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Sexual orientation and identity in diabetes health care: the experience of Type 2 diabetes among lesbian, queer, and women-loving women

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BOSTON UNIVERSITY
SCHOOL OF MEDICINE

Thesis

**SEXUAL ORIENTATION AND IDENTITY IN DIABETES HEALTH CARE:
THE EXPERIENCE OF TYPE 2 DIABETES AMONG LESBIAN, QUEER,
AND WOMEN-LOVING WOMEN**

by

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DEDICATION

To the Loving Memories of Donald M. Welch and Dr. Diane Weiner.

Two bright lights of inspiration, love, warmth, and support that were taken away from this world way too soon. Their absences continue to leave ripples behind. I will always remember their life lessons with laughter and smiles.

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an insurmountable amount of Kleenex. Their mentorship, wisdom, and teachings have helped me as a medical anthropologist, a student, and as a human being.

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“And once the storm is over, you won’t remember how you made it through, how you managed to survive. You won’t even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won’t be the same person who walked in. That’s what this storm’s all about.” – Haruki Murakami

**THE SEXUAL ORIENTATION AND IDENTITY IN DIABETES HEALTH
CARE: THE EXPERIENCE OF TYPE 2 DIABETES AMONG LESBIAN,
QUEER, AND WOMEN-LOVING WOMEN**

MICHELLE LOUISE WELCH

ABSTRACT

This Master's Thesis reports on the experiences of Type 2 Diabetes of Lesbian, Queer, and Women-Loving Women. The thesis examines the impact of sexual orientation on experiences with diabetes, and how this chronic disease affects the way a woman views herself, her health, and her body image. Each participant presented her narrative and world views in regards to her diabetes health care and management, stress and trauma, and management of relationships. Through narrative analysis, I have revealed differing mechanisms of coping and explanatory models; the many women of this study selectively chose to be more open about her sexual orientation than her diabetes status.

Key Words: *Lesbian, Queer, LGBT, Diabetes, Type 2 Diabetes, Minority Stress, Chronic Illness Narratives, Coping Mechanisms with Chronic Illness*

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ABBREVIATIONS

ADA	American Diabetes Association
AHRQ	Agency for Healthcare Research and Quality
BAWL	Boston's Alternative Women's Softball League
BIDMC	Beth Israel Deaconess Medical Center
BUMC	Boston University School of Medicine
BUSPH	Boston University School of Public Health
BWFFL	Boston Women's Flag Football League
CMA	Critical Medical Anthropology
HPC	Health Promotion Center
IOM	Institute of Medicine
IRB	Institutional Review Board
LGB	Lesbian, Gay, Bisexual
LGBT	Lesbian, Gay, Bisexual, and/or Transgender
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer
LQWLW	Lesbian, Queer, and Women-Loving Women
MACCP	Medical Anthropology and Cross Cultural Practice Program
MDPH	Massachusetts Department of Public Health
NIH	National Institute of Health
PCOS	Polycystic Ovarian Syndrome

PFLAG	Greater Boston Parents and Friends of Lesbians and Gays
SJPHC	Southern Jamaica Plain Health Center
TFI	The Fenway Institute
WHO	World Health Organization

CHAPTER I:
INTRODUCTION

“The most beautiful people we have ever known are those who have known defeat, known suffering, known struggle, known loss, and have pulled themselves out of the depths. These people have an appreciation, a sensitivity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.” – Elisabeth Kübler-Ross

Chronic illness sucks. There are no “ifs, ands, or buts,” there are no “gentle ways of putting it,” “beating around the bush,” or “academically speaking” ways to say it. Chronic illness simply sucks and Type 2 Diabetes is within that category. Type 2 diabetes can be classified as a disease of civilization; it has become “one of those diseases” that goes along with the fact that people are beginning to live longer (Smith-Morris 2008, Weiner March 27, 2013). As a result of the constant, continual rise in diabetes in modern populations, diabetes has become matter-of-factly accepted as an almost trivial “consequence” of the stress of living in a civilized world (Smith-Morris 2008, Weiner March 27, 2013).

Now, there is a sense of inevitability within the population that they will, at one point in their lifetime, know someone diagnosed with Type 2 diabetes, or they themselves will be diagnosed. This inevitably changes the impact and shapes the individual’s life experiences and their view of the world. Additionally, diabetes begins to change not only their provider-patient relationships and management of their healthcare, but

their relationships with others and daily management of life. It is here where my study lies; within the aspiring academic work of interest in Type 2 diabetes and experience, how the experience influences day to day life, the pain and suffering that this chronic disease causes, and are there things that we have the capability of doing that better serves people affected by this chronic illness.

Mutual Sharing as the Outsider Within

When I was about 10 years old, my Dad was diagnosed with Type 2 diabetes. I say about because I actually cannot recall my age, or the age of my Dad when he was diagnosed. I just remember that I was young, and my Mum and Dad casually mentioned that Dad had a bad Doctor's visit where he was told to take better care of himself. When it happened, my brother and I were not confidantes of my parents—all we knew was we were to change our food to ones with less sugars and carbohydrates. This then coincided with the constant barrage of the latest health fads: the South Beach Diet, the Atkins Diet, joining Weight Watchers, and to drink more flavored water. Words such as diabetes, Type 2, blood sugars, blood-sticks, insulin, overweight, obesity, and chronic became everyday words of my family's vocabulary.

When I was in middle school, I began to see the blood tests on the strips; My Dad had struggled for most of his 40s to his late 50s (he died

when he was 61) with his chronic illness; he had yo-yo dieting and weight loss, a mini-stroke, the steady progression of blood sugar counts to insulin injections, and the beginning of loss of adequate blood flow to his legs. Some days he would try so hard to be “a better diabetic” and on other days, I could see his fear envelop him when he began to discuss his legs needing so much attention. He would try to hide it, because that’s the stereotypical expectation of the stoic British male. Hide all of the emotions inside, until eruption—“never let them see you cry.” *Diabetes became our life. Diabetes was our life. Diabetes is and will continue to forever be part of our life.*

I share my brief familial background of dealing with Type 2 diabetes because my passion for understanding chronic illness narratives is rooted within my own experiences of being the daughter of a diabetic. It has become such an ingrained part of my own identity, and the fact that my Dad died due to a stroke and complications of Type 2 diabetes further emphasizes this chronic disease’s impact on my life. My own narrative and identity may have affected my thesis project from the initial research design, recruitment method, interview construction, and data analysis.

In this project, I draw on the theoretical concept developed by Collins (1986), who spoke of the anthropologist as being the “outsider

within.”). This concept refers to the position of the researcher to be both inside of what is being researched, and on the outskirts (Unluer 2012: 1). As a qualitative researcher determined as an “outsider within,” I have a possible range of “roles” of membership of the group being studied to that of being a complete stranger (Unluer 2012: 1-2, Adler & Adler 1994). Not only does this status have the capability to understand both sides, there is comprehension of the probability of multiple identities of the researcher and for the participant (Unluer 2012: 1-2). Bonner and Tolhurst identify three key advantages of being an “insider researcher”:

- (a) Having a greater understanding of the culture being studied;
- (b) (b) not altering the flow of social interaction unnaturally; and
- (c) (c) having an established intimacy which promotes both the telling and judging of truth...they know how to best approach people (, Unluer 2012: 1)

Although I am a non-diabetic, heterosexual (LGBT ally) woman with a diabetic father, this application of identity became very useful in recognizing the influence of my own identity on my participants and study. It had helped me develop a style of interviewing through mutual sharing (which will be discussed later in this text) that enabled unique interviews of shared and unshared experiences.

Due to my experience with diabetes and my dad’s personal management of the chronic disease, I shared an understanding of the patient-diabetic care provider relationships, the various methods of

management, and the stigma and stress surrounding the diagnosis of Type 2. Being a part of a family with a history of diabetes and overweight issues, I connected with the participants on a biomedical level, understanding the influence of the familial health backgrounds on your own health and the need to steer your own body and well-being from the genetic health trap and diagnosis. Additionally, as a woman interviewing women, there was an understanding of gender minority experiences, feeling of camaraderie, and a calm atmosphere that permitted the women to feel at ease with discussing their personal narratives and experiences with their diabetes.

I must state that although I self-identify as a heterosexual woman, this did not necessarily impede my participants' willingness to divulge their stories. It did, on the other hand, influence my understanding (or lack thereof) of their experiences as a sexual minority and how being a Lesbian, Queer, and Women-Loving Women (LQWLW) affected all aspects and meanings of their lives. At times I would attempt to understand, especially at points during my thesis research when I would divulge my sexuality and sexual orientation because of assumptions made by other parties. Yet, this is minimal in comparison to what my participants have to continually do, and selectively divulge, in their day-to-day lives. By being the outsider, and taking upon this role

as an interview, I persistently sought to comprehend their experience and, as a result, create an in-depth analysis to their voices and narratives.

Thesis Overview

The purpose of this study is first, and foremost, to understand the experiences and behaviors of LQWLW living with Type 2 diabetes in Boston, MA. This study is to concentrate on two key challenges of finding voice and illness narratives within such a stigmatized minority population, and to incorporate dialogue and analysis of the process of LQWLW navigating the multi-faceted management of their diabetes and their identity role.

In Chapter II, I provide a brief historical and epidemiological overview of Type 2 diabetes and an extensive review of the diabetes epidemic on a state and national scale. I will provide a biomedical definition of Type 2 diabetes, its symptoms, the health care system's biomedical evaluation and screening for Type 2 diabetes, and the biomedical health care providers' recommendations for management of the disease. This definition in conjunction with the overview coincides with a comparison of LQWLW and related health disparities. Lastly, I will review the theoretical approaches that I have applied to the analysis of my data and will utilize within my discussion of intersectionality of

identity, structural violence through minority stress, sick role and illness narratives, and explanatory models of diabetes.

Chapter III describes my planned process, initial goals, and research design for the primary conceptualization of my study project. The chapter discusses the qualitative methods and literature review that I utilized to collect data for the study, along with the re-design of my recruitment strategies due to lack of participant recruitment and closed avenues. This incorporates the various ways in field methods such as participant observation and informal interviews (with LGBTQA researchers/ academics and diabetes health care professionals) that allowed me to assess the access of quality care and experiences of LQWLW. The chapter also details the various recruitment avenues that I pursued, the study's "failures" and limitations, and the "doors that remained closed" when I sought insight and recruitment access for my project. My initial goal (and hope) was to gather extensive interviews with approximately ten to fifteen who self-identified as LQWLW with Type 2 diabetes. However, as a result of time constrictions and great difficulty of recruitment, I conducted interviews with four women, and coded the transcriptions using Atlas.ti software to pick out and analyze prominent topics, patterns, and themes in their discussions. These findings were then utilized in analysis within the two content chapters of this paper.

Following these extensive background and method chapters, Chapter IV, examines my encounter of silence in soliciting participants for the study and the meaning of silence and voice for LQWLW with Type 2 diabetes. I explore how these silences are part of the lived experiences of this population and use a theoretical application of stigmatizations and stress for further knowledge of these silences. This chapter also depicts particular moments of participant observation and semi-formal interviews of my field notes. By sharing of my field notes, I hope to reveal the various social and cultural realms of LQWLW, and depict my interaction with the LGBTQA community. This will lead into a discussion of identity and shaped life experiences. Finally, there will be a brief examination of the intertwining of trauma, trauma portfolios, minority stress, and their influences on identity frameworks in chronic illness.

Chapter V shifts my paper's focus on discovering more of the voices and narratives behind this research. As a result of the small number in study participants, I have decided to incorporate more of an in-depth, phenomenological case study for each woman. My research focus is on their chronic illness experience, and thus, their voices and narratives should be at the forefront. I also examine coping narratives in the theme of "dealing with it" when faced with living with Type 2 and how this coincides with the aspect of relationships in daily life. Lastly, I will

briefly explore the varying management of diabetes and the approach these women take daily for their health care.

In my concluding chapter, I end the study with general discussion of LQWLW experiences with health care providers and a brief literature review of advocacy for better understanding of sexual orientation identity and adult differences in health. I will also reiterate the dearth of research on this topic matter with a discussion of participants' recommendations and final thoughts on their health care. Moreover, I will call upon the need for future adjustment in clinical practice for better quality care and clinical practice. Lastly, I will discuss my personal reflections on this study and the impact that these women and their narratives have had upon my own life.

CHAPTER II:

BACKGROUND

“I didn’t really have any real signs or symptoms of diabetes. Um. Even though I knew sort of all about the signs and symptoms of diabetes. Anddddd. I think that’s what sort of freaked me out a bit...I was 28 when I was diagnosed. Anddddd. It. Definitely. Freaked me out a bit.” – Participant One

“Ya know... I never thought of diabetes as being an LGBT issue... but, I guess it is... It’s everywhere”—Participant One

Introduction

As I delved further into the related research connected to this study, began to develop relationships with my participants, and adapted my research design, my main analytical question began to evolve and become more focused: how do LQWLW experience their chronic illness and how do they manage it? In order to gain an insightful answer, or at least engage in multi-faceted reasoning, I conducted an extensive literature review and analysis of Type 2 Diabetes among LQWLW.

In this chapter, I construct a brief epidemiological and historical overview of Type 2 diabetes, and review how this chronic illness has become an epidemic within the nation, and within Massachusetts. This overview then allows for comparison with the smaller population of the LQWLW, and for a review of related health disparities.

I then review the theoretical frames that I have applied to the analysis of my data, specifically phenomenological theory in connection

with illness narratives, chronic illness role, and explanatory models in the experience of LQWLW with diabetes. Each of these will play a part in the discussion of identity, and the intersectionality of identity with various aspects of structural violence, and a brief focus of Critical Medical Anthropology (CMA).

Diabetes: The Modern Day Epidemic

By the year 2030, the number of adults with diabetes worldwide is estimated to grow to be approximately 366 million (Chaturvedi 2007: S5). Much of the increase in Type 2 diabetes will be due to the increasing prevalence of obesity (Chaturvedi 2007: S5). Although obesity is not the primary focus of this thesis, it has a highly significant relationship with Type 2 diabetes, the most widespread form found in the United States (not including those who are unaware that they have diabetes or are pre-diabetic (ADA 2012)).

According to the American Diabetes Association (ADA), Type 2 diabetes occurs when “either the body does not produce enough insulin or the cells ignore the insulin” (ADA 2012). As a result, the body has a higher than normal blood sugar. Insulin is a hormone necessary for the body to be able to use glucose for energy “fuel” for the muscle and tissue cells of the body. (MDPH *Diabetes in Massachusetts* 2010, ADA 2012). This fuel is obtained from two main sources: everyday food that a person

consumes and from the person's liver. When a person becomes afflicted with this chronic illness, his/ her whole system is working improperly. Additionally, the hormonal change that occurs alongside diabetes impacts co-morbidities and creates greater health complications for the body.

Once someone develops Type 2 diabetes, he/she may experience an extensive number of symptoms: increased thirst, increased hunger, frequent urination, weight loss, fatigue, blurred vision, areas of darkened skin, and slowed healing of bruises and contusions. These symptoms become more apparent as the body develops resistance to insulin or when the pancreas stops creating enough insulin (ADA 2012).

Untreated, diabetes can cause serious health issues, because high blood sugar damages blood vessels that supply blood to vital organs (MDPH *Diabetes in Massachusetts* 2010). As a result, people with diabetes have a greater risk of having heart disease, heart attacks or myocardial infarctions, atherosclerosis, heart failure, coronary artery disease, and/or stroke (CDC *Diabetes Health Concerns* 2013).

Uncontrolled diabetes can also cause vision problems (diabetic retinopathy), nerve tissue damage (which often leads to kidney failure), kidney disease, skin and mouth conditions such as periodontal disease, blindness and higher risk for non-traumatic lower limb amputations,

stomach nerve damage (gastroparesis) (MDPH *Diabetes in Massachusetts* 2010, CDC *Diabetes Health Concerns* 2013). Diabetic neuropathy is the lack of feeling caused by nerve damage, can lead to a sore or an infection, and greatly affects legs and feet (NDIC *Prevent diabetes problems* 2013). Diabetes also increases risk for peripheral vascular disease, creating poor blood flow through the entire body (NDIC *Prevent diabetes problems* 2013). In addition to these former issues, people with diabetes are more likely to die of pneumonia or influenza. Type 2 diabetes may also increase the risk of Alzheimer's disease and vascular dementia; the poorer blood sugar control, the greater risk for dementia and Alzheimer's (Mayo Clinic 2012).

There are also several studies that have indicated diabetes creates greatest risk for the development of cancers of the liver, pancreas, and endometrium, and lesser risk for cancers of the rectum and colon, bladder, and breast (ADA *Diabetes Care* 2013). In regards to the liver, "since insulin is produced by pancreatic β -cells and then transported via the portal vein to the liver, both the liver and the pancreas are exposed to high concentrations of endogenously produced insulin" (ADA *Diabetes Care* 2013). This then increases the susceptibility to liver cancer through diabetes-related factors, such as: steatosis, nonalcoholic fatty liver disease, and cirrhosis (ADA *Diabetes Care* 2013). In regards to

pancreatic cancer, diagnosis is complicated by the abnormal glucose metabolic levels (symptoms of both diabetes and of the cancer) (ADA *Diabetes and Cancer* 2013). Lastly, “epidemiological studies suggest that diabetes may significantly increase mortality in patients with cancer... [Also,] higher pre-diagnosis C-peptide levels (an indirect marker of insulin resistance) have been associated with a poorer disease-specific survival for prostate cancer and colorectal cancer” (ADA *Diabetes and Cancer* 2013). Although there have been consistent associations of diabetes with increased risk of the common cancers, it remains unclear if it is direct, despite many of the aforementioned facts. Individuals continue to endure this chronic disease and its conditions over time, while further complications are more likely to increase and negatively impact their quality of life.

Demographics of Diabetes

The demographics of diabetes are not distributed evenly throughout the population of the world or within the United States. As of 2011, the World Health Organization (WHO) estimated approximately 346 million people worldwide to have diabetes (who.intl). From 1980 through 2007, the number of people with diabetes in the American population has more than tripled from 6 million to about 21 million cases (this number fluctuates greatly depending on sources) (BMC 2012).

According to data from the 2011 National Diabetes Fact Sheet (released January 26, 2011) of the ADA, approximately 25.8 million children and adults in the United States (8.3% of the population) have diabetes. Out of that number, 18.8 million people are diagnosed while 7.0 million people remain undiagnosed; 79 million people are estimated to be pre-diabetic (ADA *Diabetes Statistics* 2013). Furthermore, 1.9 million new cases of diabetes are diagnosed in people 20 years of age and older (ADA *Diabetes Statistics* 2013). For age specific prevalence rates, as age increases, so does the risk and proportion of individuals with diabetes. This prevalence peaks in the category of 65 to 74 years old and remains high among those 75 years of age and older (MDPH *Diabetes in Massachusetts* 2010).

In the United States, it is evident that Type 2 diabetes and its complications disproportionately affect specific populations, including African Americans and non-Hispanic Blacks, Native Americans, Hispanics, Asia-Americans/ Pacific Islanders (ADA *Diabetes and Cancer* 2011). There is greater prevalence of diabetes among both Hispanics and Black non-Hispanics; this is more than double that of White non-Hispanics (MDPH *Diabetes in Massachusetts* 2010). Different studies have found that non-Hispanic blacks are from 1.4 to 2.2 times more likely to have diabetes than whites (AHRQ *Diabetes Disparities* 2001);

12.6% prevalence rate according to a 2007-2009 national survey collected by the ADA for people diagnosed with diabetes (ADA *Diabetes Statistics* 2013). This survey (which was adjusted for population age differences, aged 20 years or older) also includes the following based on prevalence by race/ ethnicity: 7.1% of non-Hispanic whites, 8.4% of Asian Americans, 11.8% of Hispanics. Among the Hispanic rates, the prevalence was the following: 7.6% for Cubans, 13.3% for Mexican Americans, and 13.8% for Puerto Ricans (ADA *Diabetes Statistics* 2013). Yet, the survey does not indicate any prevalence rates for Native Americans. According to the Agency for Healthcare Research and Quality (a department part of the U.S. Department of Health and Human Services), Native Americans have a prevalence of diabetes that is 2.8 times the overall rate (*Diabetes Disparities* 2001).

It is pertinent to state that certain minorities have much higher rates of diabetes-related complications and death; this can be as much as 50 percent more than the overall population (AHRQ *Diabetes Disparities* 2001). Agency for Healthcare Research and Quality's (AHRQ) funded research has also shown cultural variations and economic barriers to treatment that have influenced these minority populations.

This research has also shown that marginalized populations are at a higher risk of diabetes. For especially the Hispanic population, AHRQ

has found that many of those that are diagnosed are reluctant to place their own medical needs over needs of family members. Additionally, there have been findings to indicate a distrust of medical care providers, and insulin therapy, a preference for alternative remedies, and even a fatalistic acceptance of the disease (*Diabetes Disparities* 2001). This data highlights the risks of diabetes for minority populations and can give great insight of the disparities and prevalence of diabetes within the LQWLW population.

Diabetes in Massachusetts

The obesity epidemic has acting as a primary association (some may say driving force); the prevalence of diabetes has dramatically increased around the United States as well as in Massachusetts. As of 2005, over half of Massachusetts adults were overweight, greatly increasing the risk and prevalence of Type 2 within the Commonwealth (Cáceres and West 2007: iv). In Massachusetts, most people with diabetes have been diagnosed with Type 2 diabetes (MDPH *Diabetes in Massachusetts* 2010). Diabetes estimates within Massachusetts are consistently lower than the national data estimate, but this does not diminish the prevalence of diabetes in the state since a great number of the population is afflicted by this chronic disease (MDPH *Diabetes Statistics* 2012).

Between 2000 and 2009, the number of Massachusetts adults diagnosed with diabetes has increased, on average, 4.1% each year (MDPH *Diabetes Statistics* 2012), making diabetes the ninth leading cause of death in the Commonwealth, and the fourth leading cause for Blacks, Hispanics, and non-Hispanics during 2007 (MDPH *Diabetes Statistics* 2012). Much older adults and the elderly were recorded to have a higher prevalence of diabetes compared to younger adults. In the population range of 65 to 74 years of age, 19.7% reported having been diagnosed with diabetes; whereas 17.1% of the category 75 years of age and older, reported having diabetes (MDPH *Diabetes Statistics* 2012). This correlates with the diabetes hospitalization rate, which were approximately 140 per 100,000 hospitalizations within the state of Massachusetts (MDPH *Diabetes Statistics* 2012). This was within the overall population.

The Massachusetts Department of Health (MDPH) has recently has published that “between 2002 and 2007, 1,300 Massachusetts residents died each year with diabetes listed as the underlying cause of death (MDPH *Diabetes Statistics* 2012). This means that nearly four Massachusetts residents died from diabetes every day” (*Diabetes Statistics* 2012). Diabetes was found to be the ninth leading cause of death in the Commonwealth; the fourth leading cause of death for

Blacks, Hispanics, and non-Hispanics during 2007; the mortality rate was 16.5 per 100,000 deaths (MDPH *Diabetes Statistics* 2012). The MDPH also states, “overall, Massachusetts males have a significantly higher prevalence of diabetes compared to women, but this gender difference compared to [the differences of] those with a college degree or higher, those who live in a household earning \$75,000 or more, and those with private health insurance, respectively” (*Diabetes in Massachusetts* 2010). This statistic is just an example of how the rising epidemic of Type 2 diabetes and the profound changes in society, cultural patterns of communities, and the health care system within the United States is becoming mirrored within Massachusetts.

Even though Massachusetts has been ranked among the best performing states in the nation, when examining the diverse groups that makes up the state’s population there are subgroupings that have far worse health in comparison to the overall population (Cáceres and West 2007: i) The greatest disparities in health are those experienced by ethnic and racial groups within the state. In a relatively recent publication made by MDPH and the Executive Office of Health and Human Services (EOHHS), the largest racial and ethnic group in Massachusetts is White Non-Hispanics, who are 81% of the population (Cáceres and West 2007: i). The second largest group is Hispanic, 7.9%, followed by Black Non-

Hispanics, 6%, Asian Non-Hispanics, 4.9%, and 0.2% American Indians (Cáceres and West 2007: i). In terms of fair or poor health: “overall, 13.0% of Massachusetts residents reported fair or poor health in 2005. Hispanics have the highest percentage of fair or poor health in 2005 in the state for any race or ethnicity group at 23%, which. is 1.8 times the state level” (Cáceres and West 2007: iii). Again, this data parallels the health disparities found in research of the national population of other minority populations.

The MDPH reiterates the seriousness of diabetes in their Health Survey Program report: “as a result, diabetes is a leading cause of morbidity and mortality in the US, as well as a leading economic burden with an estimated \$174 billion per year in medical fees and lost productivity” (MDPH *Diabetes in Massachusetts* 2010). “Lost productivity” works as a negative market force, hurting the job force and economy (Rorie 5 December 2012). These bleak statistics only emphasize the reality of this epidemic. While the impact of diabetes is not as extreme in Massachusetts as it is in other parts of the United States, it is still one of the most important public health issues facing the Commonwealth (MDPH *Diabetes in Massachusetts* 2010). More individuals are becoming diagnosed, and it is evident that those of marginalized populations are in the “diabetes’ cross hairs.”

Women and Diabetes

It is anticipated that in the near future, women will be the majority of the adult population diagnosed with Type 2 diabetes (AHRQ 2008: 12). In 2004, women accounted for 51.4% of the approximate 220.4 U.S. million residents who were 18 years old or older (AHRQ 2008: 10). By the year 2050, it is estimated that the female population will grow to an estimated 70 million (AHRQ 2008: 10). In regards to gender division of diabetes within the overall numbers: men are 13.0 million, or 11.8%, of the population (20 years of age or older) versus women who are 12.6 million, or 10.8% of all women (20 years of age or older). As the population of women continues to experience exponential growth, the number of women at risk of diabetes grows as well. According to the AHRQ's evaluation of demographic and socioeconomic characteristics of women, "the number of women diagnosed with diabetes is projected to reach more than 14 million by 2050, nearly 60% of whom will be age 65 and over" (2008: 10). When this criterion is applied to diabetes, it can be differentiated as a prominent health issue for women (Beckles GLA et. al. 2001: 1). As women age, they are more likely than men to have reduced access to care and receive subpar health care services, with minority women even more likely than white women to have similar, if not worse, risks (AHRQ 2008: 11).

Women with health complications linked to other vulnerable health statuses, like obesity, weight gain, or lack of physical activity, face greater risks than men in all population subgroupings with related health issues (Beckles GLA et. al. 2001: 2). For example, women with diabetes are more likely to have a heart attack at a younger age in comparison to those women that do not have diabetes (ADA 2012). The risk for cardiovascular disease, which is already a big diabetes complication, is greater for women than men (Beckles GLA et. al. 2001: 1). Moreover, “women with diabetes lose their premenopausal protection from ischemic heart disease and have risk for this condition as great as or greater than that of diabetic or non-diabetic men.” Blindness can be even more likely (Beckles GLA et. al. 2001: 1).

Yet, I believe it is important to point out that the subgroupings of diabetic women who are further marginalized—whether by sexual orientation, race, ethnicity, etc.—face even higher risks for such health outcomes. This is also what I hope to explore and reiterate within my study analysis. Obesity is a contributing factor in the development of the disease, associating women of marginalized subgroups with a higher probability of becoming diabetic. Health, unfortunately, is moderated by influences of ethnicity and gender, which then in turn has been associated with variations of socioeconomic status (Beckles GLA et. al.

2001: 25).

Women's health is also mediated by the influence the individual's and group's socioeconomic status (Beckles GLA et. al. 2001: 25). Despite the increase of women attaining higher education and becoming part of the labor force), women are less likely to be employed in comparison to men, regardless of their level of education (AHRQ 2008: 12. This also coincides with the fact that women obtain median earnings that are three-quarters of what men are paid (AHRQ 2008: 12). This then further influences their economic status, which thus affects their access to quality health care. The U.S. Department of Health and Human Services reports:

In 2004, more than 14 million (13%) women lived in poverty (at or below 100% of the Federal poverty level), accounting for 3 out of every 5 poor adults age 18 and over. Most poor women (59%) were in the reproductive years and nearly 20% were age 65 and over. The poverty statistics for minority women of all ages are especially grave: overall, 1 in 4 Black women and 1 in 5 Hispanic women lived at or below the Federal poverty and there was little variation with age. Women were also more likely to live in poverty if they were foreign born, were age 65 and over and lived alone, had not completed high school, worked part time, or lived in single female headed households or central cities. (AHRQ 2008: 12).

Moreover, women who have lower incomes, who are part of lower-income households, and/or have lower levels of formal education, are more likely to have diabetes. Independent marital status, the size of a household, or the individual's employment status are also factors (AHRQ 2008: 12).

Health-related research on women in general is important for marginalized sub-populations, like lesbian, gay, bisexual, and/or transgender (LGBT) women. Here, “LGBT” is an umbrella term, with each letter representing a community/distinct population with its own health concerns (IOM 2011: 20). As Lea Mollon argues:

...for the purposes of research and advocacy, the LGBT populations have been combined into one entity. However, the groups within this umbrella term are distinct and have their own specific health care needs. Many members of the LGBT communities are also part of other communities that face additional challenges and disparities. Their experiences are not uniform; they are shaped by race, ethnicity, primary language, socioeconomic status, geographical location, age, disability status, and other factors. (2012: 3).

An individual’s health is affected by the community and social circumstances of which she/he is a part, as well as by the situations from which she/he is excluded. Sexual- or gender-minority status is only one of the many factors that influence the health and lives of individuals (IOM 2011: 26). Yet, although LGBT are separate populations (as Mollon points out), they are often considered a group for health statistics.

One reason for this assumptive grouping is that they are non-heterosexual, or gender non-conforming and, as such, are often stigmatized (IOM 2011: 26). Yet an assumptive grouping does not consider specific disparities and vulnerabilities associated with the

health impact of specific factors for each particular individual. Instead, health care is generalized and thus, inadequate to fully meet all of their needs.

Barriers to Care among Lesbian, Gay, Bisexual, and Transgender People

Barriers to care related to sexual orientation and gender identity are based in, and are a reflection of, the historical stigmatizing of LGBT people (IOM 2011: 51). Many encounter stigma from an early age, shaping how they perceive and interact with all aspects of society, including health care. Additionally, institutions and systems that affect the health of LGBT people have evolved within a culture and society that have excluded or stigmatized these populations (IOM 2011: 51).

National Institute of Health (NIH) studies do not require the representation of sexual minorities in studies of sexual, reproductive, and other health issues (Hutchinson 2006: 399). LGBT people bear higher rates of violence and chronic stress associated with systemic discrimination/ structural violence and obstacles to access health care. Also, lack of legal recognition and a high percentage of uninsured same-sex partnerships, prevent coverage by employee health plans (Mollon 2012: 3).

Generally speaking, social support plays an important role in an

individual's mental and physical health. Yet the particular roles of families, schools, workplaces, community organizations/ populations, and religious institutions also need to be understood more fully, in order to identify how each can also operate as a barrier against which LGBT people, as a larger group, struggle when trying to obtain equal social and cultural standing (IOM 2011: 27). This is especially the case in health care. As the Institute of Medicine (IOM) report states, "understanding outcome disparities, provider attitudes, and education, ways in which the care environment can be improved, and the experiences of LGBT individuals seeking care would provide a base from which to address these inequities" (2011: 27).

A presidential memorandum, signed on April 15th, 2011 by President Barack Obama, focused on hospital visitation and health decision making for same-sex partners. It stated that hospitals and health care providers accepting Medicaid and Medicare must respect the rights of patients for the designation of their visitors, and respect their advance directives. It further established that "hospitals cannot deny visitation rights based on 'race, color, national origin, religion, sex, sexual orientation, gender identity, or disability'" (Mollon 2012: 2). Not only was this a key advocacy point in the health decision making and care rights of the LGBT community; it also pointed to the kind of basic

health inequality that the community has faced and continues to face.

The care environment and providers' attitudes and education, of course, are dependent on their geographic and demographic location. Sobo points to key socioeconomic and sociopolitical conditions that drive individuals to locations, whether these are cities, states, and/ or even countries (2009). LGBT people living in areas with larger LGBT populations may find more support services and have more access to health care providers experienced in treating LGBT individuals—also referred to as social geography (IOM 2011: 35).

We find an example of such concentrated support services in Boston, at Fenway Community Health Center, an example of health care access for LGBT individuals, as well as for the population in that particular area of Boston. Fenway frames this role in its mission: “to enhance the wellbeing of the lesbian, gay, bisexual, and transgender community and all people in our neighborhoods and beyond through access to the highest quality health care, education, research, and advocacy” (fenwayhealth.org: 2012). Fenway is also affiliated with Beth Israel Deaconess Medical Center, a facility that offers services for diabetes.

Conron et. al suggest “that the Massachusetts Gay, Lesbian, Bisexual, and Transgender Health Access Project, launched in 1997,

succeeded in raising awareness of institutional and provider-level barriers to care for gays and lesbians across Massachusetts.” However, they go on to argue, “improved cultural competence within the health care system may have been insufficient to address economic barriers to care,” and that the disparities found could have resulted from socio-economic status. The authors speculate that the potential determinants for health disparities in this group may be due to the elevated exposure to adversity, discrimination, and/or unequal access to health resources (Conron et. al. 2010: 1958-9).

The authors also observe that sexual minorities report higher rates of violence exposure and victimization, which can be connected directly to physical and mental health issues. Their findings support those of other studies suggesting that mental health, drug use, smoking, violence, and health care access therefore remain key priorities for Healthy People 2020 (Conron et. al. 2010: 1959). Health People 2020 is a foundation made up of multi-faceted group of individuals and organizations that was developed on December 2, 2010, on the basis of a 10-year agenda to improve the Nation’s health. It strives to identify nationwide health improvement priorities, increase public awareness, strengthen policies, improve practices, provide measurable objectives of care, and identify critical research, evaluation, and data collections needs (*Healthy People*

2012). Although there is a clear pursuit of health care equality, there remains a great gap in opportunities and health support.

Contemporary health disparities based on sexual orientation and gender identity are based in, and are a reflection of, the historical stigmatization of LGBT people (IOM 2011: 51). Many encounter stigma from an early age, and these experiences shape how these individuals perceive and interact with all aspects of society, including health care. Additionally, institutions and systems that affect the health of LGBT people have evolved within a culture and society that have stigmatized these populations (IOM 2011: 51). LGBT people bear higher rates of violence and chronic stress that is associated with systemic discrimination/ structural violence and obstacles to access health care (Mollon 2012: 3). Also, lack of legal recognition and a high percentage of uninsured same-sex partnerships, prevents coverage to employee health plans (Mollon 2012: 3). These disparities combined with the high probability of lack of support for alternative family structures, creates an even more insurmountable barrier for LGBT individuals (Mollon 2012: 3). This has great importance and influential implications for their ability to address all needs of sexual and gender minorities, including the chronic illness of Type 2 diabetes.

Health Disparities of Lesbian, Queer, and Women Loving

Women (LQWLW)

Such barriers and related health disparities play out in ways specific to Lesbian, Queer, and Women-Loving Women (LQWLW). According to IOM, more than two million women self-identify as lesbian (Hutchinson 2006: 393). Despite representing a wide realm of ages, race, class, and geographic boundaries, LQWLW face a myriad of factors across client, provider, and health care system levels that contribute to health care disparities (Hutchinson 2006: 393).

For example, LGBT people—especially Lesbian women—are frequently targets of stigma, discrimination, and violence because of their sexual- and gender-minority status (Anon 2011: 5). This situation translates to their health behaviors and self-perception of their body. Relative to heterosexual women, lesbians experience significant health disparities and stigma in preventative-care utilization and health outcomes (Hutchinson 2006: 393).

Theresa Garnero (2010) observes that Lesbians experience a higher prevalence of polycystic ovarian syndrome (PCOS)—approximately 38% versus 14% among heterosexual women—which is a dominant risk factor for Type 2 diabetes. Rates of overweight and obesity tend to be higher among lesbians than among heterosexual women (Garnero 2010: 180). Higher rates of obesity, and even breast cancer, have been connected to

the lack of recognition and support for alternative family units; many women choose not to bear children as a result, influencing their overall wellbeing (Mollon 2012: 3). Additionally, uninsured rates and difficulty obtaining medical care occur most frequently for Bisexual women and Lesbians. Binge and heavy drinking are significantly more likely to occur among lesbians than in heterosexual women. Garnero goes on to observe that such challenges to receiving equal health care affect the detection of diabetes, as well as the care these women receive. Papanicolaou tests and breast exams are less likely to occur in lesbian populations, which may translate into less frequent diabetes maintenance tests for Lesbian women (Garnero 2010: 180).

Although there are at least six million LGBT individuals within the United States, a limited body of related medical and public health literature has addressed their health needs, and even less those of LQWLW women. Using Ovid SP, D.J. Snyder's trend analysis of medical publications about LGBT persons from 1950-2007 found that, out of 21,728 publications, 31% were devoted to HIV/AIDs and other sexually transmitted infections (STIs), with an overall lack of attention to general health topics or the causes of mortality (Snyder 2011: 164).

In a review of twenty years of public health research, Dr. Ulrike Boemer's findings relative to the inclusion of lesbian, gay, bisexual, and

transgender populations coincide with those of Snyder. Using the MEDLINE database, she examined publications of public health research (in the English language) between the years, 1980 and 1999 (2002: 1125). She found that most were related to STDs, pointing “to the dominance of a biomedical paradigm that narrowly understands LGBT health in relation to sexual behavior” (Boehmer 2002: 1127-8). Social trends in LGBT communities of the early 1990s created expectations of a concentration of AIDS and breast cancer publications. Indeed, during that period, attention did focus on breast cancer and AIDS in the communities and national media (Boehmer 2002: 1126-7). Nonetheless, only six articles on breast cancer appeared, creating the impression that chronic illness research for LQWLW remained minimal.

More recently, Fenway Health and The Fenway Institute (TFI) have focused their research on health care disparities in Massachusetts, and in Boston in particular, in order to support the growth of inclusive health care for the LGBT community. The TFI is an interdisciplinary research center that “ensures[s] access to quality, culturally competent medical and mental health care for traditionally underserved communities, including lesbian, gay, bisexual, and transgender (LGBT) people and those affected by HIV/AIDS. (TFI *About* 2013). TFI was built on the experiences of Fenway Health, expanding on the commitment to advance

health care practices and policies for the community (TFI *About* 2013).

In regards to LQWLW health, TFI implemented Lesbian health research in 1988, following successful advocacy during the HIV/AIDS epidemic. Much of this research has included surveys, clinical studies, and methodological experiments (TFI *About* 2013). In 1998, Fenway created its Women's Health Task Force, which also initiated the Lesbian and Bisexual Women's Research Forums that year (TFI *About* 2013). Their research built on the latest, most relevant methods for population-based research.

Diabetes and Lesbian, Queer, and Women-Loving Women

Nevertheless, there remains a lack of research and acknowledgment of potential connections between obesity and diabetes for LQWLW. Data on rates of diabetes within the LQWLW community are also lacking. Drawing on currently available information and statistics related to Lesbian women and research into obesity and overweight (Garnero 2010: 179), one can only speculate about the exact percentage of the LGBT population with diabetes. Likewise, one must estimate the percentage of Lesbian women with Type 2 diabetes. Garnero posits that if "at least 8.8 million LGB people belong to a subgroup with significant diabetes risk factors, and 15.3% reported diabetes as one of their top three chronic illnesses...then it is possible that 1.3 million LGB

individuals have diabetes, or at least 5% of the 23.6 million people with the disease in the United States” (2010: 179-80).

One can also work from literature that addresses health conditions prevalent among LQWLW that have a direct connection with diabetes in similar populations. For example, much of the literature that I examined—although not directly connected to Type 2 among LQWLW—focused on obesity/overweight issues, eating behaviors, and physical activity for sexual minority women. Many of these studies involved population-based data, rather than data examining specific individuals as one would find in qualitative or case studies. Boehmer et. al. have reviewed smaller studies that provided possible explanatory factors for obesity in lesbians—self-perception, exercise behaviors/ physical activity, and/ or body image based on physical function (2007: 1134).

Although these studies do not adequately consider covariates shown in other literature to be possible risk factors, Boehmer et.al.’s is the first national population-based study to test the hypothesis that there is a greater probability for lesbian women to be overweight and obese (Boehmer et. al. 2007: 1138). Thus, they are at higher risk for negative health outcomes “secondary” to obesity. One of these negative implications and health outcomes is Type 2 diabetes. The little research that does connect this community to Type 2 diabetes has focused on

providing culturally sensitive diabetes care and education to the LGBT community as a whole.

Phenomenological Theory: Illness Narratives, Intersectionality, Stigma, Minority Stress, and Structural Violence

Paul Farmer characterizes a phenomenological approach as aiming to understand the personal perception of illness (1988: 62-3). He adds that, within phenomenology, one must explore the ideas and the social forces that give rise to epidemic disease, in order to understand where the people are coming from and the relevancy of the disease to their lives (Farmer 1988: 62-4). Phenomenology explores how perceptions are shaped, and how person's life world is constructed through the interplay of culture, society, performances, testimonials, and/or relationships.

Irving A. Hallowell characterizes the goal of the researcher and anthropologist as understanding another's experiences. Individuals, he argues, do not have "naked experiences," but ones that are culturally shaped by a "culturally constituted behavioral environment" (Good 2010: 43-5). Scheper-Hughes and Lock describe the phenomenological approach as "a sense of the lived experience of the body-self, the constituent parts of the body—mind, matter, psyche, soul.—and their relations to each other and the ways in which the body is received and experience in health and sickness" (1987: 7).

As a heterosexual female without Type 2 diabetes, I undertook this study recognizing that there would be ways in which I might have difficulty understanding the experiences of the women who chose to participate. Knibbe explains the benefits of a phenomenological approach: “[when] seeing the scholar as part of the life-world of the people in whose lives she participates, phenomenology in anthropology goes against the tendency to privilege ‘scientific’ knowledge over other kinds of knowledge” (2008: 47). Fingerhut et al. provide a detailed conceptual analysis of a dual-identity framework that focuses on lesbians’ differing ties to two social worlds—“the majority heterosexual society and the minority subculture of the lesbian or sexual-minority world” (Fingerhut et al. 2005: 129).

Fingerhut’s work also takes us beyond a “uni-dimensional” identity model that only considers relationships/interactions between lesbians to gay “others” (Fingerhut et. al. 2005: 129). The authors surveyed 116 self-identified lesbians, who answered questions regarding their identity, and experiences of gay related stress (Fingerhut et. al. 2005: 134). Although questions about the dual-identity framework remain, the authors believe it provides fruitful directions for future analysis (Fingerhut et. al. 2005: 137). The categories developed by the researchers (integrated, assimilated, lesbian-identified, and marginalized)

enable one to think about the full range of lesbian experiences. Yet, as they note, it is important to recognize that these categories/identity patterns must be investigated “to test value judgments rather than assuming their validity” (Fingerhut et. al. 2005: 138). However, it still effectively provides an analytical approach that will help understand lived experience of the participants, understanding their narratives in their own terms, to try to achieve similar world view perspectives. It enables a more comprehensive perspective on identity that can explain key differences between individuals, and the impact of the exposure to stigma on health outcomes.

Sara Axtell interviewed lesbians and bisexual women with disabilities or chronic illnesses and their significant others/ partners to understand the participants’ different perspectives about their disability and chronic illness identities (Axtell1999: 53). Axtell then explored the process of creating collective or shared identities (1999: 54). Through this qualitative, semi-structured process, she gathered narratives that spoke about disability as one of multiple identities. For example, some women discussed and identified the ways that these various aspects of identity interact, while others spoke about how each part of their identity was independent of the other.

Additionally, Axtell collected differing perspectives on the fluidity of

the disability identity and the “permanency” of the chronic illness identity (1999: 58): “in describing their experiences, participants talked about finding balance in their lives, making accommodations, and advocating for access for themselves and others” (Axtell 1999: 60). Some women described changing of relationships and friend networks related to their chronic illness and disability. Lastly, others discussed how their illness influenced their access to their communities and the barriers that chronic illness created in their interactions with the LGBT community (Axtell 1999: 67-8). This phenomenological approach permitted Axtell to explore the complexity of multiple identities, and explain how different aspects of identity can interconnect to form an individual, integrated whole.

In connection with my own work, Fingerhut’s dual-identity network illuminates how these women “choose” the identity they want to utilize in a specific interaction, and how their choice shapes their experience, and the value of their social capital in a specific social field. The model of a dual-identity network contributes to understanding the balances between being a diabetic and a woman, to being LGBT and a woman, and to being LGBT and diabetic. The women on Axtell’s study utilized multiple identity combinations within their narratives. This theoretical application therefore permits analysis of the fluidity of

diabetic and LQWLW identity, and their impact on the women and their partners. It also allows me to pinpoint the intersectionality¹ of their multiple identities in their illness narratives.

Critical Medical Anthropology and Systemic Theory: Shaping of Experiences

Critical Medical Anthropology (CMA) theory defines health as “access to and control over the basic material and non-material resources that sustain and promote life at a high level of satisfaction” (Baer et al. 1986: 95). Baer and Merrill Singer characterize this approach as focusing on “the importance of political and economic forces, including the exercise of power, in shaping health, disease, illness experience, and health care” (2006: 41). The application of CMA theory sets the experiences of LQWLW with Type 2 Diabetes within their political, economic, social, cultural, and historical context.

One useful example of the application of CMA theory appears in Mark Padilla’s work on the male commodities/ workers in the sex tourism of the Dominican Republic, including their social-cultural roles in the sex industry, and their experiences with stigma and chronic

¹ Intersectionality is a theoretical approach that conceives social inequalities as interdependent and mutually constituted (Fish 2008: 2). The focus of the analysis is expanded from only describing differences and similarities to actually showing how multiple identities within various systems of oppression can be interconnected (Fish 2008: 2, Gamson and Moone 2004).

illness. Padilla linked his application of CMA to his key research question of how HIV/ Aids interventions and policies could be best implemented for this population (Padilla 2007: 205-6). He explored the political economy of sexuality and how it framed the experiences of the tourists and sex workers of the island. The tourism industry determined the personal worth of these individuals; the men constructed themselves according to certain identities to be part of the overall native, exotic package for these tourists as a form of currency (monetary and psycho-social (Padilla 2007: 143-5). The “gay politics” and economic forces of the culture influenced these non-gay identified Men who have Sex with Men (MSM), shaping their experiences, and their connections, relationships.

With Padilla’s work in mind, I aim to understand how the women in my study, juggle their social identities based on the “politics” of their relationships. Although Padilla’s work centers on men and the sex industry, he also briefly examines how stigma surrounds these men’s identities and the epidemic of a chronic illness in their society. I wonder if there is a parallel construction of authenticity or identity when these women approach their endocrinologist, other health care professionals, and even their loved ones. What are the psycho-social aspects of the relationships, in which these women define themselves, how they

manage their identities, and how they define their relationships? Did they select certain experiences or certain aspects of their identity to achieve social capital within their social networks, and does this selection include or excluded either their diabetic or their sexual identity?

M.K. Hutchinson et al formulate an analysis of the myriad factors that transect the different levels of clients, providers, and healthcare systems, contributing to disparities in preventive healthcare practices among Lesbians. The study adopts a multisystem, ecologic approach to identify barriers to access, treatment, and preventive care (Hutchinson et. al. 2006: 393). The authors note, “Lesbian women, as compared to their heterosexual counterparts, more often underutilize preventive health measure, perceive difficulty in obtaining needed care, and when a health issue arises, may delay seeking treatment or seek care only after the persistence of severe symptoms” (2006: 398). They authors go on assign the health care system and professionals who care for women the responsibility for being “competent and skilled in interacting and providing appropriate care,” and being “able to provide practice environments that convey a sense of respect, acceptance, and welcome to all women, regardless of sexual orientation” (Hutchinson et. al. 2006: 398).

Studies taking a more applied approach generally advocate for specific measures. For example, Harvey Makadon's study on ending LGBT invisibility in health care promotes three key points: (1) LGBT people's care can be managed in traditional health care settings rather than special clinics; (2) physicians must become more comfortable asking LGBT patients about their sexual health, identity, behavior, and other queries; (3) a given individual's sexual behavior does not always remain congruent with routine understandings of sexual identity (Makadon 2011: 220). Mayer et. al discuss the specific needs of LGBT populations and also discusses the barriers that LGBT populations encounter when obtaining appropriate care and services (Mayer et. al. 2008: 989). Mayer et. al explore the key barriers to optimal health care for sexual and gender minority patients, stating similar issues that Makadon had addressed in his article:

sexual and gender minorities continue to encounter numerous barriers to accessing care, clustering around 4 main issues: (1) reluctance by some LGBT patients to disclose sexual or gender identity when receiving medical care, (2) insufficient numbers of providers competent in dealing with LGBT issues as part of the provision of medical care, (3) structural barriers that impede access to health insurance and limit visiting and medical decision making rights for LGBT people and their partners, and (4) a lack of culturally appropriate prevention services. (Mayer et. al. 2008: 992)

These barriers are not only intimidating and a challenging gauntlet universally, but overwhelming on an individual basis. As a result, many

LGBTs choose not reveal their “true” identity, delay seeking care, or withhold information that may be crucial in treatment (Mayer et. al. 2008: 993). Although attitudes are progressively changing, societal misperceptions and discomfort towards the LGBT persist; even amongst health care professionals. This stigma still then influences and shapes the health care and illness narratives of LGBT.

Conclusion

The overall macro-picture of the epidemiology, and biocultural aspects of diabetes (whether related to geography, population, race, and/or gender), remind us to address the influences that have shaped these women, their identity, their actions, and their narratives. They set the suffering of a chronic illness in the context of the greater power structures within our society and culture. They inform, as well, LQWLW’s stigma management—what do these women choose to disclose, to whom, and in what ways? Under what circumstances do they censor and silence themselves? Likewise, how do such factors influence on how LQWLW manage the relationships in their lives, and what does this mean towards their management, perception of their chronic illness, and overall well-being.

CHAPTER III:

METHODS AND RESULTS

Introduction

In this chapter, I will discuss my process and research design for my study. During primary conceptualization of this project, I wanted to prioritize the voice of sexual minority women with Type 2 diabetes and their experiences of this chronic disease. I wanted to understand the experiences and world views of a marginalized population, within a greater marginalized population. Based on a year's training and readings of critical and medical anthropology literature on sexual minorities and health, chronic illness identity, and social stresses and stigma surrounding diabetes and the body, I aspired to provide voice where there was silence. Much of the literature that I had found did not provide qualitative analysis of sexual minority women with Type 2, but more so in relation to obesity/ overweight issues and dietary behavior. This literature was also more within the public health literature, than that of medical anthropology.

When I began this research, I wanted these women to feel comfortable sharing their life stories and to feel that their views mattered. I also wanted to convey that I was really listening, meaning that I was hearing what they had to say without judgment or knee-jerk

reactions that they have previously experienced from their peers, friends, and families. I wanted to hear not only what my participants said, but in the context that they said it; I wanted to see/ hear how badly the other person wanted to be heard, if at all. As a result of these concerns and specific research desires, I developed an inclusive methodological approach that would provide the means of my participants to share all aspects of their diabetes narratives and their individuality.

Research Question

When I began this research project, my objective was to explore the experiences of Type 2 Diabetes and the various aspects of the relationship between these women and their health care providers. I was interested to see if their sexual orientation and the experiences of being a sexual minority would influence their experience of care with their health care providers and with their diabetes. I conducted fieldwork, interviews, and participant observation using this research question as my guide. Once I began interviewing the women and analyzing my data, I started to realize that it reflected much more than simply the relationship that these women had with their health care providers and their networks of care within the health care system.

The experience of a chronic illness, such as diabetes, is much more than a diagnosis, patient-physician relationships, and management of

body and health status (Weiner GMS MA 677, January 23, 2013).

When I conducted my interviews, observations, and developed these great interactions with my participants, I continuously adapted my semi-structured questions and probing questions to delve deeper into the complexity of identity and diabetes. Although many of the probing questions were similar for each participant, they were worded and delivered in a way that was specific for each individual. Additionally, as I will explore further in later chapters, these questions revealed the meaning of diabetes in regards to these women, their identity, and their selfhood. It was my goal to really focus on how the women believed society perceived themselves, how they defined themselves based on their experiences, and how they then talked about their narratives.

Literature Review

When I first began the process, I recognized the need for an extensive literature review and analysis of Type 2 Diabetes within the LQWLW population. Bernard states, “The first thing to do after you get an idea for a piece of research is to find out what has already been done on it” (2011: 75). A literature review is a critical, analytical summary of the current knowledge of the topic; it should then be compared in relation to different findings, theories, populations, etc. (Bernard 2011: 75-6). It can also be designed towards a particular focus or theme for

organizational purposes (Bernard 2011: 75-6).

When I searched directly using the terms of Type 2 Diabetes with LQWLW, I found that there is little to no medical anthropological, academic publications found. Many of the publications, as I mentioned in this chapter's introduction, that I initially found were public health literature that centered on other chronic illnesses, such as cancer or mental health. Additionally, the closest related articles to my research topic were those of sexual minority women in constructs of body image, physical activity behavior, and overweight/ obesity issues. Again, a majority of the publications were written as public health literature; some were psychology, behavioral science, and social science.

Once I noticed that I would not be able to find any related academic articles through direct terminology search, I then began to approach the literature review through different avenues. I realized then that my study would possibly be a tip toe into the waters of particular field that is in its beginning stages; meaning that I could not find anything directly related to my study, because not much research has been done on this particular population before. Thus, I gathered as many articles as possible, with various angles of methodological approaches and topics.

I first studied the various articles on Type 2 Diabetes, whether it be

anthropological studies or medical/ public health publications. These primarily concentrated on management, health care provider interactions, and the influence of diabetes on mind, body, and behavior. I looked at related articles of chronic illness such obesity and diabetes in other sexual-, gender-, racial-minority populations, and vulnerable populations—these assessed any disparities in the quality of diabetes care processes, mortality rates, and narratives/ experiences of the illnesses. Furthermore, I examined sexual stigma and sexual minority health issues in context; understanding the experiences of stigma and prejudice and how it relates to health practices and behaviors. Some articles discussed cultural sensitivity and proposals of how to close the current LGBT health disparities gap. Lastly, I attempted to gather as many publications as possible that studied illness identities, narratives, and experience, differing identities and the exploration of relationships within particular constructs, and embodiment; these were to incorporate a theoretical application for future analysis of my collected data.

Research Design

My research study was closely monitored and approved by the Institutional Review Board (IRB) at Boston University School of Medicine (BUMC). The experimental design of the study was first directed to incorporate a two pronged approach for recruitment participation, that of

Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) community resources/ venues and the other of social media and social network group sources/ list serves. On the advice of other researchers from Public Health and Medical Anthropology, I determined that a multi-media/ multi-faceted approach would be a more beneficial way to attract this particular population of participants. I had initially attempted to interview between fifteen to thirty people using this widespread approach, and to include individual interviews and focus groups. However, due to unforeseen complications with choice of venues for recruitment, the lack of people willing to identify to all criteria of the study, and the timing of the study, the number of participants was greatly reduced. I had to restructure my study and incorporate more sites in addition to the ones that I utilized in order to conduct my research. Discussions with Dr. Ulrike Boehmer (Ph.D., Associate Professor, Department of Community Health Services), Dr. Jennifer Jabson (MPH, Ph.D., Post-Doctorate Fellow), and Dr. Deborah Bowen (Ph.D. Professor, Department of Community Health services, BUSPH Prevention Research Center), all of whom are part of the School of Public Health (SPH) at the Boston University School of Medicine, helped me clarify ways to recruit more participants for my research study.

Dr. Jabson was particularly helpful with my research since much

of her earlier academic path and studies mirrored my own. During her MPH, she studied women's health and chronic disease, and became aware of this particular component in Public Health research was in its infancy in sexual minority women's health. She was then funded for a three-year postdoctoral fellowship to study sexual minority women's health and cancer prevention by the American Cancer society. With several discussions/ brain storm sessions, we recognized the similarities in difficulty of gaining access to these women's narratives in our research and the participation levels (or lack thereof). Much of my own research, I believe, is in its infancy within the medical anthropological field of sexual minority's women's health and chronic illness (similar to how Dr. Jabson's was within Public Health). With her guidance, I then developed a very diverse, inclusive methodological approach for recruitment and interviewing.

Initially, I had designed my recruitment strategy incorporating "hard sources" (physical locations and group settings in the Boston, MA area) of research/ recruitment sites, I would include local cafes, bars, LGBT oriented entertainment venues, LGBTQ community libraries, and local LGBTQ club organizations. One primary organization from which I planned to recruit was the Greater Boston Parents and Friends of Lesbians and Gays (PFLAG). For social media sources and social

network group sources/ list serves, I expected to utilize several commercially available LGBTQ social organization list serves such as the Boston University School of Medicine's Department of Medicine, Faculty of Development and Diversity, Dignity Boston, BLUSH North Shore Ladies LGBT and North Shore Lesbians, publicizing the study in local, online LGBTQ press such as Bay Windows and in other popular online forums, blogs, and list serves such as Meetup.com, Craigslist, and Boston's Queer Agenda. Also, I had hoped to use direct recruitment of possible participants by posting/ handing out flyers for the research study at many of these locations.

The details of the aforementioned organizations, forums, online sites, and list serves are as follows:

- The Committee for BUMC's Department of Medicine, Faculty Development and Diversity is a core group of faculty members whose goals are to recruit, retain, promote, and nurture a vibrant and diverse faculty—this includes LGBT faculty or those that work with the LGBT community in their own research.
- Dignity Boston is a progressive, inclusive community of gay, lesbian, bisexual, and transgendered Catholics and allies. They are a member chapter of DignityUSA.

- BLUSH North Shore Ladies LGBT is a social network organization for Lesbian women and Women-loving-Women that post LGBT community news, events, venues, and other interests to a list serve of women wanting to get involved.
- Bay Windows is New England's largest weekly publication for lesbian, gay, bisexual, and transgender readers. Bay Windows is distributed throughout the greater Boston area and all of New England at over 400 locations. It is also accessible through the internet.
- Meetup.com is an extensive network of local groups that organize events and meetings in local communities based on common interests. Meetup makes it fairly easy for anyone to organize a group or find an already organized group that is meeting up face-to-face. Meetup's mission is "to revitalize local community and help people around the world self-organize. Meetup believes that people can change their personal world, or the whole world, by organizing themselves into groups that are powerful enough to make a difference" (Meetup.com 2013).
- Craigslist is an online site that promotes local classifieds and discussion forums that are community moderated, and

largely free. For this study, I posted in the volunteer section, where many other research postings can be found.

- Boston's Queer Agenda is a free weekly email calendar of events and bi-weekly classifieds for the Boston region. The List encourages networking and centralizes information about upcoming events, volunteer and job opportunities, apartment postings, and community announcements. The List has over 3000 subscribers.

I had designed my recruitment strategy around the use of the snowball sample technique to increase my sample size and connect to more individuals (Sobo 2009: 136). Snowball or chain link samples are “built using each participant as part of the recruitment team. The sample groups are largely gathered in a chain “through people who know people”, adding to itself like a snow ball rolling downhill” (Sobo 2009: 136). I had planned for my entrees into the LGBTQ Community to be through many of these multiple community outreach avenues. Additionally, participants with whom I had already gained interviews were to spread the word to other individuals about my research. However, as I have mentioned before, many of these strategies proved to be very resistive or even dead ends.

For example, through Dr. Lance Laird (Ph.D., Assistant Director of

the MACCP, Assistant Professor of Family Medicine), I was introduced to Abigail Ortiz (MSW, MPH), the Manager of Community Health Programs of the Southern Jamaica Plain Health Center (SJPHC). The SJPHC is a community health center licensed by Brigham and Women's Hospital that provides a full range of quality primary care and medical services for the Jamaica Plain community. There is also the Health Promotion Center (HPC) of the SJPHC, which utilizes "the lens of Health Equity/ takes an approach that considers social determinants of health/ strives to be antiracist through its programming and campaign work" (SJPHC 2012). I wanted to talk to Ms. Ortiz about my project design, recruitment strategies, and gain an insight she had on the matter. I wanted to specifically look at recruitment possibilities in Jamaica Plain since I had informal conversations with others of the LGBT community who had informed that Jamaica Plain was becoming home to more of the LGBT (especially LQWLW).

I will discuss further in Chapter IV about our informal conversation about the identities of the LQWLW population in Jamaica Plain and how this impacted my research study. However, Ms. Ortiz did tell me to expect my estimated study participant number to be a gross over-estimate. She had informed me that it was very difficult for women to voice both identities—that of being a LQWLW and a diabetic. She

believed that many were more willing to adopt one or the other. Again, I will explore the meaning of this statement more thoroughly in the sequential chapter. Lastly, Ms. Ortiz guided me into examining morbidity rates of the LQWLW populations versus the heterosexual and overall populations of the Boston area. Here she said my lack of number of participants would be supplemented with the literature review research.

Through another research avenue, I sent a recruitment email through the Committee of the Department of Medicine Faculty and Diversity of the Boston University School of Medicine, to connect with LGBTQ faculty on raising awareness in the medical school and hospital about my study. The committee is made up of individuals that are actively involved in the efforts to recruit, retain, promote, and nurture a vibrant and diverse faculty. Here, I was able to connect with a member (my first participant) who is part of the LGBT community and has diabetes. Later on, she would also guide me to contacting other organizations for recruitment. In retrospect, this approach was not a dead end; I garnered one more contact through this by contacting the referred LGBT friendly sports organizations.

Many on the committee suggested other physicians and avenues of where I would be able to recruit. Fenway Health was also described as a

possible avenue for recruitment. Through Dr. Linda Barnes, (Ph.D., Program Director of Medical Anthropology and Cross Cultural Practice Program (MACCP), Associate Professor in the Department of Family Medicine of BUSM), I was introduced to Dr. Ruben Hopwood, a Coordinator of the Transgender Health Program at Fenway Health. Through his guidance and expertise, I was able to develop more possible recruitment strategies, methodological approaches, and starting points of discussions of LQWLW health. Furthermore, he introduced me to Dr. Aimee Van Wagenen, the Program Manager of the Center for Population Research in LGBT Health at The Fenway Institute (TFI) of Fenway Health. After a lengthy conversation, she informed of current projects occurring throughout Boston, and what she and these other projects have done for betterment of health with the LGBTQ community.

However, as a result of an overload of other studies that are connected with the several research studies at Fenway, she informed me that I was not able to recruit participants from their population. Moreover, I was informed by several other researchers from SPH, who have worked with Fenway, that there was a lot of “red tape,” and thus it is fairly difficult for researchers outside of the institute to collaborate/ “jump onto” other research projects for recruitment purposes. It was also implied that because I was a Master’s student, and not a Ph.D. or a

post-doctorate fellow, my access within Fenway was limited. Despite all of this, I was not discouraged and continued to pursue other avenues of recruitment.

Additionally, I had hoped to use the help of the committee to gain access to individuals for informal conversations. Unfortunately, none resulted and many emails that I had sent either went unanswered or were passed along. In one discussion, I was told I would have the opportunity to talk to the committee directly at a meeting in the early spring. Yet, they were unable to fit me into their meeting schedules, so I continued attempting to contact individuals through email and phone calls for approximately two to three months (during the last months of spring 2012 and beginning of the summer 2012).

It was at this point, around the end of June 2012, in time that I determined to solely focus on the recruitment of participants with Type 2 diabetes and their health care experiences; I realized I did not have the capability to additionally interview health care professionals since time was limited and I already was having great difficulty in recruitment. These sites that I have attempted to work with, “look” as though they should have yielded something, but did not. I will go further into detail about why I believe I had so much difficulty in recruitment in a later chapter.

Re-grouping

After several discussions with Drs. Boehmer, Jabson, and Bowen, and my advisors in the thesis program, I restructured my recruitment strategies. It appeared to me that all that I had been doing—despite the support of BUSM, SPH, and other organizations—I was having difficulty in collecting data and connecting with participants. In retrospect (as I write this now), I realize that I was collecting data by learning these obstacles to recruitment and how hidden this populations really is. The re-grouping conversations that I had with these researchers did shed some light on new approaches that could help my lack of participation. Dr. Boehmer first suggested trying to expand my research to include a larger geographic location or even incorporate a national demographic. This is more a Public Health approach that would not be suitable for my study. Also, due to the time restrictions of my thesis program and the need to maintain the study within the Boston area, this option was not available.

Dr. Jabson had suggested the “church route” and “club route,” where I focused on sending out my information and flyers about my research study through various LGBTQ accepting churches and religious centers. She also suggested going to Jamaica Plain (an area of Boston with a large demographic of LGBTQ women) and to attend many of the

cafés and bars there. Unlike Dr. Bowen, Dr. Jabson believed I would still be able to find my target participant population at locations that could be demarcated “for the younger generation,” such as clubs. Dr. Jabson also informed me that creating business cards would be another way of getting the information out there for my study. Any time that I had contacted a site or a participant, I would give them a business card in hopes that they would spread the word about the study or share the card. Lastly, she had me connect with Boston Women’s Flag Football League (BWFFL) and the Boston’s Alternative Women’s Softball League (BAWL). According to Dr. Jabson (and a reference from a participant of my study), both of these sporting leagues have members who fit the criteria of my study.

When I met with Dr. Bowen, she informed me that my lack of participants was a direct result of not looking in the right places. She believed that many of the locations that I tried to recruit from were unfruitful because diabetic LQWLW did not go to these types of places. I needed to target an older audience, within the range of middle age to elderly and go to where this demographic congregated. Some suggestions that she made were the LGBT Aging Project of Boston and other aging councils/ committees. After these discussions, I also began to recruit from church organizations and groups for aging LQWLW.

These areas included several meet up organizations such as Ova4D (a group of LGBTQ women over forty years of age), the Boston Aging Project, the Somerville Council of Aging, and Somerville-Cambridge Elder Services. I also tried to get in touch with a chronic illness support group on MeetUp.com, but because of their group restrictions and safety measures, they thought it best that I would not recruit from them. Although I applied to other sites as well, these were the only ones that agreed to help me with my recruitment strategy and provide information to their listserve/ populations.

In the end, I was able to recruit four participants for interviews. As a result of limited time, and the fact that I had to restructure much of my recruitment strategy towards the middle of the summer period, I conducted a total of five interviews that lasted approximately sixty to ninety minutes. Two interviews were conducted with my first participant, and the rest of the participants had one interview each. The amount of interviews may not have been what I have wanted initially when starting this project, but the quality of each interview has surpassed my expectations. Each woman has provided great insight into their experience with their Type 2.

Participants

Initially, I intended for my study to include women from 18 years of

age and older, who report that they have been diagnosed with Type 2 diabetes, and self-identify as LQWLW. I had also clarified that within this study, sexual orientations/ sexual identities are not synonymous with sexual behavior. Individuals must state their self-identification. Dr. Boehmer reiterates this statement, “there is a difference between sexuality and sexual orientation. These are not synonymous terms” (February 27, 2012). This statement was especially important when gaining approval from the BUMC IRB; sexual behavior and functions of the body can be influenced by diabetes. However, understanding the impacts of diabetes on sexual behavior was not the intent of my study and none of the questions within the interview were to focus on diabetes’ influence on sexual bodily functions. I specifically designed my study so that participants would not be asked to divulge any sensitive information concerning their sexuality or sexual behavior.

I excluded men and any other women who were under 18 years of age. I also excluded women that are non-English speaking, women who refuse to answer the question about sexual orientation, women who do not have Type 2 Diabetes, and who do not self-identify as Lesbian, Queer, and/or Women-Loving women, and women who are unable to meet face to face for interviews. I created specific screening questions for when the participant would first initiate contact with me, to ensure that

the participant met the primary qualifications of the study.

Interviews

First, I must state that the interview process did not go according to plan. I had originally hoped to incorporate a focus group of eight to fifteen people. I had planned to recruit the focus group individuals through the general recruitment process of study participants. The process was designed to allow the participants to feel comfortable to share their general experiences of being a LQWLW with Type 2 Diabetes. It would allow me to see the interactions that occurred among group members as well as their responses to the questions that would have been posed (Olson 2011: 41). I was particularly interested in how they would assess their experiences based on these interactions. I had believed that the focus group in this particular study would have aided in eliciting understanding with experiences of diabetes self-management and insight in the presence, or lack thereof, of cultural competency in the women's diabetes care (Vincent et. al. 2006: 91). However, due unforeseen difficulty with the initial research design and the lack of participants, this focus group approach was never implemented.

In regards to the individual interviews, I must note that according to the guidelines of my research proposal, the potential participant had to contact me first for initial recruitment before any interview. Once they

had contacted me through phone or email, I described the study in more detail. If they were still interested, I asked initial screening questions and determined if they had fit the criterion for the research study. If they did, I asked for verification that they would like to participate in my study and then asked about their availability to meet and discuss the consent form and to be interviewed. Once consented, I began to interview the participant. Each interview was recorded with the participant's permission. The audio recordings were utilized to enhance accuracy, and each interview was predicted to last an hour to two hours long. Again, in retrospect, the constraints of the guidelines of how conversation was initiated between me and the possible participants may have influenced the number of individuals that I actually recruited.

I had designed a semi-structured interview to aid in understanding health experiences, behaviors, and beliefs of LQWLW women living with Type 2 diabetes in the Boston area. The semi-structured interviews permitted me to construct questions within a relatively open structure and allowed for a focused, conversational two-way communication (Olson 2011: 40). It allowed the participant the ability to guide the direction of the interview according to her issues of interest or thoughts at the time (Olson 2011: 40). I also believe that the directions in which the participant took the interview revealed additional, pertinent aspects of

evidence to analyze (Olson 2011: 40). I believe the flexibility in these interviews enhanced the opportunity for participants to discuss what is essential and valuable to members of their community about diabetes care.

The main objective for these semi-structured interviews was to understand the illness narratives and explanatory models of LQWLW patients and to examine their multiple etiologies, and their access to care and their management that shapes their diabetes health beliefs. I also wanted to explore and understand their interactions with the physician, the comparison of their explanatory model with their physician/ health care professional, and how this impacted their diabetes behavior, the perception of their health, their body image, and of themselves. This was the core list of questions that I had asked during the interviews:

1. How long have you been living with Type 2 diabetes? / When were you diagnosed?
2. How did you know that you had diabetes?
3. How/What do feel about your diabetes?
4. How does your feeling about your diabetes influence how you view your body?
 - a. How does it influence how you view your health?
 - b. How does it influence how you view your position/

relationships with others?

5. When you have questions about diabetes, who do you ask? *Probe for different topics*
6. Have you received diabetes care education? From whom?
7. What do you do to take care of your diabetes?
8. What can you tell me about being a Lesbian, Queer, and/or Woman-Loving Woman, and having diabetes?
 - a. Or what should HCPs know about being a Lesbian, Queer, and/ or Woman-Loving Woman, and having diabetes?
9. What might be some parts of health care needs to be changes in your view? Why?
 - a. For LGBT patients?
 - b. For specifically Lesbian, Queer, and/or Women-Loving Women?
10. What do you believe needs to be done for your own health care?

These were other probing/ core questions that I utilized:

11. How do you describe your sexual orientation/ sexual identity?
12. Can you explain what this identity means to you?
13. How do you tell your sexuality and sexual orientation/ sexual identity to your physician or other health care professionals?
14. With whom do you talk about your sexuality/ sexual identity?

15. Where do you go for your primary care? Does your primary care physician know your sexual orientation?
16. How did you choose your physician; what made you choose him/her?
17. When do you feel it is the best time to talk about your sexual orientation to your physician?

Depending on the reaction or comments of the participant, I would then branch out from the topic of interest that she brought up by probing further with follow up questions or even asking points for clarification. At times, I would remain quiet or nod my head and the participant would continue leading the discussion of her narrative.

My goal as a researcher and interviewer was to have these women feel completely comfortable in explaining their experiences. I wanted them to realize that their stories were significant to share and their voices should be heard. I believed the best approach to interviewing (and how I conducted all of my interviews) was to reduce the typical, hierarchical relationship between researchers and their participants. In order to do so, I shared my own experiences with diabetes and its influence on my life, and the reasons I wanted to conduct this study. In many of the informal conversations that I had before and after I began recording the interview, I shared fears of getting the disease and my

family's struggle with my father's diabetes. In a way, I showed a glimpse of my lived experience and vulnerability to "even the playing field" between my participant and I. Our relationship was not merely a researcher and participant, but two women sharing stories and emotions, and facilitating trust.

This methodology can be described as a feminist approach to social science, defined as mutual sharing. As Campbell and Wasco state, "feminist research seeks to respect, understand, and empower women. Therefore, feminist epistemologies accept women's stories of their lives as legitimate sources of knowledge and feminist methodologies embody an ethic of caring through the process of sharing those stories" (2000: 778). As reiterated in the article by the authors, by applying a feminist research approach, I was able to capture these women's lived experiences in a manner that was respectful and legitimizing of their voices. The process of this research method is just as important as the outcome (Campbell and Wasco 2000: 783).

Participant Observation

Throughout the recruitment, interview process, and re-grouping discussions/ brainstorming with other researchers, I was also conducting participant observations. Participant observation is a mixed methodological strategy that allows the researcher to "observe behavior

in a natural context (behavior that might be otherwise impossible to witness), and lets you collect any kind of data you want” (Bernard and Ryan 2010: 41). During the participant observation, the data that is collected is mostly qualitative and can range from field notes about things seen and heard in the setting/ environment, to photographs, video, and audio recordings of events, people, and settings (Bernard and Ryan 2010: 41). Some of the participant observation can also consist of informal, open-ended interviews or even materials at the location; these materials can consist of brochures, flyers, business cards, posters, etc. (Bernard and Ryan 2010: 41-2). In the end, participant observation provides great rapport with the participant community and fantastic insight through data analysis.

Although I will go into more detail about specific participant observations in chapter IV of this text (as part of understanding the difficulty of recruitment and gaining access to this very marginalized population), I did engage in several observations and informational interviews to correlate with my interviews and recruitment strategies. Participant observation was a huge data mining area; I gathered information at key events for the LGBT community such as the Boston Pride Parade 2012 and an Interfaith LGBT Ceremony at the Old South Church of Boston. I also gathered information at every café/ bistro, bar,

and club that I tried recruiting from; each location that I went to were LGBT friendly or aimed specifically at serving the LGBT community. If I had the opportunity, I would talk to patrons and employees (I had a very lively discussion on LGBT health and diabetes with a bartender and a man drinking a finger of whiskey at one bar near Tremont Street). Many times, the individuals that I had conversations with would direct me to other places of recruitment, or inform me that they never even made the connection of diabetes with LQWLW. This lack of a public connection of diabetes with the LGBT community (in general) is another indication of the infancy state of this research.

At Fenway Health, SJPHC, BIDMC, and other health institutes, I took field notes on the environment, material evidence such as the brochures, posters/ signage, business cards, etc., and the activities that were occurring in that particular moment of time that I was visiting. Additionally, I conducted informational and informal interviews whenever I had the opportunity, whether it was with a lesbian couple that I was introduced to at a BBQ, or a lesbian woman I met through the cohorts of my roommates. Lastly, I gathered more insight through observing “safe-havens” of the LGBT community, such as book stores. I would visit Calamus book store quite often, and talk with the shop owner about LGBT history and health issues. Yet, it is pertinent to state that in every

location that I had visited, it was difficult to find and access resources that identified as both LQWLW and Type 2 diabetes. Many of the resources, material or otherwise, were focused only one or the other of this particular marginalized population.

Data Analysis and Coding

The intent of my research thesis was to examine a sample of LGBT population and the experience of these individuals with Type 2 diabetes in the grouping. The analytical focus and coding is of the different experiences of diabetes care in the clinical and social setting. I want to examine the impact (if at all) of sexual orientation/ sexual identity on experiences with diabetes. I wish to understand identity within the health care community, the nature of being part of the LGBTQ community on top of being diabetic and receiving diabetes care, and perspectives of living with chronic illness. I focused on how diabetes affects the way a person views herself, her health, and her body image.

The primary question that arose from initial interviews was: What are some experiences of Lesbian, Queer, and Women-Loving women with diabetes? Additional queries of focus were: How does sexual orientation influence diabetes care? Is there a difference and why? And, from their experiences, what works and does not work in diabetic LGBT care? I addressed these specific questions and train of thought when exploring

the experiences of these LQWLW women when dealing with their diabetes in a very heterosexually dominated socio-cultural system. The three main focus points of my primary question (and what I created a theoretical framework around) were: What is experience? Who/ What are Lesbian/ Queer/ Women-Loving Women? And, who are Lesbian/ Queer/ Women-Loving women in health care in the context of diabetes? These focus points drove my theoretical application and coding analysis to better understand this particular topic according to several theoretical applications of phenomenology, biocultural, political ecology and critically applied/ critical medical anthropology.

I coded the interview transcripts for content, line-by-line. Triangulation of these theories, materials, and interviews, also tested the validity and reliability of the data gathered and my analytical findings (Sobo 2009: 134). Based on Sobó's methodology of triangulation, data collected with one specific method is compared to data collect with other methods. This is "one way of trying to correct for the biases inherent in specific methods of data collection" (Sobo 2009: 134). Additionally, "triangulation provides a richer and more complete picture of the study material" (Sobo 2009: 134). There was disciplinary triangulation of medical anthropological and the clinical perspective, a methodological triangulation through data collected from the interviews,

material triangulation of printed information and educational brochures/booklets for diabetes and the LGBT community, and theory triangulation of the aforementioned theories.

From the data gathered and the comparisons made, I generated different theories and interpretations on the experiences of LQWLW with Type 2 Diabetes. I also made interpretations using basic grounded coding data analysis. The basic data analysis approach is to code the interviews while focusing on key words, phrases, metaphors, and narrative themes. This approach also incorporated content analysis of the interview transcripts and field notes, along with the narratives collected (Bernard and Ryan 1998). I coded the interviews line by line and created a code book for overlapping/ connecting terms and phrases. I collapsed these terms to create any themes that had been found while coding these interviews.

These methodological and analytical techniques enriched a detailed individual perspective and led to a fuller understanding of the experiences within the realms of diabetes care, LGBT health care, and women's health.

CHAPTER IV:
SPEAKING SILENCE, GAINING VOICE, AND THE STIGMA AND
STRESS OF `IT ALL

“And when people try to minimize your pain, they are doing you a disservice. And when you try to minimize your own pain, you’re doing yourself a disservice. Don’t do that. The truth is that it hurts because it’s real. It hurts because it mattered. And that’s an important thing to acknowledge to yourself. But that doesn’t mean that it won’t end, it won’t get better. Because it will.” – John Green

Introduction

When beginning this extensive research project, my encounter of silence was deafening, and the barriers of accessing opportunities through the “gate-keepers” of organizations were stalwart. As I discussed earlier in my previous chapter “Methods and Findings”, I experienced great difficulty in not only finding organizations that would permit my recruitment, but of gathering participants willing to reveal their narratives as diabetic, LQWLW women. Many of the places that I began to pitch my research would find the topic of interest and importance, but then kindly guided me elsewhere to other institutions they convinced me would help me in this research endeavor. After weeks of being pushed aside, I realized that even (what can be determined) as a privileged researcher, I had straddled a line of silence and voice—learning forms of adaptation of identity and methods of speaking up in order to obtain access. It came at this point that I recognized the necessity to

understand what these research silences meant; how was I to give these silences a voice, determine the meaning behind these silences, and why were only a select few women able to find or willing to share their voice? As other medical anthropologists and qualitative researchers would point out, this lack of data and the inability to obtain a great number of participants *is* data in itself. These silences, which I will explore further in this section, symbolized the various experiences of LQWLW, and the varying levels of stigmatization and stress that permeated their lives.

In this chapter, I will first begin by briefly exploring particular "moments" within my field notes that consist of specific LGBT events, observations of certain environments that I encountered, and informal interviews/ conversations that I had had during my research study. These field notes will exhibit the various social and cultural realms that LQWLW navigate and selectively participate within, revealing the complexity behind the silence and the choices that these women make in their daily lives. Furthermore, these field notes depict my interaction as a researcher with the LGBTQA community, searching through these complex realms for the reasoning behind the silences, and the diverse life experiences of contemporary LQWLW. My discussion will then highlight the manner in which the participants, and LQWLW in general, are possibly shaped by the differing connections to the two social worlds of

the majority heterosexual society, and the sexual/gender/chronic illness minority, and how this may have influenced the silences of my study.

Additionally, the women that I interviewed revealed in their narratives the challenges of their minority status and the barriers they face daily. Within this dialogue, I examine how the intricacy of minority status influences the formation of these women's identities, their interactions with the world, and the experiences. Simultaneously, I briefly delve into understanding the multi-faceted "statuses" these women have, their specific barriers, and the consequential stress of it all. During these narratives, I also encounter experiences of trauma and how the aspect of the trauma portfolio shapes identity and increases the levels of stress in life experiences. Lastly, the chapter forms a dialogue focusing on the intersectionality of LQWLW with Type 2 diabetes by examining the intertwining of stigmatization, stress, trauma, and minority status.

Speaking Silence and Gaining Voice

I selected the following collection of field notes and participant observation for the primary purpose of examining the clear dichotomy of identity, acceptance/ collectiveness, and aspects of voice within my study population and community. When I was redesigning my recruitment strategy, as depicted in the aforementioned "Methods"

chapter, I encountered instances where the collective, united populations were open with identity and a dynamic “voice” within society. In other moments, I came across a more subdued identity; a glimpse of the experiences of the women on an individual scale and without the collective force. Both are key examples of the diverse life experience and voice (or lack thereof) of contemporary LQWLW.

Field Notes, June 9th, 2012.

As I climbed up the steps in Copley Square Station towards Boylston Street, I could hear the bustling crowds from above before I even reach the pavement. Once I reached the exit of the MBTA train station, I walked to the corner of Boylston and Dartmouth Street. Looking to my right, to the West, the street was lined with hundreds upon thousands of people, gathered in groupings of organizations and floats. The colors were indescribable—layers upon layers, whether through decorations of the floats, banners waving in the air, or the costumes that many people were wearing. I could see vendors across the way in the garden of Copley Square, shouting out if people wanted to buy stickers, pamphlets, or pride memorabilia. Many people surrounded one vendor passing out noise makers, beads, and flags, trading whatever cash they had in their wallets and pockets for the rainbow of colors.

The city skyline blended in with the crowds; the bright blue sky of

early summer acting as a backdrop and reflecting within the glass mirror of the John Hancock Building. The white clouds in the mirrored imaged contrasted brilliantly with the floating balloons of bright neons and sparkles. I smile, because you cannot help smiling at such a joyous occasion; bright colors and bright music. It is beautiful within the amazingness that is Boston.

One prominent image/symbol was the rainbow flag, the symbol of the LGBT community that could be seen everywhere. There were even rainbow balloon arches hanging over parts of the street, indicating the starting point for the parade. I continued to observe those that were walking around me, whom were all enjoying the festivities in the surrounding area before the beginning of the parade. Since I was located near the gathering area for the start of the parade, many individuals walked past me to meet up (well, I assumed anyways) with their organization or others that were to march in the parade. The tone of the atmosphere was electrifying. I excitedly waved at a group of Drag Queens that sauntered passed me, wishing me a Happy Pride Day and to keep an eye out for them later in the parade. Another group passed by, wearing S&M outfits, and again, I wave, this time after being offered a whip from one of the dominatrix. Maybe next time.

Finally, I turned to my left to see the Old South Church of Boston

which is located directly across from the Boston Public Library. This is my destination for the Interfaith Pride Ceremony, starting at 10:00 am before the Pride Parade that would circle around the downtown Boston area. By this point, it was approximately 9:47 am and there were small crowds of people standing outside the double door entrance.

Before walking in, I looked straight up to see the many arches and walls of stone, striped with alternating colors of deep red and yellow-beige. There are large open arches decorated with some sort of gothic design, where stained glassed is framed. There are columns and porches of some sort that frame the bottom exterior of the church, giving access to many entrances into the main building of the church. I also noticed decorations of ornate wrought iron on the upper arches of these expansive porches on the side of the church. The roof of the building seemed to be alternating bands of red and dark gray, with a surrounding edge of iron decorations. Additionally, the church had a tall tower on the Western end of the church, rising high above the remaining part of the church. Here, I guessed, was where the bell was stored, ready to chime the beginning hours of service for its visiting patrons.

When entering the church, I could not help but feel a mixture of wonderment and anxiousness. As an individual who declares herself on the fine line between agnostic and atheist, I was anxious to see what the

ceremony was going to be like, how religious it would be, and the different messages that were going to be discussed by the main speakers.

However, my anxiousness was quelled by the awe I experienced when first resting my eyes on the interior of the Church.

From gathering information at the prideinterfaith.org website, the Pride Interfaith Coalition is “an independent organization dedicated to advocating inclusion of LGBT people of faith in Boston. It is the longest-serving LGBTQ interfaith organization in the nation.” The group specifically desires to promote and advocate for the cooperation and understanding of diversity and acceptance among groups/ individuals of all religions, traditions, and spiritual faiths. The service was a beautiful collaboration of faiths.

Later in the early afternoon...

The inner city is buzzing with excitement as people gather along the sides of Boylston Street between Copley Square and Massachusetts Avenue. The 42nd annual Boston Pride Parade was to start in the area where Clarendon Street and Boylston Streets meet, then take the markers from Boston’s Back Bay through the South End, up the Boston’s Common, continue past the State House, and to finish at the City Hall Plaza where the festival was to be held. The parade, as mentioned by many Boston officials and leaders of LGBT organizations, is a march to celebrate and

promote equal rights for the region's LGBT communities during Pride Week. Also, and having noted that I gathered some of this information from bostonpride.org, this parade is the most popular and scenic gay pride march in the country.

It was amazing to learn that organizations and individuals from around all of New England would be marching together to advocate for equality, respect, and inclusivity. The Pride's theme, to my awe, was to celebrate 30 years of the Worldwide Pride Movement. The small town girl in me begins to question how conservative my town was, where in comparison Boston is celebrating openly and the city government has closed down streets, provided officers for support, and has city officials in the parade. I must also note that the route of the parade passed through neighborhoods specifically of strong supporters to the community— basically the entire city. Also, the parade went past many of the city's most prominent historic sites, indicating the strong acceptance the city had with the parade and the desire to celebrate/ march with many of those involved within the parade.

It was approximately 12:01 pm, and I began to hear the vibration of the revs from the leading motorcycle clubs geared towards the LGBT community. The crowd began to anxiously peer around those in front of them, trying any avenue to get a better glimpse of the possible group or

float walking/ driving past them. Music blasting, the bass of floats vibrating through the pavement, into my sneakers. Streamers floating in the air, beads being thrown, condoms and pamphlets being handed out. Everyone's dancing and having a fantastic time...

Field Notes, June 16th, 2012.

The setting of the kitchen was very modern, with a marble top "island" in the middle of the kitchen. On one side of the island there was a sink and a food prep area. A lot of food stuff was scattered around the kitchen as a result of all the BBQ preparation. There were also pitchers of sangria on the island. On the other side of the island, was a clear area of marble top where people could eat or sit at on stools. Surrounding the island, on the outer edges of the room, there is more countertop, the stove top, refrigerator, freezer, and cabinets. On the "opposite" side of the kitchen, there is a dining alcove with a large kitchen table and chairs. At the top corner of the room, right side, there is the door to the outdoor patio deck, grill, and pool. In the "middle" of the rectangular room, there are doorways. One leads to the other side of the house with rooms and a bathroom. The other is connecting to the living room, which is directly adjacent to the kitchen. Most of the party is confined to outside of the deck, but the foot traffic of people is concentrated within the kitchen and the hallway/ other side of the house to the bathroom area.

After I had introduced myself to the women. They asked me what I did and I told them that I was a graduate student at Boston University. They then asked what program and I informed that I was a Master's Candidate at the BUMC, with the MACCP.

They then asked the question of what my thesis was on, to which I responded with the topic and said that I am trying to look into/ understand the experiences of women with the chronic illness and how they interact with their care providers. I also told them that I would like to understand how this influences identity, the way they talked about their experiences (or the experiences themselves), and the management of their diabetes.

They were surprised about the topic and had told me that it was very interesting. Also, they informed at this point that they were partners ("outing" themselves at the same time without clearly identifying their exact sexual orientation) and told me that they didn't necessarily know anyone with Type 2 and weren't type 2 themselves, but they told me that they thought this was an important point of understanding the interaction between the woman and her care providers, as well as friends and family, because of their own personal experiences.

**Note* Because of the public area that we were located in, I was very mindful of what questions were asked and the tone of voice that I*

used. I didn't want them to be uncomfortable if I did begin some questioning about their care or ask too many questions since we were in a public location.

They started the conversation talking about what they had to go through in order to become pregnant and have children. They have three children, two of them twins. The focus of the story was on their experiences with their pregnancy with the twins. Because of the fact that they were at a higher category of risk, they could not go to their usual care where they lived (outside of Boston) but needed to go into Boston for the OB/GYN care. They described themselves as high risk because of age, because of being a lesbian couple with pregnancy, and having twins.

We discussed the difficulty of having to deal with some physicians and health care professionals that made assumptions about their relationship and about their sexual orientation. They had a great OB/GYN who knew about their partnership and was very respectful of their relationship. However, in one instance, they went to a new location because of the risk of their pregnancy. The medical intern/ younger doctor following their OB/GYN came in to talk to them about their health. Their other OB/GYN stood in the back and observed the interaction between the newer physician and the patient.

The newer physician only talked to the mother/ "pregnant patient"

and had her back turned to the other woman, her partner. It is not clear whether or not she assumed that the woman was straight or not, but for both women, they felt that was the logical answer of why she ignored the other woman.

They also stated that the newer physician regarded her partner as a “Friend” and directed all questions and answers to only the pregnant woman. At the end, their primary OB/GYN regarded the newer physician and commented that next time she is to address both women, since they will both be mothers of the child and they are partners. They both tell me that she quickly apologized but at the same time it made them feel disrespected and angry at the assumptions that this other physician had made when first meeting them.

I asked if they feel that they see a heterosexual dominance in care. They replied with a strong yes, saying that a great deal of the time there are assumptions made by others in regards to their sexual orientation and partnership.

They then list the example of when they are given forms in regards to the care of their children, they cross out husband and put partner/significant other. They believe that especially in Massachusetts, where there is marriage equality and more acceptance of same sex marriages and partnerships, that forms should reflect this also. They also continue

that it does not make them feel discriminated per se, but more of less respected and less recognized. They also state that although the forms may not necessarily be malicious, there needs to be change to indicate more inclusion, to add more acceptance, and to get rid of those assumptions. They are “fed up with having to cross out every single time husband/ father of child, and write partner/ other parent of child.”

In these two key moments within my field notes, I hope to show the differing “worlds” of these women. In one instance, the LGBTQA community is celebrated; the annual parade in Boston is a highly anticipated event, with enormous amount of participation and respect from the surrounding cities. Preparations are made with weeks in advance, with the city allocating funds, organizational support, and police support for parade traffic and security. Many individuals are represented from various backgrounds, i.e. socio-cultural, ethnicities, orientations, race, gender, religious, and socio-economic statuses. It is a day full of excitement where many are comfortable in rejoicing the occasion. The celebration is not even limited to the Boston area; in the Cape Cod area of Provincetown, MA (a vacation destination for the LGBTQA community), there is an entire week dedicated to Gay Pride where the celebrations are much more extravagant in comparison to those of Boston. Additionally, as a self-identified heterosexual woman

(and as read in my field notes), I did not feel shunned or less accepted because I was only an ally. I was thoroughly involved in participation at both the inter-faith ceremony and the parade because this day is to be seen as a collective.

The other moment captured in my participant observations was of a couple learning to affiliate themselves within the mainstream, heterosexually dominated medical field. It is a more reserved and quiet setting where the couple was confronted with the ignorance and lack of training of a physician. There is a lack of connection and unity within the setting, and an aspect of voice is missing, when the physician focuses on the one woman (the patient) and ignores her partner based on presumptions. It is within this example where my study is most pertinent; the minority voice within the minority collective.

These glimpses into my field notes were to exemplify the diverse life experiences of LQWLW and how their experiences are shaped by their differing ties to the heterosexual and LGBT societies. In “A dual identity framework for understanding Lesbian experience,” Fingerhut et. al. focuses on this theoretical application of the *dual-identity framework*, which concentrate upon the simultaneous affiliations an individual maintains with certain groups of identity (2005, 129). In the case of my study, this framework is applicable to the LQWLW simultaneous

affiliations with both lesbian and mainstream heterosexual communities.

As Brown (1989) notes, “lesbians [and LQWLW] are ‘simultaneously participants in both [the] heterosexual experience and the lesbian and gay experience.’” (449, Fingerhut et. al. 2005, 129). The framework provides great use in capturing the diversity among LQWLW better than “existing uni-dimensional models that consider connections only to lesbian and gay others” (Fingerhut et. al. 2005, 129-30). It incorporates a comprehensive identity—explaining the important individual differences among LQWLW in exposure to prejudice, discrimination, and mental health outcomes which can then further inform more insight on experiences and new agenda for research (Fingerhut et. al. 2005, 130). It is within this theoretical framework where there can be further exploration of the diversity among the LQWLW community, how they identify themselves, and to others, how they participate in efforts to advance LGBT/ LQWLW rights, and how much they immerse themselves in LQWLW culture and institutions. The diversity of possible identities and personalities within the LQWLW community reflects the ways that women relate to the mainstream society (such as within the context of family members, workers, and cities), and that of their connection to the LGBT/ LQWLW society (Fingerhut et. al. 2005 130-1).

Now, if I were to immediately point out this conception that the participants within my study selectively chose particular identities within a certain context of presentation, some may initially disagree and emphasize that they remain “true to themselves and their identity.” However, the “selection” of a way a woman relates to society is not, not being true. It is a method of navigation through social and cultural constructs when dealing with a multi-faceted identity, and attempting to find differing ways to create personal and social identities, incorporating differing allegiances. There is a nuanced way of how many of these women incorporate particular identities for assimilation (Fingerhut et. al. 2005: 131-2). Some LQWLW may de-emphasize sexual orientation as a basis for personal identity to be treated as an individual rather than a member of a group, or over-emphasize for conformation and greater sense of belonging.

This is a theme throughout all of my participants’ narratives. In the beginning of my interviews, I specifically asked each woman a question of “How would you describe yourself?” in order to have an “ice-breaker” and give an initial glimpse of their personalities. Participant One discusses her balancing act of identities in context with her relationships. At certain points within the day, she is a physician, while others she is simply a friend, a partner, and a woman part of the team in

her flag football league, etc. In her framework and self-representation, she selectively chooses when to represent certain aspects of her personality. Participant Two, when asked this question, completely lights up and discusses her passion for Cosplay, Doctor Who, gardening, CampCamp, and the love that she has for her niece. This question allows her to break away from her choice of reserved identity for protection, and permits her to be vulnerable. Participant Three discusses her identity of being a partner with a loved one, LGBT advocacy, her EMT work, her love for sport, and her pursuit of medicine. Lastly, Participant Four discusses her identity as an alternative healer, an artist, an older woman with chronic pain, a hippy-like individual, and a love for beauty and serenity. In all of these brief descriptive responses, diabetes was either not mentioned or was one of the last talking points. For many of these women, diabetes is not their identity.

This is a key representation of all the women in my study. Many at times select to represent their sexual orientation in preference to that of their diabetic identity. In the sequential chapter I will discuss the coping mechanisms and management aspects of these particular identity selections and representations, but in this instance, I examine how their diabetes is only one aspect of their totality. Kitizinger's (1987) research has similar parallels to that of my own in the pursuit of understanding

the characterization of identity. In his study, apolitical women whom acknowledged being lesbian, “[characterized] their sexual orientation as highly personal, and only one aspect of their total life in the broader society.” (Fingerhut et. al. 2005, 131). In Kitzinger’s study, one woman explained how she was a representation of a multi-faceted identity, where being a lesbian was just a “matter of fact.” “I’m me...I’m a social worker; I’m a mother... I like Bach... I enjoy doing a thousand and one things and, oh yes, in amongst all that, I happen to be a lesbian...But that’s just a part of me” (Kitzinger 1987: 110, Fingerhut et. al. 2005: 131-2). Like Kitzinger’s study, the women of my qualitative research all create a wide representation of themselves to immerse their identity in active involvement with these two social worlds.

Stress, Stigmatization, and Diabetes

Stress can be defined as “the physiological demand placed on the body when one must adapt, cope, or adjust. It can be healthful and essential in keeping an individual alert; however, intense or prolonged stress can be overwhelming on the body” (APA 2011, Nevid and Rathus, 2003). Physiologically, and in regards to Type 2 diabetes, stress is a contributor to chronic hyperglycemia in diabetes and has been shown to have drastic effects on metabolic activity. Chronic stress critically alters the body; there is an inhibition of lymphocytes (regarded as natural

killers in the human body) that detect and destroy cells that have become infected. Chronic stress also suppresses T-lymphocytes and anti-bodies that destroy pathogens. This in turn causes higher vulnerability and risk for threatening diseases, such as causing the sugars in the blood to drop and leading to a biomedical diagnosis of Type 2 Diabetes (Ferreria et. al. 2006: 42-3).

In recent years, much has been examined in order to understand the intracellular signaling pathways activated by inflammatory and stress responses, and how these pathways inhibit and intersect with the signaling of insulin in the human body (Wellen and Hotamisligil 2005: 1112). Stress creates a fight or flight response in the energy of human body, stimulating various hormones and increasing the elevation of blood glucose levels. This stress induced increase in glucose cannot be metabolized properly and thus, if in a body with relative or absolute lack of insulin, it can be detrimental (ADA 2012, Dr. Joanna Rorie 25 September 2012). Physiologically, stress over a lifetime can have cumulative effects on the body. It is then important to examine the causations of stress and the influence on the causation/ experience of Type 2 diabetes.

It is unavoidable in stating that Diabetes is a “minority” experienced chronic illness. As mentioned in the demographics of Type 2

diabetes, there is greater prevalence of diabetes among both Hispanics and Black non-Hispanics; this is more than double that of White non-Hispanics (MDPH Diabetes in Massachusetts 2010). The prevalence of diabetes amongst blacks in the United States has quadrupled during the past 30 years, with increasing incidence in black youths. Also, blacks were 3.2 times more likely to be discharged from a hospital with a diagnosis of diabetes than whites (MDPH Diabetes in Massachusetts 2010). The question then is, why? Why are these numbers the way they are, disproportionately distributed? And why have there have been no close examinations of gender and sexual minorities?

The roles of chronic stressors in health disparities among racial/ethnic groups are shocking. Racial and ethnic minorities have health that is worse overall than the health of White Americans. These can stem from education, geography and neighborhood, economic determinants, environment, inadequate access to care, lower quality of care, inability to navigate the health care system, provider bias/ignorance, and/ or stress. The role of social and biological stress are greatly connected to the more economically disadvantage and more susceptible to illness, ethnic and racial groups (APA 2011, Warnecke et. al., 2008).

Stress due to racism and perceived discrimination contributes a

great role in unhealthy behaviors, chronic illness, and mental health disorders among racial/ ethnic groups. This is usually as a result of acculturative stress, which “refers to the feeling of tension and anxiety that accompany efforts to adapt to the orientation and values of dominant culture (APA 2011, Rathus and Nevid 2003). This then has an influence on physical and mental health disparities. However, minorities do not solely deal with acculturative stress. There is also the aspect of socioeconomic, daily, and family stress.

Daily stress has been associated with lower social position and poor family functioning. This then leads to adverse health outcomes, such as Type 2 Diabetes (APA 2011, Kasper et. al. 2008). Additionally, studies have shown early onset of morbidity among African American women in response to persistent chronic stress and active coping in conjunction with the necessity to meet with daily demands (APA 2011). [need more information on women and stress] Lastly, it has been discovered in a longitudinal study that African American women of long-term poverty and family stress were strongly associated with less physical mobility. Thus, creating a domino effect that leads to greater risk factors for Type 2diabetes (APA 2011, Kasper et. al. 2008).

Other research evidence focuses on the prevalence of mental health and well-being in LGB populations (unfortunately, there still lacks

research for the Transgender population). The conceptual framework *minority stress* focuses on understanding the excess prevalence of disorders/ chronic illnesses in minority populations. It explains how stigma, prejudice, and discrimination create a hostile and stressful social environment that then influences the individual (Meyer 2003: 674). The model also describes stress processes, including “the experience of prejudice events, expectations of rejection, hiding and concealing, internalized homophobia, and ameliorative coping processes” (Meyer 2003: 674-5).

Within Ilan H. Meyer’s article, *Prejudice, Social Stress, and Mental Health in Lesbian, Gay, and Bisexual Populations: Conceptual Issues and Research Evidence*, he “breaks down” the stress discourse in an understanding of the stress concept, minority stress, stress-ameliorating factors, and stress and identity (2003: 675-7). The social concept extends the general idea of stress theory by recommending that conditions in both a social environment and with personal events are sources of stress. This therefore supports an expectation that social stress will have a strong impact in the lives of people belonging to stigmatized social categories, especially in regards to race/ethnicity, gender, socioeconomic status, or sexuality (Meyer 2003: 676). The minority stress model explicitly discusses the adverse effects of social

conditions, such as prejudice and stigma, or the affected individuals and groups. Meyer points out previous research on the topic:

‘according to Merton, society stands as a stressor... by stimulating values that conflict with the structures in which they are to be acted upon (371)’ The minority person is likely to be subject to such conflicts because dominant culture, social structures, and norms do not typically reflect those of the minority group... interactions with society provide the individual with information on the construction of the world; health is compromised when such information is incongruent with the minority person’s experience in the world. (2003: 676)

This aids in the process of understanding intergroup relations, and the impact of minority position with health, social identity, and self-categorization (Meyer 2003: 676-7). With minority stigma, there must be a distinction between the prejudice, discrimination, and the state of mind that the experience of stigma may create in the minds of the stigmatized. For example, within current research, evidence indicates that for LGB individuals, hiding sexual orientation can be seen as a proximal stressor. It is a stress that can be derived from internal psychological processes (Meyer 2003: 678).

For the women of my study, this is the complete opposite. Many of the women hide their diabetic status than hide their sexual orientation. This may be due to many factors, such as that the women of my study were Caucasian, living in Boston, Massachusetts (a very liberal city and state), in higher socio-economic statuses, well-educated, and have access

to care. Many of the women hide their diabetes for management purposes (which I will discuss later in this paper), but they also hide because of the socio-cultural stigma that is associated with diabetes.

Participant Two discusses the prejudice she faces with her diabetes:

All those people...It's like people assume...people assume that if you eat too much, and you get fat, and you get diabetes. They totally miss the fact that a side effect of insulin resistance is increase in body size. It's like... HELLLLLLOOOO. It's not a cause, it's an effect. And for some people, it's not even that. For some people its irrelevant... that's not true.

I have a lot of body image problems. And a lot of the problems I probably wouldn't have if I wasn't the size that I was... and the fact that I have diabetes is because of body image problems... [But] From understanding diabetes more... I have gotten over my body image and fat shame...

Participant Two discusses the stigma and stress that dominates her life as a woman of larger stature with diabetes. She discusses the nature of looks she receives when walking down the hallway, or her interaction with a fat-phobic physician at Joslin (which will be further discussed in the next chapter). With her pursuit of knowledge, and understanding of diabetes, she has collected a great distinction of personal and group resources as part of her coping mechanism to her experiences of minority stress. For her knowledge, and acknowledgement of the reasoning behind the stigma, helped her to accept her own stigmatization and become proud of that aspect of her identity.

In contrast, Participant Three actually shows her own inter-group

prejudice and identity stigma within her discussions about diabetes and its meaning within the LQWLW. She first admits the prejudice she contains towards other diabetes, observing their eating habits and what they do to prevent diabetic “episodes” from occurring, citing her experience as an care provider. She points out a recent dinner with friends, one of whom was recently diagnosed with Type 2, summarizing:

“and here... she’s eating a huge piece of cake, and I’m like... to myself... hey, aren’t you diabetic?!?” She continues further in judgment of body size when going to flag football practice: *“And when I run onto the field... I can’t help but think....She’s obese,.. she’s pre-diabetic. Oh, she’s definitely diabetic... overweight... obese... pre-diabetic... It’s just... very obvious....”*

This glimpse of her own prejudice (which can be linked to self-prejudice and shame), can be seen as part of the characteristics of minority stress and stress-ameliorating factors. Meyer states, “members of stigmatized groups who have a strong sense of community cohesiveness evaluate themselves in comparison with others who are like them rather than members of the dominant culture” (2003: 679). Her judgment of others is not only part of a coping mechanism, but a reaction to the stress in her narrative; for her, although she is a diabetic, at least she’s not necessarily an overtly obese one.

It is evident that stress negatively influences the body and its health. Although not the dominant contribution to the causation of Type 2Diabetes, stress does impact the body in such a way that it is a piece to

the overall puzzle of the occurrence of this chronic illness. It is important to address the fact that the physiological processes of stress negatively affect individuals with chronic illness, and puts them at risk for experiencing acute symptomatic distraction and exacerbations of their illness as a response to the stress (Kline Leidy 1989: 868).

According to Kline Leidy, “the physiologic process of stress can be a useful framework for understanding the dynamics of chronic illness, its evolution, and trajectory The manifestations or symptoms of various diseases can be interpreted as expressions of ongoing stress” (Kline Leidy 1989: 868). There must be an understanding of minority stress and the social construction of stress surrounding chronic illness in order to adequately provide better quality of care.

“Trauma Portfolio” of Diabetes

Breslau uses the concept of trauma portfolio, coined by Erica James in research in Haiti with PTSD, which may be useful here:

[it is] an official catalog of biographic events that have currency with institutions that recognize trauma. In a setting where gaining legitimacy as a victim carries significant benefits, the trauma portfolio can take on a life of its own...Her idea certainly has implications for other situations where access to valuable resources is contingent on establishment of an authorized trauma record. Second, the focus on particular past traumas...creates a preference for certain types of suffering while excluding others. (Breslau 2004: 121)

My second participant briefly comments about her own “trauma

portfolio,” citing that when her physicians examine the paperwork that is attached to her name as a patient, they treat her in a specific way. They understand that when “[she’s] talking loudly, oh... It’s just with her PTSD and we just need to realize this is how she talks about things, at certain times]. She continues with the wish that her colleagues were able to see the documentation, were able to see her “portfolio,” in order to better accept her as an individual and understand the way she experiences things.

“I’m not a bitch. I’m really not. People around here think I’m a bitch... because sometimes of how I can act, or my voice... my body language... but I just... they just don’t know what’s going on...they don’t get it.”

The pain of non-acceptance washes across her face as she finishes this statement, even when earlier in the conversation she describes in a somewhat satisfactory tone her individualistic/ independent nature. Yet, it is evident in her body language that she at times wishes for others to simply understand her and the impact her trauma portfolio has on her health and her behavior.

In understanding the trauma portfolio, it is a necessity to focus on the social roots of distress and disease (Breslau 2004: 115). This documentation follows these women around, acting as written verification for their disease, and its possible causation factors that put them at risk. Two of my participants have experienced explicit trauma in

their lives; one clinically diagnosed with Post-Traumatic Stress Disorder. There are pieces of current literature that are exploring the experiences of the chronically ill and the impact of PTSD, accumulated burden of adversity, and individual coping behaviors. There is growing evidence that suggests traumatogenic potential of chronic diseases, some sudden and unexpected onsets, and the traumatogenic changes in life circumstances, which may produce maladaptive illness coping over the life course. Alonzo writes:

Attention needs to focus on the additive effect of co-morbid life events and the traumatic potential of invasive medical therapies. Consideration of PTSD and a continuum of cumulative adversity provide a more complex and fully drawn understanding of the circumstances that surround chronic illness coping and reasons for maladaptive coping following invasive therapies and changes in the disease trajectory. The pathophysiology that produces a chronic disease does not begin at symptom onset, and the psychosocial strategies to cope with a chronic illness, whether efficacious or maladaptive, also do not begin at symptom onset, but develop over the life course. (2000: 1475).

In this reference, Alonzo calls upon focusing on the traumatic potential of “invasive” medical therapies and the maladaptive coping mechanisms that follow. Although diabetes may not necessarily have invasive surgeries or therapies for management and diagnosis, there are times when a routine procedure can be “invasive” for the individual. A diabetic, in order to maintain a status of being “on top of their care,” must allow their body to be poked, prodded, stuck, and studied at all times.

This in turn, including other medical issues in the individual's personal history, can influence the patient's ability to cope with the disease experience, its life course, and its effects on their psyche. A diabetic must develop a certain psychosocial strategy of coping in order to get their finger stuck for glucose levels, or to have the capability of grabbing enough fat and skin for insulin shots, or even to develop a coping mechanism to recognize that the redness creeping up their legs may be lack of oxygen to the legs (negative Diabetic effect) and an indication of future amputations. Medically, these procedures are not invasive; but figuratively, they are invasive for the patient.

Alonzo further explores the theories of Turner and Lloyed (1995) with accumulated burden of adversity and Fullilove et. al.'s trauma spectrum disorder on the individual's capacity to cope with disease experience and other life course events. According to Alonzo, the timely and effective responses to signs and symptoms of chronic diseases are interfered and impeded with by accumulated burden of adversity. This extends beyond just the individual, but within coping behavior to the life spheres of personal, marital, and family relations, employment, and the general quality of life (Alonzo 2000: 1476-7). Stress or emotional and/or physical traumas have a profound impact on a person's health and well-being. The growing support of research reveals the co-occurrence of

depression, anxiety, and stressful emotions, and diabetes affects marginalized populations.

Narratives of Stress, Trauma, and the Influences on the Diabetic Experience

“I just don’t deal well with people... I’m better on my own”—

Participant Two

The life and experiences of a diabetic are stressful. The life and experiences of a woman, sexual minority diabetic can be even more so. It is pertinent to note that the “overall” experience of diabetes is stressful. Additionally, it is also important to recognize that each individual has a multitude of daily hassles that they must encounter. However, when “dealing” with Type 2 diabetes and experiencing the same hassles that another individual might label as easy, these obstacles may in fact be quite difficult. A little hassle has in fact turned into a great rippling effect that has a much dramatic magnitude and ripple effect in the daily life of a diabetic. Diabetes has become something else added to the day; and if the patient has a trauma portfolio, it is another piece to the document of managing multiple chronic conditions and disorders.

Each woman that I interviewed thoroughly discussed their past and present stressors that influenced their lives, their experiences of their diabetes, and their coping with the disease. Many of their

narratives exemplify a stress-illness relationship, without them directly stating the term. Each woman acknowledges that their lives contain traumatic and stressful situations, but they themselves do not link these “events/ situations” directly to the causation of their disease, merely an added layer to the overall experience. The question then is, were these stressful events/ situations in their lives acting as a greater ripple/ domino effect on their body? I must also emphasize the fact that the stress and trauma are significant to understand and explore within these women’s narratives, even when they do not necessarily make the linkage themselves.

Nancy Scheper-Hughes and Philippe Bourgois examine this concept of discerning stressful experiences and traumatic influences of narratives in the theoretical application of continuum of violence. Both juxtapose the routine violence and stress of everyday life to that of “larger instances” of violence on personal, social, and political levels (Scheper-Hughes and Bourgois 2003: 3-4). Additionally, in their research, Scheper-Hughes and Bourgois focus on the inevitable gendered contours of gendered violence, and the interface of three bodies in the context of the social, political, and individual (Scheper-Hughes and Bourgois 2003: 22). In other words, whether male or female bodies are being raped, whether it is in times of conflict or peace, this act of violence against the

female body is classic symbolic violence. In Bourdieuan terms, it is a “discourse shared by the dominated and the dominant (Scheper- Hughes and Bourgois 2003: 22-3). For the women of my study, each experienced trauma in the hands of men as young adolescent women and children. They were the dominated. Each woman expresses differing viewpoints on stress, trauma, and violence within their narratives. Additionally, for each woman, the levels of stress and trauma are at different levels—what affects one greatly may not necessarily create such a traumatic impact on another. Within the first interview that I conducted with Participant One, she describes the stress of medical school, family issues, and eating unhealthy at the time of her diagnosis:

There was a lot going on with me at the time [laughter]. But But It was I definitelyyyy. Um. Scared the crap out of me. I just finished my residency in medicine. Andddd... I gained a lot of weight during residency. Umm. Anddd I didn't really have any real signs or symptoms of diabetes. Um. Even though I knew sort of all about the signs and symptoms of diabetes. Anddd. I think that's what sort of freaked me out a bit. I had just sort of gone to see my primary health care doctor andddd...She had done a series of blood tests for looking for diabetes because my Dad had diabetes...And. Since I had put the weight on.... And. Um. So anyways. I was 28 when I was diagnosed...Andddd. It. Definitely. Freaked me out a bit.

Although she later on in the interview strongly connects a possible

causation factor of her diagnosis to her “bad family genetics” connected with the history of her father and her poor habits of eating, she describes thoroughly the stress of medical school, her father’s health issues, her

diagnosis, and the stress of this new identity of being a diabetic. Her trauma was her family legacy.

My second participant discusses her PTSD in connection to her alcoholism, her abuse, her eventual sobriety.

I started in therapy when I got sober 27 years ago... I bet my first therapist, when she saw me, she said, she has PTSD, but we'll deal with this later.... I don't know if you ever met someone who was getting sober...Have you ever met someone going through sobriety? They don't what the date is, the time, the year...Sobriety... I didn't even know what the words meant....I was really fucked up. People who get sober, are fucked up... Pardon for the language, but they are... You're just on edge... It's very hard to not pick up a drink...I realized at a point that I thought I was going to kill myself, so I got into therapy, got into AA...

2003 I was diagnosed with diabetes... Diabetes and alcoholism go hand in hand... There's a lot of overlap... Often times you are going to find them in the same person... It was inevitable I was going to have it, just when I was going to have it... The alcoholism,.. part of the psychological/ socially-dependent aspect of it all... I wanted something to take me away... often times, when you can't pick up a drink, you pick up something with sugar to eat.

For my Second Participant, the trauma of her childhood with her abusive father influenced her mental well-being and behavior. Early in the interview, she discusses her PTSD, and is open with her pursuit of sobriety. As I mentioned earlier with her seeking of knowledge to eliminate shame and stigma surrounding her body size, here she discusses her pursuit of understanding her trauma portfolio, facing sobriety, and the support she sought. She states how her care providers were able to identify right away that she was a woman with a trauma

portfolio, and in turn she mentions how at times she used alcohol to escape from her past traumatic experiences and what she believed as her inability to fulfill a particular social role. In the end, she ties the alcoholism, the trauma of her life, to her diabetes. For her, in addition to the genetic history of her family, her behavioral and social history made diabetes inevitable.

Lastly, my fourth participant opened my eyes when in the middle of the interview she calmly stated: “*As my therapist has me say (or likes me to say)... I am a trauma victim... I am a victim of incest.*” She states is so calmly, that at first, I thought I had misheard her. She continues on, describing the dynamics of her family, and the psychological and sexual abuse that she endured under the hands of her father. How when he passed away, she was sort of relieved because the recurring emotions of stress and trauma that would plague her while she was around him ceased to exist. She obtained had obtained closure, but still believes that the stress had a lasting impact:

I definitely believe stress influences the body. It takes over the cell, and envelops it, and takes over, It permeates the body... I truly believe that stress creates the sickness, and creates the disease.... My trauma... my incest... definitely created my diabetes...

Participant Four is very forthright in her traumatic experiences, truly believing that to be open about her trauma portfolio is part of a greater healing process. Her trauma has become part of her identity, and part of

the character of her disease. Perhaps the most important distinction is her resignation that the stress has taken over her body, and like the other participants, it was inevitable for her to be diagnosed with Type 2. She knew that her trauma would influence her state of mind and health in some way, not necessarily with Type 2 diabetes, but with some variation of chronic illness. And she calmly accepts that as part of her life course and fate.

CHAPTER V:

THE LIVES BEHIND THE VOICES: ILLNESS ROLE, COPING NARRATIVES, AND MANAGEMENT OF A CHRONIC ILLNESS

“Having a chronic illness, Molly thought, was like being invaded. Her grandmother back in Michigan used to tell about the day one of their cows got loose and wandered into the parlor, and the awful time they had getting her out. That was exactly what [it] was like: as if some big old cow had got into her house and wouldn't go away. It just sat there, taking up space in her life and making everything more difficult, mooing loudly from time to time and making cow pies, and all she could do really was edge around it and put up with it.

*When other people first became aware of the cow, they expressed concern and anxiety. They suggested strategies for getting the animal out of Molly's parlor: remedies and doctors and procedures, some mainstream and some New Age. They related anecdotes of friends who had removed their own cows in one way or another. But after a while they had exhausted their suggestions. Then they usually began to pretend that the cow wasn't there, and they preferred for Molly to go along with the pretense.”—Alison Lurie, *The Last Resort**

Introduction

Within medical anthropology and socio-cultural research, a primary goal is to pinpoint the definition of health (what it is exactly) and how it is defined. The question, “What is health?,” can depend on several factors varying from the person’s well-being, their environment, social-cultural shaping, and their interactions with others. What a medical anthropologist ponders about illness is dependent on the culture and societies in which we exist and our discourse (Weiner January 16, 2013). Illness, based on this concept and within this study, is the socially

determined deviation from the norm, i.e. being the healthy and the “majority” in power (Weiner January 16, 2013). Additionally, in regards to the clinical perspective, medical anthropologist must also consider that illness and the behavior of illness are a pursuit of understanding what the individual perceives as a healthy state in contrast to the sick state, and the management of this state (Weiner January 16, 2013).

It is the goal of the medical anthropologist to then identify the narrative of the behavior and management of the illness in context of the person’s physical, mental, and social identity. In Foucauldian terms, we think about health and its narrative within the body and within our bodily experiences: we always have health, we are never without or absent of health and health is part of the mechanics of maintaining equilibrium within ourselves (Frank 2012: 22, Weiner January 16, 2013). In other words, there is a dual sense of being and being subjected to within the narrative—individuals are both the agent and the recipient of their health and illness in their life story (Frank 2012: 21, Weiner January 23, 2013). Similarly, Parsons (1951) reiterates this theme of health being the defining factor of an individual, where illness is a determinant of a social role. Chronic illness is more than just conditions or ideas that are solely influenced and illuminated by the social and collective. It is an all-encompassing identity (Weiner January

23, 2013).

In this chapter, my focus and dialogue are engaged with the lives behind the voices of LQWLW with Type 2 Diabetes. This chapter will consist more of an in-depth case study for each participant in order to understand their narratives through a phenomenological theoretical lens. As stated in earlier in this paper, Phenomenology attempts to understand how people view themselves, create an identity, and determine how this perspective creates the world around them. These case studies are to emphasize the importance of the voices of these women within their chronic illness role and identity they selectively present to the world in their day-to-day life. These voices are representing a part of their unique illness role and behavior when facing their Type 2 diabetes. I will also examine the different coping narratives of self-preservation and explore the theme of “dealing with it” when these women are faced the difficulty of living with Type 2 and feeling that their stories of chronic illness are not relevant. In this exploration of coping narratives, I will also briefly touch on the aspect of relationships (platonic, familial, and romantic). Lastly, this chapter will explore the women’s diverse management of diabetes based on their varying explanatory models, and will create comparisons between the women’s self-management and utilization of other agencies to fit their particular narrative.

Gaining Voice within the Illness Role

“Well, I don’t know how much I can tell you.../ I really don’t know if I have much to say...I never really thought about it”

In the examination of my participants’ narratives, their interactions with others, such as friends, family, colleagues/ peers, health care providers and professionals, clearly indicate a shaping of their voice, role, and experiences of their diabetes. Narratives are the beautiful expression of individuality, with unique nuances that can take on many forms and multi-level meanings of depth. They are simply story-telling; where there can be a way of revealing and hiding, or obscuring and opening of details that in themselves can create depth in a person’s life tale. Additionally, a narrative and depiction of the illness role, or the rejection and attempt of separation from the illness role, are told to an audience(s), and thus are unfolding during the description of the narrative (Weiner February 27, 2013).

In order to truly gather the importance of revealing voice within these narratives, I will briefly examine the concept of the Talcott Parson’s (1975) sick role. Illness, within Parson’s understanding of illness as deviance from the normality of healthy, is the deterioration of the “general capacity for the effective performance of valued tasks” (Parsons 1964: 262, Varul 2010: 73). Parsons establishes three primary criteria

of an individual fitting within the social category of being sick (1975: 262). He states that the criteria first begins with “the assertion with the view to its acceptance by both self and others, that being in a state of illness is not the sick person’s own fault, and that he should be regarded as the victim of forces beyond his control (Parsons 1975: 262). The criterion also dictates that within the social-structural feature of the sick role, there becomes a status of exemption and obligation for the individual from daily activities. Rather, they are expected to seek help and become embedded within the health institution (Parsons 1975: 262). Hence, *being* sick is a role with expectations of identifying oneself as sick within the personal narrative (Parsons 1975: 262-3, Frank 2012: 19).

Sally Wellard explores how an individual may be affected by chronic illness (thus influencing their voice) by reviewing the current constructions of major perspectives of chronic illness discourse in the examination of normalization, individualism, and bio-medicine (1997: 49). In the biomedical approach, the primary aim of treatment is to “fix” or reverse, if possible, and restore the patient to a normal state of health (Wellard 1997: 49). When there is no cure, the treatment then shifts to minimization—less impact on the body, containment of the disease. Psychosocial approaches to chronic illness and narratives seek to

determine the “threads” of chronic illness, and how these influence “the manifestations of chronic illness, the ‘mapping’ of illness trajectories, the evaluation of quality of life, and the exploration of the notion of compliance” (Wellard 1997: 50).

Lastly, Wellard provides a brief discourse on the fields of individualism and science (Wellard 1997: 52). Here, there is a brief analysis of individual autonomy and its impact on notions of personal freedom, individual rights to self-determination and ownership (Wellard 1997: 51). This freedom of self-determination is then “constricted” by ideals of normalcy, normal behavior and the expectations of individuals to fulfill obligations and societal norms. Within medical discourse, individualism can be seen in the primary concentration on the patient; the patient is then compared to a greater population of individuals (who all fit within the norms). In the occurrence of an illness narrative, the patient is then implicated in the cause of their illness because of the concept of responsibilities with autonomy (Wellard 1997: 52-3). The question then arises of how much these aforementioned theoretical application influences the choice and depiction of voice within the illness narrative.

Cheryl Mattingly (2000) explores the importance of gaining voice in the narrative of the illness role in “Learning from Stories: Narrative

Interviewing in Cross-Cultural Research.” Here, Mattingly argues for the importance of voice and eliciting narratives when trying to apprehend the point of view and personal experience of informants (2000: 4). Mattingly further states:

Many phenomenologically oriented medical ethnographers now believe that verbal reports in the form of narratives are the best way to discover a person’s lived experience of particular events. While there is never any direct access to past experience, stories appear to be our best means of asking a person to ‘relive’ moments of their past, re-entering the rich emotional landscape of powerful experiences by telling stories about them...These rich narrative depictions are much more useful than abstract generalizations or belief statements in helping us to understand the complex and often quite tacit meanings (including dilemmas, hopes, anxieties, and the like)... (2000: 4-5)

The narrative and the voice behind it attests to the power of these stories and their ability to expose the bodily suffering or stigma that can shape the life of the narrator and those around him/ her (Mattingly 2000: 5).

In conjunction with Mattingly and with Parson’s sick role, Harold Garfinkel presents the process of storytelling as a form of work, “in which the incoherent is rendered coherent” (Frank 2012: 23). He explains it in terms of ethnomethodology: “[the] grounding [of] sociology in detailed observation of how people accomplish the settings in which they live” (Frank 2012: 20). The individuals narrating about themselves to others do so in order for the other to have an ideal of the choices that were made, the reasoning behind the behaviors, and that it makes sense to

them (Frank 2012: 23). The narrator (or the interview participant) wants the audience to “get” them and what they are going through. The people/ narrators do the “work of sustaining commonly shared understandings and the institutions that depend on these understandings” (Frank 2012: 20). The narrator has a role, and works at maintaining the role to achieve some variation of a normative expectation or what they desire for the “audience” to see.

Each initial interview of my study began the same, consistent way: “how would you describe yourself/ what adjectives would you use to indicate to another person about your character and personality?” Each time, the participants began to fumble for words to adequately depict their identity-- even in a positive light—and had issues describing their particular role within their life world. The question was an opening exercise of the semi-formal interview in order to allow the women to “open” up and become more comfortable. Initially, in that particular moment, it was an issue of identity in the interaction between that of the interviewer and the participant. Like Mattingly points out, “not everything a person say in an interview is a story,” but are within the body language and the silences (2000: 6, Weiner February 27, 2013). Much as I explained earlier in the previous chapter of choosing identities to represent based on context, it appeared that the women were choosing

which identity to present to me. Eventually, as the interview would continue forward and as the women became more comfortable with my presence. Yet, it was evident that there was an initial tension in the beginning stages of the interaction for the woman to determine the specific identity and role that she would want to present to me. Each woman would initially admit “parts” of the illness, but would not claim a “sick role” (as I will describe within coping narratives of this chapter). Their body language, the determination of adjectives in the beginning of the interviews, the clothes they were wearing, the setting they chose to meet, etc. were all parts of their method in telling their narrative in a comfortable, compelling manner. They may not have methodically planned it out, but each woman sub-consciously presented an initial role in the beginning of the interview and would strategically reveal more only after they became more comfortable and enthused with their narratives.

Coping Narratives and Rejection of the Illness Role

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narrative.

When people feel ill, their first instinct (in many cases) is discuss their symptoms with significant others, friends, family, and then to later go to a physician after the persist nagging of the aforementioned list of individuals. The physicians then begin the process of questions pertaining the being of the body, evaluations, and then diagnosis with the prescription of treatment (if possible) (Waxler 1981: 169). These women do not have the opportunity to “fix” their diabetes, but must answer the numerous questions and treatment options proposed by the clinicians in order to maintain “manage” mode. Their status quo is altered; as Wellard implies in her text, these women are now compared to the greater population of the norms and their autonomy now can be eclipsed in the pursuit of trying to “reverse” their diabetes. They choose the voice within their illness narrative, and the path of their illness trajectory— which individuals will know the particular “chronic illness” voice, and which individuals will remain in the dark in order to enact a concept of autonomy that is not “shadowed” by the definition of an illness role.

Just deal with it. This mantra was continually repeated throughout the interviews of these women. A key theme perpetuating within each narrative was the idea: *I don't have a chronic illness; I have*

diabetes. Not only does each woman choose carefully their terminology in self-classification, but also the autonomy and individualism she wants to maintain with her Type 2 diabetes. In this research study, each woman in a way describes a narrative of navigating personal relationships in order to obtain individuality and rejection of the illness role. Most of the women (as I have mentioned earlier in this paper) shy away from admitting their diabetes diagnosis, but have no qualms of stating their sexual orientation. They do not want to be considered a statistic of chronicity, but just having something else that they must deal with throughout the day. And in many cases of the narrative, this denial of a particular aspect of identity impacts personal relationships.

Participant One discusses her selective nature when making it known to others about her Type 2. As a physician, she feels more able to discuss her care and diabetic issues with close colleagues with a biomedical background. They understand her methodology and approach to her own care, but at the same time do not micro-manage her in her approach. While recalling her many dynamic relationships with others, she laughs and states:

Many of my friends don't know that I'm diabetic. For a number of reasons. And it... I find it a little bit sort of difficult to negotiation in sort of bringing in... because... in a lot of ways, for a lot of years, I've been a really, really well controlled diabetic, And so. I can actually... I can actually be a little more liberal with my diet than a lot of diabetics can be.... And so. I have a lot of friends who are in

medicine, and then I have a lot of friends who are not... and ... my closest friends all know.. I sorta feel like it's something that I manage.. and I don't necessarily want a lot of other people micromanaging me... So... for my friends who are not in medicine, I'm actually more concerned that they're ... they'll try like to micromanage me, because they have sort of have a global view of what diabetes is and what diabetes isn't... and that's not necessarily how diabetes affects me...

Here, participant one not only describes her management of her friends, but the autonomy she strives to obtain within her own definition of diabetes, self, and sick role. While navigating her friends in order to avoid being micromanaged, and to have friends criticizing her about the food she eats or the alcohol she drinks, she refuses to acknowledge that she is not influenced by diabetes the same way as others. For her, she has diabetes, but it is not as bad as a normal diabetic, and this is a key fact that she continues to reiterate through her narrative. Her trajectory is the “not-too-bad diabetic.”

Participant Two states directly that she is an individual that is much comfortable being by herself due to her PTSD, but does have a few friendships which she cherishes deeply. The few relationships that she does maintain, these individuals know her history, understand her background, and her chronic illness. She has divulged information with them because she is at her most comfortable. For her, her diabetes is a key component of her life that she is very passionate about, and she is a woman who does not allow many to see her vulnerabilities. Much of her

voice and autonomy within her diabetes is within her management (which I will discuss in the next section of this chapter). However, she finds her passion and her true role within her Cosplay, her gardening, her niece, and her support at CampCamp (an LGBT focused summer camp) that she attends at the end of every summer. For her, diabetes is just another added thing to her health issues. Her primary focus is maintaining more of a healthy relationship with her family and her friend, and to diminish the influence of PTSD in her daily life.

Within the illness trajectory and narrative of Participant Three, she too emphasizes the statement that she is merely a woman with diabetes, and not a chronic illness sufferer. For her, her voice centers on her focus of self and the work, but she alludes to the need of love within her life and the management of her chronic illness. She discusses her self-evolution of becoming open with her partners and the need of support that she wants to give to them, but also what she expects for herself:

I didn't tell anyone anyone. I wasn't out at work. That I was a diabetic. wasn't open about it. But then I got to a point, where I said, you know what, I really need to focus, and I became super open...I was an advocate. Like to the fact of... You need to put that butter dish down. You need to exercise three times a week or you're going to get really unhealthy, influence your liver, and die. I became super open...and... and... That evolved over time.

My wife... she was very supportive... for the women that I dated after the divorce... were very supportive... they wouldn't bring home a box of donuts, because they knew I would want one... so they were supportive in that way too...

And then there was [my last girlfriend]... who was horrified by the thought of diabetes... who just didn't deal... I just kept trying to tell her, 'Hey, I'm a diabetic'... I'm the kid in the classroom that can't have that cake, I would bring the bell pepper... I told her, I need you help me, I need to clean up my act, just don't bring that shit home... There became a time, that if I stay with her, I'm going to eat like her... that was the benchmark, that was the breaking point of our relationship... She just didn't want to get that. You can't change someone else... You can't change what they want to say, what they want to do... And you can't make them open their eyes...

Even during this discussion, there was a mixture of sadness and anger in her face as she described the interactions she would have with her previous girlfriend. In the beginning of the interview (the quote depicted here), she discusses the lack of understanding and support from her relationship and the influence that it had on her body because of her dependency on another individual with maintenance in control and diet. She also points out the denial of her girlfriend towards her diabetes and her illness role. As she continued in the discussion, she concluded with her need to go back to the “drawing board” of maintaining love for herself, for being fair to the other person in the relationship, and for her to find a companion that she would not be a burden to, in the long run. For Participant Three, she needed the support of another to help her in her navigation of her chronic illness role.

Lastly, for Participant Four, she discusses the fact that for her, since she was so recently diagnosed with Type 2 diabetes, it is still

difficult for her to develop a particular voice for her “role.” She, like Participants One and Two, does not desire the need for a particular relationship at the current moment due to her need for concentration on her own autonomy. For her, her role is still confused—she still remains focused on her traumatic past, her negative relationships with her family, and the stress of her family fighting over the estate of her father (after his recent passing), and her chronic pain. When asked about her support, she dismissively states, *“I have friends. I do have some little support group, but no lover... I can’t really be in a relationship, because of my back pain. It’s too much, and it’s not fair on her.”* She is content, at the moment, to focus on her career of alternative healing and artistry, while trying to find answers and a voice to her newly diagnosed chronic illness. And like the other women of this study, diabetes is not a definitive “illness role,” but another characteristic of her personality and an added thing needed to be conquered in her agenda.

Management of Type 2 Diabetes

In exploring the management of Type 2 Diabetes, there must first be a brief examination of the health seeking process and model. According to Noel J. Chrisman, the health seeking process is a means “to document the natural histories of illness based on five components: symptom definition, illness-related shifts in role behavior, lay

consultation and referral, treatment actions, and adherence” (1977: 351). In layman’s terms, it provides a basic guideline of steps for examining individual’s reactions to sickness (in context with biomedicine). The health seeking model, on the other hand, attempts to theorize a person’s experience by outlining relationships of health related behaviors and socio-cultural contextual features. As a result, the model facilitates more complete ethnographic descriptions into finding how diseases are integrated into people’s belief system and daily life (Chrisman 1977: 352-3).

Strauss et. al. (1984) determines chronic illness as the experience of multiple problems that do not go away; marking the individual with medical crises (Wellard 1997: 50). Chronic illness demanded management of a treatment regiment, where “ill people” seek to supplement their lives and process with many other methodologies and treatment methods. Strauss et. al. explains this in terms of juggling; people managing chronic illness reorder time and juggle both the illness and their lives. In this process of juggling, people try to obtain normalization and hide/ conceal their disease from others (1984, Wellard 1998: 50).

In regards to Type 2 diabetes, a rather “invisible” disease, the person develops a particular illness behavior to juggle and maintain

“invisibility” to the norm. Illness behavior, again, “refers to the ways in which given symptoms are perceived evaluated and acted (or not acted) upon by different people” (Chrisman 1977: 355). These influence whether or not a person will seek help for a health problem, based on differentiating elements of a cultural process or different assignments of meaning in ill health experiences. Based on this idea, Kleinman, Eisenberg and Good all argue that people develop culturally based explanatory models of the mechanics to their illnesses (Chrisma 1977: 355). This is evident with my each of my participants’ navigation through their diabetes care and management identity.

For each participant, there is a different way of managing their Type 2 Diabetes and differing ways of weaving their management within the control of their culture, identity, and everyday lives. However, each participant emphasized the point of the “ongoing struggle” to control their diabetes, maintain their relationships and identities, and “deal with it.” These narratives and the expressive devices the participants employed implicated a commentary on more of an ambivalence of chronic disease management, autonomy, and a presentation of positive subjectivity (Broom, Whittaker, Mattingly 2004: 2376-7).

CHAPTER VI:

CONCLUSION

“Most people live in fear of some terrible event changing their lives, the death of a loved one or a serious illness. For the chronically ill, this terrible event has already happened, and we have been let in on an amazing secret: You survive. You adapt, and your life changes, but in the end you go on, with whatever compromises you have been forced to make, whatever losses you have been forced to endure. You learn to balance your fears with the simple truth that you must go on living.” – Jamie Weisman, As I Live and Breathe: Notes of a Patient-Doctor

Hope and Survival Amidst the Dealing with it and the Stress

Throughout this study, and especially seen within the last analytical chapter of my dialogue, it became evident that there was a key determination from the women of not being labeled with the identity of Chronicity. As I depicted in my analysis of understanding their management of the disease, many of the women continue to maintain diligence of activity, diet, and wellbeing, and strongly advocate for the type of care that they want from their health care providers. As Participant Two stated earlier in the paper, the women are the project managers for their health care, and they must selectively choose providers that meet their needs and beliefs with their diabetes management.

At the same time these women are combating the social stereotypes of what it means to be a diabetic, continually emphasizing

what Participant One was able to state very eloquently: “I do not have a chronic illness, I just have diabetes.” Chronicity is what these women continue to fight against and what society tries to continue to do with diabetes—an emphasis of the stigmatized sick role with a life-long, life-inhibiting disease. The resistance that these women exhibit of accepting diabetes as chronic is a reiteration of the mentality of “just dealing with it;” for these women, to admit that diabetes is a chronic illness is in their mind fitting into the social and cultural stereotypes of sickness and invalidity. By just emphasizing, “well, it’s just diabetes,” they are, in turn, trying to “soften the blow” of its true meaning. Whether or not this coping mechanism is for me (the interviewer) or for themselves is still yet to be determined.

Personal Reflections

Within the introduction to this paper, I briefly gave insight to my familial background and the impact diabetes had on my life, the life of my family, and my research interests. Being the daughter of a Type 2 diabetic, I experienced early the stress of individual responsibility for individual health, body weight, and physical well-being. I have also undergone the stress and fear of the possible inevitable: that the family genetic influence and history of diabetes will be my fate one day. Additionally, through my own father’s illness narrative and experiences, I

sympathize with these women and their encounters of stigmatization for their diabetes. I have experienced on a first hand basis the will of family and friends to maintain management on another's diabetes, and the constant push for biomedical initiatives.

My background not only had powerful guidance on my academic passion of conducting ethnographical research on illness narratives and voices, but my methods as a qualitative researcher and my process of analysis. The loss of my father at an early age in my life has provided a pathway into the route of advocacy and sharing voice of illness narratives. It has been my wish as a medical anthropologist to share chronic illness stories because my dad's story was not shared and heard. It has given me a passion as a qualitative researcher, which I hope is depicted in the representation of this study and the interaction with my participants. As Dr. Weiner had told me, I owed this research not only to myself, and to my father, but to my participant's as well. I believe that much of this zeal is due to my inside-researcher position.

Yet, this role as an insider researcher/ outsider within provides many advantages, as I have described in earlier chapters, but it does provide for some disadvantages. One in particular was the fact that I hold a closeness to the situation/ research at hand, and this may hinder my capabilities as a researcher from seeing all dimensions of the bigger

picture, i.e. I become too emotionally involved (Unluer 2012: 6).

This was quite evident when one of my participants asked me during the informal interview, “have you been tested for diabetes?” As a result of mutual sharing, many of the individuals that I talked to informally and many of my participants for this project asked if I was ever tested. This is based on the belief that genetics/ family history are a definite influence on health, and with my father having Type 2 Diabetes (a bad case of it), it is highly probable that I am at risk. This simple question invoked so much fear within me about my own identity and possibility of having chronic illness. It has even caused me to reflect upon the possibility of my future diagnosis/ fate. Like Participants One and Two, do I become consigned to the fact that no matter what I do, I will (eventually) be diabetic? It is a self-reflection that truly creates vulnerability within an individual—the recognition of the fragility of health when there is a chance it might be “taken” away.

Future Goals and Recommendations

Despite the evolving academic research within the LGBT community, there is still a dearth in research focusing on the LQWLW population. Unfortunately there is a trend of first investigating chronic illness and narratives influencing the heterosexual population, then translating it over into an application towards the LGBT population.

Even then, the research trend is with a primary focus is first on the males. It is essential then to promote academic work that focuses equally on each particular grouping of the LGBT community.

Additionally, I hope that my work and pursuit of advocacy sheds some light on the suboptimal care that LQWLW receive, especially in regards to diabetes care manage. As Dr. Jennifer Potter states, “knowledge of each patient’s sexual orientation and behaviors is critical for the development of a productive therapeutic relationship, accurate risk assessment, and the provision of pertinent preventive counseling” (2002: 341). This coincides with the publication from the Office of the Public Advocate (OPA) in New York City, and the New York City Health and Hospitals Corporation (HHC), which focuses on the heterocentric bias in public health and medical education and practice. This leads to gaps in knowledge for providers, and eventual subpar clinical practice (Gobaum 2008: 7).

It is necessary to provide “welcoming” health care in order to avoid the common emotions of shame, fear, and isolation that permeates the causation of risky behaviors, stress-related health conditions, substance abuse, depression, and attempted suicide (Potter 2002: 341). In order to do so, there must be an establishment and display of zero-tolerance discrimination policy for both patients and staff. There needs to be

recommendations for advertisement of LGBT friendliness and reach out to the community. Medical forms within health care provider offices must be changed to allow all diversity of patient identification. And in addition to the increase research on all LGBT health issues, there must be an establishment of a review process to gauge facilities progress and acceptance of patients (Gotbaum 2008: 12-13). By parsing out the cause-effect of stress mechanisms for LQWLW (as I have briefly discussed in previous chapters) and the multiple co-morbidities and diseases that affect LQWLW, clinicians will be able to meet the need for dignity and respect within clinical practice.

In the end, the future relies in the voice and prominence of these women. Diabetes is becoming an epidemic in which was once invisible, and for each one of my participants it has become a way of life that has profound impact; to them it is not invisible. By examining the intersectionality of identity, sick role, coping and illness narratives, and stress, there provides an opportunity to understand how a minority population has become silent and what must be done to help in the sharing of their stories and voice. At the very beginning of each interview, the women truly believed that they had nothing to share. They should have never felt that way in the first place.

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