see it out there.”

The desire to focus and commit was linked to another pattern Steve had pieced together: the inverse relationship between “having energy” and high BG levels. The “fog” Steve talked about was mentioned by a number of people as a feeling of not quite being present in the world, “being in a stupor” as Marie called it, as though a transparent film created a barrier from being part of the world. For Steve, being in a bad cycle, overweight, and in a state of stasis were all connected. Focusing only on carbs and measurement had not been enough to create a sustainable practice of staying healthy – in fact, his body’s ability to handle carbs was declining. As Steve pieced together past patterns of diabetes control, they more clearly connected to other patterns of thinking and value judgments about the future.

Towards the end of the interview Steve stated, “I’m looking forward to feeling better and that’s very important to me. That’s your day-to-day, that’s you, your world, that’s your body, how you perceive life. If you feel lousy, then life is lousy. Right now I’m not trying things because it’s easier not to. I’ve been allowing myself to remain relaxed. Now I’m realizing life is a struggle, there never, ever is a smooth sail. It’s not when I get to here, then I’m done. Coming
to that understanding has been good for me. I don’t see myself going back to the bad way this time.” For the future, Steve’s new goal is to get off of medications completely, something he had thought about for a long time, but also something he never realistically committed to. Getting off medications is now a goal for the future. Having more energy by controlling diabetes and losing weight also means being honest with himself.

Measurement is an important tool to gain control. It intensifies observation and understanding of one’s body and moods. But for Steve, to sustain control for years required more than disciplined measurement. At the time of our interview, Steve was contemplating a new meaning of control that went beyond matching numbers to an external scale, one that was drawn from his own experiences and reasoning. He is making sense of T2DM through the abstracted space of medical science but also transforms it into knowledge that explains his unique daily existence, the opposite goal of T2DM education programs. In those programs, knowledge is left at the level of learning facts and skills, with no connection to how measurement is given meaning through lived experience and the broader context of a person’s existence. Steve used measurement to monitor how his body was progressively losing its ability to regulate carbs. This knowledge pushed Steve to reformulate aspirations for the future that included (rather than held separate) dealing with his body and diabetes, and most importantly, connected to meanings unique to him.

In the next story, I discuss the ways measurement and monitoring can lose meaning they once held when the circumstances that held an individual’s life together change. Rick, who I presented earlier, struggles to make sense of diabetes self-care practices in a new way, after
losing his job and the ability to do the type of skilled labor he has performed since high school. The entirety of Rick’s everyday life has changed and he must also find new motivations and ways to structure diabetes self-care practices. For Steve, quitting paid employment allowed him to make a positive space for contemplation. Rick’s story presented earlier shows how work can also function as a positive force structuring self-care practices. His story illustrates how the loss of work can disrupt what time means, the possibilities of self-creation, and the ability to move forward.

9.2 Contemplation as a double-edged sword: Rick’s story

In the previous chapter, I discussed how Marie and Laura were detached from concern for their health or bodies outside of their ability to work. In contrast to Laura or Marie, work anchored Rick’s whole sense of being, along with the means to pay for medical care and prescriptions. Without work, Rick’s place in the world was profoundly dislocated. His job at Louisiana Pacific provided the same sense of belonging Rick found playing high school sports: “I need to be part of something greater than myself. My job was part of that. Working in the sawmill, I was good at what I did. Before I got hurt, I was just starting to get to be the guy that was needed again. Now that’s been taken away from me.” Work also provided a structure of progression to his life, from “pushing a broom to management, the whole bit.” After 30 years, he was the most senior and second highest paid employee on “the floor.”

Without work to organize his day, measuring, monitoring, and scheduling to control T2DM had no purpose. The loss of his sawmill job also led to an increasing financial strain of treating T2DM, and both played a role in the end of his 25-year marriage. Rick felt his wife was
more concerned about the increasing expense of his T2DM medications than his health after he lost medical coverage. Since losing his job, Rick was casting about, trying to get back the motivation, to get out of “the state I call ‘Poor me’ (whiny voice). The more work I do, the more active I am, the less insulin I use. I know this. I know this.” Babysitting his grandkids was one activity that gave Rick enjoyment and structure, but he was looking for “this calm feeling you get from having a purpose. I think this disease is as much physical as mental. And it’s really hard for me, just dealing with that part. I know how to take care of myself, but its not enough to get me out there. There’s something to be said for being scheduled. Everything was set up, everything fell into order. Now it doesn’t feel that way. Now it’s just ‘Oh, I’ll get to it.’”

Rick said he knew that it will no longer be possible to find motivation to care for himself based on work. He says he is both too old and too experienced to start over in a new career. “No, it won’t come from work. Just having a job right now would not solve a lot of these issues. I have other problems that I need to take care of other than just having a job. For all I know, just having a good job is just going to get in some small way of taking care of these issues and it’s hard to explain that. Or, maybe it’s just that I have more time to feel sorry for myself that I don’t have a job (laughs). Some of it is I finally have time to concentrate on what I’m doing. I think that’s part of it as well.” Rick laughed and told me that he would readily give up this “opportunity” to understand “these issues” if he was offered a good job. Like Steve, Rick’s lack of employment has given him time to contemplate his life, unwelcome as this opportunity is. Unlike Steve, Rick seemed to sustain good control of T2DM and not cycle through “good” and “bad” periods of self care. Having time to think, however, reminds him that he is no longer
working, of the unethical business practices that ended his job, and of the loss of his retirement pension and his job-related disability.

I asked Rick how he felt about using insulin. “Well, that’s one thing that bothers me is I’m OK being on insulin. ‘Well, why don’t you want to get to a point where you can take less or quit altogether?’” Answering his own question, he said, “I’ve lost this mental push.” Unlike Steve, Rick is looking to regain the motivation he once had. In a slightly different way than Steve, Rick is having to re-make sense of his body now that he is no longer working. Instead of the loss of work and gaining time to think a positive factor, the loss of work has undermined Rick’s ability to find motivation for self-care practices. This inability to continue activities that controlled diabetes while he was working is frustrating because he cannot change his emotional state and cannot begin to re-gain control of diabetes.

Similar to interviews in the first chapter, he must find a new meaning for self-care as the conditions, beyond just financial ones, that allowed him to control diabetes while he was working no longer exist. Self-care techniques require scheduling and portioning time into repetitive acts, intensifying an inward focus, which heightens the isolation Rick already feels. Rick emphasized here how he sees treatment as an individual problem and places responsibility for self-care squarely and solely on his own shoulders, even as he describes the larger purpose and sense of belonging he knows is important to him. The focus of Rick’s life has narrowed to his diabetes care schedule, which is not enough to motivate him to resume the walking and swimming he did when he worked. Self-care was shifted from something he did willingly as part of his daily life to a burden with no meaning or place within his daily routine. Perhaps, as Rick
figures out new possibilities for the future, he will also re-incorporate self-care into daily practices.

9.3 The bureaucracy of safety-net assistance: Earl’s story

Like Rick’s story, the next interview examines how an injury and the loss of employment can affect T2DM self-care practices. Earl, a 52-year-old African American man, moved to Tacoma from Baltimore decades ago to find work and to live near his sisters. He came to love the beauty, the rain, and grey skies of the area. Like Rick, he worked full-time after high school, but moved continually from one job to the next. Talking to Earl, I learned that work seemed to provide money, but not the sense of identity it did for Rick. The jobs we discussed seemed to change through the course of the interview with Earl, but the details of employers or the differences between jobs did not seem important to him.

Earl worked as a skilled laborer on large construction jobs and had developed a hernia in 2002, which is what brought him to see a doctor. At that appointment he was told his BG level was 430mg/dl (very high) and that he needed to get it down right away. Earl said he was “overwhelmed” at hearing this news and he “went to all the classes” offered through St. Joe’s Hospital and “followed the long list of things I knew I had to get rid of” in terms of food. Classes and medications were covered by medical insurance through his job. Earl also had to deal with getting the hernia repaired. Once that had healed, Earl began exercising seriously to control his diabetes. He had always been in shape and enjoyed being physically active, so this was not a burden to him at all. After a year and a half, he was off almost all T2DM medications and he had figured out how much he needed to exercise to lower his BG levels a particular amount. From
2007 to 2010, his new job provided no insurance, and Earl used a stockpile of medication (metformin), got extras from friends, and exercised a lot to manage his diabetes. He heard about VolunteerCare through members of his church, and I met Earl there in September 2013.

Earl had reinjured himself at work in November 2012, making serious exercise and work impossible. Earl qualified for L&I, but in Washington State, L&I did not (and still doesn’t) cover any medical expenses other than those directly related to work-related injuries. With no work, Earl had a hard time paying for medications and was forced into emergency housing after losing his apartment. When I talked to him, Earl said the whole situation was “past frustrating.” When we talked, Earl was stuck in the middle of a treatment standoff between Washington State L&I and his surgeon. The surgeon wanted to try a new surgical repair and the State did not want to cover it. While waiting for L&I issues to be resolved, he still had to keep his BG levels and blood pressure down so that he would be eligible for surgery.

Steroid shots to help with pain had sent his sugar levels very high, and despite hating needles and having vowed to never go on insulin, Earl found that he needed it. When I talked to Earl, he was acutely aware of the connection between his lack of ability to exercise, stress, higher medication doses, and the addition of new drugs to control his T2DM. Earl had always been critical of people who used extra insulin. “They just eat cake or they drink pop and they just take more insulin and all that kind of stuff. And I was always, ‘He shouldn’t be doing that,’ now I see myself doing the same thing! I still don’t like it, but that’s the only way I can live, so… Now I’m on a long shot of insulin in addition to the short shot, so I’m on two types of insulin and they keep saying the same thing over and over, ‘We just need to get it down a little more.’ Now
they’ve got me on all these shots, all these pills and I think ‘I’ll never get off of all this stuff.’ It’s just like…I never wanted to be on this stuff. It’s just darned if I do, darned if I don’t.”

The most frustrating aspect of the whole situation to Earl was his dependence on medication instead of exercise to control diabetes. Like many people interviewed, Earl had a goal to get off of medication, but unlike many, he had been able to accomplish this in the past. “My cousins and my auntie, she got off of being a diabetic just by her diet and exercise. So I knew it happened before. And I watched it happen to me, so I know it can happen.” As the options for work, money, and physical activity diminished, medications replaced practice. The discipline Earl had established through exercise was replaced by a more rigid schedule of insulin shots, oral medication, and monitoring calories. Earl recited a number of bits of nutrition advice he had learned at VolunteerCare, now that he was controlling his sugars through diet and medication, “But it’s just one of those deals, you just got to keep on being persistent and keep doing the same thing again and again. And keep on working on it, and better your diet each and every time.” As other options were no longer available to him, Earl had to depend on medication to a much greater degree than ever before. This lack of being able to control his body through his own work added greatly to his frustration with his current situation. What had once been within his ability to control through daily activities was now managed through medications.

Earl had lived in a shelter for the past two months. “Right now I’m in a no-man’s zone. The stress level is just past. Cause it’s just like, I’m where I don’t want to be, who I don’t want to be around. It’s just a lot of stressed people, back-biting. You don’t want to be angry or upset there [at the shelter], cause you’re not going to get no love and kisses there (laughs), or no warm
feelings. You gotta just take care of yourself. You’re there for lodging and that’s about it. I mean, people will share food or help you out if they can, but everyone there has their own problems, trying to not end up completely out on the street or what’s worse than what they got right now.” Without money and with the compounding effects of worsening T2DM control, Earl focused all his energy to maintain integrity as an autonomous individual.

Earl’s life unraveled, like many of the people I talked to, from a cascade of events and not just one factor. “The main thing is you’re not in charge of nothing, everybody else is in charge of everything, so I have get by all these different people’s personalities. [I say to L&I and his MD] ‘You have to really look at the big picture. This is me,’ and that’s what I was trying to get people to look at a few times, but they just keep saying, ‘You got to do this, this, this and this’ (sighs), but it’s ME. So, it’s just one of those deals.” Although Earl sees the whole of his situation, he was viewed as a set of isolatable parts to be addressed individually by state L&I and medical staff. Earl’s desire to be independent once again is confronted daily with the need to take medication to control diabetes. While medications do control his BG levels, this is not the type of control Earl wants. However, Earl also has the motivation and fortitude to keep this increasing loss of control and isolation at bay. “I got social support. I got different meetings and different groups I go to, different people I talk to, I try to listen to their problems, they listen to my problems so I can vent some, I go to church.” When I say that it sounds like Earl has put a lot of work into having support, he says, “Oh yea, cause if I don’t (laughs) I’d be off the wall, cause I know I can’t tell everybody everything but I at least have to let some of this out...I find peace where I can, take a break and just think and think and try and relax. Explosions just get you into
trouble, so I learned a long time ago to calm my temper a lot.” Although Earl’s situation is far more stressful than Steve’s or Rick’s, he is able to create some stability and space for contemplation, which he welcomes.

For Earl, finding strength and regaining individual autonomy was the primary focus. His desire to get out of the shelter, which was stressful and unsafe, was closely connected to his desire to regain control of T2DM by getting off of all medications. Although his world was upended to an even greater degree than Rick’s, Earl’s desire to take care of himself was not disrupted to the same degree. Earl recognized many years ago that having a social network and finding ways to create space for thinking were important and useful survival skills.

The stories of these three men show there is no uniform expression of how they shift from the abstraction of medical models and treatment of T2DM to the demands of daily life. Each has a story that is uniquely their own as they integrate or re-integrate diabetes self-care into new social contexts. All three men realize the necessity of this to control diabetes, and yet for Rick especially it is difficult for reasons he cannot articulate well. There is something about the very nature of diabetes self-care practices that cause them to conflict with who he is now in ways they did not in the past. However, it is this conflict that also produces transformation. Diabetes self-care requires personal meaning to be sustainable and transformative; measurement and monitoring (as self-care practice) alone does not supply the needed traction. Additionally, the value of contemplation is viewed in a variety of ways and becomes part of the equation of self-transformation. In the next story, I describe the interplay between these forms of space in a
slightly different way, again reflecting the individual process through which the abstract rationalism of diabetes self-care practices becomes an integrated part of daily life.

9.4 Discovering control: Jane’s story

The next and final story of this chapter presents a slightly different example of how individuals integrate the spatial and temporal forms that distinguish the social space of medical science into everyday life. New factors converge to instigate personal transformation. For Jane, this process came about through losing full-time work, taking a new part-time job as a medical translator, and becoming a patient at VolunteerCare.

In 1998, Jane had been feeling dizzy off and on for a few days, but ignored the feeling, kept working, and ended up passing out on her job as a caregiver. In the ER, she was told that her blood sugar, blood pressure, and cholesterol levels were all high and that she needed to control all three problems much more carefully. This was not the first time Jane had been told her blood sugar was high. In 1995, at a general medical appointment, she was told that she needed to start medication for T2DM and make changes to her diet. Jane was 42 years old at the time and had been in the United States for only two years, after moving from the Philippines. She felt the diagnosis reflected only the disruption of moving to a new place and not something permanent, so she ignored it for the next three years until she passed out. For the ten years after her ER visit, Jane tried half-heartedly to manage diabetes. Like many other people I talked to, she did not make big changes to her diet very consistently. She loved rice and did not want to eat only ½ cup at a meal as she had been told in T2DM education classes. Her daily schedule as a caregiver was unpredictable, with little time to cook regular meals. Her blood sugar levels went
up and down (mostly up), and more medications, including insulin, were added. Jane became more frustrated with each addition: “Even if I conserved my food intake, my readings were still high, so I got very upset because I don’t know what else to do, even though I was on insulin.”

Eventually, Jane had to discontinue the physically demanding labor of caregiving due to neuropathy and constant fatigue. With the loss of work, Jane also lost her health insurance; however, in a paradoxical way, after losing her job, her ability to control diabetes began. One change was her new job as an on-call translator for St. Joseph’s Hospital. Jane now translated the same advice she had been given multiple times to other people with T2DM, watching people listen and react with her own disbelief or dismissal to the same medical advice. Through these translations, Jane explained how she began to understand the perspective of the medical clinicians and the patients’ (and her own) resistance and struggles trying to control T2DM. After being in the middle, she began to understand the gap in understanding that existed between both parties. Most importantly, she began to understand what the focus on numbers, risk and monitoring actually meant in her own life.

Another important factor that contributed to Jane’s understanding was that she started going to VolunteerCare. “It’s only since I started VolunteerCare (pause). It’s always been difficult, especially before last year, because I was always getting sick, always getting colds or the flu, which makes blood sugars go up. Since last year I’ve been more disciplined, I’ve cut down on my rice, more vegetables and fruits (pause). The people there [VolunteerCare] are so very patient, very helpful. It took awhile, they work with me and my blood pressure and blood sugar have been really stable.” When I asked Jane to describe this change more she said, “I’m
getting to be more disciplined.” When I asked her (again) to explain what she thought made her want to be more disciplined, she told me that at VolunteerCare she felt a personal connection with the medical volunteers, “and because I saw them there really sincerely making me well, I feel ashamed that I’m a disappointment to them (laughs). So, I promised them I’d work on it better. To think that I was getting free help from them and they also gave me medication and referred me to a specialist. So, I feel guilty not helping them. If they’re working so hard to help me then I should also be helping them. So, I’m grateful for everybody there.” Jane also explained how she previously placed responsibility for diabetes control on medications. “For so many years I tried to do what they said, but I just thought, ‘These medicines are not working for me.’” Over a slow process, Jane began to comprehend the much larger and deeper implications to her daily routine, relations to family members, and what diabetes meant in her own body.

Jane repeatedly mentioned she was making blended vegetable smoothies, something she had recently learned to do. “I can eat more vegetables and fruits, just one cup, and my sugars stay level. If I take one cup in the morning then for a long time during the day I don’t feel hungry.” For Jane, losing her job gave her the opportunity to create a consistent daily schedule for herself, and learning to make smoothies and their effectiveness for keeping her blood sugars down was one product of the change in focus her life was taking. “Now that I have slowed down on my work, I have time to prepare my food at home and my schedule is consistent.” Listening to Jane’s voice during the interview, I heard the sense of triumph when she recounted how much longer a 25-pound sack of rice lasted, and how her craving for rice had diminished. But she also said, “I still have to work some more.” Jane said her next goal is to stop eating heavy meals after
She is also becoming protective of her diet and the effects food has on her self-monitoring. She said that when she goes out with friends “I am learning to say ‘no’ to them, ‘No, no you’re spoiling my diet’ (laughs) (pause). Sometimes you have to learn the hard way.” The new self-care practices Jane adopted came from a variety of converging events, not just one determining factor. Most important in Jane’s mind was the personal connection and obligation to change she felt from being a patient at VolunteerCare. The volunteer nature of the clinic and the strong personal connection Jane felt from going there enabled her to really try hard and integrate the monitoring and discipline needed to control diabetes. Jane also slowly learned that diabetes was not a condition easily fixed by medication. Management required the restructuring of her entire life.

Jane is the first person in her family to have T2DM, and she described the struggle over the past years to explain how tired she felt, or the moods and emotions she couldn’t explain, even to herself. She said her family is “very important, we are close, even if the kids are married they visit often. But one thing, when one person in the family has diabetes, other people in the family should be educated also. Because they don’t understand what’s going through that person. So, they don’t understand, like my husband didn’t understand in the early days, and I didn’t either, so it causes conflicts sometimes because of what you’re experiencing, even your moods, your emotions. I didn’t understand either. But later as I tried to understand diabetes myself, when I start to have symptoms now I check myself. So now I know what’s going on inside me (laughs). I didn’t understand those things. In the past, I get moody, I get irritable and I don’t understand myself either. I didn’t know they were related to my sugars. Now I back off and try to get in
control of myself. I felt like my family didn’t understand me and I felt down, I felt alone, like they didn’t have any interest in me either. You go through some kind of depression (laughs). It was hard. It’s been a long climb. I hope I will be able to maintain this, especially now getting old!... I feel lighter (laughter).” This was hard-won knowledge and Jane took a well-earned sense of pride and accomplishment in being able to relate it to me. Control came from being able to use numbers and measuring, but also learning a much more complicated and difficult process of taking care of her body and transforming herself.

In particular, Jane described an important shift in how she used numbers and measurement. Reducing calculated risk or keeping her BG levels within a particular range meant little to Jane for many years. Slowly, however, she has begun to understand how to use measurement as a tool to understand what she can grasp through embodied experience. The discovery of the relationship Jane makes between high blood sugar levels and moods, BG levels and the subsequent feelings of isolation, were repeated in many interviews (and will be discussed in more detail in the next chapter). Like Jane, many people did not realize that the fatigue, impatience, and irritability they felt were related to T2DM. “I thought it was just me!” They assumed that they were “just getting old,” that they were “just lazy,” or “just stressed out all the time.” The interviewees’ discovery of how much BG levels affect mood and personal relationships illustrates the tight inter-connections between what Lefebvre calls conceived and lived space in daily life, and how the meaning of numbers translates in different forms of space and their much different social purposes. Jane’s explanation of mood, her sense of isolation from her own family, and how she learned to relate these experiences to BG levels makes these
uniform and homogenous measurements unique to her. This has been a slow process that has taken her almost ten years to make sense of abstracted uniform medical advice and integrate this into her daily life. The spatial and temporal structures of medical science bracket off history and continuity even as they hold out the promise to maintain these aspects of an individual’s life. Abstracted practice, as discussed in the previous chapter, brackets off what is necessary for people to make sense of T2DM in terms that are local and unique to an individual. In Jane’s situation, and for many other people I interviewed, the volunteer nature of the VolunteerCare clinic was an important mediator between the two.

9.5 **Concluding remarks**

One of Lefebvre’s main points regarding the production of abstracted space is that it enables knowledge and practice to become uniform and exchangeable. As discussed in chapter four, biological explanations make T2DM as a disease state and it’s treatment uniform, regardless of the person living with the condition. The value of life histories of T2DM is obscured by promises of health through rational decision-making skills and medical facts. Most importantly, data and professional expertise based on abstract rationalism are privileged, while the hard-won knowledge Jane has acquired to make sense of T2DM through her own experience is left unacknowledged. Instead, as presented in the Journey for Control training, discussion of individual experience is discouraged. Uniform facts and skills drive how people learn to control diabetes, as opposed to self-care. But, as will be discussed in the next chapter, sustained control comes from taking care of both self and body through each individual’s unique history. Diabetes
in medical practice and education programs is treated as an entity separate from an individual’s life or the social world they live in, and yet this is where diabetes is both produced and treated.

In contrast to the linear temporality and ahistorical, uniform self-taught in T2DM education programs, a complex variety of possible selves are engendered from everyday life, as multiple factors converge or disappear over time. Steve, Earl, and Jane pieced together new variations of self in a continual process of formation and reformation, of which T2DM is only one factor that fits within a unique convergence of many other factors. For example, Rick is still struggling to make sense of losing his identity as a worker and how that affects his ability to control T2DM. He understands the necessity of self-care practices for his health, but finds little motivation to do much and is complacent to use medications to fill in for his lack of motivation. Simply following directions for medical treatment does not supply the meaning or the need for integration; the very purpose of abstracted space (and linear temporalities) is to preclude individual meaning. The abstraction of diabetes becomes the unseen problem for individuals mentioned in this and the preceding chapter. While many people identified that clinicians simply did not understand how difficult it was to make changes in daily behaviors, biological conceptions of diabetes were treated and accepted as unproblematic by both medical clinicians and people living with diabetes.

In this chapter, Lefebvre’s model of simultaneous but distinct forms of space is again useful to explain how abstracted and lived space shape T2DM self-care practices. People in this chapter understand the relationship between measurement and daily activities and have established beneficial methods of dealing with T2DM for long periods of time. However, I also
show the cyclical nature of control (Steve), how it can be disrupted by social forces beyond an individual’s control (Rick and Earl), and finally the length of time it can take to establish control (Jane).

The interviews presented here show how work structures daily life as both a motivator and barrier to self-care, but in either case it plays an important role in how people relate to themselves. Work enabled people to maintain social roles as autonomous individuals, a promise also held out in T2DM education programs; in both instances, time becomes predictable and knowable. These uniform and mechanistic qualities of time are also embedded in the formation of self. Notions of the self as unique and learned through experience were something people in these last two chapters had to learn, or begin to learn. And so, a paradoxical pattern emerged, where losing work because of T2DM symptoms also forced or enabled people to assume responsibility for self-care from lived experience, uncovering possibilities of transformation quite different from rational decision making skills. Rather than uniformity and norms, one gets a sense of permanently fluctuating selves from the stories told here. The opening of time for creative self-reflection is integral to this process, as will also be discussed in the next chapter. Unfortunately, for many people I interviewed, opportunity for contemplation only happened after losing jobs. Rick connects losing his job and dealing with T2DM as events that are forcing him to deal with new and still confusing issues. He recognizes that going back to work full-time might hide those issues again. Earl, on the other hand, grabs whatever chance he can find for quiet contemplation. As he loses control over many aspects of his life, creating space to think and gain a sense of stability becomes increasingly important.
On one level, the discipline of rational decision-making may appear similar to the discipline of lived experience. In both cases, responsibility for control is invoked through the individual, in keeping with American ideals of personal mastery and autonomous choice. The social relationship that gains importance is self-management, an inward movement towards further isolation rather than social connections between people, but the two are quite different. Living with T2DM does indeed require discipline; many times requiring additional help from pharmaceuticals. But individual discipline constructed through lived experience is different from the discipline of medical compliance. Most importantly, they differ in temporal structures and forms of social space. The passage of time, learning from lived experience and making sense of one’s past, and characteristics of transformation and movement are missing from the temporality of T2DM education programs. In this chapter’s stories, the ability to use time productively for contemplation was an important tool for making sense of T2DM.

In the next chapter, I discuss the ways people do make sense of diabetes over extended periods of time. Instead of being external to care of the self, diabetes is one factor of everyday self-care practices. People in this group are always aware of diabetes, but they control it by making it internal to who they are without accepting the medical identity of “being a diabetic” or identifying themselves as a diabetic (no one I talked to identified themselves this way). As in the other chapters, there was no overarching process everyone went through; in fact, that seemed to be quite variable. What was similar was the ability to make sense of diabetes in each individual’s own terms.
Chapter 10: Care of the Self

In “Just Beginning”, I described how people struggled to make sense of the “medical facts” of T2DM. Laura’s story in particular showed how mastery of T2DM self-care skills such as daily scheduled insulin dosing, food measurement, and calorie calculation caused further alienation of an already fragile relationship between self and body. It was only with the onset of severe complications and the experience of physical deterioration that she began to seriously attempt T2DM self-care practices. For Laura, responsibility for T2DM was invoked through physical decline. The second chapter, “Still Learning,” dealt with the ways T2DM self-care practices can fluctuate over time, as larger social forces rearrange lives. For example, Steve was just beginning to understand diabetes and self-care as a life-long practice, an understanding that came from his recognition that how he cared for his health and how he experienced his body and mood greatly impacted his commitment to projects and how he thought about the future. I also showed how the meaning and responsibility for T2DM shifts over time, as people gain understanding of or lose the ability to integrate measurement and self-monitoring into their daily lives.

In this third and final chapter about how people living with T2DM take responsibility for their condition, I discuss people who have come to a stable and sustaining comprehension of T2DM. What emerges from the interviews in this chapter is a much different trajectory of dealing with T2DM. The people presented here are not motivated by the debilitating physical effects of T2DM, nor are these practices the hyper-disciplined, mechanical repetition (abstracted practices) taught in diabetes education classes, which translated into greater fragmentation of
body and self for Laura in chapter “Just Beginning” and the unsustainable bursts of “good control” described by Steve in the previous chapter. The scientifically abstracted body and corresponding self-care practices are still present, but they exist as one part of a self-disciplined life, not an all-consuming disciplinary burden. Responsibility for self-care is invoked through each individual’s lived experience.

However, while the need for self-discipline was ever-present, its meaning was invoked through lived experience and not the scientific subjectivity described by Daston and Galison (2007) in chapter four. Equally important, how people described themselves and how they discussed living with T2DM made it clear that the simplified subjectivity/identity of “being diabetic” presented in T2DM education programs (chapter five) did not begin to describe how these people saw themselves. Daily life that dissociated body from self, such as focusing all energy on work or the inability to find meaning for self-care outside of work, also did not play a role in these stories. Work, of course, was an important part of daily life presented here. Financial stress and other overwhelming events such as physical injury (described in Earl’s story, last chapter) could have disrupted the control and stability people described here. However, what emerged from these interviews was an ability to hold body and self, past and present, in constant tension: to detach from one’s past relationship of body and self and yet maintain a sense of continuity.

In contrast with the preceding two chapters in which I have described the various ways people are unable to meet the new demands of their physical being in daily life, in this chapter, mastery of the flux of lived experience dominates. Crucial to this understanding, however, is that
while people acknowledge the necessity of and are able to incorporate medical abstraction into everyday life, they also do not give it sole responsibility for self-care practices. In daily practice, this involvement of lived experience contradicts the locus of control attributed to rational decision-making and medical facts in T2DM education programs.

While the degree of alienation of body and self described in Laura’s story was not evident in these interviews, it was also not replaced by a discrete, unified subject exercising free will or wholly adopting the mechanical discipline of T2DM education programs. Rather, what emerged was a subject in continual process of formation and reformation within the equally indeterminate larger social space of everyday life. Both are product and producer of the other. One could argue that this process of change applies to all people, and it does, but the quality of this process in each individual is unique, and this chapter focuses specifically on the ways individuals are able to come to terms with T2DM. Even though self-care remains a distinctly American individual responsibility, what I believe made it successful for the people presented here was the ability of each individual to hold the social space of medical abstraction in constant tension with their own lived history.

For the people in this chapter, scientific abstraction was still a part of understanding T2DM; indeed it was an important part of coming to terms with one’s condition in all of the cases presented. But the people interviewed here have also made scientific explanations of T2DM and rational decision-making something unique, local, and positive to their own existence. It is this critical process that was ignored in T2DM education programs and their larger application in the global health services industry. In those contexts, the crucial importance
of the responsibility to learn through one’s own lived experience was dismissed under the heavy emphasis on technology and medical facts. But as the following stories show, the role of biological abstraction, although ubiquitous in everyday life, cannot be given responsibility for personal transformation.

Following the format of the previous chapters, I have selected a few interviews to represent the patterns I identified for this group. I spend more time on the first interview presented, and then discuss a small number of stories that capture the thinking and history of the group, rather than giving more details of a greater number of interviewees. Also, the examples chosen show the various ways T2DM presented, how the course it took differed between people, and the varying attitudes people had regarding T2DM medication use.

10.1 Finding pieces to a puzzle: Maggie’s story

Maggie a 60-year-old, Anglo-American woman, was a patient at CHC clinic when I met her in June of 2014. At the time of our interview, she was working at Wal-Mart as a cashier and enjoying what she described as one of the healthiest and happiest periods of her life. This present stability had come at a price, however. Maggie began her story in 2008 after being fired from Target, explaining that for almost six months that she had been feeling constantly fatigued and “not herself.” “It just got to the point where I couldn’t do anything anymore. I couldn’t figure out what was going on with my body. I had so many unanswered questions it was unreal. I had just unbelievable fatigue and that didn’t make any sense. I’ve always been a go-getter and healthy person, OK? So, when all of a sudden this started happening it confused me and then I lost my job, the depression…” Over the six-month period, Maggie called in sick one too many times.
Months after losing her job, she and her high school-aged son lost their apartment and then lost the belongings they had in storage.

Maggie had medical insurance while she worked at Target, and I asked how her doctor could have missed checking her blood sugars. She told me that she didn’t even know that she needed to see a physician; instead she kept telling herself, “It’s all in my head, I’ll get over it and everything will be fine. No. It never got fine, it got worse actually. It got to the point I was blaming myself for what my body was doing to me. I kept saying ‘Something’s got to give, something’s got to tell me what’s going on with my body.’” Maggie did make one appointment at an urgent care clinic before losing her job, but the physician did not check her BG level. Maggie was not over-weight and didn’t fit the physical stereotype of someone with T2DM, and because she was adopted, did not know her family medical history.

During the interview, Maggie described her attitude during this period as denial. “To me it feels like denial. Yeah. Because I didn’t want to know what was happening to my body. So, why should I go look up symptoms? ‘My body’s OK, it’s going to come back (laughs).’” At first I didn’t understand what Maggie meant by denial. To me, it seemed like the physician was not thorough and missed a crucial diagnosis. But Maggie disagreed with me, saying she knew something was wrong. However, she really did not want to confront whatever it was, so she never investigated what her symptoms might mean by going to the library or looking up symptoms on the internet. As Maggie talked more about herself, I realized these auto-didactic practices applied to much of her life.
After losing her job, it took Maggie another three to four months to get medical insurance through Washington State. Almost a year of symptoms had elapsed when Maggie finally saw a second physician in 2009. “The first doctor was just a fly-by-night doctor. He [the second physician] started to ask me all these questions that the first doctor never asked me! This doctor was like a textbook, ‘Do you have this, this, this?’ and I thought, ‘Oh my God, that’s all me. Really? I really have diabetes? No, no I’m not fat!’” Maggie says her A1C was around 11 or 12 and her BG level on that first medical visit was “over 400” (very high). In this account, Maggie relates a story of mixed responsibility: on one hand blaming herself for not looking into her own symptoms and on the other, she could have been saved an unbelievable amount of stress by doing a simple finger stick.

But Maggie had little understanding of what was making her feel so bad for so long. She had no way of knowing how serious her condition was, or that an urgent care physician was not a good choice for an in-depth consultation. In her reluctance to confront the continuing symptoms she experienced, Maggie also struggled to understand what was “self” and what was “body.” “It confused me. I didn’t want to do anything. It got to the point I was a recluse. I was just completely lost.” From the details of this period Maggie related to me, she was unable to separate the extreme financial stress she was under after losing her job from the fatigue and “fog” of T2DM. The fatigue, irritability and not “being able to cope” seemed a part of who she was, not a disease. Maggie said she kept waiting for “something to give me the why’s and why not’s, something to grasp onto to” while her life seemed to spin out of control.
By the time Maggie was eligible for Medicaid, she was ready “to find out why my body was doing this, what’s going on.” Looking back now, Maggie told me, “It was just the highs and lows of my sugars. I didn’t know then how to react to them.” Two months after her diagnosis, Maggie realized that the oral medication she was prescribed (metformin) did nothing to lower her sugars. “I was mad. Why do I have to go through all this? The first form of pill they put me on did nothing at all. That was totally nonsense. I kept on telling him [her doctor] ‘I’m still having these high counts’ and whatever, so they put me on insulin immediately.” Maggie’s experience of diabetes was more like the autoimmune type that afflicts younger people than the slow onset of diabetes in older adults. She has little ability to produce insulin on her own. Because of this need for insulin, Maggie has had to be much more diligent about testing and measuring food intake than many of the other people with whom I talked. Measuring and numbers quickly became part of Maggie’s daily routine.

“When they first told me I was going to have to do that [injecting insulin] I said, “I’m not going to do that.’ I’m not good with needles; I’ve never been good with them. They had me see a diabetes nurse for the first two weeks I was on insulin and I was adamant ‘I can’t do this,’ but the nurse kept encouraging me until she just put it straight to me ‘If you don’t do this, you’re going to die.’ And when she said that, bam, I was like ‘I’ve got to do this.’” I asked Maggie how she felt after being told that. “She [the nurse] told me afterwards, ‘The reason I wanted to let you know you could die is to let you know that you could do this. So I wanted to put a scare in you’ And she did! For the next two weeks I kept telling myself, ‘You can do this,’ and when I finally figured out how to do it [injecting] without it hurting, wow, that was, that was crazy.” To
Maggie, learning what T2DM was, how to use insulin, and how to adjust doses were the pieces she had been trying to put together on her own. Fear was certainly a part of her desire to learn these pieces, but as Maggie talked about herself, I became aware that making sense of the world through her own ability to analyze situations was also an inherent part of who she was.

Diabetes seemed to make sense to Maggie right from her diagnosis, and the missing piece Maggie had been looking for was her physician’s medical explanation of the process of T2DM. “That’s when I figured out what my body’s doing, you know exactly that, and he [her physician] was telling me the diagnosis of a diabetic and, yeah, it all made sense, it all came together into a little puzzle and I was like ‘Wow, I know now.’” Learning to coordinate BG measurement, food and calorie counting, and estimation of insulin dosage was difficult, but never something Maggie avoided. She did not have an easy time of getting her BG levels lower, and it took at least four months for her to begin feeling better after she started insulin. However, unlike many of the people interviewed in the previous chapters, Maggie never gave up or avoided the monitoring her insulin use required.

At the time of the interview, she felt that her BG levels were getting lower, but she also told me, “They’re good for me, but they should be better.” In large part I think this is due to the high degree of insulin resistance in Maggie’s particular case. Maggie is constantly aware of her body. She explained to me details of what her physician has told her, but in her own terms. “He [her M.D.] called it [her body’s resistance to insulin] rejection, cause my body got another culture shock. Putting in insulin in my body, it doesn’t know why it’s in there. That’s what he [the M.D.] was trying to tell me. It took it [her body] a little bit for it to figure out ‘I got to have
it,’ you know what I’m saying? So now, with what I’m doing, cause it knows and it will tell me. And it’s really weird. I don’t know if you can understand that.” Maggie makes sense of what her physician told her by paying close attention to details of her own experience, and yet this knowledge does not further alienate self and body as it did for so many people in the previous chapters.

“Sometimes in the morning it [her body] will automatically get me up and tell me that ‘This is time for you to do insulin.’ Anymore, I don’t have to set the clock or nothing. I just get up, get into the refrigerator and get my insulin because it knows. It’s hard to explain. But it’s amazing to me how your body learns, yeah, like it really knows.” In contrast to the periods of intense measurement and moral judgment that numbers and “good food” had for Steve in the previous chapter, or the disciplinary burden self-care presented to Laura or Cedric, needing and using insulin for Maggie is something she understands with her body and has a meaning that she can’t really even explain. While her A1C or the refill record of insulin from her pharmacy would imply a compliant patient to me as a pharmacist, as she explained her life more, Maggie’s understanding of diabetes and the meaning it has to her was a much different and complex process than compliance to medical treatment.

What Maggie described was a process of becoming aware of possibilities. “But I’ve learned to watch my carbs. I used to do regular plates and now I do the small plates. That’s really helped. I figured out how to eat in between which I wasn’t doing. A lot of it has made me more aware. I eat salads more. I eat…healthy, which I wasn’t doing before. I’m the first one to tell you, I was a junk food addict (laughs).” Maggie started making big changes in her life a few
months after starting insulin, which she first attributed to having watched a good friend go into a diabetic coma: “I didn’t need that. I didn’t want that in my life. I had a son to take care of.”

Maggie was sent to a diabetic nutritionist, “and that made me more aware too, and I also went to the library and looked up your diabetic recipes, diabetic information…yeah, so that’s really helped a lot. I have a Kindle Fire and I have a diabetic website to where I can go and look up recipes and things about diabetes and that’s helped me out a lot too.”

What is striking about Maggie’s description of learning to live with T2DM is how it has shifted possibilities in her life. “It made me more aware of the things I could control. I’m in control.” Maggie described what this sense of learning felt like: “Like I said, at first I was in denial so I didn’t, I could care less back then. But when I found out, it was like a major, major, major realization… something just clicked and said, ‘That’s enough, you’ve got to give up this, you’ve got to give up that.’ And you know me, I didn’t want to give up nothing! I thought I can still eat this and eat this and I’ll be fine, but no.” The precarity of her body led to a new sense of awareness and possibilities for her own life that she had never contemplated before. For Maggie, these possibilities were exciting and motivating rather than a disciplinary burden.

“And another good thing, too is it [self-care] made me start walking more. I’m a bus-rider, so I have to walk. But even if I didn’t, I’d still walk because walking is really good for you and healthy.” Like many of the people interviewed, physical mobility for Maggie was limited, but walking was something she could do within her limitations. “I can’t do a lot of exercise…for numerous reasons, but walking to me is very healthy, you can get out there in the fresh air, get out there with friends, walk the beach with a friend. This person here [the friend who went into a
comma] she doesn’t even want to do *that*. I can’t really do the rest of the stuff [exercise] they want me to do, but I think that’s [walking] the best thing I can do, so I just grab up a friend and away we go, or I’ll even walk by myself. I’ve lost another five pounds just from walking. Yeah, this is the healthiest I’ve been in a long while. So that makes me feel good.” Walking has also been a way for Maggie to indulge in looking for new possibilities.

When I asked Maggie whether she had noticed that walking lowered her BG levels she simply said, “Yeah, um huh” and then told me, “But it puts you in a good mood, it really does. Wherever you go outside you’re in the healthy air and you’re exploring! It’s gotten to where I explore now. I didn’t used to do this either, but wherever I’m at, I look at my surroundings, which is really weird because I never thought of that. But now wherever I go I see the surroundings, I never used to do that, I would just go. Everything was just one way. Now I have all these other ways that I can look and view and it’s so amazing.” Perhaps Maggie sounds a little too optimistic, but as I listened to her describe the years from 2009 through 2011, after she lost her job at Target, and her apartment and possessions in storage, I realized that her optimism was a hard-won victory over an extremely dark period of her life.

“My son and I were actually on the street for awhile. That was very scary, we were just staying wherever we could, you know. I lost everything. That was just devastating, because I had relics given to me by a relative, worth a lot of money. We had to start over from just the clothes on our backs.” But something also prompted Maggie that her life would change. “I knew I had to move on. Something positive had to happen. Something had to give. There had to be a way through it.” What happened was a chance meeting at a bus stop with an outreach worker from a
local non-profit, who asked Maggie if she was doing okay. “I just broke down. Normally I don’t do that but I was just in so much turmoil.”

Maggie had no knowledge of the social safety net that did exist in Tacoma to help people get back on their feet. “Oh, you go here, you go there, yeah, I actually had someone positive in my life who was helping me. Once he gave me the clues and the numbers and whoever I could get a hold of, everything went into place. I could look to the positive instead of that dreary negative.” In the same way that Maggie was looking for some shift in the pieces of her life to explain why she felt so bad pre-diagnosis, she was also looking for the shift that would get her off the street.

At the time of our conversation, Maggie was still in disbelief at the kindness and interest that an unknown man took in her. In our interview she asked, “Why? Why did he stop and talk to me when no else was taking any interest in me? Then I stop and think ‘Well, the Lord works in mysterious ways.’” Maggie was able to get disability, an apartment, and a job at Wal-Mart. She felt safe in her new neighborhood and financially stable, but also told me “I have to keep being diligent and keep up with the diabetes. I have to nurture me.” Maggie seemed to have a lot of “best girlfriends” and mentioned repeatedly organizing outings and get-togethers. “To have a relaxing day, you need it, you really need it.” Maggie was chatting with the library staff when we met at the library; she told me knows them well because she spends so much time there reading and checking out books. All of these activities, she told me, helped her take care of herself, because she knows she has little outside resources such as family or a financial cushion.
Not unlike Jane in the previous chapter, Maggie related how diabetes has, after much hardship, changed her life in positive ways. “The physical part of diabetes has opened up new doors for me. It’s made me stronger. With everything that I’ve been through in my life and there are lots of stories I can tell you cause I was adopted and because I had, such a not good childhood at all, growing up, I’ve actually had to grow up too soon, because of certain things in my background.” Maggie told me she learned at a very young age that she had to “grow up and be an adult before I was old enough to be an adult. It’s made me strong. No one’s going to stop me. So now, with the positive attitude that I have now, that I didn’t have before, it’s like a whole new area, a whole new… Maggie. This is the new Maggie, the old Maggie’s gone now.”

I asked Maggie the first time she had to deal with overwhelming stress and she told me, “My whole life. Ever since I was little, let’s see since I was five years old. Not fun. But there’s always a new, there’s always something to look forward to.” Like Laura, Maggie related having little concern for her body before being diagnosed with T2DM, but Maggie also related a very different approach in coming to terms with it as a condition of her life. Maggie developed a skill early in life to create space for analysis and hold her past in tension with possibilities in the future. Her story of dealing with diabetes describes a positive pattern in which autonomy is obtained not through further alienation through disciplinary power, but through self-discipline learned through her own past.

“I don’t have to go back to who I was, to not controlling who I am. There’s always something new, always something there. Life keeps going on no matter what. Because of all the bad things that have happened to me, it was going to take over me. I was never going to let it,
that was instilled in me at an early age.” When I asked Maggie who instilled that in her, she said, “By me, by me, because there was nobody there. When you don’t have nothing, you have to piece it together. I was always finding things on my own. I always thought there was a different road, there’s a different road I can take. So that gives me hope to find out who I am.” In a similar way that being diagnosed with HIV/AIDS has given people an opportunity to reinvent themselves (ref), diabetes gave Maggie another tool to understand herself also.

Maggie and Laura’s experiences illustrate the heterogeneity of how people make sense of the self-discipline needed to control T2DM. What was an almost unbearable schedule of repetitious acts and calculation of insulin dosing to Laura is a revelatory process of discovery for Maggie. To Maggie, insulin and its scheduled dosing became a way of giving her body something it “had learned” it needs. The two women’s experiences illustrate the differences between self-discipline and disciplinary power. Maggie has learned over time what she needs to do in terms of understanding her own singular relationship between body and self as opposed to the uniformity of self-care practices derived from T2DM as a biological entity. These uniform practices strip self-care, and the relationship between body and self, of meaning derived through lived experience.

Maggie’s story illustrates how these types of discipline are intertwined in daily self-care practices. She initially uses a biological explanation (and therefore abstracted space and disciplinary power) to explain what is happening to her body. However, for Maggie to really make sense of T2DM, she achieves a much deeper understanding of her condition through lived experience and daily practice. Daily self-care makes diabetes unique to Maggie. It is this step
that Laura is unable to even begin to attempt and that Steve has trouble sustaining for long periods of time. For both of these people, T2DM remains something abstract and external to their own lived construction of self and body.

Too often, the process of self-care as personal transformation is conflated under medical compliance or ignored by converting people into abstract bodies and disease, and big data flows used in the health services industry. The way Maggie is able to control the symptoms of T2DM requires an understanding of diabetes acquired through multiple experiences, as something unique to her; a much different understanding from the depersonalized practices of T2DM education programs. Most importantly, the transformation Maggie goes through after being diagnosed with diabetes belies treatment success as medical compliance or self-care practices as a uniform commodity provided through the health services industry.

Maggie appears to be a compliant patient; on the surface she meets the criteria of someone who does all of the correct T2DM behaviors. But how she came to that place is through life-long survival skills and the ability to dismantle and reformulate new relationships between body and self. Instead of further alienating body and self as discussed in the previous two chapters, Maggie more firmly unites them to create an understanding of T2DM that is unique to her. In the next two shorter cases, I wish to discuss two patterns of behavior common to the people able to create self-care practices that control the symptoms of T2DM. The first is the ability to create space for contemplation and analysis, and the ability to bracket off self-discipline from stresses of daily life.
In the next story, self-discipline was the result of seeing the physical effects of uncontrolled T2DM firsthand in many family members, and illustrates the devastating impact the global T2DM epidemic has on families. But Luis’s ability to manage diabetes was also something that set him apart from other family members who were not able to manage it well. Luis saw the responsibility and self-discipline of controlling diabetes as an individual responsibility, which closely reflected his strong belief in working hard to be successful in the United States. Dealing with diabetes seemed to be another problem Luis had to confront and then act on, like escaping the poverty he had grown up with in Mexico. Like everyone in this chapter, Luis approached the obstacles in his life as problems he had the capacity to reason out.

10.2 An American success story: Luis’ story

Luis was born in Mexico in 1968 and came to the United States in 1993 when he was 25 years old, married and with two children. He has been living in the United States as an undocumented worker since then, although his children are all U.S. citizens. “We came to the U.S. to make a better life and my youngest son, he made it. He graduated from the University of Washington. He made it. Now he is in Chicago at Loyola University for two years.” I met Luis at his first appointment in the CHC clinic. Until quite recently, he had been a patient at Group Health through his job’s medical insurance, but had quit as a foreman at local manufacturing business after 18 years and a protracted denial of Luis’s request for a higher wage. After he quit, Luis learned from former co-workers that production at the company was down and overtime was up. Luis was not boasting about himself when he said this, rather, it was a way to explain his leaving as a bad business decision of his former employer. Despite the unfairness that Luis felt
the owner displayed and the severe stress this disagreement created for him (he broke out in a painful episode of shingles), Luis still answered technical questions from his old boss when problems arose at the business. Luis’s willingness to even answer calls from his old boss, let alone help him out and laugh about the ridiculousness of the situation to me, explains much of his character.

Luis was motivated to control diabetes to avoid the pain his father went through before dying from diabetic complications. Shortly after Luis’s own diagnosis with T2DM ten years ago, he returned to Mexico to help care for his father, who needed dialysis due to diabetes-related renal failure. After a few weeks of going to dialysis, however, his father refused any more treatment, saying it was a waste of money for the poor quality of life he had to endure. Luis stayed in Mexico for two months. By that time, insulin did little to help control his father’s high blood sugars. His father developed severe, painful edema, and this was what Luis said he wanted to avoid at all costs. “Physical health is important because I don’t want to have the pain. I want to feel good, always.” But physical health was also important because it allowed Luis to work, solve problems, and make money. “I want to be able to work. When I was a supervisor, I could help people to make things work. I know how to be able to fix things, to make them work better. ‘This is the problem, what am I going to do about it?’ I do things, I can fix things to make them produce and make money.”

However, making money for Luis had a bigger purpose. Most importantly, it allowed him to help his family and social network in the United States and Mexico. He also sent money to the small town where he grew up, which was controlled by a drug cartel. “I help all my family

254
always when I can. I also send money to people not in my family, because they are real poor people. I am always involved in something, to do something.” Money, problem solving, and helping others are tightly connected in Luis’s world. “I can handle it. I don’t want to spend time in the house, I always have to do something because (voice changes to a severe tone) ‘Time is money, you have to do something (laughs hard) Yes, yes.’” Luis proceeded to tell me a long list of people he and his wife have helped and the items they bought for other people including cars, dentures, homes, donkeys, cows, and a horse, since coming to the United States. By helping people, Luis feels that they will be able to help themselves. “I tell my wife, let’s support these people and they can make money for themselves, they can make something. Because I come from the poor people. We come from very, very poor families. We appreciate all we have.” The role of money and staying healthy for Luis came from the ambition to have a better life, but this ambition was anchored in family and his “home.” Luis understood his responsibility as caretaker to both himself and others as keeping healthy to work.

Luis also told me that almost every person in his family (including his wife’s parents) had diabetes. Unlike Maggie, Luis watched the complications of diabetes almost destroy his family. Nine days after the death of his father, Luis’s mother, who had lost her vision due to diabetes, passed away from a heart attack. Luis’s brother also died, three years after being diagnosed with diabetes and not doing anything to control it; an older sister in the United States was facing the prospect of going on dialysis and her oldest son had quit school to help care for her. A younger sister had BG levels that were always around 300-400mg/dl and had a hard time coping and
taking care of her two small children. Luis and his wife took her in and helped babysit so she could get her diabetes under control. However, she left their home after two weeks.

“\text{I said, ‘OK, but you know the door is always open if you want to come back.’ I think everybody is responsible for himself. To me, I have to take care of myself. I know my dad drank a lot of soda and eat whatever he wants. In my town [in Mexico], it looks like everybody has diabetes. I don’t know why.’}” When I asked Luis what might have changed in the past decades in the way people eat or live, he told me, “I’m not sure exactly what is it, but one thing, my grandmother never used oil to cook food, no fried foods.” The huge impact of diabetes in Luis’s life reflects the global presence of diabetes and the severe consequences it will continue to have as people are unable to live in ways that prevent it or cope with it once it appears.

Luis was aware that simply having access to medical care was not enough to prevent diabetes complications. He was worried about the health of his sisters, because he understood the reality that they might die. He had nagged his younger brother into seeing a physician when he began showing the same symptoms of diabetes Luis had seen in his mother years ago in Mexico. Luis worked at the same job with his brother in the United States and watched him drink a gallon of water in a day and still complain of being thirsty. But when Luis tried to get him to see a physician, his brother denied that he felt bad or that anything was wrong. Luis’s brother finally did see a physician, but he died only three years later, after returning to Mexico.

“Because he don’t take care. That’s why, when I start feeling the same thing, I don’t wait, maybe less than a week. I had insurance, so I say to my doctor, ‘I think I have diabetes’ and he does the labs and says, ‘You are not too high, like around 200, but you have diabetes.’” When I
asked Luis why he had such a different way of dealing with diabetes than other members in his family, he couldn’t really explain, other than saying it is each individual’s responsibility. But Luis also told me, “One of the big things in all of this is my wife too. She is one of the stronger hands in all of this to help me.” In all of the decisions to lend money or help family members, his wife was an active partner.

When I asked how he felt after his diagnosis, Luis said, “I wasn’t surprised because I know all my family has it. So I say, to me, people can survive if you take care.” Luis then tells me that when he went down to Mexico to take care of his father, he did not tell anyone that he had diabetes, and hid his medicine. “I don’t know why I couldn’t say it.” It is evident from the great deal of effort and money Luis spends on his family that they anchor his life. But the details he related about sharing or not sharing his own diabetes shows how “having” or “not having” diabetes shifted family dynamics. At family gatherings, for example, he is fixed a smaller plate without question, because “he has diabetes,” while his younger sister with the constantly high BG levels eats the same food as everyone else. For Luis’s family members, “having diabetes” represents the insurmountable break in daily life discussed in the first chapter.

For Luis, self-discipline was a responsibility, like working, which enabled him to support his family. Just weeks after losing his insurance through Group Health, he made the appointment at the CHC clinic where I met him, so that he could pay on a sliding scale. Taking medication was also important to Luis. “I always remember to take my medicine, morning and night, morning and night,” the same way he checked his BG levels for the first three to four months after he was diagnosed. Much more than Maggie, Luis seemed to always be aware of how the
present would impact the future. For example, paying more money for healthier food made sense to Luis because the extra cost at the time was worth the complications it prevented in the future. Avoiding the pain his father and mother experienced and being able to provide support meant bracketing self-discipline off from the behaviors of family. I think in Luis’s cost-benefit analysis, the separation he may have experienced from being in control of diabetes was balanced by the ability to support his family in the long run. His role as caregiver, however, was balanced by a sense of individual responsibility that he felt everyone had to assume. Like Maggie, Luis was continually looking towards the future for possibilities, but still connected to family and place. Work was not something he did at the expense of the future, like so many of the people in the “Just Beginning” chapter, but something that his present concerns made him responsible to plan for. Luis’ outlook that if he “took care” he could prevent complications of T2DM was repeated by many of the people who were able to control their BG levels.

10.3 A lifetime of self-discipline: Sara’s story

In this next (and last) case, controlling T2DM without medications was the goal from diagnosis. However, the outcome described next was possible through a number of factors, including sustained self-discipline, and equally important, the presentation of diabetes. Maggie, for example, could not get off insulin. Sara was a 54-year-old Anglo-American woman who grew up on a small farm in Puyallup, an area near Tacoma that is rapidly urbanizing, located on the Puyallup River delta (chapter three). I met Sara in October 2013 at the VolunteerCare clinic, where she had turned to for help for medical conditions other than T2DM. At Sara’s first VolunteerCare appointment, her A1C was around 5 (the range for people without diabetes) and
she was on no medication, even though she had had T2DM for 20 years. She told me the physician she saw jokingly asked her, “Are you sure you have diabetes?” Over the years, Sara has refused medication, even when her A1C went above 6 and her doctor wanted her to start. “The doctor just said, ‘Well, it’s your life.’ Great. You’re right, it’s my life. This guy would just laugh at me. ‘You’re just too stubborn.’” Sara does take medication for blood pressure, and that was what actually prompted her visit to the clinic.

Sara had vaguely heard that a number of aunts and her grandmother on her maternal side had “sugar diabetes,” but other than that, had little knowledge of it. She said she was very overweight and that her mother had nagged her about losing weight because of diabetes, but she had felt that she “still had time, at some point to get it together,” before she really needed to start worry about diabetes. Sara’s BG level was almost 400mg/dl (very high) when she was 29 years old and diagnosed in 1994. Her BG level had been measured as part of routine blood work. She had been diagnosed with what was then called “non-A, non-B hepatitis” which she had acquired from a blood transfusion during delivery of her last child. Sara was “devastated. I just felt helpless and scared and totally overwhelmed. It probably didn’t help that I was dealing with hepatitis at the time…But, within a couple weeks I had to go to a diabetes class and that was very helpful and also very overwhelming because there’s so much information being thrown at you.” However, Sara also decided that the intent of the class from the nutritional information and the attitudes of the instructor and other students were completely different from her own.

“I decided that the diet they taught us in class, I couldn’t, the diet they taught us was all based around medications. And I didn’t want to take medicine. I just felt out of control and I
didn’t like that.” When I asked Sara to give an example of what didn’t make sense to her, she
told me, “So, we were told if you’re at a birthday party and you want cake, have the cake and
take a couple extra units of insulin. And I’m thinking, ‘Don’t have the cake in the first place!!’ I
just couldn’t get that. If you’re not supposed to be eating that stuff, then don’t eat it, you know?
But everyone in the class was just like ‘Oh, OK. I can do this, yeah, yeah.’” And while Sara said
they were told to only have a small piece of cake, she still felt that the class made medications
the center of treatment.

“I was just sitting there thinking, this kind of thinking is just a little skewed.” After one
week in the class, Sara had decided “If eating cake meant an extra shot of insulin, then I wasn’t
going to eat the cake.” When I asked Sara if she had been given medication to get her very high
BG level down, she said no. “Maybe stupidly, I refused. I told them give me three months and if
I still need medication then I’ll take it. I just decided that I’ve got to figure out a different way to
eat. Fear was the motivating factor. I really did not want to take the medicine. It felt like once
you did that it was a slippery slope to getting worse. I don’t know whether that’s true, I just felt
that at the time. You were giving up, somehow.” Sara decided that diet was the way to regain
control. Since she had always heard the term “sugar diabetes” growing up referring to her
mother’s relatives and from the class, Sara eliminated all of the high carb foods she loved:
noodles with butter, garlic bread, peanut M&Ms.

Sara also felt the American Diabetes Association (ADA) diet taught in the class didn’t
work for her and decided to try the new Atkins diet that was very popular then (1994). The
elimination of carbs and sugar in Atkins fit with what she saw as the cause of high blood sugars,
“I just started to eat vegetables and meat.” In one year she lost about 100 pounds, dropping from “about 300 pounds to 202 pounds.” She stuck with the diet for about four years, before she got “sick of eating the same things.” Sara has kept most of the weight off; she told me she currently weighed 230 pounds.

The second way Sara quickly learned to lower her BG levels was to move around. “I’d check my blood sugars and if they were too high, I’d say ‘OK!’ and I’d walk around the room, I’d do something, drink a bunch of water. They told me in the class exercise lowers blood sugars, so I guess I just figured that if I check and it’s too high then I better do something.” When I mention to Sara that that connection between moving and lowering BG is not something everyone recognizes or does, she was surprised and told me, “Well, I guess I just thought it was obvious.” What seemed to make “just common sense” to Sara were connections many other people I talked to struggled with for decades.

Sara lives in a house owned by her father and she does not pay a mortgage or rent. But due to bad investments, the property is facing foreclosure. Sara is also unable to work more than half a day a few times per week because of the constant fatigue she feels, which she attributes to hepatitis C. Like Jane and so many of the people I talked to, Sara also discussed the isolation feeling bad has had on her relationships with her family. “I don’t even understand how I feel, how can they possibly understand? I don’t mean this to sound bad, but sometimes I’m amazed that I can keep diabetes under control with all the stuff going on…but on the other hand, there are moments when I want to say ‘Screw it all, forget it’ but what’s that going to do for me? If eating better makes me feel better [Sara had recently started a vegan diet] then eating worse is
going to make me feel worse. Family is huge to me. To be able to participate means everything to me, so that’s why my physical health is so important.” To Sara, like Luis, the self-discipline required to keep her blood sugars low means participation, not isolation.

But Sara also talked about growing up with a huge vegetable garden and goats, cows, and chickens in Puyallup. “I guess we were organic long before we knew the word.” She had friends that she knew since grade school, and getting together with them for meals and social events was important for the social connection. “I’m fine with saying no [to desert] but other people seem to have a problem with it. It does make people uncomfortable for some reason. I don’t care what they eat. Eat the cake if you want! But that’s not how they see it. I think society is so much based around food. I think they feel like you’re not fully engaged. And at first I felt that way. Everyone’s sitting around, you’re talking, whatever, and eating brownies and you can’t be part of the full circle unless you’re eating those brownies too and discussing whatever it is about them. Maybe at first it bothered me, but I’d made up my mind so…I just knew I couldn’t do it. I made sure, and maybe this was just my perception, but I made sure to keep in there, keep talking. But it does cause a funny reaction. I think it affects the social [domain] greatly, but I never don’t go somewhere or don’t do something. I can’t say no! I hate to think I’d miss out on anything, what if I miss something important? (laughs).” Although Sara seemed to have diabetes well-managed, she did not view it as anything to be complacent about: “Definitely, definitely an ongoing project. I don’t ever want to think ‘I’ve got this.’ I can always see ways to do better. As I feel better, I see new ways to improve. I’ve fought depression a lot. I was sick of being sick.”
In this process of continual construction, the individuals presented in this chapter decenter the norms they have grown up with or that are held by family members, friends, or co-workers. Their skill lies in being able to dismantle and then rearrange their own relationship between self and body. And while medical facts and rational decision-making taught in T2DM education programs play a role, the responsibility for transformation goes to much deeper factors. Most importantly, sustaining self-care practices play a mediating role in a continually evolving relationship between self and body.

This relationship was not uniformly exchangeable and arose out of the lived experience of each individual. It is this singular and local meaning that puts it at odds with self-care as a uniform commodity taught in T2DM education classes, such as “Journey for Control.” While “Journey” in the title gives the impression of movement and discovery, the importance of lived experience, one’s personal feelings, confusions, and conflicts are minimized. The people in this last chapter have a gift of being able to analyze problems and then take steps to make changes. But the real motivations for change come from within their own lives, something that people presented in the two previous chapters struggled to put together.

10.4 The roles of medication and concluding remarks

In the stories grouped in this section, responsibility for self-care is primarily invoked through knowledge gained through lived experience. Credit was not given to knowing scientific facts or technological progress and identity promoted in T2DM education programs in any of the interviews I conducted. The ability to pull back and analyze was a form of contemplation, albeit a much more concise version than what Steve described in the previous chapter. This ability to
make space for analysis led to control. Briefly in these ending paragraphs, I will discuss the varied role medications played in achieving this sense of control. Maggie and Luis considered diabetic medications necessary to keep blood sugars within the range they wanted. Maggie was insulin dependent and treated this physiologic dependency as an embodied understanding of what diabetes actually was: “My body finally figured it [insulin] out and when my body figured it out then I figured it out. It [insulin] made me feel strong, it made me feel stronger and it made me know that you’re going to be OK now.” Among the people here there was no consistent goal to get off medication altogether. The bigger goal was taking care of one’s body and self in sustainable ways; medication use was evaluated in terms of this end goal. However, in striking contrast to Randall in Just Beginning, medications were not used to make T2DM or the need for self-discipline disappear.

All of the individuals presented in this chapter could be classified as compliant patients. However, the reality of what makes people self-disciplined is much different than disciplinary power or the mechanical and repetitious practices of compliance. Unfortunately, it is only by diminishing the value and reality of one’s own internal visions and lived experience that practices of T2DM self-care can become uniform commodities. However, because of the power of medical discourse and the increasing global reach of the health services industry, identity as a diabetic is held to be factual and more real. The creative capacity of individuals actually dealing with T2DM and the flux and transformation of the relationship between body and self, especially the essential step of creating meaning important to each individual, is deemed secondary.
Chapter 11: Spirituality, Reciprocity And The Ethics Of Self-Care

In the preceding chapters, I discussed the complex processes through which people took (or did not take) responsibility for T2DM self-care practices. In those sections, I discussed three patterns of behavior, Just Beginning, Flux and Care of the Self and the events that emerged within each individual’s life. What emerged was people’s ability to hold the past in a new tension with present, as the relationship between body and self was reconfigured. Successful control of diabetes was not characterized by a blind adherence to medical facts or giving these facts sole responsibility for the need to transform daily life. Instead, medical facts, measurement, and monitoring became one part of a transformation of self, one that required making sense of one’s body in terms of medical abstraction. Rational decision-making and medical facts were incorporated into self-care practices, but they did not motivate people or form a framework for transformation to the significant degree that spirituality or reciprocity did. In this next chapter, I will discuss these two aspects of daily life to which people did assign substantial responsibility in creating of self-care practices: spirituality and volunteering.

11.1 Spirituality

Unlike self-tracking through measurement and monitoring, spirituality and reciprocity through giving to others and volunteerism get at a different type of relationship people have with themselves. For many people interviewed, religion, God, or belief in a spiritual order played a crucial role in the construction of diabetes self-care practices. “I know that He didn’t create us for us to do the things to ourselves that we do, that a lot of us do. We were entrusted to take care of our bodies, those were supposed to last us for life. So, I can always pray and ask Him for
healing, etc., etc. but I’m the one that has to put those cookies down. It all comes down to habits of thinking, of recognizing past mistakes,” one woman told me to explain the role spirituality played in the care of her health. For many people I interviewed, spirituality was used to create order in a chaotic world. Unlike the order created through numerical scales rooted outside of lived experiences and individual history, this type of order was created in relation to lived experience. The environment in which many people I interviewed lived forced them to give up their past without providing much in the way of creating a future. Spirituality and reciprocity provided an alternate framework for making sense in a world where so much had changed. Much of the reason people were able to connect life events with they understood diabetes came from the design of the interview.

As described in the methodology section, the interview consisted of two parts. The first was a linear event history of living with T2DM, and the second was a “care map,” a diagram of six domains related to health: physical, psychological, spiritual, social, economic, and environmental. Each domain had a short, printed list of attributes (appendix 3) that helped interviewees understand what was included in that domain. In this second interview section, people described the importance, or not, of each domain to “how you take care of yourself.” Discussing life events first, before the care domains, allowed people to think about all the events that had happened over the course of having T2DM. Discussing the domains after that allowed people to explain 1) what helped them make sense of their condition, 2) what enabled them to recognize the need (or not) to change behaviors, and 3) what kept them motivated for the future.
It was during this section of the interview that the crucial roles of spiritual, social and psychological domains emerged.

Without being asked specifically about these domains, however, people did not discuss these issues in the descriptive recounting of living with T2DM. Over the course of doing interviews, I realized that many people had not put together for themselves how living with diabetes also tapped into ways of thinking, letting go of the past, stress levels, reasons for hope, or connecting with people. As they explained the lists of attributes to me, the speaker also clarified for themselves struggles they had been dealing with. “What really pops out to me is self-worth,” a woman named Cheryl told me. She and her husband were “camping” while they tried to save enough to rent an apartment. “Cause I’ve been working since I was 15 years old, always providing for me and my children. And now, to not be able to do that… and I can’t, I can’t figure out how to get out of it. Yea, my self-worth. It’s like I feel less of myself.” For Cheryl, God was a sustaining factor that underlay all the events of living with T2DM we had just discussed. Without hesitating, she told me “God is all. He is everything. Without him in my life, I may not be here. That’s what keeps me going.”

A back injury and inability to work created crises that threatened Cheryl’s whole existence: “There’s a feeling of accomplishment, confidence that work gives a person that I don’t have in my life now. I have seven brothers and my dad was a logger, so that was the kind of work [heavy labor] that I was prepared for. So this back injury has really messed me up. Really.” Like Rick, not being able to work upended Cheryl’s entire sense of who she was. Her relationship with God, however, provided continuity with her past, where she had been able to
provide for herself and her children. At the time of the interview, however, this unquestioned relationship to God and a connection to her past still did not give Cheryl a clear path forward. Like Rick, Cheryl was realizing that she had to create, somehow, an entirely new way of caring for herself.

For Carol, losing her Starbucks job after a stroke and by-pass surgery meant also having time to sleep, much less stress, and more time to prepare healthier foods. “But I really do miss that [working]. Having structure in my life, you know. It’s kind of a, a double-edged sword. I mean, you know, I’ve worked since I was like 16, so it’s always been a part of my life. I want to be a productive person in society.” Faith and her relationship with the congregation at her church provided a way to deal with her uncertain future due to no work, poor health, and being rejected for SSDI. “Faith is very important to me. Um, God’s going to take care of me. He always has, so…He’s not going to…he throws things in our path, I mean it’s not an easy life compared to the majority of people. I mean, He’s just, I know He’s going to take care of me no matter what happens. I don’t know how else to explain it. There’s a lot of people out there that don’t have that in their lives. It’s very important to me.” Carol did not spend much time asking “why me?” It was clear from the way she described her faith and church that they both sustained her sense of self and continuity between past and future. In return, she reciprocated by supporting and playing a part in the lives of the people at her church.

Spirituality was expressed in a number of ways. Not everyone that mentioned the importance of God thought religion or belonging to a church was important to them. However, an underlying similarity was that spirituality provided an alternative to the chaos of
unemployment, bad health, and uncertainty regarding the future. Faith provided a purpose when finding one was difficult and unclear or seemed to disappear as life events became overwhelming. Trust and faith worked together to keep stress and diabetes controlled. Instead of feeling insignificant and like non-productive, unemployed citizens, those with faith were provided a challenge and internal critique to uncontrollable forces that had changed their lives so much. Maggie in Care of the Self expressed how faith, trust, and purpose worked together:

“Because I’ve had to endure so much, I always think there’s something ahead of me. There’s something there, there’s a reason God put me on earth. And part of that is to be aware that you’re going to be OK, that you’re going to go on.” She especially wanted me to encourage the people I interviewed after her that they should never lose hope and that present bad circumstances would change.

However, trust in God or a higher power did not mean fatalism or an escape from the discipline required to keep diabetes controlled. In fact, it meant just the opposite in all of the interviews. As Sara put it, “God wants us to take care of ourselves as well as we can. I can take the responsibility to do what I can physically, reasonably do and what I can control. And what I can’t control and what I can’t do, the rest of it, God will deal with it. And I have to trust He will. I’ve ruined days worrying over things that didn’t happen.” I asked Sara if trusting God was a way of being more realistic. “Yea, I think so. I think so. The world is going to keep turning. If I take the responsibility that I can, I’ve learned I can’t do it all. ‘You [God] deal with it.’”

Importantly, as I discussed in Sara’s interview, she does not want to ever feel she has diabetes under control or feel complacent about it. Her trust/faith in God creates a space so that she can
realistically handle the uncertainties she feels about the future: the threat of losing her home to foreclosure and not being able to work full-time.

The love God provides is not “all daisies and roses” as one woman put it. “Sometimes it’s telling you ‘You’re wrong. You need to fix this.’ But no one deserves scorn. I feel sorry for people who have no purpose in life, but I don’t scorn them. The self-worth I give to other people comes from the self-worth I give to myself. My belief in God means that I can’t have negative values of myself. If God is allowing this [diabetes] then there is a reason for it.” Repeatedly, faith was not seen as an escape from reality but as a way of dealing with it, of providing hope and possibilities for the future that were difficult to see in the present. Faith required effort to learn and was not passive belief. Faith was learning to see “the positive and not the negative. There is rationality to everything. God is always in control,” Desiree told me. “No matter what happens to you, I [God] will always be with you. I [God] never change, people will let you down.”

Desiree told me that the time she spent homeless and abusing crack came from taking her eyes off God and focusing on things that could kill her. “By my bad choices, I was killing what God calls holy. Yea.” Desiree realized that food had replaced drugs as an addiction after she stopped using. More strongly than anyone I talked to, Desiree saw controlling diabetes as directly related to her faith, perhaps reflecting how much she needed to restructure her life, but also how working to understand how the New Testament gave her life meaning.

As I discussed in chapter nine, Care of the Self, contemplation and the ability for self-reflexive thinking was a key process in gaining control of T2DM. Spirituality was an important cultural tool employed by many people to answer the question “Who cares?” when biological
definitions of T2DM did not give a framework for understanding the unexpected complexities of living with diabetes. In fact, it was the simplification of diabetes to biological facts that seemed to cause a great deal of frustration and shame for people. Rational decision-making could not explain the difficulties people experienced trying to overcome food addictions, loss of identity, and uncertainty about the future. Likewise, spirituality did not provide a uniform solution or set of easily followed behaviors. It did, however, provide the spatiotemporal continuity some people needed to grapple with the greater degree of objectification required to manage diabetes, frequently occurring during periods of great upheaval, and inability to manage daily life. Providing for the future and a purpose in life through God was measured by trust in God, not necessarily by BG levels, although this latter measurement was necessary.

The importance of spirituality was corroborated in a Community Health Improvement Plan (CHIP) city survey completed in Tacoma and Pierce County in early 2014. The survey was part of a national project coordinated through the CDC to help local health departments set goals through needs assessment surveys. The five key areas identified by community members were: 1) mental health, 2) health disparities, 3) access to quality care, 4) substance abuse, and 5) protecting and improving the environment. Survey results from the three largest (non-Federally funded) health care providers (Franciscan Health System, Group Health, and MultiCare Health System) all identified chronic disease and obesity as the top health priority. The difference in the two perceptions of health care needs are striking and reflect the gap between the importance given to managing bodies and how those bodies exist as socially embedded beings.
I attended the two community meetings organized by the Pierce County Health Department to discuss the survey results in a public forum. There were very few, if any, community members attending who were not also involved in health care in a professional capacity. Results presented from the community portion noted how people discussed the connections between mental health issues, substance abuse and health disparities in the survey results. At the second, much smaller meeting, two Health Department employees commented on the importance placed on spirituality by community respondents as a source of connection and stability and a way for people to access support.

However, the Health Department decided instead to focus on quantifiable benchmarks to improve health in Pierce County: 1) develop standardized chronic disease management measures, 2) develop a web-based medical record registry, and 3) standardize and increase capacity of community health workers as health care extenders. Despite the emphasis from community respondents on issues strongly impacted by unemployment, poverty, and other structural forces, someone involved in the process told me that these three areas were chosen in part because of the familiarity and necessity of being able to produce measurable results.

However, the community’s concerns and those identified by the three health care systems are perhaps not so different. Unfortunately, judging by the approach taken by the Health Department, the connection between the two will not be directly addressed. In the next section, I discuss how reciprocity and the volunteer structure of VolunteerCare the free, chronic disease clinic, created an informal bridge between medical management of bodies and the social forces that affected the everyday life of those bodies.
11.2 Volunteering and reciprocity

Volunteering time and helping others played important roles in two different contexts in this project. The first is the volunteer clinic where I recruited approximately half of the people interviewed; the second were the ways volunteer work and reciprocity were used to create stability and control. Frequently, reciprocity overlapped with spirituality, but the two were different. Spirituality gave a sense of continuity where reciprocity created human connections and a sense of doing good for oneself and others. Two examples from the previous chapters are the ways Luis helped family and community members and Earl’s volunteering even though he was living in emergency housing. As one person told me, volunteering created “a loophole, making my inner-self feel good,” in contrast to the stress of not knowing if he would lose his house to foreclosure. “If I do one nice thing a day it battles the evil side of mankind,” he told me.

These practices took a variety of forms, but repeatedly they served as a coping mechanism, to create a space for making connections, creating a sense of satisfaction from doing and preventing further loss of social stability. The importance of reciprocity as a practice was not something I noticed at first. David was one of my first interviews, and I took the appreciation he expressed for the volunteer clinic for simply being able to access medical care. He was extremely grateful for getting free medications and that VolunteerCare providers changed his medications to a less expensive regimen. He also told me that since he had been to VolunteerCare he had lost 13 pounds, and when I asked how VolunteerCare had helped him lose the weight and he said, “Well, they’re doing it for free, so the least I can do is help myself. If they’re doing it for free
then I figure have to be serious about doing it too. I had been serious, but I wanted to help them for helping me.”

After hearing similar comments during other interviews, like Laura’s about the incredible stress created by being both unemployed and in poor health, I realized people’s gratefulness was not just about being able to access medical treatment, but also that the volunteers’ act of donation and the reciprocity on the part of patients entailed a particular way of being that created a framework for self-care. Throughout David’s interview, he used reciprocity as a way of ordering self-care practices. He related talking to a co-worker about diabetes, “She wasn’t going to take it seriously, and now she lost 40 lbs. and doesn’t have to deal with it. Just by eating right.” He expressed pleasure that she is now off diabetic medications and that she is thankful for his concern. He and his girlfriend encourage each other to walk everyday: “We’re helping each other.” Even his use of insulin has the same sense of reciprocity. “It’s something to help me, to get me to a level of being healthy so I can lose some more weight ” and get off diabetes medications completely.

David was not the only person who appreciated the unique structure and mission of the clinic, as I have noted previously in interviews (Laura, Jane). This, and the ease of recruiting at the clinic speaks to a sense of trust and accessibility that was absent at the larger, much more impersonal CHC clinic. The support and sense of mutual obligation at VolunteerCare included the volunteers at the clinic as well, again something I missed at first in my focus on recruiting and understanding access to treatment. What became clear over time, however, was the volunteer staff and especially the clinic manager, enjoyed the challenges of keeping the clinic going.
despite very limited resources. All of the nurses had a great deal of clinical experience and enjoyed problem solving that required common sense, flexibility, and innovation. The clinic was an opportunity for all of the volunteers to work in a supportive, professional environment. In turn, clients had access to medical care, many for the first time in years, and also a space of sorely needed social compassion.

In one sense, the success of the clinic was measured by the improved blood sugars, blood pressures, and cholesterol levels of patients at the clinic. The clinic staff generally saw these results as a reflection of their medical work and ability to improve compliance with few material resources. However, the limitations of the clinic, its small size, limited means, and volunteer nature, were also its strengths. What I learned from interviews of both volunteers and patients was that the clinic itself had become a mutually constructed safety net that ultimately contributed to the clinical improvement of patients. The volunteer and non-hierarchical nature of the clinic, the flexibility with which it operated, and the open acknowledgement of life’s vicissitudes, all created an atmosphere of trust, common purpose, shared knowledge, and professional support.

The medical care provided at the clinic was not exceptional or unique. The treatment protocols followed were basic, borrowed from Federal guidelines designed to keep treatment costs minimal. However, the clinic’s success at managing chronic conditions was unique--enough that its clinical success after one year became a presentation at the 2011 annual meeting of the American Public Health Association, described as “what could be done on a shoe-string budget.” On one level, the results of decreased blood glucose levels, weight, and blood pressure can be attributed to access to care, and most of the volunteers view the success of the clinic that
way. However, that hides another story, one that is invisible to measurements of treatment success. Rather, it reflects how personal autonomy grows from mutually beneficial social connections and not from greater emphasis on medical facts and rational decision-making.

However, not all things were perfect at the clinic, and certainly people expressed complaints or frustrations in interviews. Also, creating “the space” of the clinic took effort. The clinic manager did not invite back volunteers who viewed volunteering as social time, or who were judgmental of patients. The patients themselves were referred to the clinic through local ERs or another volunteer clinics that only saw people for urgent care. In other words, people needed to make some effort to get into the clinic. Most importantly, the manager reminded me, the success of the clinic in terms of what services it could provide was in no small degree due to its uniqueness. “Everyone feels good about donating to a charity medical clinic. Democrats, Republicans, Wal-Mart, and [local big] Hospital.” She went on to say that if more than one clinic operated in the local area, if they were a threat to the local medical establishment, then the donations of needed medical services would not have been possible.

What happened at the clinic was a unique convergence of factors that allowed for the development of supportive relationships over time, outside of an administratively set goal or threshold. In other words, self-care practices that are individually beneficial in the long-term and therefore sustainable grow out of and not in opposition to mutually supportive environments. In Earl’s interview (chapter eight), he contrasted how stressful living in the men’s temporary housing was with the social support he gets from church, friends and social groups to which he belongs: “I got social support. I got different meetings, friends, different groups I go to. Different
people I talk to. I try to listen to their problems; they try to listen to my problems. So I can vent some. I go to church.” Earl told me finding support is something he has put a lot of effort into throughout his life, “Cause if I don’t (laughs) I’d just be completely off the wall.” Volunteering through his church helps Earl deal with stress by helping “me to get out of my problems. That’s the main thing. If I feel like I’m helping somebody then I don’t even have to worry about my problems. I’m not forgetting about it, but I’ve got something else on my mind. Now I’m putting a positive twist where I’m helping somebody where they need it or helping the church where they need somebody to just be there, or just talking to somebody. Sometimes it’s one of those deals where I get as much as I give and that’s where I like it the most, you know. I’m not trying to measure who’s doing the more or less but just trying to do.” Earl’s comments show the way that social connections between people, freely given and taken for mutual support, help in the long-term to maintain social autonomy. Personal autonomy and social support do not oppose one another, but instead reinforce each other. The self-intensification that measurement and monitoring brings would not be possible for Earl without the temporary stability he creates through social connection.

11.3 Concluding remarks

One of the fundamental attributes of disciplinary power is how it “organizes an analytical space” (Foucault 1977), namely how it isolates people into an individual space: “Each individual has his own place; and each place its individual. Avoid distributions in groups; break up collective dispositions; analyze confused, massive or transient pluralities. Disciplinary space tends to be divided into as many sections as there are bodies or elements to be distributed” (143).
This arrangement of space as a form of power, however, is not absolute. Instead of trying to discover answers to the Cartesian question of “who are we?” Foucault (in Dreyfus and Rabinow 1982) states the task of critical analysis is to understand “what are we?” More critically, “Maybe the target nowadays is not to discover what we are, but to refuse what we are. We have to imagine and build what we could be to get rid of this kind of ‘double bind,’ which is the simultaneous individualization and totalization of modern power structures” (216).

The intensification of alienation and isolation (and homogenization through the health services industry) through self-monitoring is a “type of individualization which is linked to the state” (1982:216) and exemplifies the double bind that not only Foucault but also Lefebvre and other social theorists have discussed (Crary 1990, Goonewardena et al. 2008; Osborne 1995). The use of spirituality and reciprocity show how practices of resistance emerge to “re-constitute subjects” as Foucault might put it. The ethics of self-care, according to Foucault, are manifested through “the practice of creativity and not authenticity,” meaning that subjectivity is not given or fixed: “we have to create ourselves as a work of art” (Foucault in Dreyfus and Rabinow 1982:237). People learn new things about themselves in the process of dealing with T2DM, a process that involves reconfiguring the mundane behaviors of daily life: eating, drinking, sleeping, and exercising. Biological abstraction shapes knowledge of the self, but always in relation to past experiences and knowledge, which are continually and creatively reshaped to meet current needs. Spirituality and the reciprocity of helping others not only created space for contemplation but also provided a framework to help re-defined a life-purpose.

As one woman, Deena, told me, “social to me, means giving support.” She repeated what
other people told me of losing everything and realizing how strong they could be:

I truly feel things happen for a reason and that I needed to learn that I can go to rock bottom and still live and exist. And I have the skills to do that. I can change my lifestyle to have nothing. I can do that. It has made me reassess what I’m going to do in life. And one of the things, since I can’t walk or stand very long, I’ve thought about is doing the super-couponing. And I don’t have a place to stock-pile anything, but I can take that stuff and give it to a food-bank…The stuff I needed the most [when she was almost homeless] were personal items, toothpaste, soap, detergent, shampoo, stuff like that…Going through this ordeal has shown me what matters in life and what doesn’t, you know? You have to have a healthy mind and body. If one of them is bad it’s going to affect the other.

Deena now qualifies for disability (SSDI) because of neuropathy from T2DM, but since she is no longer working, she has re-focused her energies and has begun to lose weight and pay attention to her diet. She is finding a new sense of control, not only from the attention she pays to herself, but also from the sense of purpose she finds helping others. Her dreams for the future include taking care of others as a way of making sense of her past experiences.

As I have tried to show throughout the preceding interviews, relationships between body and self do not take just one form. Focus on the abstracted biological body that is measurable and interchangeable exacerbates the alienation between body and self many people already feel when they are diagnosed with T2DM. Spirituality and the reciprocity of volunteering are a move towards the de-alienation between creativity and self-care practices. Medical facts and self-monitoring are still a part of T2DM self-care, but they play a smaller part than the significant role they are assigned in T2DM education programs and pharmaceutical care. Like so many issues in medical practice, the complexity of treatment is not resolved only by educating people with medical facts, but by becoming more aware of the complexity involved in how people
maintain beneficial relationships between body and self, which are reflected in practices of self-care.
Chapter 12: Affordable Care Act Coda

Most of the people with whom I talked would have qualified for Washington Apple Health, the state’s version of expanded Medicaid under the Affordable Care Act (ACA). From November 2013 to June 2014, I trained and volunteered as a Health Navigator, signing people up at an outreach center in the Hilltop neighborhood of Tacoma. The people I met there told me stories similar to those of the people I interviewed—of going for long periods without medical insurance, medications, and medical care. The relief many people experienced once qualifying for insurance was palpable; one woman started crying when, after completing all the application hoops, the ending message popped up: “Success! You have qualified for Washington Apple Health.”

But applying for medical insurance was also very intrusive, requiring people to divulge income, residence history, family dynamics, and employment, with the threat of fines and legal action if any of those were falsified or if changes were not reported to Washington Apple Health. “I hate dealing with stuff like this,” one man told me, motioning to the computer as we went through the steps of creating a user name and password, verifying address, employment, income, household members, tax status, and social security number. The process became both routine and unexpectedly complicated (very similar to processing prescriptions as a pharmacist) when people’s lives and the tightly defined boxes their lives needed to fit into for medical insurance did not mesh together.

The similarities between documenting and presenting facts about one’s life to qualify for medical care and documenting and tracking BG levels, calories, and activity levels were also
hard to ignore. Facts about one’s past that people preferred to keep private, such as having been in jail, being adopted, losing work, or having no income, were now tied to the documentation of daily activities and T2DM treatment as all of this data became part of accessing and receiving medical treatment. For example, Maria told me she was born in the United States, but her husband was an undocumented resident. She had T2DM but had been without consistent medical care for years because neither her job nor her husband’s provided medical insurance. She was hoping that finally, through the ACA, she would be able to access medical insurance. But the process of signing up was not so simple. Although she and her husband paid taxes, he was not eligible for medical coverage as an undocumented resident. However, because the ACA is tied to income tax returns and they filed jointly, his income had to be considered. Their combined incomes pushed their household into a higher income bracket than Maria’s alone, and she had to purchase insurance at a higher rate.

The more unsettling part of applying, however, came when her claim of U.S. residency was rejected after her address and social security number were entered. After a long moment of awkward silence, Maria explained that she had been “unofficially” adopted as a baby. Perhaps that was causing the problem? I did not ask Maria the particulars of her past, because she obviously did not want to talk about it. However, her status as a U.S. citizen would require further explanation and documentation for her to get medical insurance. Maria was not the only person whose past life did not fit the categorizations provided by the Health.gov and HealthFinder application process. What had been unscrutinized in the past was now becoming
problematic as people tried to fit complicated arrangements of households, incomes, and employment to the application forms.

Maria could not finish the application process that day at the outreach center, since we needed to submit a problem request to HealthFinder and try calling the help line, a time-consuming process. However, Maria called the next day after discussing the situation with her husband; they had decided to forego medical insurance for another year. Instead, they would pay the $99 fine for not having medical insurance and hope for the best. Unlike the empowerment promised by health literacy campaigns or Quantified-Self Meet-ups, a new and intrusive hoop of categorizing one’s life was added to the categories and numbers for T2DM treatment and management. Maria and her husband decided that the benefits of medical insurance were not worth exposing their lives to greater bureaucratic scrutiny.

12.1 Self-objectification and self-care

T2DM is more than a biological condition that begins when BG measurements hit a certain number. Analyzing the preceding interviews reveals T2DM as a continuous process, one that arises as a condition of everyday life. As one woman at the CHC clinic said to me after I explained what my study was about: “You mean how you go from saying ‘Why me?’ to dealing with having diabetes?” In the preceding interviews, self-care practices range from either ignoring or half-heartedly tracking numbers and calories, to giving those numbers sustaining meaning through daily practices and lived experience. Self-care practices to control symptoms bring into clarity what Foucault described as “technologies of the self” (Foucault 1988). In terms of T2DM, technologies of the self are expressed in this dissertation as practices that both hinder self-care.
and motivate people to care for themselves; how disciplinary power of abstracted space shapes our knowledge of the self but also the ways people use knowledge from lived experience for self-transform.

An important theme that emerged from the interviews is how care of the self cannot be distilled down to a disease state’s biological boundaries and the adoption of rational actions prescribed by medical professionals. Even more importantly, the nature of self-care practices advocated in health literacy or pharmaceutical care programs are not neutral, medical facts. They invoke a particular relationship between body and self that for many people interviewed strained an already tenuous connection. The objectification of one’s body through practices such as measuring blood sugars and calories was beyond many people’s capability. Even talking about diabetes was uncomfortable for some people. Alice cancelled two interviews before she decided to talk to me. When she cancelled the second time, I started to explain that the interview was not about judging how she managed diabetes. “I know, I know, I read the flyer!” she told me. On the phone, she described being in a dark place where making choices was not an option. She knew she could die from diabetic complications, but also described how she had ignored her health issues for so long hoping they would just go away on their own. However, months later, we did meet for an interview. When we met, Alice told me she could no longer “Give credence to blackness and pain,” and she had finally been able to commit to a choice. Her comment eloquently describes the complexity of relationships between body and self and the hard honesty needed to figure them out.
T2DM self-care practices as taught in T2DM education classes reflect the dominant ethics of technologies of the self in 21st century United States: self-mastery through technology and the collection and analysis of data. These ethics of care are expressed through a variety of mediums: pharmaceutical care services, the use of digital tracking devices, and groups like the Seattle Quantified-Self. However, technologies of the self expressed through interviews of Tacoma residents described a much different locus for control. Perhaps because stability was absent from the lives of so many people I talked to, or they had been through intense periods of having no control over events in the past, control of one’s body related much more to a state of being in the world, expressed in the CHIP community health survey results. In other words, technology and data were not going to reverse age discrimination, out-sourcing of a job, lack of medical insurance, or insufficient money to pay for medications.

12.2 Simplification, exclusion and power

In the previous chapter, I noted the correlation between gender and control of diabetes symptoms. As both a product and producer of everyday life, diabetes self-care reflects the stability and social autonomy in other aspects of life. As Earl and Cheryl’s stories showed, their everyday struggles were too disruptive to maintain the discipline T2DM requires. On the other hand, stories from the people in the group with sustained control of T2DM symptoms all described the ability to create a space for paying attention to diet and exercise on a daily basis. This self-monitoring was not (or no longer was) the irritating and time-consuming practice it was to the people in the other groups. It also did not rule their lives: “I just realized it’s going to be an everyday struggle. You’re going to have good days and bad days, but you just stick with it. If

285
you do things haphazard, that’s when you get problems. You have to know where point A is and then set it and then go to point B,” one man told me. Clearly, imposing this type of order into one’s daily life was not possible for many of the people I talked to.

The pattern between gender and T2DM control reflects the importance of being able to maintain the level of social stability and autonomy enjoyed before diagnosis of T2DM and the unequal way social stability and autonomy exists in the lives of men and women. Likewise, for Rick, who was able to maintain self-discipline while working, losing employment was also meant losing the social stability needed to control diabetes symptoms. Work, for Rick and many others, was both a stabilizing force that allowed positive practices of self-care and a priority that made ignoring one’s health a necessity. This mutability of factors was repeated in other domains besides work, so that what could provide beneficial structure for some people provided a barrier for others. More importantly, however, was how people strategically used these different domains the individual sense of purpose they provided. Rick stated that after losing his job at Louisiana Pacific on a Friday, he was still able to begin working at a new job the next Monday. This social stability disappeared after his injury. As he explained, working in manufacturing gave him a sense of belonging to a world much bigger than himself, and he struggled to find some way of replacing this loss. In a similar way, spirituality provided this sense of purpose and belonging that was hugely important in providing the stability to deal with T2DM.

One aspect of belonging that was uniformly not mentioned as giving a sense of purpose was identity as a diabetic. At the ADA Expo (chapter five), the entire focus of daily life seemed to revolve around all things diabetes all the time, where the medical definition of diabetes
dominated. People I interviewed certainly talked about medical facts and how important T2DM education classes were to learn how to think about food and calories in new ways, the effects of medication, and what symptoms to consider. However, the rationality presented at the Expo required no self-realization, reflexivity, or the deep confrontations of “what are we?” that caused struggle for so many people I have presented.

This is the crux of what both Foucault and Lefebvre (and many other thinkers) have identified as the colonization of everyday life or the internal shift of colonization: the abstraction of scientific definitions of bodies (as social space) becomes more real as the lived experience of a living subject is ignored. Rather than being a neutral backdrop for things that happen, how bodies are conceived as social space is a form of power. It includes and excludes forms of knowledge and practice that allow subjectivities to change over time. Identity as a diabetic is fixed, along with self-monitoring, measurement, and medication usage that T2DM self-care requires. Lefebvre identified these practices as static because they remained “homogenous, repetitive, and fragmentary” over time. Identity as a diabetic does not include the historical past of the individual, but focuses instead on a particular type of temporality “with a distinctive combination of presentness and repetition” (Osborne 1995: 195), the same temporality of progress and development (chapter three). In a perverse way, the linear temporality taught in T2DM education programs, which is supposed to teach people how to make healthy choices, exacerbates the sense of having no choice that Alice described in our phone conversation. It is this lack of space with which so many people find difficulty.
Programs like “Journey for Control” (in chapter five) promise movement but not transformation. They supply uniform facts and skills, which do not always supply the traction to change daily life for those who need it the most. Transformation of the self, as Foucault and many scholars have pointed out, comes from one’s own knowledge, grasped from lived experience, whereas rational thinking, with its focus on the immediacy of the present, does not provide this needed connection. However, as presented in so many of the interviews, people already live in the immediacy of the present. In the life-stories people told me, satisfaction and comfort from junk food—which many people depended on to get through their days—or the need to give priority to work over self-care took precedence over abstract concerns for the future presented during quick medical visits, if they were even able to access medical care. Knowing rational facts did not give people the ability to apply them when care of the self more often meant being able to work while ignoring one’s bodily health. It was only when symptoms of T2DM made these facts concrete and a very real part of the present that some people began tracking BG levels and trying to watch carbs and calories.

For many people, instead of finding a way to even make a connection between care of the self and care of the body, let alone to understand the complexity and fluidness of subjectivity, just the opposite happened. At diagnosis, people were presented with the singular identity of being a diabetic, to measure and monitor their bodies according to a uniform and external scale to make sense of not only what was happening to their bodies, but also how they needed to act for the rest of their lives. In this way, T2DM education programs facilitate the integration of a particular type of social space (scientific abstraction) into everyday life. The increasing
prevalence of conceiving our bodies through medical abstraction corresponds to how Foucault
describes power as a productive force: medical abstraction is a necessity to manage bodies
afflicted with T2DM, but also introduces greater alienation between body and self and
dependency on technology to exist in the world.

Listening to people describe their struggles as they tried to make sense of overwhelming life events was also overwhelming to me as listener. But, over the course of listening to many people describe their lives, it became apparent that much more was needed besides “good advice” or even a job. It meant coming to terms with it in the context of personal values, lived experience, and all the other singular factors that made that person who they were. Managing diabetes was far more complex than simply managing a disease state. As both a product and producer of everyday life, diabetes self care as presented in educational programs and pharmaceutical care services created a kind of proxy life that created more alienation than connectedness for many people. However, those people I interviewed who were able to control T2DM did not credit medical facts or compliance for sole responsibility for their self-care practices. Instead, responsibility for self care was invoked through what was meaningful to them. For those people without the control, time for contemplation, or ability to create meaning in their lives, controlling T2DM in a sustainable way was an almost impossible task.

Making sense of one’s body through measurement, self-monitoring, and linear temporality is an inherent part of living with T2DM. Self-care practices are constructed from a variety of ways of conceiving bodies. Practices are based on decision-making and medical facts as well as lived experience, and are not so much opposed by but emerge through the creative
energies of people who live with diabetes. As I have tried to show through the life-story interviews, the great obstacle people experience is learning to make sense of their bodies through measurement. However, this central struggle arises from the conditions and problems that already exist when people learn they have T2DM, such as the already established relationships between body and self that enable or thwart one’s ability to integrate measurement, self-monitoring and scheduling into daily life.
Chapter 13: Conclusion

In this ethnographic examination of diabetes self-care, I explain a central dilemma faced by people living with diabetes. In order to control the symptoms of diabetes they must first learn to objectify their bodies through scientific abstraction as they measure and monitor blood glucose levels. Through these practices, they learn to adopt the subjectivity of the controlled, detached observer, which Daston and Galison (2007) describe as part of the new sciences of the mid-19th century. As many of the diabetes life-stories presented here show, although these practices provide a needed tool to manage the increasing dysregulation of one’s body’s, these practices also dissociated self from body and lived experience. People, who had spent years or decades ignoring their bodies or using them to escape the stress of everyday life, were faced with further alienation but in the guise of hyper-awareness through disciplined daily routines.

Much anthropological work has been done showing how biomedical definitions of diabetes simplify the complex social contexts that give rise to the condition and how the diagnosis of diabetes leaves out the real-world experiences of those living with diabetes (Borovoy and Hine 2008; Broom and Whittaker 2003; Guell 2012; Hunt and Arar 2001; Mendenhall 2015; Mol 2008; Schoenberg et.al. 2005; Smith-Morris 2006). However, instead of focusing on the scope of a diabetes definition, or the dichotomy between biomedicine and the individual, I have discussed scientific abstraction as a structural issue that a plays out in the self-care practices of people living with diabetes. While I have focused on the lives of people living with diabetes, I have also shown how abstraction, as a form of social space, shapes all aspects of everyday life and can be used to analyze the practices of both clinicians and patients. This
perspective also allows greater understanding how some people are able to come to terms with diabetes and others are not. Rather than focusing on issues of compliance as an ideology (Applbaum and Oldani 2010; Conrad 1992; Dumit 2010), viewing abstraction as a structural force moves anthropological focus away from dichotomies between physicians, patients, marketing and/or medical insurers to understand the role of abstraction in the production and destruction of social relations (McCormack 2012). I have used diabetes life-story narratives to understand processes of individual reasoning over time in a population most likely to both experience diabetes and suffer the consequences of it. Focusing on scientific abstraction and subjectivity in this present work adds another perspective to the large body of anthropological work on health practices and chronic illness (Biehl 2007; Brodwin 2015; Ferzzaca 2000; Lester 2014; Leibing 2010; Veenstra and Burnett 2014). It also moves anthropological discussions away from understanding abstraction as something that is done to patients by medical providers, and instead tries to understand how people grapple with an increasingly prevalent form of social space.

The concept of structural violence is frequently employed by anthropologists to explain disparities of health, (c.f. Farmer 1992; 2004). Farmer (2006 et. al.) references the work of Johan Galtung (1969) who defines structural violence as the social structures; economic, political, cultural, legal that can prevent people from reaching their full potential. This definition of structural violence is used in the present study, following the work of Mendenhall (2015) on structural violence and diabetes, to understand how symbolic representations like abstraction, also have a great impact on the ways people meet, or fail to meet, their full potential. The
usefulness of scientific universals is achieved at the expense of the experience of those living in concrete reality (McCormack 2012), in this case people living with diabetes. I have shown how the manner in which we are taught to objectify ourselves through biomedical abstractions gives many people living with diabetes little traction to really understand self-care in terms of their own history. Scientific abstraction, meant to simplify and make manageable, also disconnects body and self, preventing self-transformation, process needed to maintain one’s body over decades of living with diabetes. The emphasis on monitoring, measuring and learning medical facts, which are necessary to control diabetes, also means that self-care is alienated from lived reality and directed towards a scientifically neutral, detached body.

However, I have also shown that abstraction and lived experience do not exist as a dichotomy and these abstracted practices can become constitutive of lived experience and self-transformation for many of the people I interviewed (McCormack 2012; Roberts 2006). The story of Marie is an example of how the heightened attention to her body and everyday routines that diabetes monitoring required became transformed to a beneficial awareness of what her body and self needed to survive. However, in clinical practice the self-transformation Marie experienced is largely attributed to following medical advice, or labeled as compliance, and the hard work of learning to understand oneself in new ways is unacknowledged, largely because it gets buried under the structural constraints within medical practice and also because of the legitimate need for technological fixes of medical problems (Farmer 2013). That the value we place on health and our bodies through everyday practices is of equal social importance (and not
just a medical concern) is a point I hope this project conveys. It is also subject well suited to ethnographic methods.

In this project, T2DM has been studied as not only the biological and social conditions that define it but also as the treatments and self-care practices which continually modify it. Many of the people I interviewed could not tolerate the increasing scale and level of abstraction that diabetes self-care practices required. This inability to make changes in daily routines, which was inexplicable and confusing to many people, is not simply an individual’s lack of will power. It reflects deeper conflicts of how bodies are conceived and how these conceptions shape relationships between body and self, a conflict that increasingly manifests itself as the incidence of T2DM increases globally.

Self-care practices also reflect the unevenness by which constraints of everyday life effect different populations. Even in this small study, these constraints fell more heavily on women than men. Men, and particularly married men were more likely to be in the group who practiced sustained self-care. However, these differences can be subsumed under the neutrality of biological abstraction and rational decision-making, a point that has been made in many other anthropological studies of diabetes (Borovoy and Hine 2008; Broom and Whittaker 2003; Moll 2008; Schoenberg et.al. 2005). Unfortunately, the responsibility for changing the scope of medical practice to include the social realities of people’s lives in medical treatment is largely put on the shoulders of biomedical physicians in these studies, without paying much attention to structural issues of bureaucratic medical practice. I hope by showing how deeply abstraction shapes conceptions of bodies the structural issues that shape biomedical practice can be
addressed in ways similar to discussions of structural vulnerability among marginalized populations (Quesada, Hart and Bourgois 2011).

The violence of abstraction, however, is not something that is only “done to” patients by medical providers. The convergence of the abstract and lived exists not just in diabetes self-care, however. It is increasingly common; as daily life becomes more and more technically mediated, it becomes more abstracted. This increasing abstraction shapes the ways social problems are identified and solved. Medicalization can be viewed as part of this larger social process to reduce difference, to fragment, and control. Defined as “a process by which non-medical problems become defined and treated as medical problems, usually in terms of illnesses or disorders” (Conrad 1992:209) medicalization has also been defined as a form of social control, because it strips social context from biological understanding of disease. Increasingly, how we view our bodies, the places we live, the things we do, become pinned to ways of thinking that make all things commensurate with each other, regardless of history or social context.

The desire for unambiguous and value-free rules of thinking about disease is a tantalizing ideal. In her well-known essay “Illness as Metaphor” (1978), Susan Sontag looks forward to the day that cancer will be stripped of all its negative and particularly militaristic metaphors: “It must change, decisively, when the disease is finally understood and the rate of cure becomes much higher. It is already changing with the development of new forms of treatment” (86). Of course, the scientific ideal Sontag looks forward to comes with particular ways of relating and forms of practice that strip away the importance of lived experience, of how we make sense of ourselves. The responsibility to make sense of our own lived history is supplanted by mastery of
medical facts, technicity and rational decision-making based on this type of knowledge. However, this is not the type of knowledge that sustains self-care practices.

Throughout the interviews I have presented here, there is a process of self-discovery, although some are far more successful than others. In the life-stories in “Just Beginning,” people are recognizing important facts about how they conceive of their bodies. They are beginning to recognize that one’s bodily health requires a completely different way of thinking and behaving, practices that will disrupt established routines and relationships. Forgetting one’s body, ignoring it or using to not have to think, as a way to escape, was an established routine for almost every person I talked to. Overcoming these former routines was a stumbling point for many. It was only with the threat of blindness, amputation or kidney failure that they began to address the just the mechanics of diabetes self-care. Throughout the interviews there is a process that people undertake, to varying degrees of success, as they learn to identify needs, aspirations and values that they have been unable to address or have not been able to address consistently in the past. People slowly become aware that controlling diabetes is as much about knowing their own lives as it is taking care of a biologically defined body.

Medical care as a business service holds the promise of shortcutting around the work of self in self-care. For the vast majority of people I interviewed, work and the ability to maintain social autonomy through work shaped conceptions people had of themselves. However, with the advent of diabetes, new ways of thinking were imposed that encompassed not only ideas about oneself, but most of the routines making up daily life. Instead of work, now people had to think of their corporeal body and consciously apply measurement, monitoring and schedules to
manage them. What are made to seem like easy steps: eating a ½ cup of starch, walking 25 minutes, not drinking soda are actually quite difficult changes in how we think about ourselves. They are the barely visible surfaces of complex interior relationships. Without acknowledging how the objectification of one’s body and the transformation of daily routine into disciplined, quantified acts further strain an already tenuous relationship between body and self, the difficulty people have coming to terms with T2DM cannot be addressed adequately.

Sontag’s hope that increasing biological understandings and technologies for treatment will strip diseases like cancer of negative metaphorical meanings is also reflected in Rose and Novas’ (2003) definition of biocitizenship: “By making up biological citizens, we also mean, the creation of persons with a certain kind of relation to themselves…These narratives provide techniques for the leading of a life in the face of illness” (12), creating, “a prudent yet enterprising individual, actively shaping his or her life course through acts of choice” (36). Rose and Novas also connect and commend the quantification of bodies discussed in chapter three with their commodification: “[Bodies] contain the potential to transform the vitality of each and all of us into a standing reserve for the creation of biovalue” (30).

Rose and Novas’ perspective also illustrates Foucault’s definition of power as a productive force as it relates to medical knowledge and practice (Lupton 1997). However, the “seductiveness” of biocitizenship, its ability to solve social problems through the hope, agency and sociability it will bring, begins to give way through the stories presented here of people living with diabetes. While Rose and Novas argue that this “biological turn” is a beneficial progress, I have tried to show the ways that biological abstractions increasingly alienate body
and self, but more importantly mitigate the importance of knowledge created from lived experience. The neutral scientific expertise that seems ideal to Sontag, Rose and Novas is also the characteristic people interviewed had the most trouble dealing with. With greater and greater attention paid to medical facts and technology, there is a simultaneous diminishment of the importance of individual creativity capacity and lived experience. The responsibility to learn from lived experience becomes hidden as people managing diabetes become a fixed, single self, unchanging in relation to the changing nature of scientific facts and technology. Increasingly, the creative capacity for change is put aside as we rely on medical technology to short-cut the work of transforming ourselves. As many of the people I interviewed discovered, diabetes self-care required profound self-reflection and coming to terms with not only making changes to daily routines, but also the realization that one’s values, ethics and attitudes about life also had to change. By examining the social construction of biological bodies the difficulties people have controlling diabetes can be better understood but also how on a societal level, responsibility for beneficial change is attributed to knowledge seemingly external to lived experience, a process Margaret Lock (2015) recently discussed in regard to epigenetics. The work of Lefebvre provides a possible theoretical framework to understand this central role of the body, but as mentioned in the Introduction, needs ethnographic accounts of actual lived experience.

How bodies and self are held fluid or static lies at the heart of understanding how people transform themselves (or not) for better or worse. For many people in the “Just Beginning” and “In Flux” chapters, repetitive acts, such as measurement and monitoring, remained endlessly mechanical and offered no real sense of movement or change to one’s daily existence.
Understanding oneself can be painful, it takes work, and requires the space and time for contemplation. It is only through the attachment to an individual’s history that these acts were not endlessly repetitive and provided a sense of movement and change, necessities for self-transformation. Monitoring and measurement were still routine, but became embedded in the lived history of the individual. People moved beyond the stasis of mechanical repetition to create self-care practices that were local and singular and their very own. In conclusion then, how might this inquiry into scientific abstraction and self-care practices fold into the concerns of medical anthropological research?

Ecks and Sax (2005) write that a strength of ethnographic fieldwork and anthropological discussions of health is its tendency to keep a critical distance from development interventions (202). I would like to add that another contribution ethnography makes is illuminating the ways people can effect positive change in everyday life by describing how social space needed for these processes is constructed and what it might look like. The autonomy necessary for self-care develops along with mutual aid, cohesion and cooperation. It cannot be provided as a uniform medical service. It comes from the values people collectively hold for their health and how responsibility for health is invoked. It also comes about when unexpected connections are made, for example, during diabetes life-story interviews, where both interviewer and interviewee create a shared space of mutual discovery, or within the context of a volunteer clinic where both clinicians and patients receive needed social support.

Spirituality also gave the space needed for comprehension through connection to a higher-being/consciousness/power that shared responsibility and an intimate knowledge of an
individual’s life. In a less profound way, the volunteer clinic provided a space where the stories and realities of an individual’s life were acknowledged along with non-judgmental medical treatment - a shared responsibility. As I discussed in chapter ten, the success of the volunteer clinic was not only due to the medical services it provided but because it existed outside of the social relations of traditional clinical medical practice. I have shown in this study the discipline needed to control diabetes evolves through the ability to re-create oneself through connections to others, and re-configurations of practice and material life. Self-care emerges as people create meaning and construct their own (re)evaluation of themselves and health. Unfortunately, for all of the people I interviewed in the Care of the Self group, the ability to create meaning stays at an individual level. People may come to a new sense of themselves through connection, but the question remains of how to challenge, on a structural level the well enforced dichotomy between abstraction and lived experience. Perhaps a direction for future ethnographic observation is to find examples, similar to the volunteer clinic, of collective efforts where human creativity and self-care are re-connected. Specifically, looking at what we hold as static and what is allowed movement gives insights into understanding not only how power is expressed through abstraction, but also how people find agency and self-transformation through lived experience.
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301


303


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Appendix 1: Interview Timeline

LIFE TIMELINE: medical social experience
Appendix 2: Care Map

CARE MAP

What issues affect how you take care of yourself?
Use the spaces to note them.

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
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How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

How important is this area of life for you?
☐ Not at all  ☐ Up to a point  ☐ A lot

Years living w/ DM-2 ____________________________
Occupation ____________________________
Sex ____________________________
Age ____________________________

Date ____________
Appendix 3: Care Map Domain Suggestions

Physical
Feeling healthy
Fit for living
Medication
Pain
Disability
Concerns about illness
Sleeping
Eating

Psychological
Understanding my feelings
Behavior
Habits of thinking
Stress levels
Fears
Grieving and losses
Self-worth
Confusion
Learning from life

Economic
Salary
Job benefits
Public assistance
Money for emergencies
Financial needs
Making ends meet
Providing for others
Working to live
Social security

Spiritual
Purpose in living
Reason for hope
Growing as a person
Resource for challenges
Values
Connecting with people
Time for reflection
Letting go of the past

Social
Friendships
Family
Sense of belonging
Available support
Giving support to others
Getting along with people
Community support

Environmental
Housing conditions
Neighborhood
(walking, groceries)
School
Crime
Safety
Work environment
Appendix 4: Port of Tacoma Development
Overlay of 1877 survey of the Puyallup River emptying into Commencement Bay with the
Appendix 5: Glossary of Terms

The Everyday

Lefebvre defined the everyday as a social development of post WWII resulting from the massive industrialization and urbanization of Europe. Lefebvre felt that studying the social relations of labor and work no longer explained the accumulation of capital, which was increasingly concerned with the production and consumption of culture and the habits and routines of daily life. Lefebvre studied the spatiotemporal forms and rhythms of everyday life that shape how people interpret and create subjective experience. Space is always “social space” to call attention to its social production and active role in all social life, rather than as a neutral backdrop or stage for human action. Lefebvre did not see the everyday as “A sphere of mindless, dehumanizing routine to be contrasted unfavorably with exceptional events and experiences, whereby daily life must be liberated” to an idealist utopia. Instead the everyday encompasses both mechanical repetition, mass production and uniformity (which allow the accumulation and expansion of capital), but also reflexive, creative qualities of subjective experience (or lived space as Lefebvre defined it).

The Body as Social Space

As mentioned above, the everyday is a plurality of spatial and temporal structures. At the center of the everyday is the body and its corporality is integral to the possibility of transformation that defines Lefebvre’s work. Bodies are mediators of relationships between the different dimensions of social space Lefebvre identifies but is also its own force that is never fully understood, contained or static. Bodies form a “confictual unity” between habit and innovation, cyclical and linear temporalities that seems to extend everyday life “from the human body to the global economy and then back again”. Lefebvre envisions social space and the everyday in a way that connects human bodies and the phenomenal with macro-level forces so that how we care for ourselves is always in relation to a broader social context. In this way, new connections can be made between formerly disparate stories that explain more clearly the world we live in. For example, Kristen Ross’ study of commodities in post-war France connects two periods of French colonialism, one external and the other external, that are not conventionally linked but explain how older forms transpose into new ones.

Cyclical and Linear Time

An essential characteristic of the everyday is the cyclical and transformative routines and repetition of daily life. However, repetition, in Lefebvre’s analysis, does not lead to stasis. It is through repetitive qualities of daily life, its cyclical nature, that difference, innovation and social change occurs. Linearity offers no inherent method of change because even though repetition occurs, as each repetition is exactly the same as before creating a sense of stasis. through uniformity. Like corresponding forms of social space, cyclical and linear temporalities do not form a binary pair. Instead, both linear and cyclical exist in perpetual interaction, one being the
measure of the other (Gardiner 2004). With the increasing development of urban space Lefebvre described an increasing dominance of linear time. Temporality becomes structured by the demands of economics and technology rather than planetary changes or bodily rhythms (Stanek 2008).

**T2DM or Diabetes**
I have used these two terms interchangeably through the dissertation. In both cases I am referring to Type-2 diabetes.

**Blood Glucose Or Blood Sugar**
These two terms are used interchangeably throughout the dissertation.

**A1c Vs. Blood Glucose/Blood Sugar Levels**
An A1C is a very quick test that can be done by finger stick or through a blood draw. It measures the percent of hemoglobin that becomes “attached” or glycalated with glucose in the blood. The higher the percent, the higher the amount of glucose in a person’s blood. This measurement reflects the average glucose level for two-three months (the average life-span of a blood cell). A1C levels give a long-term (two to three month) view of a person’s blood sugar levels. This is a much different test than a single check of a blood sugar level, which can vary widely from day-to-day or even within the day.